



# WHEN IS PATIENT EDUCATION UNETHICAL?

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Although patient education is central to the ethical practice of nursing, it can be practiced in an ethically contested or unethical way. It is sometimes used to: forward a societal goal the individual might not have chosen; assume that patients should learn to accommodate unjust treatment; exclude the views of all except the dominant health care provider group; limit the knowledge a patient can receive; make invalid or unreliable judgments about what a patient can learn; or require a patient to change his or her identity to meet a medical ideal. Both health promotion education and manipulating patient beliefs in situations of uncertainty are ethically contested. Nussbaum's capabilities approach is used here as a moral framework through which to view the goals and practice of patient education. This provides better guidance than the current conception of patient education as an instrument to carry out the directives of medical practice.

## Introduction

Each new technological development and stable research evidence provide an opportunity for more effective outcomes, but some established practices in patient education have not been examined from a moral point of view. The purpose of this article is to comment on ways in which some practices of patient education can be unethical or ethically contested, and to distill lessons for its ethical practice. Examples from the current literature are used for illustration.

The expansion of preparing patients to self-manage chronic disease provides an excellent opportunity to support patient self-determination and better quality of care. It is important to remember that patient education is a moral endeavor that affects patient identity, agency, perceptions of self-worth and possibility.

Exciting progress is being made in testing technologies for patients to learn to use. This has both instrumental and moral goals. Two examples used in this article are instructive. The first is of a new opportunity in the field: a newly developed digital frequency analysis monitor enables early detection by the patient of prosthetic heart valve dysfunction, which is essential to prevent thromboembolic complications. The

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ThromboCheck (OGHAM GmbH, Münster, Germany) device measures the frequency range of mechanical valve sounds digitally and automatically. The test can be performed by patients themselves as often as they wish and takes no longer than a minute,<sup>1</sup> offering an improved sense of control and self-efficacy.

The second example used assesses an old technology with new evidence: the common patient self-management practice of peak flow monitoring for asthma. This came into vogue four decades ago because it was thought to offer an objective way to gauge asthma severity. A recent review of the evidence showed the strength of the relationship between peak flow and asthma symptoms to be low to moderate, varying between individuals, and that the benefits of patient self-management of peak flow monitoring in asthma provide, at best, no more than a small increment in effectiveness beyond that afforded by symptom monitoring.<sup>2</sup> Many patients have preferred symptom monitoring and have not been compliant with provider recommendations for peak flow monitoring. This new evidence offers an opportunity for patients and providers to renegotiate more effective treatment approaches congruent with patient beliefs and lifestyle. This discussion has to be set within a moral framework in which patient education can be situated.

## **Moral framework**

As an intervention, patient education can be seen to be instrumental in solving immediate problems (e.g. how to care for one's surgical site) or in a more comprehensive framework as further development of the patient's or family's capacity for self-management. Most people will face chronic illness and will encounter a need for health skills at multiple times throughout their lives; I therefore argue for considering all patient education to be for building capabilities.

The capabilities approach focuses on developing what people are able to do or be, guaranteed at least to a threshold level, beneath which truly human functioning is not available. As the intrinsic aim of education should be to expand people's capabilities,<sup>3</sup> this is an appropriate moral framework through which to view the practice of patient education. The capabilities approach is arguably preferable to a framework of rights, which is often linked to particular cultural and historical traditions and thus may not contain recognized, or may have enforced, ways in which oppressed groups such as women are not afforded the same rights as more privileged groups.

In addition, rights are secured only when people have the capability to function. It is important to patient education that capabilities can be the object of an overlapping consensus among people who have very different conceptions of the good,<sup>4</sup> presumably including health. With this approach it is not essential to agree on a definition of health.

Of the 10 central human capabilities discussed by Nussbaum, 'life (being able to live to the end of a human life of normal length; not dying prematurely ...) and bodily health (being able to have good health ...)' (pp. 78–80)<sup>5</sup> are the most relevant to patient education. Four other central capabilities affected by patient education are: (1) being able to use the senses, imagine, think and reason; (2) being able to have attachments to things and people outside ourselves (emotion); (3) being able to form a conception of the good and to engage in critical reflection about the planning of one's life (practical reason); and (4) being able to live with and towards others (affiliation).

