**COMPETENT PATIENTS’ REFUSAL OF NURSING CARE**

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Competent patients’ refusals of nursing care do not yet have the legal or ethical standing of refusals of life-sustaining medical therapies such as mechanical ventilation or blood products. The case of a woman who refused turning and incontinence management owing to pain prompted us to examine these situations. We noted several special features: lack of paradigm cases, social taboo around unmanaged incontinence, the distinction between ordinary versus extraordinary care, and the moral distress experienced by nurses. We examined this case on the merits and limitations of five well-known ethical positions: pure autonomy, conscientious objection, paternalism, communitarianism, and feminism. We found each lacking and argue for a ‘negotiated reliance’ response where nurses and others tread as lightly as possible on the patient’s autonomy while negotiating a compromise, but are obligated to match the patient’s sacrifice by extending themselves beyond their usual professional practice.

**Introduction**

There is a general consensus regarding the right of competent persons to refuse life-sustaining therapies such as mechanical ventilation, artificially provided nutrition and hydration, or blood products. The ethical and legal arguments that support this basic right have been framed primarily around the principle of autonomy, the right of the individual to self-determination over what is done to one’s body, and the right to privacy or the right to be left alone. Is there a similar right to refuse acts that are typically associated with nursing care? We pose this and the following questions and imagine how they could be answered by different ethical frameworks. Do competent persons have the right to refuse therapies such as turning or management of incontinence? Why would we accept a refusal for cardiopulmonary resuscitation, dialysis or mechanical ventilation yet decline to honor the same patient’s refusal of turning, hygiene procedures or skin care? Is nursing care different to care more commonly associated with medicine? If so, what is the ethical significance of this difference?
Nursing care can be life sustaining, just as medical care can be. Assisting a patient postoperatively to ambulate helps to protect against deconditioning, deep vein thrombosis, pneumonia and skin breakdown. Cleaning patients after urinary or fecal incontinence prevents skin breakdown and reduces the risk of infection. Turning patients who are bedridden is a crucial component of maintaining skin integrity to prevent skin breakdown or bedsores. When this basic care is withheld, patients can develop life-threatening complications that may not be manageable with antibiotics or other technological advances. Although death may not be imminent following the withdrawal of nursing care, for the most vulnerable patients, refusals of nursing care may precipitate death, just as decisions to forgo medically invasive treatments such as mechanical ventilation or artificial nutrition and hydration often predictably lead to death.

Determining a plan of care to prevent skin breakdown, to manage incontinence, or to maintain physical activity requires specialized education and training akin to the skills necessary to manage renal failure, respiratory failure or other conditions. While we accept the right of a patient to refuse dialysis or other treatments, we hesitate when the refusal is for nursing care. Why? Must we respect a competent patient’s right to refuse therapies such as turning or management of incontinence, or must an intervention be invasive or extraordinary for the health professions and courts to comply with a competent patient’s refusal? We describe a competent patient’s refusal of nursing care, analyze six possible responses and recommend a stance of negotiated co-operation.

Case history

Ms Winnow (based on an actual case history, however all names and non-essential details have been changed for patient and provider privacy) was a 50-year-old morbidly obese woman with a history of diabetes, hypotension and chronic atrial fibrillation. She suffered from acute renal failure secondary to gentamicin toxicity and had developed large areas of skin breakdown and ulceration, resulting in unrelieved pain. For the previous five years, she had been living in a skilled nursing facility where until recently she was able to ambulate between her bed and a chair. During these years, she gained 150 lb (68 kg) and slowly became more and more deconditioned. On her admission to the acute care facility, five people were needed to turn or clean the patient, or perform wound care safely.

Moving Ms Winnow for any reason elicited screams, cries and pleas to let her die. Numerous strategies to manage her pain had mitigated but not eliminated her discomfort. She experienced some pain relief with her patient controlled analgesia pump when at rest, although she still complained of general pain and discomfort while awake. Even boluses of opioids prior to turning did little to provide comfort. Other strategies to reduce the need to turn Ms Winnow, such as using a rectal tube to minimize fecal incontinence or special beds to reduce pressure, were also unavailable or ineffective. After agreeing to several rounds of hemodialysis, the acute renal failure began to resolve and the physician team decided that she could be discharged to a skilled nursing facility. However the social worker could not locate any such facility because of the high staffing needs associated with her care.

