

West Chester University Digital Commons @ West Chester University

Nursing Faculty Publications

Nursing

2009

The Artificial Nutrition Debate: Still an Issue ... After All These Years

Cheryl Monturo

West Chester University of Pennsylvania, cmonturo@wcupa.edu

Follow this and additional works at: http://digitalcommons.wcupa.edu/nurs_facpub

 Part of the [Critical Care Nursing Commons](#), and the [Dietetics and Clinical Nutrition Commons](#)

Recommended Citation

Monturo, C. (2009). The Artificial Nutrition Debate: Still an Issue ... After All These Years. *Nutrition in Clinical Practice*, 24(2), 206-213. Retrieved from http://digitalcommons.wcupa.edu/nurs_facpub/7

This Article is brought to you for free and open access by the Nursing at Digital Commons @ West Chester University. It has been accepted for inclusion in Nursing Faculty Publications by an authorized administrator of Digital Commons @ West Chester University. For more information, please contact wccressler@wcupa.edu.

The Artificial Nutrition Debate:

Still an Issue...After All These Years

Until the case of Terri Schiavo, most in bioethics, law and health care believed the debate over withdrawal and withholding of artificial nutrition was settled. Guidelines predicated on judicial rulings were developed for this difficult and highly emotive process. Few cases triggered any serious reconsideration of the position that artificial nutrition and hydration were similar to other life-extending measures and could be withdrawn or withheld in specific circumstances. Despite the appearance of resolution, there is growing concern that the consensus has eroded.^{1,2} The purpose of this paper is to provide a historical review of the bioethical opinion concerning artificial nutrition since it represents both a bioethical consensus and perhaps the seeds of dissent concerning this difficult and highly emotive issue.

Artificial Nutrition

Clinical Evolution

Artificial nutrition is a viable and highly effective therapy to ameliorate the effects of temporary or chronic conditions for those unable to ingest food and fluids.³ Despite the positive impact of technology, widespread utilization of this treatment in end-of-life, persistent vegetative state (PVS), severe cognitive impairment, and advanced progressive dementia creates an ethical dilemma for some who believe that the withdrawal or withholding of artificial nutrition is cruel, inhumane, and tantamount to starvation.

The focus of this paper is on enteral nutrition, which dates to ancient Egypt and Greece and continued as rectal feedings into the 18th and 19th centuries.⁴ Similarly, feeding into the upper gastrointestinal tract through a nasopharyngeal tube was first documented in the sixteenth century (His' study as cited in⁵), and was quite common in the latter part of the nineteenth

24 century. Technological advances in tube development, formulas, and surgical procedures
25 continued throughout the 19th and early 20th centuries.^{5,6} Innovation continued into the late 20th
26 century with introduction of the percutaneous endoscopic gastrostomy (PEG) in 1981⁷, offering
27 patients a decreased risk of complications during placement. Despite the value of this
28 groundbreaking technology, some voiced concerns about the potential for over-utilization and
29 creation of ethical dilemmas.⁸

30 *Religious Evolution*

31 Significant to the bioethical debate are religious positions on the morality of withdrawal
32 and withholding of artificial nutrition. While considerable variation occurs within individual
33 religions, basic tenets are available. In a recent review on end-of-life decisions, the authors
34 categorized several religious views on life-sustaining therapies noting that Protestants and
35 Buddhists accept withdrawal of artificial nutrition, while Catholics, Greek Orthodox, Muslims
36 and Orthodox Jews reject this practice.⁹ Information from other religions including Hindu, Sikh,
37 Taoism and Confucianism are less clear on this issue.⁹

38 Notwithstanding this recent review, most religious views on artificial nutrition are not
39 well represented in the literature, although more is available about Catholicism and Judaism. The
40 Catholic Church historically obliges an individual to strive towards prolongation of life, although
41 it does not require one to do so if great effort is required or if little hope exists.¹⁰ More recently
42 confusion erupted over a Papal address to the International Congress on Life Sustaining
43 Treatments and Vegetative States in March 2004. During this address Pope John Paul II
44 categorized all food and water, regardless of the means by which they are delivered, as
45 obligatory and a natural vs. medical action to preserve life. Accordingly, cessation of artificial
46 nutrition resulting in death is viewed as euthanasia by omission in PVS patients.² Despite this

47 confusion, some theologians argue that little has changed in the Catholic teaching on artificial
48 nutrition and hydration.¹¹

49 Consistent with Bülow's review on Judaism⁹, some conservative rabbis regard artificial
50 nutrition and hydration as basic and therefore dissimilar to medications and machines.¹²

51 Conversely, others classify artificial nutrition and hydration as medicine, thereby allowing for its
52 withdrawal.¹³ Although these guidelines provide some insight into various faiths, no group is
53 homogenous, and therefore it is difficult to apply these tenets uniformly for individual patients.

