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Ethics in Burn Care

From the Editor

Ethics Cases

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Podcast

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Policy Forum

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FROM THE EDITOR

Opening Dialogue on Current Ethical Issues in Burn Care

Ashwath Gunasekar

In 1973, Dax Cowart was critically injured in a propane gas explosion that took the life of his father. The ensuing care that he received, despite his opposition to it, prompted him to pursue study of the legal and ethical issues related to his treatment following his recovery. He would go on to advocate for the view that it was wrong for clinicians to disregard his wish to be allowed to die and to promote greater respect for patient autonomy. Through his activism, he opened the door to constructive discourse on ethical issues surrounding the practice of burn care.[1]

Despite the discussion of burn care ethics initiated by Dax's case, there has been a paucity of literature published since. In a review of literature presented to the American Burn Association, Khandelwal and colleagues found only 53 articles on burn care ethics published between 1975 and 2015, with the majority of publications focusing on respect for patient autonomy and end-of-life care.[2] With an estimated 40 000 burn-related hospitalizations in 2016 alone[3] and issues of pain management, live skin grafting, end-of-life decision making, and burn prevention continually evolving, the existing literature seems deficient. The lack of literature may, in part, be due to a lack of communication between ethicists and the primary health care team. For example, an informal poll conducted in 2015 at the American Burn Association showed that only 3 of the nation's 128 burn centers had an ethicist rounding with their teams regularly.[2] Consequently, we have yet to determine how best to approach ethical issues that arise in burn care.

This issue of the *AMA Journal of Ethics* seeks to open dialogue on burn care ethics. The contributors use various approaches and perspectives to examine a range of clinical and policy issues in an effort to identify and understand some of the most pressing ethical issues that arise in burn care.

Pain is a complex construct with significant impact on the burn patient. The long-lasting course of burn wounds, their excessive healing time, and the repetition of highly nociceptive procedures can result in extreme distress if pain control is inappropriate.[4] In a case of differential treatment of pain in a pediatric and an adult burn patient, Sharmila Dissanaike reviews the differing approaches to pain management in adults and children and argues for the need for individualized pain management strategies that include nonpharmacological adjuncts.

Early excision and autologous skin grafting are the gold standard for large burns.[5] In instances in which grafts from autologous tissue cannot be procured, donated skin—either cadaveric or live—can be used. In developed countries with resources to maintain cadaveric skin banks, live skin donation is used only in the case of identical twins.[6] In such cases, using live skin donation can greatly reduce recovery time, hospital stay, and, consequently, burn-related morbidity and mortality.[7] In a case of a potential identical twin donor, Anjay Khandelwal explores the risks and benefits to donors and recipients of monozygotic sibling (MZS) skin grafting.

End-of-life decision making is an issue often dealt with in burn care and medicine as a whole. In the care of burn patients, survival and function have historically been at the forefront of decision making. Recovering from burn injuries is a difficult and emotional experience for patients, who face painful treatments and sometimes a process of personal transformation, depending on the extent of their wounds. In the podcast, Monica L. Gerrek and Andrea Rubin explore what clinicians can learn from patient experiences and strategies for providing sensitive and individualized care.

Goals-of-care discussions, however, have evolved to incorporate cosmesis as well. In a case of potential surrogates with conflicting views on the preferences of an unconscious burn patient, Yuk Ming Liu and Kathleen Skipton Romanowski examine the scope and role of surrogate decision makers, how to weigh different goals of care, and how physicians should respond when surrogates suggest disfigurement as a reason for withdrawing care.

In the rigors of clinical practice, it is often easy to lose sight of our patient's lives outside the medical setting. Debra Ann Reilly and Steve Langan discuss how creative writing can help physicians start conversations with burn patients and their families in new ways and develop deeper relationships with them.

To understand the current nature of burn care, it is important to have a historical and conceptual perspective. Gerrek compares the oft-cited case of Dax Cowart to that of a more recent burn patient, Andrea Rubin, to examine medical decision making in burn care. More specifically, she examines the role of paternalism through the lens of these patients' experiences, calling into question the assumption that paternalism is problematic and disrespects patients' autonomy and arguing for a more nuanced understanding of burn patient decision-making capacity and autonomy. Chad M. Teven and Lawrence J. Gottlieb provide an alternative to principlism for approaching complex ethical issues in burn care. In particular, they show how the "four quadrant" approach of Jonsen, Siegler, and Winslade[8] can help burn care physicians navigate complex ethical issues they might face in the care of burn patients.

Two articles explore the role of policy and education in burn care. Laura S. Johnson and Jeffrey W. Shupp discuss the exclusion of burn patients from research on quality metrics and why these metrics are inappropriate for delivering burn care. Patrick T. Delaplain and Victor C. Joe discuss the overwhelming patient burden of burn care delivery and inequities in the current system as a result of overtriage. They argue that these problems are exacerbated by the lack of fundamental burn and wound care knowledge among graduating medical trainees and outline the need for formalized burn care curricula in medical training to provide better care for patients suffering from burns.

Finally, two articles discuss care of burns in underserved and vulnerable populations. Shelley Wall, Nikki Allorto, Ross Weale, Victor Kong, and Damian Clarke explore ethical challenges in providing burn care in low- and middle-income countries, which lack resources found in high-income countries. They also offer insight into how predictive mortality scores can be adapted in these settings to allocate resources to at-risk patients and thereby address issues of access to care and justice. And Lauren C. Nigro, Michael J. Feldman, Robin L. Foster, and Andrea L. Pozez discuss a new multidisciplinary method for identifying suspected nonaccidental pediatric burns, which might provide a more reliable method for identifying victims of abuse and preventing readmissions.

This issue of the *AMA Journal of Ethics* brings attention to the ethical dilemmas clinicians encounter when caring for patients suffering from burn injuries. It seeks to provoke thought about the clinical and policy dimensions of burn care in an effort to understand how best to approach ethical issues that arise in burn care and provide better care for patients.

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CASE WITH COMMENTARY

Is It Ethical to Treat Pain Differently in Children and Adults with Burns?

Commentary by Sharmila Dissanaike, MD

Abstract

This commentary discusses ethical implications of the common practice of treating children's and adults' burn pain differently. Physicians have obligations to ensure that (1) their own discomfort with children's pain doesn't lead them to make pain management decisions that could place a patient at greater risk and (2) to engage in thoughtful, individualized pain management strategies. Long-term consequences of overzealous pain medication administration, for example, could include delayed recovery and integration or opioid dependence. The need to create individualized approaches to pain management, based on published guidelines, is discussed along with uses of nonpharmacological treatment for both adults and children.

Case

Asmin is a new fourth-year medical student rotating at Franz Hospital's burn and wound care unit for both adults and pediatric patients. The resident physician, Dr. Mason, arrives and Asmin presents the patients she had been following.

"Frankie is a nine-year-old girl who presented a few weeks ago with second-degree burns to her neck and face and 5% total body surface area (TBSA) third-degree burns to her chest following a cooking accident. She received a sheet graft, which was secured with dissolvable sutures. Frankie's vitals are now stable and she has been doing well overnight; complete blood count (CBC), basic metabolic panel (BMP), and other lab results are within normal limits. She has finished her course of antibiotics. Her dressings will be changed today and we can likely plan for discharge tomorrow."

Dr. Mason nods in affirmation and adds, "Be sure to call anesthesia for conscious sedation during the dressing change." Asmin makes a note and continues.

"Ms. Joplin is a 45-year-old woman who presented several weeks ago with 9% TBSA third-degree burns to her chest, breasts, and abdomen after falling into a fire in a friend's backyard fire pit. She received a mesh graft secured with staples. She had no issues overnight and is now in stable condition; she rates her pain as a 7 on a 10-point scale this morning. CBC, BMP, and other labs are within normal limits. She is due for a dressing change and needs oral hydromorphone to manage her pain. We can consider discharge in the next few days if her condition remains stable. I assume we should call anesthesia for her dressing change, so I'll do so."

Dr. Mason says, however, "There is no need for conscious sedation for this lady. Give her some IV hydromorphone during the dressing change and see how she does on acetaminophen in the meantime."

Confused, Asmin asks, "Other than age, these patients seem pretty similar. Why is their pain management different? I guess it's not really so obvious, at least to me. If the sheet graft is more intensive and takes longer to perform, I guess it makes sense that she'd get different pain care. Please help me better understand why the strategies are different for patients whose injuries were so similar."

Dr. Mason considers Asmin's question, and responds, "We just tend to be more cautious with pediatric patients."

Commentary

This realistic case scenario is a practical demonstration of how physician perceptions, patients' nociception, and psychosocial and cultural constructs all coalesce in our approach to pain management in a clinical setting. While the approach described in this case is common, it is not ideal from a pain management perspective. This case highlights the need for a thoughtful, individualized approach to each patient based on sound scientific and ethical principles.

The resident physician Dr. Mason and medical student Asmin in this scenario are faced with the common challenge of developing a pain management regimen for procedural pain associated with dressing changes in two burn patients on their service. Based on the details presented in this case, and focusing purely on the biophysical dimension of nociception as a cause of pain, the adult patient Ms. Joplin is likely to suffer a stronger pain stimulus during her dressing change than the child Frankie. This is due to her having had a larger TBSA burn from the outset and to staples being used to secure the graft instead of absorbable sutures. The lack of adequate baseline pain control for Ms. Joplin, as described by Asmin, is another risk factor; failure to control baseline pain usually increases the difficulty of providing adequate analgesia for a subsequent procedural intervention.[1]

Therefore, if one were only to consider the data regarding the burn injury, baseline pain, and operative treatment, it would be expected that the adult Ms. Joplin would require stronger analgesia and sedation than the child Frankie. However, Dr. Mason's initial contrary response is not far from conventional practices in many burn centers across the country, where adult and pediatric pain are viewed and treated completely differently. Clearly, factors beyond the nociceptive process are being considered.

Differing Pain Management Approaches for Adults and Children

The vast majority of normal adults are instinctively moved by seeing or hearing a child in pain; this innate emotional response is likely to incline most clinicians to take additional steps to minimize the pain and suffering of children. While clinicians are also concerned about their adult patients' pain, it may not "tug the heartstrings" in quite the same forceful manner. As adults, we have the cognitive capacity to understand why a painful procedure is necessary for our eventual well-being; this understanding might mitigate the discomfort that nurses and physicians feel at having to inflict short-term pain in adults for a longer-term benefit. Performing procedures in awake children can feel cruel, since children are unable to comprehend the reason for the procedure and the noble intent behind it; this increases the discomfort on the part of the physician and other health care practitioners, none of whom wish to be placed in this uncomfortable position. Thus a greater effort is often made to prevent children from feeling pain in many health care settings.[2,3]

Several guidelines exist on pain control in burn patients[4,5] and children.[6] Interestingly, there is very little published work on pain control in children with burns as compared to adults and only one recent practice guideline for pediatric burn patients,[7] thus leaving a knowledge gap in the optimal management of pediatric burn pain. Many burn specialists recommend the liberal use of nonpharmacologic pain control, especially in children, in addition to the standard opioid ladder and medications such as nonsteroidal anti-inflammatories and anticonvulsants.[2-5,7] There is growing recognition that our perception of pain is influenced strongly by fear, anxiety, and lack of coping mechanisms[8,9]; in children, the impact of these factors is usually greater than in adults, since they have not had as much time and experience to develop robust coping mechanisms such as distraction and rationalization.[10] A multifaceted approach that recognizes and treats these associated factors in addition to the nociceptive pain is likely to be a more successful strategy that meets our expectations of ethical care than simply increasing the potency of analgesics based on clinicians' judgment of how much pain they would expect in a given situation based on their prior experience. While requesting anesthetic-grade sedation for all procedures in children is common in my experience and stems from the noble intention of protecting the child from hurt, this strategy may not be the most beneficial for the child in the long run. Reintegration of the child into the home and school environment is the eventual goal of burn care, and requiring heavy sedation for every dressing change might eventually delay the successful completion of inpatient treatment and leave the child and parents ill prepared for transition to the home.