After many weeks, Ms Winnow finally said she had had enough. She adamantly refused to be turned or to accept wound care. After several more weeks, she also
refused tube feeding and resuscitation, and rarely ate as she became somnolent. Occasionally she would drink a fruit punch her cousin would bring, but she was severely malnourished. Her refusal to be turned and cleaned prompted an ethics consultation and engendered increasing distress among the nursing staff. (Case history adapted from Dudzinski et al.\textsuperscript{3})

**New taboo territory**

We begin by characterizing four reasons that make this type of case different from a competent person’s refusal of artificial nutrition and hydration, a ventilator, dialysis or other medical therapies.

**Lack of paradigm cases**

First, there is scant precedent in case law and no established consensus in the law or professional literature about how best to proceed when a patient refuses nursing care. Refusal of blood products, mechanical ventilation, hemodialysis or artificially-provided nutrition and hydration has received ample attention by legal and ethics scholars. In contrast, refusals of nursing care have been approached on a case-by-case basis, allowing idiosyncratic responses to occur. Through the casuistic approach of examining cases as a taxonomy,\textsuperscript{4} reasoned articulation of the cumulative arguments around a particular type of case can occur. By writing about this case, we hope to spark further discussion and debate as a precursor to consensus.

**Social taboos**

Second, Ms Winnow’s refusal violates a social taboo, which means that her refusal is both ethically troubling and socially an anathema. Not only is Ms Winnow refusing wound care and hygienic management (both life-saving interventions in her case), but her choice may feel dangerous to nurses and others because it challenges broader social norms. The implication of her refusal – lying in excrement while her wounds deteriorate and infections proliferate – is socially dangerous because the patient herself becomes ‘polluted’, leading to social isolation and alienation.

In *Purity and danger*, Mary Douglas\textsuperscript{5} explored anthropological and religious implications of pollution and taboo: ‘Primitive rules of uncleanness pay attention to the material circumstances of an act and judge it good or bad accordingly. Thus contact with corpses, blood or spittle transmit danger’. Allowing excrement to pool on the bed and floor with a foul smell creeping into the hallway and nearby patients’ rooms constitutes such disorder as to be deemed both irrational and dangerous. However, Ms Winnow has a very rational reason for refusing such care – she is in pain. How does our need for order and cleanliness weigh against Ms Winnow’s pain? Are we callous if we force her to experience pain simply to maintain some social order?\textsuperscript{6} Are we also callous if we allow Ms Winnow to sit in a pool of feces while her wounds fester?

When are taboo behaviors permitted? It is not taboo that babies soil themselves, because they know no better. Likewise, patients with dementia or quadriplegia require help with bowel management and nurses often provide it. Soiling oneself becomes taboo when one voluntarily lives with such danger and disorder, especially when help

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is offered and refused. A competent person’s refusal elicits feelings of abhorrence in others. Although many will sympathize with the indignity or pain of being turned and cleaned, most of us implicitly think of accepting such care as socially (not medically) required for acceptance in the human community. Is the context the problem? Charging medical professionals to respect informed refusals may be different to expecting them to respect socially taboo behaviors. If Ms Winnow just went home and we did not have to watch her wallow in filth and die of infection, our discomfort would be alleviated but her suffering would endure. Then the patient’s wish would be granted but nurses would not be enlisted in the neglect. As we argue later, many would interpret this as more egregious neglect, but neglect that certainly respects an autonomous patient.

Nurses routinely tolerate the revulsion they experience when caring for a patient emitting the foul odors of a gastrointestinal bleed or vomit after acetylcysteine administration for an acetaminophen overdose. Yet Ms Winnow’s refusal seems qualitatively different. Why? We speculate that this is primarily because the revulsion of bloody stool or vomit is short term and part of a treatment plan. Health care providers, not patients, devised the treatment strategy. A plausible explanation for our discomfort with Ms Winnow’s refusal is that it encroaches on the professional terrain of health care providers. Some may interpret Ms Winnow’s refusal as disrespectful of the care the entire institution strives to provide. Her refusal is taboo while the stench from gastrointestinal bleeding is not. Because nursing care seems to be implicitly expected of hospitalized patients, her refusal also seems ‘non-compliant’ in a way that refusal of tube feeding and ventilators does not. We have not yet reached consensus about the parameters for refusals of nursing care, therefore the refusal may be seen as defiance rather than an exercise of individual liberty.

