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# Artificial nutrition and hydration at the end of life: Ethics and evidence

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## ABSTRACT

The case of Terri Schiavo resulted in substantial media attention about the use of artificial nutrition and hydration (ANH) especially by percutaneous endoscopic gastrostomy (PEG). In this article, I review ethical and legal principles governing decisions to choose or forgo ANH at the end of life, including issues of autonomy and decision-making capacity, similarities and differences between ANH and other medical treatments, the role of proxies when patients lack decision-making capacity, and the equivalence of withholding and withdrawing treatment. Evidence for palliative or life-sustaining benefits for ANH are reviewed in three disease processes: amyotrophic lateral sclerosis (ALS), cancer, and dementias, including Alzheimer's disease. Although more recent studies suggest a possible palliative role for ANH in ALS and terminal cancer, feeding tubes do not appear to prolong survival or increase comfort in advanced dementia of the Alzheimer's type.

**KEYWORDS:** Palliative care, Amyotrophic lateral sclerosis, Cancer, Alzheimer's disease, Percutaneous endoscopic gastrostomy (PEG)

The case of Theresa Schiavo highlights continuing conflicts regarding the ethical and legal standards governing artificial nutrition and hydration (ANH) among patients with severe medical illness. The goals of this article are to (1) review the ethical principles that serve as the basis for decisions to stop food and hydration and (2) examine empirical evidence regarding the benefits and burdens of ANH among severely medically ill patients.

ANH can be delivered by several methods. Intravenous routes deliver enough fluids to sustain hydration status, but cannot deliver substantial nutrition. In general, the risks of intravenous fluids are very low, such that written informed consent is not required. Delivery of fluid by hypodermoclysis (subcutaneous infusions of less than a liter of fluid

per day) is being reevaluated in some palliative and home settings (Fainsinger et al., 1994). Temporary nasogastric tubes placed during acute episodes of illness have rare risks but may cause discomfort. Two-thirds of nursing home patients will become agitated or remove the nasogastric tube within the first 2 weeks of treatment (Ciocon et al., 1988). When it is anticipated that patients will not be able to resume oral feedings for many weeks, nutrition is delivered through percutaneous endoscopic gastrostomy (PEG) or, less commonly, jejunostomy tubes.

The ethical principles governing decisions to treat with ANH are well articulated in the United States. The principle of autonomy supports that adults have the moral right to follow a life plan of their own choosing. Legally, this right to self-determination means that each individual has the authority to control his or her own body and the expectation of protection from unwanted intrusions. The concepts of beneficence and nonmaleficence require that the clinician's actions must benefit the patient and avoid

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harm when possible (Beauchamp & Childress, 1994; Lo, 1995; Jonsen et al., 1998).

Overall judicial consensus upholds that because any and all medical interventions can be declined by competent adults and because ANH is a medical treatment, patients may refuse ANH, even if death results (Ahronheim & Mulvihill, 1991; Sieger et al., 2002). Though this right exists no matter what the patient's prognosis, decisions by patients with good prognoses to stop ANH are more likely to be questioned and, in practice, clinicians appear to apply higher standards and thresholds for refusal of life-saving treatments in such situations (Ganzini et al., 2003*b*; Volicer & Ganzini, 2003).

"Informed consent" is the process by which patients who are advised about a medical treatment agree or decline an intervention such as a PEG tube: Surgically placing a feeding tube without consent leaves the clinician at legal risk. To give consent, the patient must be free to make a decision without coercion or undue influence from the medical team and must have decisional abilities. Although the legal standards vary from state to state, expert clinicians agree that there are four core standards that are necessary for decisional capacity. First, the patient must be able to communicate a consistent preference for one treatment over another. Patients who are in a persistent vegetative state (PVS) or severely demented obviously cannot express a preference for or against ANH. Second, the patient must understand the risks, benefits, and alternatives to the treatment, including the risk of death. Brain dysfunction, such as in delirium and dementia, often interferes with this ability. Third, the patient should be able to "appreciate" the information, that is, apply the information to his or her own situation. For example, a severely depressed patient may be able to understand the risks and benefits of a treatment but fail to believe that a good outcome is possible for herself. Such a patient may have a good prognosis with a temporary, low-risk course of feeding by nasogastric tube, but refuse if she is so hopeless she cannot imagine any benefit. Finally, patients must use some form of rational thinking to arrive at their choice. This does not mean the patient must come to the same conclusion as the clinician, only that his reasoning must be recognizable and logical (Grisso & Appelbaum, 1998). Clinicians tend to apply more of these standards and use higher thresholds for meeting each standard when they disagree with the patient's decision. Though ethically suspect, this "sliding scale" allows clinicians to give extra consideration to decisions that are unusual or do not seem reasonable; questioning the decision may facilitate

invitations of assistance from other clinicians and ethics committees (Ganzini et al., 2003*b*).