These (and other) central capabilities are not just instruments to further pursuits, they are held to have value in themselves and be of special importance in making possible any choice of a way of life.<sup>5</sup>

The development of capabilities and the resulting agency require an infrastructure of laws and institutions that will avoid entrenched traditions serving only the interests of some and demoting the interests of others. Capabilities should be pursued for every person, treating each as an end.<sup>4</sup> Thus, institutions making policy for and delivering health care must provide the requisite affirmative support for developing the capabilities that patients need.<sup>5</sup> Direct care institutions must provide education that enables patients to make decisions and self-manage health and disease; both public and institutional policies must support these goals. These support mechanisms are critical to the development of capabilities to live a life of normal length and be in good health. Unfortunately, both these have never been, and are not currently, adequate to help patients to develop the capabilities they need to sustain life and bodily health.

This service is especially important to persons of low socioeconomic status, who suffer: worse health and shorter lives; low self-esteem, self-efficacy and self-mastery; and diminished moral agency.<sup>6</sup> Yet, in contemporary health care systems in which highly intensive medical care has the highest priority patient education has predictably received lowest priority.

## Examples of unethical patient education practice

Ethical lapses in patient education are largely unexamined. The most common error is usurping patient choice by assuming someone else's goal (societal or provider), or depriving patients of the knowledge and skills to exercise choice. Each of the examples that follow, although they violate other moral precepts, also depicts thwarting of the development of capabilities.

### To meet a societal and not necessarily a personal goal

An example can be found in the work of Rodrigue *et al.*,<sup>7</sup> who argue that the shortage of deceased donor kidneys and superior clinical outcomes with live donor kidney transplantation makes it imperative to know how best to educate patients and their family members. The outcome by which this education is judged is the rate of live donor kidney transplantation. Even though the outcome of family education includes the good of the patient receiving a kidney, and a chance for the donor to express love and altruism, there is an inherent coercion in asking a family member to give a kidney to another family member. This can misuse capabilities of emotion and affiliation.

Who chooses which families should receive education on live donor kidney transplantation, thereby easing the pressure on the inadequate supply of donor kidneys from other sources? At the very least, a potential donor should have an independent advocate to protect his or her interests, and it should not be assumed that the medical perspective should be given more weight than social, psychological and other perspectives.<sup>8</sup>

This example thwarts the basic goal of the capabilities approach, which is to give people (patients and family) an honest and well-informed choice of a way of life.

### **When the ideal being taught is morally wrong, even if societally sanctioned**

A historical example is teaching that 'mentally deficient' individuals should be sterilized for eugenic purposes. A more modest but contemporary example is teaching only the medical view about a health problem and requiring patients to adopt this dictum and comply with it. This medical morality tells patients they are morally remiss and their lives unworthy if they fail to submit to medical examinations and proactively to minimize their risky behaviors and states of mind.<sup>9</sup>

A still largely hidden example is the differential treatment of younger and older individuals with disabilities. Older people and their caregivers usually share the societally taught belief that disability results from underlying disease that is a natural consequence of aging, that institutional care is inevitable, and they must make do with care that maintains them in a dependent and subordinate role. Younger persons with disabilities reject these options. Teaching patients and families in the presence of these ingrained social ideas raises issues of justice.<sup>10</sup> Continuation of this system of allocation depends on underdevelopment of the capability of practical reason and negatively affects all other central human capabilities listed above.

Nussbaum<sup>5</sup> notes that some preferences are deformed by ignorance, malice, injustice, blind habit and social conditioning, and manipulated by tradition and intimidation. This example demonstrates that, before being taught, presumed ideals must be deeply examined for what they do to the development of capabilities and to their expression in function.

### **Not providing patient education when the standard of care requires it**

This can occur when a patient needs to make a treatment decision or cope with a health problem. The view that in such situations patient education is essential is reflected in the usual practice in research of not using a control group but rather comparing a to-be-tested educational intervention with 'usual care'. At the same time, outcome-oriented standards of care in patient education are virtually absent. For example, what success rate should a practitioner be able to obtain in helping persons with low literacy to make a health care decision consistent with their values and goals, and with which they are satisfied?

