

Smuggled donuts and forbidden fried chicken: Analyzing ethical tensions around family and food restrictions in hospital settings

Dr. Megan A. Dean

Assistant Prof. of Philosophy | Michigan State University | deanmeg2@msu.edu

Dr. Laura Guidry-Grimes

Staff Bioethicist | Cleveland Clinic | GuidryL@ccf.org

Hi everyone and welcome to our talk “Smuggled donuts and forbidden fried chicken: analyzing ethical tensions around family and food restrictions in hospital settings.” We’ll begin with a case vignette.

Section 1: He put *WHAT* in the PEG?

The following case reached the clinical ethics consultation service at a large, urban hospital in the United States. The case has been deidentified to protect confidentiality.

Ms. Jones was a 45-year old woman brought into the hospital for myasthenic crisis, resulting in admission to the medical intensive care unit (MICU), intubation, and mechanical ventilation. Her past medical history was significant for schizoaffective disorder, which her records indicated had gone untreated for most of her life. She had had a percutaneous endoscopic gastronomy (PEG) tube for several years, which she relied on to receive nutrition at home. Her partner of almost a decade, Mr. Richards, was her only involved family. He would regularly create a kale smoothie for Ms. Jones at home. In addition to treating her respiratory failure and evaluating her ongoing needs for management of her myasthenia gravis, the medical team was also concerned about Ms. Jones’s level of malnutrition. They believed she was not receiving adequate nutrition at home, and they kept her on a tightly controlled, medicalized PEG tube formula while in the hospital. Ms. Jones initially was incapacitated; she was incapable of communicating any decisions or preferences for the first week she was in the MICU. During this

time, the team turned to Mr. Richards to make medical decisions as Ms. Jones's surrogate decision-maker (which was legally permitted in this jurisdiction).

Near the end of the first week of her hospitalization, Ms. Jones no longer needed mechanical ventilation and began communicating to an extent, though she mostly communicated with Mr. Richards and did not respond to most questions from the medical team. She appeared significantly altered, and the team was unclear whether this was a dip in her cognitive baseline. Mr. Richards came into the MICU one evening and pushed the kale smoothie into her PEG tube. When nursing learned what he had done, he was promptly asked to leave the MICU, and a note was added into Ms. Jones's chart stating that Mr. Richards should not be allowed to visit unsupervised, and his behavior was described as "dangerous and sketchy" in the subsequent chart notes from the night staff, which prompted the medical team in the morning to call the clinical ethics consultation service to ask about the process for appointing someone besides Mr. Richards as the surrogate decision-maker. Members of the team also speculated that the patient's emaciated state and unwillingness to discuss her partner were because Ms. Jones and Mr. Richards had an unhealthy, medically neglectful, or potentially abusive relationship.

The ethicist gathered the medical team and Mr. Richards to discuss Ms. Jones's dietary requirements and the controversy surrounding the blenderized kale mixture. Mr. Richards was surprised that the doctors considered the kale smoothie unsafe, since he had been making this for Ms. Jones for years. When a physician asked why Mr. Richards was not giving her tube feeds from a medical formulary, Mr. Richards explained that Ms. Jones did not trust medical institutions and had enjoyed kale before needing the PEG tube. He reported that he and Ms. Jones had spent weeks trying to find a home-blended tube feed that she preferred before choosing this kale smoothie. When the medical team told Mr. Richards that he would be barred

from the MICU unless he promised never to bring in food from home again, Mr. Richards expressed sadness but agreed. Over the remainder of Ms. Jones's MICU stay, which was extensive, nursing reported a few occasions where Mr. Richards seemed to "sneak in" something to her room and feed her through the PEG tube.

This case demonstrates how food can become a source of conflict and distrust between medical teams and families. This kind of case is not unusual; clinicians and clinical ethicists can attest to frequent struggles around food when family members bring in anything that contravenes the prescribed diet. Doughnuts and fried chicken are more common sources of disagreement than kale smoothies, but any outside food can be of concern if the clinicians believe it will hinder the patient's recovery. This concern is particularly pronounced when a patient lacks decision-making capacity and is in a medically fragile state, relying on their family to make healthcare decisions on their behalf and (perhaps) for everyday caregiving. In this situation, concerns about Mr. Richards's actions quickly escalated to visitation restrictions, suspicion of his motives and the nature of his relationship, and the medical team trying to remove him as a surrogate decision-maker.

