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UMI
Divergence and Domination:
A Feminist Critique
of
Power in Medical Relations.

by

Chloë G. K. Atkins

A thesis submitted in conformity with the requirements
for the degree of Ph.D.
Graduate Department of Political Science
University of Toronto

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Thesis Abstract

Chloë Atkins, *Divergence and Domination: A Feminist Critique of Power in Medical Relationships.* Ph.D., 2000, Graduate Department of Political Science, University of Toronto.

For the most part, modern medicine's capacity to cure lies in its ability to think categorically about human ailment, unfortunately medical categorization is simultaneously a harmful vehicle for the domination of patients by medical professionals. Using my own experience as a patient, my dissertation employs feminist methodology to construct a theoretical link between the powerlessness I have personally experienced when being treated in health care environments to aspects of medical history, culture and nosology. My work focuses on the tension between subjective and objective relations in the clinic. In particular, I look at the sharp divergence between patients' accounts of illness and techno-medical discussions of disease. Further, I explore medicine's use of "hysteria" (i.e., psychosomatic disease) as a diagnostic category. Its use is a poignant example of the extreme dissonance which can occur between doctors and patients. As a result of this sort of dissonance, methods of coercion and domination filter into clinical practice which bypass biomedical ethical efforts to treat patients with equality and respect. Despite the enormous structural constraints which inhibit ameliorating this situation, my dissertation discusses some possible alternatives which may revise doctor-patient relationships in the future and thereby diminish practices of domination in the clinic.
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Introduction

It is both a blessing and a trial to have my personal life intersect with my academic passions. In choosing to write about power and medicine, I inevitably encroach on and exploit my personal experience. I am interested in a theoretical discussion of power in medicine precisely because I have a great deal of intimacy with clinical methods and practices. I cannot write about power and medicine without disclosing the manner in which I have been a chronic patient for the last decade. It would be misleading to pretend to have an objective stance about medical practice simply because I do not.

My willingness to speak of my intimate connection to an academic topic resides in my belief in the feminist phrase that ‘the personal is political.’ Feminism usually uses this term to characterize issues of power in gender relations within the family. In this project, however, I expand on this notion by using my personal experience to elaborate on broader political concerns about the exercise of personal agency within care-giving relationships. In
discussing my experience of medicine in particular, I trace the manner in which the screen of privacy shields certain kinds of relationships from justice based critiques — not only for male-female relationships, but also for adult-child relationships and doctor-patient relationships as well. In particular, the medical relationship involves an extraordinary act of intimacy between two relative strangers and while both law and ethics govern such interactions, aspects of domination seep into clinical encounters. To some extent, the successes of modern medicine are the result of enormous gains in a knowledge of and power to intervene in the human body. Unfortunately, this mastery also has political ramifications which affect personal agency.

As I show in later chapters, medicine often subjugates patients in its powerful effort to cure them. In the next chapter, I describe my early family life as well as several incidents from my medical care that outline the dichotomy between power and powerlessness in intimate and confidential relationships. In the second chapter, I draw on other patients' accounts of their illnesses and treatment within the clinic. Here, I focus on the divergence between individual subjective narratives of illness and the legal, object accounts of disease which exist in medical charts. The enormous gulf in the interpretation of symptoms between patients and physicians indicates a breach in the therapeutic relationship. This breach, combined with medicine's over-whelming power to vanquish disease, tends to alienate patients from both medical personnel and from their own sense of individual agency. Both my own narrative and the patient narratives I examine speak of a sense of powerlessness, voicelessness and

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1 I thank my colleague and friend, Melissa Williams, for helping me to articulate this point.

2 There is a subtle but important distinction I make in this work between 'illness' and 'disease.' Illness is the subjective experience and interpretation of symptoms by an individual. Disease is the medical categorization of such symptomology into an observable and factual (i.e., objective) entity.
vulnerability when immersed in the medical realm. It is the experience and quality of this impotence which ties all of these stories together across the dimensions of both time and space. Chronicles of illness and disease reveal the strong historical and structural components in medicine which tend toward domination rather than egalitarianism. The personal accounts of patients thus evince the subtle politic of the doctor-patient encounter.