Need for Individualized Pain Management Strategies

In the case presented, Dr. Mason's plan for the pain management of each patient during her dressing change appears to be based on habit and routine ("this is how we do things here") rather than a thoughtful, individualized response to each patient's situation. Unfortunately, based on my extensive experience in resident education and the anecdotes of other faculty members, such cognitive shortcuts are common, especially among trainees who are struggling to cope with increasing workloads (e.g., clerical and administrative tasks) in fewer work hours, a phenomenon known as work compression.[11] The human tendency to compartmentalize leads the physician to memorize a few narrowly defined pain management options that are successful in most cases, such as those mentioned in this case (i.e., IV hydromorphone and acetaminophen versus conscious sedation), and then to deploy these methods based on broad categories (adults versus children) rather than assess an individual patient's clinical situation, pain, and anxiety. Individualized medicine takes time, the one commodity in short supply for most modern physicians.

This case should also be viewed in the context of the dramatic shift in physician attitudes and public perceptions about opioid prescription over the past decade. The pendulum has swung wildly based on whether the short-term goal of maintaining a patient's pain at the lowest possible level or the long-term goal of preventing the devastating consequences of opioid addiction is emphasized.[12] Minimizing opioid use in favor of using other analgesics, as is the current trend, can have unintended adverse consequences that become apparent after several years, such as nephrotoxicity, gastrointestinal complications, and delayed wound healing from high-doses of nonsteroidal anti-inflammatory drugs.[13,14]

In burn patients, the severity of pain usually necessitates the use of opioids, including long-acting potent agents such as methadone. In this case, both patients should have detailed assessments of baseline pain levels including median pain at rest and during activity, whether the pain (and the anxiety or other symptoms that might be related to acute stress disorder) is decreasing or increasing with time, and whether the pain restricts their ability to participate in therapy or sleep through the night. Based on their responses, an appropriate long-acting oral analgesic agent should be prescribed for baseline pain, which might include long-acting methadone or morphine or, more likely at this stage in their treatment, less potent opioids, opioid analogues, and nonsteroidal agents. The patients' procedural pain should then be closely assessed, including the timing of the symptoms, as acute pain at the very onset of dressing change is often related to anxiety and can be reduced by treatment with an oral anxiolytic an hour prior to removing the dressings. Pain during the entire procedure suggests the need for intravenous or transmucosal short-acting opioids (such as a fentanyl lollipop) that provide powerful immediate relief of pain without causing unwanted sedative effects long after the procedure is complete. Appropriate management of pain requires that we frequently reevaluate the pain management method and aim to reduce the analgesic dose required (by using adjunctive therapies, for example) in order to allow the patient to continue to heal and regain function as comfortably as possible without incurring long-term dependence.

Conclusion

Regardless of whether the patient is an adult or a child, assessing the patient's pain needs thoroughly and systematically at the outset will allow the development of a comprehensive pain management plan that prevents these decisions from having to be made by covering or on-call physicians who might not have the time to devote to this endeavor and thus might be more likely to rely on shortcuts. Regular reassessment and readjustment of the plan by the multidisciplinary health care team, which should include nursing and pharmacology colleagues, and inclusion of nonpharmacologic adjuncts as the patient gets closer to discharge will hopefully prevent the type of practice inconsistency illustrated in this case scenario.

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CASE WITH COMMENTARY

When Is It Appropriate to Put a Live Donor at Risk to Help Another Patient?

Commentary by Anjay Khandelwal, MD

Abstract

This article considers the nature and scope of ethical decision making in monozygotic sibling (MZS) skin grafting. Although rare, identical twin-to-twin skin grafting has been reported with excellent survival rates in burn patients. Of 16 cases published to date, only a few address the ethical decision making process that is involved with monozygotic sibling skin grafting; this article discusses clinical indications and ethical challenges.

Case

Shara, age 16, has been in the burn unit as a patient of Dr. Fran for 3 days, with mostly third-degree burns covering 85% of her total body surface area (TBSA); her neck, groin, axilla, and some spots of her scalp are not burned. She has had one surgery to excise the burn but is scheduled for several more. She's responding well to fluid administration and is currently intubated and sedated.

During teaching rounds, Dr. Fran explains to the students that once tissue debridement is complete, Shara will need about 15 more graft surgeries during a 4- to 6-month stay in the unit. If there are complications, such as infections, she will likely need to stay longer. "Now an interesting thing about Shara," Dr. Fran continues, "is that she has an identical twin sister who could be a potential skin donor. Her name is Alia. A decision we need to make about this patient's care is whether and how to talk with Shara, Alia, and their parents about the possibility of recruiting Alia to donate skin."

One student asks what would be involved. Dr. Fran clarifies, "We would need to harvest Alia's skin from both her legs and back. Removing from Alia the amount of skin we'd need for Shara means that Alia would suffer a lot of pain and become, for all intents and purposes, a second critical wound care patient. That is, the required amount of skin removal from Alia's legs and back would result in the equivalent of substantial TBSA second-degree burns, infection risk, and pigment changes. If Alia would agree to taking on this pain, risk, and hospital stay with her sister, the benefit to Shara, if all goes well, would be a reduction in risk for possible complications: isografting (grafting using genetically identical tissue), like autografting (grafting using the patient's own tissue), would avoid immunologic responses seen with allogeneic (nongenetically identical) tissue and lead to greater long-term graft acceptance. In addition, Shara's hospital stay would likely be reduced to less than 2 months with only 5 to 6 surgeries, since she will not require the additional procedures to harvest skin. Reduced hospital time and not utilizing cadaveric tissue would probably reduce exposure to infection. Overall, it could be a good option to reduce risk of graft failure, pain, and infection, among other complications."

One student, Min, who has met Shara's family, adds, "I've learned that Shara's family members are recent immigrants. I don't know about their insurance status, but my guess is that the decrease in costs that would probably accompany a shorter hospital stay, at least for Shara, if all goes well, could be an important factor for this family. I don't know whether it would be appropriate to bring that up during a discussion with them, however."

"Thanks for adding those important points, Min," Dr. Fran responds. "So, team, if you were me, how would you help this family understand the risks and benefits of the different options? How would you talk to Shara about this? What would you say to Alia?"

Commentary

The term "identical twin-to-twin skin grafting" has been used in the past to describe instances in which an identical twin has donated skin to assist with skin grafting to cover large total body surface area (TBSA) burns sustained by his or her identical twin. However, in light of several case reports involving triplets,[1,2] the author proposes to use the term monozygotic sibling (MZS) skin grafting.

A review of the literature identified numerous reports of MZS skin grafting, although only 5 of 18 published articles discussed ethics, and the 16 articles with multiple patients mostly focused on pediatric cases and revolved around the issue of informed consent.[1-16] Only one article addressed multiple complex ethical issues in a pediatric case.[15] Here, we discuss clinical indications and ethical challenges relevant to MZS skin grafting in the case scenario involving a pediatric patient.

Skin Grafting for Burn Care

Before exploring the ethical challenges, it is imperative to first understand the role of skin grafting in modern burn care. The process of early excision of burns with skin grafting has had a great impact on outcomes, given that early wound closure reduces morbidity and mortality.[17] Wound coverage can be achieved by various methods and can be temporary or permanent. Nonbiological temporary coverage involves the use of dressings, while the more common biologic temporary coverage can be accomplished through the use of *xenografting*, *allografting*, or the use of skin substitutes. Xenografting refers to transplantation of tissue grafts from one species—most commonly porcine in the United States—to another. Allografting involves transplantation of tissue grafts from a genetically nonidentical donor of the same species. For burn patients, the most common form of allograft is a cadaveric allograft. Permanent wound coverage can only be achieved either by allowing the wound to close itself through scarring, which is not ideal, or by *autografting*, the transplantation of tissue from one part of a body to another part of the same body, or *isografting*, the transplantation of tissue to another genetically identical body. Unfortunately, because skin is the most immunological organ in the body, autografting—or MZS skin grafting, in which the genetic make-up of both bodies is identical—represents the only viable option for permanent wound closure, which decreases a patient's morbidity and mortality risks from a burn injury. Xenografts or allografts are used for burn patients with large TBSA injuries. For example, patients with 75% TBSA burns have, at the most, 25% of their skin that can be used for autografting, but that's only in cases in which patients' remaining skin is suitable for harvesting, which is often not the case. Patients with large TBSA burns simply don't have enough skin to cover their wounds. Surgeons must then wait for harvested sites to heal, which can take as long as three weeks, so that they can "re-harvest" those sites, repeating this process until the wounds are healed. In the interim, xenografts and allografts are used for temporary coverage of the wounds. During this time, due to a severe systemic metabolic insult and risk of infection, patients must be kept in an intensive care unit setting.

In the case scenario, it could be assumed that Shara, with an 85% TBSA burn, only has about 6% to 7% TBSA of skin that is useful as donor sites (assuming that Alia does not serve as a skin donor). Even expanding her harvested skin would only cover perhaps 15% of her body, and therefore the team would still potentially have to wait 2 to 3 weeks to re-harvest her donor sites—to cover another 15% of her body—and this process would need to be repeated until her body is completely covered. The need to repeatedly harvest patients' skin while allowing the donor sites to heal in the interim leads to extended hospital stays. In addition, the longer the wounds are not completely covered, the longer the patient's body is tormented by a massive catabolic and inflammatory response. For these reasons, MZS skin grafting, if indicated, should be considered as an adjunct or alternative to autografting.

Indications for MZS Skin Grafting

Unlike traditional organ transplant recipients, whose life depends on whether they receive a transplant, burn patients can survive without MZS skin grafting, albeit at a significant physical cost. Survival and nonsurvival are not two absolutes in this case but represent two ends of a spectrum, with varying degrees of functional impairment and cosmetic alteration in between. When entertaining the notion of MZS skin grafting, the survival, functional, and cosmetic benefits must be considered in that order.

Although mortality statistics based on age and TBSA burn are available to determine the potential benefit to the recipient, the likelihood of mortality is in constant daily flux for the severely burned patient, and therefore it is difficult to pinpoint a single number upon which to base decisions. From my review of the records of previously reported cases, I estimated that the projected mortality rate of MZS skin grafting, based on TBSA burn—calculated after the cases were individually reported—ranged from 4.6% to 67.5%, although the end result was that there was 100% survival in all the patients (A.K., unpublished data). Although it is an important question for burn surgeons, it is beyond the scope of this review to discuss at what predicted mortality rate MZS skin grafting should be considered and, even then, the risk of mortality should not be the only or even the primary factor in considering MZS skin grafting.

The main benefit of MZS skin grafting would likely be a significantly shortened time to wound closure, which decreases the likelihood of developing complications commonly associated with a burn injury (eg, sepsis and multi-organ dysfunction) and hence reduces the risk of mortality seen in the later phases of a burn patient's hospitalization.[17] In addition, the recipient would likely undergo far fewer surgeries and his or her hospital stay and hospital costs would be reduced.[17] All of these factors combined would likely lead to improved quality of life for the patient—a benefit that cannot be measured numerically. In Shara's case, MZS skin grafting would likely result in far fewer surgeries and a shorter hospital stay. With an anticipated shorter time to wound closure, she would also face a far less catabolic and inflammatory response, potentially decreasing her risk of morbidity and mortality.

From an ethical viewpoint, the clinician's focus is mainly on the risks to the donor. There are no medical benefits to the donor and, although difficult to quantify, there are inherent medical risks and consequences in harvesting skin, including but not limited to anesthetic risks, severe pain (which may be prolonged), infection, and permanent scarring or altered pigmentation. These risks must be balanced against the psychological and emotional benefits to the donor such as being responsible for saving a sibling's life, as in Alia's case. At the same time, in the event the skin graft fails or the recipient succumbs to his or her injury, the donor might experience guilt as a result of self-blame or being blamed by family members and friends. This potential negative psychological impact must be weighed against both the benefits of donating and the potential negative psychological impact of not donating if the patient has complications or even succumbs to his or her injury. In addition to experiencing guilt, the donor might also feel neglected or unappreciated, as attention focuses on the more critically ill recipient.[18] In Alia's situation, the risk to her would likely be limited to potential anesthetic or surgical complications and a small risk of infection postoperatively. The most significant factor for her would be pain from the donor sites, which, although not to be trivialized, might not outweigh the psychological benefits of saving her sister's life.

Timing is of utmost importance in cases of large TBSA burns. Unlike most situations involving organ transplantation, in which the donor's medical condition is relatively unchanged on a daily basis, the medical condition of a burn patient is in constant flux. Although historically most cases of MZS skin grafting were performed later in the hospital course, achieving early wound closure in a burn patient is of paramount importance and can translate into significantly decreased morbidity and mortality.[17] In the above case, if Alia were to donate her skin, the medical team should consider this option sooner rather than later, as time is of the essence for a patient with a large burn injury.

