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Competing interpretations of 'death with dignity'

John L. Allen Jr. | Sep. 28, 2007 All Things Catholic

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Given intense bioethical debates these days over end-of-life care, Catholics naturally look to role models for guidance as to how the church's traditional principles, especially the distinction between ordinary and extraordinary means of preserving life, ought to be "cashed out" in concrete situations. Perhaps, therefore, it was inevitable that the protracted illness of Pope John Paul II two years ago would become a battlefield for competing interpretations of what "death with dignity" actually means.

Even that realization, however, hardly prepared anyone for the explosive charge recently made by a physician in a prominent Italian journal: That the medical care given to John Paul in his last months of life was so insufficient that his death on April 2, 2005, amounted to a form of euthanasia.

The physician, an Italian anesthesiologist named Lina Pavanelli, was not part of the medical team that treated John Paul II, nor did she have access to his medical records. She based her analysis upon news reports during the period from early February 2005 to the pope's death on April 2, as well as a book later written by the pope's personal physician, Dr. Renato Buzzonetti.

Pavanelli's essay appeared in the journal *Micromega*, edited by Paolo Flores d'Arcais, a philosopher, self-described atheist, and frequent Vatican critic.

Initially, Pavanelli's argument presumed that John Paul II was only given a nasal feeding tube on March 30, four days before his death. In response, Vatican officials said that while the first official confirmation of the use of a tube came on March 30, in fact the pope had used a tube intermittently since late February.

Veteran Italian journalist Luigi Accattoli reported that from Monday of Holy Week in 2005, meaning March 21, the tube was left in place permanently, removed only for the pope's few fleeting public appearances. Those who remember John Paul II's final days will recall that on Friday of Holy Week, TV cameras showed the pope in his private chapel, holding a Cross, while he watched the annual *Via Crucis* procession from the Coliseum on a television monitor. Accattoli reported that the reason the cameras only showed the pope from behind was, in part, because he was wearing his nasal feeding tube at the time.

In response, Pavanelli revised her argument. In a Rome press conference on Wednesday, she argued that

regardless of what happened at the end, John Paul II should have been given a feeding tube inserted into the stomach much earlier. By using only a nasal tube, she charged, John Paul II became dangerously underweight and lacked the strength to combat the infection that ultimately killed him. She continued to hint that failure to treat the pope's condition more aggressively reflected a choice to "let nature take its course" that contrasts with the church's public rhetoric on end-of-life care.

For his part, Buzzonetti broke a two-year silence to strenuously reject suggestions that the pope, or his medical team, had given up. In fact, Buzzonetti said, the pope used a feeding tube for the better part of two months, his IV drip was administered until the moment of his death, and even after he went into septic shock on March 31 he was given assistance with his heart and lungs. At no point, Buzzonetti said, was a decision made to let John Paul die.

In that light, two points about the story seem worth making.

First, while Pavanelli's article may raise legitimate questions about medical decisions made with regard to John Paul II, charges of euthanasia seem a stretch. Taking into consideration the pope's two extensive hospitalizations, plus the round-the-clock care given to him in his private apartment from March 13 through his death on April 2 by a whole team of physicians (most of whom were not on the Vatican payroll), it's hard to conclude that routine efforts to preserve his life were neglected.

Further, the first person to have resisted more aggressive measures earlier in 2005 might have been John Paul II himself - and not because he wanted to die, but because he insisted upon living. Throughout his two hospitalizations, the pope repeatedly demanded to return to the Vatican in order to resume at least a minimal level of activity. He also insisted upon making public appearances, even when he couldn't speak. Most famously, he appeared at his window overlooking St. Peter's Square on Easter Sunday, March 27, struggling to deliver a blessing, but in the end remaining mute. The pope stayed at the window for 12 minutes and 15 seconds, and at two points pushed away aides who tried to wheel him back inside.

Dr. Corrado Manni, who treated John Paul II after the assassination attempt in 1981, expressed sympathy for anyone trying to persuade the pope to accept treatments that would further restrict his activity: "I understand the difficulties his aides must have in dealing with such a situation ? the Holy Father is difficult."

