

Understanding the Lived Experiences of Patients: Application of a Phenomenological Approach to Ethics

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This perspective article provides a justification, with an overview, of the use of phenomenological inquiry and the interpretation into the everyday ethical concerns of patients with disabilities. Disability is explored as a transformative process that involves physical, cognitive, and moral changes. This perspective article discusses the advantages of phenomenology to supplement and enhance the principlist process of ethical decision making that guides much of contemporary medical practice, including physical therapy. A phenomenological approach provides a more contextual approach to ethical decision making through probing, uncovering, and interpreting the meanings of “stories” of patients. This approach, in turn, provides for a more coherent and genuine application of ethical principles within the “textured life-world” of patients and their evolving values as they grapple with disability to make ethical and clinical decisions. The article begins with an in-depth discussion of the current literature about the phenomenology of people with disability. This literature review is followed by a discussion of the traditional principlist approach to making ethical decisions, which, in turn, is followed by a discussion of phenomenology and its tools for use in clinical inquiry and interpretation of the experiences of patients with disabilities. A specific case is presented that illustrates specific tools of phenomenology to uncover the moral context of disability from the perspective of patients. The article concludes with a discussion of clinical, educational, and research implications of a phenomenological approach to ethics and clinical decision making.

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Physical therapy continues to emerge as a health care profession whose central role is the ethical commitment to caring for patients with significant disabilities.¹ As greater numbers of people survive life-threatening disease and injury, greater interest has developed about the ethical meaning of long-term rehabilitation, the nature of clinical caring, and the healing qualities of physical therapy around the notion of disability.^{2,3} Yet, caring for patients with disabilities presents several ethical challenges for physical therapists.

Patients with significant disabilities due to spinal cord injuries, stroke, or closed head injuries experience both physical and psychic discontinuities.⁴⁻⁹ As a result of life-changing diseases and injuries, many patients with disabilities undergo transformations in their physical abilities and personal identity. These patients face changes in their social roles, including their family roles. Husbands may no longer assume their traditional role as “breadwinners” in the family. Patients with severe closed head injuries may exhibit childish outbursts of inappropriate behaviors, making it difficult for them to serve as proper role models for their children. Patients with long-term disabilities also may experience significant social stigma.²

The burgeoning field of rehabilitation and disability studies has raised some interesting questions regarding how we view disability. Some au-

thors argue that people with disabilities have the misfortune of being a minority living among an insensitive majority. Therefore, it is the civil right of people with disabilities for society to accommodate to their particular conditions.⁵ Yet, the need for physical therapists to move, as Purtilo¹ advocated in her Mary McMillan address, to acting on meeting society’s health care needs makes it particularly relevant for physical therapists to understand the moral concerns of patients with disabilities as they assimilate back into their communities.

As a result of these challenges, we believe that caring for patients with disabilities calls for a unique type of ethical reflection and decision making. The traditional approach to clinical ethics is to apply principles such as autonomy, beneficence, nonmaleficence, and justice using an ethical framework such as deontology or consequentialism to solve an ethical problem involving patient care.¹⁰

This type of ethical decision making tends to be rationalistic, detached, and fact oriented. For the most part, the principlist approach has been the accepted norm for hospital ethics committees addressing significant end-of-life issues.¹¹ Critics, though, point out that this type of approach is not as useful to uncover the changing moral concerns and ethical issues associated with long-term disability.^{10,12-17} Purtilo¹⁸ defined *ethics* as a systemic reflection of a person’s morality (values and beliefs about right and wrong and good and bad behaviors). She argued that, in the presence of moral conflict, ethical reflection uses special methods and approaches to examine moral situations. This type of ethical reflection necessitates exploring and uncovering the values and value conflicts embedded in the daily experiences of individuals living with disability. We agree with Purtilo, and, as argued below, we advocate for an

ethical reflection that focuses on uncovering and understanding the everyday moral concerns of patients living with disability who are undergoing rehabilitation. Understanding the everyday moral concerns of patients living with disability opens up potentialities for caring that most closely relates to the transforming values, concerns, and self-identity of those for whom care is provided. Ethics, in these instances, is, as Moules wrote, “a pause to wonder, to question, to step back and to notice.”^{19(p3)}

This type of ethical reflection should include the changing ethical concerns and needs of all stakeholders who are affected, including the patient’s family and the local community members, if possible. The intent is to uncover the manifold meanings of a patient’s illness experience from the perspectives of all relevant stakeholders, including the patient living with the disability.

How we do this type of reflection is the concern of this perspective article. The purpose of this article is to provide a framework for a type of ethical reflection based on phenomenology. We argue that a phenomenological approach to ethics can be used as a process of reflective inquiry that is fundamental in a human caring profession such as physical therapy. This type of approach will help us understand the experiences and ethical concerns of patients living with disabilities that are critical components of patient care. This understanding, in turn, is imperative to aid a patient adjusting to disablement and discovering a new self-identity. Reflective inquiry using the tools of phenomenology also has the potential to help us uncover or construct “clinical knowledge” that includes consideration and action directly linked to understanding the patient’s experience and meanings. Therefore, the tools of phenomenology, as argued in this article, help us under-



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stand the patient more fully and potentially are part of our clinical knowledge that is now either tacit or implicit.

