

Disposition Decisions in Cases of Medical Complexity and Health Inequity

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The question of optimal disposition for children with complex medical and social circumstances has long challenged the well-intentioned clinician. The coronavirus disease 2019 pandemic created unique difficulties for patients, families, and health care providers, in addition to highlighting long-standing racial and socioeconomic inequities in health care. In pediatric hospitals, necessary public health measures such as visitor restrictions shifted many shared decision-making processes such as discharge planning from complicated to impossible. Here, we present the case of a medically complex adult (with a long-standing pediatric condition) whose surrogate decision-maker objected to discharge to a long-term care facility because of restrictions and risks associated with the coronavirus disease 2019 pandemic. We offer the commentary of experts in clinical ethics, intensive care, inpatient subacute care, and palliative care. Our discussion includes analysis of the ethical considerations involved in the case, concrete guidance on steps toward an ethically permissible discharge, and suggestions for how a health equity lens can improve communication and decision-making for families who are victims of systemic racism and economic discrimination.

abstract

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Disposition planning for children with complex medical conditions is a challenge for pediatricians and pediatric subspecialists in many settings. Providers are tasked with balancing the patient's medical needs with the practical and emotional needs of the family. The coronavirus disease 2019 (COVID-19) pandemic has made it increasingly hard to strike this balance. It has introduced novel ethical conflicts and forced difficult sacrifices. These burdens, like so many others brought on by the pandemic, fall disproportionately on patients who are already victims of racial and socioeconomic inequity. We present the case of a patient hospitalized during the pandemic whose family and care team are faced with only undesirable options for discharge. We ask which of these is most ethically permissible and discuss actions to facilitate communication and decision-making in this situation.

THE CASE

Teresa is a female aged 32 years with ataxia-telangiectasia who has received care at a children's hospital all her life. In the summer of 2020, she presented to this pediatric hospital with altered mental status. Diagnostic evaluation revealed she had experienced multiple hemorrhagic strokes, which substantially worsened her neurologic condition. Before this hospitalization, she was verbal but nonambulatory, with significant cognitive impairment. She now only responds to painful stimuli and requires full support for all activities of daily living. After 5 weeks in the hospital, her neurologic status has not changed. Her doctors think this is her new baseline. She remains gastrostomy tube- and nocturnal BiPAP-dependent, as she was before this admission.

Teresa's mother, Sarah, is her legal guardian, and before this admission, she cared for her at home assisted by 8 hours a day of home nursing. During a pre-discharge visit, a hospital social worker found that their ninth-floor apartment lacks consistent electricity, reliable elevator service, or space for a nurse to sleep, as is required by all local home health agencies. The medical team is concerned that discharge home would not be safe and recommends that Teresa be transferred to a skilled nursing facility (SNF).

This took place in the early days of the COVID-19 pandemic, a time when no SNFs were allowing visitors. Sarah is unwilling to consent to having Teresa transferred to an SNF and insists on taking her home. She has relatives who were neglected at such facilities and fears that this will also happen to Teresa, especially if she cannot visit her. She understands the risks of taking Teresa home and is willing to accept them. She laments that she and her daughter would not be in this situation if they were not poor and Black. When asked to expand on this, she says it is difficult for them to get the care her daughter needs because they are poor, and she feels their health care providers are discriminating against them because of their race.

The medical team requests an ethics consultation to determine if it is permissible to discharge Teresa to home.

DR SHAPIRO, ETHICIST AND PEDIATRIC EMERGENCY MEDICINE FELLOW AND DR MADRIGAL, ETHICS PROGRAM DIRECTOR AND PEDIATRIC INTENSIVIST, COMMENTS

Reaching consensus on a plan of care and an acceptable level of risk for medically complex patients is challenging. Teresa's care team

makes a strong case that, given her new neurologic baseline, her new inability to assist with her cares, and the challenges of a physical space that may not accommodate the nursing assistance she now requires, discharge to an SNF is in Teresa's medical best interest. Receiving the frequent care and rehabilitative services that such a facility can provide would give her the best chance to optimize her health. It would also be the best setting to prevent and mitigate future illness.

