Q Should patients for whom all standard treatments have failed be autom enrolled in a hospice program?

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CASE TWENTY-THREE: A FEVERED HAND ON A COOLING BROW – THE NURSE'S ROLE IN AID-IN-DYING

Discussions of aid-in-dying (AID) have been seen increasingly in public venues since Oregon passed its Death with Dignity Act in 1997. This law "allows terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose" (Death with Dignity Act n.d.). The legitimacy of physician-

prescribing activities covered by this Act has been the subject of much debate. In particular, opponents have contested that prescribing lethal medications for the purpose of suicide violates the Controlled Substances Act (CSA 1994/1996), which authorizes the use of such drugs only for "legitimate medical purposes" (ibid.). In 2001 then-Attorney General, John Ashcroft, announced that assisted suicide did not count as a legitimate medical purpose and threatened to revoke the licenses to prescribe controlled substances of physicians who were determined to have aided their patients' suicides (Ashcroft 2001). In 2002, the US District Court for the District of Oregon found that Attorney General Ashcroft had exceeded the authority of the CSA, and issued an injunction against revoking the licenses of participating physicians. The legitimacy of physicians' ability to prescribe drugs to assist in suicide was upheld, in 2004, by the US Court of Appeals for the Ninth District.

Although the legal and public discussions of aid-in-dying have been couched almost exclusively in terms of its moral implications for physicians, this narrow focus overlooks the role of nursing in the dying process (De Beer et al. 2004). Nurses are often asked: "How long do I have?" They are also questioned regarding which drugs could cause death, how to insure death, what diseases portend – particularly in terms of pain and suffering – and how to discuss AID with families, friends, etc. (Hall 1996). Nurses also devote their professional expertise to "listening to and interpreting the patient's request, reporting and explaining the request to other nurses and physicians, and lending support to the patient and the patient's family" (De Beer et al. 2004: 497). Furthermore, a survey of physicians found that those who agreed to patients' requests for euthanasia (although euthanasia remains illegal almost everywhere) asked nurses to administer the lethal agent in approximately one-third of the cases (Meier et al. 1996). As the public discussion of the moral propriety of AID continues, nurses must determine whether participating, as professionals, in AID is ethical (Davis et al. 1995; Kopala and Kennedy 1998; De Beer et al. 2004).

The International Council of Nurses (ICN) acknowledges that assisted suicide "is a real problem in Switzerland and also in other countries such as the US" (WHO n.d.: 5). But although the Council recognizes the presence of ethical issues surrounding euthanasia, it has no formal policy on aid-in-dying (ICN 2006). In the Netherlands, the only country in which euthanasia is legal, the National Nurses Association has established guidelines for the role of nurses in this process: "One of the guidelines states that the involvement of nurses in decision-making is desirable because of the nurses' specific skill and everyday involvement in patient care. The administration of the euthanaticum, however, is an action that is reserved for physicians" (De Beer et al. 2004: 495). Great Britain's Royal College of Nursing remains officially opposed, though 60 percent of their membership favored aid-in-dying (Joffe 2006).

The American Nurses' Association gives four moral objections to assisted suicide by nurses:

(1) The profession of nursing is built on the Hippocratic tradition 'do no harm' and an ethic of moral opposition to killing another human being;

(2) Nursing has a social contract with society that is based on trust and therefore patients must be able to trust that nurses will not actively take human life;
(3) In order to preserve the moral mandates of the profession and the integrity of the individual nurse, nurses are not obligated to comply with all patient and family requests; and
(4) There is high potential for abuse . . . particularly with vulnerable patients such as the elderly, poor, and disabled. (ANA 1996: 84)

Although these objections suggest that professional integrity requires practitioners to stay clear of assisted death, they bear closer scrutiny before their prohibition of AID can be definitively ascertained.

Do no harm. The implications of the claim that nurses should do no harm are not straightforward. Nurses regularly harm patients (e.g., administering toxic chemotherapy that damages normal cells; causing pain during rehabilitative efforts), but the harms are typically thought to be morally justified because they contribute to a projected greater benefit – saving life, minimizing disease or disability, restoring health, or preventing even greater pain and suffering.

