

## CASE WITH COMMENTARY

### Should Cosmetic Outcome Influence Discussions about Goals of Care for Severely Burned Patients?

Commentary by Yuk Ming Liu, MD and Kathleen Skipton Romanowski, MD

#### Abstract

We focus on surrogate decision making and, specifically, the topic of cosmetic outcomes following burn injury in a case in which potential surrogates dispute what the patient would have wanted. In particular, we examine the choice and role of surrogate decision makers in light of ethical principles that guide surrogate decision making. We also examine whether and when cosmesis should enter into goals of care discussions and consider potential roles cosmetic outcomes could play in such discussions. Finally, we discuss how caregivers should respond when surrogate decision makers suggest cosmetic results as a reason for withdrawing care.

#### Case

Piper is a 30-year-old news anchor who was injured in a car accident two days ago, which resulted in third- and fourth-degree burns covering 40% of her total body surface area (TBSA) including her face, scalp, and neck. She suffered inhalational injury and is thus sedated, intubated, and currently ventilator dependent. She will need extensive facial grafting and reconstruction while hospitalized over the next few months and will likely have partial vision loss and also partial bilateral loss of nose, ear, and hair tissue. With good care, she can likely be functional in six to twelve months, although it is not clear that this is what she would want.

Piper doesn't have a health care power of attorney, but clinicians have spoken with her parents, who favor aggressive continuation of her care. During a team meeting, one of Piper's nurses, Sandy, expresses concern about Piper's parents' role in making decisions about Piper's care. "Piper ran away from home at age 17, and her parents have been only sporadically involved in her life since then. She has been living with friends in Nebraska since she ran away and those same friends have been here to visit her regularly. They tell me Piper wouldn't want to go through painful surgical treatments over several months and then have to live with facial disfigurement. One of them asked the chaplain when we were going to stop torturing her and take her off the ventilator."

Piper's surgeon responds, "We can ask our chaplain and social work colleagues to help us establish who among Piper's family and close friends would be best suited to act as her

surrogate decision maker. Until one is appointed, however, we should continue to approach her care by prioritizing her survival, then her functioning, and only then, cosmesis. If we proceed as planned, we can probably wean her from the ventilator and, with good occupational therapy, she will likely be able to function in her daily life. Over time, with the help of good grief counseling, she might very well come to terms with her facial disfigurement. We should continue as planned.”

Another of Piper’s nurses, Geri, also contributes to the discussion. “Supposing Piper wants to do occupational therapy and grief counseling, that’s a lot of work over many years. We’re making a lot of assumptions here about how her desires and outcomes, and it’s still very early after her trauma. Why don’t we get some more information and consider these questions again in a couple of days?”

No official surrogate has been appointed, but input from Piper’s parents and friends has been gathered over a couple days while she remains sedated. The team meets again and considers next steps.

### **Commentary**

This case highlights ethical issues often encountered when caring for seriously burn-injured patients. Burns, especially large burns, can profoundly affect patients and their life course. In addition to enduring immediate life-threatening physiological changes and pain, these patients can also face permanent alterations in their physical health, mental health, physical functioning, and appearance. Given a frank and honest discussion of the pain that must be endured, the effort required for recovery, and uncertainty about cosmetic outcomes, some patients might opt not to continue treatment. Unfortunately, patients are often critically ill at the time at which key decisions must be made and therefore cannot participate in discussions about their wishes. It is this lack of [decision-making capacity](#) that presents us with the first ethical issue at hand in this case: the nature and scope of the role of surrogate decision makers in considering aesthetic outcomes. A second ethical issue is how we as caregivers handle discussions about patients’ cosmetic and functional outcomes as they relate to end-of-life care decisions. A third question is how burn professionals should respond when cosmesis is suggested as a reason to withdraw life-prolonging therapies.

### **Choice and Role of Surrogate Decision Makers**

In this case, since Piper is sedated, she is not in a position to make a decision about her preference for proceeding with treatment. Furthermore, she does not have a living will or a health care power of attorney to aid her caregivers in treatment decisions. In a situation like this one, in which the patient is judged to lack decision-making capacity, a surrogate decision maker is needed. Ideally, Piper would have chosen a surrogate in advance, but she did not.

*Choosing a surrogate.* In the absence of a designated surrogate, laws vary from state to state regarding who can serve in this role. In general, the order of appropriate surrogates is first a patient's spouse, then adult children, parents, siblings, or other relatives, respectively, although there is a great deal of variety in this scheme from state to state.<sup>1</sup> However, Nebraska—the state in which Piper resides—does not have a mandatory default surrogate hierarchy.<sup>1</sup> Despite the lack of a state law, the Nebraska Department of Health and Human Services (DHHS) State Unit on Aging has published a guideline for surrogate decision making for clinicians who work with the elderly and the disabled.<sup>2</sup> Piper could be considered disabled given the nature of her injuries and her inability to communicate her wishes. Thus Piper's clinicians could consider referencing the DHHS guideline to determine how best to identify a surrogate decision maker. However, a legal process might be necessary to determine whether the DHHS guideline can be applied to Piper's predicament.

The question of who should be Piper's decision maker from an ethical standpoint comes down to which group (her parents or her friends) can best carry out this charge, as discussed below. This situation is complicated because it is unlikely that Piper has had a discussion with either her friends or her parents that addresses the specific issues raised by her burn injuries. In our experience, this quandary is not unlike most surrogate decision-making situations.