Such cases raise important ethical questions: How should food-values be weighed against health-values, especially if a patient is medically frail and family is serving in a caregiving and decision-making role? Even if a favorite food does not fit the prescribed diet, at what point is it *too* medically suboptimal to be allowable in a hospital environment? Is food an area for shared decision-making with families, or is this an area of justifiable protections and strict limits with vulnerable patients? What are the moral costs of refusing or excluding certain food options for diverse patients?

Section 2: The Ethical Importance of Family Feeding

We suggest that understanding the ethical importance of family feeding is essential to answering these questions.

According to Hilde Lindemann, families have at least two characteristic moral functions: first, to care for its members, and second, to hold family members in their identities (Lindemann 2019).ⁱ Feeding is a central means by which families fulfill both these roles, and that the moral importance of this feeding can be heightened when a family member is in the hospital—especially if that member is decisionally-incapacitated and medically fragile.

First, families have the important function of caring “for their own.”ⁱⁱ When a family member is hospitalized, opportunities for families to provide care are highly circumscribed by hospital policies and visiting hours; however, bringing in food is generally permitted and within a family’s reach. Thus, feeding can take on particular moral importance as one of the few ways families can care in contexts where they might otherwise feel, “helpless and at a loss” (Lindemann 2019, 8).ⁱⁱⁱ

While in many contexts hospitals are responsible for ensuring inpatients get adequate nutrition, some patients report going hungry due to hospital meal schedules (Naithani et al. 2008). Allowing a family member to go hungry—even when this hunger is temporary—can feel like failure of a family’s central obligation to care. In addition, bringing in food that is enjoyable and familiar can be a way to provide a family member pleasure and comfort in an otherwise sterile and stressful setting. In this way, family feeding can provide emotional as well as physical care.

The second characteristic moral function of families is holding members in their identities. For Lindemann, families are “primary sites for identity formation,” and also identity *holding*: which includes “treating [someone] in accordance with their narrative sense of [who they are]”

(Lindemann 2009, 418).^{iv} The moral work of holding someone in their identity is particularly important when someone is in hospital. The illness or injury that the person is experiencing can itself threaten the person's sense of self (Lindemann 2019, 6), and medical institutions can be alienating as patients are removed from their usual places, relationships, activities, and routines, which may all be central to their identities.

We argue that feeding is a means of holding family members in their identities, and one with special significance in hospital given the limited forms of interaction allowed in these contexts. Whether family brings in foods that are “family favourites,” in line with cultural, religious, or ethical commitments, or specific to the patient's dietary preferences and patterns—such as Ms. Jones' kale smoothie—family feeding can reinscribe hospitalized family members in their identities as members of the family, particular cultural, religious, or ethical identities, or simply in their uniqueness as a person whose preferences are known and matter to those who love them. Supporting a family member's food preferences can take on particular importance when their sense of agency and connection with food and eating are already highly constrained, such as with tube feeding.

Diagnosing the Tension

We argue that family feeding of patients can have significant moral importance for the patient and family alike. However, as with the case of Ms. Jones, when the foods being brought in contravene dietary recommendations, this can create conflict and distrust with providers and the care team.

Fundamentally, the tension between a family and medical team may center on what it means to *care for* the patient. Especially when a patient is not capable of communicating their own preferences, a medical team can understandably focus on trying to maximize the patient's health.

This is indeed a form of care when clinicians try to protect the patient from unnecessary harms and risks, so the patient can avoid a prolonged hospitalization and recover as quickly as possible. The family, however, may view health maximization as too demanding of an expectation, given the patient's other interests; alternatively, the family might doubt that a smuggled doughnut (or in Ms. Jones's case, a kale smoothie) could possibly be *that* harmful. This disagreement can then turn on whether the medical team's concerns are overblown or evidence-based. Repeatedly telling the family to abide by dietary restrictions, therefore, may come across as berating a family for trying to care for their loved one in one of the only ways available to them. As a result of this kind of disagreement, the medical team may have concerns about whether discharging the patient home with the non-compliant family is truly in the patient's interests, and concerns about safe discharge can lead to more conflict and extended length of stay – which is risky in itself for the patient.

In Ms. Jones's case, the medical team talked *to*, not *with*, Mr. Richards about the dietary restrictions. He was simply told that the kale smoothie he had been making for years was *dangerous*, and he was implicitly scolded for doing so -- despite this being Ms. Jones's preference for her meals. When the ethicist asked the frustrated physicians about the evidence base for medical formulas versus blenderized tube feeds for PEGs, the physicians were unaware of any evidence either way. The medical team's default toward medicalized feeding was evident. Perhaps Ms. Jones really did need to have the special medical formulas in her PEG while in the MICU, and perhaps she needed additional calories or other nutrients at home to prevent malnourishment, but this topic was not treated as an area of shared decision-making with Mr. Richards or, later when she regained a level of capacity, with Ms. Jones herself.