**Ordinary care**

The third reason that Ms Winnow’s refusal of nursing care differs from refusal of medical care is that our society generally accepts that patients may refuse medicalized procedures that have become burdensome but lacks consensus on refusals of ordinary care. Dialysis, feeding tubes, ventilators, even bags of blood fall neatly within the purview of medical care in part because they are not usual and involve invasion of the body. Yet there is nothing extraordinary about having one’s bottom cleaned – intimate, yes, but extraordinary, no. One could view these cases under the rubric of ordinary versus extraordinary care, concluding that nursing care is always ordinary and, hence, cannot be refused. However, this belies the intensity of the treatment at stake and Ms Winnow’s pain.

**Moral distress**

Fourth, this type of case provokes unfamiliar moral distress. Moral distress arises when there is an inconsistency between one’s beliefs and one’s actions, often because one knows the right thing to do but feels constrained to pursue that course of action. Nurses who strongly believe that a patient’s right to refuse incontinence and wound management should be respected and therefore believe that being compelled to provide such care against a patient’s wishes constitutes battery, would experience deep moral distress, yet also revulsion. Likewise, nurses who believe that Ms Winnow’s
dignity must be maintained by means of incontinence management would also experience great distress if her refusal was honored, yet feel anguish with her cries. Because we still have no consensus on this type of case, moral distress can hinder creative ethical reflection. An analysis of options, such as we present here, can diminish moral distress and improve decision making.

Possible ethical responses to the competent person’s refusal of nursing care

Pure autonomy response

Respecting autonomy assumes that one’s professional obligation to Ms Winnow is primarily to respect her autonomous choices. We would be obligated to ensure that she had decision-making capacity and was not unduly constrained in expression of her autonomy. In addition, we would have an obligation to ensure that her refusal was informed: that she was aware of the reasons for the treatment, its possible risks and benefits, possible alternatives, and the consequences of refusal. After being assured that her refusal is informed and uncoerced, what then? A pure autonomy response would suggest that we would allow her to sit in an ever increasing swamp of feces and urine, with the accompanying odor permeating the unit, and with health care providers reluctantly and repeatedly entering her room to provide medications, emotional support and sustenance, and to support her right to die buried in human waste. How are we to respond to the nurse who expresses revulsion at this approach, feels it constitutes abandonment of a vulnerable person, and experiences moral distress? According to the pure autonomy position, if health care professionals experience anguish, helplessness and moral distress, it is up to them to cope because respecting a competent patient’s refusal is one’s paramount obligation.

The advantage of a pure autonomy approach is that it is consistent with legal and ethical standards that allow competent patients to refuse treatment. Repeatedly, court opinions have emphasized that a competent patient’s right to refuse a particular therapy is independent of a health care provider’s own view of that therapy.

A pure autonomy response idealizes independence even though most health care decisions are made within a familial or social context of dependence. Autonomy has been criticized as an ideal that prioritizes self-reliance to act without help, independence, personal preference and self-assertion. Some feminist scholars claim that autonomy is better conceived as relational. Autonomy is not about evoking a decision from an independent, rational individual, but concerns how a person’s values and decisions should be respected in the context of relationships. Hence, we must be careful not to confuse Ms Winnow’s isolation with her autonomy.

