Health care reform is currently in the forefront of pressing social, political and economic issues. There is the wavering hope that, in the midst of this bureaucratic turmoil and market language, all types of health care services will be available when needed. But, there is also an uncertain fear that when these services are needed, they will not be accessible.

Another aspect of contemporary health care delivery which generates frustration, anger, and perhaps, litigation, is the 'indignities' of being a patient. The person afflicted with an illness may be designated as a consumer of services, a client, or traditionally, as the patient. However, these role-descriptive terms do not capture or even suggest the meaning of illness for the person. It is not surprising, then, that those afflicted with illness are now telling their stories of what it means to them to be sick. Their self-revelations are poignant as they introduce the healthy to their inner world. This paper examines the importance of these stories for the health care professional-patient relationship. It is ethically important to attend to the experience of illness by the patient.

Current literature on professional caregiver/patient relationships characterize them along a spectrum from being a contract to something much deeper and profound. For instance, Eric Cassell describes the most skilled practitioner as one who "raises the relationship to an art, not only encouraging its growth and promoting trust and faith on the part of the patient, but negotiating between intimacy and separateness, between empathy and objectivity."1 Notice that he is describing the

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relationship from the caregiver's point of view, not the sick person's perspective.

S Kay Toombs, a philosopher and a person living with multiple sclerosis, explores the different perspectives in the physician-patient relationship in her book *The Meaning of Illness*.²

She explains that it is particularly difficult to establish a shared world of meaning between the physician and the patient because of the failure of the 'interchangeability of standpoints.' Toombs goes on to note "that the physician and the patient apprehend illness from within the context of separate worlds, each providing its own horizon of meaning."³ One concept which she develops is 'focusing.' Both the patient and the physician attend to the patient's illness, but each one focuses on different aspects of the experience. The physician seeks to understand the illness in terms of particular disease states while the patient is experiencing the bodily effects and the impact on day-to-day life.

Physicians and other professional caregivers are recognized as being 'professional' because of their specialized knowledge. One goal of their education is to develop certain 'habits of mind' which create a horizon meaning and a 'system of relevances' in order to interpret 'reality.' These particular 'habits of mind' also contribute to the establishment of the culture of the profession.⁴ Thus, the designation of 'expert think,' unique to each profession and to variations within the dominant schools of thought within each profession.

Even though medical education is changing and many physicians respond to their patients in alternate ways, it can be said that there are 'habits of mind' of the medical profession regarding the apprehension of illness. When encountering a person who claims to be ill, the physician will respond in terms of his or her training and the goals of the profession. Often, this approach means taking a medical history, establishing a diagnosis, a prognosis, and a treatment plan. In the scientific medical model, the individual is assumed to be healthy when clinical tests appear within normal ranges. Disease may be indicated when the objective tests deviate from the norm. The clinical goal is to treat the disease and alleviate the symptoms. One of the reasons that


³ Ibid., 10.

⁴ Ibid., 10-11.
What is it Like for You?

This medical model is still influential is that, in many situations, it works well. The subjective reality of the patient as person is not factored in by the physician or patient in the cause of illness or the treatment.

Nursing, as a profession, also has its 'habits of mind' and 'systems of relevances.' An often cited claim is that nurses account for the 'whole person' in relationship to his or her environment. One nurse explains that:

the goal of nursing focuses on the quality of life as perceived by the person or family. The nurse guides changing health patterns that shape the quality of life, while recognizing the authority and decision making power of the person or family.⁵

Ideally, if this theory could be put into practice, patients would be well served. Clearly, there are many models of nursing theory which attempt to overcome the sick person's experience of being treated just as a body and acknowledge the subjective reality of the patient as person. However, these 'habits of mind' assume too much. Just as the physician and the patient find it difficult to communicate about the experience of illness because there is not a basis of a shared set of assumptions, nursing theory, even with the explicit intention of assisting the patient to make choices out of his or her unique experience of illness, does not share the same basic set of assumptions with the patient. A recent Canadian study found that in caring for critically ill patients without explicit advance directives (and often for those who do), nurses and doctors make decisions based on their own ethical, social, moral, and religious values as well as their own work experience. In addition, it was found that there was great variability in what level of care may be chosen when the caregivers were asked what they would provide to twelve hypothetical patients with different medical conditions.⁶