Comparison of Skin Grafting and Organ Transplantation

Skin grafting is not considered an organ transplant. In accordance with the Organ Procurement and Transplantation Network (OPTN), transplant organs are vascularized tissue such as the heart, lungs, kidneys, and pancreas. In recent times, transplant organs have expanded to vascularized composite allografts (VCAs), including limbs and the face.[19] Cadaveric skin allografts are grouped under human cells, tissue, and cellular and tissue products.[20]

Skin grafting and organ transplantation also differ in terms of regulation. While cadaveric skin allografts are regulated by the Food and Drug Administration (FDA), conventional organ transplantation is regulated by the Health Resources and Services Administration. Importantly, surgeons are not required to take any additional training to perform skin grafts beyond their basic surgical training in either general or plastic surgery. Moreover, skin grafting does not have to be performed in a hospital that meets Centers for Medicare and Medicaid Services (CMS) conditions of participation for organ transplant programs.[21] In fact, many hospitals that are not considered burn centers by the American Burn Association (ABA) nonetheless treat burn patients.[22]

Respect for Autonomy in Skin Grafting

Although a skin graft is not considered an organ transplant, many of the ethical principles relevant to organ transplantation, including respect for autonomy, pertain to skin grafting.

Living donor advocate. In 2007, federal regulations mandated that transplant centers have either an independent living donor advocate (ILDA) or a donor advocate team,[21] and, in 2015, the American Society of Transplantation's Living Donor Community of Practice (AST-LDCOP) provided recommendations for the ILDA role.[23] Among other things, these guidelines recommended that: (1) the ILDA must have a certain skill set rather than a specific profession, (2) the ILDA must be educated and demonstrate competence in core knowledge components, (3) the ILDA's primary role should be to assess components of informed consent, and (4) transplant centers must develop a transparent system to define ILDA independence.

Although skin grafting does not fall under the purview of the OPTN, it is certainly justifiable that all MZS donors, adult and pediatric, have an ILDA and that the AST-LDCOP's recommendations be upheld, as skin donors are donating an organ and are subject to risks and benefits that are similar to those of traditional organ donors. In both MZS skin grafting and organ donation, the medical team might tend to prioritize the recipient or there might be some degree of coercion of the donor. In Alia's case, an ILDA should be appointed and be present for all discussions related to the process of MZS skin grafting, including the conversation during which her assent and her parents' consent to the procedure is given.

Informed consent. For pediatric patients, legally, parental permission is all that is required for consent to clinical treatment, although from an ethical standpoint the minor's assent should also be obtained. The Worldwide Network for Blood and Marrow Transplantation (WBMT) supports that minors can physically and ethically participate as hematopoietic stem cell donors.[24] This recommendation is reiterated by the American Academy of Pediatrics (AAP) and the World Marrow Donor Association (WMDA), although they call for (1) an unbiased health screening and consent process with the parents performed by physicians or equivalent health care practitioners who are not involved in the care of the sibling and (2) assessment of the relative risks and benefits of collection from a given donor by an ILDA, who might not be the health professional screening the patient.[25,26]

The risks of hematopoietic stem cell transplantation, however, are significantly less than the risks of solid organ donation. The American Academy of Pediatrics has put forth five criteria for determining when children may ethically serve as solid organ donors.[27]

1. The donor and recipient are both highly likely to benefit.
2. Surgical risk for the donor is extremely low.
3. All other deceased and living donor options have been exhausted.
4. The minor freely assents to donate without coercion (established by an ILDA).
5. Emotional and psychological risks to the donor are minimized.

Most of these criteria are applicable to MZS skin grafting, although it might not be feasible to exhaust all other deceased donor options, as doing so would consume time and, as mentioned previously, potentially lead to greater morbidity and mortality. Assent of the minor in these situations would require both an explanation of the proposed treatment that would be congruent with the minor's understanding and solicitation of the minor's willingness to accept the proposed care. It is also plausible that the ILDA's opinion could conflict with that of the parents or medical team, in which case referral to the hospital's ethics committee should be considered.

Conclusion

Overall, the ethical dilemmas in MZS skin grafting are numerous. They revolve mainly around risk-benefit and quality of life analysis as well as respect for autonomy as manifested in appointment of an ILDA and informed consent for the donor and recipient. Although skin grafts are not considered organ transplants, many of same ethical principles governing organ transplantation apply to MZS skin grafting and must be taken into consideration. Early and appropriate involvement of ethical and legal teams, as well as providing an ILDA, is of paramount importance.

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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.[1] However, Nebraska—the state in which Piper resides—does not have a mandatory default surrogate hierarchy.[1] 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.[2] 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.[3] 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.[4] 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.[5]

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."[6] 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.[7] 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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ORIGINAL RESEARCH

A Model to Improve Detection of Nonaccidental Pediatric Burns

Lauren C. Nigro, MD, Michael J. Feldman, MD, Robin L. Foster, MD, and Andrea L. Pozez, MD

Abstract

Context: Pediatric burn patients warrant thorough evaluation because a sizeable proportion of pediatric burns are nonaccidental.

Design: A multidisciplinary method involving an internal child protection team (CPT) was developed and used to identify suspected nonaccidental pediatric burns in all pediatric burn patients 5 years of age or younger who were evaluated by the CPT and social workers at our institution over a 55-month period.

Results: We identified 343 cases for review that fit our age criteria, 6 of which we identified as cases of suspected abuse or neglect. On average, these patients were younger, suffered greater total body surface area burns (TBSA), and required a longer length of stay in the hospital than the total population. We have not had readmissions for repeat nonaccidental pediatric burn injuries in this group of patients since this model was implemented.

Conclusions: Our multidisciplinary method might provide a more consistent and reliable method for identifying cases of suspected abuse.

Nonaccidental Pediatric Burns

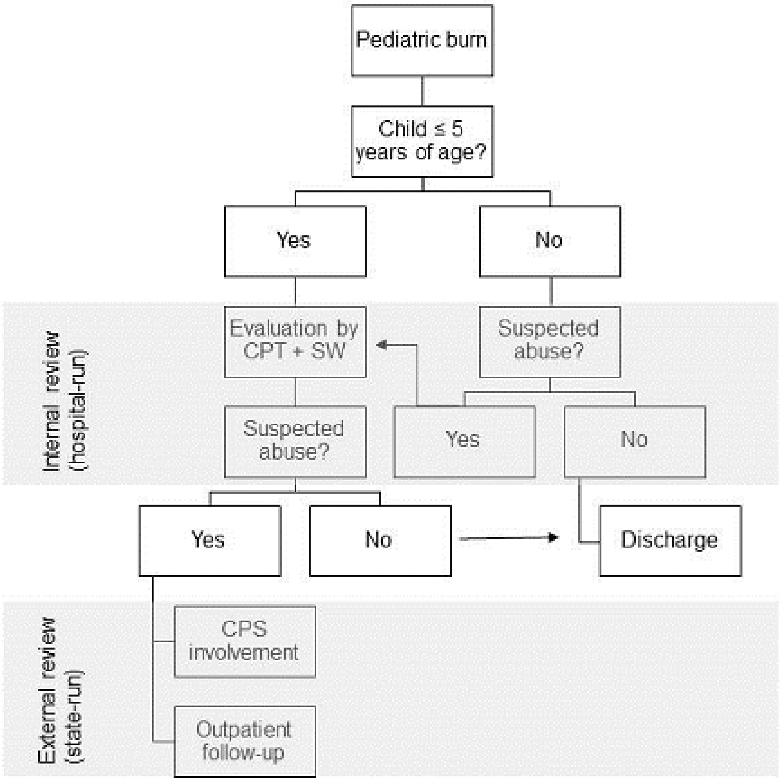
In the pediatric population, it has been suggested that up to 20% of burns are nonaccidental.[1-9] A variety of strategies have previously been described to identify instances of abuse or neglect that have already occurred in an effort to mitigate this problem. These include practitioner education and reliance on pattern recognition, protocols, algorithms, and assessment by a multidisciplinary team.[10-12] As stated by one child safety board in the United Kingdom (UK), "there are no simple formulae for recognizing abuse," and, unfortunately, the methods noted above have the potential to miss instances of abuse or neglect.[10] It is critical to properly identify and address all such cases of nonaccidental pediatric burns. We developed a reliable, inclusive, multidisciplinary model for this purpose involving an internal child protection team (CPT), which might improve patient safety after discharge. Here we discuss our findings and provide a description of our approach to reviewing case of pediatric burns, including the CPT.

Methods

Data sources and inclusion criteria. We conducted a thorough review of the literature regarding pediatric burns secondary to abuse or neglect with a particular focus on their identification and management. After receiving Virginia Commonwealth University (VCU) institutional review board approval, we identified patients five years of age or younger who were admitted to our medical center with burn injuries. We collected data over a 55-month period from January 1, 2010 to July 31, 2014 for all pediatric burn patients evaluated by the CPT and social workers. The information collected included age, race, place where the injury occurred, mechanism of injury, total body surface area (TBSA) involved, region of the body that was injured, and hospital length of stay (reported in days).

Method for identifying nonaccidental pediatric burns. We approach pediatric burns using the model depicted in figure 1. The CPT is a hospital-based group founded in 1992 to address situations of suspected child abuse and neglect. It is composed of a medical director, who is board-certified in child abuse and neglect through the American Board of Pediatrics; nurse practitioners certified in pediatrics; and a coordinator. The team provides a number of services, including an inpatient consult service for child physical abuse, sexual abuse, and neglect cases; 24/7 emergency department coverage; and an outpatient clinic for referrals from physicians, child protective services (CPS), and law enforcement. The CPT works closely with the burn surgery team to evaluate pediatric patients for possible abusive or unsafe environments. The model was developed based on national statistics, which have shown that the risk of nonaccidental burns is greater in children under five years of age.[7-9,13,14] Therefore, the CPT evaluates *all* burned children five years of age and under. A social worker also sees children over the age of five years; in these cases, CPT involvement is at the discretion of the burn surgery team. In the event of suspected abuse or neglect, social work acts as a liaison to CPS to arrange outpatient family assessment and follow up.

Figure 1. Approach to Pediatric Burn Patients Using the CPT



CPT indicates child protection team; CPS, child protective services; SW, social worker.

Results

Between January 1, 2010 and July 31, 2014, the Evans-Haynes Burn Center at Virginia Commonwealth University Medical Center cared for 343 children 5 years of age or younger. The majority of injuries occurred in the home setting, with scalds, followed by contact burns, representing the most common mechanism of injury. The extremities were most likely to be effected. Hospital length of stay (LOS) ranged from 1 to 51 days with an average stay of approximately 5 days. There were 6 cases of suspected abuse (2%), with 2 of these patients being discharged to alternative locations (ie, foster care). The average age of suspected abuse cases was 1.9 years as compared to an average age of 2.11 years in the total population, corroborating that younger children are more likely to be victims of abuse. The proportion of scald injuries was similar in abuse cases and in the total population (50% vs. 57.7%, respectively), suggesting that these factors cannot reliably be used to identify nonaccidental burns, although nonaccidental cases were more likely to have involvement of the perineum. However, injuries tended to be more severe in abuse cases than in the total population. The TBSA burned ranged from less than 0% (inhalation injury) to 30%, with an average of 8% in children with suspected abuse and an average of 2.9% in the total population. Moreover, the average LOS was 15.6 days for suspected abuse cases as compared to 4.6 days for the total population. While LOS was increased by CPT involvement and investigation, the findings also suggests that nonaccidental burns might be more severe and require more extensive care. Results are detailed in table 1. Since this model has been in effect, we have not had readmissions for repeat nonaccidental pediatric burn injuries.

Table 1. Characteristics of Patients Evaluated by the CPT, 2010-2014

Variable	Total Patient Population (N = 343)	Suspected Abuse Cases (n = 6)
Average age in years	2.11	1.90
Race, No. (%)		
African American	165 (48.1)	3 (50)
White	113 (32.9)	2 (33.3)
Hispanic	28 (8.2)	1 (16.7)
Asian	6 (1.8)	0 (0)
Other[a]	31 (9.0)	0 (0)
Place Injured, No. (%)		
Home	325 (94.8)	6 (100)
Non-home	18 (5.2)	0 (0)
Mechanism, No. (%)		
Scald	198 (57.7)	3 (50)
Contact	101 (29.5)	1 (16.7)
Flash	14 (4.1)	0 (0)
Electrical	12 (3.5)	0 (0)
Other	18 (5.2)	2 (33.3)
TBSA (%)		
Average	2.9	8.0
Range	0-40.7	0-30.0
Region burned, No. (%)		

Head and neck	97 (28.3)	0 (0)
Trunk	123 (35.9)	0 (0)
Perineum	19 (5.5)	2 (33.3)
Extremities	271 (79.0)	5 (83.3)
Length of stay in days		
Average	4.6	15.6
Range	1-51	1-29

[a] Includes chemical, radiation, conflagration, and degloving.