*Role of the surrogate.* In a case such as this, with disagreement among potential surrogates, the scope of the surrogate decision maker's role warrants closer evaluation and discussion. Generally, a surrogate decision maker is charged with basing decisions on either a patient's previously expressed autonomous wishes or that patient's best interests, given the information available.<sup>3</sup> A good surrogate should first honor a patient's prior expressed wishes (respect for autonomy) by relying on [substituted judgment](#)—what the patient would have wanted had the patient been able to express his or her own desires. If that patient's wishes are unknown, then it is generally accepted that a good surrogate should make decisions based on that patient's best interests (beneficence).

The truth is that many surrogates (even when clearly identified) are unaware of particular patients' preferences. Covinsky et al. found that surrogates' understanding of a patient's preference for cardiopulmonary resuscitation was only moderately better than chance.<sup>4</sup> All too often, designating a surrogate decision maker does not lead to an informed discussion between the patient and the decision maker about the patient's wishes prior to the decision maker being called upon to make a surrogate decision.

With this perspective, Piper's case is not unique and may even be similar to many scenarios in which health care proxies or surrogate decision makers find themselves in a quandary as how to proceed with a complex, yet survivable, case. The best scenario for Piper would be for the two groups—her parents and friends—to come together to make

a decision that, to the best of their knowledge, honors what they think Piper would want done in this situation. In the absence of a consensus about what patients would have wanted or about what constitutes their best interests, the American Medical Association (AMA) *Code of Medical Ethics* suggests that the process of consensus building might benefit from engaging an institution's ethics committee or ethics consultation process.<sup>5</sup>

### **Roles of Cosmesis in Decision Making**

In this case, what must be considered is not only the choice of an appropriate surrogate decision maker for Piper but also the suggestion made by her friends, as well as the nursing staff, that Piper might not want to proceed with treatment if there was a possibility of facial disfigurement. Based on our review of the available literature, how cosmesis, survival, and function should be assigned moral weight in goals-of-care discussions has not been evaluated. In the absence of literature on the topic, we discussed this issue with many of our colleagues in the burn community and received a wide range of opinions on how cosmesis should be considered in discussions of goals of care. Although there was not a consensus among the clinicians we spoke with about what role cosmesis should play in these discussions, almost everyone agreed that this is an important ethical discussion to have, especially since burn care is one of the few areas of decision making in which cosmetic outcomes, impaired physical function, and survival intersect.

From an ethical perspective, important guiding principles in this scenario are nonmaleficence (to do no harm) and beneficence (to do good). As members of the health care team, we have a responsibility to provide patients with an open and honest assessment of what we think will be their likely outcome during a goals-of-care discussion. With respect to cosmesis, however, what constitutes harm and benefit is highly individual. What one person considers an acceptable cosmetic outcome might not be acceptable to another patient. For this reason, it is difficult for clinicians even to discuss cosmetic outcome in the context of goals of care unless it is brought up by patients or their surrogate decision makers. In this case, cosmesis was brought up by Piper's friends, but one can imagine that a discussion of cosmetic outcome as a reason for withdrawing care—when survival is likely with continued support and functionality is otherwise spared—might engender resentment in a family member or patient for whom this aspect of recovery is less important. We, as professionals, can only weigh cosmesis in relation to patients' determination of its importance as part of their outcome. Without understanding patients' values, it might be impossible for us to prevent harm and do what is best for patients with respect to cosmetic outcome. In the case of Piper, it is suggested that she is likely to survive and that her functional outcome would be reasonable. However, her friends indicate that cosmetic outcome would be very important to her. Obviously, Piper's friends know her better than her medical team, but interpreting the importance of cosmetic outcome to her, and to any patient, is incredibly challenging. In fact, it might not be possible for a surrogate decision maker to accurately assign the importance of cosmesis to a patient, particularly following burn injury.

While it might seem logical to assume that a patient's previous feelings about cosmesis will remain the same after a burn injury, the situation is rarely that straightforward. Simply put, burns change people and their view of life. The Phoenix Society, the support group for burn survivors, draws its namesake from the legendary bird that is "consumed by flame, but rises again—reborn from its ashes—more brilliant than it was before."<sup>6</sup> Burn survivors are often physically and mentally transformed following their injury. What they valued before their injury might not be what they value after their injury.<sup>7</sup> This change in patients' perception is likely due to the experience of surviving a burn injury, the treatment involved, and the alterations in both appearance and function that patients experience. More importantly, it is likely due to the large network of support that is available to burn survivors. In every burn center, there are significant resources devoted to aftercare in the form of support groups as well as peer support staff.

In situations in which surrogate decision makers wish to [withdraw care](#) due to cosmetic defects despite the fact that the patient would be fully functional and independent, we as caregivers must utilize all the resources specific to the burn community to ensure that they are making a fully informed decision. We need to put surrogate decision makers in touch with burn survivors and their families so that they can fully comprehend what life as a burn survivor can be like. Only after having a frank discussion regarding life as a burn survivor can surrogate decision makers develop a clearer insight into whether or not they think that the patient would want to proceed with treatment. If, following these discussions, a surrogate decision maker continues to believe that the patient would not want to proceed with treatment because of a potentially poor cosmetic outcome, then it would be up to the individual clinician to decide whether to comply with this request, involve the ethics committee, or defer the care of the patient to a practitioner who would be willing to work with the family. Because we found no literature on how issues of cosmetic outcome and withdrawal of care should be ethically handled in medicine generally and in severe burn cases specifically, what constitutes nonmaleficence and beneficence in individual cases is not completely clear, and there is no consensus on how to proceed. As such, practitioners have some leeway in deciding what they are comfortable with and what is best for the patient in a particular situation.

### **Conclusion**

In the case of Piper, the most ethically sound decision would be to continue aggressive treatment until Piper is able to participate in decisions about her care and the value that she places on cosmetic outcome. If Piper decides that she does not want to continue with care due to her likely cosmetic outcome or for any other reason, then her autonomy should be honored.

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