The Nature of Disability

In the current World Health Organization model of disability (*International Classification of Functioning, Disability and Health* [ICF]), *disability* is defined as a limitation in or loss of a person's ability to participate in a social role.²⁰ The limitation in or loss of a person's social role includes the ability to participate in his or her vocation, hobbies, sports activities, or family role.

Some authors argue that limitation in social role functioning due to disability results partly from what society and its formal institutions consider socially important and willing to support.⁵ For example, legislation such as the Americans With Disabilities Act²¹ recognizes that potential discrimination directed toward patients with disabilities for future employment and access to facilities should be addressed proactively and encoded in law. The legislation underscores the social responsibility that members of society have to not discriminate against otherwise capable individuals based on their disabilities.

Notwithstanding society's roles in reducing potential discrimination for individuals with disabilities, changes in social roles that result from significant impairments in body function and structure and activity levels have a profound effect on a patient's moral understanding of his or her own identity and roles in society. People with disabilities, for example, are confronted with issues of re-identification and value transformation related to the people they were, who they are currently, and what they might become as they and their families come to terms with the nature and scope of their disabilities.⁹ Charon¹⁵ referred to patients with

life-changing disabilities as caught between stable states. Undoubtedly, rehabilitation for many patients and their families is characterized by periods of emotional and moral turmoil as they confront the meaning of their disabilities. Boylstein et al underscored this point, writing that a "chronic illness, such as a stroke, can lead to biographical disruption, about which people use narrative to reconstruct their self-identity."^{22(p279)}

Many patients undergo an existential loss of self and an existential awareness of loss, distortion, fear, and entrapment.²³ Entrapment can take many forms, including emotional and physical (eg, consider the previously active patient with a severe spinal cord injury who uses a wheelchair). This type of entrapment is illustrated in the following comments from 3 patients with spinal cord injuries who are in wheelchairs:

I didn't know what I was supposed to look like sitting in this chair. . . . I started buying clothes that were really big on me. I was trying to hide and get lost in the chair so that nobody would notice me.^{6(p276)}

It's not the freedom of being able to jump into the car and go wherever you want to go; you have to rely on public transportation. Also, I just don't have the freedom of doing a lot of spur-of-the-moment, spontaneous things.^{6(p279)}

I felt like I was looking into a mirror. I hated what I saw. I tried to pretend that I wasn't in a wheelchair and I wasn't disabled. In my heart, I didn't feel I was, but if I saw someone else in a wheelchair, it reminded me, like a big slap in the face.^{6(p277)}

Other authors describe the ontological assault on a person's sense of space and time that occurs in the presence of severe disability. In a qualitative study exploring the phenomenology of patients with strokes, one participant described her lived experience with changed mobility:

I wanted to get to the chair by the window. I just couldn't go to see the garden. It was always the same place that I stopped. I just do not seem to go any further. I thought I had been doing well.^{4(p305)}

Gadow⁸ described the dehumanizing effects that life-changing injuries can have in a person in terms of dissolution of the individual's embodied self. Her qualitative exploration of patients with severe stroke indicates that many of these patients experience an initial and often long-term feeling that their bodies are separated from their minds. She describes that, for most of us, the body is experienced normally as an aspect of self. More precisely, for most of us, in our normal daily activities, we experience no distinction between body and self. The result is that our embodied self has an immediacy of being in the world, "the feeling of being able to affect one's world and be affected by it as a unified whole."^{8(p88)} In patients with stroke, an inversion of the embodied self occurs. Instead of the self and body acting together, the self is felt acted upon by part of itself. The primary unity between body and self is disrupted, and the body obtains a new and often strange distinctness, in many cases as a force that needs to be governed or an object that needs to be overcome. Gadow described the dissolution of the embodied self as a disrupted immediacy experienced by patients with strokes. As she describes this relationship, patients with stroke often perceive their bodies in the same way that they experience the immediate world around them—as an objective and external reality apart from themselves. For these patients, the body often becomes a source of impediment to normal function. Instead of the body and self working as one, the patient with stroke often feels encumbered by his or her body.

This dichotomy between self and body has a profound impact on an individual's self-identity. How many of us have awakened from a deep sleep frightened because we have slept on a numb and useless arm. Thankfully, we shake it out, blood flow returns, and the arm starts to work under our control once again. Imagine, though, the patient with a massive spinal cord injury, for whom no amount of shaking (if possible) would restore a sense of feeling to a limb.

The sense of loss of control in cognitive and physical function can be overwhelming, as uniquely explored in an autobiography written by Claudia Osborn.²⁴ Osborn, who is a physician, wrote about her loss of control over her cognitive and physical functions after a closed head injury. Attempting to return to clinical care, she wrote about her existential angst as she realized she was a different person than before her injury.

The rules had changed, and everyone but I was privy to key information. I alternated between moments of anger and despair because I could not will myself to improve, then I quickly forgot both emotions until the next mishap, when I would relive the emotional cycle.^{24(p38)}

In summary, the quotes provided above illustrate ontological changes that occur within individuals who are forced to live with disability. These changes invariably will result in different ethical concerns that these individuals did not face in their daily life. By giving voice to patients' lived experiences, clinicians have the opportunities to uncover the changing ethical framework of patients in order to apply ethical principles that are consistent with the ethical concerns of these patients. The next section provides an overview of principlism, as it is currently understood in medical ethics.