In the third chapter, I examine hysteria 3 as a trenchant example of the extreme dissonance which can occur between patients and physicians. In this instance, individuals experience symptoms which they understand to be real, while doctors view such symptoms as manifestations of unconscious conflicts rather than of representations of actual physical disease. The result of this divergence is that patients feel isolated and misunderstood. Conversely, doctors feel frustrated by their incapacity to identify and treat these illnesses. Consequently, given the power and knowledge imbalance that is inherent in patient-physician relationships, along with both participants’ extreme sense of alienation, the clinical approach to diagnoses of psychosomatic disease can result in coercive treatment methods which betray egalitarian standards of justice.

In the final chapter, I return to my personal narrative as well as reflect on the possibility for change in medical relationships. Here, I resolve some of the conflict and confusion that my own narrative arouses. I elucidate some of the successful medical alliances which have allowed me to not only to regain my health but also to achieve a degree of agency in my clinical encounters. I review the political lessons of my own treatment and reflect on the

3 Hysteria is also known as "conversion reaction/disorder," "Briquet’s syndrome," "somatization disorder" and, "histrionic personality disorder."
appropriate application of these lessons to health care policy in general. I thus discuss possible strategies which might facilitate personal agency within medicalized settings. I credit the discipline of bioethics for attempting to reform paternalistic forms of practice, for example, by encouraging family medicine to focus on contractual rather than hierarchical relations with patients. Nonetheless, ethicists' efforts have only partially succeeded. They have made only a fissure in the edifice of medical power traditions. More political change is required to alter the dynamics of power within the clinic. Consequently, I propose the introduction of 'consumer satisfaction surveys' which would influence the financial remuneration of physicians from third party payers (in this case, the provincial health insurance plan). This is in an attempt to provide a dimension of accountability and responsibility to patients themselves in the provision of health care services. When the personal responses of clinical consumers have a direct effect on the assessment of clinical practice, physicians themselves might provide the impetus for structural changes. Medicine needs to reconstruct itself politically so that it can be successful not only at curing disease but also so that it can be more successful at justly mediating the power and knowledge imbalances of the physician-patient relationship.
Chapter I
Impotence

First Person Narratives

In this chapter, I undertake a subjective narrative approach as an introduction to a more generalized discussion of medical power. Nonetheless, I have made great efforts to shore up my personal observations with as much reading and research as possible. While my examination of the 'politics of medicine' is inspired by events in my own life, I believe that it is a topic which affects most people in western society; for each one of us will, in all probability, become ill, and thereby, a patient.

I am not the first one to take a personal approach to a theoretical topic nor, am I likely to be the last. For example, a number of legal academics employ this type of approach. Susan Estrich uses an autobiographical account of her own rape to introduce her discussion of rape law in the United States (Estrich, 1986). Marie Ashe writes graphically about her experience of childbirth in an analysis of the medico-legal treatment of human reproduction (Ashe, 1991). And, Patricia Williams' book The Alchemy of Race and Rights is perhaps one of
the best known examples of this type of narrative (Williams, 1991). In it, she relates her experiential reflections on racial relations and law as a black, female academic.

Susan Estrich's article opens with a powerful first person account of her own sexual assault. It then describes the police reaction to her story after the rape. Estrich draws attention to issues of credibility in women's narratives of rape as a factor in the prosecution of rape crimes. Apparently, hers is a believable story in the sense that she is battered, robbed and raped in a public place by an unknown, black stranger. Her goal, then, is to reveal the inherent sexism (albeit tempered by class and racism) of the legal system. According to the authorities, the fact that she is white and her attacker, black, makes her more credible. As well, her attacker robs her which makes the assault an armed robbery; the robbery is apparently "better than a rape." Unfortunately, Estrich (Estrich; 1087) is acutely aware that most rape victims are not credited with being "really raped" because they are assaulted by men they may know. As Kathryn Abrams (Abrams; 984) observes, Estrich demonstrates that "the law of rape has been formulated and implemented from a perspective wholly distinct from, and often antithetical to, the experience of the victim." Rape law was constructed by males in large part to protect their possessions from other males; it did, and still does not, take the victim's experience of assault into account in determining crime and punishment. While Estrich's autobiographical account is confined to the introduction, it nonetheless endows the piece with the authority of personal experience that is absent in a traditionally composed article. Moreover, it demonstrates the powerful role that personal experience can play in the exploration and reconstruction of knowledge.
Marie Ashe's piece "Zig-Zag Stitching and the Seamless Web" "quilts" together narratives of her various childbirth experiences with a discussion of the medical and legal regulation of childbirth. She intersperses her own story with that of Angela Carder, a twenty-seven year old pregnant woman who in 1987 had terminal cancer and was forced by court order to have a Caesarean section at twenty-six weeks gestation. The fetus did not survive the surgery and Angela died two days later.\footnote{Although Ashe's point is not a legal one, it is interesting to note that the District of Columbia's 1987 decision with regard to 'coerced cesarean section' was reversed by the District of Columbia Court of Appeals in 1990. "The court found that a court order compelling a woman to have a cesarean section violates her rights to bodily integrity and to refuse medical treatment, protected under both common law and the U. S. Constitution." \textit{(Encyclopedia of Bioethics, Vol 3; pp. 1416-1417)} This decision was the direct result of an appeal of the ruling on Angela Carder's case.}

