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Withholding and Withdrawing Life Support: Moral Dilemmas, Moral Distress, and Moral Residue

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Abstract

This paper argues for the following points. (1) Despite the recent public controversy surrounding the Terri Schiavo case, withholding and withdrawal of life support rarely presents any moral dilemmas. (2) Given this, we ought to turn our attention to how end of life care is done rather than whether it ought to be done. (3) A ‘caring perspective’ is an essential ingredient in end of life care. Unfortunately, as nurses undergo their ‘professionalisation process’, they often lose this caring perspective. Hence, ways must be found to avoid this loss. (4) Assuming success in this enterprise, it is necessary that nurses be integrally engaged in both end of life care and decision making.

Keywords: Terri Schiavo; End of Life Care; Ethics Of Justice; Ethics Of Care; Moral Dilemma; Moral Distress; Moral Residue

**Withholding and Withdrawing Life Support:
Moral Dilemmas, Moral Distress, and Moral Residue**

It has now been over thirty years since Karen Anne Quinlan collapsed at a party after swallowing what turned out to be a deadly mixture of alcohol and Valium. Doctors were able to save her life, but she suffered brain damage and entered into a permanent vegetative state (PVS). Quinlan's parents wanted their daughter removed from her respirator, allowing her to die. The hospital's officials disagreed, however, and the matter was turned over to the courts to resolve. Eventually, the Supreme Court of New Jersey did so by reversing a decision of a lower court and gave Joseph Quinlan, Karen Anne's father, status as legal guardian. His request to have her respirator removed was approved and, despite an agonizingly long ten years when she breathed on her own, Karen Anne Quinlan finally died in 1985.

This case in particular gave urgency to the need to develop the field of bioethics as a practical guide to deal with a variety of issues in health care. Most obviously, this case led in part to a radical change in how we define and conceptualize death and end-of-life care: the case also began a process that eventually brought us living wills and advanced directives that gave patients (and their proxies) greater control over the time and means of their death. Indeed, at present, withholding and withdrawing life support – passive euthanasia, in other words – is generally thought to be morally acceptable (under certain restraints, of course), and in fact these practices have become absolutely common in North American hospitals. For example, the number of deaths in neonatal intensive therapy units due to the withdrawal of therapy has increased nearly fivefold in the last thirty years from 14% to 66% (Shooter and Watson, 2000). 65,000 chronic dialysis patients die each year in the U.S. due to withdrawal from dialysis (Moss, 2001) and in fact withdrawal from dialysis has become the second leading cause of death among dialysis

patients in the US and Canada (after cardiac disease) (Oreopoulos, 1995), accounting for 20% of dialysis patient deaths (Moss, 2001).

The recent Terri Schiavo case would seem to suggest, however, that end of life care and withholding or withdrawal of life saving treatment is far from a dead issue in the United States at least. Like Karen Anne Quinlan, Ms. Schiavo was in a PVS and had her life support withdrawn only after a long and protracted legal and political battle.

Appearances can be deceiving, however. The evidence cited above suggests that the Schiavo case was merely the exception that proves the general rule. This would explain why 82% of Americans said they disagreed with President Bush and the American Congress for attempting to intervene in the case to force the continuation of life support (CBS poll, cited in Rosen, 2006). In the first section of this paper, I will argue that these Americans are right and that withholding and withdrawing life support in a wide array of circumstances and in a vast number of cases are both legally and morally correct. In other words, we might say that in 'ordinary' circumstances passive euthanasia presents few if any moral *dilemmas*. If this is accepted, then it is permissible, indeed it is advisable, to turn our attention away from thinking of the moral dilemmas that end of life care allegedly presents to moral issues having to do with *how* end of life care ought to be carried out in practice. The end of this paper focuses on one facet of this care: how to deal, and hopefully to avoid, the moral *distress* and moral *residue* that faces nurses whose work involves end of life care. More specifically, this paper argues for three main points: (1) that the ethics of care offers valuable, indeed necessary insight into proper end of life care; (2) that a caring perspective is often compromised or lost as nurses become professionalized in today's hospital setting, and that we therefore need to find ways to avoid this

loss; and (3) that it is vital that nurses and their caring perspective be part of a shared decision-making process when decisions are made about how to carry out end of life care.