Foundational Ethics: Principlism

Principlism is an approach to making ethical decisions that involves the application of ethical principles to solve ethical dilemmas. Table 1 provides a summary of definitions for the concepts described herein. Beauchamp and Childress²⁵ argued for the existence of a common morality that contains basic moral norms that bind all serious moral people. According to Beauchamp and Childress, the common morality contains moral norms that include 4 major principles: beneficence, nonmaleficence, justice, and autonomy. These principles are basic to biomedical ethics.

The 4 principles identified by Beauchamp and Childress²⁵ are role specific—they are duties that health care professionals owe to patients. They are sometimes called “mid-level principles” because they occupy a level of generality and abstraction below universal, foundational principles such as the principle of utility, or the categorical imperative.²⁶ According to the usual framework of the 4-principle approach, there is no intrinsic priority to any of the principles—they are all of equal weight or are *prima facie* duties that are considered always to be in effect.²⁵ Critics of principlism argue that the original principlist approach did not provide a framework of moral deliberation to help health care professionals choose one principle over another to solve an ethical dilemma.²⁷

In some cases, the principle of respect for autonomy (respecting the patient's right to refuse treatment) may conflict with the principle of beneficence (the treatment is medically imperative for an individual to recover function). In response to this criticism, Beauchamp and Childress²⁵ added several justificatory conditions for infringing on *prima facie* norms, including choosing a principle-

based approach that must be realistic, an approach that minimizes infringement of patient rights, or an approach that offers no other morally alternative action possible that would fulfill both conflicting principles.

Critics point out, despite the justifications, that the locus of certitude in applying principles is embedded in the particularities of a case. That is, although the 4 principles of Beauchamp and Childress' approach²⁵ apply in most cases, the particularities of the cases should influence their application and justification. Interestingly, Beauchamp and Childress agree that principles provide only an abstract starting point for making ethical decisions and argue for a process of specifying the particularities of conditions and context in the application of principles. The evolution of medical ethics toward case-based decision making, casuistry, narrative, ethics of care, and phenomenology underscores the recognition from many medical ethicists of the limitations of a pure principle-based approach, and the importance of the context and story to shape the ethical concerns and application of principles.^{4,8,12-16}

The question for many ethicists is how (and how much of) the case story should unfold. Should the case simply reveal the major facts and issues, or do we need more telling of the story through the voices and perspectives of the major stakeholders? For phenomenologists, it is clearly the latter case. We agree with the position of Wiggins and Schwartz²⁸ and Zaner,²⁹ who argued that clinical ethics takes on reality in the concrete and actual human relationships that exist among patients and their families, friends, physicians, and other caretakers. They see the application of principles, as we do, as simply the starting point for a much fuller set of moral considerations that remain particular to the patient's past, present, and future being.

Table 1.
Definition of Concepts Related to Phenomenology and Principlism

Concept	Definition
Phenomenology	The study of the meaning of experiences from an individual's own subjective perspective.
Consciousness	The subjective understanding of phenomena from an individual perspective.
Inter-subjective understanding	A broader interpretation of an understanding of a particular phenomenon from the perspectives of several individuals. In phenomenological research, inter-subjective understanding often is presented as unifying themes.
Epistemology	The study of how we know things.
Intentionality	Intentionality refers to the human condition that we are always conscious of our external world and always trying to make sense of our experiences.
Natural attitude	The natural attitude reflects our default position of our lack of attending to and making meaning of our daily experiences. Phenomenologists often point out that many of us function at a preconscious level of understanding. In other words, we take things for granted without reflecting about their meaning.
Phenomenological attitude	The phenomenological attitude refers to a conscious effort to recount and understand our lived experiences.
Bracketing	Bracketing is a component of our attitude in which we consciously identify our values and biases that influence our assumptions about patient care.
Respect for autonomy	Respect for autonomy "encompasses, at a minimum, self rule that is free from both controlling interference by others and certain limitations such as inadequate understanding that prevents meaningful choice." ^{25(p99)}
Beneficence	The principle of beneficence refers to our moral obligation to act for the benefit of others. This obligation may include protecting and defending the rights of others, preventing harm, removing conditions that will cause harm to others, helping people with disabilities, and rescuing people in danger. ²⁵
Nonmaleficence	The principle of nonmaleficence imposes an obligation not to inflict harm on others. Rules specifying the principle of nonmaleficence include: do not kill, do not cause pain or suffering, do not incapacitate, do not cause offense, and do not deprive others of the good life. ^{25(p153)}
Justice	The principle of justice obligates us to treat like cases alike; distribute benefits and burdens fairly.
Deontology	Ethics based on one's duty.
Consequentialism	Ethics based on weighing the best or most optimal outcomes for all parties involved.
Categorical imperative	The Kantian philosophy that enjoins us to act in such a way that we can also will our act to become a universal law.
Principle of utility	The principle that requires one to balance benefits and drawbacks to produce the best overall results.

Phenomenological Ethics

The experiences of patients living with their disabilities described above were revealed through phenomenological conversations. Phenomenology, as argued here, is predicated on understanding the experiences and the "everyday ethics" of how a person lives with disability from

that individual's own viewpoint. This type of perspectival understanding, we believe, will best determine lived experience with disabilities. The following section provides a brief overview of phenomenology.

