Making Meaning in Medicine:

The Role of Narrative and Storytelling in Clinical Ethics

by

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ABSTRACT  

The project of the Clinical Ethics enterprise ought to be to pay attention to the moral quality of the life lived in the health care community.  

In the thirty or so years that the Clinical Ethics enterprise has been around (in this incarnation), it has developed a dominant discourse. Called "principlism" it is a model which attempts to reach resolution of the ethical dilemmas by adhering to a set of articulated principles. In this thesis I make the claim that the principlist approach is not adequate to the Clinical Ethics project.  

Further, I make a claim that story and storytelling within the health care community are a means to furthering the Clinical Ethics project. In this discussion I utilize theory, story and personal experience to support this claim. Drawing the thesis to a close, I discuss an example of the praxis of storytelling within the health care community.
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CHAPTER 1: INTRODUCTION (A STORY)

The meeting, as always, was held high in the hospital in a dingy seminar room, stuffy from a parade of students, doctors, teachers, caregivers crammed in for meetings, teaching and consultations. The window opened onto the shaft of the courtyard, the door onto a patient care floor. The slim authority I carried as the representative of the Clinical Ethics Service, I wore uncomfortably. While it gave me entrée into the group, I was yet unsure what it meant and what service I could provide to these experienced professionals. The meeting had been a subdued discussion of ethical issues embodied in certain professional roles, political issues around the roles and responsibilities of the nurse-physician relationship, and of a new ethics policy implementation across the hospital: nothing too confusing or taxing. The meeting was over and I began to assemble my papers, getting ready to head back to my office.

One of the committee members approached me – “May I ask you something?” she ventured. She looked worried.

I was both elated – that someone wanted my opinion about something – and terrified – for the same reason. I invited her to take a seat, “Sure,” I wanted to be as welcoming as possible, “What is it?”

Checking to be sure the door was closed she sat down beside me. “Sometimes when a patient is dying and you give them more analgesia it suppresses their respiration and they die sooner. My colleagues and I were wondering if we are committing euthanasia when we do this?”

Listening to her I breathed a sigh of relief. I knew this one, I had read about it – it was a clear case of the Principle of Double Effect. Easy. No problem. Relieved, I quoted the Principle to her and explained how it meant that increased pain relief for these patients did not mean they were being killed. “Therefore,” I said confidently, “you don’t have to worry about anything.” Smiling, I picked up my file and walked out of the room with her. By the time I had reached my office I felt cold inside. I hadn’t served her at all – I had paid no attention to why she and her colleagues were asking the question, I had not bothered to ask what it was like being a caregiver to a patient who is dying and is in pain. I paid no attention to her lived experience. While my answer was soundly rooted in principle, it was inadequate to the task of attending to the moral character of the lives lived in the community of health care.
The new enterprise of Clinical Ethics has developed a dominant discourse in the thirty or so years that it has been around (in this incarnation). Called “principlism” or “principle-based ethics” – it is a model which attempts to reach resolution of the ethical dilemmas that occur in the health care community by adhering to a set of articulated principles and the many action guides and decision-making models that come from those principles. It is a discourse that is inadequate to the Clinical Ethics project. The past decade or more has witnessed an increase in criticism of the dominance of principlism in Clinical Ethics (Beauchamp, 1995:181) and I would add my voice to those critics. In the following I make the claim that the traditional principlist approach – especially as articulated by Beauchamp and Childress in *Principles of Biomedical Ethics*, is not adequate to serving the Clinical Ethics project, as I outline it below. Further to that I claim a role for story and narrative in the health care community and as a means to further the Clinical Ethics project.

My method is straightforward: I will begin with an overview of Clinical Ethics and move to articulate what I believe is the project of Clinical Ethics within the health care community. From there I will move to a description and critique of the dominant discourse of principlism. Finding principlism lacking, I will move to a discussion of narrative and storytelling within the health care community. From that discussion I will outline specifically how story can further the Clinical Ethics project. Finally, I will discuss my using stories about my father,
“The Dad Tales”, paying particular attention to ethical issues raised in their
telling. I will be drawing both from theory and from my own experience, both
as a storyteller and as a member of a Clinical Ethics Service that served three
hospitals.

A treatment of story and narrative naturally depends on stories. In the
following I utilize personal experiences and story as a way to further the
discussion and to support its theoretical components. Along with smaller
tales taken from my practice in Clinical Ethics, I will use two major narratives.
In telling these stories I have attempted to respect the requirements of
confidentiality and privacy while striving to sustain the integrity of the story. It
is a difficult line to walk and I may not have been completely successful. For
this reason I ask the reader to add yet another layer of protection to the
subjects of the stories by respecting their privacy.

It is not without irony that I must make these efforts for much of the
discussion that follows is to do with ownership of voice and story and the
obstacles that are institutionalized within the health care community that
prevent members of that community from owning and speaking their stories.
At least in this act of writing and demanding the attention of a reader I
exercise some power to create stories and to ‘tell’ others as I chose. It is this
power that must be exercised with discretion and integrity, for those who
people the stories I tell do not, in the present context, have a say or a voice.
I will set the stage for their further discussion by here outlining the two larger narratives. Ten years ago this August my father suffered a massive stroke. There are a multitude of stories around that experience and the stories are ongoing even now. In the aftermath of the stroke I created stories from my experiences with Dad. For reasons that will become abundantly clear I do not tell any of these “Dad Tales” in this paper. I do, though, tell about their telling— it is an important distinction.

Close to three years ago I became very sick. For months I sought a diagnosis and eventually a cyst was found in the center of my brain; it was weeks away from rupturing and killing me when I had surgery to have it removed. The whole experience is one of the most foundational of my life and I have a need to tell the stories of it over and over again. I do so in this paper and I use them to comment on the discussion and to situate my commentary.

A story to start: the day after Labour Day, some 17 years ago, I found myself seated in my small office in an ivy-covered building on the gracious campus of the University of Toronto. Fleeing the bitter prairie winters of Edmonton, and a broken heart, I had accepted the job of research associate at a new bioethics center. Apart from some vague notion that ethics had something to do with right and wrong and morality, I really did not have a clue what I was doing there. I was fiddling with my pen, daydreaming out the window when my boss, a moral theologian, knocked and entered. He was carrying two books: one was a daunting green volume of close to a thousand pages, the other an early edition of Principles of Biomedical Ethics by Beauchamp and Childress. “Here,” he said, placing them on my desk, “Read these and you’ll know what we’re about.” I thanked him.
enthusiastically and closed the door after he left. I pulled the largest volume toward me, opening to the Table of Contents: “Abortion,” “Euthanasia,” “Allocation of Scarce Resources,” “Human Experimentation.” I felt a blank expression creeping across my face and within minutes I fell asleep.

The past twenty-five or thirty years have seen a growing acceptance for formal Clinical Ethics enterprises within the context of the health care community. Dating from the time of the Karen Ann Quinlan case (1976) in the United States, Clinical Ethics has been a growth industry, spawning institutional ethics committees, a profession (of sorts) of ethics consultants or bioethicists, and a growing awareness of certain ethical issues that arise in the delivery of health care. The growth of a formal Clinical Ethics enterprise within health care reflects both a need and a desire on the part of the health care community to gain some insight into its moral character and that of its individual members. In addition, the growth reflects the hope for answers to value questions (and legal concerns) that render health care increasingly complex.

I have chosen to use the term “Clinical Ethics enterprise” for a couple of reasons. I worked in a Clinical Ethics Service and it is, therefore, the context of the experiences that inform so much of the following paper. Secondly, the term implies a clinical focus – in our case a hospital- for our work, as opposed, for example, to a university-based academic centre, like the one where I first started my work in ethics. The director of the Clinical Ethics
Service in which I worked was the first fulltime hospital-based ethics consultant in Canada, marking a move away from the academic setting of the university and more “into the trenches.” I use ‘enterprise’ to designate particular undertakings for the purpose of achieving the goals of the Clinical Ethics Service. Ethics has always been a component of health care and medicine – it is only in the past twenty-five or thirty years that a formal enterprise has been undertaken as apart from the ethics that has always been embedded in medical practice. \(^{ii}\)

The work of the clinical ethics enterprise supports and generates a large literature: journals devoted solely to ethics and health care journals that contain a large ethics component. The existence of numerous programs of study in clinical ethics and of academic centers devoted to the study of these issues and to ‘doing’ ethics would seem to indicate some progression in the awareness of and acceptance of clinical ethics in a broadening social context. In the fourteen years that I worked in the field I witnessed a change of profile and acceptability of clinical ethics both within the health care context – as demonstrated by the large number of health care professions that now require an explicit component of ethics education in their training programs – and among those outside of the health care community.

This increased acceptance of the clinical ethics enterprise cannot be assumed to reflect a high degree of success or effectiveness of the enterprise
in meeting the needs of the health care community in which it functions. I do not think that it can be assumed that the apparent growth in its profile reflects a certitude that the resources devoted to this enterprise have good or desirable outcomes. I think it is more likely that the increase in popularity reflects an increase in the number of issues and conflicts that arise with the delivery of health care and a strong desire to find a way, or ways, to address them.

In my experience there was an unfortunate lack of evaluation and assessment undertaken of the work that we did under the umbrella of clinical ethics. In an era of constant quality control and measurement tools this was an anomaly. Efforts were made to determine if tools existed that could measure success and outcomes but none were found that enabled us to truly determine how well we were meeting our broad objective of increasing ethical awareness in the hospital community. Of course, we could count the number of people who attended a session, we could attempt to gage the degree of acceptance of a decision taken or the rate of compliance with a new policy and we could test students for their recall of the content of a teaching module. None of this, however, seemed to give us a sense of the lives of the members of the moral community that was a hospital. (By this I do not mean to imply that we did not have such a sense – as members of the community that sense was strong, but formal evaluation tools could not have been equal to the task.)
To some extent, the lack of measurement or evaluation tools for the success of the clinical ethics enterprise as it is lived out in the moral community of a hospital reflects the lack of consensus among that community, including the members of the clinical ethics community, about the objectives of a clinical ethics enterprise and the ways that these can be realized. For some, clinical ethics ought to play the role of moral police, for others clinical ethics consists in the formulation of rulebooks and guidelines, for others it consists merely in teaching the members of the health care community what is considered to be morally correct or incorrect, and for still others it is a tool to encourage the individual to think critically of her moral agency.

While the work of Clinical Ethics generally fits into one of the three main areas of education, policy development and consultation (Ross, 1986), there is little consistency about how these are accomplished and what the specific objectives are. What is the goal, for instance, of successful ethics education in a health care setting? Is it a teaching of a decision-making model or is it an attempt to enable the practitioner to be insightful into her life as a member of the moral community of the hospital? What can it be? Can one hope to teach an individual to be more ethical? Who would determine the criteria for “more ethical?” This lack of consistency is at the heart of much of the difficulty of assessing the value of the clinical ethics enterprise. Given that it is, at heart, concerned with the values that are held by members of the health
care community, it is 'soft stuff' and will always be elusive in a context such as health care that is accustomed to hard facts and measurable outcomes. (Years ago a senior administrator, who had an open hostility towards clinical ethics, asked me to tell her why my work was worth ‘x’ number of hours of dialysis treatment. It was a difficult question to answer.)

There are likely as many approaches to the Clinical Ethics enterprise as there are practitioners but two main types can be defined, distinguished by the locus of the moral gaze. The first functions at a remove from the community and its moral agents and, from this removed perspective the gaze is focused onto the life of that moral community. In this approach, when an ethical situation (often, though not always, a dilemma) is experienced, relevant considerations are removed, viewed from the remote location and returned after consideration and action: judgment of what is correct or necessary action for instance. The view is from the outside looking in; the stance one of presumed objectivity, the seat of expertise more safely considered apart from the experiential realm of the moral life. The moral question from this perspective may be “what is the right thing to do in this situation?” The second approach focuses the ethical gaze from within the moral community itself, valuing the subjectivity as essential to the moral life of the community and to the nature of the ethics enterprise within the context. From this involved stance, the ethical question may be differently shaped to become: "How can I best be in this situation?" The context of moral agency is
considered of vital importance to the Clinical Ethics enterprise and therefore, not to be abstracted away. While both of these views may have as their focus the moral life of the community and its members, the difference in stances is significant to their ability to define and meet the goals of the clinical ethics enterprise. The measure of their success depends very much on the goals that are set. The effectiveness of the goals can be critiqued only when a project for the clinical ethics enterprise is articulated.

What, then is the project of the Clinical Ethics enterprise? Each of these two gazes implies, to some degree, some perception of the role of the enterprise. The first implies a role of determining the right and the wrong for the moral community by the application of some external standard onto the situations that are abstracted from the milieu of the community's moral life. The second implies this standard is generated from within, or at least influenced from within the context of the moral community of the hospital.

