CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Parental Presence During Treatment of Ebola or Other Highly Consequential Infection

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This clinical report offers guidance to health care providers and hospitals on options to consider regarding parental presence at the bedside while caring for a child with suspected or proven Ebola virus disease (Ebola) or other highly consequential infection. Options are presented to help meet the needs of the patient and the family while also posing the least risk to providers and health care organizations. The optimal way to minimize risk is to limit contact between the person under investigation or treatment and family members/caregivers whenever possible while working to meet the emotional support needs of both patient and family. At times, caregiver presence may be deemed to be in the best interest of the patient, and in such situations, a strong effort should be made to limit potential risks of exposure to the caregiver, health care providers, and the community. The decision to allow parental/caregiver presence should be made in consultation with a team including an infectious diseases expert and state and/or local public health authorities and should involve consideration of many factors, depending on the stage of investigation and management, including (1) a careful history, physical examination, and investigations to elucidate the likelihood of the diagnosis of Ebola or other highly consequential infection; (2) ability of the facility to offer appropriate isolation for the person under investigation and family members and to manage Ebola; (3) ability to recognize and exclude people at increased risk of worse outcomes (eg, pregnant women); and (4) ability of parent/caregiver to follow instructions, including appropriate donning and doffing of personal protective equipment.

BACKGROUND

During the peak of the Ebola virus disease (Ebola) outbreak in West Africa, the American Academy of Pediatrics (AAP) held regular weekly conference calls with the Centers for Disease Control and Prevention

abstract

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(CDC) to identify issues of concern to health care practitioners and to address them using the best available information. One of the most frequently asked questions was how to handle parental or legal guardian presence in the setting of a child with suspected or confirmed Ebola. As a result, consultations were held with infectious diseases and infection-control experts who had already handled suspected cases in the United States, and the literature was reviewed for the best possible guidance. Bioethicists and family-centered care experts also were consulted. It was clear that there was not a single approach that was uniformly viewed as creating the greatest safety for health care providers, while also fully taking into consideration the ongoing social and emotional needs of the child and his or her parents or legal guardians. Given the strong ongoing requests for such guidance, the AAP developed this clinical report to offer guidance to health care providers and hospitals regarding options to consider that could meet the needs of the patient and the family while also posing the least risk to providers and health care organizations. Although this guidance is based primarily on the opinions of experts, the principles proposed are ones that have been vetted carefully and represent consensus intended to enable health care providers and health systems and organizations that care for children to consider these important issues in their preparedness plans before the arrival of any child suspected of having Ebola or similar highly consequential infectious diseases. Because sufficient data do not yet exist to create an evidence-based policy, as data accumulate both in the United States and worldwide on the appropriate care for children with Ebola, this consensus guidance will be reevaluated.

Goal: To provide guidance for health care providers and health care organizations to consider when determining the extent of legal guardian presence at the bedside of a child with suspected or confirmed Ebola virus disease (Ebola).
Intended Audience: Pediatric health care providers, transport teams providing care to children, and hospital and ambulatory care centers providing care to children.
Definition of a caregiver for this guidance: Parent or legal guardian; in the event a parent or legal guardian cannot be present at the bedside, an alternate adult caregiver (such as a relative) may be designated.

Advance preparedness planning can mitigate risk, reduce material and operational losses, improve financial stability, strengthen the medical home, and help promote the health of children in the community.[1] Children need psychosocial support and comfort from their caregivers in times of extreme stress.[2–5] Pediatric health care providers generally support parental or legal guardian presence during prehospital and interhospital transport by emergency medical services personnel, emergency care, inpatient care, invasive medical procedures, and resuscitation attempts. However, adaptations and limitations may apply to this approach when a child is suspected or confirmed to have Ebola or another similarly transmitted disease of high consequence.

Because of the risk to other family members,[6] it is preferable to minimize contact between the patient under investigation and family members whenever possible, while working to meet the emotional support needs of both patient and family.[7] There may be times when caregiver presence may be deemed to be in the best interest of the patient. Efforts made surrounding caregiver presence with a child that is suspected or confirmed to have Ebola or another similarly transmitted disease of high consequence must limit potential risks of exposure to the caregiver, health care providers, and the community.[8,9] Although there are limited evidence-based criteria to inform practice, factors that should be considered when determining the extent and conditions of caregiver presence are discussed in the following sections.

CAREGIVER PRESENCE DURING INITIAL EVALUATION OF A SYMPTOMATIC CHILD

(Example: initial presentation to an ambulatory care center or hospital emergency department)

During initial presentation to a health care provider, caregivers will likely accompany the child. Health care providers, in consultation with state and/or local public health authorities, will need to evaluate the child to determine whether the child is

- a "person under investigation" (PUI) (with a plan to test for Ebola)[10] or
- not a PUI (with no plan to test for Ebola).

While this initial evaluation of the child is being conducted, the following guidance should be considered:

- All people accompanying the child must be evaluated to determine whether they are at risk of Ebola (or another disease in question)[11] and symptomatic. If these people refuse evaluation, public health authorities should be contacted promptly. If they are both at risk of and symptomatic of illness, the facility should offer isolation for the adult(s) and activate their adult care protocols. If these adults refuse isolation and care,

public health authorities should be notified immediately.

