Ebola: An ethical approach

Bruce Gamage
Provincial Infection Control Network
IPAC BC Education Day
November 4, 2016

Outline

- Background
- The Question
- The Decision
- Risk Assessment
- Key Facts and Assumptions
- Ethical Dilemmas and Justifications

Background

- First Ebola virus species was discovered in 1976 in what is now the Democratic Republic of the Congo near the Ebola River.
- EVD is a severe, often fatal, illness that starts with the abrupt onset of fever, usually with headache, malaise and myalgia
- Hemorrhagic symptoms (e.g., petechiae, ecchymosis, and hemorrhage) may also occur
- The case fatality rate ranges from 50 to 90 per cent.

EVD 2015

- 2015 outbreak in Western Africa provided an opportunity for international transmission
- Patient from an area within the outbreak zone travelled to Dallas where he became ill with EVD and died – 2 HCW became infected
- This incident highlighted the awareness of the ability for transmission of EVD across continents and the need for health care services to be prepared for such an event.

An ethical framework

- The office of the PHO developed an EVD ethical decision making framework in August of 2015
- PICNet was asked to form a working group and apply the framework to answer a specific question pertaining to the role of visitors in the care of EVD patients
- Will be incorporated into the provincial EVD plan, should we encounter a case in the future.

Ethical Framework

Priority	Does This Decision	Value Theme	Yes	No	Only if:	N/A
1	Treat all patients in similar situations similarly, (e.g. like as like – small town as other small town	Equity	x			
1	Minimize the risk to care providers of being exposed to Ebola	Care Provider Safety, Well-being and Sustainability	x		The risk assessment is favourable based on the infectiousness of the patient and the capacity/resources of the unit. More staff will be needed to support visiting and more staff will be potentially exposed. Care of other patients should not be compromised with increased workload.	
1	Distribute health care resources, including care provider support, based on need	Equity	x			
1	Ensure patients with EVD symptoms are given the best care (not necessarily treatment) possible	Patient well being	x			
1	Are based on the best available evidence and well-grounded assumptions	Equity	x			
1	Minimize the net harm to the public, (including through the spread of disease, disruption to essential activities and services, etc.)	Community Well-being (solidarity, integrity)		x	We believe that patient, family and caregiver well-being is balanced with the increased risk to the community because patients, family and loved-ones, as well as care providers will be severely emotionally	

http://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/office-of-the-provincial-health-officer/reports-publications/special-reports/ebola-virus-disease-ethical-decision-making-framework.pdf

The Question

- Given EVD patients will be cared for in strict isolation, should family members be allowed to visit? Should they be allowed to visit a very sick patient who is likely to die?
- If a child is infected would we make the same decision?

Ebola Ethical Decisions Working Group

- Joanne Archer – Provincial Infection Control Network, PHSA
- Bruce Gamage – Provincial Infection Control Network, PHSA
- Janice de Heer, Corporate Director Infection Prevention and Control – Interior Health
- Debora Giese, Infection Control Practitioner – Northern Health
- Ruth Dueckman, Clinical Nurse Specialist – Fraser Health
- Patrice Gordon, Nurse Practitioner, Chilcotin Primary Health Services and Canadian Red Cross Emergency Response Unit Nurse in Sierra Leone (Ebola treatment facility)
- Dr. Bonnie Henry, Deputy Provincial Health Officer
- Dr. Dee Hoyano, Medical Health Officer – Island Health
- Jacqueline Per, Director Clinical Quality & Patient Safety – Vancouver Coastal Health
- Karen Roussy, Patient Representative
- Brenda Sawatzky-Girling, Patient Representative
- Duncan Steele, Ethicist/System-Level Ethics – Fraser Health
- Alice Virani, Clinical Ethicist – BC Children's Hospital, PHSA

The Decision

- *Connecting family and loved-ones with patients, of any age, who have a confirmed case of EVD is part of the broader context of providing support to patients and their care providers in a stressful and traumatic, life altering situation. Connecting family, loved-ones and patients through cell phones or other electronic means as well as visual contact through windows poses the least amount of risk for transmission of infection and should be encouraged. Physical visitation of the patient by family/loved-ones is permissible; however the decision is contingent on a favorable case-by-case risk assessment by the patient care team.*

Risk Assessment

- The patient:
  - Infectiousness of the patient:
    - The physical condition of the patient may rapidly change and transmission risk may increase as patient exhibits more symptoms
  - Patient has indicated that they want the visit

Risk Assessment

- Capacity and resources:
  - Physical setting allows enough space for visitor to don and doff safely
  - A health care professional is available to train the visitor on the use of PPE
  - A HCP is available to be in the room to supervise and support the visitor and while donning/doffing
  - PPE supply is available and assessment of future need for PPE has assured that sufficient supply will be available
    - note: priority for PPE is for HCPs providing direct patient care

Risk Assessment

- The visitor:
  - Essential for well-being of patient
  - Able to fit and wear PPE properly
  - Capacity to give informed consent
  - Capacity and willingness to comply with direction
  - Understanding that permission to visit may change based on patient condition

A note of caution

- A visitor, especially a family member, may have received instruction from Public Health to self-isolate or may be under investigation as a potential EVD case. Consultation is required with the MHO to considering/accommodating the visit in this situation.