I have seen both perspectives at work in clinical ethics. To determine which of them is most effective I believe it is necessary to make a claim for a certain kind of project for the clinical ethics enterprise within the moral community of a hospital. It seems to me this claim itself is a value-based one and, thus, I am not prepared to argue it philosophically. It is, rather, my starting point for the claims that follow about the effectiveness of the clinical ethics enterprise within the context of health care. My claim is rooted in my own experience in
the clinical ethics enterprise and in my multiple positionings within the health care community. Much of it is intuitive, but it is intuition informed by my own gaze from within the health care community.

When we ‘do’ ethics, we consider how we live according to how we ought to live. Ethics is the study of our lives as moral agents – the investigation of the “ought” of what we do. This “ought” implies a standard by which our moral actions can be measured or, more accurately, the existence of multiple standards by which our moral lives can be measured. Clinical Ethics focuses on the moral quality of the health care enterprise and recognizes that ethical issues and dilemmas are lived out in the health care community.

My positioning within the hospital community gave me a certain gaze onto the role of ethics in that context. It is my conviction that ethics is about the people we are as we live in the relationships that ground us. It is a tool to assist us to look at our lives as members of a moral community and to lay open our role in relationships and in the creation and sustenance of that community of a particular moral character.

Narrative ethics sees health care as a part of life which must be engaged on its own terms rather than as a special time outside of history and culture to be analyzed with the professionalized (and then popularized) ways of thinking about life choices. It conceives of patients, family, doctors, and nurses as individuals engaged in social and personal relationships rather than as interchangeable decision-making monads. It recognises the importance of circumstance and historical setting in medical cases. It understands that narrative
coherence must be constructed from a person’s history of moral choices and relationships with others. This, rather than the theoretical consistency, will determine how family, patients, and health care workers evaluate meaning and duties in clinical situations. It shifts the weight of the standard for evaluating ethics problems from "well-reasoned solutions" to "well-lived lives." (Miles and Hunter, 1990:63)
As mentioned above, the predominant methodology for clinical ethics has been the use of principles to guide ethical decision-making. Referred to as “principlism”, or “principle-based ethics”, it has become the most common and influential approach to the clinical ethics enterprise within the health care context. It is an example of clinical ethics from a removed stance. Adherents to principlism attempt to analyze and assess ethical dilemmas within the framework of particular principles. Relevant facts are abstracted from the lived experience and ordered according to these principles and the numerous decision-making models and moral action guides that are derived from them. Resolution is reached by the weighing of conflicting principles and defining the solution in terms of which principles are considered paramount.

For more than twenty years Principles of Biomedical Ethics (1979, 1983, 1991, 1994) by James Childress and Thomas Beauchamp has been influential as the paradigmatic example of principlism in the field of clinical ethics. (Clouser, 1995:219) It is one of the most popular texts for introductory ethics courses and seems to be well known by most who work in the field. It is not, however, well liked by all who work in ethics and the criticism of the work has mounted in the past ten years. The authors have changed their work over its many editions, at least in part to address some of the criticisms that have been leveled at their approach. They do take credit, however grudgingly, for
the genesis of the term “principlism”, noting in their 1994 edition that it has become a somewhat disparaging term for their theory of biomedical ethics. (Beauchamp and Childress, 1994:37)

Their’s is not the only approach to biomedical ethics that utilizes principles as applied to situations in order to generate resolution of the problem but theirs is one of the few that seeks general biomedical principles, rather than adapting more universal principles into biomedical ethics. Beauchamp and Childress attempt in their work to come up with an approach specific to biomedicine, and in so doing claim some originality.

An earlier edition of Principle of Biomedical Ethics (1979) included a much more straightforward approach to their theory of ethics than does their more recent edition. This may well be because of criticism leveled at their earlier work as being too formulaic, too linear. This most recent edition of the work does not, for example, include the diagrammed decision-making models of the earlier edition. It includes much more discussion than the earlier editions do – this may indicate a recognition on the part of the authors that their earlier work did indeed imply a much more simple formulaic approach to life lived in the moral community than is possibly the case.

The goal of the work of Beauchamp and Childress is to develop an ethical theory that will apply in the setting of biomedicine. “A well-developed ethical
theory provides a framework within which agents can reflect on the
acceptability of actions and can evaluate moral judgments and character.”
(Beauchamp and Childress, 1994:44) They list eight conditions that an ethical
type needs to meet in order that it be adequate to the job: some theories
will exhibit more or less of each of these conditions but all must have them.
These eight conditions are: clarity, coherence, completeness and
comprehensiveness, simplicity, explanatory power, justificatory power, output
power and practicability. Using these conditions as a template, they describe
and critique ethical theories that have been utilized in the biomedical context.
In their work they strive to provide a balanced account of each – highlighting
not only what they consider to be their weaknesses but also their strengths.
Thus, for instance, they recognize that certain characterizations of the Ethics
of Care may provide some balance to the hyper- rational approaches that
have been favoured in the field of biomedical ethics. (Beauchamp and
Childress, 1994: 92)

The authors eventually arrive at their discussion of “Principle-Based,
Common – Morality Theories”, the category in which they situate their own
theory. They state: “common-morality theory takes its basic premises
directly from the morality shared in common by the members of a society –
that is, unphilosophical common sense and tradition.” (Beauchamp and
Childress, 1994:100) They specify two major characteristics of common-
morality theory: first, that it is pluralistic, encompassing two or more
nonabsolute (*prima facie*) principles and that there is no one supreme principle to support all other action guides as, for example, one find in Kantianism, and second, that it “relies heavily on ordinary shared moral belief for its content, rather than on pure reason, natural law, a special moral sense and the like.” (Beauchamp and Childress, 1994:100)

They give the work of William Frankena and W.D. Ross as two twentieth century examples of this type of theorizing and list Ross as especially influential to their work. For Ross “the moral convictions of thoughtful persons are the data of ethics just as sense-perceptions are the data of a natural science…” (Beauchamp and Childress, 1994:103) and Ross maintains that principles are “recognized by intuitive induction as being implied in the judgments already passed on particular acts….we know principles in the same way the plain person knows the main lines of moral obligation.” (Beauchamp and Childress, 1994:104) Beauchamp and Childress strategize that after the principles are formulated they will still have to be further interpreted, specified and balanced to produce an ethics for biomedicine. (Beauchamp and Childress, 1994:104) For them, principles are *prima facie* binding and subject to revision.

Beauchamp and Childress recognize that there are limitations to their theory and they anticipate certain criticisms. It is, they note, impossible for any theory to pre-determine its applicability in every concrete case, “we come to
understand principles and what they exclude and include by making judgments in particular circumstances.” (Beauchamp and Childress, 1994:107) Citing an example of the principle of respect for autonomy as it would be realized in a mental health institution, they note the need for growth of moral understanding that results from the lived experience informing the application of principles onto particular cases.

An outline of the approach taken by Beauchamp and Childress follows: their starting point is a set of considered judgments (also called self-evident norms and plausible intuitions) that are acceptable initially without argumentative support. (Beauchamp and Childress, 1994: 24) These judgments are not merely a matter of individual intuition but have a history rich in moral experience. From these considered judgments is generated a framework whose workability depends on whether its principles and related rules can be specified and the specifications justified. (Beauchamp and Childress, 1994:30) This means for them that the moral theory they are developing be able to move from general levels of theory to particular judgments and policies to everyday decisions in the moral life and still be applicable. “...Our pragmatic goal,” they write, “should be a method of resolution that often helps, not a method that will invariably resolve our problems.” (Beauchamp and Childress, 1994:32)
They consider their principles as generating *prima facie* obligations, that is, an obligation that is binding unless overridden or outweighed by competing moral obligations. (Beauchamp and Childress, 1994: 33) For them few, if any, absolute rules exist to guide one's behaviour, making it necessary for the agent to determine what she ought to do by finding an actual or overriding (in contrast to prima facie) obligation, that is, the agent must locate "the greatest balance of right over wrong." (Beauchamp and Childress, 1994:33) Caution must be taken to ensure that the assessment is neither too intuitive nor too subjective: "justified acts of balancing entail that good reasons be provided for one's judgments." (Beauchamp and Childress, 1994:33) (Presumably good reasons do not include intuitive judgments.)

Having outlined these general requirements for a principle-based, common-morality theory, Beauchamp and Childress move on to outline their ethics for biomedicine: "principlism" or the "four-principles approach." They specify four clusters of principles, stating "these principles initially derived from considered judgments in the common morality and medical tradition..." (Beauchamp and Childress, 1994:37) as found in such things as the tradition of medical practice, legal tradition and professional codes of ethics. They list several types of normative action-guides as components of their theory: principles, rules, rights and virtues and specify that principles operate as general guides that leave considerable room for judgment in specific cases and that provide substantive guidelines for the development of more detailed
rules and policies." (Beauchamp and Childress, 1994:38) In their theory, rules are more specific in content than are principles and more restricted in scope. They respect three types of rules: substantive rules, which need to be formulated as guides to action that are more specific than abstract principles; authority rules: rules that establish decisional authority and procedural rules that establish procedures to be followed, “we often resort to procedural rules when we run out of substantive rules and when authority rules are incomplete or inconclusive.” (Beauchamp and Childress, 1994:39)

The core of their moral theory for biomedicine is the four clusters of principles:

(1) respect for autonomy (a norm of respecting the decisionmaking capacities of autonomous persons), (2) nonmaleficence (a norm of avoiding the causation of harm), (3) beneficence (a group of norms for providing benefits and balancing benefits against risks and costs), and (4) justice (a group of norms for distributing benefits, risks, and costs fairly) nonmaleficence and beneficence have played a central historical role in medical ethics, whereas respect for autonomy and justice were neglected in traditional medical ethics but have come into prominence because of recent developments. (Beauchamp and Childress, 1994:38)

Wherein lies the fault with principlism as it is outlined and advocated by Beauchamp and Childress? From where comes the desire to supplement it or challenge its hegemony within the field of clinical ethics or bioethics or biomedical ethics? How effective is principlism in accomplishing the project of clinical ethics?
There is little doubt that principlism is the dominant discourse of the clinical ethics enterprise. There are many reasons for the dominance of a formulaic model such as this. For one, it sees ethics conducted in a manner reflective of the medical model wherein a problem is identified, a course of treatment is prescribed and progress is monitored. Thus it is familiar to the care providers who face ethical issues and are expected to resolve them well. (Chambers, 1996:28) Additionally, it is a model that admits of little nuance and tonality, appealing in a context where the complex is broken down until it is simplified and, therefore manageable and it can provide a template that is teachable and usable with signposts and markers that indicate a job well-done, or at least completed (highly valued in the outcomes-obsessed health care environment). Especially when mired in a difficult ethical issue an approach that appears to simplify matters can be seductive — it appears to be effective and efficient with measurable outcomes and, therefore, very popular within health care.

A small tale: as the clinical ethics representative on the Nursing Ethics Committee, I met monthly with a group of staff nurses. The purpose of the committee was to provide an opportunity for the nurses to talk about the ethical challenges of delivering care at the bedside. There was always an undercurrent of confusion about the role of the committee: some members were frustrated that our goal was not to ‘fix’ ethical problems. (What does “fix” mean in this context I wonder?) One of the committee chairs decided that the
only way to “do” ethics was to teach the members the decision-making model outlined by Beauchamp and Childress: interestingly it was the approach she had been taught in a nursing ethics course. She argued that it was the only way to enable the nurses to meet the needs of membership on that committee. Their frustration, she posited, stemmed from a lack of tools to fix ethical problems. As members of a profession that is highly outcome-oriented she felt that the model would meet the needs of the nurses on the committee. I strongly disagreed and worried that a focus on the model would stop the flow of conversation and the attention to the nuances of moral agency that a sharing of experiences could generate.

I watched as the members struggled to fit their stories (and those of their colleagues) into the four principles. For some, at least in the beginning, it felt good – like something was being accomplished as they made it productive of a frame to put around situations that had notoriously soft edges. Soon, however, the old frustration crept back – this was no way to come up with the answers that the members wanted – it was a least incomplete to the task of paying attention to the moral agency of nurses and it frequently disregarded the quality of that lived experience. Leading ethicist, Warren T. Reich, tells of similar experience when he relates the story of a particular ethics case consultation in which his usage of traditional ethics methods proved unable to assist him. While he defends principlism he asserts that “principle-based ‘quandary ethics’, which today is the dominant paradigm for health-care
ethics, is inadequate for ethical reflection on the moral issues in health care.” (Jones, Neohelicon:384) Physician-poet Jack Coulehan shares a similar view in his commentary on a poem he wrote after the death of one of his patients, “The Man With Stars Inside.” He writes: “I believe that the human work of wrestling with physician aid in dying has to begin with specific life narratives and relationships rather than with abstractions like rights, autonomy and beneficence.” (Coulehan, 1997:800)

The attractiveness of principlism in this context rests on some valid points that may have some merit. There is some benefit to owning a common lexicon to generate some common ground when undertaking the discussion of the ethical life. Many of the caregivers I encountered (and all of the members of the Nursing committee at the time of this story) felt ill equipped to contribute to such a discourse. Common knowledge of the work of Beauchamp and Childress provided some confidence to undertake the discussion and brought with it a perception of a shared understanding rooted in this common lexicon. Thus, for instance, the group felt some comfort that all knew what was meant when something was discussed as an “autonomy issue,” (or so it was assumed).

