

Keleen Lee Burgess Memorial Lecture  
By  
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Keleen Burgess brings to mind very mixed emotions that have to do with my own ethical standards, my realization that sometimes acts of God intervene in the well-laid plans of men. Keleen Burgess' story unfolded in the midst of the hospital where I was Surgeon-in-Chief and required the cooperative help of the Department of Surgery of the University of Pennsylvania of which I was a part. Keleen Burgess perhaps was also the most noteworthy individual patient that represented the tremendous medical advance produced by members of the Department of Surgery at the University of Pennsylvania and what later became to be known as "total parenteral nutrition". A lecture and commentary appear elsewhere in this archive on contributions of the Pennsylvania group and my own association therewith. There is now a unique plaque to the memory of Keleen Burgess in the atrium of the Children's Hospital of Philadelphia. Keleen never knew what she was contributing. but because of the tremendous amount of what was learned in providing her care countless children and adults have benefited since and what was an inspiring, unique landmark situation has become routine care for many individuals -- care which has led them from the throes of despair to normal life thereafter.

Keleen Lee Burgess was born on July 16, 1967, weighed 3 pounds 5 ounces, and had multiple small intestinal and colonic atresias with malrotation of the colon and mid-gut volvulus that ended in an impossible situation for any child hitherto – the absence of a small bowel. On August 9, a central line was inserted and the next day on the 10<sup>th</sup> total parenteral nutrition was begun – not as a permanent feature of her life, but something to tide her over until we found a different solution, including small bowel transplantation.

Keleen had her first birthday in the hospital, but she was never able to go home. In May 1968, intravenous fat was first started – a most remarkable situation for that day. As she approached her second birthday, she began to present other complications, directly or indirectly related to her continuing difficulty in taking nourishment. Later we learned that her duodenum was only 9 centimeters long and her jejunum measured only 6 centimeters. It wasn't enough.

Keleen became the darling of the hospital. Although, I was the chief of the service on which she experienced her ups and downs, I was not her operating surgeon, but was substituting for him while he was away from the hospital, where I prescribed an antibiotic to control pneumonitis. She developed an immediate anaphylactoid reaction from which we could not resuscitate her, and on May 26, 1969 she died. It was a terrible time for me because it was very clear to the nursing staff: Keleen had pneumonia, Koop prescribed penicillin, the penicillin killed Keleen, therefore Koop killed our baby. Even though this was a milestone in medical history we were, of course, criticized all along the way by those who thought we were foolish to try to save her life. Some said it was too costly; some said she would not lead a normal life anyway. Others said we were going against nature trying to play God and so forth. Fortunately, we had the support and understanding of Keleen's parents who believed, as we did, that Keleen deserved all the life to which she was entitled and we had the moral and ethical obligation to help her live.

I would like to make very clear here that so often things that we attempt to do for children (or adults) with very best of intentions, appear to observers to be the wrong thing to do and when we are proven unsuccessful, there is always "I told you so!" . What unknowing observers never fully appreciate is the contribution that is made to knowledge in the very presence of apparent disaster. Keleen Burgess is perhaps one of the better examples in my life of such a circumstance.

Keleen was born in 1967; this lecture was given in 1986 at which time she should have been a gangly nine-year-old – a fourth grader exhibiting nine-year-old kinds of behavior, the kind that we can't stand while it's happening, but forever remember.

What a contrast Keleen Burgess, her parents, and her complicated life were to "Baby Doe's" parents, and the medical profession and the legal system that failed to do what they could. In the "Baby Doe" case the Indiana State Supreme Court essentially allowed the parents to sanction a mercy killing. "Baby Doe" died before the Supreme Court could act. and the whole question was moot. Moot as far as the courts were concerned, but not as far as medicine and public policy were concerned. At the time I gave this lecture "Baby Doe" regulations were in effect. The regulations promulgated by the Department of Health and Human Services were taken essentially verbatim from the law itself, which named a basic principle: "that all disabled infants with life-threatening conditions must be given medically indicated treatment". The law does not say "should", or "might", or "ought" but said, "must".

Of course the medical profession as well as its supporters and critics questioned what was meant by "medically indicated treatment." My own personal opinion is that, if you have to ask what is "medically indicated treatment", you probably can't afford to stay in medicine – but that's a personal view for which I've been cheered and booed. The government came up with an answer. "Medically indicated treatment" is "defined in terms of action to respond to the infant's life threatening conditions by providing treatment (including appropriate nutrition, hydration, or medication), which in the treating physician's ...reasonable medical judgment will be most likely to be effective in ameliorating or correcting all such conditions."

Clear enough? Not really! Physicians know that there are some situations in which “treatment” simply is not “medically indicated”. We also spelled that out in those same regulations, Section 1340.15 (B) (2) of the 45<sup>th</sup> chapter of the code of federal regulations.

Some things were clear as Congress debated this issue. One was, they did believe that patients – in this case, infant patients, should be starved to death no matter what the prognosis. Given all the fine print, the law will accept the doctor’s judgment on what is non- medically indicated treatment of a baby if the baby is chronically or irreversibly comatose... if treatment would just prolong the act of dying or if treatment itself would be inhumane.

The government was afraid that it was still not clear enough – that somebody would find a loop-hole and so the regulations are quite clear by adding that “ Even when “...one of these circumstances is present and a physician decides to withhold medically indicated treatment...even then -- “The infant must nonetheless be provided with appropriate nutrition, hydration, and medication.”

The point of all this is to tell you that what we tried to do and did do for Keleen Burgess back in 1967 was the law when I gave this lecture in 1986. The bible says that the Lord giveth and the Lord taketh away. But many people think that doctors have the power of the Lord and to some extent maybe we do. But it is the power to give not to take away. We don’t have the power – and we certainly don’t have the right to take life away. Keleen Burgess wanted to live. She couldn’t talk about it and she obviously couldn’t write about it. But you could tell. For 20 months she stayed with us, instinctively fighting to stay alive, until she finally lost her battle against overwhelming odds of disease and debilitation. But her memory is very important to us. Her struggle for life permitted us to learn many new things about the technology of total parenteral nutrition. She gave us that; and it turned out to be a profoundly generous gift from so small a child.

I was very pleased to say these things, because I said them in the hospital where I spent 40 years, and I was happy to remind all who would listen that that is just what it was, that we did in that hospital. We saved lives. We didn’t take them.

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Anaphylactic shock  
“Baby Doe”  
“Baby Doe Regulations”  
Inhumane treatment  
Irreversible coma  
“Medically indicated treatment”  
“Nutrition, hydration, & medication”  
Penicillin  
“Playing God”  
Pneumonia  
Power of the medical profession  
Prestige of the medical profession  
Prolongation of the act of dying

Short bowel  
Total parenteral nutrition

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Bloomington, Indiana  
Keleen Lee Burgess  
Stanley Dudrick, MD  
Supreme Court of the United States  
Douglas Wilmore, MD