When patients lack decision-making capacity for ANH, others may decide for them. Proxies named in durable power of attorney for health care (DPAHC) documents take precedence over all other decision makers, including legally appointed guardians, unless the surrogates act in bad faith, decline the role, or are themselves incapable (such as a spouse who subsequently develops dementia). When a competent patient assigns future health care decisional authority to a proxy, he is advised to have explicit discussions with the surrogate regarding his preferences in case of future incapacity and/or to assign this role to someone who knows his values well. The surrogate's role is to choose the options that would be favored by the patient. Some jurisdictions also have legal documents that allow specific clarification of preferences regarding some types of treatments. In absence of specific documentation, surrogates should base their decision on past conversations or knowledge of the patient's values. For example, the patient's previous statements expressing abhorrence at living in a nursing facility may influence the surrogate's decision regarding PEG insertion. If the patient never articulated any views, the decision maker must decide what is in the patient's best interest (Beauchamp & Childress, 1994; Lo, 1995; Jonsen et al., 1998). When considering PEG tubes for conditions such as PVS, the best interest standard can be especially troublesome if it pits quality of life against quantity of life. Alas, "best interest" may be the most commonly used standard for ANH. Callahan et al. (1999) reported that among family members of 100 patients with a PEG, only four reported the loved one had expressed a preference regarding tube feeding before losing capacity. Several researchers have demonstrated flaws in the assumptions of the surrogate model. Pasman et al. (2003, 2004) in a qualitative study of the decision-making process around ANH in nursing homes confirmed that personal emotions in the surrogate (most often family) can serve as a barrier for authorizing or directing treatment even when it is known what the patient would want. Patients appear to prefer family members have this role, even when confronted with information on discrepancies (Fagerlin et al., 2001; Cherniack, 2002).

In the absence of a surrogate named in a DPAHC, guardians may be authorized to make decisions regarding ANH, though in some states the role of withholding or withdrawing life-sustaining treatments, especially ANH, must be specifically assigned by the courts. Because so

many patients lack DPAHCs, families and clinicians collaborate to make these decisions in the absence of clear legal authority in many states. Sieger et al. (2002) reviewed state legislation on ANH and reported that 20 states have one or more legal provisions indicating a separate or higher standard for the refusal of ANH compared to other medical treatments. In contrast, there is a judicial consensus based on case law that ANH can be forgone like other treatments. In examining the prevalence of PEG tubes, however, states with more stringent laws do not have a larger proportion of residents with feeding tubes. These laws do not clearly contribute to the substantial variation in the use of these technologies (Mitchell et al., 2003a).

There is no ethical or legal difference between withholding a treatment such as a feeding tube versus placing the feeding tube then later removing it (Beauchamp & Childress, 1994; Lo, 1995; Jonsen et al., 1998). Despite uniform agreement on this issue, clinicians often report that these actions feel different. Removing a PEG tube from a patient who cannot maintain fluids in any other way (such as PVS) will almost certainly lead to death, and some physicians may believe they are “killing” the patient. These interpretations are strengthened by sloganeering of groups who may label removal of a PEG tube under any condition as “murder” (Ahronheim & Gasner, 1990; Solomon et al., 1993). Alternatively a decision to never start a feeding tube may be perceived as allowing a natural death. This emotional component may explain health care professionals’ lack of awareness on the ethical equivalence of withholding and withdrawing of treatment. For example, in a study of 115 neurologists who were self-identified experts in the care of patients with amyotrophic lateral sclerosis, 39% agreed that withdrawing a treatment is ethically different than withholding one (Carver et al., 1999). Furthermore, at times, withdrawal of some treatments such as dialysis or mechanical ventilation is believed to be permissible, but stopping ANH unacceptable (Derr, 1986; Siegler & Weisbard, 1985). In one survey of 1400 physicians and nurses, now almost 15 years old, 42% endorsed that even when other life support was withdrawn, food and water should always be continued (Solomon et al., 1993). These attitudes may represent a barrier to potentially beneficial trial of ANH, if clinicians fear that once started feeding tubes cannot be stopped. Finally, physician characteristics influence views on tube feedings. For example, among 502 U.S. physicians, both African-American and women physicians were less likely to believe that tube feedings in terminally ill patients were “heroic” (Mebane et al., 1999).