I: Moral dilemmas: Distinguishing between the real and the apparent

A moral dilemma can be defined in a host of different ways. One way to think of it is when you are faced with a situation when you appear obligated to do two or more conflicting courses of action, and it is not clear which one you ought to pursue. Alternatively, we may think of a moral dilemma arising when there is some reason to think that a particular course of action is the right thing to do, but other reasons to suggest it is wrong, and you are unable to decide what to do as a result (Webster and Baylis, 2000).

Did the Terri Schiavo case present us with a dilemma of this sort? That is, specifically, are there good reasons to think that withdrawing life support from Terri Schiavo was both the morally correct and morally wrong decision? Or are there reasons to believe that we are obligated to take two conflicting courses of action in this case? I argue in this section that there are not; moreover, the case presented no legal dilemmas or ambiguities either. Rather, the Schiavo case presented us with moral and legal issues that had been resolved at least a decade and a half earlier in 1990 when a decision was reached in the Nancy Cruzan case, which is discussed below. The ‘problems’ with the Schiavo case, then, have rather to do with issues surrounding how to deal with family disputes, and the fact that all of us will eventually die, no matter how much health care improves. (Needless to say, the case obviously also brought partisan politics into play, but that is not the focus of this paper.)

In the United States, there have been several cases that resulted in landmark legal decisions regarding end of life care. First, in the 1950’s, important rulings were made regarding the right of Jehovah Witnesses to refuse blood transfusions on the basis of their religious beliefs.

Next, there was the Quinlan case, which established two things. First, it confirmed that the legally based right of privacy grants permission to a patient to refuse medical treatment. Chief Justice Hughes of the New Jersey Supreme Court made this clear in stating that “no external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life” (Supreme Court of New Jersey, 1976; in Munson, 1992, 173). Second, the court made it clear that this privacy right to refuse treatment could be exercised by a parent or guardian when the patient was not able to speak for herself. Indeed, the court stated that the privacy based right to refuse medical treatment “should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice” (Supreme Court of New Jersey; in Munson, 1992, 174). As a result, the court held that

Upon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibility of Karen’s ever emerging from her present comatose position to a competent, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult the hospital “Ethics Committee” or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen’s ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefore on the part of any participant, whether guardian, physician, hospital or others (Supreme Court of New Jersey; in Munson, 1992, 174).

The Paul Brophy case both confirmed and extended the ruling made in the Quinlan case. Brophy suffered an aneurysm on March 22, 1983, resulting in PVS. Because he was unable to chew or swallow, Brophy had a gastrostomy tube (G-tube) inserted through which he was hydrated and fed. However, after weeks of therapy with no improvement, Mrs. Brophy and her counsel requested that the G-tube be removed, and Mr. Brophy allowed dying. Brophy's physician and the hospital refused to withdraw the G-tube and the matter went to court. Eventually, the Supreme Judicial Court of Massachusetts authorized Mr. Brophy's guardian to transfer him "to the care of other physicians who [would] honor Brophy's wishes (Cited in Perry, 2006, 567). Their ruling was based on evidence that Mr. Brophy had expressed prior to his affliction stating that he would not want to be kept alive on life support. In such a case, the court said that:

[I]t does not advance the interest of the State or the ward to treat the ward as a person of lesser status or dignity than others. To protect the incompetent person within its power, the State must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons.' ... A significant aspect of this right of privacy is the right to be free of nonconsensual invasion of one's bodily integrity (Cited in Perry, 2006, 567).

