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“Prix Fixe” or “À La Carte”? Pediatric Decision Making When the Goals of Care Lie in the Zone of Parental Discretion. Amy E. Caruso Brown and Julia Ciurria, *The Journal of Clinical Ethics*, 2021¹

Short summary

This article considers parental decision making around goals of care for children with medically complex conditions. The paper outlines a pediatric case that was presented for a review at a departmental morbidity conference. On basis of this case, the paper discusses how clinicians and health care teams can best support parents of children with medically complex conditions making health care decisions that are in their child’s best interest. The paper argues that presenting an evolving ‘set menu’ of intervention options provides an opportunity for the health care team to explain limitations on treatment options and to build trust with the family. This may prevent misunderstanding and delay in situations where earlier intervention is crucial for the ability to meet the goals of care.

Introduction

The paper conceptualizes pediatric decision making for medically complex pediatric patients, where both palliative intent and curative intent are possible goals of care. At one end of the scale, if the overall intent is palliative, there are certain interventions that physicians would deem inappropriate due to the risk of suffering. At the other end of the scale, if the intent is curative, physicians would identify certain interventions as required or essential for achieving the goal of care despite some risk of suffering. Parents have the discretion to choose between possible interventions on this scale. In principle, the chosen goal(s) of care sets the direction for the decision making when choosing from possible interventions, but in some cases, parents may make decisions about individual interventions without reference to the overall goal(s) of care, and thus may decline interventions that the physicians deem essential to achieve the agreed upon goal(s) of care. The key question considered in this paper is whether parents of a child with medically complex conditions should be presented with several set combinations of interventions to achieve the agreed goals of care, or if parents should be able to consider individual options for interventions and accept or reject these on a case-by-case basis.

¹ Caruso, A.E., and J. Ciurria(2021). “Prix Fixe” or “À La Carte”? Pediatric Decision Making When the Goals of Care Lie in the Zone of Parental Discretion. *The Journal of Clinical Ethics*, Vol. 32 (4):299-306.

A case is outlined for the purpose of the discussion:

Summary of case: The case describes the health care team's interaction with the parents of baby Arya, an infant born prematurely (25 weeks of gestation) who developed necrotizing enterocolitis. Due to her condition, Arya had a tube placed into the midsection of her small intestines. After this procedure, Arya was dependent on parenteral nutrition (TPN). She later developed chronic liver disease as a complication from use of TPN. Baby Arya spent a couple of weeks at home and was then admitted to ICU due to pneumonia and sepsis. Mistrust between her parents and her medical team developed after child protective services responded to an unfounded claim of non-accidental trauma that was made against the parents. During Arya's hospitalization complications arose, and as a result of these the only option for reaching the goals of care was to transfer her to a specialty hospital as soon as she was stabilized. The team revisited the goals of care with the parents, but the parents remained fixed on the original goals of care. However, treatment of Arya was complicated by the growing mistrust between her parents and the health care team. When Arya's condition deteriorated, and she needed urgent blood transfusion and transfer to the PICU, the parents refused, as they were concerned that these interventions would delay her transfer to the hospital that could provide specialty treatment. After long discussion the team managed to convey to the parents that admission to PICU was necessary to ensure Arya's immediate survival, and the parents agreed to admit her. Shortly after admission to PICU Arya went into cardiac arrest and died 12 hours later.

The paper analyses each of the four levels of decision making involved in the case:

Goal(s) of care: The goal of care for Arya was set out at an early stage. In Arya's case, cure-directed therapy and palliation were both reasonable goals of care, as a good outcome of a cure-directed therapy could not be guaranteed. The parents were set on cure-directed therapy, and remained consistent in their preference, yet, as complications arose, they refused some interventions that were deemed critical by the medical team to achieve the primary goal of care.

Major interventions required to achieve the primary goal of care: this level of decision-making included decisions around interventions that would be necessary to achieve the goal of care for Arya, namely for her to be able to live at home, and with minimal ongoing medical care. As Arya's condition deteriorated the possible interventions to achieve this goal narrowed down to one option, namely transfer to a specialty hospital for a surgical procedure.

Supportive care and management of complications: This included interventions to stabilize Arya's condition when she was first admitted with pneumonia and sepsis and later to manage her internal bleeding. Arya's parents refused some of the recommended interventions, in spite the interventions being crucial to prevent Arya's condition from deteriorating. Since the parents had the discretion to decide between palliative and curative intent, legal action to override the parents' refusal was not pursued.

Routine care (including nursing care and communication): Although routine care is typically not considered a choice, communication to the parents about these care interventions is customary.

Parental refusal of routine care interventions can compromise the overall quality of care for the patient. In Arya's case, the parents refused some routine interventions and accepted others. This contributed to confusion among the team.

There may be several reasons why Arya's parents refused some of the medical interventions needed to achieve the goal of care. For example, their decisions might have been driven by differences in interpretation of risks and benefits, misunderstandings, mistrust, or a focus on Arya's current pain or suffering in isolation from the goals of care. In Arya's case, the reasons for disagreement and refusals of interventions should have been explored fully.²

The authors emphasize that in some cases, parents may have good reasons for wanting to modify the goals of care, and that refusals of interventions if a curative path is unlikely to succeed should be respected. Legal action to overrule the parent(s)' decision, in cases of disagreement, is a last resort, and should only be pursued if the following conditions are met: The child is old enough to express preferences, and disagrees with the parent(s)' goals; cure is either highly likely or impossible; the parent(s) are refusing interventions deemed essential for the goal of care, preferred alternative interventions have been assessed objectively and rejected; an alternative intervention would cause harm beyond harm associated with withholding treatment; the parent(s)' rationales for refusing have been assessed and are not tied to perceptions of spiritual or moral harm or to other patient interests; misunderstandings, misinterpretations and mistrust have been addressed; the parent(s) are consistent in their wishes around goal(s) of care; and harm beyond what is associated with legal actions is anticipated if the parent(s)' wishes are followed.

Conclusion

The paper concludes that in the given case, all stakeholders would likely have benefitted from a) having palliative care team involved at an earlier stage and b) having an ethics consultation where the ethics consultation team could facilitate a discussion around options and goals of care. In answer to the paper's key question the authors conclude that under certain circumstances where parent(s) are making health care decisions for a medically complex pediatric patient, presenting intervention options as an evolving 'set menu' of possible interventions rather than a constant list of required interventions may benefit all parties involved. It would provide an opportunity for the health care team to discuss the rationale for and clarify limitations of the various intervention options in relation to the ultimate goal of care and thus enable better communication and establishing trust between the family and the health care team in the shared decision making around the patient's care.

² Especially because she is a child and the parents' obligation is to act in the child's best interest.