

## HISTORY OF MEDICINE

### Getting Past Dax

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#### 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.<sup>1-5</sup> 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.<sup>1</sup> 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."<sup>2</sup> 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.<sup>5</sup> According to Dax, his physicians generally ignored these requests even after he was deemed to have decision-making capacity by a respected psychiatrist.<sup>1-5</sup>

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.<sup>1-7</sup> Dax's case has since been discussed at length in books, articles, and videos.<sup>1-20</sup> There is also widespread belief that burn units are problematically paternalistic.<sup>1-23</sup> 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.<sup>1-20,24</sup> 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).<sup>25,26</sup>

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).<sup>25,26</sup>

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."<sup>27</sup> 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.<sup>28</sup>

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."<sup>29</sup> 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."<sup>2</sup>

### **Burn Treatment and the Culture of the Burn Unit**

To this day, Dax describes his time in the hospital as "pure hell."<sup>6</sup> 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."<sup>1,6</sup> 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."<sup>6</sup> 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.<sup>2</sup>

Andrea does not question the nature of Dax's experience (A. Rubin, personal communication, 2017-2018).<sup>25,26</sup> 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).<sup>25,26</sup>

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."<sup>30</sup> 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."<sup>31</sup>

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."<sup>32</sup> 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.<sup>33</sup>

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).<sup>25</sup>

### 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,<sup>2,34–38</sup> and thus it is a mistake that cannot be afforded.

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