Phenomenology began with the writings of Husserl³⁰ as a philosoph-

ical movement in the early 20th century. An in-depth description of his philosophy is well beyond the scope of this article. There are, however, certain concepts of his phenomenology that have relevance for our discussion. Husserl's philosophical quest was to explore how individual *consciousness* is formed. His episte-

mology can best be described as skepticism of inter-subjective understanding of external reality. Put more simply, he doubted that we all experience external things and events in the same way. Instead, Husserl believed that the ideas and meaning we develop come from our experiences and our reflection about things in the world. That is, we are highly *intentional* beings. Husserl was not alluding to the ordinary usage of “practical intending to do something.” Rather, he was alluding to *phenomenological intending*—the belief that we have a conscious relationship with an object, either external or in our memory, which we interpret and develop meaning about. The basis of intentionality indicates that every act of consciousness we perform, every experience that we are conscious of having, is an experience of something or other. Sokolowski wrote about intentionality:

All our awareness is directed toward objects. If I see some visual object, such as a tree or a lake; if I imagine, my imagining presents an imaginary object, such as a car, that I visualize coming down a road; if I am involved in remembering, I remember a past object; if I am engaged in judging, I intend to a state of affairs.^{31(p8)}

What is particularly important about intentionality is that it elevates experience of things to the forefront of knowing. Phenomenology raises the questions:

- What is my patient’s daily experience like?
- How does my patient’s lived world present itself?
- How does my patient reconceive his or her values in light of his or her disability?
- What do those reconceived values mean for caring for this patient ethically?

More simply put, phenomenology helps us to understand what an indi-

vidual is experiencing and how. From an ethical standpoint, the goal is to uncover the moral predicaments and everyday moral concerns inherent to the patient’s illness experience. It is at that point of understanding that we can more fully and accurately assess which principles may apply to a particular situation and how.

Like Dewey,³² Husserl³⁰ believed that consciousness and meaning about things are made through and in experience. We are constantly in a reciprocal relationship with our experiences of external reality. Subjective knowing cannot exist without objective experiences. Husserl referred to our subjective-objective life as part of our life-world (*Lebenswelt*). Therefore, to understand our subjective meaning of things, we have to explore our experiences (our intentionality). Part of how we do that, according to Husserl, is to disengage temporarily from our natural, everyday attitude about things and move toward a phenomenological attitude of self-reflection. Similarly, Dewey would argue that we do not learn from experience alone, but from thinking about our experience.

Natural attitude is the viewpoint we assume of everyday life. Some may call this the *default position*, others the *nonreflective position*. Heidegger,³³ a protégé of Husserl, talked about a *prereflective attitude*. What he meant by this attitude is that often we do things so automatically that we fail to reflect on them, or we do things when we are not particularly conscious of what we are doing. In this attitude, experiences sift through our subconsciousness, influencing, unawares, our behaviors. The goal of phenomenology is to shift our and our patients’ viewpoint from the everyday, natural attitude to refocus in a reflective way. We want to help our patients (and ourselves) to examine and describe our

internationalities associated with their everyday experiences and their subjective correlates.

The importance of phenomenological exploration of the illness experiences lies in its ability to increase our broad understanding of boundaries, limits, and responsibilities as health care professionals. Jaeger,¹³ for example, argued that phenomenological reflection opens up the possibility of understanding the contextual and embodied understanding of one’s particular predicament. Eventually, understanding multiple patient perspectives may open up the possibilities of broader understanding of patient experiences with particular disabilities.

Benner et al³⁴ saw the goal of interpretive phenomenology as to uncover and understand the meaning of one’s experience in his or her own terms by being critically reflective and engaging in a dialogue between practical concerns and the lived experience of the patient. Kestenbaum³⁵ asserted that phenomenology captures the humanness that is central to the illness experience. Phenomenology, he argued, seeks to suspend the habits of mind inculcated through medical training based on a rational and detached process of decision making from the medical viewpoint. For example, attending to a patient’s discourse about her changing experiences during her process of disablement enables us to understand her shifting values, her transforming identity of herself and her place in the world, her changing moral and ethical concerns, and her own relationship between her dimensions of human suffering and the cultural and structural contexts in which they occur. That is, as Benner et al pointed out, it is within her own terms (and not ours) that we reconstruct meaning about her illness experiences. It is, necessarily, within the context of these

Table 2.

Applying a Phenomenological Approach to Ethics Cases: Key Concepts

Key Concept	Application/Sample Questions
Phenomenological attitude	Explore the meaning of the patient's circumstances from the patient's perspective. What do I believe about this patient's experiences with his or her injury or disability is motivating his or her behaviors?
Identify own biases (bracketing)	What do I believe are the experience of patients with this injury in general?
Thick description of patient's experiences	Facilitate the patient's description of his or her experience with his injury or disability. What is it like to live in a wheelchair? Describe your daily experience.
Identify key themes of meaning for this patient	What are the main ideas that my patient is expressing? What are the "meanings" about self that are emerging? How do these meanings of self fit with ethical principles that are embedded in the care of this patient?

changes that we are able to uncover everyday ethical concerns that may remain hidden with a more rationalistic and detached process of decision making.

Phenomenological Attitude

The question for health care professionals is: How do we shift into a phenomenological attitude with our patients? The following case taken from Kuczewski and Pinkus³⁶ provides a useful example to compare the traditional principlist approach and the phenomenological approach to the moral concerns of a patient with spinal cord injury. Table 2 provides the key constructs of phenomenology applied to this clinical case.

