A Conversation on Ethical Considerations for a Fair and Effective Health Care System

October 24, 2018
Today’s Moderator:

Christopher Stille MD, MPH

Professor of Pediatrics and Section Head, General Academic Pediatrics, University of Colorado School of Medicine, Children’s Hospital Colorado
A SUPPLEMENT TO PEDIATRICS

Building Systems That Work for Children With Complex Health Care Needs

Rishi Agrawal, MD, MPH, Christopher Stille, MD, MPH, Editors

Sponsored by the Lucile Packard Foundation for Children’s Health.

Based on follow-up from a symposium held December 7-8, 2015, Washington, District of Columbia.

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Ask Questions!

We look forward to a lively discussion with our audience.
Enter questions in the GoToWebinar question box.
Meet Our Speakers

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Ethical Framework for Risk Stratification and Mitigation Programs for Children with Medical Complexity

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Perelman School of Medicine at the University of Pennsylvania
Director, Department of Medical Ethics
The Children’s Hospital of Philadelphia
Ethical Framework for Risk Stratification and Mitigation Programs for Children With Medical Complexity

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abstract

Those in hospitals and health care systems, when designing clinical programs for children with medical complexity, often talk about needing to develop and implement a system of risk stratification. In this article, we use the framework of an ethical evaluation of a health care program to examine what this task of risk stratification might entail by identifying specific and detailed issues that require particular attention and making a series of recommendations to help ensure that programs for children with medical complexity avoid potentially ethically problematic situations and practices.
Ethical Framework for Risk Stratification and Mitigation Programs for Children With Medical Complexity

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FIGURE 1
Characteristics of risk stratification and a risk mitigation program.
<table>
<thead>
<tr>
<th>Ethical Consideration</th>
<th>Questions</th>
</tr>
</thead>
</table>
| Transparency                                     | - What is the underlying purpose and justification for the program? Is this purpose ethically appropriate? Our argument is that the chief justification should be that the program benefits patients and families, largely by lowering the risk of undesired events or outcomes.  
- From whose perspective is the program evaluated: patients, families, health care systems, payers? |
| Clarifying potential benefit                     | - What is the specific undesired outcome that is being targeted when seeking to reduce the risk? The target might be a decline in a child’s health, functioning, development, or quality of life; unmet health care needs; the parents’ and family’s function and quality of life; or excess health care use and cost.  
- Whose values and priorities does the selection of the target risk or outcome reflect? |
| Benefit via effectiveness                         | - Is the program effective in reducing the risk and improving outcomes? Ineffective programs are ethically problematic.  
- How is the program’s effectiveness being evaluated? The program’s effectiveness should be evaluated regarding how well the program lowers or otherwise improves the target risk. |
| Potential burdens and costs                       | - What are the costs of creating and maintaining an accurate risk stratification model?  
- Who will bear the burdens and costs of the risk mitigation program? Will the burdens and costs be fairly distributed? |
| Fairness, effectiveness, and accuracy            | - How accurate is the predictive model at estimating the probability that a given individual will, in the future, experience the specific event or outcome? Inaccuracies can threaten fairness and erode effectiveness.  
- How is risk estimated? Is it by a clinician, an algorithm, or some other means? |
| Fairness of distribution                         | - Will the probability of risk be stratified fairly and not in an arbitrary fashion?  
- Will the greatest risks or burdens align with the greatest potential for benefit from the intervention?  
- Does the program unnecessarily burden families with less financial or social resources? |
| Fairness of processes and respect for autonomy    | - Does the program have a formal, auditable complaint process and appeals process?  
- How does the program inform parents about the program and obtain consent to enroll a patient? |
| Potential unintended harm                         | - Will a classification of medical complexity be used inappropriately, resulting in less or worse care?  
- What are the potential consequences of program termination? |
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Potential Benefits and Burdens or Harms

• Clarifying potential benefits
  • Range of potential benefits – what’s the program’s focus?

• Benefits via effectiveness
  • Does the program have evidence of effectiveness?

• Potential burdens and costs
  • What are the time commitments or costs of participating?