Discussion

Nonaccidental burns in the pediatric population are a significant problem that might lead to recurrent, life-threatening injuries to the patient and financial strain on society.[3,15,16] For instance, burns by abuse are associated with a longer LOS, as corroborated by our study, with one source citing an average of 18 days, and typically require more surgical intervention (eg, grafting) than nonaccidental burns.[2,3,8,9,12]

Recognizing characteristics that distinguish nonaccidental from accidental burns, such as burn type, depth, and distribution, can be a helpful tool for health care workers evaluating pediatric patients. Although scald injuries from contact with hot liquids are the most commonly seen burns in the pediatric population and are typically the most common mechanism of burn abuse or neglect,[4,7,12,13,17-19] in our study they were not a distinguishing feature. The average TBSA for patients with suspected abuse in 3 previous studies was somewhat higher than in this study (13%-15% vs. 8%); however, the correlation between TBSA and abuse/neglect in these studies was inconsistent.[7,9,12] Several authors have identified additional patient characteristics for burns by abuse or neglect: single parent family, parental drug abuse, family instability, younger patient age, and delay of presentation.[1,4,5,7,9,15]

In our study there were no nonaccidental pediatric burn injuries readmissions, in contrast to previous studies. Hight et al. demonstrated that 15 of 40 burn patients were readmissions after sustaining previous nonaccidental burn- and nonburn-related injuries.[7] This finding was corroborated by Andronicus et al., who noted that 46% of children with nonaccidental burns were victims of previous abuse.[1] After finding that 31% of nonaccidental pediatric burn patients had documented prior abuse/neglect encounters in the health care system, Rosenberg and Marino emphasized the importance of closely reviewing a child's medical record.[5] As mentioned earlier, others have described approaches to identifying instances of abuse and neglect using multidisciplinary teams, home assessments, algorithms, and practitioner education.[10-12] Unfortunately, while these methods can improve detection, they are not 100% sensitive, and potentially abusive situations might go undetected. Given our 0% readmission rate, we believe our unique method for detection and prevention of abuse using the CPT is reliable and improves the safety and quality of care for children 5 years of age and younger who have nonaccidental burns.

Nevertheless, our rate of detected, nonaccidental pediatric burns was 1.7%, which is considerably lower than the rate of 16% reported by Hight et al.,[7] thus drawing into question the strength of our model. However, our study is limited by a small sample size, with insufficient numbers to perform formal statistical analyses. Additionally, the model described only evaluates children 5 years old and younger unless a treating clinician has a compelling concern about an older child. There is therefore a possibility that older children who are victims of abuse might not be recognized.

Another limitation of the study is that the model requires additional staff resources (social workers, nurse practitioners, physician support) and time, which might contribute to health care expenditures. Future studies should analyze the cost effectiveness of our model on the hypothesis that it reduces patient morbidity and mortality from readmissions and might ultimately be a cost-saving measure.

Benjamin Franklin's old adage, "an ounce of prevention is worth a pound of cure," is particularly relevant in instances of nonaccidental pediatric burns. Toon et al. note that the best way to reduce the burden of nonaccidental burns is by prevention.[20] Prevention efforts currently include community outreach as well as clinician education. Detecting abusive situations while a patient is in the hospital is critical. We encourage trauma and burn centers nationwide to implement a model that evaluates all pediatric burns using a multidisciplinary team.

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MEDICAL EDUCATION

Problems and Costs That Could Be Addressed by Improved Burn and Wound Care Training in Health Professions Education

Patrick T. Delaplain, MD and Victor C. Joe, MD

Abstract

The current system of burn care delivery attempts to meet the needs of the nearly 500 000 patients in the United States who require medical treatment annually. However, specialization of care and lack of fundamental burn and wound care knowledge among graduating medical trainees has unintended consequences, leaving the system inefficient, with inherent inequities in care delivery and with the potential to be overwhelmed in a mass casualty event. While increasing accessibility to specialty burn centers through technology could mitigate some of these problems, increased education is more practical. The implementation of a formal wound care curriculum in medical school would address the problems associated with chronic wounds in the United States. Additionally, this curriculum would be a natural extension of exposure to the basics of burn care, a relevant skill set in any specialty.

The Current State of Burn Care

Nearly 500 000 patients in the United States require medical treatment for burn injuries annually, and 40 000 of those patients require acute inpatient hospitalization.[1] Significant advances in the field of burn care have led to improved survival across all age groups. In the mid-twentieth century, half of patients with burn wounds in excess of 43% total body surface area (TBSA) would die.[2] Now, most patients are expected to survive with burn areas up to 60% or 70%TBSA,[2] but more than 3000 patients still die annually from burn-related injuries.[1]

Looking globally, the economic impact of burns is considerable. In fact, the incidence of burns severe enough to require medical attention ranked fourth in global injuries in 2004.[3] Thankfully, most burn injuries are not severe enough to cause death, but 90% of the worldwide deaths from burn injuries are in low- and middle-income countries.[3] While prevention is undoubtedly the most important aspect of reducing the impact of burn injuries, it is impossible to eliminate them. This means that equitable and efficient allocation of burn care is of paramount importance.

It is undeniable that there has been significant progress in burn care: optimization of fluid resuscitation, advances in critical care, topical antimicrobials, and improvements in timing of excision and grafting of full thickness (third-degree) burns are just a few examples. And much of this progress can be attributed to research efforts and centralization of care at specialized burn centers. As part of this push to improve early and aggressive referral to burn centers, the American Burn Association (ABA) published referral criteria targeted at increasing early triage to appropriate centers.[4] Here, we discuss these referral criteria and show that there have also been unforeseen challenges in the delivery of burn care that cannot be fully addressed solely by specialized centers. Perhaps the largest impact can be made by training nonburn clinicians, and this training needs to start at the earliest stages of medical education—medical school and residency.

Referral Criteria Lead to Inequities in Care Delivery

As understanding of burn wound care and treatment of the burn patient improved, specialized centers began to outpace the care that could be offered at nonburn centers. Accordingly, there was a push to consolidate the care of burn patients at these specialized centers. This strategy was not just aimed at improved survival, however. Delayed or inappropriate treatment of burn wounds can have late complications that are functional (e.g., scar contractures), psychosocial (e.g., depression, posttraumatic stress), or both.[5-7] These sequelae in turn can affect quality of life via their impact on social reintegration and return to work.

The ABA referral criteria attempted to mitigate both problems facing burn patients: early survival in severe burns and long-term complications in less severe burns. However, these criteria, as established, are based largely on expert opinion and fail to take into account differences in regional resources, making their application potentially problematic in some instances. Under the current system, all patients with burns that "involve the face, hands, feet, genitalia, perineum, or major joints" should be referred to a burn center for definitive management.[4] It's unlikely that anyone would question the wisdom of referring a six-year-old girl with a full-thickness burn to her face and lips to a burn center, but what about quarter-sized superficial partial thickness (i.e., second-degree) hot water scald to the back of the hand?

Overtriage has been one of the consequences of broad referral criteria. Carter et al. reported that 41% of patients referred to their regional burn center with less than 10% TBSA burns were either sent home from the emergency department or discharged within 24 hours of arrival,[8] implying that these patients likely could have been handled on an outpatient basis or perhaps did not need specialty burn care at all. An additional 30% of these patients went home within 48 hours,[8] a group that could have likely been handled on an outpatient basis. Similarly, Kashefi et al. estimated a 20% overtriage rate, specifically among patients that were transferred by air.[9]

These questions seem insignificant in regions such as Southern California, where there are five burn centers within driving distance.[10] But the reality is much different for a patient being evaluated in Montana, where there is no burn center. In addition to Montana, there are several other states without a burn center and several more with only one for the entire state.[10] Some critics might argue that this degree of overtriage is acceptable when some centers are already facing issues of late or absent referrals for more serious burns,[11] but we argue that this challenge should be met with increased education for clinicians at referring centers, not more aggressive referral criteria.

Fortunately, the ABA is attempting to tackle part of this problem already via its Organization and Delivery of Burn Care Committee. As a member of the committee, the second author (VCJ) is currently part of a working group that is reevaluating the transfer criteria. The goal of this work is to provide clear, concise criteria for determining not only whether patients should be referred to a burn center but also when such a referral should take place (i.e., immediate transfer versus outpatient referral). Local and regional infrastructure, resources, and relationships will always impact how such guidelines are applied. While problems of over- and undertriage will always exist, the goal is to mitigate them.

The Consequences of Overtriage

Unfortunately, the increased triage of burn patients to burn centers, partly resulting from the implementation of ABA referral criteria, has come at the expense of increased discomfort among general practitioners (medical and surgical) with caring for the burned patient, which can be inferred from the increasing number of referrals despite decreasing overall burn size.[12] This problem is compounded by a broader issue facing the medical community—rapidly increasing specialization of care. Some of the trend toward increasing specialization is in response to the exponentially increasing amount of medical knowledge—requiring specialization for competency. Medicolegal concerns and increasingly packed emergency departments and primary care offices are likely also factors. But, as we move towards increasingly specialized care, the economics of this system of medical care delivery is drawn into question. At what point does the system become unsustainable? That question is not unique to burn care and is outside of the scope of this piece. However, the "super" specialization of burn care delivery certainly also raises questions about its ethicality.

Burn injury is already a burden carried disproportionately by those of lower socioeconomic status, as increased frequency and severity of burns have been associated with lower educational status, lower income, and substandard living conditions.[13] While it is undeniable that centralization of burn services has allowed for the standardization of care, it has diminished what nonburn clinicians can offer. And while burn centers are able to provide resources that a general hospital might not be able to offer, the cost of specialty burn care is significantly higher than general medical admission costs.[14] For lower-income people, lost wages alone might make travel to a burn center, much less payment for services rendered, impossible. This leaves them to settle for inadequate or even nonexistent treatment for their burns. The population of patients that is most adversely affected by burns thus has the least access to burn care services.

A Disaster Waiting to Happen

The responsibility for the inpatient management of US burn patients rests largely with 128 identified burn centers. Currently, 60% of acute hospitalizations related to burn injury take place at one of these centers, each averaging approximately 200 admissions per year for burns or major wounds.[1] While this system is currently sustainable with the baseline number of burns, there is significant concern that it would be overwhelmed by natural disaster or terrorism. An estimated 20% to 30% of injuries related to mass casualty events are burn related, and a major event could quickly overwhelm this resource-limited system.[15] The burn community is aware of this fact, and disaster planning focuses on optimizing available resources and prioritizing triage to burn centers in the event of a mass burn event.[16] However, this plan is predicated on emergency room physicians, surgeons, and general practitioners having enough experience and burn education to effectively manage patients with severe injuries for up to 72 hours and to provide definitive care for those with less severe injuries.

The most straightforward method for handling disaster preparedness, as well as access disparities in regions without burn centers, would be to increase the accessibility of burn specialists. However, this goal doesn't necessarily need to be accomplished by increasing the number of burn surgeons or burn centers. In 2009, Saffle et al. reported their experience with a Salt Lake City-based telemedicine program, which connected local emergency departments with burn specialists via video conference.[17] They showed that pre-arrival estimates of burn size made by burn specialists were an improvement over those made by referring physicians and that both referring and receiving physicians reported a high level of satisfaction with the telemedicine program. Costs of burn care could potentially be reduced even further by using pre-existing smartphones, as they don't require significant investment in new technology and might increase the utility of telemedicine even further.[18] Moreover, improved utilization of technology has the potential to reduce overtriage and improve pre-arrival care. While telemedicine would mitigate some of the inequities of burn care delivery, it fails to address the underlying problem—lack of burn education.

Inadequate Burn and Wound Education

As mentioned previously, there is now a nearly insurmountable fund of medical knowledge that needs to be conveyed during a physician's short time in medical school. So why should burn care be prioritized? Why should every physician be at least familiar with basic burn care and competent in the effective triage of these patients? Burns differ from other disease processes in a few key ways that make education about their care essential:

1. *Unpredictable volume*. While burn injuries can be tracked and estimated, a single mass causality event could quickly overwhelm local resources, requiring nonspecialists to provide care.