The pure autonomy response also fails to recognize Ms Winnow’s vulnerability. Despite evidence that multiple genetic, social and environmental factors contribute to obesity, overweight patients experience discrimination. The stigma of obesity is associated with social perceptions that obese people ‘lack self-discipline, are lazy, less conscientious, less competent, sloppy, disagreeable, and emotionally unstable.’ Nurses are not immune to stereotypes and their beliefs may impact on the care of overweight patients. One study found that over 62% of nurses in the USA believed that obesity in adults could be prevented through self-control and nearly half said they felt
uncomfortable when caring for obese adult patients.\textsuperscript{15} Another study suggested that nurses believe that non-compliance is the most likely reason for an obese patient’s inability to lose weight.\textsuperscript{16} Some health care providers may accept Ms Winnow’s refusal because it sanctions further neglect under the auspices of a laudable ethical principle. For a few, this patient may be viewed as obese, repellent and non-compliant, a patient who has made another pitiable decision and even deserves the neglect she has requested.

A final objection to a pure autonomy approach is that it tends to oversimplify the nature of Ms Winnow’s refusal. In the context of a therapeutic relationship, a nurse explores why a patient is refusing care, suggests creative treatment options, and negotiates short- and long-term goals based on the patient’s preferences. Nurses often negotiate with patients, coaxing them to consent to unpleasant procedures or painful physical therapy. They do this because difficult short-term sacrifices are often necessary for healing. In this case, Ms Winnow’s refusal of nursing care is a dimension of her genuine request to allow her to die. It may still be reasonable to provide hygienic care periodically as a way of negotiating patient and provider interests, as long as her pain is managed aggressively. We explore this option below.

Conscientious objection response

The conscientious objection response represents another ethical framework from which to view this case. This response supports Ms Winnow’s right to refuse nursing care, but also respects nurses’ rights to refuse to participate in actions that they find morally repugnant or impermissible. Similar to the health care provider who refuses to participate in abortions, a nurse who objects to this refusal would continue to provide the contested care, would not abandon the patient, but would aggressively pursue finding a health care provider (and possibly a facility) that will support the patient’s choice. How would we advise the nurse who believes this is simply another kind of abandonment that is also unlikely to be successful because finding another group of willing care providers will be unlikely?

The conscientious objection response is attractive because it is consistent with already accepted professional standards that allow professionals to refuse to participate in procedures to which they are morally opposed, provided they actively help the patient to find another provider. This standard recognizes the moral standing of nurses in the therapeutic relationship and respects nurses’ right to uphold their own values even if they differ from the patient’s.

This response is open to criticism, however. First, nurses enter the profession knowing that intimate care such as hygienic and wound management are staples of their work. Reasonable people disagree about whether abortion or assisted suicide is ethical. Few, if any, people think that dying in a pool of feces with infected wounds constitutes a ‘good death’. Given the taboo previously discussed, the only reason Ms Winnow would consent to become swamped in her own excrement would be to avoid a worse fate (in her case, pain).

Second, Ms Winnow cannot be discharged home because of her health condition, and there is little chance of finding a nursing home that would abide by her refusal. The acute care hospital may be the only health care facility where her autonomous request can be negotiated. While the USA courts have established patients’ rights to refuse medical therapies such as mechanical ventilation, blood products or artificially

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provided nutrition and hydration, they view inattention to incontinence and immobility as neglect and routinely bring administrative and even criminal charges against nursing homes, home health care providers, and family caregivers who do not provide food, fluid, assistance with turning, and management of incontinence to vulnerable persons. For example, nursing homes are charged to ‘ensure that residents do not develop pressure sores and, if a resident has pressure sores, provide the necessary treatment and services to promote healing, prevent infection, and prevent new sores from forming.’ These legal issues disproportionately affect home health and long-term care, making these institutions unlikely to offer Ms Winnow sanctuary. A claim, therefore, by the nurses in an acute care setting that they will provide care against her wishes only until a willing care provider can be found is a hollow promise.

Finally, the conscientious objection response saves the nurses by simply transferring responsibility to another nurse, and some may regard a conscientious objection as unjust abandonment, causing more harm to the patient by asking her to make her case to a new group of strangers, in the interest of saving these nurses from moral distress and feelings of revulsion.

**Paternalism response**

A paternalistic response, as an ethical approach to this case, would sanction disregard of Ms Winnow’s refusal of nursing care and would permit turning, cleaning and providing basic nursing care against her wishes in consideration of her ‘best interest’. How should nurses be counseled, given that they provide this care against the competent patient’s explicit refusal, shouted through tears and accompanied by efforts to escape the stronger and more numerous hands that touch her, intimately and repeatedly, against her wishes? Arguably, both nurses and the patient would consider such physical intrusion as assault and battery, even if the stated intention of the nurses was the patient’s best interest.