Mr X is an inpatient in a rehabilitation hospital. He is a 70-year-old man with a history of an L5 spinal cord injury that occurred 1 month ago due to a motor vehicle accident, which has left him as a lower-extremity paraplegic confined to a wheelchair. Mr X was formerly a proud steelworker. A history of chronic pain contributed to his decision to take to an early retirement buyout from a local company about 10 years ago. Since his retirement, Mr X has gained a great deal of weight, although 2 attempts to control it resulted in significant weight losses. Mr X's lifestyle includes occa-

sional alcohol consumption, and he smokes a pack of cigarettes each day. His medical history also is significant for rheumatoid arthritis and chronic obstructive pulmonary disease.

Mr X's mood is quite variable. It is observed that when he goes to his various therapies, he participates well and seems to make some progress. Unfortunately, Mr X sometimes refuses therapy, stating that it is "[expletive deleted] awful that he had to be taken care of like a little baby" or that his pain is too much that day. When asked by the nursing staff why he is not going to therapy, he sometimes says, "What's the use?"

Mr X has a 33-year-old son, Skip, who is a banker. Skip is married with 2 children. He says that his father was always a fighter. Skip says that he believes his father can be so again. If Mr X can get to the point where he can take care of most of his daily living functions ("If he just doesn't stay in bed all day," says Skip), Skip and his wife would like Mr X to live with them. If not, Mr X will have to find some sort of a structured living situation.

As it stands based on principlism, the case concerns the scope of a patient's autonomy to refuse treatment, which conflicts with the obligation of the medical staff to act

in the patient's best interests. Approaching this problem, a principlist would consider which principles apply, how we might specify those principles based on the issues in this case, and how we might apply moral theories to those principles. In this particular instance, from the viewpoint of a detached and rational process of decision making, the medical team might draw upon a mixture of deontologism and consequentialism to arrive at a solution. For example, the medical team may frame their discussion with Mr X based on their preconceived notion that their duty, in the best interests of the patient, is to encourage him to attend therapy. To the extent that the medical team views their duty of beneficence as more important than their obligation to honor patient autonomy and the right to refuse treatment, the medical team can justify acting paternalistically toward this patient. The rationale for this approach is that this patient has not had sufficient time to adjust to his disability and is unable to make a proper value judgment about his choices. In any event, the medical team may be making assumptions about what ethical concerns are important for this patient, when, in fact, the medical team, the

patient, and the patient's family have not had opportunities to explore the meaning of their circumstances.

Let us now propose a different way of reflecting or deconstructing about this case. Based on the shift to a phenomenological attitude, the health care team prepares to see the world differently. That is, the rehabilitation team members must be willing to explore the experiences and their meanings from the perspective of the patient.³⁷ To do this, the health care team must first address their own biases or preconceived ideas about what is occurring and what course of action is most appropriate, based on their obligations. A process of *bracketing* or a filtering process occurs.³¹ In this process, originally identified by Husserl³⁰ as *phenomenological epoche*, the health care team members should discuss their beliefs and assumptions about this case and try to hold them in abeyance in order to be open to phenomena of the lived experiences of this particular patient as he recounts and explores those experiences. In effect, the process of bracketing requires that we set aside our own personal values and beliefs to focus on the values and beliefs of another individual. This process requires a commitment of ongoing self-reflection about our own personal and professional values. Part of this self-reflection can take the form of an internal dialogue with oneself or, as mentioned, an external dialogue with colleagues about each other's values and beliefs pertaining to patient care and practice. Either circumstance, we believe, is critical to phenomenological understanding of another individual.

In phenomenological ethics, we must be open and willing to set aside time to engage in dialogue with ourselves and then with our patients in an ethics of reflection and listening. This course involves respect, a cer-

tain humility, sensitivity, and flexibility. Simply put, we must be able and willing to step out of our professional role. Stepping out of our professional role requires some explanation toward our understanding of the clinical encounter based on phenomenology.

Physical therapists, like most health care professionals, are trained to develop clinical judgments based on a medical framework of patient diagnosis (whether that is a medical or impairment-based diagnosis) that is expressed in the patient's own everyday language. Zaner²⁹ suggested that most physicians mistakenly listen to a patient to identify a locational index that frames the patient's story within his or her medical framework. Misunderstanding results when the patient's interpretation of experiences is displaced by the health care professional's interpretation. Rather, phenomenological discourse offers an authentic understanding of the patient's existential predicament of his or her disability that is grounded in his or her own life experience, shaped through his or her own voice, tempered by his or her own emotions and feelings, and embedded in his or her own values. Stepping out of one's professional role, then, depends upon the willingness of the clinician to hold in abeyance his or her own biases about a patient and be willing to listen to the patient's whole story in his or her own voice to allow his or her own life-world to reveal itself.

Finally, Zaner²⁹ reminded us that ethical issues often are deeply buried and rarely recognized as such within the experiences of patients. It often is the case that we can best uncover these ethical issues by not directly talking about them. That is, indirect discourse, and allowing the patient to talk about whatever is important to himself or herself—regardless of however seemingly trivial you may

think it is—may be the best way to go about understanding things human, especially in the matter of ethics. In the case of Mr X, what would fit the idea of indirect discourse is not to directly talk about the ethical issues involved, or rather talk about them by never talking about them. The therapist would just give him a chance to talk, to come to what was bothering him in his way, in his own voice, and at his own pace.