2. *High variability in severity of injuries*. Burns vary from fingertip stove burns (for which patients may not even seek medical care) to whole body burns from a structure fire, and much of this spectrum does not require specialty care.

3. *Unequal distribution*. Rural areas have been shown to have higher hospitalization rates for burns and to treat more severe burns than urban areas,[19,20] and access to a major burn center may be hundreds of miles away.

While many might argue that the time constraints of medical education prevent adding dedicated burn care education, it can easily be implemented as part of a larger, much-needed wound care curriculum. Currently, most medical schools do not have a dedicated wound care curriculum.[21] This means that most students graduating from medical school lack competency in practical wound care.

Estimates place the number of patients affected by chronic wounds (i.e., wounds that fail to follow the normal healing process and time) at 6.5 million.[22] And chronic wounds cost the US medical system roughly $37 billion annually.[23] These wounds are frequently associated with other chronic medical problems,[22] and, as the population ages, chronic wounds will continue to increase in prevalence.[22] Wounds are a growing problem that medical education needs to address, and the implementation of burn education as part of a larger wound care curriculum would be a natural addition. After this initial introduction, further practical training should take place during residency. Again, this training could take place as part of a larger dedicated wound care curriculum.

Conclusion

The burned patient has benefited from the centralization of care for major burns at specialized centers. However, the sustainability of the system, especially if forced to handle a major disaster, is uncertain. The current model is hampered primarily by the growing inexperience of nonburn physicians and disparities in access. Some of these problems could potentially be mitigated using technology (e.g., telemedicine) or clarifying the current burn referral criteria. However, common knowledge among physicians about the basics of burn and wound care would go a long way towards improving effective triage, redundancy when specialists are not immediately available, and quality of overall care.

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POLICY FORUM

Defining Adequate Quality and Safety Metrics for Burn Care

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Abstract

While current evidence-based practices might be applicable to caring for patients with routine diseases and common injury patterns, their application to burn care is less clear. Quality metrics created for large patient populations have failed to account for diseases that are not included in landmark research. Tasked to provide not only medically appropriate but also high-quality and cost-effective care for patients, burn clinicians must find a balance between patient-specific quality metrics and external quality metrics.

Evolution of Burn Care

Burn injury treatments have been documented since the beginning of recorded history and have occupied the minds of great historical figures in the practice of medicine: Paré, Marjolin, Dupuytren, and Curling, to name a few. In the last 100 years, foundational work in the understanding of fluid and electrolyte imbalances, shock, and metabolism was done by surgeons managing patients with thermal injury.[1-7] Dramatic reductions in morbidity and mortality have been made possible through a combination of aggressive goal-directed resuscitation coupled with early surgical management. The transition from conservative to aggressive surgical management in the 1970s to 1980s, coupled with advances in our understanding of critical care and the formation of dedicated burn centers, has decreased mortality in even the largest injuries.[8]

As the burn community has finally begun to come up for air and look across the horizon of health care, it struggles to apply current metrics of quality care to its patient population. We review these quality metrics, which are based on large patient populations with routine diseases and common injuries, arguing that they are not applicable to management of burn patients. Tasked to provide not only medically appropriate but also high-quality and cost-effective care for patients, burn clinicians must find a balance between these external quality metrics and patient-specific quality metrics.

Origins of Quality Metrics

Parsimony in the practice of health care has become increasingly relevant in the last decade. Defined by the American College of Physicians as care that "utilizes the most efficient means to effectively diagnose a condition and treat a patient," parsimonious care is one facet of the movement to balance quality and cost in medical care.[9] Programs such as the Choosing Wisely® campaign, established in 2012 and participated in by over 70 medical societies and society collaboratives,[10] encourage physicians to rely on evidenced-based guidelines to limit costly, unnecessary, and potentially dangerous care.[10,11] Effective implementation of these guidelines requires patient education and involvement as well.

Attention to the costs of care has been coupled with increasing attention to the quality of care. The 2000 Institute of Medicine Report, *To Err is Human*,[12] suggested significant opportunities for improvement in the delivery of health care that were framed in a subsequent report as containing 6 elements: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity.[13] The growing complexity of science and technology, the increase in chronic conditions, a poorly organized delivery system, and constraints on exploiting the revolution in IT were cited as reasons for the inability to improve quality of care.[13] Quality and safety departments are now a standard part of most hospitals and do significant work to support initiatives ranging from hand washing to the prevention of central line-associated blood stream infections (CLABSI) and catheter-associated urinary tract infections (CAUTI).[12] Treatment "bundles" exist to minimize post-intensive care unit (ICU) syndrome, enhance recovery after gastrointestinal surgery, and standardize pneumonia prevention in intubated patients.[13-14] Unfortunately, 15 years after the publication of *To Err Is Human*, a National Patient Safety Foundation (NPSF) report suggested there is still significant work to be done, including creating appropriate metrics that reflect meaningful outcomes in safe patient care and supporting health care practitioners to "fulfill their highest potential as healers."[15]

Available Quality Metrics

Despite the conclusion of the NPSF report, the practice of delivering high-quality medical care already had some metrics ascribed to it. The 2008 Hospital-Acquired Conditions Initiative attempted to define preventable adverse events and motivate hospitals and clinicians to eliminate them by establishing limits on reimbursement for certain preventable hospital-acquired conditions, such as deep pressure wounds, infections associated with indwelling catheters, surgical site infections, and deep vein thrombosis, to name a few.[16] Arguably, as a result of this initiative, hospital patient safety initiatives targeting documentation of preexisting pressure wounds, nurse-driven catheter removal, and perioperative antibiotic dosing have increased in volume and frequency.[20] With further awareness of the consequences of extended critical illness, it is not a stretch to imagine current ICU best practices being turned into metrics of quality care.

Quality Metrics Applied to Burn Care

The paradox of the current health care environment is the application of quality metrics created for large populations to a population of patients routinely excluded from the development of those metrics. Sepsis response teams patrolling the hospital will routinely identify markers of sepsis in patients with thermal injury that prompt extra blood tests that are inevitably negative—despite the American Burn Association's 2007 consensus guidelines on the differences between standard markers and those that are useful in the population of patients with burn injury.[21] Repeatedly, burn patients are noticeably absent in the data supporting the implementation of quality care. At the top of every list of exclusion criteria for large system studies in critical disease, surgical site infection management, and sepsis is burn injury.[22-24] While the alphabetical order of these lists by nature results in these patients coming at the top, nevertheless the exclusion of burn patients from these large studies merits evaluation.

Why Exclude Burn Patients from Data for Metrics?

Burn patients spend a significant amount of time in the hospital during the acute phase of their care, averaging around one hospital day per percent area injured.[25] In an era of minimally invasive, same-day or short-stay surgery for hernias and cancer, how does a system prepare itself to handle a 2-month minimum stay in the hospital for a young patient with a 60% total body surface area (TBSA) burn? The hypermetabolic response to burn injury results in the most pronounced catabolism of any clinical condition studied in medicine; without adequate nutritional supplementation, this profound tissue breakdown for energy generation can leave patients unable to heal even the smallest of wounds. While burn surgeons have the luxury of daily visualization of the burn and donor wounds to determine if nutritional support is adequate, it becomes impossible to generalize burn healing success to wound healing success in cardiac or gastrointestinal (GI) surgery. Can mediastinitis or an anastomotic leak after GI surgery be compared to failure of burn wounds and grafts to heal? In the delicate balance between patient and microbe, alterations in the integrity of the skin and mucus membranes can have significant consequences for the ability of patients to maintain their normal microbiome. Infection control practices are predicated on the idea of intact or minimally damaged skin; can these criteria be applied when the single largest organ in the human body is damaged?

Ultimately, the lack of large populations of patients with thermal injury, coupled with these patients' extreme response to injury and their treatment in specialized centers, limits the ability to include these patients in larger cohort studies examining processes and practices that do have substantial impact on outcomes. On average, roughly 486 000 burn injuries receive medical treatment per year; of these cases, roughly 3% die and 8% are hospitalized.[26] In 2005, there were approximately 5 times as many trauma centers in the United States as there were burn centers[27]; while burn centers see over 60% of acute hospitalizations, acute care hospitals each typically average 3 burn admissions per year.[26] The small number of burns treated outside of regional burn centers contributes significantly to the inability to standardize practice and outcome metrics for burn injury management. While data suggests that every 42 seconds an American will suffer a myocardial infarction, giving physicians in hospitals around the country the opportunity to hone their clinical management skills, those same physicians can go years without seeing a burn injury.[28] The number of surgeons interested in treating burn injuries remains small; the authors have personally had conversations with colleagues who express a variety of emotional responses to the idea of managing burn injuries, very few of which are positive. With clinical care taking precedence, it becomes difficult to pursue the large-scale studies necessary to define and refine quality metrics for burn care.

Problems in Defining Quality Burn Care

The hyperfocus on quality and safety, appropriately necessary for both life-saving and cost-saving reasons, has resulted in metrics that are not applicable to teams managing burn patients. For example, extrapolating from the CLABSI and CAUTI prevention initiatives, zero infections is not a reasonable metric in a patient with a 70% TBSA burn[29]; appropriate antibiotic stewardship with the avoidance of multidrug-resistant microbe evolution over a hospital stay could be. By failing to educate our colleagues, administrators, and the public on disease-specific deviations from quality care and instead spending much of our focus on burn injury prevention, the burn community has left itself open to undeserved criticism and financial penalties under the Hospital-Acquired Conditions Initiative, whose incentives are based on metrics that have no bearing on burn patient outcomes.

Meanwhile, despite trying to provide cost- and resource-conscious care, clinicians are often left tilting at windmills flying insurance company flags. Although novel therapies have emerged that have been shown on a small scale to significantly improve patient function without costly and complex staged reconstructive surgery, their adoption by the burn community at large is hampered by the lack of studies necessary to produce evidence-based guidelines, complicating reimbursement. Laser scar revision is a good example; the authors have personally been told on the same phone conversation for preauthorization that the procedure would be denied because it was experimental, and then when papers suggesting it was routine were provided, they were quickly told it was cosmetic, with the result that preauthorization was again denied. While cosmesis might be a valuable benefit, there is no part of the surgical management of burn patients that does not have roots in functionality. This disparity in burn patients' access to novel therapies, as well as a lack of transparency by insurance companies, contributes to the failure to standardize care for this patient population. It also, unfortunately, contributes to potentially preventable variation in patient outcomes, the very thing the focus on quality care works to avoid.

Fulfilling Burn Care's Potential

While the numbers of practicing burn surgeons, nurses, therapists, pharmacists, and other allied health professionals—all of whom are dedicated to the management and study of these complicated patients—is barely enough to keep all the centers staffed, as a community we are perhaps the closest to achieving the NPSF's goal to "fulfill [our] highest potential as healers" through teamwork.[18] Burn patients by their very nature demand a multidisciplinary team; functional recovery requires attention to details ranging the gamut of joint positioning in bed, micronutrient deficiency impact on skin healing, manifestations of posttraumatic stress disorder (PTSD), transportation to and from the burn center for outpatient follow up, and the optimal timing of scar revision therapy. While many other disease processes are managed by multidisciplinary physician teams, team members are often siloed based on the phase of care the patient is undergoing. There is no silo in burn care—everyone is involved from the day of admission. Interestingly enough, in a survey of burn surgeons spanning the gamut of experience (5 to 40 years in practice), there was very little evidence of burnout (L.S.J., unpublished data, 2015-2016). Similarly, a comparison of nurses on a burn unit to other nursing groups demonstrated lower risk of burnout; this was primarily attributed to high sense of personal accomplishment.[30] The focus on quality medical care for patients cannot neglect the nurturing of the medical team along the way; the sum of these individual parts will truly be greater for the attention paid to each.

Conclusion

Medicine in general and burn care specifically continues to walk a fine line between applying population-based health metrics and providing individualized care. As health metrics are being developed for broad application based on science, it is important to have flexibility in applying them to account for the art of caring for the sick. While quality and safety are core tenants of patient care, it remains to be seen if markers that make sense from a 30 000-foot view are just as applicable at the foot of a burn patient's bed.