There is considerable evidence scattered throughout the literature of large numbers of patients not receiving the required education. In one of the most recent reports, out of a total of 1448 respondents with pulmonary fibrosis, two-thirds reported a clear lack of information and resources, and less than half said that they felt well informed about treatment options, the role of supplemental oxygen, pulmonary rehabilitation, and transplantation.<sup>11</sup> Education is probably provided at the time of diagnosis for many chronic diseases but is not consistently available over the course of the disease as new learning becomes necessary.

Withholding knowledge that is essential for understanding and thus helping to create needless worry and feelings of inferiority in the patient is unethical; it is a

reasonable part of care to anticipate such a patient need. Nurses are legally and morally answerable for their own practice, with primary responsibility to those people who require nursing care. This unethical practice directly affects the development of patient capabilities to attain bodily health and often to live a life of normal length. Thus, standards of care may be thought of as the threshold defined by Nussbaum, and justified not only by empirical data but also by the criterion of truly human functioning.

### **Disenfranchising the moral agency of some health workers to sustain the views of physicians is unethical**

At least two situations related to the practice of patient education cause moral distress in nurses. This is especially poignant because patient education is central to the culture of nursing as well as to its legal practice. Those situations are: (1) strict physician control of the content of or access to patient education, which is a blatant form of paternalism and an infringement of the moral agency of other practitioners; and (2) inability to protect the patient from incompetent medical management that becomes obvious during education of patients for self-management. Such a moral conflict was dominant (75% of ethical conflicts) among registered nurse and diabetes educators in a study completed in the mid-1990s. Many of these participants 'knew what happened to nurses who take on MDs'; others resolved the dilemma by educating the patients in how to achieve optimal parameters and allow them to resolve the situation with the physician.<sup>12</sup>

Various health disciplines provide different kinds of knowledge and skills to patients. It is easy to see how privileging the dominant health professional, even though this practice may be outdated or outright wrong, limits the capabilities that patients can develop. It does so by depriving them of the accurate information and help in the development of judgment that is necessary to independent functioning.

### **Limiting the knowledge that patients have a right to receive and/or stigmatizing them or their group**

For example, recently approved Outcome Standards for Diabetes Education specify patient knowledge as an outcome only to the extent that it is actionable (i.e. knowledge that can be translated into self-management behavior).<sup>13</sup> One can surmise that such treatment of knowledge is related to the behaviorist tradition in health education, which specifies that the only useful outcome is patient behavior change, and the related finding that patient knowledge is necessary but not sufficient to create behavior change.

Knowledge exchange with a patient may be limited because of an assumption that individuals from this group cannot learn or will not give up 'deviant' beliefs, thus further adding to the stigmatization of vulnerable groups. Such systematic discrimination on the basis of race, sex and other categories is a form of capability failure in the area of dignity and avoidance of humiliation.<sup>13</sup> Such traditions are ethically unsustainable. Patients should have access to and choose to focus on any knowledge development they wish, even if the goal to which they agreed is patient self-management. Education can be intrinsically important; a person may value knowing something simply for the sake of this knowledge,<sup>3</sup> even in a field as instrumentally oriented as health.

### **Assuring people's ability to learn to care for themselves and family members and the clinical actions (such as the need for sheltered living environments) that flow from those judgments**

Caution is in order here. Of first concern is the accuracy of the judgment and consistency across patients in the same circumstances with the same or different providers. Such decisions are mostly based on the clinical judgment of the practitioner without the use of explicit criteria or objective measurement instruments, both of which are required in many areas of clinical medicine (blood pressure, temperature, etc.).

Criteria and measurements help to define the boundary of appropriate protection of patients who have not yet learned or cannot learn to self-manage. Accurate and well-reasoned judgments support the development of patients' capability to self-manage or choose an appropriate level of support. A supporter of the capabilities approach would argue that a threshold level of capability should be developed in all who need care; the choice to function with it should be largely up to the individual within a framework of his or her responsibilities.

### **Requiring identity change without the patient's permission**

Learning, especially in preparation for a medically-directed role change such as significant responsibility for self-management, can involve a change in identity. Faith in one's body, in one's ability to manage problematic situations, incorporation of pharmacologic and/or technical devices, and accepting ideas foreign to one's culture, all involve identity change. The feeling of integrity of the body and one's sense of competence may be invaded without a sense of affirmatives and under pressure of being labeled 'non-compliant'.