Ashe describes a sense of humiliation and powerlessness during her own medicalized births. One doctor tells her that there is no need for her to moan when she is pushing her first child out. He then accuses her of not pushing hard enough and asks for forceps. These types of scenes, along with the story of Angela Carder's forced birthing, are sharply contrasted with Ashe's portrayal of her subsequent home births. Despite the risks, she feels safe and empowered at home. She births her children within the embrace of her family and home. This peacefulness in the article is offset by other medical scenes and by footnotes which remind us that 46% of doctors who head ob-gyn programs favour the detention of women 'who refuse medical advice and thereby endanger the fetus.' \textit{(Ashe; 356)}\footnote{This statistic comes from an article published in the \textit{New England Journal of Medicine} in May 1987 entitled 'Court-Ordered Obstetrical Interventions.'} Because so much of Ashe's own story appears throughout the article, it forms the basis of her argument. It tells of a medico-legal system which interferes in women's physical processes, simultaneously controlling them and denying them. I suspect that Ashe includes the case of Angela Carder not just as an example
of legal malignancy, but also as example of medicine's willingness to engage in actions which curtail women's decision-making powers. Ashe states, "I want the law that will let us be -- women." (Ashe; 383) She believes that the law needs changing, although it is not entirely clear how. Despite, or perhaps precisely because of, her ambiguity, given that my own endeavor is closely allied to that of Ashe's desire to deconstruct the medico-legal elite, I am sympathetic both to her method and to her cause. In the end, while it is not certain what Marie Ashe proposes as an alternative to reproductive regulation, her pained voice is a legitimate addition to the complex problem of legislation in this field.

Perhaps one of the most familiar examples of first-person, feminist, academic prose is Patricia Williams' volume, The Alchemy of Race and Rights. This work manages to be legal analysis, social critique, autobiography and a work of fiction all at the same time.6 From Williams' descriptions of growing up in Roxbury, Massachusetts to a discussion of the controversy over the rape and assault of 15 year old Tawana Brawley, the author manages to evoke not only the particularity of events but also their universality. Her prose has the poetic quality of illustrating the universal in the particular. It tells the truth without facts or statistics abstracted from experience. What is most evident in Williams' discourse is that there is no boundary between her various stories and analytical arguments. They interpenetrate one another. Williams embeds herself in her text, not simply as a victim of racism, but also as an observer and, more importantly, as a participant in the delusions of race relations in the U.S. She says:

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6 In fact, according to Williams, the Library of Congress had great difficulty in classifying her book, for it fell into no clear category. She writes, "This battle seems appropriate enough, since for me the book is not exclusively about race or law but about boundary." (Williams; 256)
writing for me is an act of sacrifice, not denial. . . . I deliberately sacrifice myself in my writing. I leave no part of myself out, for that is how much I want readers to connect with me. I want them to wonder about and to think about some of the things that trouble me. 

(Williams; 92)

In thinking about rights' discourse, Williams wants us not to be just thinking of our own independent autonomies, but of the fragility of autonomies in general. Her point is that legal and social rights' language often transgresses the spirit of justice itself. Justice exists in the exchange between autonomous individuals. Individuals may indeed possess rights but this does not guarantee that they will be able to exercise these rights in a manner which results in a just relationship with others. It does not mean that they will be treated or treat others with equity. As a result, the notion of 'right' does not easily capture the relational aspect of justice. Overall, the narrative style of the book contributes to the poignancy of this theme by bringing into focus the ambiguities inherent in trying to inject legalistic rights into complex human interactions.