Phenomenological ethics reminds us about the potential of our relationship with our patients as human beings. Daly wrote:

Morally speaking, the caregiver is neither superior nor better nor even necessarily at an advantage. As a matter of fact, the caregiver not only must understand himself or herself as equal to the care receiver, but...the act of caregiving ought to be as perfective and changing of the caregiver.^{38(p34)}

In this case, the caregiver should take some time to reflect on his or her assumptions and beliefs about this case and the patient's motives, the issues involved, and possible methods of resolution. The caregiver may ask himself or herself:

- What is it I believe about this patient's experiences with spinal cord injury and paraplegia that is motivating his behaviors?
- What do I believe are the experiences of patients with paraplegia and with disabilities in general?
- What do I believe are the experiences of a patient with spinal cord injury and paraplegia undergoing rehabilitation?
- What is it that I believe is the proper course of action in this case?

In the case of Mr X, a once proud and independent man, a phenomenological exploration of these questions might have revealed his terror about the loss of control of his life, his

uncertainty of whether a future without independence held any meaning, and his belief in the limits of a medical cure to reverse his condition. Further exploration might reveal what Gadow⁸ termed the “disrupted immediacy” of his body from his self. Many patients with spinal cord injuries face the existential angst of the incapability of the self to control the body, the sense of a changed spatial reality that confinement to a wheelchair presents (eg, “I must look up to everyone like a child”), and the vulnerability of relying on others for basic human needs. In such a case, the primacy of autonomy often is trumped by fear of humiliation and the need for reaffirmation of respect.

In the next step, the health care team and caregiver make a conscious effort to uncover the experiences of the patient in his own words and with little prompting. The initial goal is to develop “thick description” of the patient’s experiences. As much as possible in an initial interview, the caregiver wants to determine the way things present themselves to Mr X and through his own experiences. To do this, the caregiver should begin with very broad and open-ended questions (eg, “Mr X, describe your lived experiences of your spinal cord injury?” “What is it like to live in a wheelchair?” “Describe your daily experiences in rehabilitation?”). This manner of dialogue places greater value on embedding understanding in concrete experiences over asking more general, abstract questions that lend themselves little to uncovering the subjective understanding of Mr X’s illness experiences. The process should be iterative. The caregiver should explore ideas and examples in as much concrete detail as possible. The importance of language becomes paramount. The caregiver should listen for particular uses of metaphors to describe experiences that may represent complex thought processes that reflect the patient’s

understanding of embodied concepts and his or her reality of daily life.³⁹ Changes in the use of language and metaphor over time can help the caregiver determine changes in a person’s recovery experiences and self-identity.

As the narrative emerges, the caregiver should probe emerging ideas for clarification. The goal at this point is to identify dimensions and aspects of indented experiences. For example, the caregiver may question Mr X about how he views his current experiences in rehabilitation in view of his past life and future expectations.

The final stage of phenomenological understanding involves developing some thematic understanding of the patient’s experiences. The caregiver should ask himself or herself: What are the main ideas Mr X is expressing? How do these ideas reflect his lived experiences? In this stage, it is important for the caregiver and the patient to continue to move back and forth between interpretation and his lived experiences and their meanings. Further questions to clarify include: What are the philosophical assumptions about self that are emerging from Mr X’s stories? and How do these assumptions of self as “changing from what was” reflect my own perceptions of caring for this patient? Finally, how do the caregiver’s philosophical assumptions of self stand behind most of the central ethical principles we use to direct ends and procedures of health care?

In summary, a phenomenological approach may result in a deeper understanding of Mr X’s and Skip’s world, which, in turn, could facilitate the development of a mutual plan of action that is embedded in the values and goals of the patient and his son. In contrast to the principlist approach based on deduction, the phe-

nomenological approach provides an alternative approach that is inductive, contextually based, and involves an iterative process of decision making. Most importantly, the tools of a phenomenological approach are particularly sensitive to uncovering the transformative nature of disability.

Implications

The importance of phenomenology to a human caring profession such as physical therapy underscores the importance of the connection between caring and exploring the lived experiences of patients with disabilities. To care for patients with disabilities, for example, the physical therapist combines cognitive decision-making processes to correctly identify and prioritize relevant impairments and functional losses to be treated. Treatment interventions, in turn, are influenced by clinical judgments, experience, values, and the best current evidence. In addition, many authors have pointed out that the nature of the moral relationship that is built between the therapist and patient^{40,41} fosters the emotional climate of trust and respect that has a direct impact on patient care and outcomes.^{42–44}

Research that has explored the nature of caring demonstrates that experienced and expert physical therapists have embraced a broadly construed vision of caring.^{45,46} For many physical therapists, an ethic of caring defines their approach to patient care. This type of ethical commitment to caring values the human experience associated with the patient’s suffering. An ethics of caring opens up the possibility of making an empathetic connection with patients in order to make ethical decisions that reflect the totality of their emotional and physical needs.

Empathy, in turn, disposes individuals to ongoing communication with

patients and reflection about their changing conditions and needs. Rogers⁴⁷ described empathy as being sensitive to the changing felt meanings of another person. Davis⁴⁸ described a phenomenological empathy that involves a unique moment of shared meaning between 2 people that is based on a deep, committed form of listening. Peloquin⁴⁴ described empathy as an expression of connecting deeply with another person by entering into his or her own experiences. Both empathy and caring, like phenomenology, acknowledge the importance of being other directed, accepting feelings as part of practice, acknowledging the different contextual factors that influence illness experiences, and being willing to take time to listen deeply and openly to the meaning of others.