The assumption that professional caregivers are able to communicate readily with patients about illness on the basis of a shared understanding may in fact leave the patient more isolated. Toombs asserts the "unshareable characteristic about illness . . . derives from its being


an inner, rather than an outer, event."7 There are many 'inner' effects of illness for a person. First, the person relates to her own body differently. The body is separated from the self. It is objectified. The person/self has to deal with this body which may be the source of pain and loss of function and eventually will die. Depending on the bodily disruption, the body may become an 'oppositional force' (beyond the control of the self — loss of motor function) or even a malevolent force (threatening one's dignity — loss of bladder function). The illness may cause a disruption in the day-to-day life of the person, affecting personal and social relationships and the ability to work. There is no easy access for the professional caregiver to know how the illness has affected these aspects of a person's life. As well the experience of pain by the patient is not easily shared. Elaine Scarry explains:

When one speaks about 'one's own physical pain' and about 'another's physical pain, one might almost appear to be speaking about two wholly distinct orders of events. For the person whose pain it is, it is 'effortlessly' grasped (that is, even with the most heroic effort it cannot be grasped): while for the person outside the sufferer's body, what is 'effortless' is not grasping it (it is easy to remain wholly unaware of its existence; even with the effort, one may remain in doubt about its existence or retain the astonishing freedom of denying its existence; and finally, if with the best effort of sustained attention one successfully apprehends it, the aversiveness of the 'it' one apprehends will only be a shadowy fraction of the actual 'it.')8

In addition, illness affects the sick person’s experience of time and space. The sick person has to live with two experiences of time. In order to communicate with caregivers, there is the need for the patient to communicate in outer 'objective' time. However, illness is experienced in terms of inner time. The sick person has to contend with waiting for the test results, getting through the night, and counting the hours for the next dose of pain medication. The effort it takes to live through the inner time remains a private and isolated task for the patient.

Orientation to time changes with certain illnesses. Goals set when healthy may no longer be attainable. A person facing a life threatening illness may feel that she has lost their future altogether. Or time may

7Toombs, The Meaning of Illness, 23.
expand, as previously simple tasks such as getting dressed or eating may take hours to accomplish.

Illness may also alter the sense of space. A person orients themselves in terms of the space around them. However, when a person is sick, his functional space may involve lying in a hospital bed or trying to manoeuvre in a house which has been altered to be wheelchair accessible. Instead of standing face to face with others, the sick person must look up from a sitting or lying position. Toombs notes:

To be able to 'stand on one's own two feet' is of more figurative significance. Verticality is directly related to autonomy. Just as the infant's sense of autonomy and independence are enhanced by the development of the ability to maintain an upright posture and 'sally forth' into the world unaided, so there is a corresponding loss of autonomy which accompanies the loss of uprightness.⁹

The inability to stand vertical leaves the person with the feeling of helplessness and dependency.

Eric Cassell distinguishes between the pain and the suffering caused by the illness. He states that one suffers, not necessarily when one is in pain, but when there is a threat to the integrity or intactness of the person. Suffering can occur in any aspect of the self. Suffering is alleviated when the threat is lessened. He goes on to note that usually the patient and the general public believe that health care should be about relieving suffering, but little preparation and education takes place to help health care professionals sort out what suffering entails beyond physical pain.¹⁰

Working Toward a Shared World of Meaning

What can the health care professional do with the patient to address the different standpoints and 'habits of mind'?

1. Recognize that the patient has a lived experience of illness which is different from the medical description of the illness.

The illness is experienced as a loss for the patient: a loss of wholeness, certainty, control, and freedom. The taken for grantedness of everyday life is gone. The meaning of illness can only be determined

¹⁰Cassell, The Nature of Suffering, 33.
by the person afflicted with the illness. Toombs asserts that the goal of medicine must shift from curing to healing. It is this change in focus which takes the patient's experience of illness seriously. When healing takes place, there is a restoration or preservation of 'a sense of equanimity and personal integrity' in the encounter with illness.  

