

# Ethics of Outbreaks Position Statement. Part 2: Family-Centered Care

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**Objectives:** Continue the dialogue presented in Ethics of Outbreaks Position Statement. Part 1, with a focus on strategies for provision of family-centered care in critical illness during Public Health Emergency of International Concern.

**Design:** Development of a Society of Critical Care Medicine position statement using literature review, expert consensus from the Society of Critical Care Medicine Ethics Committee. A family member of a patient who was critically ill during a natural disaster served on the writing panel and provided validation from a family perspective to the recommendations.

**Setting:** Provision of family-centered care and support for patients who are critically ill or who have the potential of becoming critically ill, and their families, during a Public Health Emergency of International Concern.

**Interventions:** Communication; family support.

**Measurements and Main Results:** Family-centered interventions during a Public Health Emergency of International Concern include understanding how crisis standards may affect regional and local traditions. Transparently communicate changes in decision-making authority and uncertainty regarding treatments and outcomes to the family and community. Assess family coping, increase family communication and support, and guide families regarding possible engagement strategies during crisis. Prepare the public to accept survivors returning to the community. (*Crit Care Med* 2018; 46:1856–1860)

**Key Words:** decision-making; disease outbreaks; ethics; family-centered; moral duty; nursing; public health

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The purpose of this position statement is to continue the dialogue from Part 1 (1) with a specific focus on the provision of family-centered care in critical illness during a public health disaster.

This report was constructed by literature review, and validated by a family member of a patient who was critically ill during a public health disaster. The Ethics Committee of the Society of Critical Care Medicine (SCCM) iteratively reviewed and approved the document during development and approved the recommendations by expert consensus. Recommendations were further approved through the SCCM leadership team. The SCCM for providing critical care within the context of a shared decision-making model. This is especially important in serious outbreaks of disease such as Ebola. Those supporting an endangered country/region/segment of society in a Public Health Emergencies of International Concern (PHEIC) must be cognizant of avoiding a paternalistic stance. Further, it is important to understand how families and communities are structured and the regional/local traditions that affect public discourse.

Decision-making in the diverse cultural milieu of the affected region(s) must be acknowledged and respected despite competing priorities. The American Academy of Pediatrics has recommended that family-centered care (FCC)

be provided during mass critical care disaster (3). Although mass critical care disasters are similar to emerging outbreaks, the nature of infectious disease complicates provision of FCC even further. In accordance with the respect for persons (autonomy), SCCM/American College of Critical Care Medicine advocates for providing critical care within the context of a shared decision-making model (4). Further, a joint statement between SCCM and the American Thoracic Society has recommended that healthcare providers (HCPs) default to a shared decision-making model and then further refine the approach to decision-making following an assessment of patient/family wishes and values for involvement (2). In shared decision-making, medically appropriate options for care are outlined, and decisions are made together between the patient or their surrogate and the provider. In an emerging outbreak, aspects of patient/family involvement in decision-making, and individuals' rights to self-determination, are threatened on many levels and may be replaced by crisis standards, a paternalistic decision-making model (5, 6). Competing priorities exist in all elements of crisis management complicating efforts to sustain patient-centered care/FCC. Herein we will address, explore, and make recommendations regarding decision-making and outbreaks, respect for family presence and engagement, and maintaining family integrity through a crisis such as an emerging outbreak.

## SEARCH STRATEGY

The SCCM reworks account for FCC including all known citations for family, and ICU or intensive care was searched for relevant manuscripts on topics of postintensive care syndrome-family (PICS-F), shared decision-making, and family integrity.

PubMed was searched iteratively for combinations of family (outbreak or pandemic or PHEIC or Ebola), (ICU or intensive care or critical care), ethics, (decision-making or [visit\* or family presence]), survivor syndrome resulting in 188 citations. After deleting duplicates and those that were off topic, 13 citations were found to have information that could inform this document within the context of critical care.

Articles were selected from these searches that matched the topic of FCC in ICUs during outbreaks. Background manuscripts describing FCC are cited as indicated for topic introduction. We explore the following:

- 1) Decision-making and outbreaks,
- 2) Respect for family presence and engagement, and
- 3) Maintaining family integrity through crisis.