What we believe sets phenomenology apart from caring and empathy is it's recognition that phenomena occur everywhere within a person's experience. As a result, from a phenomenological approach, we are careful not to assume that any experience as we care for our patients is too trivial. An ethics of caring reminds us of the importance of context in caring. The tools of phenomenology provide an iterative process of embedding meaning in an individual's unique experiences. An ethics of caring provides the moral impulse to connect with our patients as fellow human beings in need. The tools of phenomenology, as described below, allow us methods to do so as one person caring for another person.

In physical therapy, we acknowledge that there are aspects of our work as physical therapists where understanding the patient's experience, the belief and value system of the patient, or the context of the care delivery is important in patient care, but as a profession, we remain too comfortable with and committed

to analytical reasoning and knowledge creation through that analytical process. We are not alone in this struggle. Sullivan^{49(p250)} argued that this strong emphasis in professional education on formal analytic reasoning leaves out one of the most essential elements of expertise: the act of inquiry in the context of the relationship in practice (reflection).

What should we do in our educational programs and clinic practices to integrate core elements of a phenomenological approach as part of practice? In this article, we focus on the role of phenomenological framework for ethical reflection. Exploration of the lived experience of the patient is a core component, but it is more than asking the right questions and listening to the patient's responses. Although procedures and skills are important, interpretative phenomenology is guided by an ethic of understanding and responsiveness to the needs and goals of patients. In this way, phenomenology has similarities to an ethics that is based on caring. The connection to an ethics of caring is particularly important for best practice based on previous research that has examined the characteristics of experienced and expert physicians,⁵⁰ nurses,⁵¹ and physical therapists.⁴⁶ These studies have universally demonstrated the importance of contextual understanding of patients' experiences with illness in ethical and clinical decision making.

This discussion leads us to the question of the impact phenomenology has on clinical reasoning. Edwards and colleagues⁵²⁻⁵⁴ described 2 clinical reasoning strategies in physical therapy. One strategy is *diagnostic reasoning*, which is the formation of a diagnosis related to a patient's physical disability or functional limitation and associated impairments. This hypothetic-deductive process of diagnostic reasoning has a strong

presence in physical therapy. The second strategy is *narrative reasoning*, which maps out the landscape between the patient's actions and motivations. Narrative reasoning involves understanding the patient's story—his or her illness experience and its context and his or her beliefs and values. This strategy involves an interpretive paradigm, similar to phenomenology, focusing on context-dependent and subjectively constructed knowledge (about phenomena). Like a phenomenological approach, this reasoning strategy is consistent with the therapist's ability to listen to the patient and to fully understand the patient's lived experience. Embedded in narrative reasoning are aspects of caring and empathy, as the therapist must be open to a committed form of listening and acknowledging and accepting feelings (patient's and therapist's) as part of practice. It is the making of a history through patients telling their story that represents their interpretation of their experiences and events over time.

The tools of phenomenology offer strategies for developing students' narrative reasoning skills. As previously indicated, we believe that these skills have to begin with a focus on self (one's own phenomenological attitude). This belief follows the logic that one cannot fully connect with patients and engage in a process of reflection without the ability to engage in critical self-reflection.^{55,56} Phenomenological bracketing (Tab. 1), as a way of filtering one's own perspective and prior experiences to control bias, provides a tool for educators to use with students to facilitate self-awareness critical to reflective practice and understanding of the patient's perspectives. Reflective inquiry is an important meta-cognitive skill that needs nurturing and development in professional education. The phenomenological practice of solic-

iting “thick descriptions” of experiences, both one’s own and of others, is an important tool to embed reflective practice in concrete experiences. Students are taught that meaning is embedded in experiences and that to fully understand meaning is to uncover experiences. This process facilitates habits of reflective practice that pay great dividends for the future development of reflective skills.⁵⁷

These processes of self-reflection can be facilitated by reflecting together between a student and clinical instructor at the moment of a clinical encounter or small-group discussion. Part of this reflection includes the identification and understanding of emotions as steps in strengthening novices’ capacity to hold on to and name their own emotional experiences and having students uncover the emotions they are feeling rather than telling them what they should feel or should have felt when interacting with patients or others (eg, empathy, compassion).

Simulations or standardized patients provide learning opportunities for novices to interact with simulated patients or real patients in a clinical situation, experience emotions in a safe environment and then reflect on their experiences in their own words.^{58,59} Reflection on emotions emphasizes the relationship between a student’s behaviors or words that begin or trigger an emotional response. By openly acknowledging that different emotions are evoked in different circumstances, novices have an opportunity to reflect on their emotional repertoire in a way that is encouraging and safe. Although some people may argue that emotions are a somewhat fragile platform upon which to build heavy obligations such as moral duty or care, it is by attending to emotions we can see that they highlight certain aspects of a situation. The reflection

on this experience can serve as a mode of communication, lead to deeper self-knowledge, and provide insight into motivation.⁵⁹ Grounding and naming emotions in specific examples from novices’ and experts’ experiences in clinical practice begins to create a framework that legitimizes this component of the self in one’s professional role. Novices then can examine, question, and develop their skills in emotional sensitivity—an important part of ethical comportment and caring for others.⁵⁹

Another educational strategy related to phenomenological approaches also acknowledges the importance of language and metaphoric descriptions of illness and disability. Phenomenology opens up the possibility of exploring metaphors with students as they begin to engage in patient interaction. Students can be taught to identify patterns of metaphors that patients use to impart meaning to their experiences. Students and professors can review previously described studies that explore the metaphoric understanding of disability from the perspectives of patients with strokes or spinal cord injuries.