Teresa's neurologic disease is likely to steadily worsen and her care become more physically difficult. Were Sarah to take Teresa home, she would be her sole care provider and would be without adequate help from home health workers. She would be at risk for providing suboptimal care for her daughter that may put Teresa at risk for infection, unrecognized hypopnea, or death. A long-term care facility would be able to provide any needed medical care and allow prompt recognition and appropriate treatment of any deterioration in her health. It is understandable why her care team feels this is in her best medical interest.

Best interest judgments, however, must consider more than just medical outcomes. A purely medical lens is an inadequate conception of best interests for this case. This is a unique family and a complex situation. An adequate analysis should consider family interests and weigh potential harms beyond the medical risks.¹ Because of the COVID-19 pandemic, transferring Teresa to an SNF requires an uncommon and dramatic sacrifice from this family. They will be separated indefinitely. Sarah has cared for Teresa daily for 32 years and they undoubtedly share a powerful emotional bond. Asking her to leave Teresa at this vulnerable time introduces a

tremendous emotional burden and raises the frightening possibility that, if her condition rapidly deteriorates, she may not be at Teresa's side at the time of her passing. Similarly, we should not assume that Teresa's new neurologic deficits make her unable to experience the comfort of her mother's presence. Transfer to long-term care may mean she is tragically without her closest connection and strongest advocate for an extended time.

It is also worth considering that, although there are clear medical benefits associated with a long-term care facility, the extent to which these benefits are an improvement from discharge home needs to be considered. Teresa has lived to 32 years of age. The typical life expectancy of patients with ataxia-telangiectasia is 19 to 25 years.² Her mother has beaten the odds to raise her to adulthood with relatively few complications. She consistently receives all her necessary medications and therapies, and she has had few hospital admissions over the past decade. Sarah has demonstrated extraordinary commitment and skill in managing Teresa's health. Despite the expected difficulties of providing care at home, it is not clear Sarah could not rise to meet the challenge as she has consistently done in the past.

In situations where families and health care providers cannot agree on the best interest of a child despite robust and exhaustive attempts at consensus-building, we typically defer to the parent's judgement unless it is clear their preference will significantly increase the likelihood of serious harm when compared with other options.³ In this case, application of this framework, referred to as the Harm Principle, is challenging. There are potential physical and emotional

harms associated with both discharge home and to long-term care. The likelihood and severity of these risks are not clear, nor is the time frame in which they might be suffered. Given the indeterminacy of the harms, we do not see clear justification to deny Sarah her parental authority and would next think critically about what actions and conditions would be prerequisite to an ethical discharge.

First, a time-limited trial at home should include a plan for close follow-up and a robust attempt to optimize conditions in the apartment. This should include arranging outpatient appointments, ongoing attempts to obtain the proper home care through insurance, and legal support to address building issues or find a more suitable apartment. It might also include going so far as to alert the local fire department to the circumstances of this family should there be a power outage or other emergency.

Second, although the medical team may recognize that Teresa would be at risk for dying at home, it is imperative they explore this possibility with her mother and ascertain how that outcome might affect her. The guilt and helplessness of having Teresa die at home with only her at the bedside may lead the mother to reconsider what might be best for both of them.

There are no "good" options in this case. We are left with the prospect of discharging the patient to a suboptimal environment and accepting the real medical (and legal) risks that come with that decision or seeking state intervention to place the patient in an appropriate nursing home that would separate her from her mother indefinitely. In light of Sarah's exceptional track record of caring

for her daughter alone and the unique burdens imposed by the COVID-19 pandemic, we believe it reasonable to discharge Teresa home with her mother.

It is also important to discuss how this case is complicated by Sarah's belief that her daughter is receiving suboptimal medical care because of her socioeconomic status and race. Although Teresa may have received excellent and equitable care during this admission, we must understand and acknowledge that economic and racial discrimination in health care are real and consequential. The effect can be seen at the individual and societal level and Sarah's perception is not manufactured. A large body of evidence shows that experiencing race-related discrimination has a negative impact on health.⁴ On a larger scale, socioeconomic discrimination and structural racism reinforce unequal systems of education, employment, housing, nutrition, and criminal justice. Each of these leads to worsening health inequities.^{5,6} Poor patients and people of color receive a lower quality of care as measured in a wide range of categories, such as patient safety, care coordination, and patient centeredness.⁷

This mother's fears are grounded in reality and should be treated as such by the health care team. Although the accusation of racism may rankle the care team, the mother's self-awareness and open communication present an opportunity as much as a challenge. The team has the chance to identify and confront the effect of their implicit biases in this interaction. Ultimately, they will have greater success if they can convey an understanding of the hardship and unfairness this family has encountered because of their poverty and race. Empowering Sarah to share her family's experience and encouraging the

clinical team to listen to her narrative empathetically and actively will improve the therapeutic relationship and give the best chance of reaching consensus.