The Nancy Cruzan case solidified the Court's opinion to an even greater extent and formed clear guidance on what States were allowed to do to protect both the privacy interests of incompetent individuals and the State's interest in protecting vulnerable citizens, including those in PVS. The judgment reached in Cruzan continues to be the basis upon which American law now decides the legitimacy of the withdrawal of life from individuals suffering from maladies such as PVS. In 1983, Nancy Cruzan, then 30 years old, was in a serious car accident. By the

time rescue workers arrived at the scene, her brain had been deprived of oxygen for 12-14 minutes, causing her to enter into PVS. When it became clear that Ms. Cruzan would not regain her mental faculties, her parents requested the withdrawal of the hydration and feeding mechanisms being used to keep her alive. As in the above cases, the hospital refused, and the matter went to court, eventually being resolved at the Supreme Court of Missouri (see Perry, 2006, 568-570). The Cruzan case turned on a single question. Granting that a competent person has the right to refuse medical treatment, how are we to determine what a person in PVS would choose regarding end of life treatment, given that she is of course unable to communicate her wishes, and has not indicated her wishes in an advance directive? Obviously, a surrogate must make the choice, but on what basis are they to choose? Cruzan answered this by claiming two things: (1) that States were not acting unconstitutionally by requiring “clear and convincing” evidence of the incompetent’s wishes; but (2) if such “clear and convincing” evidence were presented, then the withdrawal of life-support, including the withdrawal of tubes providing nutrition and hydration, is lawful (Mueller, 2005).

According to law professor Edward Larson, “Terri Schiavo’s case cannot be materially distinguished from Nancy Cruzan’s case. Reaching a different result in the Schiavo case would require that *Cruzan* be ignored, overruled, or distinguished to the point that its meaning would be reversed” (Larson, 2005, 405-406). Like Nancy Cruzan, Terri Schiavo was in a PVS, this time as a result of a cardiac arrest, possibly brought on by a potassium deficiency in her blood as a result of bulimia (Perry, 2006, 574-583). A feeding tube was inserted shortly after she was admitted to hospital in 1990, and until the mid-1990’s Terri was given extensive and aggressive therapy – including physical, occupational, speech, and recreational therapy -- all too absolutely no effect: she continued to be unresponsive to neurological and swallowing tests, and revealed

no functional abilities or cognitive movements (Perry, 2006, 572-573). Indeed, no one has ever recovered from being in a PVS for as long as she was (Larson, 2005, 406). Despite all the appeals and attempted legislative interventions, the Schiavo case was relatively straightforward *legally*. When her husband, Michael, filed a “Petition for Authorization to Discontinue Artificial Life Support” in May, 1998 (eight years after she entered a PVS) he had to establish two facts: (1) Would Terri Schiavo ever regain consciousness and be able to make decisions for herself, and (2) Would Terri choose life prolonging treatment in her circumstances were she competent (Perry, 2006, 575-578)? With respect to the first question, according to the best medical advice available, Terri would never regain consciousness: indeed Judge Greer, who presided over the case, called the evidence “overwhelming” (Cited in Perry, 2006, 577). Regarding the second question, the courts consistently ruled that the evidence was also clear. Proxy decision makers here are required to use “substituted judgment.” This requires that the proxy decide what the incompetent patient would want, not on what they, the proxy, would want. And, as the earlier Cruzan case stipulated, the court can (and did) require “clear and convincing” evidence of the patient’s wishes. This was provided primarily by two witnesses, Michael Schiavo’s brother, Scott, and Terri’s sister-in-law, Joan Schiavo, who both recounted statements from Terri Schiavo that she would not want to be kept alive by artificial means of life support and be a burden to others (Perry, 2006, 578-579). Hence, whatever caused the political machinations and media spotlight in this case (as opposed to literally thousands of withdrawal and/or withholding of life support that occur regularly in the US that transpire unacknowledged and undisputed) it had nothing to do with the legality of the process to withdraw, since it was crystal clear that the process was scrupulously clean.

What of the ethics of cases like this, as opposed to the law? Is there reason to believe that there is a great divide between what American law allows and what is morally proper? Is there a moral dilemma here: that is, do our moral principles obligate us to take two conflicting courses of action thus making morally thing to do unclear? Or are there reasons to suggest that withholding life support, including feeding and hydration tubes, is both morally right and wrong? Despite appearances that there is a moral dilemma in cases such as Schiavo, I suggest that there actually isn't. The withdrawal of life support for people in PVS, when there is clear and convincing evidence that is what the patient in PVS would have wanted, is absolutely consistent with our most entrenched ethical principles, such as autonomy, and when properly analyzed, is not inconsistent with any moral principle, even the principles of non-maleficence and the sanctity of life. The appearance of a dilemma, then, is simply the product of muddled thinking rather than a tragic truth of the matter.