## DECISION-MAKING AND OUTBREAKS

During an outbreak governmental authorities take over a proportion of medical decisions (7). For instance, if a medical worker is volunteering in a resource-poor country and contracts the disease, one of the first decisions is whether or not to evacuate to the country of origin. Timely evacuation may

affect health outcomes because resuscitation in diseases such as sepsis, for instance, is time sensitive. Government officials on both sides have input into the decision to evacuate instead of the patient/family or even medical providers. Medical specialists should collaborate with governmental agents and public health officials during decision-making (8). The public at large should be informed when decisions are made through crisis standards (8, 9).

Evacuation decisions can be complicated. Should victims who originate from resource-intensive nations be evacuated whereas others die? Should those who volunteer in known risky situations receive the resources of evacuation when others native to the region do not have basic medical supplies for resuscitation (10)? Or should they be repatriated to decrease the burden of their illness on the resource-poor country? These questions cannot be answered on a personal level and require societal agreement to conditions, terms, and transparency about decisions (11). Such answers require analysis of context; values, available resources, burdens, and benefits cannot be preordained in a one-size fits all standard.

For those evacuated from resource-poor areas to receive superior care elsewhere, the patients and their families may experience distress in the form of survivor's guilt or depression (12). Healthcare workers need to be available to listen to patients or families experiencing guilt and support them as they work through this iterative process. Such a decision may be governmentally controlled. A declination of a family's preferential request for care may cause distress/anger. In PHEIC, the decision of where to receive healthcare is not made by the critically ill patient's family, as it would be in other situations. Communication needs to be increased when decisions cannot be shared. In the American College of Chest Physicians (ACCP) consensus statement for PHEICs, it is recommended that decisions made through a crisis standard be communicated to patients and their families so that there is complete transparency of the process (5, 6). Disaster preparedness programs need to preestablish a structure for providing information to families who are geographically separated from their disease-affected family member (13).

Decisions regarding distribution of resources and rationing will occur if the need for resources exceeds capacity. Clinicians executing clinical decision-making during a crisis may also need to make decisions in the best interest of the public, rather than the individual, thus sacrificing autonomy and normal civil liberties of the patient and family. More specifically, authorities may infringe on autonomy by demanding the administration of a vaccine or encroach on civil liberties by enforcing quarantine (1). Where to draw the line for the common good, or what is permissible, may be unattainable or unanswerable until a particular threat presents itself. Describing the rationale for these decisions with those affected is an important part of the process (14).

The ability to share in decision-making is also affected because there is less certainty about medically appropriate

options (15). There can be dissonance between the need to take action and the sense that action should be evidence-based (15). Following the severe acute respiratory syndrome (SARS) pandemic in Canada, it was recommended that a “precautionary principle” be deployed during decision-making in future pandemics. The precautionary principle supports action to reduce risk prior to scientific certainty (15). In contrast, U.S. government health officials caution that premature use of untested therapies may cause mass harm (16). The balance point between action and preventing harm is not known.

Panic, anxiety, and uncertainty are heightened during an outbreak. Provider confidence is compromised in proportion to what is known about the available treatments, and relinquishing control may be difficult. This creates a situation of needing to act autocratically in a time-sensitive crisis.

Because of the overt uncertainty, some families that may have preferred a shared decision-making model, now expect a paternalistic approach. Conversely, a paternalistic approach (such as that used during implementation of crisis standards), although instilling a sense of order may also breed mistrust if the family is accustomed to involvement in medical decision-making. Where the opportunities for involvement in decision-making are limited, good communication is needed. It is important that there is transparency around decision-making. It has been suggested that engaging the public prior to a disaster is indicated to: 1) develop better disaster plans, and 2) prepare the public. Advanced preplanning and bidirectional dialogue will prepare the public for the loss of autonomous or shared decision-making during an outbreak (with or without consensus) (17–19).