While on one level this enhanced comfort may be considered a good thing, it seems to me it may indicate a problem with the way that the ethical life is perceived within the health care setting: if it could not be comprehended or fit
into a principlist language, then it could not be accommodated by the discourse. It seems to me that one of the consequences of the formulaic approach and the language which serves it so well is to bar a multitude of experiences and situations from entering the ethics discourse in the first place. Thus, time and again I would hear “this probably isn’t an ethical issue but, I have something I want to tell you about”, as a prelude to a story of the lived life of a moral agent within the health care community.

As well, there is no certitude that a shared lexicon implies a shared understanding or a mutual comprehension. Indeed, one of the problems of the application of the principlist approach within the clinical setting rests in the fluidity of the concepts that are articulated in the four principles. I would certainly not argue for rigid conceptualizations but I would note that there is a difficulty when it is believed that they exist where they do not. Thus the assumption of a shared understanding is faulty.

In addition, the very sense of the model and approach as being removed from the subjective – or as a way to remove something from the subjective- was seen to provide a safety to those engaged in the ethical discourse – a safety that is highly valued and necessary in a context such as the health care community. Emotional noninvolvement is touted as being core in the culture of health care and a formulaic approach enhances the sense of the rational that is so strongly valued at the same time as providing an emotional
displacement from the thorny value issues of life in the moral community of health care. The principlist approach reflects the hermeneutic of health care that sees rational knowledge as prime and superior to non-rational forms of knowing. (Hunter, 1991:124) Thus, those engaged in this sort of discourse felt confident that they were undertaking ethics in the right or correct fashion and that they could trust the outcome of the process more than they could the outcome of a process that did not allow the abstraction of all relevant details from the discussion.

Once again this safety is not to be minimized, particularly when it serves to allow those often unvoiced to give voice. However, the removed gaze that such an approach requires and values runs the risk of demeaning the very community that it is intended to serve. What message would be given if a person’s experience were constantly abstracted in order to be safe for the telling? What message would be received about the importance of relationship and subjectivity in the creation and sustenance of a moral community?

Many commentators point out that while principlism and other analytic approaches to ethics may be considered ‘correct’ in ethics work, they are, in fact, inadequate to the task of clinical ethics. Howard Brody writes “The analytic tradition has been powerful in condemning anecdotal or ad hoc reasoning as hopelessly subjective or intuitivist and in insisting that reason in
ethics requires that conclusions be logically deduced from more general principles" but, in fact the practice of hospital ethicists shows a different picture. (Brody, 1987:144)

Robert Coles tells of having taught medical ethics and moral philosophy to medical students and coming to the realization that the end product was that his students had become superb logicians, but not necessarily more ethical human beings or physicians. (Jones, Neohelicon: 385) Another well-known medical ethicist, Larry Churchill, who has become well known for his use of story and narrative in his clinical ethics work, states “human beings and their experiences do not fit rigid, abstract, rational systems…Applied as normative imperatives such systems are immoral because they deny people the right of interpreting their own experiences and telling their own stories.” (Jones, Neohelicon: 385)

In “From System to Story: An Alternative Pattern for Rationality in Ethics”, Stanley Hauerwas and David Burrell view contemporary ethical theory as parallel to the scientific ideal of objectivity. What they call “The Standard Account of Moral Rationality”, contemporary ethical theory, wants to free moral behaviour from the “arbitrary and contingent nature of the agent's beliefs, dispositions and character” (Hauerwas and Burrell, 1989: 160) According to them the nature of moral life is distorted and there is an unwarranted emphasis on particular decisions or quandaries. From this
comes a picture of ethics as decision procedures for situations of conflict. Thus, if moral concerns are primarily seen as problems, then ethics can be seen as a rational science that evaluates solutions. And, thus, ethics becomes a branch of decision theory.

An additional criticism that is outlined by Burrell and Hauerwas has direct bearing on the health care community. They claim that the Standard Account of Moral Rationality further distorts the nature of the moral life by working to separate the agent from his interests, or the person from her community. It makes alienation the central moral virtue by obligating us to view our own projects as outside observers. After all, if ethics is only to do with decisions about problems, then judgements can be justified apart from the agent. Hauerwas and Burrell take their critique one step further than most and attempt to explain why the standard account has developed and why it is so attractive. They state: “... we suspect that the basic story underlying the standard account is... namely, humankind’s quest for certainty in a world of contingency.” (Hauerwas and Burrell, 1989:14)

From this criticism some conclusions may be reached about how well the principlist approach serves the project of the clinical ethics service. It is a reductionist view of the moral life and in that lies some of its attractiveness in a complex moral community. The reduction is, however, too severe and is such that the true moral life within the health care community cannot be
served by it. Some may argue that it has definite value in arbitrating ethical quandaries, even if it has limited capacity for generating insight into the full moral life. This may be the case in certain limited situations but I would always question what was cut out of the picture to make it fit the framework of the four principles and their attendant action guides. The approach in no way attends to issues of power: how is a moral problem encountered? Whose voice articulates it and shapes the discourse? And, if the moral life of the community can only be cast as ‘problems’, surely there is a risk that ethics becomes solely a tool for problem solving and does not cast the moral gaze onto the moral life itself.

In some limited circumstances I see value for a principlist approach to the clinical ethics enterprise. The language of the four principles and the action guides that have been developed by them is ubiquitous in the health care setting and therefore, it may be argued, it has enhanced the awareness of the presence clinical ethics within the practice of health care. There may lie in this, however, a false sense of security and confidence that ease with this language and these principles equates to ethical choices and sound ethical reasoning. The picture of the moral life that principlism endorses and sustains is incomplete. The moral life is not comprised mostly of dilemmas and quandaries but of how we live our lives as moral agents in the communities in which we are embedded. (Benner, 1991:1) The moral question posited by principlism is not wrong, it is simply not enough:
Applied ethics has conferred some order upon the messy domain of illness by positing the centrality of a set of principles – beneficence/nonmaleficence, autonomy, and justice – and by deriving such rules as informed consent, confidentiality, and truth-telling from those principles to guide action in quandary cases. A formalist sanitization of chaos, however, may not be sufficient for comprehending the significance of these events; the parties require a particularized (and usually affectively charged) grasp of their meaning. If, as Bruner suggests, “we organize our experience and our memory of human happenings mainly in the form of narrative – stories, excuses, myths, reasons for doing and not doing, and so on”, then an understanding of biomedical ethical cases that is informed by the knowledge of narrative theory may offer the essence that is unobtainable using solely formalistic methods. (Charon, 1994:262)

In my work I discovered the truth of this. The gaze from the outside, it seems to me, is good only for providing a removed view of the life of the moral community. Such a gaze enables a stance of non-involvement in the moral community – in fact it would seem to value such a stance. In the hospital I witnessed countless stories as they were flattened in the ongoing effort to reach resolution of the ethical issue by distorting it into an ethical quandary. A multi-layered, nuanced story was objectified and removed from the realm of the personal and, in so doing, it seems to me much of importance was lost.
CHAPTER 3: THE MOVE TO STORYTELLING

At the same time as I was working as the educator in the Clinical Ethics Service, I was also working as a storyteller and a writer. At first I tried to keep the two lives separate: I considered my life as an artist to be a balance to the stress of the work in clinical ethics and I was still struggling to find a way to make the principlist approach serve the project that I was beginning to see as central to the clinical ethics enterprise. I struggled mightily to apply the principles to the life of the moral community around me and, finding that it was ineffective to my project, began to lose confidence that I could “do” ethics or that the ethics enterprise had anything of value to contribute to the life of the moral community of which I was a part and in which I valued my membership keenly. I began to seek other ways to ‘do’ ethics, or perhaps I simply started to be more aware of things I had been doing already.

As a storyteller I was learning a multitude of things which, I now realize, bled into my work at the hospital. Storytelling is an art that is relational. It reflects relationships, creates relationships and sustains relationships and the communities in which they are embedded. Time and again as a storyteller I realized that my act of telling a story forged relationships with those who listened to me. The relationships were based in the exchange of images that is the heart of the act of storytelling and some of them lasted for only as long as that exchange, while others were more durable.
Time and again, I witnessed the building of community that could be forged through the exchange of stories. Shared stories are one of the markers of community or group membership. I watched as certain stories impacted certain listeners more intensely than they did others. I witnessed engagement as the eyes of the listener brightened and the breath was held still, the better to listen, as the person leaned forward and entered into that space created by the narrative and shared by all of us. And I learned about the role that story plays in each of our lives and in the communities in which we are situated. I recall one ten year old boy brightening as he listened to me tell a British fairy tale: “England is where my parents come from,” he said, “that is my story isn’t it?” And I learned the value of listening to others tell their stories, helping them find their voice or simply respecting the space they needed to tell it. “This is what happened to me” started a multitude of stories that connected me over and over again to those with whom I shared stories. Listening to the stories told by a group of residents of a chronic care facility I watched as they changed before my eyes into people whose lives extended far beyond the wheelchairs in which they now lived, as they changed from two-dimensional objects into nuanced, complicated subjects. And I watched, time and again, as the telling of one story generated a multitude of other stories, as the connections between people were wrought across time and space, through words and shared narrative.
It is likely that my commitment to narrative and my approach to relationship both created of me a storyteller and led me to a certain positioning within the moral community of the hospital. It is one of the ways that my own moral agency was shaped and lived out. Circumstances conspired to move my storytelling more deliberately into the clinical ethics context. When my colleague went on summer vacation I was asked to fill in with a group of pastoral care students and to teach a three hour workshop with them one Friday morning: the topic was to be Clinical Ethics. I asked whether I could do a storytelling workshop: “Storytelling as Relationship”, explaining that I believed that relationship is at the core of caring and at the core of clinical ethics. My proposal was accepted and I ended up working with pastoral care students for the next five years.

A short time later another opportunity presented itself at a conference I was helping to organize. On short notice one of our scheduled speakers cancelled and we were left with a session in the last afternoon. I offered to fill it with storytelling. It was a nursing conference with the theme of “Caring Relationships” and I argued that nursing is a culture of storytelling and that relationships are key to storytelling. Sally Gadow, a nursing theorist, makes the claim that for nursing narrative is a key form of knowledge. (Gadow, 1996:8) Pedagogically as well I felt the use of a more creative artistic session would provide a good balance to the previous two days of highly theoretical and academic content. After my colleagues agreed, I
invited five nurses to work with me to craft and tell a story about a caring relationship that was significant to them.

Looking back onto that session I can say that it “worked” — and it became the first in a five-year series entitled “Stories of Care” wherein members of the health care community (including patients and family members) shared their stories in that forum and later in a grand rounds at the hospital.

My primary objective in undertaking the “Stories of Care” series was to give space to the personal stories of those who are the health care community. The nurses who worked with me that first year to create and tell their “Stories of Care” were, quite simply, committed to doing honour to relationships and patients that they had cared for in their combined many years of providing care at the bedside. We wanted to remind the listeners of the flesh and blood reality of those that we cared for — we wanted to shift the gaze from outside, from where it was one of objectivity back into the center of the relationship, where it would be one of intersubjectivity.

It had been my experience that nurses in particular often felt unvoiced and that their experiences were devalued within the culture that is health care. For Patricia Benner ethical expertise is lodged in the practice narratives of the nursing community and, therefore, narrative is essential to the development of moral agency in nursing. (Benner, 1991) I believed that the way in which
knowledge is constructed within the health care context, clinical ethics included, cuts off many of the relevant components of life in the moral community that is health care. I was also convinced that the full picture was not seen when the discourse was so limited. How, I wondered, could we truly take part in a conversation about the moral life of health care and our own moral agency when we did not have the full picture? Most important to me was the conviction that the true caregiving, the most ethical moral agency if you will, took place in relationships which were intimate ones, where both parties were subjects in relation with one another and where that relationality was acknowledged and valued. For many of the women who told that first year the valuing of that relationship and of that experience happened for the first time as the process of crafting the story and telling it unfolded.