Despite this compelling objection, the paternalistic response is attractive for several reasons. First, some will view Ms Winnow’s refusal as a sign of diminished decision-making capacity. Once this implicit or explicit shift is made, then the impetus to protect her from an irrational choice becomes stronger, and providing nursing care over her objections may seem justified. However, this approach is built on an illusion because Ms Winnow does have decision-making capacity and offers valid and rational reasons for refusing turning and management of incontinence.

Second, it could be argued that patients may refuse medical care but not custodial care. The legal parameters around care in a nursing home suggest that this is precisely the case. In a way, this position nods to the distinction between taboo and refusal of treatment. That is, patient autonomy is well and good for medicalized procedures but not for basic hygiene, the neglect of which leads to social repulsion and ostracism. This position raises the question of whether the distinction between nursing and more aggressive medical care is conceptually or ethically sound. If the logic of refusal is that the patient rejects a violation of personal privacy even when there are health risks, then perhaps the nature of what is being refused should not matter. Turning, bathing and wound management may constitute not only a violation of privacy but also a very intimate violation, more intimate than a ventilator, for example. Third, some may argue that the patient may later appreciate the temporary invasion. However, the cases
of Dax Cowart and Elizabeth Bouvia are paradigm cases refuting this justification for paternalism. Dax Cowart suffered a massive burn and was treated against his wishes. Later he said that he was glad that he had survived an explosion and subsequent aggressive burn treatment, but still steadfastly maintained that he would have preferred that his repeated and clear requests to stop treatment had been respected. When Elizabeth Bouvia refused to eat and receive tube feeding, the court’s initial insistence that she be force fed was ethically problematic because an invasion of a patient’s private person against his or her will constitutes battery and an unjustified intrusion. Even though Bouvia ultimately chose to eat again, both Cowart and Bouvia demonstrate that short-term gains are not always justified by later appreciation. We will argue that curtailed short-term negotiation for turning and incontinence management coupled with aggressive sedation can be justified under some circumstances when it is truly negotiated with the patient rather than unilaterally imposed.

Fourth, like the pure autonomy approach, paternalism may diminish the importance of negotiation and reciprocity in the therapeutic relationship. The assumption in this approach is that the care providers know best, that insisting on nursing care is correct, and that the patient should comply – a stance that may seem to permit justified force and coercion. Rather, humility could lead to richer discussion with the patient and more creative medical and ethical management. While a paternalistic approach certainly does not preclude a sensitive process of negotiation, the conviction that the use of force may be necessary may require stalwart resolve that precludes a gentler strategy.

Finally, we would like to comment on the special skills and role of nurses. When vulnerable strangers vomit, defecate and urinate, nurses voluntarily and graciously clean it up and make sure the patient remains clean, dry and warm. The rest of us may take on that role for a beloved family member, but rarely for strangers. Nurses and nurses’ aides make sure that people who would be ostracized and abandoned are not. They ensure that what revolts most people remains in its proper place, safely out of contact with the patient’s body. They do this by walking in the liminal space between purity and danger, between pollution and cleanliness. In situations of refusal of nursing care, nurses may adopt a maternal stance in relation to difficult and ‘non-compliant’ patients, forcing upon them the care they ‘need’. Nurses may expect compliance, perhaps because some of the care they provide is familiar to the patient (bowel and bladder management) or perhaps because the nurse’s interactions with patients are so intimate that co-operation is both more mundane and more essential for the provision of care. Nurses who become accustomed to acquiescence in the absence of consent may object more strongly to Ms Winnow’s refusal. In a sense, compliance may be expected as part of nursing culture, and resentment and labeling as ‘difficult’ ensues when a patient makes an informed refusal of ordinary nursing care.