Of course, there are many reasons to lambast the subjective narrative approach to scholarship. On a general level, some might see it as a part of a larger trend in the secularization of the soul. By telling our personal histories as a form of substantial analysis, we are trying to place a bridle on the human soul, subjecting it to the discipline of empirical knowledge. Further, it is too easy, and perhaps too untrustworthy, to give much credence to personal storytelling in academe. If we are looking for truth, then a constancy of approach is important. Narratives of this type manipulate or reconstruct reality to suit their own purposes. They are

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7 Ian Hacking talks about this with direct reference to the "sciences of memory" in his book, Rewriting the Soul. I think that his critique of the current tendency to constantly seek social meaning in personal memory in the psychological sciences has some relevance here.
cunning and rhetorical. They may not only falsify facts and events, but they also may be a medium to mask the guilt and responsibility of the author for those events (Bruner; 177).

There are also a number of more specific criticisms of first-person accounts. These narratives can be considered suspicious because (i) they lack normative content; (ii) they provide no equal time to opposite viewpoints by affiliating themselves with particular points of view; (iii) they not only undermine the objectivity of the author, but also that of the reader; furthermore, (iv) they are anecdotal and cannot be the basis of socio-political change; and finally, (v) they discourage and disenable counter argument and discussion (Abrams; 978-980).

I shall try to answer each of these objections as best I can. Firstly, biographical accounts describe personal and social settings which, if the reader finds them believable, form a normative foundation for these pieces. Secondly, most traditionally constructed articles have a point of view and rarely provide equal time to opposing views; this point of view is falsely presented as objective. In any narrative form, in my view, it is up to the reader to seek out contrasting opinions and evidence to those presented in the text. Thirdly, narrative theory has shown that texts are far more complex than they first appear. There are real authors, implied authors, narrators, narratees, implied readers and real readers (Chatman; 23). There is never any one objective author or objective reader. The author is responding to the many, many voices that comprise her complex subjectivity and her readers are variously attentive to different tones of voice and different levels of argument. Indeed, each reader is not a unified, homogeneous unit any more than complex writers are. The author’s and the reader’s job, therefore, is to be cognizant of the various strands of academic argument in the manner that playwrights and audiences should attend to all the persona in a play, not just the protagonist or a chosen character.
Fourthly and finally, while anecdotes do not create policy, they can begin or encourage a greater discussion of issues. Feminist narrative methodology produces treatises which read rather like conversations. These tracts oscillate between personal accounts and meditative observations. They function in the manner of real, spoken dialogue. Thus, by making abstract claims more tangible, feminist narratives may well provoke readers into seeing the world a little differently. "The entire point of the feminist epistemology reflected in narrative is to argue that there are forms of knowledge that may not be generated or validated by scientific objectivity, through which we may nonetheless learn critical things about ourselves and our world." (Abrams; 1029)

In a pluralistic society, this type of theorizing does not have to be considered a deficiency.

My own desire, then, in employing experiential prose, is to make my project of examining the power-laden relationship between doctor and patient more real – more concrete, less abstracted from lived experience. Given, that most people will eventually become ill and require medical services, my narrative is less particularistic than it may first appear. My hope is that some of the vivid and intimate details will give rise to more generalized concerns about how we treat the more vulnerable members of our community. In Canada, people support a publicly funded system of health care and for the most part rightly presume that the quality of that care is of a high quality. Nonetheless, there are lapses in this system which sometimes have less do with available resources than with medical culture. In a subsequent chapter I will show that patients

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8 The story of Rosa Parks is a case in point. In 1955, her refusal to vacate her seat for a white man on a bus in Montgomery, Alabama led to her arrest. Subsequently, she challenged the legality of racial segregation in court. Her action led to the Montgomery bus boycott. The story of her personal activism is sometimes viewed as a seminal anecdote of the civil rights movement in the United States.

9 I am not dealing explicitly with the issue of resource allocation in this, or any other chapter. However, I am acutely aware of the huge impact that funding decisions have on patient care. To a large extent the reduction in
experience a sense of impotence that often has far less to do with their physical ailments than it
does with the manner in which they are treated by health care professionals. This loss of agency
is a matter of concern in any democratic society, but perhaps even more so when it occurs in an
arena that is funded by public revenues.