To tell a story is to shift the ground under people, it is to change the world, and this happened as the women told their stories of care to the audience which consisted mostly of nurses. Nothing that the women were saying would have been unfamiliar to the nurses and other caregivers who were in that room, but to hear it told in those voices, in that forum, was new indeed. The alliance of the subjective personal accounts, the idiosyncratic details of the accounts, the emotion of the teller and the space provided, physically and emotionally, for the telling with the more rationalistic, objective accounts of the previous two days was powerful. The storytellers would not allow the listeners to remain aloof from the experience and in the telling drew them in
so that they too shared a relationship with those in the story, with those who
listened with them and with the women who told. And from within that
relationship and that community the meaning of the ethical gaze must have
changed. No longer was it a question of “scarce resource allocation” and
denying access to care to the uninsured: now it was the story of Robert, a 16
year old boy who died alone in Ecuador after being denied care in Canada,
even though he had lived there for ten years: deported ‘home’ because of his
need for dialysis (after contracting HIV from tainted blood), and it was a story
told by the woman who had been his caregiver for years, who had been
asked by him to tell his story and who told it from within a relationship of
intense caring and emotion that was hard to witness yet was compelling and
engaging.

Where did the clinical ethics enterprise fit into this? Juxtaposed with more
rationalistic approaches to ethics, the subjectivity and engagement of the
stories came as a surprise to many in the audience (as reflected in evaluation
forms) and for many, a welcome one. “Ah yes” they commented, “this is who
we are and what we are really about.”

If one claims, as I do, that clinical ethics is fundamentally to do with the
quality of the relationships that we live in the moral communities we inhabit,
then stories have much to offer to the enterprise. They provide at the very
least a window onto the life of that community, in a deliberately and
necessarily subjective fashion. The story of Robert does not live only, or even mostly, in the bare facts of his medical chart (which are subjective anyway albeit in a different sort of framework); he lives in the experience of his nurse, in her rendering of the facts that is based in her subjective account of life with Robert. Her story told not only about Robert but told about what it was to care for him and about him and told what was significant to her about that person and their relationship. Her manner in the telling, her voice and her stance and the words that she chose all reflected her personal experience of Robert. "He wore a blue ski jacket," she began, "and it always smelled of the cold air when he came in for his treatment." For those with ears to hear how could the listener not be brought to a place with Robert?: a place of subjectivity which called out of us a response that is different than a more clinical rendering of Robert.

Some comment should be made here about the distinction between truth and fiction in autobiography or, to use Arthur Frank's term, "self-story". There has been much discussion about the truthfulness of autobiography and about personal stories, and about their reliability in the face of the subjective rendering of events. In *Reconstructing Illness: Studies in Pathography*, Anne Hunsaker Hawkins offers an analysis of "pathography" – the genre of stories by and of the ill. Her main thesis is that pathography is one way the person who is ill, has been ill, or has kept close company with the ill, finds meaning in
that experience. Her comments are applicable to stories told orally as well as those written. She writes:

Pathographies may indeed be read as “true stories”, but the emphasis must be as much on the word “stories” as on the word “true”.... To emphasize the “story” element in these narratives is in no way to denigrate their truth-value.... Narrative form alters experience.... The past, then, is not simply recorded in the autobiographical act but given a structure, a coherence, a meaning.... Thus the process of autobiographical recollection is part self-discovery and part self-creation.

(Hawkins, 1993: 14,15)

The telling of one’s story, then, is not the same as a so-called objective account would be (if that were possible), it is a construction, a seeking of meaning that puts a certain shape to the events, gives certain things priority, leaves other details out. This shifts the story from one of ‘brute fact’ to one of experience, as in, “this is what happened to me, I experienced it this way.” Paraphrasing Hannah Arendt, Robinson and Hawpe state that “stories are...situations viewed from different angles – all in the attempt to discover and reveal what happened in a way that is faithful to reality and at the same time illuminates it. “ (Robinson and Hawpe, 1986, 114) When I hear stories told from multiple locations I am struck by what is left out of some accounts and what is included in others. One employee tells of a confrontation with a co-worker, the co-worker tells the story of a conversation. Both are true stories and both reflect the experience of the person involved. In “Perplexed About Narrative Ethics”, Tom Tomlinson discredits the use of personal story in health care because he finds the subjectivity of it renders it unreliable. (Tomlison, 1996) He does not seem to take into account the subjectivity of
the clinical renderings of the patient's case story. It is well known that the
objective clinical voice of the case report is constructed. As Hunter writes,
they "do not drop pure and untouched from the sky.... They are narratives
created and presented by human beings....framed by their all-but-
invisible tellers and interpreted by their audience." (Hunter, 1995: 1792)

In short, then, Stories of Care “worked” for the following reasons: they
reminded the listener of the who of the patient, and of the caregiver, with
whom we all kept company in the community of care that is health care; they
honoured the experience of the teller and of those in the stories; they gave
voice to members of the care community who rarely feel that they have voice;
they validated the subjectivity of the teller, the patients, and those who heard
the stories: a subjectivity that is necessary to a clinical ethics project that has
as its focus the quality of the moral life of the community; they fleshed out the
bones of the more rationalistic approach.

And where would principlism have gone with the “Stories of Care?” The
stories would have been seen as a tool to collect the relevant facts from
which to abstract the information necessary to evaluate the ethical issues.
For some, the emotional aspects reflected in the act of telling the story would
be considered important facts to include in the ethical assessment. For
some, they would be seen as too subjective, leading to an inadequate
account that needed to be balanced in order to be more objective and to lead
to a more accurate assessment of the situation. Emotion, it could be argued, makes the account inconsistent. The charges brought against storytelling would be inarguably correct. The gaze, however, would be insufficient to the tapestry of life lived in the moral community of healthcare. In addition, the valuing and validation of the stories and therefore of the women who told them, could, it may be argued, enhance their ability to contribute to the ethical discourse and, in so doing, round out the discourse in a way more consistent with reality than the unbalanced account of the rationalists. (What is non-rational about the emotionally laden telling of Robert's story?)
CHAPTER 4: STORYTELLING IN THE HOSPITAL COMMUNITY

You have the power to reach him, to make that massive movement out of yourself into his experience. Do you know what that will do for him? It will let him tell his story to the end. Your words, your understanding will act as a comfort and a charge – a current of power. Your compassions can free your patient to understand the incomprehensible, to make sense of the tragic, to speak the unspeakable. You, together with your patient, will finally grasp the meaning of what takes place in our lives. Moved by suffering, you will ease that suffering. You will become an instrument of healing.

(Rita Charon, “Let Me Take a Listen to Your Heart”, 305)

In early July 2000, a tornado devastated a campground in Alberta – killing eleven people and injuring hundreds more. Shortly afterwards I heard two women who had survived the Edmonton tornado of 1985 being interviewed on CBC Radio. After describing their experiences, which had been horrific, the interviewer asked them what advice they would have for the survivors of the recent tornado. One of the women urged the survivors to tell their story over and over again to as many people as they could. She advised that they tell it as often as possible for a very long time. Her claim was that it would only be through telling the story that they would regain a sense of control and understanding of what happened to them. She concluded by urging others to listen as often as they could to the stories the survivors needed to tell.

What, then, are the multiple roles of story and storytelling for those who tell the story and those who hear it? If we are to make a strong defence of the
need for story in the health care community, what is it we are defending? If
we are to condemn, as I do, a relationship of care provider to patient in which
the patient's story is removed from her, and told by others, why are we
condemning it?

While I find much of what story' is can be inferred from what story does
(which becomes clear in what follows), a brief discussion of the word "story"
may be helpful at this point. The definitions of story that are available in the
literature range from the highly technical: a story is a "narrative with a certain
very specific syntactic shape (beginning-middle-end or situation-
transformation-situation) and with a subject matter which allows for or
encourages the projection of human values upon this material." (Tirell:15) to
the more pedestrian (and more useful in this context): narrative discourse is
defined as "someone telling someone else that something happened." (B.
Herrnstein Smith in Charon, 1996:244) Hauerwas and Burrell write that
narrative is "the connected description of action and of suffering which moves
to a point." (Hauerwas and Burrell, 1989:177) and for Wayne Booth narrative
is "every presentation of a time-ordered, or time-related experience that in
any way supplements, re-orders, enhances, or interprets unnarrated life."

Narrative is a construction that we place over the events of our life in order to
create of them a coherent pattern. It is the connection of events through time,
as Churchill and Churchill wrote: "Narration is the forward movement of
description of actions and events which makes possible the backward action of self-understanding. (Churchill and Churchill, 1982:73) Narrative is a particular take on and shaping of events – either what has been, what is, or what could have been. A much quoted description comes from Kathryn Hunter: "In using the word ‘narrative’ somewhat interchangeably with ‘story’ I mean to designate a more or less coherent written, spoken, or (by extension) enacted account of occurrences whether historical or fiction." (Hunter, 1991: 306) Further, in the Encyclopedia of Bioethics, Kathryn Hunter makes the distinction that ‘story’ is more often used informally to connote spoken or fictional accounts while “narrative” emphasizes the inclusion of non-fiction accounts. (Hunter, 1995:1789) For me, as for many other writers, the terms “story” and “narrative” are essentially interchangeable although colloquially ‘story’ may imply a more inclusive, less formal idiom than does “narrative”: I would not agree with Hunter that story is more often “fiction.”

The narrative impulse is foundational to what it is to be human – some work has been done to show that we developed language as a means to narrate our lives to ourselves and to one another. For Ursula LeGuin narrative and story are fundamental operations of the normal mind. “To learn to speak,” she writes, “is to learn to tell a story.” (LeGuin, 1989: 39)

Peggy Carey Best puts it well when she writes: narratives are interpretive accounts of events over time and signal a perspective on those events.
Stories are a kind of narrative." (Best, 1994:93) “Story is an unspooling of narrative,” says literary critic Charles Radey. (Radey, 1992: 39) An unspooling that is captured in the “then this happened, and then this and then this” movement of narration.

Story is the way that we come to own the events of our lives. It is an interpretation, a situated knowledge that constructs of our lives an intelligible pattern. (Churchill and Churchill, 1982:74) For each of us that construction is the consequence of our own situatedness – the culture, the group, the home, the specifics in which we are located inevitably impact the interpretation of our life’s events which come out in story. In light of this the experience of serious illness is critical to the construction a person puts on their life’s events. “Being sick radically alters the moving image of ourselves through time.” (Radey, 1992:40) That is, it radically alters our story.

Story can take innumerable forms, from the formal novel, or professional performance to the confused answers given by a young mother with her child in the emergency room when the Resident asks her “Tell me what happened…”.

Narratives exist for the individual as well as in the broader context of groups - ranging from families to countries. Cultural narratives provide an example of this wherein members of a certain culture share ownership of certain
narratives that serve as parameters in which that culture exists and which
give that culture meaning. A close look at the cultural narratives that frame a
certain groups' understanding of the world and their place in it can provide
tremendous insight into the life, values and traditions of that culture. (Charon,
1994:261)

The characterization of health care as a community is useful when
considering story and storytelling within the health care context. Stories are
one of the markers of community: shared stories function in a multitude of
ways: as history, as demonstrative of certain values (not only reflected in the
story told but in who gets to do the telling, what language is used, etc.), as
constructions used by the collective to understand certain things, and as
markers of membership (Brody,1987:15) Consider the role of story in a
family, for instance: what stories are told? How are they told? By whom are
they told? What do they reflect about that family and what role do they have
in sustaining that family?

As mentioned above, at the same time I struggled with the application of
Principlism to my work in Clinical Ethics I was becoming more aware of the
role of narrative and storytelling in the health care community. Over and over
again I was drawn into the life of the moral community of the hospital by the
hearing of the stories of those with whom and for whom I worked. As a
storyteller I was perhaps more keenly aware of the importance of paying
explicit attention to these stories as a way of learning about the life of the community: not only the brute facts of the happenings but the values that were reflected in which stories were told and which did not get told, or could not be heard, in whose voices were privileged, what made it into the folklore of the community and what was discarded. As with any community the stories that are told within the health care community reflect much about that community. One of the pivotal roles of story is the creation and maintenance of community and relationship.

Story is the way that we come to understand ourselves – we are the stories we tell. We use narrative in order to make sense of the chaotic events of our lives, indeed “the primary human mechanism for attaching meaning to particular experiences is to tell stories about them.” (Brody, 1987:5) We tell stories to ourselves about ourselves as a way to gain understanding of the contingency of our existence – we understand our experiences with and through stories. (Churchill and Churchill, 1982: 73; Charon, 1994:261) A story shapes the mundane as well as the tragic and chaotic – providing a thread that weaves the occasions of our lives into a tapestry, a pattern that we can then look at, put out into the public space, ponder intimately. The woman I heard interviewed understands this – hers is a story of chaos that threatened to overwhelm her – telling her story helps her, literally and metaphorically, to reassemble the pieces. Story provides a package, an artifact if you will, that can be given out over and over in a way that is not
threatening and can be healing. Told over and over again the story takes on substance, shape, firmness, the person can get a hold of it and control it and look at it and change it's shape, find its place in her life, view it from the (relatively) safe distance of time and place and allow herself to experience the events in a way that she can control. And, over time, the hope is the story will be placed in a good and right place within the story that is her and the chaos will no longer carry the threat of disintegration.

