In A Nutshell

Competent patients' refusal of nursing care

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At our recent Edmonton Area Ethics Committee meeting, I shared this article with our members. The case study in this article from Nursing Ethics highlighted issues familiar to us. A lively discussion ensued that celebrated the knowledge and expertise of our members. So, with apologies for repeating myself to those who were in attendance, I thought that the article deserved wider readership.

Dudzinski and Shannon open this article with a series of questions about whether nursing care is equivalent to medical care when considering patient refusals. They point out that ethical/legal frameworks exist to allow competent patients to refuse medical treatment. However, the literature offers little regarding refusals of nursing care. The authors wonder whether the distinction between medical and nursing care is a real one.

Clearly, providing nursing care such as wound management ultimately impacts the patient’s medical status and is a preventative measure. Given the lack of paradigmatic cases as found in the medical ethics literature, the authors hope this article offers a starting point for further discussion. In order to explore the ethics of patients’ refusal of nursing care, Dudzinski and Shannon offer a case example followed by their observations on the contributions of commonly employed ethics approaches.

The authors describe a 50 year old lady who is morbidly obese. Ms. Winnow was diagnosed with diabetes, hypotension, and chronic atrial fibrillation. She spent the previous 5 years in continuing care where she became deconditioned, gained 150 lbs, and was, until recently, able to ambulate between her bed and a chair. Some details of Ms. Winnow's condition include:

- She was admitted to hospital with renal failure secondary to gentamicin toxicity
- 5 caregivers are required to safely clean and turn her
- She experiences unrelieved pain from large areas of skin breakdown/ulceration
- Due to this pain, Ms. Winnow cries, screams, and pleads to others to let her die
- The care team's strategies to mitigate her pain were not effective

After Ms. Winnow agreed to and received several hemodialysis rounds, her physician stated that she was ready for discharge as her acute renal failure resolved. However, the social worker was unable to find a continuing care facility willing to accept her. Ms. Winnow
declared that she had had it and refused tube feeding and resuscitation. Occasionally, Ms. Winnow would accept fruit juice. She adamantly refused turning and peri-care.

Ms. Winnow’s refusal is troubling. Her refusal placed her in danger, left her isolated, and challenged social norms about cleanliness. However, her call of pain was real. At this point, the nursing team requested an ethics consultation. The nurses were stressed about the situation and divided over what to do. The nurses asked, “How far can we go to make Ms. Winnow accept turning and hygiene management?”

**Ethical perspectives**

Dudzinski and Shannon turn to the ethics resources commonly brought to bear on a consult. First, they discuss the “pure autonomy response”. Our consults often begin with a survey of the four principle approach made famous by Beauchamp and Childress (also known as the “Georgetown mantra”). The nurses were struggling with respect for the patient’s autonomy and their commitment to beneficence (i.e., to do good). Though aware of the risks, Ms. Winnow, a competent decision maker, persisted. If we hold on to the view that Ms. Winnow’s request should be respected, we risk abandoning her and experiencing moral distress from not providing the care we know is needed.

Common criticisms of the Pure Autonomy Response highlight its idealization of the independent rational decision maker. Considerations of context, history, and psychosocial concerns are ignored. Our response would take Ms. Winnow’s rejection of nursing care on face value. There would be no exploration of what prompted Ms. Winnow’s refusal, no discussion of her vulnerability or of the impact of stigma attached to obesity. At its extreme, the Pure Autonomy Response could mask a willingness to neglect this patient.

A second approach, the Conscientious Objection Response allows respect for the patient’s choice but permits some nurses to opt out of her care (NB: willing nurses would still be needed). Health care professionals are familiar with the notion of conscientious objection as outlined in our respective codes of ethics, standards, etc. However, offering this response protects some, but not all nurses, and most certainly does not add any insight into the patient’s refusal or offer a way forward.

A third approach is offered by the “Paternalism Response”. This response would elevate best interests above respect for autonomy in order to justify overriding the patient’s refusal. At a practical level, several staff would have to restrain and touch the patient’s body against her wishes. This would be akin to assault even though we may console ourselves by thinking that we are saving the patient from her “bad” choice. The “paternalism response” is often defended by pointing out that there are short term costs for long term gains. However, high profile cases like Dax Cowart illustrate that patients are not always appreciative when their wishes were disregarded by the best interest standard.

The fourth approach, the “Communitarian Response”, brings into view the concerns of the entire community and seeks to balance the needs of one member with those of the greater group. Communitarianism, as an ethic, calls for restrictions on individual choice. Though compassion and excellent pain management would be offered, a “personal sacrifice” from
the patient is needed to maintain community homeostasis. However, the authors state that “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.” (p. 617)

The fifth approach, the “Feminist response” would offer an understanding of Ms. Winnow’s condition within a sociopolitical context. From a feminist philosophical perspective, we would note that obesity disproportionately affects women, is associated with lower SES, is related to lower levels of physical activity in girls and women, and is strongly linked to depression. While such an analysis is useful in delving deeper into the forces that influenced Ms. Winnow’s life, the feminist response does not offer practical tools for resolving the situation in this case.

The final approach examined by the authors is the “Negotiated reliance response”. This response carefully navigates the concerns of the parties involved. It calls for trade-offs to be negotiated between nurses and Ms. Winnow. The negotiated reliance response aims to balance the concerns about autonomy, respect for vulnerability, as well as respect for others in a framework that simultaneously considers all community members. In this way, it combines elements of communitarian and feminist views in that respect for autonomy is retained, but looks to community benefit as well. In a practical sense, this would mean more aggressive pain control can be traded for willingness to acquiesce to minimal hygiene management. Such reciprocity is familiar in palliative care settings where shared decisions are made that allow immediate interventions with a view to longer term goals at the end of life (i.e., a “good death”).

**Summary**

This article provides the reader with insight into the various ethics resources those of us who work as ethicists might bring to a consult. Though the authors’ descriptions are brief and concise, readers are provided a survey of some of the thinking tools we possess. Within each approach there are useful ideas that bear on individual patient situations and permit nuanced responses. Though the analysis in Ms. Winnow’s case favours the “negotiated reliance response”, other cases could reasonably be resolved with deeper tools available in the other responses outlined.

As to the questions posed by Dudzinski and Shannon regarding drawing a line between medical and nursing care, no easy answer is evident. Each nursing care situation must be worked out in its context until decided cases emerge. In the end, for the patient who refuses care, does it really matter whether the care is defined as medical or nursing?

This article, appearing in a nursing journal, directs attention to nursing solutions. Our Ethics Committee, consisting of members from a wide range of health care disciplines, pointed to additional resources to help the staff and Ms. Winnow. Ms. Winnow repeatedly asks to be allowed to die. This we interpret as a call for Spiritual Care. As our Health Ethics Guide states, we are dedicated to caring for the mind, body, and soul of each individual.