Beth Israel Lahey Health
Beth Israel Deaconess Medical Center

Creating a Shared Model: Patient/Family Advisor Input into Crisis Standards of Care

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Introduction/Problem

- As the first COVID-19 surge in early 2020 threatened to overwhelm health care system resources, the prospect of potentially needing to implement Crisis Standards of Care (CSOC) loomed over Hospital Incident Command (HICS) teams.
- CSOC provides a process for allocation of scarce resources (i.e., when demand for certain resources is greater than the supply of those resources) that is fair and equitable, and meets the values of the communities impacted by the CSOC.
- Accordingly, leaders at BIDMC quickly recognized the critical importance of engaging patients and families from across the Beth Israel Lahey Health (BILH) network to explore how they would understand and respond to CSOC, and how best to communicate about such changes.

Aim/Goal

Convene Patient/Family Advisors (PFAs) from BILH institutions to:

- Solicit their feedback about the Massachusetts Department of Public Health (DPH) and proposed BILH CSOC guidelines, which were developed based on DPH guidelines.
- Gather their suggestions about how best to communicate about CSOC should they ever need to be implemented.

The Team

- David Sontag, BILH Managing General Counsel, BIDMC Ethics Advisory Committee Co-Chair
- Lauge Sokol-Hessner, MD, Med/Surg Physician Leader for BIDMC HICS, Senior Medical Director of Patient Safety, Department of Health Care Quality, BIDMC
- Barbara Sarnoff Lee, LICSW, Senior Director of Social Work and Patient & Family Engagement, BIDMC
- Melissa Doyle, LICSW, Patient & Family Engagement, BIDMC
- Patient/Family Engagement Leaders from across BILH
- Patient/Family Advisors from across BILH

The Interventions

- BIDMC Patient/Family Engagement (PFE) & BIDMC/BILH CSOC Leaders quickly identified the most optimal PFA engagement strategy and functioned as a centralized planning team supporting other BILH PFE leaders in recruiting their PFAs by providing background and sample scripts to increase buy-in to the project.
- Ultimately, PFAs from all BILH entities were invited to attend a two-part series:
  1. Large group presentation defining & outlining DPH guidelines & publicly available CSOC communication strategies
  2. Smaller group bidirectional listening sessions where PFAs offered feedback, posed questions, and made suggestions
- In advance of the listening sessions, PFAs were asked to reflect on the following questions and were encouraged to bring their own:
  1. *The stated goal of the crisis standards of care is "to maximize benefit to populations of patients, often expressed as doing the greatest good for the greatest number," which it does by giving priority for critical care resources to patients who are most likely to survive with treatment to hospital discharge and in the near term after discharge (i.e., beyond five years). Does this seem like a fair approach?*
  2. *Imagine if your loved one was admitted with COVID and didn't need a ventilator at the time of admission, but might need one in 1-2 days. How would you suggest we describe to patients and families what CSOC are, and what it might mean for them?*
  3. *Now imagine that your loved one who was admitted with COVID gets sicker and warrants being placed on a ventilator, but unfortunately the Decision Team is unable to allocate them a ventilator because there are too few ventilators, and your loved one's Priority Score is too high relative to the other patients who need ventilators. How should we communicate such decisions to patients and their families?*

Results/Progress to Date

- >100 BILH Patient Family Advisors (PFAs) and staff joined the initial presentation; ~45 PFAs and the staff authors engaged in the 4 subsequent listening sessions.
- Participants were primarily white women. All sessions were conducted in English. The lack of racial, ethnic, sex, and language diversity *was* reflective of current PFAC membership, but it *was/is not* reflective of BILH's general patient population.
- PFAs acknowledged that allocation of resources is a difficult topic and offered opinions around fairness, communication needs, advantages & disadvantages of the allocation framework, and the emotional impact of CSOC. See next slide for more details.

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More Results/Progress to Date

Dominant themes from PFAs

Fairness: PFAs considered alternative allocation frameworks, but in general, agreed that the proposed framework (focused on maximizing lives and life-years saved) was acceptable, **so long as it did not disproportionately affect marginalized and vulnerable populations**. PFAs noted the importance of considering spiritual needs.

Communication: PFAs identified two major areas of communication needs:

1. **General communication about CSOC**
   - **When CSOC are imminent**, this must be communicated to the general public. Different communities may benefit from different media strategies. Key points: what CSOC entails, why CSOC may be needed, what the public can do to help avoid CSOC, and how CSOC guidelines were developed.
   - **If CSOC are implemented**, additional communication, especially for patients/families entering hospitals, will be necessary. Key points: CSOC are coordinated with other regional health systems and all hospitals follow the same guidelines. The amount and detail of information conveyed should be titrated to meet a range of patient-family information preferences.
2. **Communication with patients/families when the patient would not be receiving a scarce resource based on the CSOC allocation guidelines**
   - Focus on communication skills; pre-emptively provide health care professionals the training and tools they need to most effectively and empathically communicate with patients/families (e.g. Vital Talk framework for talking about CSOC), recognizing the value of multi-disciplinary groups that can provide both medical information and emotional support.

Continued…

- Communicate early and often, in culturally sensitive ways, about (A) the people and processes that make allocation decisions, emphasizing that allocation decision teams take into account each patient's unique situation and are separate from treating teams, (B) that despite any unfavorable allocation decisions, all other available medical care will still be offered whenever appropriate, and (C) any additional resources.

Need for More Advance Care Planning: PFAs appreciated that allocations should be consistent with the patients' values and preferences (to the extent possible), and recognized the need to better engage in advance care planning conversations with primary care providers and family members, prior to any suffering any serious illness.

Lessons Learned

- It is critical to engage patients/families *early* when working on time-sensitive challenges that may significantly impact their health and care experience
- To encourage a diversity of perspectives, take a system-wide approach, and continually work to find ways to better engage underrepresented and unrepresented populations
- When the topic is complex and emotionally charged, *first* make time to explain the topic, *then* allow time for absorption, *then* elicit feedback

Reflections from CSOC Leaders

Next Steps

- Should CSOC ever be imminent or actually implemented, consider iterative testing and revision of communication materials and tools with patient/family advisors
- Consider proactively using a similar collaborative model between health system and patient-family engagement leaders to address other challenging/sensitive topics that arise

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