Recommendations

We suggest that it is imperative to recognize that food can be a way in which families show care for and sustain the identity of their loved ones in hospital settings where those things are routinely diminished. Family feeding is an ethically important practice and should be acknowledged as such, even while restrictions on it may be necessary. We conclude with several strategies for creative problem-solving that clinicians can employ with families when there are current or potential tensions surrounding food, particularly for decisionally incapacitated and medically fragile patients. Our recommendations reinforce food as a topic for values discussion and shared decision-making:

- Early in a hospital admission, the family should be explicitly asked if the patient has any known dietary restrictions – including for cultural, religious, or moral reasons – and any known food and eating preferences. If the medical team has any concerns about being able to conform hospital foods and feeding plans, the medical team should be transparent about their doubts and consider calling a multidisciplinary meeting with a dietitian and nursing in attendance, so the team can work with the family on a plan that is medically reasonable and respects the patient’s feeding and eating interests to the extent possible.
- When updating the family during rounds, phone calls, or in-person meetings, the medical team should regularly discuss what the patient is and is not able to eat, as well as the justification. If it is medically reasonable for the family to bring any foods from outside the hospital to the patient, the family should be explicitly told so. If this is not medically reasonable because outside food would pose too much risk, the family should be informed of what the meal schedule is so they can participate or be present if they wish.
- Any holidays with traditional foods or communal eating, such as Thanksgiving or Diwali, should be acknowledged by the medical team, and they should determine to what extent the

patient can safely participate if the family wishes to honor their traditions in the hospital setting.

- Staff should be trained to take care with chart notes when family brings in food that does not match the prescribed diet. For example, instead of “family insists on bringing fried chicken into the ICU, putting the patient in clear danger,” or “family obstructing safe diet,” the staff should have a values-based conversation about food with the family and document what was discussed and what decision was reached, including any potential compromises that are medically reasonable (even if not strictly medically optimal). Documentation should reflect that respectful collaboration.
- Finally, if the medical team has concerns about safe discharge home with family because of the family’s history of bringing in unhealthy or risky foods to the hospital, the team should first communicate their concerns clearly to the family and provide information about the patient’s nutritional requirements verbally and in writing using health literacy best practices. The team should try to ensure that the nutritional requirements are not unreasonably demanding, costly, overly medicalized to the exclusion of favorite foods altogether, or clearly in violation of the patient’s values and preferences. The family should be invited to look over this information, ask questions, and express any concerns.

We look forward to discussing this further during Q and A. Thank you

Sources

- Barnhill, Anne, Katherine F. King, Nancy Kass, and Ruth Faden. 2014. “The Value of Unhealthy Eating and the Ethics of Healthy Eating Policies.” *Kennedy Institute of Ethics Journal* 24 (3): 187–217.
- Lindemann, Hilde. 2009. “Holding One Another (Well, Wrongly, Clumsily) in a Time of Dementia.” *Metaphilosophy* 40 (3–4): 416–24. <https://doi.org/10.1111/j.1467-9973.2009.01592.x>.
- . 2019. “Why Families Matter.” In *What About the Family?: Practices of Responsibility in Care*, edited by Hilde Lindemann, Janice McLaughlin, and Marian A. Verkerk. Oxford University Press.
- Naithani, Smriti, Kevin Whelan, Jane Thomas, Martin C. Gulliford, and Myfanwy Morgan. 2008. “Hospital Inpatients’ Experiences of Access to Food: A Qualitative Interview and Observational Study.” *Health Expectations* 11 (3): 294–303. <https://doi.org/10.1111/j.1369-7625.2008.00495.x>.

ⁱ We hold a broad understanding of family here, encompassing biological family, adopted family, and chosen family, and we can say more about this during Q and A.

ⁱⁱ Lindemann asserts that it is “not just that families do this, but that they must and should do this” (Lindemann 2019, 6).

ⁱⁱⁱ Lindemann writes: “The inability to give familial care in a hospital setting, even when the family recognizes the need for professional help and is grateful for it, may leave family members feeling helpless and at a loss, frustrated by not being able to do what they do best” (8).

^{iv} Also, less relevant here: “weeding out the stories that no longer fit and constructing new ones that do” (2009, 418). Another quote for long version: our identities “consist of a tissue of stories, constructed from...first-person but also many third-person perspectives” (Lindemann 2009, 417).