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MEDICINE AND SOCIETY

Ethics of Burn Wound Care in a Low-Middle Income Country

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Abstract
This review focuses on burn care in low- and middle-income countries (LMICs). It attempts to put the burden of disease in perspective by showing that burn care is under-resourced across the spectrum of LMICs and by interrogating the ethical dilemmas and challenges that staff face in caring for burn patients in this environment, with a focus on South Africa. More specifically, it will attempt to address the following issues: the threshold for utilizing the intensive care unit (ICU), how to balance treatment against cost, the percentage burn considered survivable and how it should be determined, the use of skin from both cadavers and living related donors, and the appropriate ethical guidelines for LMICs.

Burden of Surgical Disease

The Lancet Commission on Global Surgery has highlighted the fact that the vast majority of surgical care is delivered and consumed in high-income countries, yet about two-thirds of the burden of surgical disease is in low- and middle-income countries (LMICs) where resources available to address this disease burden are inadequate.[1] A number of diseases have been highlighted as being major contributors to the burden of surgical disease, one of which is burns and thermal injury.[1] According to the World Health Organization (WHO), an estimated 180 000 deaths annually are related to burn injury.[2] Burns are among the leading causes of lost disability-adjusted life years (DALYs) in LMICs. The rate of child burn deaths is 2.5 per 100 000 across 103 countries, with Sub-Saharan Africa having the highest rate (4.5 per 100 000).[3] This paper focuses on ethical dilemmas arising in the management of burn injuries in LMICs in general and in South Africa in particular.

After two decades of democracy, health care in South Africa remains fragmented along social class lines and for a number of historical and contemporary political reasons is under-resourced at multiple levels. This challenging setting raises ethical dilemmas for burn surgeons who practice in South Africa, which will be discussed in the following sections. The overall ethical themes that arise in burn care management in an environment like South Africa are those of social justice and access to care. Issues related to respect for autonomy, beneficence, and nonmaleficence are usually a consequence of issues related to access to resources.

Justice and Access to Resources

There is an opportunity cost involved in the use of any resource. Resources are finite, and physicians caring for burn patients have an obligation only to use these resources appropriately, in a way that is beneficial to both the patient and the society. This obligation is not exclusive to the management of burn injuries. Twenty-five years ago, Sir David Carter wrote an eloquent editorial on this topic as it pertained to acute severe pancreatitis,[4] in which he discusses attempts to weigh the value of the life of an individual and the cost of saving that individual's life; physicians are asked to try to ascertain exactly how to strike this balance. Acute pancreatitis, like burn injury, is a disease that can consume scarce resources but provide only marginal benefit to both patient and society.

An attempt to find this balance is demonstrated in a study of burn cases conducted at our institution in South Africa,[5] in which the second author (NA) and the fifth author (DC) reviewed the utility of so-called mortality predictive scores in our setting. Demographic data, burn details, and final outcome (i.e., whether the patient lived or died) were used in statistical analyses. Four mortality predictive scores were calculated for each patient using Modified Baux, Coste et al., Belgian Outcome of Burn Injury (BOBI), and Abbreviated Burn Severity Index (ABSI) scores. These four scoring models were developed to assist with difficult decisions regarding futility of treatment for patients with large burns, but all had been developed in high-income countries (HICs) and been shown to be sensitive and specific in terms of predicting death in patients from HICs.[6-9] Each score used clinical data to predict a so-called "break point" at which 90% or more of patients can be expected to die. The break points for each score in our institution were calculated using combinations of factors such as age, total body surface area burn (TBSA), presence of inhalation injury, and depth of burn, depending on which score was used. These break points were much lower than the break points identified in the literature. In other words, in our LMIC environment, a significant number of fatalities occur in patients with potentially salvageable burns had they occurred in a HIC. This left us with a dilemma. If we merely adopted these scoring models and replaced the break points in the literature with our own break points for predicting mortality, we would merely be normalizing deviance. Furthermore, if we accept that our patients will die with a much smaller TBSA than patients in a HIC center, then we would risk creating a self-fulfilling prophesy by using our own break points. Although we thus could not use these scoring models to predict mortality, we now use our break points to identify patients who are at risk for unexpected and potentially preventable death in our setting, allowing us to institute more aggressive interventions to prevent this outcome.[10]

The context, however, often influences the ethical dilemma. For example, in the busy winter months when 2 or 3 children with burns between 25% and 40% TBSA are admitted each week, resources are rapidly consumed. This circumstance might impact decision making regarding an adult male with a 50% TBSA burn who is admitted during this busy period. A 50% TBSA burn in our unit falls in the Lethal Area 50 Index (LA50) associated with 50% mortality. So the adult patient admitted during the busy winter months creates a major ethical dilemma. He has a potentially survivable burn if managed aggressively. Yet, if this patient's care is prioritized, the 3 children with smaller burns who have also been admitted during this period might well receive a lesser degree of care. Denying the adult patient the appropriate resources results in a self-fulfilling prophesy in terms of his outcome. However, if the same patient presented during the summer months, his major injury would be prioritized and receive the appropriate resources.

A 2013 review of intensive care unit (ICU) resources in South Africa found that only 25% of all ICU beds were in the public sector, and only 23% of hospitals in the public sector had an ICU facility.[11] The most important consideration when it comes to admitting a burn patient to the ICU in a government-funded hospital is whether the patient can be expected to survive to leave hospital. With such limited resources, it is unreasonable to allocate finite and consumable resources to a patient with no real prognosis. Once allocated to a particular patient, those resources are immediately denied to another patient. The patient most likely to qualify for ICU admission is one with a defined, easily reversible problem. One such problem is facial burns in which acute swelling results in a compromised airway. Intubation for 24 to 48 hours is usually sufficient for the swelling to resolve and for the patient to be extubated. Children who require ventilation are also candidates for the ICU. Once again, the caveat is that the burn must be thought to be survivable before the intensivist will consider admitting the patient.

Ethical Issues in Skin Donation

In April 2016, the first skin bank in South Africa was opened in Pretoria at the Centre for Tissue Engineering.[12] Nevertheless, the availability of cadaveric skin remains restricted. There is little information in the public sphere about tissue donation, and organ retrieval systems remain inadequate to identify all potential organ donors in the country. The indication for using allografts (ie, skin from a genetically nonidentical person) is massive TBSA burns when insufficient donor sites in burn patients are available. Allograft is used as a temporizing measure until the donor sites have healed and skin can once again be harvested from these sites.[13] The only center in South Africa to have much experience with the use of cadaveric skin to temporize large burns is the Red Cross War Memorial Children's Hospital in Cape Town. The availability of deceased donor allograft skin has been internationally proven to decrease mortality and morbidity in burn victims.[13]

Skin from living related donors is not typically used due to risk to the living donor as well as logistical issues and limited theater time, although at our center we had one such case, which raised significant ethical concerns. We admitted a 6-week-old child with 30% full-thickness burns. Excision and harvesting would have resulted in too great a physiological derangement, but excision without coverage was also not acceptable. After ethical consideration by the multidisciplinary team and extensive discussion with the mother, who was HIV positive, we performed a mother-to-child skin graft after excision under the cover of prophylactic antiretrovirals. Due to the small size of the child, only a 5% donor site was harvested from the mother. The child did well with subsequent autografting and has remained HIV negative up to one-year postprocedure. Although living skin donation poses risks to the living donor and logistical issues, it can be lifesaving, particularly for smaller children. It would be more practical to direct efforts towards increasing skin donation after death and creating a sustainable supply of allograft skin for major burn patients.

The Appropriate Ethical Guidelines for a LMIC Must Avoid Accepting Second Best

Inequality is a reality in terms of access to resources. The utilitarian approach to ethics aims to choose the path that increases the happiness or well-being of as many people as possible. This is a controversial approach, because it denies a minority their happiness or well-being in order to increase the happiness or well-being of the majority. However, when it comes to the allocation of scarce resources, physicians frequently find themselves making just such decisions. Who is most likely to benefit from these scarce resources is the question that must be answered. Working in a LMIC setting creates a number of ethical challenges for physicians working with burn patients, as the availability of resources directly impacts outcome and survival following a burn. It is important not to allow a creeping sense of fatalism to lead one into an acceptance of "second best" and "good enough," which can become a self-fulfilling prophecy.

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HISTORY OF MEDICINE

Getting Past Dax

Monica L. Gerrek, PhD

Abstract

Much has been written about Dax Cowart's tragic burn injury, treatment, and recovery. While Dax's case is certainly important to conversations regarding decision making in burn care, his is not the only story there is. In this article, the case of Andrea Rubin, also a severe burn survivor, is introduced as another voice in this conversation. Her experience during treatment and recovery is very different from Dax's and should cause us to at least pause and reconsider how we think about treatment and decision making in burn care.

Two Survivors, Two Stories

In 1973, 25-year-old Dax Cowart, former captain of his high school football team, former Air Force pilot, rodeo rider, and aspiring commercial pilot, was severely burned as a result of a freak accident.[1-5] Dax's father had inadvertently parked his car on a bridge over a leaking propane pipe, and a spark from an attempt to start the car caused an explosion. His father was killed and Dax suffered a burn to 65% of his total body surface area (TBSA), with third-degree burns to his face, ears, and hands.[1] Most of his fingers were amputated and he lost vision in both eyes. His words to the first person, a farmer, who arrived at the scene were, "Get me a gun. Can't you see I'm a dead man. I'm going to die anyway."[2] During his very painful 14 months of treatment—6 in the hospital and 8 in a rehabilitation facility—Dax repeatedly requested that the team discontinue treatment. He asserted that he did not want to live "as a blind and crippled person" and demanded that he be permitted to die even though his mother was consenting to treatment.[5] According to Dax, his physicians generally ignored these requests even after he was deemed to have decision-making capacity by a respected psychiatrist.[1-5]

Dax's story is a powerful and compelling one. It is the story of a person with severe, painful, and life-altering injuries who was determined by a psychiatrist to have the capacity to make medical decisions for himself, but whose refusals of treatment were disregarded by his surrogate and medical team. It is the story of someone who, after all of this, claims he is glad to be alive but also claims that his refusals of treatment should have been respected and that he should have been permitted to die.[1-7] Dax's case has since been discussed at length in books, articles, and videos.[1-20] There is also widespread belief that burn units are problematically paternalistic.[1-23] It is not a stretch to think that

Dax's case has been the primary catalyst for this belief given that it has received so much more attention than that of any other burn patient.[1-20,24] However, Dax's case is about one burn patient with one set of experiences and but one point of view about burn care.

In 2014, Andrea Rubin was a 49-year-old health insurance sales representative. She had just started this job, having previously been employed in marketing and advertising, and was looking forward to her first busy season. One evening, as she was turning around in a parking lot, her car got stuck after a tire slipped off the pavement. As she tried to dislodge the car by alternating between drive and reverse, the motion caused a spark that set the car on fire. The inside of the car quickly filled with carbon monoxide and she lost consciousness. Andrea suffered a 58% TBSA burn with third-degree burns to her face, ears, head, chest, arms, back, and legs. She suffered fourth-degree burns to her lower right arm, which was subsequently amputated just below the elbow. She also lost partial vision in her right eye. Her scalp was so badly burned that her hair will never regrow. Her father, like Dax's mother, consented to treatment. Yet, while Andrea was sedated for approximately two months to promote healing and could not participate in decision making, her friends repeatedly pleaded with the team to discontinue treatment and let her die. They were adamant that "she would not want to live this way" and that she would refuse treatment were she able to express herself. Given her father's legal standing as her next-of-kin surrogate and his continued support of treatment, the pleas of Andrea's friends went unheeded. Andrea ultimately spent three months in the hospital and two months in rehabilitation and continues to seek outpatient treatment for her burn injuries (A. Rubin, personal communication, 2017-2018).[25,26]

As noted, Andrea, unlike Dax, was not able to participate in decision making for a number of weeks after her injury due to being sedated. Moreover, after the sedation was lifted, she never refused treatment. However, Andrea defends her friends' pleas and maintains she would have refused treatment had she been able to do so. At the same time, Andrea also defends her father's decisions, which were based on the recommendations of the burn team, to continue with treatment. She is steadfast in her belief that the team would have been mistaken to have respected her friends' wishes and thus her own had she been able to express them. Andrea is firm that she did not have the capacity to make medical decisions for many weeks after the sedation was lifted and has serious doubts that burn patients with injuries like hers and Dax's have this capacity in the initial stages of their treatment and recovery (A. Rubin, personal communication, 2017-2018).[25,26]

Andrea's case, like Dax's, is also about just one patient with one point of view. Nevertheless, it is important to take careful note of Andrea's case, for the perspective it provides on burn patient decision-making capacity and autonomy—and on burn treatment and culture—calls into question the view that burn units are problematically paternalistic and disrespect patient autonomy.