Consider how the principle of non-maleficence might apply in cases such as these. There are actually two ways to consider harm here: first is the harm of non-existence in the sense that one does not get to experience the goods of living; and second is the pain from which one allegedly suffers when artificial feeding and hydration is stopped so the patient 'starves to death' or 'dies from thirst'. With respect to the first sort of harm, life's benefits are clearly the result of what one does with one's life. Hence, if one can't 'do' anything, nor have any cognitive awareness at all (as is true, unfortunately, of people in PVS) then there is no benefit which one is missing vis-à-vis one's life in PVS. Note that this is *not* an attack on the value of the lives of the disabled. To equate the life of someone with Down's syndrome, spina bifida, or blindness to someone in a PVS is simply not to understand what PVS is. PVS is not a disability; it is loss of

all but the most rudimentary brain functions, and is hence much closer, conceptually, to brain death than it is to disability.

Regarding the second kind of harm, it is simply false that persons like Terri Schiavo experience pain when their nutrition and hydration is withdrawn, according to studies that have been conducted in this area (Hook & Mueller, 2005, 1457, also notes 36-38, 1460). Indeed, Hook and Mueller note that patients who have artificial nutrition and hydration withdrawn “typically experience comfortable deaths,” in part because caregivers in such circumstances realize that “a central principle of palliative and hospice care is that withholding or withdrawing AFN (or any LST) does not mean that good oral care, bathing, pain control, and other comfort measures will be discontinued as well. Rather, excellent palliative care requires scrupulous attention to these issues” (Hook & Mueller, 2005, 1457).

What, finally, of sanctity of life considerations? As Perry, Churchill, and Kirshner have pointed out ... unless one adopts the position that sheer biological existence is what is sacred about human life, considerations of sanctity inevitably involve judgments of quality. More important, this dichotomous rendering of the issues begs the essential question of whose notion of “sanctity” and “quality” counts. By taking the autonomy and liberty interests of patients as the central question, the courts preserved the prerogative of individuals to decide according to their own values, even after they have lost the ability to speak for themselves (2005, 747).

That is to say, that as the courts correctly saw here, the moral principle of autonomy is quite consistent with sanctity of life (and non-maleficence) since we are considering the issue from the patient’s perspective (as difficult as this may be to determine this in some cases).

The morality of the situation, then, seems to be just as clear as the legality of it. There is simply no moral dilemma here. It is important to note, however, that this does not mean that

cases such as these are easy for the people involved. Hence, we can understand why Judge Greer said that the Schiavo case “was probably the most difficult case I have ever presided over” (cited in Perry, 2006, 580). But this has far more to do with the fact that we are mortal beings and that while medical science and practice have come a long way in the past number of years, death is still the end result for all of this. This is sad, in some cases it is even tragic, but it is not in itself, nor necessarily gives rise to, a moral dilemma.

There is irony in this attitude towards not accepting death because until very recently medicine could do very little actually to save lives. We need to keep reminding ourselves that the germ theory of medicine is still less than 200 years old, and that the humoral theory of Hippocrates, Galen, and others, which preceded the germ theory, was almost entirely useless in properly diagnosing anyone, let alone curing them. Moreover, even in the early stages of the germ theory, before various types of antibiotics and surgeries were possible, death was an omnipresent possibility with almost any kind of illness. Paradoxically, however, it was this ability of medicine to prolong life that caught our moral intuitions, theories, and principles unaware and unprepared for the difficulties that contemporary medicine, with its amazing array of successes, can present particularly the withdrawal and/or withholding of artificial life support. But our moral intuitions, principles, and indeed our actual practices have caught up in many ways over the past thirty years, although there is always the possibility of cases like the Schiavo one that seem to catch us broadside.

II: The ethics of justice and the ethics of care

The eighteenth century German philosopher, Immanuel Kant, has been the most influential regarding the necessity of respecting autonomy. He maintained that doing so was the most important way of following the Christian ‘golden rule’ to ‘do unto others as you would

have them do onto you.' Humans, Kant argued, are special sorts of creatures because our thoughts and actions are not simply the product of our biology or our upbringing. That is, we are not entirely determined beings; rather, we have the ability to make genuinely free choices and decide how we want to live. Hence, in our treatment of others, we must respect their capacity for autonomous choice. A much different approach to ethics was developed in early nineteenth century England by Jeremy Bentham and John Stuart Mill. They suggested that the morality of an action should be determined by the consequences of that action; in particular, whether the action produced as much pleasure or happiness as possible.