Second, it's hard to escape the impression that the controversy is less about a close medical examination of John Paul's treatment than broader political debates over euthanasia.

That hunch was bolstered by the fact that at the Wednesday press conference in Rome, Pavanelli was flanked by the widow of Piergiorgio Welby, an advanced muscular dystrophy patient who became a national cause célèbre in Italy in 2006 when his pleas to be removed from a respirator and allowed to die triggered anguished national debate. Some have compared the case to American controversies in 2005 over Terry Schiavo, though Welby remained conscious until the end.

Officially, the Catholic church took a strong position against Welby's decision to discontinue life-sustaining treatment. When a Rome parish planned a funeral Mass for Welby following his death in December 2006,

Cardinal Camillo Ruini, at the time the pope's vicar for the Rome diocese and president of the Italian bishops' conference, stepped in and refused permission. An outdoor secular ceremony was staged instead on Dec. 24, in a spot adjacent to the parish, with some in the crowd of several thousand chanting "shame, shame!" at the church. Welby's 91-year-old mother declared: "They continue to insult him after his death."

In that context, the suggestion that the church did not walk its own talk in the case of John Paul II carries obvious political significance - explaining, perhaps, both why *Micromega* has played up Pavanelli's piece, and why the Vatican has gone to such great lengths to refute it.

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On his blog for Thursday, Accattoli published what he described as "three polemical conclusions" about the debate set off by Pavanelli and *Micromega*. (For those who read Italian, the entry may be found here: www.luigiaccattoli.it/blog/?p=516 [1].) Accattoli wrote that he does so as someone who covered the pope's illness in first person.

First, Accatoli said, while a diagnosis at a distance may raise interesting questions and generate hypotheses, it cannot provide a basis for the certainty that Pavanelli apparently wants to claim - in particular, her assertion that John Paul II "must have" refused a feeding tube earlier in his illness, because there's no other explanation for why one wasn't used.

Second, Accattoli charges that Pavanelli simply didn't do her homework. Had she bothered consulting the periodic updates on the pope's condition released by the Vatican, he says, she would have found several references to his nutritional intake, all of which are consistent with a picture of slow degeneration matched by increasingly aggressive attempts to arrest the slide.

Third, Accattoli asserts that underlying the positions advanced by Pavanelli and *Micromega* is a caricature of Catholic moral teaching on end-of-life issues, which makes it sound as if any patient who isn't hooked up to every possible machine is somehow committing mortal sin. That, he suggested, fails to do justice to the church's careful moral reasoning in such cases.

All three points supply interesting grist for further discussion.

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Since I too covered these events on a first-hand basis, I'd like to add one further observation, which I hope is relatively non-polemical. In short, it's that the Vatican could have spared itself, and the rest of us, much of this spectacle had it been more forthcoming at the time with information about John Paul II's medical condition.

Accattoli faults Pavanelli for not referring to the statements released periodically about the pope's condition between Feb. 1 and March 30 by Joaquin Navarro-Valls, the pope's spokesperson, and rightly so. Nonetheless,

it's worth recalling that at the time, those statements were widely faulted on at least three grounds:

- The statements came not from a member of the pope's medical team, but from his spokesperson. Granted, Navarro-Valls has a medical degree, but he was not involved in John Paul's treatment. During past hospitalizations, medical bulletins about John Paul's condition had been signed by his doctors, which gave the world some assurance that what was being communicated was not just optimistic spin. In this case, physicians actually treating the pope were not made available to the press.
- The statements sometimes raised more questions than they answered, using reassuring and occasionally vague language that seemed more calculated to calm public fears than to communicate a realistic appraisal of where things stood. For example, on Feb. 24 the media was informed that John Paul II had undergone a tracheotomy the previous evening to relieve respiratory difficulties. Navarro-Valls told the media that the morning after his operation, John Paul II had eaten a small breakfast of coffee, yogurt, and 10 small cookies. Experts immediately cast doubt on the report, suggesting it was unlikely that a patient with a tracheal tube could actually swallow cookies. No follow-up information was ever presented, and that pattern tended to cast a degree of doubt on everything else the press was told.
- Statements were issued infrequently and unpredictably prior to the last 48 hours of the pope's life. Between March 10, two days prior to the pope's second return from the Gemelli Hospital, and March 30, not a single bulletin was released on the pope's condition, despite the fact that his public appearances had been severely limited, and that he obviously seemed to be in a weakened and distressed state. The apparent spirit of things was summed up back in early February, when Navarro-Valls announced to the press on a Friday that there would be no further information until the following Monday. Pressed by Alessio Vinci of CNN as to whether it was irresponsible to go silent for 48 hours, Navarro-Valls responded, "I can't feed your television station 24 hours a day."