54 **Bioethical Review**

55 As the oldest and most widely read bioethics journal, the *Hastings Center Report (HCR)*
56 influenced discussions in both health care and public policy. The Hastings Center, founded in
57 1969, focused on concerns of death and dying, and subsequently began publication of the *HCR*
58 in 1971. Although not a complete picture of all bioethical discussions concerning artificial
59 nutrition, the *HCR* is representative of the general bioethical sentiments and opinions. A
60 combination of classic content analysis and grounded theory formed the basis for data collection
61 and analysis of articles from 1971 through 2007.¹⁴ Only those articles with a primary focus on
62 artificial nutrition were included resulting in a sample of 63 articles and/or letters. Although
63 artificial nutrition includes both enteral and parenteral nutrition, authors used this phrase
64 interchangeably with enteral nutrition and/or tube feedings in the sample. A critical analysis
65 revealed the emergence of 8 inductively derived categories describing the context of artificial
66 nutrition withdrawal or withholding (see Figure 1). Since many articles reflected more than one
67 category, the following review is framed within a chronology of bioethical and legal events.

68 *The Right to Die Movement (1971-1982)*

69 Publications from 1971 through 1982 lacked a primary focus on artificial nutrition and
70 were therefore not included in the sample. However, it is important to review this period of time
71 since it contains important bioethical and legal events that frame the remaining years of the
72 analysis.

73 The Karen Ann Quinlan case¹⁵ was the first legal case of removal of life-sustaining
74 therapy, a respirator. Although not an issue of artificial nutrition, removal of the feeding tube
75 was also an option, but this was refused by her father and guardian, Joe Quinlan, stating: “That is
76 her nourishment!”¹⁶ Discussion of the Quinlan decision was extensive in the *HCR*, but the focus
77 was not on artificial nutrition. Shortly after Quinlan, cases involving newborns and infants arose
78 in the courts in reference to withdrawal and withholding of treatment. The Danville babies’ case
79 focused on treatment and non-treatment issues, but the article was also not specific to artificial
80 nutrition.¹⁷ Other early articles discussed death in broad terms, noting the effect of advancing
81 technology, issues of dignity concerning death, and the right to die.¹⁸⁻²¹

82 *Artificial Nutrition in End-of-Life Cases (1983-1990)*

83 In 1983, The President’s Commission for the Study of Ethical Problems in Medicine and
84 Biomedical and Behavioral Research²² found no distinction between artificial nutrition and other
85 life-sustaining treatments. From 1983 through 1987, several newborn, infant, and adult cases
86 arose centered on issues of artificial nutrition.²³⁻²⁵ Despite court rulings supporting parental
87 choice to withhold nutrition and necessary surgery to correct anomalies preventing normal
88 feeding^{24, 26}, federal regulations known as the ‘Baby Doe Directives’ were imposed assuring that
89 there would never be an adequate reason to withdraw or withhold nutrition and fluids from a
90 newborn based solely on a handicap.²⁴ At the same time, artificial nutrition publications in the
91 *HCR* became prolific yielding 3 to 6 articles/letters each year during this five-year period.

92 The category illness and treatment trajectory was the predominant focus of articles from
93 1983-1987, but many articles also addressed the category of family. Within the category family,
94 content focused on both the expressive and legal/ethical facets of family involvement in patient
95 care. Several court cases examined issues of surrogacy, substituted judgment, and best interest
96 standard, while the expressive nature of withdrawal or withholding of artificial nutrition was
97 captured in the themes of hope, acceptance, and symbolism.^{16, 27-30} Several articles used the
98 word ‘starvation’ in reference to withdrawal or withholding of artificial nutrition, providing
99 further support for the highly powerful and emotive nature of symbolism.²⁷⁻²⁹

100 A final category, personhood, was acknowledged through a focus on individual rights and
101 principles in addition to primacy of rights. Individual rights were evident in discussions of
102 patient privacy, autonomy, and liberty. Primacy of rights examined the issues of provider,
103 patient, institutional, and societal rights in relation to withdrawal and withholding of artificial
104 nutrition, much of which focused on Elizabeth Bouvia’s refusal of tube feeding.

105 From 1988 through 1989, publications focused on artificial nutrition decreased to two
106 each year. Although the focus remained predominantly within the illness and treatment trajectory
107 category, topics focused on treatment in terms of its active or passive nature, such as euthanasia
108 and the cause of death. Technology was discussed in terms of the slippery slope for the
109 vulnerable, referring to the ongoing abortion debate.³¹

110 Discussion in other categories remained consistent with the earlier publications focusing
111 on various legal and ethical facets of family involvement and legislative issues such as
112 substituted judgment, best interests, and advance directives. Finally, individual rights and
113 principles were mentioned within the personhood category, but the discussion was superficial.

