

The Case of Baby Joseph: When Is Futile Treatment Really Futile?

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While complicated by numerous factors, the case of baby Joseph Maraachli really comes down to whether the benefits of the tracheotomy *for Joseph* outweighed the burdens. Before addressing this, however, it is necessary to first tackle the issue of medical futility that was raised by physicians at London Health Sciences Centre (LHSC) in London, Ontario, where Joseph was hospitalized for several months and from where he was ultimately transferred after an intractable conflict developed between hospital representatives and Joseph's parents.

Medical futility is best understood as any effort to initiate or continue a treatment when it is highly unlikely to succeed in achieving its desired ends and when its rare beneficial exceptions cannot be systematically explained or reproduced. Various attempts to address the issue of medical futility and the underlying reasons that lead to requests for futile treatment go back well over 20 years. Yet despite this, it seems as if very little progress has been made in preventing, reducing, or successfully resolving these situations. Jeffrey Burns and Robert Truog in a 2007 article in *Chest*, help structure the debate by describing three generations of efforts to deal with medical futility ("Futility: A Concept in

Evolution," *Chest* 132 (December 2007): 1987-93).

The first is characterized by attempts to *define* futility. One author proposed seven clinical conditions for which further treatment should not be provided. Another proposed a distinction between "qualitative" futility (based on a quality-of-life judgment) and "quantitative" futility (involving a judgment about what is a reasonable likelihood of the treatment's success). Yet another recommended limiting the concept of futility to treatments that are "physiologically" futile, that is, they are unable to attain their physiologic goal or therapeutic end. Burns and Truog note that there are serious difficulties inherent in each of the definitional approaches and that they were largely unsuccessful in resolving the more challenging cases. For these reasons, clinicians and ethicists, by the late 1990s, abandoned this attempt and sought alternatives.

This led to the second generation of the futility debate which consisted in the development of *procedural guidelines* to resolve disputes over medically futile treatment. A consortium of Houston-based hospitals offered the first such procedural approach, but

the approach quickly gained in popularity and spread rather quickly to other areas of the country. In 1999 it was endorsed by the American Medical Association. Typically, the procedural guidelines are invoked as a last resort, and they attempt to ensure that all voices are heard by the ethics committee. Texas, along with a few other states, has incorporated the procedural approach into law. In addition to embodying the key elements typical of procedural approaches, the Texas Advance Directives Act (1999) mandates a 10-day waiting period between a decision of the ethics committee affirming medical futility and the actual withdrawal of treatment. The Emilio Gonzales case in 2007, however, revealed weaknesses in the procedural approach, especially in a legislated form. The case sparked a state-wide, often contentious, debate about the legislation. Right-to-life and disability groups in particular advocated for changes in the legislation which have not yet occurred.

Burns and Truog maintain that neither first nor second generation attempts to address the matter of medical futility have been successful. What they propose as an alternative is better communication between clinicians and patients or their families and the use of mediation techniques to resolve differences when disputes arise. The goal, they say, is to “mitigate conflicts as they arise but before they become intractable.” Underlying their approach is the belief that most futility cases are the result of breakdowns in communication and trust. Hence, they urge improvement in communication skills among caregivers and suggest a four-step approach to negotiation. Recognizing that good communication and attempts at negotiation

do not always work, they suggest going to court to seek appointment of another surrogate if the patient is being harmed by a family member’s decisions. Short of that, they recommend acquiescing to familial requests for “futile” treatment. Because of the potential negative impact on the morale of caregivers, toleration of requests for treatment deemed to be futile should be accompanied by support for those who continue to care for these patients, rather than try to overrule requests for medically inappropriate treatments. The authors consider their approach to the problem to constitute the third generation approach to medical futility.

Now, turning to the particulars of Joseph’s case, LHSC’s approach seems to have been based primarily on a qualitative definition of futility insofar as physicians there apparently believed Joseph’s condition was such that he would not derive any meaningful benefit from receiving a tracheotomy or remaining on mechanical ventilation. This is certainly understandable, and many people of good will might not want intensive care and other treatments beyond comfort measures when confronted with a condition similar to that of Joseph. However, this is precisely the problem with invoking futility in end of life treatment decisions. What is futile to one person may not be to another; what one person deems extraordinary and disproportionate another might judge to be ordinary and proportionate. This is the vicious cycle LHSC and Joseph’s parents entered into and remained until Joseph was finally transferred. Futility made sense to physicians at LHSC, yet for Joseph’s parents it did not because they believed the tracheotomy would achieve the ends they desired. Burns and Truog are right to criticize

the definitional approach to futility and instead advocate for an approach centered around communication and negotiation inasmuch as trying to define futility is futile in itself. In truth, unless a treatment has absolutely no prospects of achieving its therapeutic goals, futility should not be invoked as it can only exacerbate a difficult situation. Instead, the focus should be on reaching consensus on a care plan that serves the patient's best interests and supports the patient's wishes and values, assuming these are known and are not legally unacceptable or morally objectionable.