Treating patients in outbreaks creates a high profile situation. Decisions are not only scrutinized by medical colleagues, but also by the media and government. In dealing with an emerging outbreak, providers may fear retribution for mishandling cases. The fear of retribution may be so intense that it makes those involved feel as if mistakes could be career altering. This pressure may lead to an instinctive overprotective mechanism of sheltering (vs sharing) of information. This decreased communication, born from fear, may also decrease patient/family information that limits trust building when patients and families need it most. With respect to these issues, including ethicists when planning for disasters, and during the event (due to anticipated conflict of values), is very important (5, 6).

It is important to remain open to advice from others and seek advice from outside normal patterns of consultation because of situational uncertainty. The person with the most experience in handling the situation may be in another state or country. Reaching out may either validate the uncertainty of the situation or provide new insight from which to direct care.

## RESPECT FOR FAMILY PRESENCE AND ENGAGEMENT

The core concepts of FCC include, among others, patient and family participation in medical decision-making and collaboration between the patient and family, and the healthcare

system in the delivery of medical care. This closely cooperative collaboration benefits patients, families and medical care providers, but may also present challenges in the form of required or the perceived requirement of isolation in the case of an outbreak. The Pediatric Emergency Mass Critical Care Task Force acknowledges the family as a cohesive unit and encourages the housing and close physical proximity of family and patient, including during bedside rounds and procedures (3). In many cases, the family may have the most accurate information regarding the patient’s baseline status, modest changes from baseline and current needs.

An outbreak or disaster brings to the forefront the five basic emotional needs of people: to feel safe, calm, connected; to feel a sense of efficacy; and to feel hope (20). These needs are disrupted by fear and/or separation (natural or enforced). The precautionary principle invokes that it is not necessary to have fully validated evidence in order to institute policies that reduce risk to the public (15); many governmental bodies have declared isolation for outbreaks in one form or another, with the intent to protect public safety. When combined with the human tendencies toward fear and separation anxiety, these mandated requirements might increase skepticism, fear, and anxiety in those isolated from family.

Respect for persons, and the patient or family’s desire to have proximity and information can be challenged in an outbreak. Government officials and medical authorities may perceive that they need to have strong validated data and full knowledge of the anticipated risks before communicating with the family. In reality, families appreciate honest communication, even if there is uncertainty. Good communication is the key because their usual rights given by the hospital will be suspended during times of disaster or crisis, and what will be allowed will be explained on an ongoing basis.

Some families will experience both acute stress during a period of critical illness, as well as posttraumatic stress disorder (PTSD) months later. PTSD may not correlate with the severity of the patient’s illness, but with the perceptions of mortality risk (21). Communication and trust building can serve to reassure family members in the setting of their inability to be in close proximity during isolation. It can also help the medical team to understand the level of understanding and fears of the family, in order to intervene in an effective manner.

In an outbreak, the patient is the first priority, but family health and well-being is also an important priority. The health of the family depends on multiple components, including biological, psychologic, spiritual, sociological, aesthetic, and cultural aspects of their lives and the impact of the crisis of their loved one (22). In order to effectively approach and address family wellness, an effort must be made to determine the family structure, strengths, relationships, and particular needs.

Supportive strategies should be presented to the patient and family. These may include but are not limited to psychologic support, diary formation, keeping other family members, and friends informed, use of computerized technology to e-visit and promote e-presence. Patients have expressed less suffering with a significant level of family involvement and social support (22).

The family may engage in coaching activities when provided with a means to communicate directly with the patient.

The impact of isolation is heightened bidirectionally when the patient cannot see outside of the room and the family cannot see in. When constructing care and isolation units, consider choosing or building the space to include a viewing window for patients and families to see each other, in addition to a window to view the outside world.