The American bioethicists, Tom Beauchamp and James Childress, have been particularly influential in applying such theoretical normative models to the field of biomedical ethics. In their book, *Principles of Biomedical Ethics*, first published in 1979 and now in its fifth edition (2001), they specified four ethical principles – autonomy, nonmaleficence, beneficence, and justice – which they felt had to be taken account of in health care decisions. For example, principlism, as their approach came to be known, would suggest, and under the Kantian inspired principle of autonomy, that to treat a competent adult paternalistically is to treat her as a mere thing rather than a person with the ability to choose the way she wants to live, or die. Therefore, so long as a patient is fully informed and competent, if she chooses to forgo dialysis, that wish needs to be respected.

Similarly, we can see the principles of beneficence and nonmaleficence as emanating from Utilitarian concerns given that beneficence obligates us to help patients (by, e.g., restoring them to health thereby making them happier) and not to harm them, as the principle of non-maleficence requires. We can easily see the applicability of these principles to the issue of life support and its cessation. If, e.g., we have a case where initiating dialysis would not help the

patient and indeed does her harm by subjecting her to painful procedures, then we would be morally obligated not to initiate or to withdraw treatment (subject, of course, to adhering to other principles such as autonomy). Difficulties can arise here because we can never be completely certain of our diagnosis and prognosis and people's evaluation of the worth of their lives (and e.g., how much pain they can tolerate and/or find acceptable differs from individual to individual). But this shows how complex ethical decisions in health care can be and how we have to try to balance the obligations of one principle against the obligations of others.

The principle of justice typically refers to treating equals equally. This can often work itself out by reference to how many resources are spent on some patients rather than others. If we have a limited amount of money to spend on dialysis (since we need money for a whole host of other health care needs such as hip replacement, cancer treatment, and so on, not to mention other things government has to spend money on like education and welfare programs), then we want to ensure that we are spending our money wisely. Is it morally acceptable to spend a great deal of money on a dialysis patient when that treatment is futile? This is perhaps the principle we are most uncomfortable discussing with any sort of medical treatment since it looks like we are putting a price on human life (which of course in some ways we are). Hence on the micro level, at any rate, clinicians focus, correctly, on what is best for the individual patient and what treatments are medically indicated (and which ones are not) rather than focus directly on matters of justice, particularly as perceived on a macro level. Having said this, however, it needs to be stated clearly that macro level discussions of justice are just as important in health care as elsewhere and we have to ensure that our health care monies are spent fairly and efficiently.¹

¹ What counts as a "fair" use of health care dollars depends of course both on one's conception of justice and whether one's health care system is public or private.

The influence of this type of approach to health care ethics has been tremendous, perhaps especially in the codes of ethics put forward by various health care professions. As just one example, consider the Canadian Nursing Association's *Code of Ethics for Registered Nurses*, which specifies principles such as "Health and Well Being," "Choice," "Dignity," and "Justice," which can clearly trace their heritage back to the principlism first enunciated by Beauchamp and Childress. Another example, which is directly related to the topic of this paper, is the set of recommendations put forward by the Renal Physicians Association and the American Society of Nephrology Working Group, chaired by Dr. Alvin Moss. Using these sorts of principles, along with a wealth of background experience and wide consultation, they maintained that withdrawing or withholding dialysis for patients with acute renal failure or end-stage renal disease is appropriate in the following circumstances:

- Fully informed patients with decision-making capacity who voluntarily refuse dialysis or request that dialysis be discontinued.
- Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis in an oral or written advance directive.
- Patients who no longer possess decision-making capacity and whose properly appointed legal agents refuse dialysis or request that it be discontinued.
- Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment (Moss, 2001, 410,412).