114 In 1990, the Supreme Court ruled in favor of individual states' requirement to provide
115 clear and convincing evidence concerning patient wishes before treatment with artificial nutrition
116 could be discontinued.³² This ruling pertained to individuals in a PVS, favoring those with
117 explicitly conveyed wishes, preferably in writing, to family, friends, and healthcare providers in
118 advance of a life-threatening situation. The focus of this ruling was the incapacitation of a
119 healthy young woman, Nancy Cruzan from Missouri, who was found unresponsive after a car
120 accident, resuscitated and remained in a PVS for almost 8 years. Ms. Cruzan received enteral
121 nutrition for 8 years, however after 3 years of aggressive therapy, her family requested removal
122 of the enteral tube. A legal battle ensued between the Cruzan family and the state of Missouri,
123 who opposed the family's wishes, eventually leading to the United States Supreme Court. After
124 providing additional evidence to the State, Ms. Cruzan's family received permission to remove
125 her enteral tube and she died 12 days later in December 1990.³³ As a result of this landmark
126 case, the Patient Self-Determination Act was passed in 1990. This Act requires that health care
127 facilities receiving government funds determine if patients have an advance directive and if not,
128 facilities are mandated to offer the opportunity to complete one.

129 Thirteen articles and/or letters concerning artificial nutrition published in *HCR* during
130 1990 focused on the Nancy Cruzan case. Although the categories were not significantly different
131 from the remaining articles in this time frame, the discussion provided more detail, such as the
132 depth with which the legal, ethical and expressive aspects of family involvement in decision-
133 making were presented in terms of surrogacy, substituted judgment, best interests standard, hope
134 and acceptance.

135 Discussion within the illness and treatment trajectory category introduced the notion of
136 time trials. Time trials are the institution of treatment for a specified time with subsequent

137 evaluation and decision-making to continue or withdraw the treatment. This topic was discussed
138 in terms of Missouri state law and the inability to withdraw treatment once initiated.^{34, 35} Other
139 articles discussed the nature of treatment in terms of the positive and negative connotations of
140 treatment withdrawal, and the goals of treatment in terms of the dichotomy between preservation
141 of life and the right to die for Nancy Cruzan.

142 Within the category of personhood, recurring ideas evolved focused on patient autonomy
143 and the potential loss of this right for patients in a PVS. Provider issues were discussed in terms
144 of the right to identify futile care and involvement of a bioethics committee in the case of a
145 newborn with necrotizing enterocolitis.³⁶ Legislative issues were highlighted during this time-
146 period in terms of the individual, family and states' rights in the absence of an advance directive.

147 *Post-Cruzan (1991-2003)*

148 Despite the plethora of articles in 1990, no articles concerning artificial nutrition
149 appeared in 1991, and there was a precipitous drop to only 1-2 articles per year for the
150 subsequent five-year period (1992-1996). Perhaps this was an attempt to focus on the myriad of
151 bioethical issues pushed aside due to the notoriety of Cruzan. While some articles during this
152 period still referenced Cruzan, others focused on individual case studies. Illness and treatment
153 trajectory remained the predominant category; however the concerns extended beyond the
154 unconscious incompetent patient to those who were competent but without adequate swallowing
155 function. Concern also arose in the use of subterfuge and withdrawal of artificial nutrition,
156 without the awareness and agreement of the entire health care team.³⁷ This appeared ironic in
157 light of previous discussion concerning the legal, ethical or moral acceptance of withdrawal or
158 withholding of artificial nutrition. Perhaps this was the first indication that this issue was
159 resolved at the judicial and bioethical establishment levels, but not at the bedside.

160 Additional comments in the personhood category related to the notion of individual
161 principles and primacy of rights between patients, providers, institutions, and society, although
162 discussion of these issues remained superficial.³⁸ Finally, within the category legal issues,
163 patient rights and the legal nature of withdrawal emerged in terms of informed consent and
164 suicide. Informed consent was questioned in the case of a conscious and assumed competent
165 patient who insisted on eating ‘real’ food despite oral dysphagia³⁸, and Judge Antonin Scalia
166 distinguished refusal of food and water as suicide in the Cruzan decision.^{39,40}

167 Publications continued to decline after 1996 with none for a four-year period (1997-
168 2000), three in the subsequent two years (2001-2002), and then none again in 2003. In light of
169 this relative dearth of artificial nutrition focused publications for a 7-year period, the resurrection
170 of discussion and publicity in terms of the Schiavo case and Pope John Paul II’s subsequent
171 address in 2004 was striking.