The tools of phenomenology also provide a link between ethical and clinical reasoning that is embedded in everyday practice. Clinical education is instrumental in training professional health care workers to foster the practical application of knowledge, including practical reasoning. Benner and colleagues³⁴ used observations and narrative accounts of actual clinical examples as primary tools for understanding everyday clinical and caring knowledge and practical reasoning that occur in nursing practice. Finally, Benner and colleagues argued that it is not possible to separate clinical and ethical reasoning, because good clinical judgments reflect good clinical practice. Although biomedical ethical

principles and procedures such as ensuring the autonomy of the patient, informed consent, justice, beneficence, and nonmaleficence are important, they must be translated into good practice. Expert practitioners are motivated to do excellent work along with their moral obligation to help other human beings. According to Benner et al:

Learning to make good clinical judgments and be a good practitioner requires ongoing experiential learning, reflection, and dialogue with patients and their families. . . . Nursing, like teaching, medicine and social work, and other helping professions, depends on solidarity with one’s fellow human beings and on professional standards of beneficence and nonmaleficence for helping people during periods of vulnerability and distress—this is what it means to be “good” at one’s work.^{34(p17)}

Just as we have advocated that the tools of phenomenology have great relevance in education, they also have significant implications for research in physical therapy. Although expert clinicians may have great insight and skill in understanding the lived experience of their patients, little of that “narrative understanding” has been uncovered and codified in our literature. Much of that rich clinical knowledge remains tacit. In daily practice, skilled therapists engage in a situation, take action, and through reflection in action, continue to build their tacit knowledge.⁵⁹ There is great need for applying a phenomenological approach and crafting questions that would uncover the “narrative understandings” that emerge from the exchange and collaboration between patient and therapist. Imagine what we may find out about the work of physical therapists if we developed clinical case knowledge that is based on understanding the patient’s voice? How could we better hear that voice? Although the analysis of clinical cases is an essen-

tial structure and tool in ethics, there are many ethical considerations that are woven into the context of practice that remain implicit. It is only by expanding our set of research tools beyond the "traditional hammer" that we will be able to uncover this important practical knowledge.

Conclusion

Physical therapists are health care professionals who have a central role in rehabilitation and working with people with disabilities. As such, physical therapists need skills that will help them develop a rich understanding of the physical, cognitive, emotional, and moral changes and challenges that arise with individuals who have disabilities. We are not well served by a rational, principlist approach to ethical issues that excludes the possibility of contextual understanding from the perspectives of our patients.

At the very least, a starting point to apply principles to navigate ethical decisions should be the story of the individual. Phenomenology uncovers the patient's values and goals embedded in that story as they pertain to his or her direct experiences. Through these stories, we are reminded that disability is not an illness that is cured by medical intervention or rehabilitation, but it is the social and context issues that are paramount. Through our patients' stories, we also are made aware of the transformative nature of disabling conditions that challenges us to be sensitive to the changing web of values accompanying the changing physical conditions of our patients. We believe that the physical therapy profession would benefit by increased exposure to and dialogue about the role of phenomenological inquiry and interpretation in the everyday life and concerns of people with disabilities. Phenomenology opens up the possibility to capture the transformative nature of disability

better than other approaches. As a result, phenomenology opens up unique possibilities for student education and research that reflect a patient-centered approach to, and an ethics of, caring.

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Invited Commentary

Laura Lee Swisher

It is a privilege to provide commentary on the article by Greenfield and Jensen.¹ There has been extensive debate within medicine about the dominance and adequacy of principlism,²⁻⁹ but there is limited discussion of its strengths and weaknesses in the physical therapy literature. Indeed, one could argue that animated discussion about appropriate ethical decision-making models and their philosophical underpinnings is long overdue within physical therapy. The authors undoubtedly have initiated an important dialogue regarding ethical decision making within physical therapy. In this commentary, I will address specific issues raised by

the article within the context of the following broader concerns in physical therapy ethics raised by this important contribution by Greenfield and Jensen: the importance of expanding scholarship in physical therapy ethics, the moral import of disability, evaluating the value of the dominant Western principlist model of ethics for physical therapy, and hearing the patient's voice through dialogue and partnership.

Expanding Scholarship in Physical Therapy Ethics

Greenfield and Jensen point to the need not only for additional scholarship in physical therapy ethics, but

also for a different focus for this scholarship. Pellegrino defined *ethics* as "a branch of philosophy; it is not a set of visceral sensations arising somewhere in the solar plexus and suffusing the frontal lobes with 'good' or 'bad' feelings. Ethics is a formal, rational, systematic examination of the rightness and wrongness of human actions."^{10(p65)} Although the majority of the physical therapy ethics literature has focused on applying ethical principles to specific cases or problems, Greenfield and Jensen invite us to broaden the worldview of physical therapy ethics and address the adequacy of philosophical frameworks that undergird