Clearly, there is much to be said in favor of this set of recommendations. It displays an acute awareness of and sensitivity to the importance of autonomy, expressed in the first three points, and the principles of beneficence, non-maleficence, and justice, all of which are

incorporated into the final point. But is this picture complete, or is it missing something that might be observable from a different perspective? In her groundbreaking work, *In a Different Voice* (1982), Carol Gilligan argued that there is a gender difference in approaches to moral thinking. According to her, while boys tend to develop ethically by moving toward an increasingly abstract level of theorizing about universal principles (such as we see in the principle of utility, Kant's categorical imperative, and the principlism of Beauchamp and Childress), girls tend to place more emphasis on the *context* within which ethical decisions are made and the *relationships* we have with the people who are affected by our decisions. Gilligan called the former of these perspectives the ethics of justice and the latter the ethics of care. Nel Noddings (1984) especially made the ethics of care central to nursing ethics emphasizing that women in general and nurses in particular have always been closely associated with care. Unlike Gilligan, who argued that the ethics of care was just as legitimate an approach to morality as the ethics of justice, Noddings asserted that the ethics of care was superior to an ethics of justice and was sufficient in itself to operate as a complete system of ethics. Although I happen to think, along with Helga Kuhse (1997) and others, that Noddings is wrong on this point, we needn't decide this issue for the purposes of this paper. We can simply assume the much weaker claim made by Gilligan that an ethics of care provides one essential ingredient in a fully developed ethical view. Armed with this we can demonstrate some of the weaknesses of a typical bioethical approach which inadequately accounts for the importance of care.

Interesting in this regard is a recent study by Dickenson (2000) that shows a number of areas in health care practice where the ethical beliefs of medical practitioners (physicians and nurses) differed substantially from both bioethicists and the viewpoints expressed by the professional bodies of health care practitioners. For example, Dickenson's study showed that

bioethicists typically think that the distinction between ordinary treatment and extraordinary treatment is inherently muddled because what constitutes extraordinary treatment may soon become ordinary. Most secular bioethicists have tended as well to take a dim view of the doctrine of the double effect as disingenuous. This is the doctrine that maintains that, e.g., prescribing ‘excessive’ doses of pain medication is morally legitimate, even if it results in a shortening of the life of a patient, because the *intention* of the physician was not to cause death, but to control pain. Closely linked to this distinction is the concept of “futility” -- since it is used by clinicians to determine whether extraordinary interventions ought to be made – and once again represents an attitudinal difference between these two groups with clinicians generally finding it helpful while bioethicists tend to find it inherently muddled.

Most important for our purposes, however, is what this study showed about withholding and withdrawal of treatment. Most bioethicists tend to reject the distinction between withholding and withdrawing treatment because, they claim, they have the same effect. Clinicians, however, generally hold that the two processes are different and view the withdrawal of treatment to be more serious than withholding treatment. As a result, clinicians (including nurses) are sometimes reticent to initiate treatment that stands a good chance of being withdrawn soon thereafter.

One of the reasons for this difference between health care workers and bioethicists, surely, stems from the fact they have different foci on patient care. This may be particularly true of nurses since they spend considerable amount of times interacting with patients in very intimate and private settings. And indeed, it is nurses in particular who have been the most dissatisfied with certain elements of ‘traditional’ bioethics, based on an approach such as principlism since it fails to address the special *relationship* nurses have with their patients, which is based on the notion of *caring*. Hence, while someone focusing on beneficence or non-

maleficence from a utilitarian perspective, may see no real difference in the distinction between withholding and withdrawing life support, a nurse actually working with and caring for a particular person nearing the end of their life may see a radical difference since their work does not depend only upon the “end result,” however that is defined. So, for example, caring for a terminal patient who will not get better is just as important as caring for a patient who will recover even though the care to the terminal patient is *pointless* in some objective, consequentialist sense. Moreover, we must remember that nurses are not working and relating to abstract principles but to actual people. Or rather, to be more precise, nurses and technicians may have little interaction with a patient *before* life support is initiated but often form tight bonds with patients *after* such procedures have begun. This can be true even when the patient fails to attain consciousness during the entire course of this ‘interaction.’ Hence, it is little wonder that nurses and technicians tend to think that the withdrawal of life support is more serious, morally speaking, than the initial withholding of life support. Note further that in instances like this, nurses may even differ from other health care professionals such as physicians since physicians typically spend much less time with their patients than nurses do, and hence may not form the same kind of caring bond with their patients.