DR ANSPACHER, PALLIATIVE AND INPATIENT SUBACUTE CARE EXPERT, COMMENTS

In facilitating decision-making for this family, it is crucial to consider and understand what is most important to Sarah. We should ask her what is most important for her right now or what she is hoping for. We would then listen carefully to see if she prioritized Teresa's comfort, prolongation of Teresa's life, family togetherness, or something else. Our goal would be to help her prioritize goals.

Understanding the mother's expectations and hopes is paramount to supporting her decision-making. It should be the first step. It is not uncommon that a parent expresses a decision or plan that the medical team sees as unrealistic. Often, what the parent is saying is an expression of hope; hope for what she wishes could be rather than what is actually possible. Sarah may wish for her to come home, for her to get better, for things to go back to the way they were before. However, her hopes may also include maximizing Teresa's comfort, maintaining access to medical care and services, and seeking full disease-directed treatment of acute problems. It is possible that neither discharge to home nor transition to a long-term care facility will be perceived by the mother to accomplish all these goals. However, the medical team can best frame a recommendation by understanding what is most important to her. For example, if maximizing comfort and family togetherness are most important to her, discharge to home would support those goals, whereas facility-based care might best support maintaining

access to services and disease-directed therapy.

Visitation restrictions in long-term care facilities during the COVID-19 pandemic placed an incredible and unprecedented burden on patients and families. The decision to restrict visitation was a public health intervention made in the interest of the greater good. However, this was often at odds with the best interests of patients and their families. Facilities were forced to balance public health and organizational safety with the best interests of their residents.

I worked with several parents during the pandemic in a similar position to Teresa's mother. Families faced many barriers to discharge home, including home-nursing shortages, lack of child care for siblings, and parent/caregiver illness. Because of these barriers, placement in a long-term care facility was often considered, but the visitation restriction often made it unappealing and initially resulted in refusal. However, given the lack of alternative safe options, the conversations continued. We understood that we might not be able to make the "best" choice happen for a family, but we would support them making a reasonable choice under the circumstances.

After understanding a parent's hopes and goals for their child, the next important step is to ensure they have enough information to make an informed decision and enough time and support to process that information. Staff should support Sarah by helping her research facilities. She may request virtual tours if in-person visits are not allowed, ask about COVID-19 protocols and outbreaks, and learn about virtual visitation programs and other supports for residents during the pandemic.

It is important to stress the transient nature of the situation. Families often perceive placement in long-term care as permanent, but it does not have to be. It can be a transition until the best situation becomes feasible; for example, until her mother can secure alternate housing or until the pandemic ebbs and visitation restrictions are relaxed.

The difficult decisions that parents face when considering the placement of their child must be considered a journey that a supportive interdisciplinary team can help them navigate. Parents may still be processing new information about their child's condition and prognosis, facing significant lifestyle changes, and grieving the child that was "before." The psychological impact cannot be underestimated and engaging in serial conversations while building trust with the team is always necessary.

In situations where a decision or intervention is not expected to harm a patient, yet the benefits are indeterminate, it is appropriate to follow a shared decision-making model. Research has shown that most parents prefer to share in decision-making with the health care team. This approach is the ethical and professional standard for these situations. It balances the ethical principles of "best interest" to the child, which is shaped by parental beliefs and values, as well as the opinion of the health care team, with the often-competing principles of parental authority and nonmaleficence.

Ideally, if the mother continues to request discharge home, the team should ensure that she understands all the risks involved, as well as the perceived benefits, which could include family togetherness, promoting comfort, and avoiding painful or uncomfortable interventions. In addition, Sarah

may perceive that the risks or harms of being in a facility away from family outweigh the risks the medical team perceives of being at home. Given this patient's current cognitive status, no one can be sure what the emotional or psychological impact of separation would be on this patient. In these circumstances, and ideally with as much community support as possible, I would support discharge to home with the family.