Key Facts (or assumptions about the facts) - Patients

- Patients will be vulnerable
- They will be sick
- We will treat them differently than other patients
  - In terms of the standard of care and treatment we provide
  - In terms of how we perceive them (we may be scared of them)
- They will experience a lot of distress –
  - fear of EVD
  - concern with ostracism by health care professionals
  - greater social and media scrutiny
  - concern for family

Key Facts (or assumptions about the facts) - Barriers

- There will be physical barriers to accessing the patient
- Staff will have additional physical barriers between themselves and the patient
- Family will have additional physical barriers between themselves and the patient

Key Facts (or assumptions about the facts) - Caregivers

- Caregivers may be feeling scared, conflicted and/or uncertain
- Caregivers will be focused on performing clinical tasks very carefully which may be perceived as less thoughtful or caring to the patient
- Caregivers will be at greater risk of experiencing moral distress – knowing that in certain situations we are not providing the treatments/diagnostics we usually would for a patient presenting with similar symptoms but do not have EVD (e.g. hemodialysis)
- This may affect their interactions/relationship with the patient's family
- There must be an established process in place for caregivers that have concerns or do not agree with decisions to voice them and have them addressed.

Key Facts (or assumptions about the facts) – Care Team

- Only staff deemed essential for the survival of the patient will enter the room.
- There will be a social worker available outside of patient room to assist with interacting with the patient and be responsible for interacting with the family/loved-ones
- Even though we will need to know a lot of psychosocial information to provide care, much of this will fall to the nurses
- There is an assumption that caregivers will have already done some self-reflection around treating a patient with EVD **- how caregivers are feeling should not be assumed** (they will need more support from each other and an established process in the organization to debrief, etc.)

Key Facts (or assumptions about the facts) - Family

- Family may be challenging to manage due to:
  - Language barriers
  - How quickly the situation progresses
  - Complex family dynamics
  - Family may have limited knowledge of health care processes
  - Family members (some or all) are very fearful
  - Public health may have told family members/loved-ones to remain at home (self-isolate) and not to come to the hospital

Ethical Dilemmas

- **This decision does not live up to our commitment to preserve health care provider and community well-being.**
- This decision potentially increases the risk of exposure of more people to EVD and there-by increases the risk of spread to the greater public.
- More health care providers will need to enter the patient room to support physical visitation by loved-ones. This will mean that more health care providers will have an increased risk of exposure to the Ebola virus and for longer periods of time.
- Community well-being will be eroded should a health care provider or visitor acquire EVD.

Justification

- This is justified because:
  - We believe that the increased risk of exposure to health care providers and the community is balanced with patients, family and loved-ones as well as care providers' risk of severe emotional trauma caused by a policy that uniformly and arbitrarily prohibits physical visiting of EVD patients.

Balancing harms

- The harm that comes from not living up to these commitments can be minimized by:
- Ensuring that family, loved-ones and patients understand that communications through cell phones or other electronic means as well as visual contact through windows, if possible, poses less risk of transmission and is preferred and encouraged so that the need for physical visitation can be minimized.
- Ensuring that all patients, family and caregivers fully understand the risks involved, consent to physical visitation and that a risk assessment is done on a case-by-case basis to ensure that the risk can be minimized.
- Ensuring that all visitors and health care providers are skilled at donning and doffing PPE and are supervised each time they do this.
- Ensuring that all family and caregivers know how to and are able to self-monitor for three weeks following their last encounter with the patient and that they know what to do if they develop symptoms.

Contingent Actions

- Ensure that patients and families understand the reasons for the decisions where care and treatment decisions have to be made that do not align with their values and beliefs, that there is an opportunity for them to respond and, if they choose, appeal through a pre-determined channel.

- Ensure there is adequate support for our health care team members involved in caring for patients with EVD and provide avenues for care providers to communicate and share their perspectives with facility leadership in an informed, thoughtful way.

Requirements

- All possible mechanisms known to be effective in preventing transmission of Ebola virus disease to be in place to protect the health care providers, family and loved-ones.
- Consistent application across the province, support at the provincial level, and consistency with other decisions that have been made in regard to EVD patient, family and loved-ones care.
- A clear and transparent communication process is in place and the patient, family, loved-ones, care providers and the public are kept advised.

Who has the final word?

- Based on a risk assessment, visitors may be restricted from visiting an EVD patient.
- The care team, in consultation with the patient's family and loved-ones, may decide it is inappropriate for certain people to visit, or visitors may be restricted to one or two specific people in the family.
- Reasons for this decision need to be communicated to the patient, family and loved-ones in a clear, honest, transparent manner.
- Support should be given for those members not able to visit so they can communicate with the patient through cell phones or other electronic means.
- The decision to allow visitors may change if the patient's condition changes. This will be based on the care team's risk assessment. Reasons for the revised decisions will need to be communicated to the patient, family and loved-ones in a clear, honest, transparent manner.

Questions ??

bgamage@phsa.ca