Requiring new beliefs without affording patients the respect to attend to current beliefs and neglecting to help them to incorporate these new beliefs into a new web of meaning leaves them between identities and not sure of direction. The capability of practical reason involves engaging in critical reflection about the planning of one's life, which is a process often repeated throughout life. Illness and adaptation to a new lifestyle or facing a serious or terminal illness requires this kind of reflection, assisted by the thorough understanding of the options and skills and self-confidence to carry them out, which is what patient education can provide.

## **Ethically contested uses of patient education**

Some common areas of patient education practice can be seen as ethically contested or as potentially important but within ethical limits.

### **Health promotion education**

Health promotion involves finding ways (including teaching) to improve the health of the individual, frequently through alteration of population-based risk behaviors such as exercise, diet and weight. It requires readiness to change and skills to perform new behaviors.

Libertarians would view health promotion as one of the many methods used by governments to regulate individual behavior using values that would not be chosen

by the individual, and 'blaming the victim' if the person is not successful in changing the behaviors or avoiding the disease. Some forces of health promotion seem to target and monitor individuals and could be viewed as a method of surveillance and control.

Paternalists, however, could see health promotion as necessary for protecting us from ourselves, to learn new knowledge, skills and attitudes, gain control over our health, and thus enhance our freedom. A suggested resolution is to place limits on the pressure to adopt 'healthy behaviors' and to empower people to transform themselves according to their own interests and on their own terms.<sup>14</sup> Such a resolution clearly depends on a developed capability to make one's choices and to withstand paternalistic pressures.

### **Manipulating patient beliefs, especially about outcome, in situations of uncertainty**

The starkest examples come from rehabilitation. Although we know clinically that response (outcome) to a specific intervention will be influenced by the patient's expectations of it, the question has apparently not been settled empirically. It has been suggested that patient beliefs are probably reducing rather than increasing the benefits that could be achieved from rehabilitation, thus justifying explicit manipulation of patient expectations in order to improve the outcome.<sup>15</sup> Is this a form of deception? Most clinicians know well of the despair of recently injured patients.

It is important to note that patients have many preferences and desires that they must sort out after a distressing event. The correction of factually false beliefs, assistance with careful reasoning, and acknowledgement of overwhelming emotions are accepted, but applying a decidedly positive spin to patient expectations about the level of recovery in order to obtain the benefit that those expectations may yield has not yet been agreed.

### **Lessons for the ethical practice of patient education**

The identified unethical or contested practices in patient education span the range of processes used in goal setting, expectations to be taught to patients, whether instruction is delivered and what it is, and decisions made on the basis of patient learning. The 'errors' include: the blind, and therefore unreflective, following of societal standards such as elderly people deserving fewer resources; or nurses' practice being defined by physicians with whom they work; or in turning a blind eye to the many patients who need education but do not receive it in the current health care systems.

The adoption of a human capabilities moral framework provides much better guidance than does the current conception of patient education as an instrument to carry out the directives of medical practice. Yet, further development of the capabilities framework is necessary. For example, what guidance can be given regarding how to set threshold levels and to what degree do we accommodate the current possibilities? Nussbaum<sup>4</sup> suggests setting the goal high enough to goad people to take intelligent action, but not so high that it makes the whole venture impossible. Are we to worry about inequities above the threshold?

## Summary and conclusions

Clinical care situations in which patient education is essential continue to expand. For example, much more cancer chemotherapy is now taken orally and administered by patients and families in a patient self-management mode,<sup>16</sup> requiring teaching them how to do so safely and effectively. In such situations, the potential for both benefit and harm is immense. To what standard of care for that patient education are practitioners held?

Theories in patient education have largely addressed learning and teaching. A moral framework to direct practice has not been well articulated. Nussbaum's capabilities approach provides one such framework, focused on the actual abilities of people to choose and act in their social setting. This implicitly acknowledges learning as a capability and as central to the development of all capabilities. Current practice contains a number of ethically questionable or contested approaches, which, when challenged, offer lessons for the more ethical provision of patient education.

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