172 Two thousand and one (2001) marked a distinct shift in patient focus to a burgeoning
173 population, the older adult with dementia, from the unconscious incompetent or the competent
174 individual. This type of patient is examined in the context of the development of the
175 percutaneous endoscopic gastrostomy (PEG) and was discussed in terms of the over utilization
176 of technology.⁴¹

177 The category religion is mentioned for the first time in reference to artificial nutrition in
178 2001.^{41,42} The issue of religion and the historical context of burdensome treatments revealed the
179 basic tenets of the Roman Catholic tradition versus the beliefs of modern day religious leaders
180 and laity.⁴² Notwithstanding the idea that medically assisted nutrition equates to ordinary or
181 basic care, the original tenets set forth by De Vitoria¹⁰ may apply to food and water as
182 extraordinary if one’s condition dictates.

183 Four other categories (cost, provider issues, legal issues, and ethics/morality) were also
184 evident in this small sample. Institutional cost was discussed in terms of inadequate staff to
185 orally feed those who are capable, in favor of a PEG tube.⁴¹ Individual principles concerning the
186 quality of life were confused with provider rights and the ultimate sanctity and value of life.⁴²
187 The legal nature of treatment withdrawal was evident in terms of the conscious yet incompetent
188 patient suffering from devastating brain damage, but not in a vegetative state.⁴³ Despite
189 bioethical and legal discussion for more than 30 years, the apparent lack of societal consensus
190 concerning withdrawal or withholding artificial nutrition was clear in this sample⁴², as it
191 continues to be now.

192 *An Unresolved Moral and Ethical Dilemma (2004-2007)*

193 While the Supreme Court was ruling on the issue of clear and convincing evidence in the
194 Cruzan case in 1990, another young woman, Theresa Schiavo, suffered a cardiac arrest
195 secondary to a significant electrolyte imbalance. She remained anoxic after her arrest, suffering
196 irreversible brain damage resulting in a PVS. After eight years of receiving enteral nutrition, Mr.
197 Schiavo requested that the tube be removed, consistent with his wife's previous verbal wishes.
198 Between 1998 and 2003, Ms. Schiavo's gastrostomy tube was removed and replaced twice as a
199 result of numerous court orders and challenges. In 2003 the case gained national attention and
200 local officials entered the discussion. The Florida legislation enacted "Terri's Law," which
201 empowered the governor to reinsert the tube and to appoint a special guardian ad litem. Finally
202 in March 2005, Mr. Schiavo's original request to remove her tube was honored, and after 13
203 days, Ms. Schiavo died.⁴⁴ Despite a seemingly resolved issue post Cruzan, the Schiavo case
204 highlighted the vulnerable and yet unresolved moral and ethical dilemma of withdrawal of
205 artificial nutrition.

206 The Schiavo case was the focus of most publications concerning artificial nutrition in the
207 *HCR* from 2004-2007. Discussion was wide-ranging in 2004 and 2005 with several categories
208 sharing an equal focus including illness and treatment trajectory, personhood, legal issues, ethics
209 and morality, religion and family. Within illness/treatment trajectory, diagnosis and prognosis
210 were discussed as in previous years, however the concern centered on the correctness of
211 diagnosis - PVS, minimally conscious states, and/or treatable brain damage.⁴⁵⁻⁴⁸ This discussion
212 paralleled the Schiavo case in which family and some medical experts argued that Ms. Schiavo
213 was misdiagnosed and not in fact in a PVS. For the first time this discussion spilled over into
214 issues of personhood, questioning if those in a PVS were in fact disabled⁴⁹, and noting
215 Americans' negative view of disability and incompetence, while obsessing over autonomy.⁵⁰
216 Privacy, primary of rights, autonomy, and patient wishes provided a basis for discussing the
217 ongoing Schiavo case.^{45-47, 50-53}

218 The topic of religion in relation to artificial nutrition was first discussed in 2001⁴² with
219 an overview on the historical underpinnings of the Catholic Church. In 2004 and 2005, authors
220 reiterated this content and applied it to the Papal address on feeding tubes.^{49, 51, 54, 55} Some
221 projected a socioeconomic impact if all were required to be artificially nourished as could be
222 interpreted from the address.⁵¹ The discussion flowed naturally from religious topics such as life
223 is a gift from God⁵⁴ to the ethics and morality of the value of Ms. Schiavo's life⁴⁵, the basic
224 ethical principles of beneficence and nonmaleficence⁵⁰, and evaluation of the burdens and
225 benefits using terms such as proportionate vs. disproportionate, extraordinary vs. ordinary and
226 morally required or obligatory.^{49, 50, 54, 55}

227 One of the primary issues in the Schiavo case was the role of various family members.
228 This topic appeared in several publications in reference to the disagreement amongst Ms.