Most persons believe (albeit almost always unreflectively) that death is the worst possible outcome one can suffer. If this belief is correct, then death always harms patients. But this belief is not obviously true. The common-sense belief that death may not be a (or the greatest) harm is acknowledged when persons speak of "a fate worse than death." If "harm" is "thwarting, defeating, or setting back the [person's] interests" (Beauchamp and Childress 1994: 193), patients (particularly those with terminal illnesses in which death is imminent) can have legitimate interests in avoiding uncompensated pain and suffering (i.e., pain and suffering which achieve no positive physical or psychological outcomes). If the only way to end one's misery is through death, then death may not be harmful. If death is not always harmful, it cannot justify a universal ban on AID as intrinsically maleficent.

In keeping with these suspicions, support for AID in the US is roughly 65 percent (Emmanuel 2002); 76 percent in Australia (Gargett n.d.); and 80 percent in the UK (Joffe 2006). Public surveys typically show that persons are more afraid of being kept alive in misery than of dying (Blendon et al. 1992; Harris et al. 2006), and that they believe that AID can sometimes be in their best interests.

Trust. Nursing exists as a profession to promote patients' interests. At the least, patients should be able to trust nurses not to hurt them; certainly (the argument goes) patients should be able to trust nurses not to kill them. Many patients who interact with nurses are vulnerable: in pain, fearful, worried, and – as a result of these states – are not at the top of their cognitive game; being able to trust their nurses is key to achieving their interests, health and otherwise.

Whether patients even think about the possibility of their nurses killing them is unknown. One might quite reasonably assume that, were patients to consider

this possibility, they would hope their lives did not lie in their nurses' hands. But if one really wants to know the public's feelings about AID by nurses, the public should be queried about this issue. Surveys show that legalizing AID would do little, if anything, to undermine public trust in physicians who perform it. Moreover, repeated surveys demonstrate that support for AID continues to rise. In 1996, 41.6 percent of patients and 32.8 percent of the general public thought patient–physician conversations that explicitly addressed AID would increase – not decrease – trust in the physician (Emmanuel et al. 1996: 1808). By 2004 public support for AID had risen to 82 percent in the UK among the general population, and to 80 percent among persons with disabilities (Branthwaite 2005). Whether this trust would extend to nurses is uncertain, but, again, one should assume neither that the public would trust nurses who engage in AID nor that AID would destroy public trust in the nursing profession. Presumably, most people assume that nurses' duties include preventing premature, unwanted death; promoting, preserving, and restoring health; and minimizing pain and suffering. But patients for whom all these options have been foreclosed might support (even hope for) AID by nurses.

Professional integrity. Integrity is "having a reasonably coherent and relatively stable set of cherished values and principles" (Benjamin 1990: 51), and expressing those values and principles in words and actions. One clearly articulated nursing value is "an ethic of moral opposition to killing another human being" and, more particularly, that "patients must be able to trust that nurses will not actively take human life." As clear and unambiguous as these statements are, we should remember that "reasonably coherent" or "relatively stable" values can – and do – evolve. The Hippocratic Oath forbade abortion and surgery, yet both are now important for patient well-being and are regularly provided by healthcare professionals as means to their patients' best interests.

What professional practice requires will change as social and professional environments change. The Hippocratic tradition began in an era where life was much more fragile. Ancient cures were rare and ancient Greek physicians who failed to cure serious maladies often saw their patients die. Conversely, when contemporary practitioners fail to cure, their patients may survive in a state worse than death. The ancient professional who saved a life was much less likely to harm the patient than her twentieth-century counterpart (MacIntyre 1975).

In addition, saving life is only one of several cherished professional values. Nurses are also committed to relieving pain and suffering. To acknowledge other values does not denigrate life nor deny that saving life – under most circumstances – is crucial to professional integrity. Nonetheless, acknowledging a plurality of values raises the possibility of moral conflict among professional commitments. For some patients, life cannot be saved, health cannot be promoted and disease cannot be prevented or cured. But relief of pain and suffering is still within the nurse's power. When patients elect early death and the only professional value that still can be promoted is relief of pain or suffering, AID is compatible with professional integrity (White 1999). Of course, many nurses

(like many physicians) might personally believe that nurses should have nothing to do with actively participating in ending a patient's life. This possibility raises the question of whether, given the professional commitment to relief of pain and suffering, they are morally obligated to aid patients in dying if those patients are competent and request such assistance. Presumably an "opt out" clause – such as those permitting physicians to opt out of performing abortions – would permit morally opposed nurses from participation in aid-in-dying.