2. Acknowledge one's own professional caregiver narrative.

Larry and Sandra Churchill describe narration as the "forward movement of description of actions and events which make possible the backward action of self-understanding." The narrative is not an 'objective' factual description of events, but rather an interpretation of those events in a way that is meaningful to the narrator. Storytelling is both self-revelation and a connection to our common human experience. Stories draw the listener into other people's lives and enhance the capacity to understand other aspects of the human drama both currently and historically.

Often, when the importance of narratives are acknowledged in medicine, it usually refers to the patient's narrative. However, professional caregiver narratives are important as well. Patricia Benner describes how narratives, especially those that preserve practices and traditions, contribute to the ethical practice of the profession by engaging the caregiver personally with the patient. Examining nursing narratives, Benner identifies two major types of narrative themes which are operative in the fostering caring nursing practice. Constitutive or sustaining narratives present situations with insight into what it is to be a nurse. These narratives preserve and call to memory the significance of the work. The particular narrative usually echoes in some way the larger cultural narrative, for instance, the fundamental role of caring in nursing. The narrative may serve as a paradigmatic case which is illuminating and sustaining as other clinical situations are encountered.

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14Ibid., 5-7. Benner explores these themes by presenting a narrative account of a nurse, Kimberly Baird, who is responsible for the care of a young boy of
A second type of narrative theme is that of learning, which Benner explores in terms of sub-themes. Narratives about being open to experience reveal that the caregiver is personally engaged with the patient. She knows that the patient is more than a label and that there may be something to learn even from failure. Narratives of learning also include the appropriate relational skills for the professional. The narratives of disillusionment are those stories about limits with regard to knowledge, control, human capacities, and understanding and policies and rules. Narratives about facing death are shared experiences which help the professional caregiver and the wider community to confront suffering and death. Benner describes liberation narratives as a broad range of stories which may deal with issues concerning interprofessional relationships and status inequity to those stories about moving beyond biases and misunderstandings. The stories/narratives inform the nurse's understanding of her role and what it means to be a person of integrity within that role. Benner asserts that "the narrative memory of the actual concrete event is taken up in embodied know-how and comportment, complete with emotional responses to situations."15 Stories illuminate for professionals the meaning of care, not in a formal way, but by showing what caring means in practice.

3. Seek out the clinical narrative of the patient.

The clinical narrative is the story of the illness as told by the patient. It includes the story of how the patient discovered the illness, the point at which the patient sought out health care, the patient's explanations, and interpretations of what is happening. The patient explains what is significant about the illness and how it is having an impact on everyday life. It details how the illness has disrupted life. For example, consider the experience of two people: one man afflicted with metastatic prostate cancer and another man with Amyothophic Lateral Aclerosis (ALS).

Anatole Broyard, a writer for the New York Times

Just as a novelist turns his anxiety into a story in order to be able to control it to a degree, so a sick person can make a story, a narrative, out of his illness as a way of trying to detoxify it. I saw my illness as a visit to a disturbed country, rather like contemporary China. I

an Amish family who had been injured on the farm.

imagined it as a love affair with a demented woman who demanded things I have never done before . . . Having cancer was like moving from a cozy Dickinson house crammed with antiques, deep sofas, snug corners, and fireplaces to a brand-new one that was all windows, skylights, and tubular furniture . . . If I were to demystify or deconstruct my cancer, I might find that there is no absolute diagnosis, no single agreed upon text, but only the interpretation each doctor and each patient makes.\textsuperscript{16}

Dennis Kaye, a man who became known as the Incredible Shrinking Man on a CBC radio show expresses a very different experience:

Am I getting out just in time? I think not. Should I feel grateful for having been blessed with a fatal disease? I think not. Must I apologize for being happy? I think not. Sometimes I wish I could just jump up out of my chair, wipe the spit from my chin and yell at the top of my under-inflated lungs, 'I'm happy as hell and I'm not going to take it any more! I am invalid, hear me roar. I twitch, therefore I am . . .'