• Potential unintended harms
  • What will happen if the program ends?
<table>
<thead>
<tr>
<th>Domains</th>
<th>Specific Risk Events or Outcomes</th>
<th>Comments and Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care use</td>
<td>ED visits</td>
<td>These are common targets of CMC programs.</td>
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<tr>
<td></td>
<td>Rehospitalizations</td>
<td>Are all ED visits or rehospitalizations targeted or just the preventable ones?</td>
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<tr>
<td></td>
<td>Unnecessary testing</td>
<td>How are preventable or unnecessary defined?</td>
</tr>
<tr>
<td></td>
<td>Costs</td>
<td>Do costs include the potential costs shifted onto families?</td>
</tr>
<tr>
<td>Medical outcomes</td>
<td>Patient death</td>
<td>These are all important bad outcomes.</td>
</tr>
<tr>
<td></td>
<td>Specific patient morbidity</td>
<td>However, care must be taken to not create perverse incentives whereby programs are</td>
</tr>
<tr>
<td></td>
<td>Medication errors</td>
<td>disinclined to enroll patients who are at the highest risk of these outcomes.</td>
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<td></td>
<td>Hospital-acquired infections</td>
<td></td>
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<td>Psychosocial outcomes</td>
<td>Child-patient school absences</td>
<td>A variety of adverse psychosocial outcomes are also important for the child, parents,</td>
</tr>
<tr>
<td></td>
<td>Caregiver stress, anxiety,</td>
<td>and family overall.</td>
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<tr>
<td></td>
<td>depression</td>
<td>How is the program assessing this domain of outcomes?</td>
</tr>
<tr>
<td></td>
<td>Family financial strain</td>
<td></td>
</tr>
<tr>
<td>Parental work of care</td>
<td>Hours spent providing hands-on</td>
<td>Parents perform most of the tasks required to care for CMC.</td>
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<tr>
<td></td>
<td>care</td>
<td>Is the program monitoring the impact on parents work of care and the consequences of</td>
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<tr>
<td></td>
<td>Disruption of nighttime sleep</td>
<td>changes in parental work of care?</td>
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<tr>
<td></td>
<td>Absences, leave, or stopping work</td>
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<td>Logistical tasks</td>
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<td>A sizable portion of the CMC work of care involves logistical tasks.</td>
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<tr>
<td></td>
<td>services</td>
<td>How is the program measuring and evaluating the intervention’s impact in this domain?</td>
</tr>
<tr>
<td></td>
<td>Scheduling multiple appointments</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transportation difficulties</td>
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| Health care use       | • ED visits  
• Readmissions  
• Unnecessary testing  
• Costs                                                              | • These are common targets of CMC programs.  
• Are all ED visits or readmissions targeted or just the preventable ones?  
• How are preventable or unnecessary defined?  
• Do costs include the potential costs shifted onto families? |
| Medical outcomes      | • Patient death  
• Specific patient morbidities  
• Medication errors  
• Hospital-acquired infections                      | • These are all important bad outcomes.  
• However, care must be taken to not create perverse incentives whereby programs are disinclined to enroll patients who are at the highest risk of these outcomes. |
| Psychosocial outcomes | • Child-patient school absences  
• Caregiver stress, anxiety, depression  
• Family financial strain                             | • A variety of adverse psychosocial outcomes are also important for the child, parents, and family overall.  
• How is the program assessing this domain of outcomes?        |
| Parental work of care | • Hours spent providing hands-on care  
• Disruption of nighttime sleep  
• Absences, leave, or stopping work                        | • Parents perform most of the tasks required to care for CMC.  
• Is the program monitoring the impact on parents’ work of care and the consequences of changes in parental work of care? |
| Logistical tasks      | • Approvals for equipment or services  
• Scheduling multiple appointments  
• Transportation difficulties                              | • A sizable portion of the CMC work of care involves logistical tasks.  
• How is the program measuring and evaluating the intervention’s impact in this domain? |
**Fairness Considerations**

- **Accuracy:**
  - Is the process by which patients and families get access to the program based on an objective measure that accurately identifies who should be enrolled?