229 Schiavo's family^{45, 51, 56} as well as the difficulty in acknowledging the death of a child.⁴⁶
230 Although a complicated and tragic case, Dresser⁴⁷ highlighted the positive aspect of the Schiavo
231 case in bringing together other families around the discussion of advance directives.

232 Finally, the legal aspects of publications during this time were extensive in discussing the
233 basics from previous years such as substituted judgment, best interests standard, clear and
234 convincing evidence, surrogacy and advance directives^{46, 47, 50, 56}, while introducing new issues
235 including government intervention in the form of legislation concerning treatment.^{45, 46, 52, 56}
236 Subsequent to the flurry of discussion on Schiavo during 2004 and 2005, no articles on artificial
237 nutrition appeared in the *HCR* in 2006 or 2007.

238 **Discussion**

239 This historical review of bioethical opinion revealed inductively derived categories
240 addressing a myriad of physiological, psychological and social concerns over withdrawal or
241 withholding of artificial nutrition. Key points within these categories are discussed below
242 providing a necessary foundation to address these highly emotive issues in the future.

243 *Illness and Treatment Trajectory*

244 The acceptance of death as a normal phenomenon in American society is problematic,
245 since many believe death to be an option not an eventuality, and as such, a subsequent lack of
246 realism influences this discussion. A large number of reviewed publications focused on the
247 physiological issues surrounding withdrawal or withholding of artificial nutrition, and therefore
248 fell within the category of illness and treatment trajectory. Discussion of the nature of the illness
249 focused on the diagnosis and prognosis of the unconscious incompetent patient (PVS) in terms of
250 the ability to withdraw artificial nutrition. Since the Quinlan case, PVS remained a recognized
251 irreversible diagnosis in which life-sustaining treatments may be discontinued according to a

252 variety of rules dependent on individual state statutes. Seemingly, early bioethical opinion in this
253 sample reflected society's accomplishment in managing care for those in a PVS, however, Ms.
254 Schiavo's diagnosis of PVS vs. minimally conscious state sparked disagreement among family
255 members. Further, government intervention and extensive media coverage added significant
256 weight to this case focusing on the issue of starvation, with little recognition that the Cruzan
257 family fought this battle more than 10 years prior. Perhaps it ultimately returns to the same issue;
258 two seemingly healthy young women suffered tragic events without prior written advance
259 directives.

260 In addition to the diagnosis of PVS, the question of withdrawal arose in those patients
261 who were incompetent, but conscious with massive brain damage or dementia. The diagnosis of
262 dementia broadened the population in question and therefore may be more problematic for those
263 fearful of the 'slippery slope' analogy. Clinicians argued that an end stage patient suffering from
264 Alzheimer's disease was just as terminal as was a patient in a PVS. Although the argument to
265 orally feed those with dementia but without dysphagia was self evident, the concern over
266 accurate diagnosis of advanced dementia may be problematic.

267 Further, evidence points to the lack of a positive outcome when instituting enteral
268 nutrition for weight maintenance or loss, prevention of aspiration and treatment or prevention of
269 decubitus ulcers.⁵⁷ As such, patients suffering from dementia or massive brain damage demand
270 distinction from those in a PVS, and therefore require separate examination in terms of the
271 potential need to withdraw or withhold artificial nutrition.

272 Implementation of time trials may be significant for those with dementia and massive
273 brain damage, in addition to other vague diagnoses and prognoses. Since it is difficult to
274 diagnose impending death accurately⁵⁸, many decisions to institute or withdraw life-sustaining

275 treatments, including artificial nutrition, are fraught with uncertainty. Although the issue of time
276 trials was raised several times in this sample^{34-36, 59, 60}, it requires more attention at the bedside.

277 *Family*

278 Family issues received a great deal of attention in this sample, particularly in terms of
279 surrogacy from early cases such as Brother Fox to the Schiavo decision. Although debated in
280 detail, the issue of surrogacy continues to be difficult to address. With little progress in the
281 execution and interpretation of advance directives, clinicians rely on families to make critical
282 decisions. Although appropriate in many cases, disagreement in the Schiavo case resulted in a
283 difficult and tragic case.