Such is the process that people who are sick or who have been sick undertake. For the “deeply ill” - those who have suffered an illness that is perceived as lasting, as affecting virtually all life choices and decisions, and altering identity (Frank, 1998: 197), the need to tell the story is a key part of their re-integrating process by restoring the “disrupted connectedness” that is illness. (Brody, 1987:10) Illness is by definition a threat to the integration of the person – the story that she once was is shifted by the story that she has become by virtue of this catastrophic event. Cassell situates suffering in this threat to integration – the unraveling brought about by our contingency – a contingency we so often do not see until a catastrophe such as illness. He writes,”suffering occurs when an impending destruction of the person is perceived, it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner” (Cassell,1991:144), storytelling for instance.
For some, illness is narrative interruption – the threads of the story waver but can be picked up again once the event has passed, but for others it is narrative disruption whereby the former grand narrative of the self no longer applies and a new one needs to be found before the person can heal. This telling of her story over and over again is part of this search for her new narrative, one that will fit and bring her towards the new story that she now is.

When my father had his stroke he was vice-president of a large Canadian corporation. He had worked there since the age of 17 when he had trained as a machinist and 40 years later his career ended with the suddenness of the stroke. There is no doubt his grand narrative shifted drastically – the present was not the what the past was supposed to lead up to (Frank, 1995:55) – and the threads of his self-story were severed. As integral to his healing as his speech therapy and physiotherapy and the medications and surgeries, was his quest to retell himself to himself, to redefine himself in such a way that the narrative of his life could continue on in a way that was comprehensible and acceptable to him. This took considerable time. Initially the loss of his old story was devastating to him – it left a void of self-perception and a deep confusion about the next step in his grand narrative. He attended a stroke survivors’ groups for a while but bristled at the story of being “a stroke survivor” and he joined a group for retired professionals but found no place for himself there.
Throughout his adult life the little time my father had taken for hobbies or recreation had been spent dabbling in painting and sketching and working in his carpentry shop. He had never had the time to become very good at it but it always was something he wanted to return to. Within a year of the stroke Dad had started setting up a woodworking shop in their home, equipped in such a way that he could work in it with his one good hand. And within that first year he and I produced storybooks for his grandchildren – I would write the story and Dad would illustrate them with his paintings. In the ten years since that time Dad has made hundreds of dollhouses for friends and family and for charity, he has crafted dozens of folk art items and the house is full of paintings – he takes lessons from an artist who suffered a stroke about the same time he did.

This very brief outline of the process that Dad underwent, and is still undertaking, provides a literal and metaphorical illustration of the process of finding our new narratives in the face of narrative disruption. The process of building his life, so strongly mirrored in the building he undertakes in his shop, moved him from his old self-story into this new one. The process required many tellings of his story, many times looking at it and retelling it over and over until a voice and a shape to the narrative was found that he could fit into the life that he lives now.
When a person is not permitted to tell their stories over and over again, it is not as though a story will not exist for that person: for the tornado survivors the media, their neighbours, the authorities who assist them, the insurance companies, the health care professionals who work with them, will have the opportunity to tell a story about them, but it will not be their own stories.

When a person is barred from telling her own story, from refinding herself, a story will appear for that person – it will not be hers though and, so, will not have the effect of reintegrating that her own narrative would have.

In my own quest for my new self-story I have encountered many people who will hear me tell my story over and over again and to them I will always be grateful: their hearing has given me a space into which to put my tale and to see it and understand it and to help to bring all those experiences back into my life. They are woven into the fabric with me after all. There are many, however, who are unable to hear a tale or even to allow me to create it myself. This is a common experience particularly in the health care relationship. In order that a story “work”, it needs to be heard, to be received, and this is one of the core roles that can be played by the health care provider in her relationship with a patient. It is a role that is resisted, though: the story and voice are cut off in the interest of time or because they do not fit the dominant discourse. To receive a story is to be drawn into relationship with a different dynamic than is often expected between the physician and the patient. (Frank, 1998:198) It becomes one of intimacy,
shared power and increased responsibility. "Do you really want to hear this?" the person who is sick asks, knowing that listening carries a responsibility with it. In my own experience those who could not hear my story were often health care professionals and occasionally friends or family. "We don't want you to be that person." they seemed to be saying: because out of that person comes a call for a different kind of relationship.

Medicine is essentially a narrative art that uses stories, told in a particular way, as tools to assess and determine treatment and care of the person who presents with "a broken story." (Hunter, 1991:25) The clinical case is the dominant form of narrative in medicine: it is a particular telling of the person who is ill by the caregiver, predominantly the doctor. Kathryn Hunter goes so far as to characterize the therapeutic relationship and encounter as a three-storied process: the person who is ill presents to the physician with her narrative of a “broken story” and gives that story over to the physician for him to retell it in such a way as to fill in the gaps, to retell it in a way as to make it ‘work’ again and then to return it, in the third step of the process, to the person who is ill so that she can reintegrate it into her own, grand story of her life. (Hunter, 1991:25) Howard Brody uses the same metaphor of the “broken story.” (Brody, 1994) Both claim that this is the desire of the patient – that she seeks out the medical expertise of the physician, who, after all, is a repository of other broken stories and will therefore have more access to ways of fixing the story in such a way as to make it work better. The ill
person is weary of seeking a way to fix her own story and is willing to hand it over, with trust, into the hands of the physician and, finally expects it given back to her in such a way that it will respect the narrative flow of her life as it has already been experienced. Both emphasize that this is ought to be a work of co-authoring between the patient and the physician and both outline systemic and institutional impediments to this co-construction taking place.

While this model utilizes a language that I find heartening, I am concerned about the middle step – the giving over of the story by the patient and the taking it by the physician. The authority of the physician to construct the patient’s story remains untouched by such a model, although the language of the discourse would seems to make it softer than that. The giving over of one’s story for someone else to tell is an act of great ethical import, as is the taking of it. When this taking is done without the assent of the patient, much less their consent, then it is even more serious ethically.

To lose one’s story is to be disempowered – it is a classic political move to claim one’s voice and story against those who would take it from you and it is a classic move of oppression to suppress another’s voice and story. Implicit in this is the recognition that the story and the voice to tell it owns power. For Arthur Frank the telling of one’s self-story, for the person who has been or is still ill, is an act of reclaiming: reclaiming the right to tell her own experience, claiming her own voice over and against the medical voice and in so doing,
Frank claims, she reclaims a life beyond illness. (Frank, 1994 *Lit and Med*: 3)

It is a move beyond the compliant role of ‘patient’ that has been favoured by modernist medicine, a move back into person. Frank writes, “Just as political and economic colonialism took over geographic areas, modernist medicine claimed the body as its patient, as its territory, at least for the duration of the treatment.” (Frank, 1995: 10)

For Frank, as for many critics of the health care system, much of the reason for this is found in the Parsonian origins of a particular model of patienthood. “According to Parson’s theory, illness requires a person to act according to the normative expectations of the sick role, and among those expectations is the obligation to seek and comply with medical treatment. The Parsonian tradition thus reduces the ill person to the patient, and this patient’s agency is limited to compliance; the physician becomes the active agent in the illness process.” (Frank, 1997: 31)

Thus, for Frank storytelling is a core moral action that enables the ill person to realize her agency – an agency that has been suppressed by the Parsonian model of patienthood and by the current conditions of training and organization of medical practice in which there is neither time or competence to attend to the moral self – either of the patient or of the physician. (Frank, 1997: 136-137) Disempowered people, and this is one of the markers of
entry into patienthood, recognize their situations won't change until their own words are taken seriously.

Kathryn Hunter points out that a person's story is rewritten, retold, by the physician as part of the move from lay subject into medical object, a move which reduces the patient's particularities into medical generalities. (Hunter, 1991: 134) In the face of this ethos Frank claims an ethical imperative is to make space for and honour the client's voice. For him the primary ethical gesture is to honour the voices that have been submerged and let those who have been spoken for now speak for themselves. (Frank, 1995: 46)

Frank criticizes the Clinical Ethics enterprise, particularly the practice of hospital ethicists, as being especially inept at making space for and honouring patient's voices. He argues that most hospital ethics is practiced in a way that supports the airing of the already-dominant voices and stories:

Helping people to find their voices rather than responding to voices already claiming attention is a clinical task that, if recognized at all, lies outside the scope of applied hospital ethics work. But until people have found their voices, they cannot participate in decisions about themselves, without the participations of those affected by these decisions, ethics remains an inquiry practiced from above. (Frank, 1994 Second Opinion: 45)

What happens when the location of the story and the power to tell it shifts from the experts to other voices? What if, instead of giving over the story to
be retold and then returned, the person who is the patient claims the space to tell her story – rather than giving it away, draws the listeners into the relationship with her? For Frank a number of things may happen when this shift takes place; the meaning of the ethical concerns may change: while the decision taken around the ethical concern may not change, the meaning of it may when other narratives and voices are included. (Frank, 1994, Second Opinion:47) Surely this meaning changes, at least in part, because the involvement of those making the decisions, or helping make them, changes fundamentally when all are subjects in the storytelling encounter.

Some years ago I invited a young refugee woman, whom I will call Marta, to take part in one of the Stories of Care series. My intent was to broaden the tapestry of voices to include some of the voices of those for whom members of the hospital community cared. As part of her own healing journey Marta welcomed the opportunity to tell her story in a public forum – to have her voice heard. With the other five tellers she worked for four months to craft her tale and she told it at the closing session of a conference on nursing ethics. Everyone who told that year told a story of tremendous force and intimacy, the audience was engaged and moved and all the tellers felt they had done their stories, and those in the stories with them, great justice. Marta was enthusiastic about her performance and felt that the process had helped her move along in her own healing journey.
The story does not end there. Some years after the event I met someone who knew Marta and asked her to pass my greetings onto Marta. When I heard back from the woman I was alarmed at the accusations that Marta had leveled at me. She claimed that I had exploited her, used her story and her voice to further my ends, and the ends of my institution. I was heartsick to hear it and after years of soul-searching feel certain that her accusations were not sound. However, they do merit consideration. There can be no doubt that Marta had come to an increased awareness of the power of story and of its being told. While I did not control or own her story there is no question that I did control the space in which it was told, at least to the extent that I provided the physical setting and the opportunity for the telling. Once the story was put out into public space there was no control over how it would be accepted or how Marta would be received. Away from Marta, once the story had been told, it was out in a public space where it became part of the fabric of the stories of all who listened to her. In the storytelling exchange, Marta had given away some of her story. Perhaps it was the awareness of this power that had hurt her so much.

And what is this power of storytelling? Apart from the role of story in re-integrating the person who has experienced the suffering and trauma of illness, there are powers of story and storytelling that reach beyond the person who tells the story. These are critical in any group or culture, and they
are in the context of the health care community and the relationships that are embedded in it as well.

As discussed above, storytelling is an invitation to relationship. A story creates a relationship between the person who tells and the person who listens. A story creates a new place and brings teller and listener together, forging a connection through shared images, and shared experiences. Thus is a connection forged along the ribbon that is the narrative of the story. Thus do we two become subjects in a relationship. Thus can a story build a community of listeners based in the shared experience of story and the affect and residues that come of that story. The very act of storytelling can be seen to broaden moral agency out from just the frame of events into the circle of all involved in the narrative act: teller and listener both. (Brody, 1987:15) This relational quality of story, its call for intersubjectivity, is one of the qualities that Frank places at the centre of its value for the ill person and for the community beyond that person. In the act of telling her self-story the patient makes the move into being a dyadic body – a body that is an "I-thou" body, as opposed to the monadic body that the medical ethos encourages. (Frank, 1995:36ff)

To refind the story of oneself after a chaotic splintering is powerful in the healing process, providing solidity upon which to build. To tell one’s story is to be understood by others and to be drawn into relationship with them: this
building of relationships is a strengthening, empowering act. Particularly for the person who has been ill this reintegration into a community is critical. One of the markers of being ill and of suffering is the sense of excommunication, of being removed from the citizenship of the well. The reconnecting that may be wrought by story and the telling of the story marks a re-entry into a community. Each story told can be a step back from exile.

I spent three weeks as a patient in the neuro-ICU. A tube inside my brain drained excess fluid caused by bleeding during surgery and exited a hole in my neck, filling a bag hanging on an IV pole with pink liquid. I wore a green turban.

Beside me there was a large woman who was on a ventilator and was unable to speak or communicate. Usually the curtains around her bed were drawn. I only saw her once – big and bloated and mostly naked. All during the nights the alarm on her vent would ring – bringing a nurse running. Sometimes the nurse would be angry with her, scolding her for forgetting to breathe. She had been there for months.

Across from me was a Jamaican man with a lovely accent and a great sense of humour. For days we couldn’t see each other – the light hurt my eyes so I was kept behind curtains – but we bantered across the room. I told him I was as beautiful as Ingrid Bergman and he called me Ingrid for the rest of the time we were together. It was his second operation in a year. He showed me his incision – it was a row of zipper like staples from the top of his skull to the base of his neck.