- **Disparities regarding Benefits or Burdens:**
  - Does the program inadvertently benefit (or burden) some patient and families more so than others?
  - Are these differences tied to socioeconomic status?

- **Complaint or Appeal Process:**
  - Does the program have a well-defined process of handling complaints or appeals?
Transparency

• Program goals and focus
  Are these clearly articulated? In writing? In public view?

• Program elements and expectations
  Ditto

• How the program is being evaluated?
  Ditto
### Use Systems Thinking

- **Explanation and Rationale:**
  - CMC are part of a system of care that involves the parents, family, many aspects of the health care system, as well as other systems (such as schools).
  - Because all elements of these systems interact, an intervention focused on 1 part of the system may well have consequences, intended or unintended, on other parts of the systems.

### Specify Program Goals

- **Explanation and Rationale:**
  - This action enhances the transparency of the program.
  - Doing so also provides a basis for accountability.

### Detail the Intervention

- **Explanation and Rationale:**
  - This enables stakeholders to evaluate the benefits and burdens of the intervention.
  - This promotes voluntary and autonomous decision-making regarding participation.

### Assess the Accuracy of Case Identification

- **Explanation and Rationale:**
  - This helps gauge an important aspect of the program’s ability to benefit CMC in a fair manner.
  - This ensures that the selection meets stated program goals and values.
  - This helps identify and reduce bias in the selection of participants.

### Adopt Formal and Auditable Consent and Appeal Processes

- **Explanation and Rationale:**
  - Informed consent is a cornerstone of ethical interventions.
  - The appeals process promotes procedural fairness.

### Make Program Features and Performance Metrics Publicly Available

- **Explanation and Rationale:**
  - Transparency is enhanced by open communication.
  - Accountability is strengthened.
Use Systems Thinking

Engage Patient, Parents, and Families

Specify Program Goals

Specify Anticipated Benefits, Burdens, and Costs

Detail the Intervention

Assess the Accuracy of Case Identification

Adopt Formal and Auditable Consent and Appeal Processes

Make Program Features & Performance Metrics Publicly Available

**TABLE 3** Recommendations for Programs for CMC and Ethical Reasons for Recommendations

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Explanation and Rationale</th>
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<tr>
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<td>Engage patients, parents, and families</td>
<td>- Because patients and parents are the key stakeholders regarding the health and well-being of the patient, their perspectives, values, and priorities should guide the value proposition of a program.</td>
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<tr>
<td></td>
<td>- Doing so helps ensure that the program serves the interests of the intended beneficiaries.</td>
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<tr>
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<td>- Engagement also helps to ensure acceptability and feasibility.</td>
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<td>Specify program goals</td>
<td>- This action enhances the transparency of the program.</td>
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<td>- Doing so also provides a basis for accountability.</td>
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<tr>
<td>Specify anticipated benefits, burdens, and costs</td>
<td>- Benefits and burdens are key ethical considerations.</td>
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<td>- One goal is to promote fairness in the distribution of benefits and burdens.</td>
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<tr>
<td></td>
<td>- Cost is an ethical consideration regarding justice concerns and the stewardship of scarce resources.</td>
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<tr>
<td>Detail the intervention</td>
<td>- This enables stakeholders to evaluate the benefits and burdens of the intervention.</td>
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Detail the Intervention

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Make Program Features & Performance Metrics Publicly Available
Thank you for your attention

Questions can be asked at the end of all the presentations
Key Thoughts

• Implicit biases – are we correcting enough when creating a new system?

• Social determinants of health – which ones should CMC programs address and for whom?

• Societal attitude on fairness – what factors can change society’s perception of CMC deservedness?

• Do clinicians have moral neutrality (equipoise) when advising families of CMC regarding end of life options and care?
Chaplain Mark Bartel, M.Div, BCC
Manager, Spiritual Care, Arnold Palmer Medical Center

Key Thoughts

• Extrapolate

• Each one take one: sharing the risk

• Expect the Unexpected
Submit your questions in the question box

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Upcoming Conversations

A Conversation on the Effect of Payment Models in Children’s Health Care
November 7, 2018

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