While none of this excuses speculative reconstructions intended to score political points, if that is indeed what Pavanelli has done, it does suggest that the Vatican itself is partly to blame for leaving behind an inadequate public record about the course of the pope's illness, one that even fair-minded people may hesitate to trust in all its particulars.

In order to cut off the oxygen supply, so to speak, for speculation in the future, the Vatican might consider something like the following protocol when a pope is hospitalized, or sick enough that he has to curtail his public schedule for an extended period:

- Release a medical bulletin each day with as much detail as possible, signed by at least one of the physicians directly involved in the pope's treatment;
- Make at least one of the doctors on the pope's medical team available to a pool of reporters for a reasonable period each day after the bulletin is released, in order to field follow-up questions. Ensure that this pool is not hand-picked to avoid tough questions;
- In a tasteful manner and with full respect for the pope's privacy, release still images and video periodically documenting the pope's condition, so that people can match statements from the doctors with direct impressions of the pope himself.

Such a protocol would, I suspect, go a long way towards preventing the kind of discussion this week has witnessed.

At a practical level, taking these steps amounts to a realistic recognition that the pope is in the stratosphere of major global personalities, and public curiosity will be fed either by solid information or irresponsible speculation. Beyond that, one could make a very good argument that the Vatican actually has a moral responsibility to keep the world informed, especially more than a billion Catholics who have a heart-felt, and perfectly legitimate, interest in the pope's physical condition.

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From a PR point of view, the timing of the *Micromega* essay could not have been better, coming hard on the heels of a Sept. 14 response from the Congregation for the Doctrine of the Faith to two questions from the bishops of the United States about patients in a persistent vegetative state. In essence, the congregation responded that providing food and water for such patients, even through a tube, is ordinary care and thus morally obligatory.

That position confirmed the stance taken by Pope John Paul II in a March 2004 address to a Rome conference on the persistent vegetative state, in which the pope declared that providing food and water under such circumstances is "not a medical act" but a basic requirement of human dignity.

The CDF response, which was approved by Pope Benedict XVI, to some extent closes a debate that had previously remained open about whether food and water could be withdrawn from patients in a persistent vegetative state when there is no realistic hope of recovery. Some theologians, and even a number of bishops and bishops' conferences, had previously held that under such circumstances, artificially providing food and water could be seen as an "extraordinary" procedure that is not morally required.

I've prepared an analysis of the debate surrounding the persistent vegetative state which will appear in the Oct. 5 *National Catholic Reporter*, which will be posted at NCRonline.org [2] on Tuesday, Oct. 2. For now, one point seems especially important to underscore.

Experts of all stripes caution that the CDF response should not be over-interpreted. It applies exclusively to patients in a persistent vegetative state, who represent only a small fraction of cases in which feeding tubes might be considered. More commonly, a feeding tube might be used in the treatment of patients struggling with progressive illnesses such as cancer, Lou Gehrig's disease, Parkinson's, or Alzheimer's. In many such cases, a terminal stage is reached in which treatment no longer prolongs life or alleviates suffering, and nothing in the new Vatican ruling compels physicians or families to continue artificial nutrition and hydration under those circumstances.

What makes the persistent vegetative state different is that patients are otherwise stable and able to keep living almost indefinitely, albeit in a severely disabled state, as long as they receive food and water. In that situation, the Vatican has held, to deny food and water would be a form of euthanasia.

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