Burn Patient Decision-Making Capacity and Autonomy

Both Dax, directly, and Andrea, through her friends, expressed a wish to be allowed to die and, in both cases, this wish was not honored. Although Dax may in fact have had decision-making capacity when his requests to stop treatment were denied, Andrea's case serves as a reminder that, for a severe burn patient, decision-making capacity and hence autonomous choice can be significantly compromised, both acutely and for some time after the injury is sustained.

In 1978, the National Institutes of Health (NIH) issued a consensus statement on supportive care in burn therapy in which it stated, "Physical and/or emotional shock in the burn patient make it impossible for the victim to contribute to the early decision-making process."[27] This view is supported by a study conducted by Brewster et al. in which patients were interviewed two to nine years after suffering flame injuries with a mean TBSA of 61%. The authors concluded:

> All patients thought informed consent was unrealistic at the time of their injury, but they believed that the capacity to give informed consent developed over time and coincided with improved function and understanding of their injuries. In addition, they all thought that the burn physicians' role was to do whatever was medically best for their patients in an emergency situation … and that initially, patients should follow all of their physicians' orders. None of these individuals thought withdrawing support would have been appropriate for them. Two of these patients thought that withdrawing support was the patient's decision to make, but that physicians should discourage that decision. All patients were comfortable with the decisions made for them during their ICU stay.[28]

However, concern regarding patient decision-making capacity is not limited to just the acute phase. Andrea maintains that she could not have made informed, autonomous decisions until weeks after the sedation was lifted. Another burn survivor, David Jayne, concurs, writing, "I do not feel I really knew the significance of my condition for at least 3 weeks, possibly a month, when I was out of intensive care and on the ward."[29] Dax himself has admitted it can be difficult for physicians to know whether a patient is making an autonomous decision during treatment. Dax was once asked in an interview, "How can a physician be sure that a patient really wants to die, that it is not a momentary desire or that the patient won't change his mind later?" He responded, "I doubt that there is any way a physician can be absolutely sure."[2]

Burn Treatment and the Culture of the Burn Unit

To this day, Dax describes his time in the hospital as "pure hell."[6] He felt he was "being skinned alive" and that the treatments, including "whirlpool tankings in solutions to cleanse his wounds; procedures to remove dead tissue, [and] grafts to protect living tissue," were "extraordinarily painful."[1,6] Dax further explains that "it was too painful, and when I told them I couldn't tolerate it, it didn't matter ... it was like a parent telling a young child 'it doesn't matter what you want, you do it 'cause I say so' ... they weren't going to pay attention to what I wanted as a patient."[6] Dax claims he knows that the medical team did not want to hurt him, that they were only trying to help him, but he is still angry at his doctors for treating him.[2]

Andrea does not question the nature of Dax's experience (A. Rubin, personal communication, 2017-2018).[25,26] However, her experience was very different even though her injuries were similar to his. While Andrea was in significant pain, she feels it was well managed. During dressing changes, primarily during the removal of the dressing and the cleaning of the wounds on the spray table, she was in excruciating pain. Yet Andrea believes the pain was tolerable in large part because she felt the nurses were doing what they could to help alleviate the pain (A. Rubin, personal communication, 2017-2018). They would not only provide her with pain medication but also play Andrea's favorite music and sing with her, and there was, surprisingly, a lot of joking and laughing (A. Rubin, personal communication, 2017-2018). Andrea has stated that her drive to recover was, and continues to be, motivated in part by the burn team. She felt from the beginning that the team was on her side and that at some point—she is not sure when—the burn team became family to her (A. Rubin, personal communication, 2017-2018).[25,26]

Other burn survivors have had experiences similar to Andrea's. Patty Tweedle, who suffered an 86% TBSA burn in 1998, "credits her support system of family, friends, and the hospital staff with helping her make it through the dark days during rehab. Together they celebrated every milestone—the first step, the first breath, the first time she was able to wear regular clothes or shoes."[30] Lindsey Smith, whose brother suffered a 54% TBSA burn, says of her brother's burn center care team, "The staff was amazing in the way they worked with us.... It was a very inclusive relationship, just fantastic."[31]

In fact, the expressed culture of the burn unit is to be collaborative and provide broad support to patients and families. When Bruce Zawacki, a physician formerly with the Burn Center at Los Angeles County-University of Southern California (LAC-USC) refers to the "team" he means "the hospital staff, the patient, and the patient's family and friends."[32] In addition, Sharon Imbus, a nurse also formerly with the Burn Center at LAC-USC, and Zawacki explain elsewhere that:

> Our burn staff functions as a team, and the members are encouraged to speak up for the benefit of their patients. Instead of being part of an exclusive doctor-patient dyad, our patient has many people working on his behalf. His most trusted confidant may prove to be a physician, a

> nurse, a therapist, or a social worker. The burn team meets formally once a week in an interdisciplinary conference to share the patient's psychosocial and ethical problems and to seek advice, support, and a unified approach.[33]

Andrea has also experienced such far-reaching support. She credits one of the burn center's nurse practitioners with coming up with the treatment that, after many months of failed treatment, helped heal her scalp when the physicians wanted to try a more aggressive, higher-risk approach. This same nurse practitioner chose to accompany Andrea across state lines, on her own time, to Andrea's first public speaking engagement as a burn survivor (A. Rubin, personal communication, 2017-2018).[25]

Conclusion

Unlike Dax, Andrea does not believe the burn professionals who cared for her failed to respect her autonomy. Rather, she feels that the burn team acted in her best interest when she was unable to participate in decision making and that they gave her the physical and emotional support she needed throughout her recovery. So, while Dax's story is a tragic yet captivating one, close attention should be paid to Andrea's story and the stories of other burn survivors to help cultivate a nuanced understanding of medical decision making in burn care. Listening to the voice of a single patient—Dax—with just one set of experiences, when there are many to be heard, is a mistake. It is a mistake that might result in the unnecessary loss of good and happy lives,[2,34-38] and thus it is a mistake that cannot be afforded.

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PERSONAL NARRATIVE

Ask Me about My Pearls: Burn Care, Ethics, and Creative Writing

Debra Ann Reilly, MD and Steve Langan, MFA

Abstract
Channeling feelings into the written word rather than the scalpel was at the heart of the creative writing challenge that the first author (DR) accepted when she joined the Seven Doctors Project at the University of Nebraska Medical Center in 2008. Burnout has become recognized as a factor undermining physicians' quality of life, and the practice of creative writing helps mitigate stress and sustain a successful practice. When physicians partner with and are mentored by a seasoned creative writer, creative writing can serve as an exercise in ethical reflection, which is particularly valuable at mid-career; this is the subject of the following dialogue between one physician writer and the facilitator of the Seven Doctors Project creative writing class.

In 2008, the second author (SL) convened a group of seven physicians and seven seasoned local writers to explore how creative writing processes might help mid-career physicians use the written word to further develop the creativity so key to caring ethically for patients. What follows is a conversation between SL and one of those first participants (DR).

DR: The reason I came to participate in your creative writing experiment in 2008 is a simple one for an academician: I received an email invitation from my department chair. How do you turn down your chair? Was it Russian volunteer style, because I didn't already publish enough, because I was close to the participants' average age of 52, or because everyone else in the department said no? Then there was my husband, a facilitator of emotional intelligence seminars, who suggested how beneficial for my career this course would be. Plus my burn team thought it was a hoot and carved out the time for me to attend. Finally, I met you and maybe had a soft spot for helping a PhD candidate with his thesis.

Creative writing and burn care? Facts, data, and sweaty surgeries were my all-encompassing life's work. Why was I agreeing to participate in a creative writing class? The work for this thesis—the Seven Doctors Project of 2008—paired seven physicians with seven local (and successful) writers. Our goal was to facilitate translating our medical (in my case, surgical) creativity—and stress—into the written word. Not having written much except daily rounding notes, I went and found books on "how to write a poem" and plunked them down on the desk for our first working meeting. And, really, meeting at 5:30 p.m.—which is evening for the internists in the group but merely a lunch break for me—was a push. I always seemed to be running late and in the wrong room. But my seasoned writing partner, Rebecca, was a woman of incredible beauty with a free and kind spirit. She was calming and nurturing, and she published a book written in part with this group.[1]

SL: Debra, you hit on a universal among physicians. Because of how busy you are, you only make time when you really need to or really want to. In a way, in your case it sounds like there was a little of both: duty and curiosity. I am glad you found your way into the creative writing workshop. Some of the physician-participants, including Bud Shaw, your chair, were natural participants. At some stage in their education and their lives, they, like other physicians, wanted to be writers,[2] but they took the road that led to medical training. But your primary interest is music, not writing. If we could, we would individualize the experience to music or sculpture or theatre in line with a person's interests … but there are materials and multiple components that need to be put into play. Writing is portable and practical. In just a few minutes we can find ways to encourage physicians to start doing some writing. And, if we are determined enough, we can help lead them to draft an extended writing project. Thinking about the ethics of our work—which has a lot to do with helping physicians who are facing job dissatisfaction, compassion fatigue, burnout, and so on—how should we encourage other colleagues who need creative stimulation and everything that goes with it (including being part of a community) but who might not be willing to volunteer for it?

DR: Other physicians might not yet visualize a goal, not feel one, and we physicians tend to be very goal oriented. The way to entice us is to show results: the poems accepted for publication, the books now in print. While publication is always a positive accomplishment, conversations on the wards or at lunch—the hype we each created in excitedly talking about our experiences—was a welcome byproduct for me. I am not sure I had a goal in the beginning, but a worthwhile purpose certainly emerged, even if in a roundabout way—roundabout because I probably would have signed up sooner if there had been a music component. (In college I actually majored in organ performance but realized early in my music career that my talent would not take me places I wanted to go. So I turned to medicine and now am a patron of the arts rather than a performer.) Although the workshop wasn't a musical outlet, the writing provided another helpful outlet for me. I wrote two complete poems with suggestions and encouragement from Rebecca, but I didn't really learn to structure a poem. (And I certainly have a few rejection notices to show for my lack of training in poetry structure!) The value of this experience, however, was in channeling my feelings into the written word rather than my scalpel; sharing my vulnerability was at the heart of the challenge I accepted. I was not alone in being uncomfortable with a written assignment to turn my daily surgical experience into a poem. I felt alone, however, when I read those poems to the public at the end of our project at graduation.

SL: Since we have worked with about 40 physicians and health care professionals over the years—about 150 people in total—I often hear about their anxiety and fear of the public reading. And I also hear (and see and feel) how pumped up our participants are after they complete their public readings. Will you tell me a little more about this experience?

DR: The public reading was exciting. The feedback was not scary, and my husband was proud of me for following through with something that stretched my emotional openness to share my vulnerability. Subsequently, I found myself journaling phrases or even stanzas as a way to disengage my brain for a few moments in the day and reorient myself. I wondered how much introspection and reflection on others' writings I needed to help remind me that there is clearly time for humanity and balance in daily conversations with patients. I used this feeling of vulnerability to learn to start conversations with my patients in new ways. For example, I found that it was easier to meet a burn patient and that patient's family by asking open-ended questions that did not pertain to the burn injury—questions that were more personable (maybe even more neutral)—which allowed for subsequent conversations that humanized both sides of the burn family. I say "family" here because, in burn care, we tend to develop and maintain a longer-lasting relationship with our patients than in many other surgical specialties. We care for them acutely and then continue for years (sometimes decades) to address their reconstructive needs. This year I was delighted to attend two high school graduation parties for young women I first met when they were four years old. Caring for them during their difficult and life-threatening early surgical stays created significant and lasting emotional stress for me. But they have been a source of many of our burn team members' smiles and hugs as they grew up in my practice, and now they are delightful young women with college scholarships. Being able to express my thoughts in written words facilitates conversations and deeper relationships within our team and with patients.

SL: I have two thoughts in rapid succession: that extended relationship is wonderful, and it is also pressure filled. It's not just "fix the heart" or "fix the leg" or "take out the gall bladder" for you. It's repeated visits that I expect include more and different levels of pain for you and the patient. In the case of your patients—the high school graduates from your burn unit—you drew close to them, which is really beautiful. But what if—and maybe you don't want to talk about this—what if you have a patient or caregiver with whom you don't feel fundamentally connected? How does that work? How do you handle an extended relationship in which you don't feel this connection?