## MAPPING INTERVENTIONS ON GOALS OF CARE

Potential benefits of PEG are of two types. First, a PEG may prolong life. Second, a PEG may palliate symptoms by increasing comfort, enhancing quality of life and diminishing suffering. PEG benefits patients with some diseases, but not others—as we shall show, preliminary studies support some counterintuitive findings.

Clinicians are obligated to communicate accurate information to patients or their surrogate decision makers regarding the benefits and burdens of ANH, especially of PEG tubes. Even when forming a strong opinion about the correct course to take, the clinician’s duty is to support the patient in making the best choice for him- or herself. Similarly family members of patients who lack decision-making capacity need balanced information and instruction that their role is to try to come to the same decision as the patient, were he or she able.

Among ill patients and their families, prolongation of survival is a major impetus for choosing a PEG. PEG tubes are believed to extend life by improving nutrition, minimizing dehydration, reducing aspiration, and aiding pressure sore healing. PEG clearly prolongs life in patients with PVS; PVS patients may live for years with a PEG, but will die of dehydration in a few weeks without artificial assistance to maintain fluid status. Yet it would be difficult to support the claim that PEG improves quality of life in PVS. Well-done studies confirm that PEG both improves survival and decreases morbidity in acute stroke with dysphagia and oropharyngeal malignancy (Lee et al., 1998; Senkal et al., 1999; Sanders et al., 2000). Evidence for survival benefits in other terminal illnesses, including Alzheimer’s disease, ALS, and terminal stages of cancer, are lacking (Rabeneck et al., 1996).

## AMYOTROPHIC LATERAL SCLEROSIS

ALS is a relentlessly disabling neurological condition defined by progressive weakness and loss of muscular control. Patients initially note they are clumsy, then subsequently lose the ability to walk, eat, or use their arms. Eventually, they become bedbound and require breathing support, first by noninvasive ventilation, then eventually tracheostomy with mechanical ventilation. Without breathing assistance, the 5-year survival of patients with ALS is between 10% and 20%. With respiratory and nutritional support, death can be avoided indefinitely (Howard & Orrell, 2002; Ganzini & Johnston, 2006). Unlike many terminal illnesses, ALS does not influence cognition until the late course of the

illness, and most patients retain decision-making capacity until the final weeks of life.

Patients with ALS consider PEG as they lose the ability to swallow and begin to experience frightening choking episodes. Swallowing problems and choking are more prevalent and severe in patients with the bulbar form of ALS. Somewhat surprisingly, PEG, more than prolonging life, palliates by improving nutrition, lessening fatigue, alleviating the struggle and effort to eat, reducing the time spent on meals and medications, and allaying the fear of choking (Mazzini et al., 1995; Mitsumoto et al., 2003, Ganzini & Johnston, 2006), though other studies fail to demonstrate that PEG improves quality of life (Verhoef & Van Rosendaal, 2001).

The value of PEG in delaying death is less clear: Studies reporting survival after PEG have mixed results (Mazzini et al., 1995). Mitsumoto et al. (2003) compared 137 PEG and 187 matched non-PEG patients in the ALS Care Data Base. PEG had no survival benefit, though most PEG patients received this intervention late in the course of illness, perhaps too late to benefit. PEG patients had more frequent physician visits, hospital admissions, home care nurse, and support services usage and were overall more disabled. Forbes et al. (2004) examined 142 PEG insertion episodes in ALS patients between 1989 and 1998. The cumulative incidence of gastrostomy was 11%. The median survival after PEG was 5 months and one in four patients died within 1 month of the procedure. PEG patients did not survive longer than non-PEG patients. Strong et al. (1999) reported worse survival among both bulbar onset and limb-involved patients who received percutaneous endoscopic gastrojejunostomy (PEGJ) compared with those who did not receive the procedure. PEGJ recipients had a 10% 30-day mortality rate, and survival was substantially shorter in bulbar onset patients compared to limb onset patients. The authors were unable to determine if this disparity reflected worse disease among patients requiring PEGJ versus a deleterious effect of the procedure. Most experts believe outcomes are best when PEG is placed in patients with bulbar involvement, early in the course of the disease, before lung capacity is compromised.