Abuse. Critics worry that AID might be "overused" in many Western societies, in those who are undervalued (i.e., the elderly, minorities, the poor, and persons with impairments) and whose vulnerability makes them less able to protect their own interests. Such groups may be at risk if AID is permitted because they lack resources – cognitive, emotional, physical, or financial – to protect their own interests, and society is not motivated to protect these interests for them. Such worries are legitimate. Elderly and black populations, although overall in favor of euthanasia, were less supportive than younger, white populations (Hall et al. 2005). The question of abuse per se arises because of the worry that nurses (or other persons) might erroneously assume the lives of vulnerable patients are not worth living and, based on these inaccurate assumptions, provide unrequested and unwanted AID to these patients.

The data on the extent – or even the existence – of such vulnerability is contested (Death with Dignity Act n.d.; Branthwaite 2005; Quill 2007; Thorns 2007). But even if such risks are real, they can be managed procedurally or professionally. Procedural management demands criteria for providing AID. Strictly limiting AID to patients who meet carefully specified criteria should protect the vulnerable. The law is no stranger to statutes enacted to protect the vulnerable and we have no reason to think statutes could not be constructed to protect against unwanted AID. Indeed, the criteria embraced by Oregon and the data collected following legalization there of physician AID suggest that AID is used infrequently and, typically, by the least vulnerable populations (Death with Dignity Act n.d.).

Given the professional commitment to saving life, the risk of abuse is likely to be small. Persons are at greatest risk for abuse or neglect if they are poorly understood and undervalued. Nurses are unlikely to assist in early, unwanted death because, in virtue of their intimate, ongoing interactions with patients, nurses are more likely to appreciate a patient's own values and be governed by those interests. This point may be put more pragmatically: if AID is legalized, vulnerable populations are more likely to be protected if nurses are involved. So even if nursing continues officially to oppose AID by nurses, patients may be better protected when nurses are involved in these discussions.

However, nurses who practice in institutions are less likely to know their patients' social and personal backgrounds than are their physicians (although in this age of specialization and referral, many physicians may know little about their patients beyond their medical particulars). But patients may have a greater tendency to trust the role of the physician than that of the nurse. Still:

> [F]or the nurse, intensive care may actually mean spending an intensive amount of time with the patient and the family. They may see and hear first-hand of the patient's pain and suffering as the patients are being turned, bathed, medicated, and generally taken care of. It is likely that the nurse may be the first one to appreciate the patient's level of continuous discomfort, and also may be first to recognize an endless cycle of pain and suffering coupled with a dim hope for any meaningful recovery. As a result, nurses, often rightly so, feel that they have a greater and earlier insight into a patient's wishes concerning these difficult issues.
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> Therefore, at one time or another in their nursing careers, one out of five of those nurses who responded to the [Asch 1996] survey questionnaire were put in a position where a patient desperate for relief was paired with a physician unable to recognize the situation, and the nurse took matters into her own hands. But saying that one of five nurses has participated in hastening the death of a patient is not saying that the practice happens 20% of the time. . . . In fact, the survey reported that 65% of those nurses who had "hastened death" did so three times or less, and about 93% of those were based on repeated requests by the patient or family. (Miller 1996)

A profession that is responsible to the community must consider community opinions when formulating practice guidelines. Throughout the world, the public perspective is changing to support AID. In recognition of these evolving attitudes, nursing must revisit its position as a means of insuring its policies and practices truly are designed to promote the welfare of patients.

In addition, the perspective of the wider professional community is evolving. The National Association of Social Workers (2000) supports all self-determined choices, including AID. Social workers polled in South Carolina echoed this approval (Manetta and Wells 2001). While the American Medical Association (AMA) remains opposed to AID (AMA 1992, 1996), many physicians disagree (O'Reilly 2005; Lee et al. 1996; Preston 1994; Reisner and Damato 1995; Bachman et al. 1996; and Emanuel et al. 1996). And, as the American Medical Student Association favors physician-assisted suicide as a last resort (n.d.), the AMA's official position may change as students become practicing professionals. But these other professionals have distinctly different relationships with patients than do nurses. The 24/7 intimacy between nurses and patients often lends itself to brutally honest discussions of fears, hopes, anxieties, and so forth. Should AID endanger these conversations, it would likely remove a great source of comfort to patients and a great source of information to nurses that is requisite to good patient care.

Ultimately, however, death is irreversible. An unwanted or premature death deprives a person of her entire future, the particulars of which are always to some extent unknown, and the value of which may be unknown or may be revised. With aid-in-dying, mistakes are permanent.

In any case, were nurses to become actively involved in aid-in-dying, their designation as "angels of mercy" would certainly take on expanded meaning.

Should nurses be morally permitted to aid their patients in dying?