284 Part of the discussion about family issues naturally lends itself to the expressive aspects
285 of family involvement. One such aspect is the notion of symbolism in terms of food and feeding.
286 Symbolism was evident in 1983-1984^{16, 27-29} and again in 2005⁶¹ in terms of the highly emotive
287 bonds of food and water within families and society in general. The Baby Doe Directives directly
288 opposed the court rulings of the day allowing parental choice to remove or withhold treatment.
289 Perhaps the nurturing aspect of food, particularly in infants, was evident in this directive and
290 may mirror the notion that nourishment of the infirm or vulnerable individual is paramount under
291 all circumstances and at all costs, consistent with Pope John Paul II's address.²

292 *Ethics, Morality and Legal Issues*

293 Despite the lack of moral, ethical and legal distinction between withholding and
294 withdrawing care²², some clinicians, families and clergy voice strong opposition to withdrawing
295 care once initiated. This opposition is due in part to the perception that active treatment
296 discontinuation 'feels different' than failure to initiate care. Without the ability to accurately

297 predict impending death, clinician comfort to initiate and discontinue treatments as necessary is
298 critical to providing adequate and appropriate care.

299 In the end, the ethics and morality of this issue seem to be most burdensome for patients,
300 families, providers and society in general. What emerged as an early consensus on the delivery,
301 withholding and withdrawal of artificial nutrition appears to be a ruse. Inherent in the discussion
302 of symbolism and food is the assumed pain and social repugnance with removal of artificial
303 nutrition. A few of the articles in this sample used the term starvation, as did the Schiavo case.
304 Media depiction of the images of starvation and cruelty in this Florida case were similar to the
305 circumstances of mid-December 1990, when another government official (the then Governor
306 John Ashcroft) was also asked to intervene, and did so, in the case of Nancy Cruzan to prevent
307 *starvation* from withdrawal of artificial nutrition. Another case of starvation reported in the
308 Philadelphia media ⁶² in a similar fashion to that of the previously discussed cases, involved the
309 intentional withholding of oral nutrition from children by their parents, and not withdrawal of
310 artificial nutrition. It is disturbing to see the parallels drawn by the media in these drastically
311 different cases, but perhaps it is reflective of society's inability to distinguish one from another.
312 Some might argue that the cause of death is key when removing artificial nutrition. Perhaps, the
313 underlying disease that prevented individuals from ingesting food orally causes an individual's
314 death, or perhaps death ensues from the direct removal of artificial nutrition. Some would
315 classify the latter as starvation. In that sense, it is confusing at best to untangle the web of
316 causality in an individual who is either at the end of their lives, in a persistent vegetative state, or
317 suffering from massive brain damage, dementia, or severe multi-system organ failure.

318 *Religion*

342 nutrition. Rather, it is now clear that these recent events are not an unraveling of a well
343 established norm, but evidence that society never embraced this consensus as was once assumed.
344 Perhaps, some of this continued discomfort is based on the rarely addressed issue of symbolism.
345 Although well developed by anthropologists in terms of the implicit meaning of food and
346 ritualistic behaviors, this issue remains relatively unaddressed in relation to artificial nutrition
347 from a biomedical perspective.

348 While some suggest the need for a legal solution to address these issues, the ideal method
349 may lie in the concept of exploring the meaning, values and beliefs concerning food and artificial
350 nutrition. These core values and beliefs may affect treatment choices when faced with
351 irreversible illness or at end of life, and therefore may require redirection of the current
352 bioethical focus to one in which we can act without fear of legal or moral reprisals.

353 References

- 354 1. The Associated Press. Catholic hospitals grapple with Pope's remarks: Officials move to
355 reassure patients about feeding-tube issue. *The Associated Press*. Available at:
356 <http://www.msnbc.msn.com/id/4750805/>. Accessed April 15, 2004.
- 357 2. Vatican Information Service. Address of John Paul II to the participants in the
358 International Congress on "Life sustaining treatments and vegetative state: Scientific
359 advances and ethical dilemmas" *Vatican Information Service*. Available at:
360 [http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html)
361 [ii_spe_20040320_congress-fiamc_en.html](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html). Accessed September 19, 2008.
- 362 3. Fine RL. Ethical issues in artificial nutrition and hydration. *Nutrition in Clinical Practice*.
363 2006;21:118-125.
- 364 4. Jones-Humphreys YM. An easy method of feeding per rectum. *The Lancet*. 1891;1:366-
365 367.
- 366 5. Randall HT. The History of Enteral Nutrition. In: Rombeau JL, Caldwell MT, eds.
367 *Clinical Nutrition: Enteral and Tube Feeding*. 2nd ed. Philadelphia: Saunders; 1990.
- 368 6. Deveney KE. Endoscopic Gastrostomy and Jejunostomy. In: Rombeau JL, Caldwell MT,
369 eds. *Clinical Nutrition: Enteral and Tube Feeding*. 2nd ed. Philadelphia: Saunders;
370 1990:614.
- 371 7. Ponsky JL, Gauderer MW. Percutaneous endoscopic gastrostomy: a nonoperative
372 technique for feeding gastrostomy. *Gastrointestinal Endoscopy*. 1981;27(1):9-11.
- 373 8. Gauderer M. Twenty years of percutaneous endoscopic gastrostomy: origin and evolution
374 of a concept and its expanded applications. *Gastrointestinal Endoscopy*. Dec
375 1999;50(6):879-883.