Neurologists who specialize in care of ALS patients report that they discuss PEG with four out of five ALS patients and their families, at times, repeatedly. Among ALS patients who are informed about PEG, 80% decline and only 13% of ALS patients ever receive a PEG tube. More interesting is the remarkable variation across sites in the incidence of PEG placement, suggesting that there may be important inconsistencies in the manner in which physicians present information about this treat-

ment (Mitsumoto et al., 2003; Ganzini & Johnston, 2006).

Despite some support for the palliative benefits of PEG, any life-prolonging and palliative benefits are ultimately lost at later points in the disease. For example, there is little benefit of PEG at the point that the patient needs, but declines, mechanical ventilation. Eventually the comfort of PEG may be lost if associated with more troublesome respiratory symptoms, diarrhea, or decreased human contact from hand feeding. Once initiated, determining when palliative benefits have been exhausted can be difficult.

## CANCER

Patients undergoing treatments for some type of cancers, particularly head and neck cancers, may survive longer with ANH. Once the disease is advanced and only palliative remedies are considered, evidence of the benefits of ANH in prolonging life are scant (Viola et al., 1997; McCann et al., 1994). Viola et al. (1997) cited six studies of cancer patients in which ANH failed to show benefit, though, in general, the scientific quality of these studies was low. More than two-thirds of cancer patients complain of thirst or dry mouth (Huang & Ahronheim, 2000) yet, in contrast to healthy individuals, thirst in advanced cancer patients seems unrelated to dehydration and serum sodium and unrelieved by fluid therapy (Huang & Ahronheim, 2000). The burdens of fluids in terminally ill cancer patients include counterpalliative effects such as increased urinary output, diarrhea, nausea, pain, and respiratory problems (Viola et al., 1997). Among hospice patients, intravenous sites are difficult to maintain in the home environment, and methods needed to deliver fluids may decrease mobility. Most palliative care clinicians promote the use of good mouth care and sips of water when desired, over ANH (Burge, 1993; Viola et al., 1997).

Recently some experts have begun to reevaluate the administration of small volumes of fluids to palliate toxicity from opioids and diminish agitated delirium. Delirium overcomes 90% of cancer patients in the final weeks of life. Although many causes of delirium are not reversible in cancer patients, dehydration and drug intoxication are among the more treatable causes (Lawlor et al., 2000). Patients with agitated delirium appear to suffer, but even patients who have recovered from delirium and were never agitated remember the experience as very distressing (Breitbart et al., 2002). Bruera et al. (2005) randomized 51 terminally ill cancer patients with dehydration to receive either 1000 ml fluid per day versus 100 ml fluid per day.

Patients were assessed for hallucinations, myoclonus, fatigue, and sedation. Seventy-three percent of the hydration patients versus 49% of placebo patients had improvement of target symptoms ( $p = 0.005$ ). Further studies are needed to examine the palliative benefits of these small volumes of fluids in the final weeks of cancer patient's lives.

### ALZHEIMER'S DEMENTIA

Although the case of Mrs. Schiavo garnered extensive media attention, there are only an estimated 6000 tube-fed patients with PVS in the United States. In contrast, over 60,000 patients with advanced dementia in nursing facilities are fed via PEG tubes—in fact, one-third of all nursing facility residents with advanced dementia receive food and fluid in this manner (Mitchell et al., 2003a).

Advanced dementia, including Alzheimer's dementia, is associated with feeding problems, including difficulties in swallowing and choking, chewing but failing to swallow, and active resistance to hand feeding. Because patients with dementia have limited language and communication abilities, it is difficult to identify the source of aversive behavior. Pasma et al. (2003, 2004), in an anthropological qualitative study in Dutch nursing homes, reported that even among nurses feeding the same patients, interpretations ranged from "patient wants to die" to "patient does not recognize food as food" to "patient fears choking." Interpretation of cause of aversion influenced efforts to hand feed.

