The American Journal of Bioethics, 19(9): 8–10, 2019

ISSN: 1526-5161 print / 1536-0075 online
DOI: 10.1080/15265161.2019.1643944

Guest Editorial

Why Dax's Case Still Matters

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After nearly 50 years, the case of Dax Cowart still engages ethicists, lawyers, health professionals, students, and the general public. Why? Dax Cowart, who died of cancer on April 28, 2019, at the age of 71, became a stalwart champion of personal autonomy after his experience as a burn patient who unsuccessfully refused treatment in the early 1970s. The doctrine of informed consent was already fairly well developed by then. But what about the concept of informed refusal? Dax was clearly competent and had decision-making capacity, despite the views of his physicians. We now view this as an axiomatic truth in bioethics—that a patient who has decision-making capacity has the legal and ethical right to refuse any and all treatment, even lifesaving treatment. Yet, this seemed like a radical notion to some in the early 1970s.

His story is now well known to many in the field of bioethics. The 25-year-old Dax Cowart (Dax's original name was Donald Herbert before he changed it to Dax) was an adventurous young man who was an Air Force pilot in Vietnam, a high school football player, a bull rider at rodeos, and a lover of fast cars. After he retired from the Air Force, Dax planned to follow in his father's footsteps in the real estate business in their hometown of Henderson, TX. But their lives took a devastating turn on July 25, 1973. When Dax and his father were inspecting land that they were thinking of buying, they had no way of knowing that a propane gas leak had filled a creek bed. When they tried to start their stalled car a spark from the carburetor ignited a massive explosion and fire. Dax and his father were both severely burned and rushed by separate ambulances to the burn unit at Parkland in Dallas. Dax's father died on the way to the hospital. Dax's injuries were so severe that he lost his vision; his ears were damaged and his fingers were injured beyond repair.

Dax was so badly burned that he tried unsuccessfully to refuse treatment at the burn unit at Parkland Hospital in Dallas, TX, where he received unwanted and excruciatingly painful treatment. After 8 months of treatment in Dallas, Dax was transferred to a rehabilitation hospital in Houston. After a brief trial of rehabilitation, Dax refused further treatment. The rehabilitation physician actually accepted Dax's refusal; however, Dax's mother and his attorney took Dax against his will to the burn unit at John Sealy Hospital in Galveston, where he once again was subjected to unwanted and very painful procedures. After Dax finally left the hospital, he was deeply depressed and frustrated about living with such extreme disabilities.

After many years, Dax eventually made an extraordinary recovery from his depression. He subsequently attended and graduated from the Texas Tech University School of Law in 1986. He later became a successful trial lawyer and consultant to other attorneys. He also became a widely recognized advocate for patient autonomy. For the next several decades, Dax was able, with the help of his wives, friends, and colleagues, as well as later help from the Veterans Administration, to live a productive life as an advocate for patients' rights. He became an extraordinarily articulate and widely acclaimed speaker to academic and professional audiences. Why do we still talk about his case, so many years after the fact?

First, Dax's experience was well documented in two remarkable early films: *Please Let Me Die* and *Dax's Case*. *Please Let Me Die* was a videotaped interview by psychiatrist Robert White when Dax was hospitalized in Galveston (White 1974). Dr. White had been asked to evaluate whether Dax was incompetent, so the physicians could treat him against his will. White concluded that Dax was "not in the least incompetent or mentally ill." Nevertheless, Dax was once again subjected to painful burn treatments, as shown in the documentary.

A second documentary, called *Dax's Case*, was produced by then-journalist Keith Burton nearly 10 years after *Please Let Me Die*. *Dax's Case* explored his life both during the treatment period and after he was released from the hospital (Cowart 1984). This hour-long documentary included interviews with Dax's physicians, his nurse, his mother, his lawyer, friends, and with Dax himself. In addition to the documentary video *Dax's Case*, a book published in 1989 entitled *Dax's Case: Essays in Medical Ethics and Human Meaning* contains essays by numerous commentators who further explore the ethical,

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psychological, legal, and personal issues raised by Dax's treatment (Kliever 1989).

Dax's case was the first major bioethics case to be captured on film. The power of this medium is undeniable, as the graphic detail is often unsettling to viewers and often shapes initial responses to the case of Dax Cowart. These early documentaries were followed by several news programs about Dax, such as a 1999 *20/20* segment that focused on his work as an advocate and attorney. Most recently, a documentary was produced in 2012, *Dax Cowart—40 Years Later*, which showcases Dax's reflections of his experiences as a patient and lawyer. Few (if any) bioethics cases have been documented so thoroughly on film. The most we have are either case reports or legal opinions, often stripped of details and lacking a humanistic perspective.