- 376 **9.** Bulow H-H, Sprung CL, Reinhart K, et al. The world's major religions' points of view on
377 end-of-life decisions in the intensive care unit. *Intensive Care Medicine*. 2008;34(3):423-
378 430.
- 379 **10.** Cronin DA. The moral law in regard to the ordinary and extraordinary means of
380 conserving human life. In: Smith RE, ed. *Conserving human life*. Vol Part I. Braintree,
381 MA: National Catholic Bioethics Center; 1989.
- 382 **11.** Paris JJ, Keenan JF, Himes KR. Quaestio Disputata: Did John Paul II's Allocution on
383 Life-Sustaining Treatments Revise Tradition? *Theological Studies*. 2006;67:163-168.
- 384 **12.** Reisner AI. Care for the Terminally Ill: Practical Applications. In: Mackler A, ed. *Life*
385 *and Death Responsibilities in Jewish Biomedical Ethics*; 2000:265-267.
- 386 **13.** Dorff EN. Applying traditional Jewish law to PVS. *Neurorehabilitation*. 2004;19(4):277-
387 283.
- 388 **14.** Bernard HR, Ryan GW. Text Analysis: Qualitative and Quantitative Methods. In:
389 Bernard HR, ed. *Handbook of Methods in Cultural Anthropology*. New York: Altamira
390 Press; 1998:595-646.
- 391 **15.** Supreme Court of New Jersey. In re Quinlan. Vol 355 A. 2d 647, cert.: 70 N.J. 10; 1976.
- 392 **16.** Capron AM. Ironies and tensions in feeding the dying. *Hastings Center Report*. Oct
393 1984;14(5):32-35.
- 394 **17.** Robertson JA. Dilemma in Danville. *The Hastings Center Report*. 1981(October):5-8.
- 395 **18.** Illich I. The political uses of natural death. *The Hasting Center Studies*. 1974;2(1):3-20.
- 396 **19.** Cassell EJ. Dying in a technological society. *The Hasting Center Studies*. 1974;2(2):31-
397 36.
- 398 **20.** Jonas H. The Right to Die. *The Hasting Center Report*. 1978(August 1978):31-36.

- 399 **21.** Ramsey P. The indignity of 'death with dignity'. *The Hasting Center Studies*.
400 1974;2(2):47-62.
- 401 **22.** The President's Commission for the Study of Ethical Problems in Medicine and
402 Biomedical and Behavioral Research. *Deciding to forego life-sustaining treatment*.
403 Washington, D.C.: U.S. Government Printing Office; 1983.
- 404 **23.** California Court of Appeal 2nd D2. Barber v. Superior Court of State of California; Nejd
405 v. Superior Court of State of California. *West's California Reporter*. Vol 195; 1983:484-
406 494.
- 407 **24.** Caplan AL, Cohen CB. Imperiled newborns. *Hastings Center Report*. 1987;17(6):5-32.
- 408 **25.** New Jersey Superior Court Appellate Division. In re Conroy. *Atlantic Reporter (St. Paul,*
409 *Minn.)*. Vol 464: New Jersey Superior Court Appellate Division; 1983:303.
- 410 **26.** Anonymous. Baby Doe's death by starvation. *Mental Disability Law Reporter*. May-Jun
411 1982;6(3):135-137.
- 412 **27.** Annas GJ. Nonfeeding: lawful killing in CA, homicide in NJ. *Hastings Center Report*.
413 Dec 1983;13(6):19-20.
- 414 **28.** Callahan D. On feeding the dying. *Hastings Center Report*. Oct 1983;13(5):22.
- 415 **29.** Lynn J, Childress JF. Must patients always be given food and water? *Hastings Center*
416 *Report*. Oct 1983;13(5):17-21.
- 417 **30.** Green W. Setting boundaries for artificial feeding. *Hastings Center Report*. Dec
418 1984;14(6):8-10.
- 419 **31.** Annas GJ. The insane root takes reason prisoner. *Hasting Center Report*. Jan-Feb
420 1989;19(1):29-31.