Nurses frequently rely on implied rather than verbal or written consent. When patients roll up their sleeve as the nurse approaches to draw blood, nurses may interpret compliance as consent. Aveyard notes that, without disclosure of information pertinent to the procedure, compliance or acquiescence does not constitute implied consent even after a courteous request. Interestingly, surveyed patients said that conforming to ward routine was more important than participation in decision making. This suggests that patients too may feel vulnerable to pressure to comply and sense the negative implications of non-compliance.
A paternalistic response, then, may seem appropriate for what some might perceive as an adolescent rebellion against basic needs. When a patient is deemed ‘non-compliant’, ‘inappropriate’, or ‘manipulative’, as obese patients are more likely to be, then we may be less troubled by imposing a treatment that the patient refuses. We implicitly decide that poor judgment may be worse than lack of decision-making capacity and try to rescue the patient from the consequences of a bad choice. If we rationalize such a response, the imposition of nursing care feels less like abuse and more like caring for a fussy infant or a defiant adolescent. It is a parental response suggesting that we know best.

**Communitarian response**

A third ethical framework for responding to Ms Winnow’s case would be a communitarian stance, which is based on a reciprocal concept of caring where the interests of a community may impose restrictions on a patient’s autonomy. The communitarian perspective has roots in Jeremy Bentham and John Stuart Mill’s concepts of community and individual rights. During the last two decades, communitarianism has evolved into a perspective characterized by the following commitments. ‘A full model of caring should encompass more than the patient alone.’ Self-regarding choices are open to outside moral judgment and critique and when others are affected by a patient’s choice, the values of these others should be carefully considered even if it constrains individual autonomy. The decision makers in nursing homes ‘are constantly faced with the challenge of weighing the interests of the individual resident against the interests and needs of the entire nursing home community’.

In a communitarian approach, the needs of physicians and other caretakers, family, friends, the community and the institution, may also be considered. If a more democratic approach to patient care is espoused, then the resounding discomfort among nurses of not providing bowel and wound management may simply outweigh the patient’s interest in avoiding it. If Ms Winnow is considered to be a member of a community that includes not only the nurses but also other patients who will be negatively affected when the stench of feces seeps into the hallway, then maybe some personal sacrifice on Ms Winnow’s part is justified, provided that compassion and excellent pain management precede the imposition.

How would we construct a communitarian response to Ms Winnow’s refusal? A benefit/burden analysis is informative because the refusal is motivated by a desire to avoid physical pain. First, health care providers should offer improved pain management to minimize physical suffering. Second, the patient’s goal in refusing nursing care should be carefully considered. Ms Winnow refused turning primarily to avoid pain. Over time, she determined that her quality of life had diminished to the point that tube feeding and rehabilitation were also too burdensome. She was ready to allow a natural death to occur, provided that pain would be minimized. Hence, the refusal of nursing care was necessary to reach her goal of a natural death with as little pain as possible. This should lead to a shift in medical management (eg more aggressive pain management) although compromises could still be justified on the communitarian model. Yet Ms Winnow’s refusal also has moral implications for nurses, who may wonder: ‘What kind of nurse or person am I? One who tolerates a patient’s voluntary indignity or one who inflicts pain against the patient’s desperate
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pleas to stop in order to impose basic hygiene?’ In either case, the nurses’ response reflects their professional and personal integrity and their self-conception.

However, consider a quadriplegic patient who agrees to feeding, antibiotics and other therapies but refuses to be turned and cleaned after bowel incontinence. He says that turning scares him and he wants to be left alone rather than submit to the indignity of depending on nurses ‘to wipe my bottom’. He understands the implications of skin breakdown, including death. Here, a rational patient requests something socially unacceptable without a reason that seems compelling to most care providers. From the patient’s perspective, the indignity is in being helped rather than in being unclean. The communitarian approach may be more justifiable for this patient than Ms Winnow. Also consider a patient who fears being showered owing to a recent fall and requests the more labor-intensive option of a bed bath. Again, the communitarian response may justify using the more efficient bathing option while addressing the patient’s fears. One may however wonder if the community’s interest in evading taboo and revulsion legitimately outweighs Ms Winnow’s interest in avoiding excruciating pain. Imposing physical pain on a patient for the good of others would require a benefit in equal proportion to the burden. Tolerating a foul odor does not meet the criteria.