DR LANTOS, ETHICIST AND PEDIATRICIAN, COMMENTS

This remarkable case raises many important issues, all reflecting different kinds of sadness. First, one must acknowledge that Teresa is most likely dying. Her mother probably realizes this, even if she hopes that it isn't so. She may already be experiencing anticipatory grief. She may not have quite admitted to herself that Teresa is dying. But, after 30 years of providing exquisite care for her in circumstances that were likely difficult, she must be highly attuned to Teresa's well-being. She must know, deep down, that Teresa's recent turn for the worse and her failure to recover after 5 weeks is a very bad sign. We can assume, given her extraordinary care for Teresa, that Teresa has been the center of Sarah's life. It is difficult to imagine the sense of loss that she must be feeling and the emptiness that she will feel when Teresa dies. It is understandable that she wants every moment that she can get with her daughter. It is reasonable to assume that the worst thing that could happen would be for her not to be with her daughter when she dies. But, as noted above, we should clarify her priorities and then develop a plan designed to meet them.

The case also highlights the grinding and dehumanizing effects of systemic racism. When Teresa's mother laments that they would not

be in this situation if they were not poor and Black, she is accurate, insightful, and appropriately angry. Nobody should be denied the minimal decency of being able to care for a loved family member who is dying because they live in housing that has been neglected and where basic needs such as electricity are unreliable. But that is her situation. Her anger is justified, and that unfairness should be at least acknowledged.

Sarah's fears about Teresa being neglected in a long-term care facility are quite realistic. She might also reasonably fear that her chances of contracting a COVID-19 infection are likely higher in such a facility. Her desire to take Teresa home reflects concerns about both her psychological well-being and her medical well-being. COVID-19 did not create the problems of racial inequities arising from systemic societal racism that are illustrated by this case. But it exacerbated those problems and thus allowed us to see them more clearly.

This case would be very different if mother had not provided excellent care for Teresa for 30 years. If the health care team thought that she was incapable of providing such care, they would be obligated to protect Teresa from possible neglect. Instead, in this case, the mother has shown that she is not only capable, but that she is heroic. Teresa has lived longer than anyone would have predicted and has been beautifully cared for, both medically and socially, during that time.

The case would be different, too, if Theresa had a good prognosis for long-term survival and if a short nursing home stay would have been able to bring her back to the state of health that she was in before the recent strokes. But that, sadly, is not the case.

The health care team needs to be clear and transparent about Teresa's prognosis. There should be discussions about how to care for her if, at home, her condition worsens. Sarah should understand the risks that she is accepting. She should be assured that we will work with her to minimize those risks. There should be communication with the electric company so that they are aware that a power loss at home could be life-threatening. All available home nursing services should be provided. With those safeguards in place, home is the appropriate place for this family.

OUTCOME

While awaiting a decision on disposition, Teresa's conditioned worsened. She required intubation and escalation to intensive care. She was ultimately found to have progression of her underlying neurologic disease, with further hemorrhagic stroke and partial cerebral herniation. She progressed to multiorgan system failure. Her mother agreed to a do not resuscitate/allow natural death status and was at her bedside at the time of her death.

DR AN TOMM MARIA, SECTION EDITOR, COMMENTS

I agree with the commentators that Teresa and Sarah's circumstance is tragic and that maximally prolonging Teresa's life is not necessarily in her best interest. Discharging her to home instead of an SNF is justifiable to permit personalized care and intimate contact, even if it may result in shortened survival.

This conclusion is, however, contingent on there being only 2 options. The case does not describe the providers' efforts to address Teresa and Sarah's housing needs, and Drs Shapiro and Madrigal characterize legal support to

address them as part of the postdischarge plan. How long the providers should delay discharge to pursue alternatives and how they will know when all reasonable alternatives have been exhausted are difficult ethical issues.

Teresa and Sarah's substandard housing is the result of poverty and racism, which the hospital, as all health care institutions, has some duty to end. Many hospitals have implemented medical–legal partnerships to address social determinants of health and injustice, both in individual patient's care and as matters of law and policy.⁸ It is unclear whether the hospital treating Teresa has a medical–legal partnership. The ethics consultants should identify these larger-system issues and encourage hospital leadership to address them.⁹

ABBREVIATIONS

COVID-19: coronavirus disease 2019

SNF: skilled nursing facility

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