This brings us to the question of the tracheotomy and its benefits/burdens for Joseph. While a tracheotomy is not a benign procedure, its burdens can be minimal and its benefits can be significant in some cases, even for end of life patients who can benefit from a palliative perspective. This is how caregivers and ethics committee members at SSM Cardinal Glennon Children's Medical Center viewed the procedure after they had the benefit of better understanding Joseph's condition, including indications that he most likely had some degree of consciousness and, thus, was not in a persistent vegetative state nor was he imminently dying. Though it was clear to all that Joseph could not be cured and that his disease would continue to progress and take his life at some point, it was determined that the tracheotomy could provide substantial benefits to him without imposing excessive burdens. Some of the more noteworthy benefits included the following: providing Joseph with increased mobility and comfort while creating a stable, secure airway; keeping his lower airway free from secretions and protecting his lungs from inhaled saliva or

other material that could cause aspiration pneumonia; and allowing the removal of a cumbersome facial device and giving Joseph a chance to go home with his family, rather than be institutionalized for the remainder of his life.

Of note, an important question arose during the deliberations about Joseph's care, namely, what factors should be considered when deciding whether to perform a tracheotomy on a patient with a severe, incurable illness that will result ultimately in death. The concern had to do with consistency regarding which patients are offered a tracheotomy and which are not, based on clinical circumstances. From an ethical perspective, there are three interrelated questions that should be considered together before undertaking a tracheotomy procedure for patients who are critically ill and approaching the end of life.

- *Is death imminent?* It would not be acceptable or appropriate ethically to subject a patient to the burdens of a tracheotomy procedure when they will not experience its benefits because their death is likely in hours or days. For Joseph, the opinion was that he would be able to live several months, perhaps as many as nine or more, given the stable nature of his vital organs and other factors.
- *Will the procedure provide a proportionate benefit to the patient?* With any treatment decision, especially for patients who are severely ill and approaching the end of life, it is imperative that the benefits outweigh the burdens. In this sense “proportionate

benefit” is not restricted to prolongation of life but should also include other positive effects such as alleviation of pain and suffering, improved function or mobility, possible discharge from a hospital setting, and so on. As mentioned above, it was determined that Joseph would sufficiently benefit from having a tracheotomy.

- ***Does the procedure harm the patient or enhance the patient’s suffering?*** This is implied in the question above, but it should be considered separately nonetheless. While there may be benefits that accrue to a patient from a tracheotomy procedure, the fact is if the patient is harmed as a result of the procedure or is forced to endure even more suffering because of it, the benefits cannot be considered “proportionate” and as such the procedure ought not be performed. This holds even if a surrogate requests the procedure insofar as the procedure would not only be medically contraindicated but also would not serve the patient’s best interests. Burns and Trog have such a situation in mind when they suggest going to court to seek appointment of another surrogate if the patient is being harmed by a family member’s decisions. Underlying this view is the belief that the primary role of health care providers is to act as an advocate for the patient and promote her/his overall well-being. This might have been what LHSC and its physicians were basing their position on when they objected to performing the tracheotomy on Joseph and insisted on removing life-support. However, when looked at objectively, it is difficult to understand how a tracheotomy

could be considered disproportionately harmful in Joseph’s case. It’s more likely, and not necessarily inappropriate, that quality of life considerations provided the basis for their position.

One last point to mention that should not be overlooked in this and similar cases is the fact that Joseph could not speak for himself and as such, others had to make treatment decisions for him without the benefit of knowing anything about his wishes or values. These are perhaps the most difficult decisions of all in medicine and, as the late Fr. Richard McCormick long ago noted, we should proceed with “great humility, caution, and tentativeness” when making such decisions, erring on the side of life when in doubt (Richard A. McCormick, “To Save or Let Die: The Dilemma of Modern Medicine,” *Journal of the American Medical Association* 229 (July 8, 1974): 172–76, at 176).

(Editor’s note: Dr. Panicola was involved in Cardinal Glennon’s Ethics Committee and physician discussions about this case. These comments first appeared as part of Dr. Panicola’s analysis of the case for SSM facility ethics committee members).

Questions for Discussion

1. Was LHSC correct in judging a tracheotomy for baby Joseph to be “futile treatment”? What constitutes futile treatment?
2. Who should have the final say about treatment options in these types of situations—Parents? Physicians? Courts?
3. In your opinion, was a tracheotomy for baby Joseph ethically defensible? Why? Why not?
4. To what extent, if at all, are quality of life judgments ethically defensible in these types of cases?
5. Given your current policies and practices, how do you think this type of situation would be handled at your institution, assuming your facility would admit such a patient?