Common motivations for PEG in advanced dementia include prevention of aspiration, decreasing decubitus ulcers, improving skin integrity, prolonging of life, preventing suffering, and addressing "starvation."

There is no support for the belief that PEG placement for feeding failure in patients with advanced dementia improves survival. Patients with dementia who are so disabled that they stop eating have a poor prognosis even with a PEG. Randomized controlled trials to determine effect on survival are not available and are unlikely to be funded because of ethical and social concerns. Sanders et al. (2004) retrospectively examined outcomes of PEG in 362 patients—103 had a primary diagnosis of dementia. Fifty-four percent of dementia patients died within a month of PEG placement, and 78% died within 3 months. The mortality was significantly higher in dementia patients compared with patients with oropharyngeal malignancy and stroke with dysphagia. The differences among groups could not be simply attributed to age. These authors point out that the dementia patients who received PEGs were severely disabled and unable to feed them-

selves—this level of disability may be a marker of preterminal state, not remediable to ANH. Many PEGs are placed in dementia patients during hospitalization for an acute illness. Meier et al. (2001) examined 99 hospitalized patients with advanced dementia. Seventeen of the 99 patients were admitted with a feeding tube in place and half received a new feeding tube. Feeding tubes did not improve survival among these patients. Mitchell et al. (1997) examined data on 1386 nursing home residents in the state of Washington who had recently progressed to severe cognitive impairment, and compared those with PEG to those without, adjusting for risk factors for PEG placement. Again, death occurred after similar intervals in the two groups.

Similarly there is little evidence of improved comfort in dementia patients. As reviewed by several authors, there is no evidence that PEG reduces risk of aspiration pneumonia, improves skin integrity, comfort, or functioning, or diminishes suffering in elderly, debilitated, ill nursing home residents (Kaw & Sekas 1994; Finucane, 1995; Berlowitz et al., 1997; Feinberg et al., 1996; Finucane & Bynum, 1996; Finucane et al., 1999; Gillick, 2000). PEG placement remains a risk factor for the use of restraints, as patients may pick and pull at the tube. Restraints increase agitation and may counteract any potential benefits of PEG by increasing pressure sores and the risk of aspiration.

Conversely, severely demented patients who stop eating and drinking do not necessarily suffer more. Pasma et al. (2005) examined 178 Dutch nursing facility patients with severe dementia, who, in the context of increasing illness, had a decrease in food and fluid intake. In all patients a decision was made not to initiate ANH. Nurses completed a questionnaire measuring discomfort at the time the decision was made and at several points over 2 weeks. Discomfort peaked at 2 days after no hydration, but then stayed below baseline until death. Attempts to contrast suffering of these patients with similarly disabled patients who received ANH was not possible, as only 12 patients were in a comparison group. Ganzini et al. (2003a) surveyed nurses who cared for 102 hospice patients who voluntarily chose to stop food and hydration in order to hasten death. Hospice nurses reported that the patients' deaths were characterized by little suffering or pain and were peaceful. These data suggest that not eating and drinking in dying patients causes little suffering, though further studies are needed.

Many powerful factors combine to promote PEG placement in nursing home patients with dementia. Nursing homes have been the settings of scandals in the past regarding patient mistreatment, includ-

ing failing to feed patients. A set of federal and state regulations applicable to nursing homes receiving Medicare and Medicaid reimbursements requires that each resident receive sufficient fluid intake to maintain proper hydration checks. As Meisel (1995) points out, what was intended to support a patient's right to good care has become an obligation to assure hydration even when the patient may not benefit from this. Nursing homes are subject to surprise visits from surveyors, violations are reported, and results of these surveys become public information.

In the United States, complex, mostly nonclinical factors are associated with likelihood of tube feedings in cognitively impaired nursing home residents. Factors associated with a lower proportion of feeding tubes (FTs) include higher prevalence of advance directives in the nursing facility, existence of special dementia units, and availability of nurse practitioners or physician assistants. Larger nursing facilities, those in urban areas, and those with for-profit status were more likely to have patients with PEGs. Patient characteristics associated with FTs include younger age, nonwhite race, male sex, divorced marital status, and lack of advance directive (Mitchell et al., 2003a).