- 421 **32.** In re Cruzan v. Director MDH, et al. In the Supreme Court of the United States. No. 88-
422 1503. Nancy Beth Cruzan, by her parents and co-guardians, Lester L. Cruzan, et ux.,
423 petitioners, v. Director, Missouri Department Health, et al. *Issues in Law & Medicine*.
424 Vol 5; 1990:453-478.
- 425 **33.** Colby WH. *Long Goodbye: The Deaths of Nancy Cruzan*. Carlsbad, CA: Hay House;
426 2002.
- 427 **34.** Colby WH. Missouri stands alone. *The Hasting Center Report*. 1990(September October
428 1990):5-6.
- 429 **35.** Scofield G. The calculus of consent. *Hasting Center Report*. Jan-Feb 1990;20(1):44-47.
- 430 **36.** Fleischman AR. Parental responsibility and the Infant Bioethics Committee. *Hasting*
431 *Center Report*. 1990;20(2):31-32.
- 432 **37.** Brenner P, McGee EM. Word of mouth. *Hastings Center Report*. Jul-Aug 1996;26(4):19;
433 discussion 19-20.
- 434 **38.** Parker L. A hard policy to swallow. *Hastings Center Report*. July-Aug 1994;24(4):23-24.
- 435 **39.** Kass LR. Is there a right to die? *Hastings Center Report*. Jan-Feb 1993;23(1):34-43.
- 436 **40.** Kelly D. Cannon to right of them. *Hastings Center Report*. July-Aug 1993;23(4):42-43.
- 437 **41.** Post SG. Tube feeding and advanced progressive dementia. *Hastings Center Report*.
438 2001;31(1):36-42.
- 439 **42.** Panicola M. Catholic teaching on prolonging life: setting the record straight. *Hastings*
440 *Center Report*. Nov-Dec 2001;31(6):14-25.
- 441 **43.** Dresser R. The conscious incompetent patient. *Hastings Center Report*. May-June
442 2002;32(3):9-10.

- 443 **44.** Cerminara K, Goodman K. Schiavo Case Resources: Key events in the case of Theresa
444 Marie Schiavo. Available at: <http://www6.miami.edu/ethics/schiavo/timeline.htm>.
445 Accessed September 18, 2008.
- 446 **45.** Dresser R. At law. Schiavo: a hard case makes questionable law. *Hastings Center Report*.
447 2004;34(3):8-9.
- 448 **46.** Wolfson J. Erring on the side of Theresa Schiavo: reflections of the special guardian ad
449 litem. *Hastings Center Report*. 2005;35(3):16-19.
- 450 **47.** Dresser R. Schiavo's Legacy: The need for an objective standard. *Hasting Center Report*.
451 May-June 2005;35(3):20-22.
- 452 **48.** Fins JJ, Schiff ND. The afterlife of terri schiavo. *Hastings Center Report*. 2005;35(4):8-8.
- 453 **49.** Shannon TA, Walter JJ, May WE, et al. Nutrition and hydration. *Hastings Center Report*.
454 2005;35(3):4-7.
- 455 **50.** Etzioni S, Rosenfeld K, Berube M. Case study: deciding for the patient. *Hastings Center*
456 *Report*. 2004;34(5):12-13.
- 457 **51.** Shannon TA, Walter JJ. Implications of the papal allocution on feeding tubes. *Hastings*
458 *Center Report*. 2004;34(4):18-20.
- 459 **52.** Cassell EJ. The Schiavo case: a medical perspective. *Hastings Center Report*.
460 2005;35(3):22-23.
- 461 **53.** Bernacki R. In practice. Not at peace. *Hastings Center Report*. 2005;35(4):9-10.
- 462 **54.** Repenshek M, Slosar JP. Medically assisted nutrition and hydration: a contribution to the
463 dialogue. *Hastings Center Report*. 2004;34(6):13-16.
- 464 **55.** Repenshek M, Slosar JP. Repenshek and Slosar reply. *The Hasting Center Report*. May-
465 June 2005 2005;35(3):5-6.

- 466 **56.** Schneider CE. Hard cases and the politics of righteousness. *Hastings Center Report*.
467 2005;35(3):24-27.
- 468 **57.** Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a
469 review of the evidence.[comment]. *Journal of the American Medical Association*.
470 1999;282(14):1365-1370.
- 471 **58.** Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in
472 terminally ill patients: prospective cohort study.[see comment]. *BMJ*. Feb 19
473 2000;320(7233):469-472.
- 474 **59.** Meilaender G. On removing food and water: Against the stream. *Hasting Center Report*.
475 December 1984;14(6):11-13.
- 476 **60.** Kessel R. A law unto themselves. *Hastings Center Report*. Nov-Dec 1995;25(6):47-48.
- 477 **61.** Frader JE. Discontinuing artificial fluids and nutrition: discussions with children's
478 families. *Hastings Center Report*. 2007 Jan-Feb 2007;37(1):49-49.
- 479 **62.** Shiffman J, Lipka, M., Graham, K.A. Parents of gaunt N.J. sons indicted. *Philadelphia*
480 *Inquirer*. 5/6/04, 2004: A01.

Figure 1. Inductively derived categories