I repeat that I’m not arguing that such a caring perspective is always right or that the perspective of caring is superior to the perspective of justice. Rather, I claim merely that it would be wrong to discount this caring perspective entirely. Of course, this leaves all sorts of questions regarding how we are to decide what to do in cases where the ethics of justice and the ethics of care appear to prescribe different and inconsistent actions. Leaving that important issue aside, I want to focus instead on some different issues regarding nursing and end of life care: (1) Assuming that it is important for nurses to retain a perspective of care in their relationships with

patients, I want to point to some ways in which this caring perspective can get *lost* as a nurse becomes professionalized; and (2) Assuming that we can somehow acculturate nurses to retain a caring perspective in their practice, however that is achieved, we need to ensure that their caring voice is heard in decisions that are made regarding end of life care.

In arguing for these points, I am of course leaving out lots of other important issues in end of life care. In particular, I haven't mentioned patients at all and this may appear to give undue importance to the moral satisfaction of nurses, and insufficient attention to patients. If I were attempting to develop a complete and, so to speak, 'global' picture of end of life care, this criticism would be true enough. But I have no such grand pretensions: I am merely attempting to make a point about one facet of end of life care which is perhaps not noticed as much as it ought to be. Furthermore, I might add that nurses' satisfaction, moral or otherwise, must surely be correlated in some way with good patient care. Or, to put the point negatively, nurses who are experiencing moral distress and residue probably tend to provide patients with poorer care than nurses not so distressed.

III: Moral distress and moral residue

Moral distress arises when there is an inconsistency between one's moral beliefs and one's actions (Hardingham, 2004) or when one finds that one hasn't done what one thinks is right because of a personal weakness or error or because of a situation that is beyond one's control (like too many patients with too few staff) (Webster and Baylis, 2000). Moral distress can produce moral residue, which Webster and Baylis describe as: "The experience of compromised integrity that involves the setting aside or violation of deeply held (and publicly professed) beliefs, values, and principles" (Webster and Baylis, 2000, 223)

The stakes are very high in this matter since, ultimately, nurses who suffer moral distress and residue run the risk of losing their moral integrity and with it their moral identity. Unfortunately, studies indicate that nurses often do in fact experience both these moral difficulties and that in fact they represent a main reason both for nurse burnout and of nurses leaving either the hospital setting or the profession entirely. Perhaps more unfortunately still, there is some evidence to suggest that this loss of (or change in) moral identity begins very early in a nurse's career, and is in fact part of her *de facto* 'professionalization.' In a couple of fascinating studies on nurses just beginning their professional lives, Kelly (1996, 1998) found that the new hospital nurse typically goes through a six stage process as she moves into the hospital work world while trying to retain a sense of moral integrity. These are: "vulnerability," "getting through the day," "coping with moral distress," "alienation from self," "coping with lost ideals," and "integration of a new professional self-concept" (Kelly, 1998, 1138-1140).

Briefly, a nurse begins his work life with a sense of unease about his abilities, and these worries are quickly confirmed as he realizes that he has to prioritize his work because he simply hasn't the time typically to do it all. Sometimes, nurses in the study admitted, prioritizing and getting one's work done involved "neglecting the patient," by engaging in the following sorts of behavior: "I give my 5 pm and 6 pm medications at the same time. Sometimes I won't get them up in a chair even though that is the best thing for them. They are probably drowning in their own secretions and it would probably be better for them to get up in the chair. When I was really stressed out, I would not change dressings. It's not right but you haven't got the time" (Kelly, 1998, 1140). Clearly, these sorts of action can lead to moral distress -- because the nurse is acting in ways that she knows are improper -- and hence some strategies must be developed to deal with this distress. As one nurse expressed it: "There were things I thought very important. A person

dying and you wanted to be there and hold their hand ... because you knew they were frightened and lonely ... but you were very busy and people might think you were lazy. My values say that talking to a frightened person is more important than changing a bandage” (Kelly, 1998, 1140).