**The Politics of Medicine**

As a political theorist, I have always held a bit of a fascination for "applied"
theory (i.e., the taking of theory and applying it to concrete situations). In a sense, I am
attempting the reverse. I am trying to reformulate a critical and theoretical approach to medicine
out of the crucible of the lived experience of being a patient.

Some would argue that this, in fact, is already being done in the field of
"biomedical ethics." Bioethicists use case studies to explore rights, utilitarianism, distributive
justice, beneficence and paternalism in medicine. However, my own experience of medicine has
been that bioethics' influence on clinical practice remains ambiguous. While the discussions I've
read seem to influence aspects of clinical practice, they still seem too abstracted to deal
adequately with issues of power in the medical environment. As a patient, I've found that the
high ideals of bioethics are seldom manifested in the clinic, and if they are they are often a
perversion of their intent. For example, although, medical ethicists have managed to incorporate
a "patient's bill of rights" at most hospitals, patients, whether from lack of knowledge,
motivation or vital energy, are rarely able to assert these rights effectively. Physicians must now

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health care budgets has meant that the patient-practitioner relationship is under even greater stress.
obtain "consent" from those they treat, but that consent is normally routinely given and is seldom scrutinized. Formal rights may exist in the clinic, but they often seem to do so in isolation from medical practices themselves. That is, they appear to act as more of an additional, legal burden for doctors and health care professionals than as a conscious activity or empowerment of patients. They are legal barriers which protect patients from abusive medical paternalism but they don’t alter the paternalistic relationship. Thus, the inclusion of rights performs a valid and vital role in the clinic but does not transform the structure of power and knowledge in health care environments. The patient remains a medical object despite also being a legal subject. And it is the persistence (and even necessity) of the physician’s view from above and outside which obscures the patient’s subjective experience of agency. The patient is torn between the validation of her legal subjectivity and the invalidation of her knowledge of her illness.

In the Preface to *The Birth of the Clinic*, the French theorist, Michel Foucault writes that the visionary space in which doctors and patients communicate is "enclosed within the singularity of the patient, in that region of 'subjective symptoms' that — for the doctor—defines not the mode of knowledge, but the world of objects to be known." (Foucault, *Birth.*; x) In other words, the subjective experiences of the patient are converted into objective data to be studied by the clinician. While Foucault traces this development to the legalization of *post mortem* in the eighteenth century and the consequent ability to dissect, see and touch the diseased human body, he is acutely aware of the political ramifications of the move toward positivism in medical knowledge. He believes it eradicates inter-subjectivity between patients
and physicians. It thereby encourages the rise of hospitals in which the poor (mainly female) invalids of the eighteenth and nineteenth centuries are placed under the scrutiny of a medical ‘gaze.’ The clinic, thus, creates a realm in which the subject becomes an object — and thus a hierarchy occurs in which the object is viewed from above. For Foucault, the patient becomes a portrait of something other than her subjective self; she becomes the portrait of a disease and an object of medical study.

As a political scientist, I ponder how this type of objectification affects personal agency. As a patient, I wonder why it is, that as a citizen of a liberal democratic country, I feel as though I lose my agency when I am under medical care like prisoners entering jail or children going to school. But, whereas prisoners are thought to have forfeited their rights through their criminality and children lack the mature rationality for autonomous agency, patients are neither criminals nor children and thus constitute an anomaly for liberal democratic theory and practice (perhaps comparable to employees losing their autonomy in a factory or office, and civilians, when volunteering or being conscripted into the military). Perhaps the singularity of my immediate sense of impotence arises for two reasons. Firstly, my symptoms and my loss of ‘normal’ function create a profound sense of both physical and psychological threat and vulnerability. Illness is a circumstance of weakness. Secondly, the clinic’s strong, patriarchal hierarchy and its objectively scientific, and not inter-subjective, approach to patients heightens this sense of exposure.