Many experts in nursing home care believe that efforts to spoon-feed patients are more ethical, effective, and beneficial than PEG (Edwards & Beck, 2002; Faxen-Irving et al., 2002; Wilmot et al., 2002; Barratt, 2004). Yet, in many states, there are financial incentives for tube feeding over hand feeding in nursing facilities. Reimbursement costs from Medicaid are higher for PEG patients, though hand feeding is more labor intensive (Mitchell et al., 2003b). Mitchell et al. (2003b) documented that the nursing times for tube feeding patients was about 25 min per day, compared to 73 min for similarly impaired dementia patients who were hand fed. Overall costs of tube fed patients were higher secondary to more physician visits, emergency room visits for tube complications, and hospital days. These costs, however, are borne by Medicare, whereas the costs of feeding were borne by the nursing home through Medicaid.

In face of the lack of evidence for either palliative or survival benefit of PEG in advanced dementia, there are increasing efforts to educate professionals and families. Callahan et al. (1999) examined decision making for tube feeding in 100 consecutive patients in the Midwest. Family members reported that the option for PEG was brought up by medical personnel in the context of an acute event, such as pneumonia, in 73% of cases. Nursing facility staff suggested PEG to address chronic poor food intake in 16% of cases. Hand feeding was presented as an

alternative to only 2% of family members of patients. Both family members and physicians concurred that the process for considering PEG was physician driven. Perceptions of risk were focused on the immediate procedure with little information of long-term burdens such as the need for restraints. Improved comfort was an expectation. Physicians endorsed dubious benefits such as decreased aspiration and improved survival.

Shega et al. (2003) surveyed 195 physicians from the American Medical Association Masterfile in 2002; 75% had discussed PEG tube placement for a long-term care resident with dementia in the previous 2 years. Most physicians substantially underestimated the 30-day mortality in these patients. Three in four mistakenly believed that PEG reduced aspiration and improved pressure ulcer healing. Approximately one-quarter stated that this intervention enhanced quality of life and functional status and 60% endorsed that it improved survival. These data support that physicians overestimate the benefits and underestimate the risks of PEG placement in ill patients.

Increased awareness of the lack of benefit of PEG in patients has led to new interventions to educate physicians, long-term staff, and family members. Mitchell et al. (2001) reported that family members who were exposed to an audiobooklet decision aid that reviewed information on options and outcomes for feeding problems in demented loved ones reported more accurate knowledge and less decisional conflict. Monteleoni and Clark (2004) used quality improvement interventions including palliative care consultation and educational programs in a large hospital and reported substantial decreases in the number of PEG tubes placed in hospitals among dementia patients. Lacey (2005) reported that key decision makers such as medical directors and directors of nursing in nursing facilities are likely to encourage tube feeding for patients with dementia, suggesting an important role in education of those professionals. Shega et al. (2004) reported that respondents in states with low tube feeding rates were significantly more likely to correctly believe the PEG did not improve nutritional status or pressure sore healing in dementia patients, and they were more likely to endorse that dementia was a terminal illness. Increasingly, hospice enrollment in nursing facilities can be a method to avoid demerits from surveyors assessing patients who are losing weight or have evidence of dehydration and may help change the culture of feeding in nursing homes. Patients terminally ill from dementia, however, are less likely to be enrolled in hospice than cancer patients with similar poor prognoses (Mitchell et al., 2004).

## CONCLUSION

The media attention surrounding Terri Schiavo heightened awareness of ANH, particularly PEG, but may have not served the national understanding of this issue well. ANH clearly prolonged Mrs. Schiavo's life, although it had no impact on the quality of her life. However, persons with PVS are only a small segment of ill individuals who receive ANH in this manner. PEG may palliate some symptoms in ALS, but several studies do not support that it increases survival. More studies are needed to determine if small amounts of intravenous or subcutaneous fluids improve comfort in dying cancer patients. Most importantly, current information does not support that PEG either prolongs life or increases comfort in patients with advanced dementia in nursing homes.

## DISCLAIMER

The views expressed in this article are those of the author and do not necessarily represent the views of the Department of Veterans Affairs or the United States Government.

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