There is still love in our home, often joy, and rarely a day without laughter. All things considered, when I put ALS up against the things in life that really count, it doesn't stand a chance.\textsuperscript{17}

It is only through the narrative that the caregiver begins to hear what the illness means to the afflicted person. The aesthetics of the illness, personally and culturally, for that particular person may be revealed. For instance, some illnesses may be tolerable because the family may have some previous experience of it, while other illnesses are considered 'a death sentence,' 'dirty' or evil because of specific cultural connotations.

The clinical narrative can be distinguished from the medical history which seeks to establish the onset of symptoms, the diagnosis and options for treatment, and other relevant medical conditions. A person can be dehumanized by a medical history if the who is replaced by a what, for example, the 'gall stones case.'\textsuperscript{18}

The narrative can be elicited by such questions as: What has this illness been like for you? What is your understanding of this illness in terms the onset of symptoms? How have you experienced the treatment? What are your fears about this treatment? Or illness? Such


\textsuperscript{17}Kaye, \textit{Laugh, I Thought I'd Die} (Toronto: Viking, 1993), 220-21.

\textsuperscript{18}Churchill and Churchill, "Storytelling in Medical Arenas," 77.
questions help the professional caregiver have some insight into what is actually happening to the patient and adjust treatment appropriately. The clinical narrative helps the professional caregivers to determine what the patient wants. The patient goals can be identified and they may be different than established treatment goals. It is important for the professional caregiver to know if the care being administered is healing the patient or is, in fact, a source of suffering. If it is, other options for care may be explored that may be less burdensome. In some situations, the health professional can act as an 'arbitrator of meaning,' assisting the patient to change an inappropriate interpretation of the situation. For instance, a person newly diagnosed with cancer may only have knowledge of the disease offered in the popular media. The patient may have many fears about what will happen to them. The sensitive professional may be able to present information about the disease which would lessen the distress for the patient. If the patient can tell his story and the patient's meanings are understood, then, in response, it is possible for the practitioner to share her explanatory model of illness with the patient and have the caregiver's meanings understood as well.

The Ethical Implication of Taking the Clinical Narrative Seriously

Patricia Benner argues that it is necessary for professional caregivers to attend to the clinical narrative in order to care for the patient in an ethical manner. There are a growing number of ethicists who share this view.

Howard Brody explains how narrative ethics enhance current bioethical approaches. He notes that there are different approaches to doing ethics, offering various frameworks of formal reasoning. Narrative ethics attempt to determine a good moral outcome in a particular case by learning the detailed story about the case. The moral character and integrity of the stakeholders are critical components in the assessment. The analysis requires interpretation of what the facts mean within the situation. Reasoning may be by analogy, that is, by noting similarities and dissimilarities to other cases. The emotional response evoked by the story is acknowledged as an aid to ethical

19Philosophy and theology have a rich history of discourse regarding these formal approaches. Most bioethics textbooks develop the deontological approach, referring to principles, or a utilitarian approach, assessing the consequences of the action.
insight. This empathy is not considered a loss of objectivity. Referring to the dominant principles of bioethics, it is clear that it is in the patient’s clinical narrative, as well as the professional caregiver’s narrative, that the principles of autonomy, beneficence, and non-maleficence take shape. Without a narrative structure, they remain abstract. It is through the clinical narrative that the professional caregiver can know if the person is autonomous or coerced; what course of treatment will actually benefit this patient, meet the patient’s goals; and what constitutes harm for the patient.

In conclusion, professional caregivers cannot assume that they have easy access to the lived experience of those who are ill. Professional ‘habits of mind,’ ‘systems of relevances,’ and the political and economic dynamics of health care contribute to the creation of a world view which is very different from a person who is contending with a life-disrupting illness. One important approach to addressing this difficulty is learning to take professional caregiver and clinical (patient) narratives seriously. This author argues that these narratives are critical in ethical analysis.

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