Dax's case is also distinct from other major bioethics cases in that it was never litigated as a "right to die" or refusal of treatment case. Just a few years after Dax's injuries, the well-known Quinlan case reached the New Jersey Supreme Court (*In re Quinlan* 1976). This case supported the right of a patient to make decisions regarding withdrawal of life-sustaining treatment through a surrogate. The California Natural Death Act was passed in 1976 in direct response to the Quinlan case. The 1980s saw a ripple effect where dozens of states passed similar natural death acts.

Then, in the late 1980s, the famous Cruzan case reached the U.S. Supreme Court (Cruzan 1990). Like Quinlan, the Cruzan case centered on the plight of a young woman, Nancy Cruzan, who was in a persistent vegetative state. Cruzan's case was taken up by Bill Colby, a young lawyer who at the time was working at a law firm in Kansas City (Colby 2002). Like Quinlan, Cruzan lacked decision-making capacity. Her parents asserted the right to make these decisions concerning withdrawal of life-sustaining treatment. The U.S. Supreme Court ultimately concluded that states (like Missouri) could establish a "clear and convincing" standard of evidence in order for surrogates to make decisions regarding withdrawal of life-sustaining treatment.

In the past 50 years, we have seen major shifts in our attitudes toward patient choice. Old-fashioned paternalism has given way to greater patient autonomy. Patients have more information and more power. Yet some of the old paternalism still persists. Greg Pence, in a recent remembrance of Dax, claims that a burn physician at the University of Alabama at Birmingham (UAB) told him, "They all want to die, and I just ignore them. I don't let them give up on themselves" (Pence 2019). Such a response seems startling, considering all of the progress we have made when it comes to informed consent/refusal and respecting patient autonomy. Dax would probably be horrified.

There has been some empirical work on burn patients and informed consent. In 2006, Luke Brewster (who is a physician and studied bioethics at Loyola) led a study of six patients who had experienced burns and were being treated at the Loyola University Medical Center. He and his coauthors found that

> 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 … None of these individuals thought withdrawing support would have been appropriate for them. (Brewster et al. 2006)

Dax's case highlights not only the concept of informed consent but also the concept of informed refusal. Despite Brewster's findings, it's clear in hindsight that Dax's views should have been respected. This study emphasizes the importance of engaging each patient as an individual with their own set of values and preferences. For instance, Monica Gerrek (who is an ethicist and serves on the American Burn Association's Ethical Issues Committee) has expressed concern that focusing so much on Dax's case has led many to believe "that burn units are problematically paternalistic" (Gerrek 2018). She urges us to pay attention to other burn cases, such as that of Andrea Rubin, who also was severely burned in 2014; in her case, Rubin believed (like the patients in Brewster's study) that the burn team was working toward her best interests. Gerrek's point that we should listen to a variety of patients' stories when it comes to burn treatment is well taken. Each patient has a unique narrative. Yet it's important to understand that 40 years of advances in medicine and bioethics separate these two cases. Rubin herself admits that her pain was well managed (Gerrek, 2018). This is in sharp contrast to Dax's pain management in the early 1970s; he described the pain he experienced with "Hubbard tankings" as "being skinned alive" (Cosmic Light Productions 2012).

It would be a misreading of Dax's case as simply an indictment of the culture of the burn unit. Nor is it simply a "right to die" case. Rather, at its heart, Dax's case is about respecting patients as persons. Dax held strong views. But it's essential to appreciate the evolution of Dax's views as evidenced by the several documentaries and news programs made about his case. For instance, some of Dax's early views toward his disabilities would strike us as ableist today (e.g., he was initially concerned that he would have to sell pencils on a street corner). Although Dax is known primarily as someone who is a champion of autonomy, he is also someone who worked toward living a full and productive live with his disabilities. An anti-ableist approach would empower patients to live with their disabilities in as rich and fulfilling a manner as possible.

The case of Dax Cowart still engages us because we value the ability to make our own health care choices. Dax himself made this abundantly clear: "If the same thing were to occur tomorrow, and knowing that I could reach this point, I would still not want to be forced to

undergo the pain and agony that I had to undergo to be alive now. I would want that choice to lie entirely with myself and no others" (Slotnik 2019). Fortunately, most of us never have to experience the same kind of intense and long-lasting pain and suffering that Dax experienced. His case still vividly illustrates for us that patients with decision-making capacity are the ultimate arbiters of their own lives and treatment decisions. ■

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