Further up the unit was reserved for trauma patients. On Easter Sunday night a young woman was brought in – they flew her by my bed on a gurney. She and her boyfriend had been in a serious car accident. Everyday he came with her parents to see her – he walked with a cane and wore a neck brace. Her father talked to me often as I made my slow way around the hallway. He told me she would probably walk again but it would be a long time and a lot of work. Partway into the second week they cut her long hair so they could operate more easily on her neck. The day before I left the unit her father brought me a pint of Guinness in a can and made me promise to toast her health when I got home.
Each of us there were part of a community of sorts – a community of the elite on the top floor of the hospital. It was our experiences, the stories we were that forged the bonds. It was our commonality that brought us together – our scars and tubes and fears that kept us there. We shared a language which was literally written on our bodies and captured in the knowledges we held about things that are important and things that just don’t matter. The story told in my friend’s long incision, in the daughter’s shorn hair or in my tube, was not frightening to us but were marks of community.

Leaving that place the stories around each of us changed. I felt cut off, marked, and silenced as I struggled to re-enter the life that I had left behind when I walked out of our house that dark and early morning in March. The words, the sights, the stories no longer made sense to me and left me feeling as though I was speaking into a vacuum or from behind a thick plate of glass. To re-enter my relationships, my communities, I needed to re-find my story and a way to tell it. Or I would, I feared, always long for the community of the ICU.

The ill person is party to what Frank calls the “special knowledges of the ill” and, as such, is special witness to the contingency that it is to be embodied beings. In this role of witness, Frank claims, lies a responsibility to bring testimony. "People who tell stories of illness are witnesses turning illness into
moral responsibility.” (Frank, 1995:137) At heart this act of bringing testimony, bearing witness, is relational:

Testimony is distinct from other reports because it does not simply affect those who receive it; testimony implicates others in what they witness. This reciprocity of witnessing requires not one communicative body but a *relationship of* communicative bodies. (Frank, 1995:143)

The person who receives the story is drawn into a relationship with the person who tells it and, if the person has truly witnessed in her listening, it is a relationship built on a mutual abundance of need. “Listening is hard, but it is also a fundamental moral act;...in listening for the other, we listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is for the other.” (Frank, 1995:25)

When a story is told, the teller brings the listener into a new place – the forest of enchanted trees, the hallways of the old house, the bed where her friend died. It is a place made of images and intimacy. This movement is powerful for opening up the person to new experiences and perspectives, a new context in which the listener is ripe for insight and awareness.

How does this fit within the health care encounter as outlined by Brody and Hunter? The patient’s giving over of the story to the physician is certainly a giving over of authority and to authority. It is a move that marks a subordinate positioning on the part of the patient who must give over her story in order for a medical or therapeutic intervention to be determined and
undertaken. And it is a subordinate positioning when one considers the power in owning the story and having voice to tell it. It also, of course, indicates a position of power on the part of the authority, in this case, the doctor, who can take that story and impose a new telling, a new frame upon it. This may well be the only way that a therapeutic encounter can presently be constructed. The dominant medicocentric discourse would seem to result in this as a therapeutically necessary model. Similar to Hunter, Frank describes the ethos of the health care community, as it is presently constructed, as "medicocentric", that is as having the power and influence resting with the medical establishment and those who people it. In this medicocentric ethos the person who is ill is only regarded in their patienthood – the medical facts only are considered important and the construction is such as to further the interests of medicine. In this medicocentric ethos he recognizes that many such opportunities are lost when the physician is unable to assist the patient to realize her agency. (Frank, 1997:132)

In *Doctors' Stories*, Hunter provides an analysis of the ethos of the practice of medicine which would certainly support this point of Frank’s: she argues that the way that the practice of medicine is taught and supported sees the giving over of control of the patient’s narrative to the physician as fundamental to the therapeutic encounter. For Hunter the physician’s construction of the patient’s story is the fundamental act of patient care: “The construction of a meta-story about the patient’s story by interpreting events of illness, testing
them against the taxonomy of diagnostic plots and settling on one that is sufficiently likely to warrant therapeutic intervention." (Hunter, 1991: 128, 129)

The patient, after all, seeks that authority of the physician and to do so must give up some control of her own narrative. Or so seems the assumption wherein the physician has authority and the patient does not.

A patient, suffering dizziness, goes to his doctor. The doctor suggests a certain kind of test. "What will the test show?" Asks the patient.

"It will show whether you are dizzy or not," answers the doctor.

"I know I am dizzy," answers the patient. "Why would I need the test?"

"So that we will know if you are dizzy."

What happens when a therapeutic encounter is premised on the removal of the story from the patient? If the story is an important way for the patient to reintegrate in the face of narrative chaos and to gain meaning and understanding of their self-story, how can this be accomplished when, as a matter of course, they are expected to give over their stories?

In the course of my own illness journey I indeed carried my broken story with me and told it over and over to the caregivers who, I hoped would be able to help me fix it. And, as outlined by Hunter, in most of the encounters I gave my story over to be "fixed". That was not my original intention but I soon realized that the therapeutic tradition required it of me and it marked my move into being a patient. Time and again I would struggle to tell my story in a
deliberate fashion, trying to show what was happening to me, why it was troubling to me, what it meant to me, only to have the interview controlled in such a way as to render great parts of my story irrelevant, ridiculous or simply not, to use Hunter's term, "narratable." The clinical case is the dominant form of narrative within the medical setting: it is a particular telling of the story of the person who is ill by the caregiver – predominantly the doctor. In the preparation of the clinical case only facts that are considered relevant to the construction of a clinical picture are taken into consideration. The only components of the story that are narratable - that is, are worth including in the case – are the ones that stand out from the picture medically problematic. (Hunter, 1991:127)

The diagnostic model utilized in these encounters requires a certain amount of this: the physician wants and needs only certain information to render a physiological assessment – and these parameters are set long before the encounter between the patient and the physician takes place.

"My headache is so bad that after I teach a session I lie down on my office floor and turn out the lights." I would state.

"So, it's a severe headache?" The physician would ask – reducing my pain, my story and me into a checkmark on a diagnostic sheet.
There is no doubt that some of this is necessary and in the cases where the illness is not serious it may do little harm: it may even expedite the healing process. However, it often goes much further than this. For me it reached the point that the story I watched and heard being constructed about me was far from the reality that I know was true. When this happened I witnessed the patient, me in this case, being abstracted from the person, me again. I watched dumbstruck as I was constructed into any number of stories that would serve the particular physician’s therapeutic story but would not serve mine — and therefore would not help me therapeutically at all. Witness the physician who told me that all I wanted was “a name for my problem”, or the other one who snapped his fingers around and around my head. “What are you doing?” I asked. “Killing flying monkeys,” came his answer. “What?” I asked, feeling sick and angry. “You don’t see any flying monkeys do you?” I shook my head. “Right, well I don’t see that you have any problem either.” And with that I was dismissed.

This experience is not unusual for the patient: at heart the physician seeks to create of the patient’s story one that can be reduced into a rational order of knowledge. (Hunter, 1991:124) In the quest for a successful therapeutic response to the patient’s problem the desire is for as straight a line as possible between cause and effect. “Medicine’s notion of causality streamlines the account of disease, making cause and effect and treatment a straighter line than it is in fact.” (Hunter, 1991:104) Within this context a
wider narrative of disease, such as the one I was attempting to present, complicates the representation and idea of causality of medicine. Because of this the physician hopes to achieve a minimal, streamlined, scientific account of disease, making it impossible to get an effective grasp on a patient’s particular manifestation of a malady. (Hunter, 1991:106)

For Hunter, the very act of presenting for medical care is the dividing line between the subjective and the objective, resulting in a case presentation that is itself a narrative of interpretation but one that reflects the valuing of the objective account over the personal. (Hunter, 1991:134) “On the simplest level,” writes Rita Charon, “....the patients are transformed into their organ or diseases....A malignant hepatoma seems easier to face than a twenty-six year-old man who will die soon...” (Charon, 1986:61) In Arthur Frank’s terms the particularity of the individual sick person’s suffering is reduced to medicine’s general view. (Frank, 1995:11) Very seriously it may create of the patient an object that may have little bearing on the reality of the person who is that patient and so will lead to therapeutic decisions that are not helpful and may be harmful: what if I had trusted the first doctors I saw or had allowed the “flying monkeys” to stop my venturing further into seeking help?

Tied to this is the severance of any type of relationship that is based in trust and mutuality. The physician dismisses the person and in so doing ends any chance of a mutually healing relationship. For Hunter this inability to broaden
what is narratable in medicine causes considerable damage to the physician as well as the patient. For her the reduction of the patient only to her medical existence is "solipsistic and controlling". It fosters avoidance or automatic unfeeling care and "makes possible, even probable, inadequate treatment and misunderstanding of further symptoms." (Hunter, 1991: 137) She urges physicians to be clear on their role in the co-construction of the story and to be aware that it is not a removal of the story from the patient but should be a sharing of it, and should be clear that the medical account is only part of the story.

What, then, is the damage caused by taking the story away and controlling its retelling? In response to those who would argue that physicians should remain emotionally detached from their patients, Hunter states that it is this same emotional detachment that leads directly to a poor quality of work life for the physician while also resulting in poor care for the patient. (Hunter, 1991:137) Inter-subjectivity is necessary for a truly caring and mutual relationship and such a relationship, and the community of care which would result from such relationships, would strongly impact the health care encounter: "If we are to respond in caring ways to the suffering of other, we have to understand it and let that suffering come close." (Charon, 1990:295) It would, it is argued, in fact enhance the level of care and success of the medical encounter for all involved. It does, however, necessitate a sharing of power that is reflected in the sharing of voice and the co-construction of the
narratives a health care, a challenge in a forum where there is a tug-of-war over who owns the story. (Hunter, 1991:17)

For Frank the impact of this upon the physician is fundamentally in lost opportunity to enter into relationships of true mutuality and intersubjectivity. He casts the relationship between the patient who tells her self-story and the person who receives it as one of true empathy wherein the person who listens is aware that he is being served in his neediness, as much as the person who is telling the story. Being truly open to these stories, states Frank, is an opening to vulnerability and an awareness that a truly caregiving relationship is built on a “mutual abundance of need.” He writes of Nancy Mairs, a woman with multiple sclerosis and of David Hilfiker, a physician who works with the poor in Washington, who both dismiss the construction of a relationship based on charity as a means of meeting one’s own need by drawing from the abundance of others, which in a physician-patient relationships happens to be an abundance of need. (Frank, 1991:149) For them (and one assumes for Frank) genuine service is a matter of recognizing that one’s own lack can only be met by the other’s abundance of need. From this realization and acting upon it can true relationships of mutuality grow. (Frank, 1995:150) Where the agency of the patient is allowed by the welcoming of their story – a relationship of mutual need is recognized. “Applied to medicine, this thinking displaces Parsons’s idea of the physician acting as social control agent…. Instead, what emerges is an image of the
physician as servant, who understands himself as being served: Jesus
washing the feet of his disciples is the appropriate ideal” (Frank, 1991:150)

In “Illness as Moral Occasion: Restoring Agency to Ill People,” Frank further
characterizes illness as an occasion for moral work which he describes as
“seeking to do the right thing, [although] no single right thing is usually
available.” (Frank, 1997:135) The overall task for the person who is ill is to
realize a “successful illness.” He quotes Anatole Broyard that “all illness
presents an opportunity to learn about ourselves and the world we inhabit and
create, and that chronic illness in particular challenges us to ask if it is
possible to be successfully ill.” (Frank, 1997:137) Reviewing the stories of
people who are ill, Frank observes that success includes living a story that
finally can be told after facing the task of self-reconstruction, including bearing
witness and the attendant responsibility to tell what happened. (Frank,

The ramifications of this are many and call on the physician to be willing to
accept a relationship of intersubjectivity with the ill person. As a result of
medico-centricity, which places the physician at the centre of the enterprise,
the patient is often left on her own to do this moral work and the physician
misses the opportunity to accompany her and support her in this work. More
seriously, however, the physician’s incapacity to recognize and support the
patient in her moral work may result in a blocking of her way toward a successful illness.

Key to the moral work of the patient is her telling her story and having it heard and telling it over and over, redrawing in the process the moral maps of her world. Writes Terry Tempest Williams in her *Refuge: An Unnatural History of Family and Place*, her story of the breast cancer that kills all the women in her family and of her struggle as the only surviving woman in the family, “Perhaps, I am telling this story in an attempt to heal myself, to confront what I do not know, to create a path for myself with the idea that “memory is the only way home.”” (Williams, 1991:4) Many who write about their illness experiences bear witness to the task of self-reconstruction and how the present medicocentric conditions of training and organization of practice lack both the time and the competence to attend to the moral self. (Frank, 1997: 137)

One of the markers of patienthood is a sense of exclusion from an active role in one’s community – a feeling of constant receiving, that one has little to give or at least little opportunity to give it. One’s capacities may have in a very real sense been lessened or changed by the illness experience or simply assuming the role of patient, with its implied passivity, may result in this sense of being useless. And consequent to this, the patient’s sense of exile
from her community is exacerbated. When one is ill, one frequently feels cut off, remote from what used to be one's community.