In outbreaks, although respect for persons is acknowledged, priorities may change for the sake of improving the well-being of the masses. The decision to isolate a patient, while protecting public safety, may have far-reaching implications when perception is fueled by fear and ill-informed media. If the public is not informed as to knowledge and uncertainty, mistrust in the system can result, just as it may with families resulting in avoidance behaviors such as not seeking medical attention when indicated. A misinformed public could result in a delay in controlling the outbreak. Families and patients may be ostracized because of the public's inaccurate perceptions of risk. The goals of protecting personal autonomy and promoting community well-being may create stress for the family as well as the patient with respect to isolation due to the inability to be with each other. Stress following discharge from a critical illness is common but may be heightened during the reemergence of the patient and family into the mainstream. The public needs to be informed regarding why the decision to discharge is safe so that the patient and family will be welcomed back into their communities. If the family is strong in their relationships and have good support systems in place, they may cope through an outbreak crisis without external resources. Other families may need additional help in coping with the stresses.

## MAINTAINING FAMILY INTEGRITY THROUGH CRISIS

Families under the stress of critical illness are prone to anxiety, depression, PTSD, and complicated grief (in the bereaved) (23). These issues may persist past the hospitalization or death of the critically ill patient and a family such as this is described as a PICS-F (24). The exposure to critical illness and resultant caregiving burden may also cause financial stressors and strain on family roles and marriage (25, 26). Uncertainty negatively affects the ability to cope (27).

It is recognized that patients have long-term psychologic issues following survival from outbreak (28). Very little is known about psychologic health of families following outbreak. In one small study of family members of patients hospitalized during an influenza pandemic, anxiety, and depression were found at similar rates to previous studies of ICU families. Contrary to previous studies of other critical illness, the stress increased with age of the family member (29). In another small study conducted 1 year following SARS, both patients and their family members reported significant reduction in mental health (30).

When interviewed, families expect support in maintaining family integrity during the crisis of critical illness (31, 32). Family integrity is best preserved through dignity and control (33).

Normally, the family stressors stimulated by exposure to critical illness may be mediated by involvement in shared decision-making, communication, family involvement, and family presence. We have described how all of these mechanisms are limited during outbreak. Supportive measures have a heightened importance and demonstrate respect for persons, which may in turn help to preserve family integrity. Those supportive measures offered during routine critical illness should be offered during outbreak. The use of ethics, social service, and palliative care consults are endorsed by the ACCP consensus state on PHEICs and should be offered understanding that individual family preference for use of these services may vary (5).

Providers often question how deeply to engage in family issues. If enough communication is occurring, the provider should be able to assess whether or not the family members are coping with the situation and whether or not there is intra-family strain. An assessment of family dynamics is indicated. Providers should acknowledge family strain when it exists, engage in listening, provide support and reassurance, answer questions, and provide advice as needed. This obligation to provide family care is not replaced by referral to supportive services.

## RECOMMENDATIONS

- 1) Honestly disclose the unknown/uncertainty and have a low threshold to seek external advice in the setting of a rare disease causing a PHEIC.
- 2) Describe to the patient/family how decisions are being made and by whom, and how this process is different in light of the PHEIC and a rare disease.
- 3) Increase patient/family communication, including frequent care conferences. Explain why shared decision-making, while typically the standard, may not be possible and allow opportunities for families to communicate their concerns as well as to be involved in public crisis planning.
- 4) Anticipate and be sensitive to families' self-protective behaviors (e.g., distancing themselves from each other, the medical team or the patient) that may be particular to the nuances of a PHEIC and fear of public judgment (20).
- 5) Include family coping in daily assessment, providing listening, supportive reassurance, advice, and answering questions, with particular attention to the loss of typical avenues of support in light of a PHEIC and the attendant fears in society (22).
- 6) Build a program of FCC to offer supportive services particular to the unique challenges of a PHEIC, such as:
  - a) Diary or blog development, cards, or letters of healing,
  - b) Social service referral (family dynamics and financial counseling),
  - c) Pastoral care,
  - d) Behavioral health consultation,
  - e) Palliative care, and
  - f) Ethics consultation.

- 7) Consider basic architectural standards such as a window for family members and patients to see each other through when strict isolation is mandated by the contagious nature of the disease.
- 8) Provide education on family care within disaster preparedness programs for healthcare workers.
- 9) Support and foster further research to evaluate decision-making, trust-building, communication, and ICU design strategies during outbreaks resulting in critical illness.

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