WHEN I WAS HUNGRY, YOU GAVE ME TO EAT: THE DIGNITY OF HAND FEEDING IN PERSONS WITH DEMENTIA

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Preserving the dignity of those who inhabit Nursing Homes at the end of life—individuals frequently bearing the concurrent burden of dementia—is a critical feature of cultures that embrace compassion. In the United States, such persons comprise a demographic estimated at five million. One demanding aspect of care in this population is feeding. The ethical dilemma resides in the choice between hand feeding by staff or family versus feeding tubes. Hand feeding is adopted when it is comfortable and safe, that is, unaccompanied by aspiration; and although human intimacy integral to hand feeding would be preferable, feeding tubes have become de rigueur in contemporary medical practice. As Kenneth Ludmerer poignantly asked, might the efficiency in time and effort derived from feeding tubes, as well as their reimbursement as medical procedures, be the dynamic driving choice in this context? Recent publications are noteworthy in this regard.

Two Nursing Home cultures were compared for feeding technique. One was characterized by a relatively high rate of feeding tube nutrition while the other had a low rate, favoring hand feeding. The investigators expended 80 hours of direct observation addressing feeding practices at both locations. Specific observations were rendered regarding the facilities’ characteristics including physical environment, mealtine activities, decision-making processes, as well as explicit and implicit values. The result was a disturbing clash of cultures.

Although facilities were for the most part comparable—both were for profit, but they varied in ethnic mix and Medicaid volume—in staffing ratios, beds, and geographic locale, there were profound cultural and value differences. The physical surroundings and social ethos at the center known for hand feeding was more humane and caring than that of the feeding tube institution (e.g., through decoration, social intercourse, and “odor”). Enthusiastic staffing at mealtimes, designed to donate “extra time and eye contact,” were also marks of success at the hand-feeding center. In terms of explicit values, the low use feeding tube nursing home espoused “community, compassion, dignity, purpose,” with residents who were “family members” and who were “entrusted” to their care for “healing.” The predominant feeding tube institution’s mission was listed as “progression through health care services.” We receive a window into the implicit values of the hand-feeding center in a 93-year-old cognitively impaired resident:

“the family knows that she isn’t safe [from aspiration]...but [family] wish for us to continue to attempt to feed her as safely as possible just because if you don’t, you’re actively starving that patient. The only alternative is a tube and at 93, her family doesn’t want her to have a tube.”

At the contrasting site, an assumption was made that “families preferred not to be involved” and when the researchers asked to interview family members, the social worker responded, “Good luck finding them.” There seemed to be less time available there for authentic “healing” and shared community efforts.

There were other disturbing differences uncovered by the study. The feeding tube predominant site had a greater number of Medicaid and African American residents. Nationally, African American men and women are at an overall higher risk of being tube fed. The authors also referenced another study suggesting that there are financial incentives to tube feed rather than hand feed. Medical procedures are reimbursed, time spent caring is not.

The second study reinforced the notion that feeding tubes were emblematic of medicine’s corporate transformation. In 280,869 admissions in 2797 acute care hospitals for 163,022 persons with advanced cognitive impairment, higher feeding tube insertion rates were associated with for profit hospital status! It is hard to escape the conclusion that reimbursement makes feeding tubes more attractive than hand feeding.

Where have we wandered as professionals while transforming medicine into a business? Another unfortunate trend in Nursing Homes is a marked variation in anti-psychotic use in demented elderly persons. Even though those sedated run a greater risk of morbidity (such as pneumonia), they are less “bother” to busy staff when they are asleep. Are the elderly with dementia merely a biologically tenacious group who should be ignored and preferably given the basic human necessity of food by autopilot, and that through a tube reimbursed by third party payers? It was no accident that Jesus focused on personal, intimate contact in the 25th chapter of Matthew’s Gospel. The fact that we do it to Him when we feed, offer drink, and visit during times of need is also essential to grasp. Reforming healthcare is not only about money; it’s about time and touch as well. Human intimacy is not reimbursable, it transcends dollars and cents, and we cannot be said to care at all without it.

References:

1. Kenneth Ludmerer, Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care (Oxford University Press, 2005).
3. Ibid., 85-87.
4. Ibid., 86.
5. Ibid., 87.
6. Ibid.