In the face of this Frank defines a very clear operation of agency for the person who is sick – one that is critical to the community and the relationships therein. He writes: “service can take many forms but for the person who is seriously ill, a primary possibility for service is storytelling as an act of witness.” (Frank, 1995:40) In telling what happened, the narrative interruption of illness is turned into witness. Witness requires a recipient, an audience, a listener who is open to the story and it is through the act of witnessing that relationships are forged for “narrative ethics takes place in telling and listening. There is no such thing as a self-story….only self-other stories….Ultimately narrative ethics is about recognizing how much we as fellow-humans have to do with each other.” (Frank, 1995:163) Thus can the ill person create an opening for truly empathic relations of care rather than the remaining solely recipients of treatments and services. (Frank, 1995:107) In the telling of their stories they have turned their illness into moral responsibility (Frank, 1995:137) and have become communicative bodies, rather than just receptive ones. (Frank, 1995:143)

Storytelling is potent in its ability to create and sustain relationships and communities. When a story is told, the teller and the person who hears it are tied together in a relationship of shared images and experiences – it is a
relationship that may last only for the duration of the story or may be more durable. Shared story is one of the markers of community, of membership and acceptance. This power is very important to the ill person who is striving to have a "successful illness." Kat Duff, in The Alchemy of Illness (1993) understands her illness not solely as an entity with her but as a link between herself and others: "It feels as though the thin strand of my life is woven back into the web of our world." (Duff, 1993: 132) The stories of the ill represent an active responsibility to understand the self, and then "to place the self within an extensive ecology of relationships." (Frank, 1997, 142) This consciousness of relationships acknowledges an intersubjectivity of patient to the relationships in which she is embedded. It is not, therefore, a self-focused or one-sided agency of all those around the ill person. And in so being, the successful illness experience changes the fabric of all those involved with that person – the physician included. Thus can the experience of storytelling give meaning to the illness while also addressing the exile that is so often the experience of the deeply ill.

Early in her illness, Jackie was taken into the care of a physician at the hospital in which she had worked. They knew each other professionally and, Jackie thought they shared a professional respect. At her first office visit the doctor asked her to tell her story and she took this to be an invitation into a caring relationship: she felt he recognized that the best therapeutic relationship would be one in which the patient co-authors her story with the
physician. Never in her life had Jackie been so vulnerable as she was when she was so sick and first entered this caregiving relationship. She welcomed his willingness to share the co-construction of her story.

Within the first two office visits he had diagnosed depression – a diagnosis Jackie disagreed with and strongly resisted. She was angry and disappointed but agreed to try anti-depressants while he agreed to continue to search for the “real” cause of her illness (her words, not his). Weeks of pain ensued and she advocated strongly for a CT scan to be done: something to which he agreed although he seemed surprised by the request. Five weeks later the CT scan showed a tumour growing in the third ventricle of Jackie’s brain, beginning to block the ventricle and hinder the flow of cerebro-spinal fluid. It was weeks away from rupturing and killing her when she had surgery to remove it.

Post-surgery Jackie continued to be Dr. X’s patient – as her physician he was responsible for follow-up and she still trusted his willingness to help her get well. At one visit he asked her why she had come back to him after “what had happened” (he never admitted a mistake) and she answered that she had trusted his commitment to see her through things. In subsequent visits he did little for Jackie, in spite of the fact as her physician, he was expected to care for her and educate her about the likely outcomes of her surgery. Over
time the relationship became more and more strained. Dr. X became abrupt and dismissive.

When Jackie last saw Dr. X, for an appointment he had requested, over a year had passed since the surgery and she was still not feeling well. This seemed to annoy him. In frustration he spread his hands out on the desk in front of him.

"I have nothing more to offer you," he said. "I don't know what it is you want." "I want to feel better," she answered. She had listed for him her symptoms. He shook his head. "Should you take my blood pressure or something?" she asked, feeling ridiculous.

"No, I don't think I'll do that," came the response. She wanted to ask him what was going on, what had happened to their relationship, but she was tired, embarrassed and frustrated. "Dr. X," she asked, "you have always taken the same way into my story haven't you? With everything I've been through you are still caught on the depression story aren't you?" She watched his eyes carefully. He shrugged, non-committal.

"Well," she ventured, "is there another way of entering my story that may get us somewhere?"

He shook his head. "I very much doubt it. A year and a half ago you came in here with your story and ever since then you have been resistant to all of my suggestions on how to retell it. It has gotten to the point that I am chary of saying anything for fear you will knock me back on my feet."
So that was it. In the context of their relationship Jackie had understood that they were, the patient and the doctor, co-constructing her narrative. She had understood that the relationship was one where she owned the story and shared it with him who owned the expertise and that, together they would reach a point where the story they co-authored would be acceptable to her, medically useful and so much more, and would be returned to her. He, however, appeared to think differently. Where Jackie had seen them to be sharing her story, he had seen it as his to take and do with what he thought wise. In his view Jackie's deliberating with him had come to be a struggle over who got to tell the story, who owned it and who controlled it. Her disagreements with the ways he tried to retell her story were, for Jackie, opportunities to work things out but for him were an undermining of his authority and his ownership. He seemed unable to conceive of the relationship as one of intersubjectivity and Jackie could not have it be any thing but.

What purpose does this part of the Dr. X story serve in the present discussion? It is first a fine example of the model that Brody and Hunter outline wherein Dr. X invited Jackie's broken story with the apparent intent of taking it from her, fixing it and returning it to her so that she could enter it into her ongoing self-story. Had Jackie been willing and able to accept a passive role after the depositing of her story with Dr. X, perhaps the relationship with
him would have continued but it would have been one of object and subject. Apart from the blatant fact that his misdiagnosis would have resulted in her death, this would have required that Jackie somehow incorporate a story that was not hers, and possibly barely of her, into herself. How would this have served the need that she had as a deeply ill person to reintegrate herself? How would his story of Jackie have mended her narrative chaos? I doubt that it would have done any of these things – in fact it would have continued the subjective experience that she had, and share with patients, of being removed from the story, being depersonalized and objectified to the point that one is not recognizable to oneself. In the clearest terms, Dr. X removed from their relationship any chance of Jackie putting herself back together again and he missed obvious therapeutic opportunities. Jackie’s story did not fit the stories that he held in his depository and he struggled to make it do so rather than to accept the invitation that a patient offered him to co-construct, co-author a new story that may serve both his need for therapeutic expertise, and all its attendant power, and the need of the patient to be her own story and voice. For, as stated by Howard Brody: "...when narratives are jointly constructed, power is shared between physician and patient, and the sharing of power constitutes an important ethical safeguard within the relationship." (Brody, 1994:79)

The health care culture as outlined by Hunter does not often allow for this co-construction, although she certainly advocates for it, shaped as it is around a
particular locus of expertise and the power that rests with it. A woman I know who is an incest survivor tells of the hostility and fear caused in her family when she dared to speak out about their long-dead father, for in her story lies the death of so many of the other family stories that had been woven to construct of the family a certain story – false and harmful as it had been, the true story was destructive in its power. Jackie’s insistence on the right to tell her own story, implying as that did a reluctance to allow Dr X to have sole voice in it, was unacceptable to him for it undermined the power he owns by virtue of his position and because it placed him in a location of subjectivity with her, his patient. He could not allow two voices unless his was paramount.

The story of Dr. X is not unusual, unfortunately. Rita Charon writes very frankly that such co-construction would be difficult if not impossible to realize: “The notion that doctors and patients develop partnerships and collaboration within their relationship conceals the troubling realization that they are undertaking radically diverging enterprises within the medical encounter.” (Charon, 1992: 116) The relationship of physician to patient is defined in such a way that the co-authoring of a story is something that is not easily accommodated and that the medicocentric system is challenged to accommodate, much less aid. What does this do to the person who is ill, to the physician and to the broader community? Given the importance of the process of storytelling to the person who is ill, the removal of her story from
her and the refusal to allow her to co-author it has the very serious possibility of blocking her opportunity to have a “successful illness.” In so doing it may prevent her story from being woven into the broader community, limiting her ability to place herself with an “extensive ecology of relationships.” (Frank, 1997,142), thereby impoverished the patient but also the community at large. Dr. X effectively prevented Jackie from working through her own self-story in the context of what should have been a caring relationship, he demeaned her efforts and, given the vulnerability that is characteristic of being a person who is ill, he demeaned her. He was one of the many obstacles to Jackie’s making meaning of her experience and achieving a ‘successful illness” and that, apart from the human realities of misdiagnosis and ignorance, is a very serious ethical move. Until the relationship can be constructed in such a way as to honour the intersubjectivity of both its members these serious ethical acts will continue to be performed under the guise of medical expertise and its attendant authority.
Allow me to turn to the "Dad Tales" and, in so doing, provide commentary on the praxis of storytelling in a Clinical Ethics setting while bringing the discussion to a close.

Ten years ago my father suffered a massive stroke and life around him fell into chaos - a chaos that is one of the markers of the trauma of illness. Long before Dad's stroke I had found the clinical language of hospital discourse to be arid and in many cases incomplete. While this discourse serves necessary functions that are not to be negated, I found that the lack of stories perpetuated the dynamic of viewing the person who is patient as one-dimensional. It was my experience that this often was the context for the ethical problems that arose in the everyday life of the moral community that is a hospital. It is most certainly one of the reasons that patients often feel disenfranchised, poorly cared for or invisible. After Dad's stroke, when teaching in the Clinical Ethics setting I found myself crafting and using stories about that experience and the multitude of experiences around it. It was a natural thing to do and was a very strong impulse. Within a couple of years of the stroke I had created a set of stories called "The Dad Tales", comprised of
three large narratives and shorter vignettes taken from my own clinical practice.

Illness as the occasion for stories is, I think, as relevant for those tied closely to those who are ill as for the ill themselves: the narrative wreckage and interruption and the need to tell stories applies beyond the ill person. While Dad’s stroke was not my own illness, it was an illness experience that impacted on all of us who were in a relationship with him and became, in some very real ways, an illness story for all of us. My grand narrative as Dad’s daughter was ruptured along with the grand narrative that he had been living and I needed to find the meaning of these events. Keeping watch with someone who you are close to brings with it the suffering that the threat to integrity and identity brings to the person who is ill. I am not in any way equating my daughter-suffering with that of my father – that would be facile and unfair to Dad’s struggle. Rather, I am outlining the reality of those who keep company, close company especially, with those who are ill.

Dad’s stroke was hugely significant in my life and in the face of such significance we try to discover, or impose, meaning through elaboration in story. (Banks, 1982: 24) Given that I am a professional storyteller, I crafted some of these tales deliberately with an eye to sharing them in public spaces. At first I thought my impulse was simply to use my personal experience in a pedagogical context within the hospital settings in which I worked but upon
reflection I realize that I needed to craft the stories as a way of understanding the events that were occurring and that I was a part of, “the stories we make are accounts, attempts to explain and understand experience.” (Robinson and Hawpe, 1986:111)

While providing the person with a sense of coherence and narrative flow a story told, given out into a public space, has other consequences. A story can be a way of unearthing the subjective, lived experience of the person telling it. Through my stories I wanted to draw others into the experience. Indeed, for the person hearing the story, narrative offers a way to experience effects without “experimenting on their own lives.” (Hauerwas and Burrell, 1989:187) My most conscious desire in telling the Dad Tales was to bring to life the reality (my reality?) of who Dad was, who I was, and what it was like being in those places, experiencing those things. Most certainly part of my need to shape and tell my “Dad Tales” came from the desire to show people the “literal and immediate” (Frank, 1995:53) part of the experience. “This is what happened!” I wanted to shout and, more importantly, “This is how it was!” The need, the wish, was to be understood, to have my reality comprehended and, perhaps shared.

Another part of the need was rooted in the call to relationship that is story. Within this relationship there is a call for empathy, compassion, sharing. When I tell you the story of getting to know the new Dad I bring you with me
to that place, I move you into the experience with me - you share it with me. And when that happens I can hope that you will care for me, that my suffering will be real to you and call out of you a reaction of support and understanding. (Frank, 1995:53) As Arthur Frank writes, “When an illusion of oneself as the beginning and end of all things can no longer be maintained the openness to communion is all that is left.” (Frank, 1995:154) On some occasions I know I told a story in hopes that the suffering could be shifted - as though in the telling, some of the experience and the suffering it carried with it could be given away, but on most occasions it was this communion that I sought.