- Discuss with any female caregivers of child-bearing age whether they potentially could be pregnant (consider pregnancy test) because of the increased risk of severe illness and death as well as fetal loss and pregnancy-associated hemorrhage.[12,13] If a caregiver could be pregnant, consider removing her from the isolation room because of the increased risks to her and her fetus if she were to contract Ebola.
- All adult caregivers accompanying the child who are asymptomatic should be placed in appropriate personal protective equipment (PPE)[14] and roomed with the child until determination of the child's status (PUI versus not a PUI) is made.[10]
- If the child is not a PUI, then the health care facility should treat the child and caregivers according to standard procedure. If the child is a PUI, then the child may be evaluated in the hospital emergency department per protocol. At this time, family contact with the PUI should be limited to 1 parent or legal guardian wearing appropriate PPE. All other family members (beyond the 1 parent who is wearing appropriate PPE) or others accompanying the index patient should wait in a separate area pending determination by public health and/or the local infection-control expert. These experts also will determine the need for any specific infection-control actions toward the accompanying people or other contacts of the index patient.

Siblings and other children:

- If a sibling or another child who arrived with the family is determined to be at risk of Ebola or other illness in question,[15] and the child is symptomatic, that child should also be medically evaluated. Cohorting of siblings is not permissible if there is any uncertainty that both have the same illness.

Alternate arrangements should be made for the care of all asymptomatic siblings or other children accompanying the family. Siblings or other children who cannot wear the appropriate PPE (because of size, developmental level, etc) should wait in a separate room with supervision while alternate arrangements are made. The latter scenario would be the expected one for children in most situations.

CAREGIVER PRESENCE DURING INPATIENT CARE OF A CHILD WHO IS A PUI OR CONFIRMED CASE

Making the decision to allow caregiver presence:

- Consider the ability of your hospital to care for an Ebola patient (is your hospital designated by the CDC as a frontline, assessment, or treatment center?) and follow the CDC guidelines for your level of institution[16] to determine whether the patient should be retained at your institution.
- A care team conference should be convened immediately to make the decision. Care members should include the attending physician, nursing staff designee, and hospital administrative designee. The care team might also benefit from the inclusion of a medical director of infection control or designee, an ethics committee designee, a child life designee, a designee from the local/state department of public health, and the parent or caregiver. If possible, the care team conference should be convened before arrival of the patient if there is sufficient warning and knowledge of who is accompanying him or her.
- Consider the child's age, developmental level, acuity, and ability to follow directions and cooperate with caregivers.
- Consider available hospital resources to care for both the child and the caregiver in the event the caregiver must be quarantined or isolated. Consider available hospital resources (eg, PPE supply, staffing to train and observe the caregiver in donning and doffing PPE, etc) to support caregiver presence at the bedside or to provide parental support via videoconferencing or other technology that enables the ability to monitor from outside the room. The abilities of the caregiver to don and doff PPE safely, tolerate wearing PPE, and comply with all infection-control policies are also important considerations. Institutional and local public health policies for quarantine and restrictions should also be reviewed and considered.
- Consider whether the caregiver has health considerations that may increase the risk of illness or complicate the use of PPE. A pregnant caregiver should not stay with a child who is a PUI or a confirmed case because of the very high risk of death for an Ebola-infected pregnant woman and her fetus.[13]
- Consider the impact to other children if the caregiver is the sole provider for other children in the family.
- Consider the risk to health care providers and other patients and their families/visitors.

ACTION TOWARD THE SAFETY OF THE CAREGIVER IN SUSPECTED OR PROVEN EBOLA

Options for implementation:

- Consider the following options once an assessment of age, development level, risk of transmission, and acuity of the child are determined:
  - Option 1: Caregiver remains in a separate room with videoconferencing capability with which to interact with the

child and be (remotely) involved in the child's care.[7,17,18]

- o Option 2: Caregiver remains at the bedside if able to show proficiency with PPE and staff is available to observe doffing and donning, as often as allowed by PPE tolerance and hospital guidelines, following the recommendations described previously.
- o Option 3 (combined): Caregiver primarily spends time in a separate room with videoconferencing capability and joins the child at the bedside intermittently.

If options 2 or 3 are chosen:

- Only 1 caregiver should be designated to provide bedside support and comfort to the child for the course of the illness. The caregiver must be informed of the potential risks associated with close contact with a symptomatic child. Informed consent must be obtained and documented, in which the caregiver acknowledges the risks and consents to enter the child's room.
  - o Although families may find it exceedingly difficult to designate a single bedside caregiver, this recommendation is based on infection-control guidance,[19] resource and staffing considerations, and minimizing the number of individuals (caregivers and health care staff) placed at risk of illness.
  - o Additional caregivers may remain engaged with the child through the use of videoconferencing.[18]
- The caregiver must agree to and be willing to comply with CDC guidance for monitoring and movement of exposed individuals[20] and the recommendations of the local state/county health department.
- The caregiver must agree to comply at all times with directions from hospital personnel, including leaving the bedside if it is determined to be in the best interest of the patient or the caregiver.
- Caregiver visits should be scheduled and controlled to allow for the following:
  - o Screening for Ebola or other illness (eg, fever and other symptoms) before entering or upon arrival to the hospital. The caregiver must not be experiencing symptoms compatible with the illness in question. The state and/or local public health department and responsible health care provider should be involved in determining the procedure for surveillance and monitoring of the caregiver while he or she is both inside and outside the room.
  - o Evaluating the risk to the health of the caregiver and his or her ability to comply fully with infection-control precautions.
  - o Providing instruction daily, before entry into the patient care area, on hand hygiene, limiting surfaces touched, and the use of PPE according to the current facility policy while in the patient's room.
  - o Compliance with policies intended to reduce potential exposure to caregivers and other hospital staff, patients and visitors, and the community.
- The caregiver must be able to and agree to follow CDC recommendations for safely donning and doffing PPE,[19] must be trained in proper procedure, and must be observed and assisted during the donning and doffing processes by hospital infection-control personnel.
- The caregiver must wear CDC-recommended PPE before entering the room and during all contact with the child. This must be, at a minimum, the same level of CDC-recommended PPE worn by health care workers caring for the child. Higher-level PPE may be considered for the parent or caregiver if it allows for increased comfort over prolonged periods (airflow) or improves the child's ability to interact with parent (full clear face shield).
- The caregiver should limit his or her exposure to blood and body fluids while at the child's bedside. The caregiver should not change the child's diaper, assist with personal hygiene after urination or defecation, or clean up blood or body fluids.
- The caregiver must agree to follow all infection-control protocols and procedures established by the hospital.
- The caregiver's movement within the rest of the health care facility should be restricted to the patient care area and, if available, designated spaces or waiting areas for these caregivers,[18] along with any other restrictions that may be stipulated by the state and local health departments.
- The caregiver must agree to and be willing to comply with any additional guidelines provided by the hospital, health care providers, and public health authorities.
- Confidentiality must be strictly maintained at all times. Without a full understanding of the extraordinary precautions and controls built in by institutions to minimize risk to other patients and the public, there are significant potential negative consequences to a confidentiality breech in which information about the nature or circumstance of the illness of a patient with Ebola is revealed without clear explanation of what, if any, implications this may have to the public. Examples of such consequences that were noted among institutions that cared for patients with Ebola in the United States during the recent outbreak included health care workers

known to work in the unit caring for the patient being publicly shunned and their children being removed from invitations to events, among others. There is also the risk that other patients, without appropriate information, have an exaggerated sense of risk and unnecessarily decide to shun the institution providing care for these patients. Parents/caregivers should be advised not to communicate with members of the press, on social media, or through other forums the nature of their own or their child's exposure or illness.[21] Doing so may subject the child and family members to unwanted scrutiny or behaviors from the public, both during hospitalization and after discharge, and this possibility should be explained to the parents/caregivers. The child should be admitted under a protocol that prohibits the announcement of his or her presence, and the hospital should avoid giving information to anyone other than the parents, even if the parents consent to disclosure, to protect the privacy interest of the minor child.

- For any of the 3 options, particularly for option 1, if videoconferencing is not available, audiotaping advice/bedtime stories also may help to support the psychosocial health of the child. In addition, family pictures may be placed in the child's room, along with family notes for older children, all of which should be appropriately discarded and destroyed upon discharge to maintain infection control.

Preparing Hospital Plans

- The hospital should engage in risk management each time the policy is implemented.
- If the caregiver should develop symptoms concerning for Ebola, the hospital should be prepared to either provide care or transfer to a designated adult biocontainment unit treatment center for evaluation, admission, and treatment.[16]
- Vaccination should be considered in the future. Recently, a recombinant, replication-competent vesicular stomatitis virus vectored vaccine expressing a surface glycoprotein of Zaire Ebolavirus (rVSV-ZEBOV) was shown to be 100% protective in preventing disease among 4123 contacts of persons with Ebola.[22] This vaccine, also shown to be safe, holds promise for future prevention among contacts and will likely be a major mechanism of protection of health care workers and close contacts of infected people, but guidelines for use have not yet been developed, nor has its use been evaluated in children.

SPECIAL CONSIDERATIONS WHEN DEATH IS IMMINENT AND/OR AFTER A CHILD HAS DIED

Certain diseases, such as Ebola, are most infectious just before and after death[23]; the risk of exposure to these diseases may be highest at this time. For this reason, consideration of whether a caregiver or other loved ones are allowed access during this critical time with the attendant risks should involve all of the factors discussed previously in "Action Toward the Safety of the Caregiver in Suspected or Proven Ebola."

- Consider options related to memory tokens. Only materials that can be autoclaved can be used to create any memory tokens.
- Have a chaplain or other support person immediately available to family and caregivers.
- Work with pastoral care on having a service via videoconferencing, if desired by family members.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
CDC: Centers for Disease Control and Prevention
Ebola: Ebola virus disease
PPE: personal protective equipment
PUI: person under investigation

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