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10 Women formed a large part of the patient population due to the increased medicalization of the birthing process. Wealthy women managed to avoid hospitals by hiring private physicians.
While the clinic attempts to recognize patients as rights bearing individuals, it remains rigidly stratified in its activity. For example, medical education relies heavily on a pecking order in which staff physicians rule over residents and senior residents dominate junior ones, and who, in turn, direct clinical clerks. Furthermore, all the other health care professions (whose populations are largely made up of women) lie beneath this hierarchy. The feminist thinker, Joan Tronto, outlines this distinction between caring-taking [physicians] and care-giving [nurses, therapists]. She writes: "... caring about and taking care of, are the duties of the powerful. Care-giving and care-receiving are left to the less powerful." She hypothesizes that

... the association of people with bodies lowers their value. Those who are thought of as "others" in society are often thought of in bodily terms: they are described by their physical conditions, they are thus considered "dirty," they are considered more "natural." (Tronto; 114)

Thus, those who are regarded as "other" or as "object" are seen to be integrally less valuable.

Despite the entrance of women into health care specialties, the division of labour in the clinic remains deeply gendered.11 Men may certainly become nurses but they nonetheless join a female profession. Thus, they will always receive less financial remuneration for their services. And

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11 This was made readily apparent to me recently when I attended the graduation ceremonies of a Canadian health sciences program (Queen’s University, May 1998). While 29 of 80 graduating doctors were women (still less than 50%), only 2 of the 49 graduating nurses were men. In rehabilitation therapy, no man graduated in a class of 35 in occupational therapy and only 4 of 46 in physical therapy graduates were men.

This type of observation is supported by more valid statistics on women and the professions. According to Statistics Canada, in 1991 only 26.7% of physicians and surgeons were women. While this is an improvement on 10.1% in 1971, it still denotes a significant and ongoing gender imbalance in the practice of medicine (Kay; 198). This figure is made more emphatic by the fact that it is well known that women become patients far more often than men. The physician-patient relationship may thus embody aspects of traditional gender power dynamics of which feminism is so critical.
they will experience a lesser degree of power than those who come from a male profession.\textsuperscript{12} Physicians, in turn, possess a higher degree of knowledge and responsibility in health care settings, but with this also comes an expectation of obedience and respect from those who work ‘underneath’ physicians. When patients enter medical facilities they anticipate and are often told that they will be treated with equal respect. But, in a system which relies so heavily on job specialization and stratification, this expectation seems unrealistic. After all, a patient has \textit{apparently} the least relevant skill in the clinic. Patients are not professionally knowledgeable actors in the medical environment, they are recipients of care. By definition, they become objects of specialized clinical knowledge, scrutiny and treatment. In becoming objects, they lose a portion of their subjective agency. Moreover, because patients are \textit{ill}, they have usually lost a degree of normal functioning that makes them both physically and psychologically vulnerable. To some degree, this vulnerability renders them less able to articulate and tend to their own needs and concerns. The powerlessness of patients thus originates firstly in their debility and secondly in their subjective self being immersed in the objective environs of the clinic. In some sense, no matter what their gender, patients become the most ‘female’ segment of the health care setting — they are both the actual and metaphorical representatives of Tronto’s abased body — they are therefore the least powerful.\textsuperscript{13}

\textsuperscript{12} A recent article about the investigation of a pediatric cardiac surgeon who had an abnormally high mortality rate reflects this power imbalance. An O. R. nurse who was concerned about the surgeon’s technique requested that another doctor observe surgery. He responded “I don’t take orders to come to the operating room from a nurse.” Twelve children eventually died under the surgeon’s care before he was removed from his job (\textit{Globe & Mail}, 28 October 1998).

\textsuperscript{13} One can only assume that this abasement is even more acutely felt by female patients, precisely because they have inherently less social power than even their male counterparts.
In spite of all this, I should make clear that I most certainly would not be writing this, or even alive, were it not for successful medical interventions. The potency of the clinic has served me well in the sense that I am alive to criticize it. While I am aware that medicine has saved me, I am also acutely conscious that its power has coerced me both physically and psychologically. The political scientist in me cannot help seeing the political aspects of medical success. Consequently, when I am ill, I often ponder whether there really is a valid way to negotiate the power imbalances inherent in medical culture. It may seem that patients possess rights in the clinic, but in reality, they often lack the strength and knowledge to exercise these rights. When individuals and families do happen to have the resources to negotiate about care and treatment, medical establishments do not always seem able to address their concerns in an egalitarian fashion. In narrating an account of my own experience of the clinic, I hope to locate myself with regard to such power-laden issues as gender, class, professionalism, equality and rights. My narrated (and, to some extent, objectified) subjective voice tries to provide an alternate perspective to common debates on medical morals. I want to combat the predominance of scientific and legal rhetoric in discussions of clinical decision-making. In speaking of myself, I hope to evince some of the subtleties and variations of power as it is exercised in medical practice. Moreover, I want to articulate a viewpoint which can challenge the scientific monologism of clinical culture. In short, I want to reassert the validity of my subjective self in contrast to the profound objectivity I experienced as a patient. My aim is to open a dialogue about the exercise of power within medicine.
The rest of this chapter interpenetrates personal narrative with theoretical discussion. It begins with my first poignant interest in power and justice, followed by a discussion of how some of my concerns dovetail into those of thinkers from Plato to Foucault. As it gathers momentum, it moves into explicitly medical material. Nonetheless, clinical descriptions are always followed by passages of commentary and reflection.