Feminist response

Some people might argue that a feminist approach is best suited for this case. Ms Winnow is a middle-aged single woman with no ‘male protection’. She is suffering from a disease – obesity – that disproportionately affects women and is being cared for by nurses, who are predominately women and work in a profession that one could argue is a pink collar ghetto and where the physical strain of the care needed is not recognized, valued or supported in such a way as to minimize effectively any injury to the worker. Given these facts, what would a feminist approach offer the nurses caring for Ms Winnow?

Obesity and the resulting health burdens such as type 2 diabetes often affect women. The reasons for this gender disparity are multifactorial. Obesity is associated with lower socioeconomic status in women and lower family income in children. Women are more likely to be poor and to be single heads of household, and, as single parents, are more likely to live in poverty. Women are also disproportionately affected by other factors associated with obesity. Girls have lower rates of physical activity than their brothers. Women suffer from higher rates of depression, which in turn is strongly associated with obesity. Feminists view obesity as a gendered health condition in developed countries, and one that cannot be separated from the social roles and constraints in which men and women live.

A feminist approach does help us to see the social and political context in which Ms Winnow lives and in which nurses work, but it does not offer a tool to navigate the particulars of this case from a stance where one’s hands are literally ‘soiled’ in the care of the patient. A specific response is difficult to distinguish from the responses already discussed.

Negotiated reliance response

We propose a new framework for responding to cases such as Ms Winnow’s. A negotiated reliance response is an effort to negotiate a compromise that treads as
lightly as possible on the patient’s autonomy while minimizing the distress caused to others either through one’s senses or one’s sensibilities, but asking of the care provider an equivalent sacrifice. In a negotiated reliance response, the care provider can ask of Ms Winnow only the minimum in hygiene while agreeing to provide aggressive pain management. We discuss the clinical particulars in more detail later.

A negotiated reliance approach conscientiously strives for a more even handed negotiation between respect for autonomy, respect for vulnerability and respect for others. It recognizes the reliance of the patient on her care providers and the necessity of the person to be cared for in defining the role of the care provider. It combines empowerment and dependence by requiring negotiation from the competent patient while attempting to minimize harm. It presupposes a relationship of care and intimacy that acknowledges the increased power that health care providers enjoy in that relationship. It allows for more therapeutic and reciprocal responses than other approaches. A negotiated reliance approach may permit invasion of privacy and force, but, rather than to advance a paternalistic agenda, to advance a shared and negotiated agenda.

This approach combines communitarian and feminist approaches. Linda Barclay argues that, unlike communitarians, feminists hold fast to the right to autonomy. While individuals are certainly socially determined, it is through their exercise of autonomy that they challenge oppressive social structures. Autonomy allows for a resistance to oppressive cultural norms that affect individuals as well as marginalized and vulnerable groups. In the communitarian framework, the exercise of autonomy can unjustly challenge the interests of others within the community. In a feminist framework, the exercise of autonomy contributes to the growth of community and a revitalized sense of justice. Feminists begin ‘with the situated self but view the negotiation of our psychosexual identities and their autonomous reconstitution by individuals as essential to women’s and human liberation’.