DR: When there is not an immediate connection with the patient, I tend to fall back on disease and diagnosis. This approach, however, can get me only so far. That is where my burn team comes in. Someone in our group will almost always develop a bond with the patient. I use his or her insight to help plan the next stages of care.

SL: How does this now relate back to your writing?

DR: As you and I have talked further during the continuation of the Seven Doctors Project, I now realize that what many of us, the original seven doctors, wrote about was a catharsis of emotions experienced during our day or an issue with our day. We wrote about so-called “difficult” patients, lopsided interactions, emotions held in check and not shared with our teams. We had a confidentiality agreement between us, as some of the topics we discussed were not meant to be shared with others on the faculty. Opening up to other service chiefs was especially hard for me—I did not want to seem like a vulnerable surgeon. (I needed the consults!) I certainly did not want to showcase an episode of bad judgement or learn of a failing in another esteemed faculty member. In other words, we used the format of creative writing to express our personal views of the ethics of our situations. Our conversations were really ethics dialogues, safe from the scrutiny of a legal team.

SL: Yes! This is what I often say. But I haven’t had the opportunity to say it in print. Creative writing workshop practice, especially as it’s brought into professional settings, is an elaborate and mostly indirect form of ethical engagement. Not only is the text that’s being created—we specialize in poems, stories, and creative nonfiction—loaded with any number of ethical conundrums, but there is, in my experience, a kind of ethical negotiation among the participants in the group. Countless ethically fraught situations, including power imbalances and messy professional relationships, romantic entanglements, and so on, surfaced in both the writing discussed and the writing produced over the years.

DR: I still do not write poems routinely, nor do I publish enough academically for my new chief. But I do think, and perhaps dream, using a little more of my creative side, and I need to recognize that same creative side in my patients. This self-reflection, which now seems easier with seniority, was certainly sparked by testing in the processes of therapeutic writing. But we should not wait to learn self-reflection until mid-career.

SL: I welcome your thoughts on this, Debra. As you know, I was recently appointed interim director for medical humanities at the University of Nebraska Omaha, which is one of the main feeder campuses for University of Nebraska Medical Center. The documented rates of burnout among medical students and resident physicians, not to mention attending physicians, are quite high.[3] And the anecdotes certainly get your attention. Your comment provided a kind of implied warning by suggesting the need to introduce therapeutic writing to trainees sooner rather than later. In your personal experience observing and working with students, why is this so necessary? What are the other ways, besides writing, to help these students through the process of becoming professionals?

DR: One of the other byproducts of this class is a creative writing seminar now available for our fourth-year medical students that addresses many of the issues you just mentioned. We also work with first-year students in our healer's art class, where students electively participate in a national curriculum of small-group introspective sessions and journaling. Participating in these seminars has enhanced the camaraderie that comes with transition to medical life.

In closing, I share an excerpt from "The Black Pearl," a poem I wrote during my participation in the Seven Doctors Project:

> If you see me with them, ask me how I am,
> Ask me how my patients are.
> I'm not a pessimist about anything but them.
> I figure if I worry, I won't miss anything.

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VIEWPOINT

The Four-Quadrant Approach to Ethical Issues in Burn Care

Chad M. Teven, MD and Lawrence J. Gottlieb, MD

Abstract

Burn injuries raise questions about decision-making capacity, informed consent, medical decision making, patient autonomy, the patient-physician relationship, and medical futility that must be acutely addressed. A commonly used approach to managing ethical challenges focuses on moral principles including respect for patient autonomy, beneficence, nonmaleficence, and justice. Another paradigm for ethical analysis is the "four-quadrant" approach, which poses questions for a given case regarding medical indications, patient preferences, quality of life, and contextual features. We have found this approach to be very effective in the clinical setting. This article will highlight the use of the four-quadrant approach in the management of ethical challenges that arise in the care of the severely burned patient.

Burn Care and Ethics

Acute burn injuries represent a major health concern in the United States.[1] As total body surface area (TBSA) of the burn injury increases, so too does the likelihood of significant morbidity and mortality. Recently, improved understanding and management of severe burn injuries has led to increased overall survival and functional recovery of patients with such injuries.[2] Nevertheless, extensive burn injuries are associated with complex ethical as well as medical challenges. The care of patients with burn injuries frequently involves ethical issues related to evaluation of decisional capacity or surrogate decision making, since whether acutely burned patients have capacity to make informed decisions is not always clear. Additionally, medical futility, quality of life, end-of-life care, and resource allocation might need to be considered.

Numerous frameworks exist to aid health care practitioners in managing ethical challenges that arise during clinical care. The most widely known is the one introduced by Beauchamp and Childress.[3] This framework approaches ethical issues in the context of four moral principles: respect for autonomy, beneficence, nonmaleficence, and justice (see table 1). This framework has been influential because the values it espouses seem to align with our moral norms. In addition, it offers a practical approach to both the teaching and analysis of ethical challenges. A shortcoming of this framework, however, is that little empirical evidence exists demonstrating that people use the four principles in ethical decision making.[4]

Table 1. Four Main Principles in Beauchamp and Childress's Biomedical Ethics Framework[a]

Principle	Description
Respect for Autonomy	Respect for the individual patient and his or her ability to make decisions with regard to own health and future; right to self-determination
Beneficence	Doing and promoting good; preventing and removing evil or harm
Nonmaleficence	Doing no harm; avoiding harming
Justice	Maximizing benefit to patients and society while emphasizing equality, fairness, and impartiality

[a] Adapted from Beauchamp and Childress.[3]

Jonsen, Siegler, and Winslade have described an approach to clinical ethical case analysis known as the "four-quadrant" approach.[5] This framework, which relies on the four principles but takes a more practical and clinically oriented approach to ethical challenges,[6] has been popularized by its use in the University of Chicago MacLean Center for Clinical Medical Ethics fellowship training program.[7] Within this framework, all ethical problems are analyzed in the context of four topics: medical indications, patient preferences, quality of life, and contextual features (i.e., social, economic, legal, and administrative). Each topic can be approached through a set of specific questions with the goal of identifying various circumstances of a given case and linking them to their underlying ethical principle.[8]

We have used this framework at the University of Chicago Burn and Complex Wound Center and have found it to be effective in navigating ethical issues that arise. The purpose of this article is not to prove the superiority of the four-quadrant approach over other models but to discuss its utility and application in the context of burn care.

Medical Indications

The first quadrant, medical indications, includes diagnosis, prognosis, proposed measures for evaluation and treatment, and expected outcome of treatment. For all clinical scenarios, it is advisable to start by describing what is known about the medical facts of the case. In the context of burn care, this might encompass type and severity of burn injury, planned interventions, and expected course. While this topic is part of any clinical discussion, in cases with ethical challenges, it is particularly important to further articulate the purpose and goals of planned interventions.

The principles of beneficence and nonmaleficence are highlighted during this goals-of-care discussion. Indeed, any decision made regarding therapy, such as whether and when to operate, should weigh clinical and ethical benefits and risks. Issues of goals of care and decision-making capacity often arise in cases of acutely burned patients due to the severity of burn injuries and the fact that patients might not be able to make informed decisions acutely. Prior to embarking on ethically charged discussions about goals of care, we attempt to make an accurate diagnosis of the problem and to determine its severity and the expected outcome. In addition, we aim to provide the patient and family with meaningful answers to questions regarding recovery and the probability of treatment success.

It is also important to define how expected management decisions might benefit or harm the patient. For severe burns, these include the optimal timing to operate, the need for topical or systemic antibiotics, nutrition optimization, volume replacement, airway management, and rehabilitation. Importantly, severe burns often cause long-term functional and cosmetic consequences, which should be discussed and addressed with the patient and family members.

Patient Preferences

Patients' preferences are relevant from both a medical and ethical standpoint. If the patient has decision-making capacity, his or her preferences should be respected and guide medical care. If the patient does not have decision-making capacity, the patient's presumed wishes or best interests, as conveyed by a surrogate, serve as the guide. Determining decision-making capacity poses a unique challenge in acute burn care. In the 1980s, Sharon H. Imbus and Bruce E. Zawacki wrote that there is often a lucid period immediately after the injury in which patients demonstrate calmness and composure.[9] Accordingly, if informed consent could be obtained from the patient during this time, it should. Other authors, as well as burn survivors, disagree, however, suggesting that patients are cognitively and emotionally incapable of discussing, comprehending, and making decisions involving life-and-death choices immediately after the injury.[10-12] When answering the questions posed in this quadrant, it is important to discern not only whether the patient has decision-making capacity, but also whether the competent patient has been provided with adequate information to make an informed decision and whether the competent patient who gives consent does so voluntarily.

In our experience, patients and family members are unlikely to make appropriately informed decisions during this acute period. The approach we employ consists of the medical team making emergent management decisions while concurrently educating the patient and family members regarding the clinical situation.[13] The patient should be included in the decision-making process as soon as he or she can appropriately and fully take part, as determined by clinical evaluation (including assessment of decision-making capacity) by the medical team. As the situation allows, we strive to understand the patient's wishes as well as underlying beliefs.

A further ethical consideration that arises within this quadrant is the patient-physician relationship and its role in decision making. In theory, patient preferences are at the center of an approach that focuses on respect for patient autonomy. Some authors have suggested that autonomous patients should singularly make decisions regarding their medical care.[9] However, we have observed that a major limitation of this approach is the asymmetry of patients' and clinicians' knowledge and experience. In other words, decisions made without the input of the medical team are less likely to be sufficiently informed. According to Mark Siegler, a medical ethicist and the founding director of the MacLean Center for Clinical Medical Ethics, the current era of medical decision making is best described as a shared-decision making model.[14] In shared decision making, the patient and physician work in tandem to make medical decisions for the patient. Recent studies have shown this model to result in improved patient care.[14] In line with the four-quadrant approach, we believe that decisions are best made by the patient and family with support, information, and recommendations from the medical team.

Quality of Life

Illness or injury can negatively impact quality of life (QOL). Because a principle goal in medicine is to preserve, restore, and improve QOL, it is important to discuss how treatment might affect QOL. During this discussion, the principles of beneficence, nonmaleficence, and respect for autonomy must be considered.

QOL is subjective by nature. Therefore, the determination of QOL and when it will be negatively impacted in a given case is challenging. Demetris Stavrou and colleagues conclude on the basis of their literature review that burns affect patient health-related QOL in numerous ways that are not consistently predictable.[15] Factors associated with a positive influence include early integration with activities and familial support. Negative factors include severe burns, loss of function (eg, hand function), and contracture development.[15] Despite the challenges of accurate prediction, burn surgeons should aim to determine whether therapeutic interventions are likely to positively or negatively affect QOL on a case-by-case basis using clinical judgment as well as validated measurement tools.

A frequent ethical challenge in burn care concerns medical futility and the withholding and withdrawing of care. From an ethical standpoint, interventions that are unlikely to benefit the patient should not be offered. For example, for severely burned patients with no chance of meaningful recovery, further surgical intervention may be deemed futile and therefore unwarranted. Some authors even suggest that ongoing intervention in these cases could diminish quality of life.[16] Withholding and withdrawing treatment must also enter the discussion of the care of severely burned patients. Both options are considered ethically sound and morally permissible if no reasonable chance of survival exists and are not likely or intended to diminish quality of life.[17] This view has been supported in the burn care literature,[18] and we concur.

Contextual Features

Clinical cases do not exist in isolation but are part of a larger context that might be relevant to ethical analysis. Contextual features that can affect decision making include patient-specific factors such as family dynamics, financial resources, or religious or cultural identity; potential legal ramifications of care; and personal bias of anyone involved in the care of the patient. While often not explicit, these aspects can impact patient care and therefore must be considered.

Similar to trauma care, burn care requires many decisions to be made in rapid succession. There might not be time to reflect on the contextual features at play. Once the urgent issues have been addressed, however, a discussion of goals of care should be held that includes relevant contextual features. Particularly for cases that involve decisions regarding whether it is appropriate, warranted, or desired to proceed with further care, contextual features play a significant role. An example is the competent patient with a 70% TBSA burn who identifies as a Jehovah's Witness. Although we would typically advocate early excision and grafting, it might be advisable to stage the process to avoid large volume blood loss if indeed the patient refuses blood transfusions.

Conclusion

Many ethical issues arise in the care of severely burned patients, and several frameworks have been developed to address these issues. At the University of Chicago Burn and Complex Wound Center, we use the four-quadrant approach, as it allows for practical analysis of clinical scenarios and permits addressing complex issues systematically.

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