Unfortunately, their strategies for dealing with this distress – such as avoiding patients, blaming the system, co-workers, and administration, reducing their hours, or quitting – are far from ideal and can lead to the loss of their moral ideals which they then have to address. New nurses typically do this by changing their value system and coming to perceive themselves, and to act, as seasoned pragmatists who are not bothered by the demands of their job and who are more flexible, practical, and less idealistic and caring than they were as new nurses. Eventually, this leads to the creation of a new moral identity as a ‘professional nurse.’ Interestingly, nurses at this point often think that their co-worker’s opinion of them is much more important than that of their patients.

While recognizing that nurses may at times be forced into this reconstruction because of the demands of the job, we can nonetheless recognize that the transition Kelly speaks of from one self to another, new professional self is not typically a change for the better. This is especially so since a major ingredient that seems to disappear in the new self is the notion that caring is centrally important to the nursing profession. If we think that caring is an essential ingredient in our conception of a good nurse, then we must work at ways in which the loss of a caring attitude does not become the typical ‘professionalization’ of new nurses working in a hospital setting.

IV: End of life treatment: the need for more collaboration

In 2000, the Renal Physicians Association and the American Society of Nephrology published *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from*

Dialysis as a way to deal with a growing number of changes in the field, not the least of which is the growing number of dialysis patients in the 75 and older category (who tend to have much higher incidences of co-morbid conditions such as diabetes, coronary artery disease, congestive heart failure, etc.). Of the recommendations made in that publication, of particular importance to us is the emphasis it places upon shared decision-making and upon the need for earlier and fuller preparation of the health care team, the patient, and her family and friends for the upcoming death of the patient. Similar sorts of points were made in a set of recommendations by Shooter and Watson (2000) with specific reference to withholding or withdrawing dialysis in pediatric patients. Besides some obvious suggestions – e.g., always act in the child’s best interests, assemble all the available evidence before making any decisions, attempt consensus with the whole family – they specifically mention the importance of respecting the opinion of *everyone* in the health care team, not just physicians.

Additional information regarding how we might properly practice appropriate withdrawal of life support is forthcoming from a recent study which surveyed the opinions of both nurses (RN’s) and respiratory therapists (RT’s) working in an intensive care unit at four Canadian, university-affiliated, intensive care units (Rocker et al., 2005). In examining the thoughts of RN’s and RT’s, the study sought to determine how well end of life treatment is being conducted in Canada at present and what might need to change to make it better.

It should be noted first that both RN’s and RT’s reported on the whole that they were very comfortable with decisions to withhold CPR (90.4% for RN’s, 68.5% for RT’s) or to withdraw life support (88.3% for RN’s, 76.7% for RT’s) or withdraw ventilation/oxygen (with sedation) (71.3%080.65% for RN’s, 60.0%-70.8% for RT’s). Both groups felt, however, that improvements could be made as they reflected on what they would do differently in end of life

care if they were empowered to do so. Some of their concerns had to do with what could be called ‘technical’ matters: both groups urged that sedatives and pain relief be supplied sooner and in stronger doses; that extubation be done earlier; and that different methods for withdrawing oxygen be employed. Other concerns can be classified as ‘planning’ issues: Getting clear as early as possible what the health care team’s plan is and exactly how it is going to be carried out, and who is going to do what. The vast majority of suggestions, however, can be classified as ‘caring’ issues and/or issues that spring from the special caring relationship that RN’s and RT’s have (or ought to have) with their patients, and indeed with the families of their patients. For example, both groups mentioned the importance of meeting with family early in the process to explain what was going to happen and when. Both noted the need for greater privacy of patients during their dying process. Interestingly as well, nurses made special mention that at times the unit was too busy for them to deal properly with their dying patient, and that sometimes the process was started at a bad time since death would likely occur after shift change, and nurses felt that it was important to have continuity in personnel during the dying process if possible (Rocker et al., 2005).

The fear, and at times the reality of the situation, however, is that nurses have lost their perspective of care. If and/or when this happens, crucially important elements of end of life care may be absent and patients, along with their families, will receive inadequate care. To avoid this, then, we must ensure first that nurses retain this caring perspective and second that their caring voice be heard and acted upon in decisions about and practices engaged in end of life care.

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