In a negotiated reliance response, the autonomy rights of Ms Winnow and the communitarian rights of the care providers and other affected parties are weighed simultaneously. This framework shares characteristics of a palliative care framework in that the goal of intrusion is a means to a shared longer-term goal of a pain-free, natural death. In both frameworks, health care providers are willing to take greater risks to minimize patients’ suffering in order to reach shared goals. In a palliative care model, this might mean offering palliative sedation as a last resort to address suffering even though this option carries significant risks and burdens. In Ms Winnow’s case, her reason for refusing nursing care is due to pain. Clinicians must be willing to offer more aggressive pain management, even to the extreme of conscious sedation, in order to ask of Ms Winnow that she allow this infringement on her autonomy. In addition, Ms Winnow’s initial refusal should be honored immediately for a short period of time. This is to take seriously the patient’s vulnerability and to empower and respect the patient’s autonomy. It also acknowledges the professional uncertainty around her care and refusal. It is reasonable for Ms Winnow’s care to require extra steps and more resources in order to meet her needs. This extra devotion may involve finding a nurse who is less threatening for the purpose of minimizing the emotional trauma for a patient, experimenting with a combination of human and mechanical approaches to turning, and co-ordinating medical support such as anesthesia into nursing care routines. Finding an approach that works can be applied to future similar cases, just as we apply lessons from Terri Schiavo to the withdrawal of nutrition and hydration.
In a negotiated reliance approach, both the patient and the professionals are expected to make sacrifices and to have some precious values addressed, even if this imposes on the other party. Negotiated reliance can be critiqued using a consequentialist or utilitarian stance; the actions are the same as paternalism, and battery still occurs, just less of it. The patient may be unconscious when the unwanted intrusion occurs, but it occurs nonetheless. Yet this confuses the goals of the treatment. The patient’s objection is to the pain, not to the intimacy of the act or to the injection of the medication. Conscious sedation offers the patient a means to avoid pain and makes explicit our willingness to extend ourselves both ethically and practically to respect her wish. Another critique is that negotiated reliance still allows some, but not all, nurses to conscientiously object, yet does not allow the patient to avoid negotiation. The objection is that the patient’s position of extreme vulnerability should protect her from the need to negotiate. Yet this defies the notion of care as applied to adult relationships and infantilizes the competent person. The patient is not a baby whose cries we tune out nor a rebellious teenager whose protestations we disregard, but a competent adult who speaks from a position of personal exposure and expert self-knowledge. Not to involve the patient in this negotiation would be unacceptable. Although some nurses may be able to object conscientiously and thus avoid participation, a critical number will need to reach a compromise with this patient to insure 24-hour coverage of her care needs. A final objection is that Ms Winnow’s situation is guided by a different clinical and ethical standard to other patients, which is a due process objection that asks that fairness be applied to similar cases. We concur with this concern and suggest that open discussion of these cases through ethics consultation and debate in the ethics literature is crucial to explore more fully the justice considerations.

Outcome of the case

Ms Winnow steadfastly continued to refuse turning and management of her bowel incontinence. After an ethics consultation, the nursing staff negotiated turning her once per day and shifted the plan to palliative care goals. She continued to experience significant pain during turning and staff worked to ensure that she had received the maximum allowed dose of pain medication via her patient-controlled analgesia pump prior to initiating this care. Ms Winnow refused a feeding tube and her only real nutrition was occasional sips of punch. She became increasingly somnolent and eventually died after refusing antibiotics for an opportunistic infection.

On reflection, we believe that this case should have been handled somewhat differently. Ms Winnow should have received conscious sedation for turning and cleaning. In addition, rather than having a scheduled plan to turn her once daily, Ms Winnow should have been turned only to manage bowel incontinence and then not more than once daily. This would have allowed her not to be moved as she approached death, when incontinence became less of an issue.

Conclusion

Why have cases about refusal of nursing care not ignited our attention? First, they deal with taboo issues that have both social and professional implications that compel us to
confront and reflect upon our moral distress and broader social mores. Second, these cases lack the legal precedent we have seen with refusal of more medicalized procedures. Third, cases such as that of Ms Winnow deal with basic nursing care rather than invasive medical therapies. Basic nursing care has received inadequate attention in the bioethics journals and may reflect our collective discomfort, embarrassment and ambivalence. Finally, situations that nurses encounter more frequently than physicians have been largely overlooked by ethics committees and bioethicists, as evidenced by the paucity of articles on these issues in the ethics literature.

The value of seriously analyzing these types of cases is that we begin to see the features that place them on a continuum of precedent cases. An analysis of Ms Winnow’s case highlights the distinction between a refusal of nursing care by a competent patient on the basis of pain versus a refusal on the basis of embarrassment. The negotiated reliance model allows us to see our duty to extend our professional risk in such a way as to parallel the risk that we ask the suffering patient to take. Unlike many of the precedent cases around medical care, these are cases where we are in agreement on the long-term but not the short-term goals. These cases receive less attention by ethics committees and in the ethics literature, yet will be encountered by every nurse. We are tempted to treat each case as discrete and to respond idiosyncratically, rather than see the commonalities and to respond from a place of considered professional agreement. Examining situations of refusal of nursing care will deepen our understanding of these basic tensions in bioethics in new ways.

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References


