

OWNERSHIP IN THE INTENSIVE CARE UNIT

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We all know the scenario—repeated by the minute, day after day. Couples marry and divorce; new families blend while others disintegrate. Behind each coupling decision follows a trail of family members and friends. Children, often most affected, tend to become either benefactors or victims. They may be expected to share their lives with relative strangers, forging automatic new relationships. At the same time, however, beloved parents or siblings—natural or otherwise—may fade out of their lives.

When someone in this conglomerate becomes gravely ill or injured, the “immediate” (ie, most recent) family members currently living with a patient likely accompany them for medical care. If the patient becomes hospitalized, the “other” family may be totally unaware of the situation.

Such is the story of my son, John [not his real name], after his father and I went separate ways. When his father was diagnosed with leukemia, life changed but did not end. Rather, John expected to continue having his dad—on good days and bad—for a period of time. And that is exactly what happened . . . until his father required admission to an intensive care unit (ICU) in another state.

His father’s elderly sister called us in desperation, after she learned accidentally about her brother’s hospitalization. She wanted to let us know he was very sick and asked for help in getting “through the system” to verify his condition. My son and I located the hospital, but when we called there, no one would talk to us. We were told to go through his “wife.” The staff members did not realize my former husband had not remarried. The person who identified herself as

his wife, actually was not. Nurses do not normally ask for identification, do they?

We were 2000 miles away. Because of the situation and privacy laws, no one could or would discuss the patient’s status. The “proxy” refused to talk to anyone. Eventually, through the kindness of a chaplain and his recognition of us as “a former family,” we were afforded small bits of information. John’s father recovered enough to go home, which resolved the situation.

John went to live with his dad soon after, so they could share remaining time together. Once there, however, he found himself to be an outsider to the “stepmother” and siblings. Although embraced by his father—who voiced gratefulness and gladness for his presence—John felt treated like an intruder by the others.

One day while my son was at school, his father called an ambulance because he could not catch his breath. John—later crying about the unfairness of life—told me his stepmother and siblings were surprised when the ambulance arrived, because they had been outside in the yard and had not checked for hours on this gravely ill man.

For awhile, John spent his days in high school and evenings at the hospital—taking his turn at his father’s ICU bedside. On the last morning of his father’s life, my son was sent to school as usual. No one told him anything would be different that day, that death was imminent because his father’s life support was scheduled to be removed mid-morning. John learned after a “normal” school day that his Dad had died several hours earlier. The new family excluded him as they gathered around to witness his father’s last breaths. John did not even get to say goodbye.

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As the parent left behind, I am trying to tend to and nurture a forlorn young adult torn apart by loss. I grieve, silently, for a person who was part of my life for more than 20 years. Yet even the best grief counselor cannot justify how my child—his father's child, our child—became negated to nonexistence during the final and exceptionally important days of a person he loved very much.

John has graduated from high school—a milestone his father sadly missed. He continues to struggle with establishing his own manhood while trying to grasp his father's death. Sometimes my son quietly questions if he is really important in this world, if he could be erased so easily at the end of his father's life. John wonders how he fell into second place, then ultimately to no place at all, in a contest he did not even sign up for.

Ultimately I ask, Who owns the patient in the ICU? Do nurses wonder if there is anyone not present who should know about an impending death? That isn't really their responsibility. It might not do any good anyway, if patients cannot speak for themselves to authorize release of information. What is the ethical answer? We do not want others to be hurt as we were.

Complicated hierarchies can occur from divorce, as well as with numerous relationships. Significant others, including same sex partners, may find themselves alone outside a patient's door. Nonacceptance may be spoken or unspoken. Either way, life at the bedside can become very tenuous during a game of "hospital keep away."

Ultimately, my son and I remain very cognizant of privacy issues. We are equally respectful of blended families. We believe, however, the extension of life and finality of death must not be relegated to a disposable society where loved ones are purposefully excluded.

There should be no ownership in the ICU . . .

Disclaimer

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