**Rumblings of Injustice**

I was brought up with many advantages: large houses, private schools, camps and trips abroad. In no way would it be possible to imagine that I was materially deprived. In fact, I was spoiled. So, perhaps, it is more than a little surprising that I grew up with an abiding sense of justice and injustice.

In truth, amidst my lush surroundings, I felt hard-done-by.

In my family, boys mattered more than girls. My elder brother, my mother said, "was worth more." As a result, although I was a girl, I tried to be a better boy than him. I tried to outperform my brother in sports and academics. I wanted to outdo him, and occasionally I did. But my efforts really didn’t improve me in my parents’ eyes. Males were simply better. They became independent beings. They moved the world.

As a child, I tried quite consciously to not be female. I tried to be more assertive, and was told to be more pretty. I excelled in sports and my mother worried that I would "overdevelop my thighs." I shouted during games and my father reprimanded me for being "too
forward." The harder I tried – in short, the more I tried to be like a boy – the more my parents shunned me.

By the time I was in my early teens, I lived at a boarding school (not that unusual in families of my parents’ class and background). Thrust from the confusion of messages at home, I grew happier. The school sated my appetite for athletic and academic activity. It bestowed me with small honours for the work I produced. Nonetheless, despite the commonality that spoiled, bright, and slightly alienated adolescents develop for one another in a boarding environment, the act of calling home once or twice a week was an emotionally important rite. But after a couple of years, when I called home, my mother would hang up the phone at the sound of my voice. At holidays, it was never very certain that I would receive an invitation to come home.

Perhaps, my sin was to be less than feminine. But perhaps, it was merely that my parents could not love me.

My aunt told me that when I was six, my father watched me chase the dog around the lawn. He turned his back and said, "It is very clear to me. This child is not one of us."

In memory, much of my childhood is grey. The physical presence (and presents) of wealth did not comfort me. I felt left out; abandoned.

I had a recurring nightmare until my late adolescence. In it, I am quite, quite small; perhaps three or four. My family comes out of a store on a busy, city street. My father unlocks the station wagon and loads the dogs into the back. My mother, brother and father get in. But my door is still locked. Suddenly all the doors are locked. They are inside and I am still outside. I run around the car, waving and knocking on the windows. My parents do not see me.
My father slowly pulls out of the parking space. I become frantic. I shout and bang on the car. He turns into the traffic and accelerates. I chase after them. In seconds, I am left in the middle of the road with cars sweeping by me. I wake from this dream, crying and sweating; always trying to convince myself that next time I can run faster.

At ten, I crawled underneath my desk at school and refused to come out. Not once, but many times. I crawled out the window to avoid classes. At recess, I taunted other girls until I provoked fights. One student withdrew from the school because of a black eye I had given her. I had few friends. The parents of the few I made discouraged my acquaintance. At home, I was lonely. My parents traveled and left my brother and me in the care of people I liked but did not love. They all seemed to smell slightly stale. We hated their cooking.

When my parents were home, they created a bliss that could quickly change to a hell. They brought expensive and eccentric gifts from Asia, Europe and South America. My brother and I luxuriated in their attentions. Before they arrived home, we would rush from room to room checking: Was everything clean? Had the plants been watered? Were the dogs brushed? We wanted the house to be perfect in order to prolong our parents’ affection for us. Anything misplaced might provoke an ire that would overwhelm the joy of their homecoming. Inevitably, the magic would be broken by a messy drawer, an overlooked chore, a less than enthusiastic expression of gratitude for a present. A fury would overtake us. The soft, fragrant beauty of the house would be shattered by raging fragments that could wound. My mother’s anger was violent.