On another level, with the act of telling stories I was bringing those who heard me into relationship with me. I was, in effect, creating two subjects through the storytelling encounter: I, the teller, and the other person, the listener. Retelling one’s story, one can reach out into one’s community for support, for understanding or, at the very least, for shared sight. It can be a reclaiming of space in the narrative community, “it can confer recognition, communion, ending the isolation and strangerliness of sickness.” (Rita Charon, 1996:304) Over and over again, as I told the Dad Tales, I knew that new relationships were being woven and that some were welcoming the invitation into such intimacy. We simply saw each other differently.

Immersed in the life of my father as stroke patient, rehab patient, stroke survivor and the multiple other stories in that web, I felt a need to remind
those in the caring community of who the people in their care are. Arthur Frank defines at least two imperatives for those who are ill and for those who keep company with them: the imperative to bear witness and give testimony and the call to achieve a “successful illness.” To varying degrees these are both applicable to those who keep company with the person who is ill. In crafting and telling The Dad Tales I was bearing witness to events that were fundamental to my father and to all who would walk a similar path of illness – all of us in fact- and I was giving testimony as someone who stood close by the events, was woven into them and who had voice and the opportunity to use it. On another level my stories are testimony, bearing witness to someone - my father and those with him - who would not have had his story heard otherwise. It was one way of honouring the lives of not only him but those like him and in so doing it was entering his stories into a public domain where they would become part of the public discourse - even in only a small way. “Narrative as a human activity is in part intended to provide its listeners with a widened, vicarious experience... the story is not a collection of facts but an exploration of the possibility of individual variation and its meaning in relation to the whole of human experience.” (Hunter, 1986: 625)

As well, the journey of Dad and those of us who kept company with him was full of openings into the moral life. As his daughter I too strove to have a “successful illness” – to make meaning of it and to inject that meaning into the broader community. The act of telling and the act of creating the Tales did
that quite literally by allowing me to weave the thread of my narrative out into
the community of listeners – tying them to me and to the Dad of my tales in
the way that storytelling does.

So much changed for me with Dad’s stroke. First - I became differently
situated with the health care community. Now I straddled the line between
health care professional and patient - I was, to extend Susan Sontag’s
metaphor - a citizen of two kingdoms. (Sontag, 1978:3) I knew more than
ever the importance of good care and I had felt more poignantly than ever the
suffering of those who are not well cared for. I also knew that the caregiving
relationship is one built on subjectivity, one rooted in intimacy, not
characterized by clinical distance. Story, especially one in which I was
strongly immersed, is one way to achieve this engagement - at least for the
duration of the storytelling exchange and hopefully for a longer time.

Through my stories, both the Dad Tales and others, I experience the value of
stories and their telling in opening up discussion of many ethical issues, and
of lives lived in the moral community of the hospital in a way that is safe and
non-threatening for those listening. (Hunter, 1996:225) A story provides a
way of entering into an experience with the safety of not being directly
involved. It is an opportunity to bring testimony – to show others “this is how
it is,” recognizing with Martha Nussbaum that none of us is able to experience
the broadness of human experience and story is one way to broaden our experience. (Nussbaum, 1990:386)

Cassell writes of suffering rooted in a loss of our intactness and coherence and I recognize in that the fallout of the massive stroke of ten years ago. The suffering of my Dad’s stroke was intense - as it still is at certain moments. Out of that suffering came my need to tell stories. As I look back I see that the stories were not so much a choice as a natural occurrence. It is through story that my eyes could see and comprehend the immensity of what was happening.

I no longer tell the Dad Tales. I believe it is too simple to say that the suffering has stopped so the story is no longer needed as one tool to “re-integrate” myself, although I think there is some truth to that. The loss of coherence that resulted from the loss of my “old” Dad stories is no longer so acute; I have re-grounded myself in the story of my “new” Dad. The narrative repair that Arthur Frank writes of has been wrought (Frank, 1995:55) and the post-stroke Dad is many new stories. The web of relationships has changed but is now intact in its new form. Our coherence is largely re-established: not the same as it was, but strong.

I can credit story for helping me reach this place. Story gave me a context, a frame and a way to look at the happenings and myself over and over again
from the position of the now-time. From it I learned who I am and where Dad and his story fit with mine. I could give words and images that hinted at my suffering and I was thus, piece by piece, reconnected, reclaimed. And so the need to tell those stories, as least as a way of understanding and easing my pain, has softened.

There is more to my silence that that. There are problems with my telling those stories in a public space and they have mostly to do with the fact that my father does not know that I do so. I could not, many years ago, ask his consent and I have not told him about it since. I have not wanted those stories to go untold and I have been reluctant to give them up but I am unable at this late date to tell him what I have been doing. At first I cast this as a tension caused by the principlist approach to ethics that would see the stories I told as unimportant to the ethical deliberation (except perhaps as a fact-finding tool) and would disallow my telling them for the simple principled reason that my father’s confidentiality had not been respected in the telling of the tales. In response to this I argued as follows: the stories are not mostly about my father and nor are they only his – they had their genesis in my narrative impulse in the fallout of the stroke that ruptured the narrative I had been living as his daughter. They were, in fact, my tales and he is simply a character in them. The stories are my bearing witness to the story of Dad and to the story of me as his daughter; he was unable to do so and did not and now does not have the opportunity to do so – an opportunity that my
work in the hospital setting enabled me to create. The stories are respectful and full of dignity and therefore do him no harm. I can argue that, if Dad knew that I was telling them, he would have no problem with it – therefore I may be able to argue from a position of implied consent. It is true that if I do not get to tell the stories then they are not able to go out into the ecology of relationships of which Dad and I are a part and if I do not get to tell the stories, my chance at finding meaning and making a “successful illness” is blocked.

When I undertook this process it was my belief, or perhaps my hope, that an argument in favour of the use of storytelling and narrative in the health care setting and in clinical ethics would provide me a way to justify my using the stories without Dad’s knowledge, up and against the principlists’ concern about confidentiality. It has not done so. There is no doubt that the linear, formulaic approach of the traditional principlist approaches is inadequate to the clinical ethics project and the mounting criticism of this approach is much deserved. Equally there is no doubt that the role of story and narrative in the health care community needs further attention and that it has much to offer the clinical ethics project – and the health care community at large. The ownership of stories and the locus of the storytelling voice are critical ethical matters within health care and are core to the healing process of the person who is ill.
At its core storytelling is about relationship and community. The act of telling a story and having it received is a powerful one of intersubjectivity – drawing people together in the co-creation of a new fabric that weaves them into relationships and the communities in which they exist. Those who are ill need their stories to understand, to comprehend, to control and define themselves in the face of the chaos that illness can bring. They need to have their stories received as a way for them to inject their experiences, themselves into the community beyond themselves. And that community needs those stories in order for it to understand itself.

Many years ago as I struggled with the principlist approach to ethics, I learned that clinical ethics is about “how do I care well in this situation?” and “what am I doing when I’m doing what I’m doing?” I came to learn that ethics was, at heart, about relationship and the nature of the community in which the multitude of health care relationships exist. At the same time I was learning the same thing about storytelling – that it is all to do with relationship and intersubjectivity, that it is a dynamic interchange between teller and listener that has the potential to draw both together and change each – if even in just a small way.

And so I am stuck with what to do with the Dad Tales, but I do not need to turn to the principlist approach to assist me with the issues raised by my father’s ignorance of the Tales. I simply must turn to the ethos of storytelling
and ask myself what the telling of the Dad Tales means to the relationship between my father and me. My relationship with my father has changed hugely in the ten years since the stroke – we are closer now than I ever would have dreamed we could have been and we can claim a good relationship of mutual respect. So I am faced with that relationship when I ask myself about the effect of the Dad Tales and their telling on that relationship – and on the community beyond it, my family for instance.

The Tales themselves would not have harmed Dad or that relationship, had I told him about them some long time ago. They may have actually helped my family and the community beyond to understand and make more of a "successful illness" from the experiences. What would harm Dad and the relationship now is the fact that so much time has gone by and I have not made him party to the telling of the Tales. For the stories are about him and are, to a great extent, his. The principle of confidentiality rests on the belief that to own information about someone is in fact to own part of that person. I would agree. My Dad Tales do not take Dad’s voice away from him and they do not silence any stories he may have to tell and need to tell. They are, however, powerful in the sense that they privilege my voice over his.

This is a murky standard at best and I would hesitate to make it universal. I recognize there are many circumstances where a story about another person needs to be told, even must be told without that person’s consent or
knowledge. The memoirs written by survivors of childhood abuse cannot, and should not, be silenced. What needs to be attended to, however, is the impact of such stories on the web of relationships into which the teller is woven. “What am I doing when I’m doing what I’m doing?” How does this impact this particular relationship?

Did I have misgivings about the morality of telling the Tales without Dad’s knowledge when I started with them? No, I did not. At the time I could see no harm in telling the Tales and could see much benefit. Trying to look back with a critical eye I believe that, at that time, I felt my duties to my community, the health care community, were prior to my duties to my father. I believe I must have done some accounting which enabled me to balance the benefits to the health care community, as it was in my own context, against the chance of harm to my father. Additionally, the benefits were immediate and real, the harm to Dad remote and unlikely.

What has changed for me is the ranking of my relationships and the duties inherent in them. When my father had the stroke, he and I had a relationship that was characterized by distance. My duties to him and his to me were no more than the most basic familial ones. The impact of the stroke pulled me, somewhat reluctantly, into a relationship of caring with him. He became needy and vulnerable and that called out of me a different response, a different characterization of duty and obligation. In the frame of this new
relationship I was enabled to see him as needing protection and care, as the ill do, and to experience, in caring for him, the mutuality of need that is the foundation of a caregiving relationship. The relationship evolved and with it my recognition that my duties to Dad are indeed prior to those to the broader community.

The principlists would not have brought me to the place where I would have been convinced that I ought not to tell the Tales without Dad’s knowledge. Likely principlism would have argued for the general requirement of respect for confidentiality, at least within the context of the health care community. To further bolster that requirement an argument based on duty to respect one’s parents may have been used. For me this would not have been adequate motivation for me to stop telling the Tales without Dad’s knowledge. The rules needed more grounding than simply yet more rules or action guides. Given the nature of my former relationship with my father the appeal to filial duty would not have convinced me to act in any particular way. Removing the lived experience from consideration of my obligations and duties would not have led me to a conviction of what was right or wrong and without that conviction I could not be convinced to act in such a way that would compromise the benefits I knew accrued from my telling of the Dad Tales.

A principlist solution would have cast the situation in terms of a quandary— and the reality is so much more than that. It is only from within the flesh and
blood, nuanced, multitonal context of the lived relationship with my father that a moral gaze could take me to a resolution, a stance with my father. Out of that stance of involvement, history, mutual caring, could be derived a duty not to put my father in harm's way: that is what the relationship calls for. The very involvement and subjectivity, the very emotional core of the relationship is what calls me to this duty with my father. Removing this subjectivity, in the interest of rationality, as would have been sanctioned by the principlists, would have removed my allegiance to my father.

The Dad Tales accomplished much: they gave me a way of understanding chaotic, life-altering events, they provided insight into the lived experience of the patient and the family – an insight very useful and important to those who keep company with the ill, they contributed to the construction of a community of care by creating subjects of the patients, not just objects, and of the listeners as well. All of these things are ethically important moves and they have the potential of accomplishing the Clinical Ethics project. All of these moves would remain valid if I told my father about the Dad Tales, many of them would remain so even if I didn't. However, as a person committed to the life of the moral community, which is based on the relationships we live as moral agents – I cannot continue to tell the Tales without Dad's knowledge.
My use of the term “community” is broad and by it I mean the components both inside and outside of the official health care system who have the shared goal or purpose of health care – on any number of levels. This community is comprised of a multitude of players and has fluid parameters: the health care providers, health care institutions, the community in which these institutions exist, the patient and those with ties to her and, increasingly, the so-called ‘informal’ caregiving sector. The notion of community designates shared goals and objectives, although these may be differently understood and acted upon.

"...this movement [medical ethics, bioethics, clinical ethics] can also be seen as simply a systemization of the ethical dimension of medical situations...the recent bioethics movement must acknowledge the fact that physicians have been ‘doing’ medical ethics long before philosophers came on the scene." (Hawkins, 1996 June: 344)

I credit Edmund Pellegrino, Professor of Medicine and Medical Ethics, Georgetown University, with making this clear distinction in a conversation I had with him in January, 1997

The term ‘narrative ethics’ is used to designate a number of different ways that narrative is utilized in an ethics context – there is little consistency with its use and I am not claiming it for a label for the work that I am undertaking.

Rita Charon considers the act of creating the case to be a reflection of the “ideology and epistemology of Western medicine [that] ropes the writer into forms of discourse founded on beliefs about professional authority and omniscience.” (Charon, 1994:266)

In Rita Charon’s view the medical encounter is constructed in such a way that “whatever singular expression of the patient complicates the doctor’s attempt to replicate the perfect form will be experienced by the doctor as interference.” (Charon, 1992: 126)

These are the two core questions as phrased by Prof. Wm. Harvey, Department of Philosophy, University of Toronto.


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