At times, I hid when I heard my mother’s car turn into the driveway when she was coming home from an errand. The place she never found me was at the top of the linen closet
underneath the down pillows. I feared all the possible things that I might have done wrong. I couldn't predict what she might ignore and what might tear her asunder.

I felt that I wasn't perceptive enough; that I was stupid.

Mostly, I braced myself for a torrent that did or did not come. I tried to just take it, learn from it all, improve myself and avoid the violence next time. But sometimes, I grew too tired and afraid, and I simply hid.

After years away, I returned to my parents' city in my mid-teens to attend university. I thought we might restart our relationship. I felt as though I were now an adult. I thought that it was my being a child that had led to all our difficulties. Perhaps, physical size and maturity would make the difference. I now had an adult physique. I was more powerful. I felt as though I had some agency. I ceased to seek love from my parents, but sought out respect. I received neither. I tried to broker a peaceful coexistence between us, but failed. I found myself consistently hurt.

My elder brother returned briefly to the city to work. I introduced him to my friends. One afternoon, I found two friends waiting for me. They were going to my parents' house to dine. 'Why wasn't I ready?' I told them I hadn't been invited. They didn't believe me. After much discussion, I got dressed. When we arrived at my parent's house, my mother turned to me and said, "There's not enough for you, you can have a boiled egg in the kitchen." I looked at the elaborately laid dining table and left.

Throughout my childhood and adolescence, I remained confused as to my identity. I could never correlate the extreme luxury, wealth and beauty of my surroundings with my inner sense of isolation and despair. I knew I was lucky but I didn't always feel it.
My family was very often generous but also surprisingly miserly. My mother smelled sweet and looked lovely. Her skin was deliciously soft. But she could also be wantonly cruel. One of her nicknames for me was "cloaca," the Latin name for sewer. My father seemed dashing. I admired and, even adored him. But he could be very hard towards me. I once sprained my ankle playing games. That evening, he took my crutches away and said he would "thrash" me if I continued to limp in his presence.

My bedroom had French wallpaper and antique furniture. The chairs and the bed were too delicate to sit on. As I grew bigger, the bed became too small. My feet and head were crushed against the foot and head boards at either end. The bed was too valuable to change. I tried to sleep curled up or on the floor. I grew too tall for my legs to fit under the washstand that served as my desk. It seemed as though I had grown unappetizingly big. My room felt imprisoning. It was large and beautiful, but it wasn't mine.

My friends often told me how lucky I was to have had a pool, to have learned to sail and to ride horses and, to know how to eat oysters out of the half shell. They were right, I was lucky. I reveled in many of these things and more. Was I crazy then to feel slighted? I didn't know. Was I oversensitive? Did I have too fertile an imagination?

On a Christmas Eve in my late teens, my brother appeared at my college room to tell me that he had convinced my parents to invite me home for the evening. After we ate, my brother and mother retired to the library upstairs. My father and I washed dishes and wrapped leftovers. Later we sat at the kitchen table and drank milky coffees. Straining with hurt in my chest, I asked him whether it was true that he favored my brother. He spread his hands out in front of him and said "Yes." I talked about his unfairness. He answered me plainly and without
heat, "There is no such thing as fairness. There is no equity in life. So, don't speak to me about ideals. Justice doesn't exist." He sighed, "You're still young, you must stop believing in it. It doesn't help. It only creates stress. Between my wife and my children, I choose my wife. Between my children, I pick my son. You are last. No one is equal." — A rush of elation surged through me. I wasn't mad or crazy. Suddenly, I felt lighter. I was loosed from a torture of silence. It was true. They did treat me differently. His words confirmed it.

During one of the few times I've seen my father since, we talked about charity. I told him I encouraged my own children to donate a sum to an organization every year. He responded that he and my mother do not believe in charity. Most years they choose not to give anything. When they do, it is because he is serving on the board of a foundation.

We were brought up to view any type of weakness as intolerable. Financial weakness was particularly suspect. I never met close relatives whom my parents viewed as failures. My parents revered those who had more than us, they tolerated those who came from good families and had a little less, and they disdained the rest.

Inevitably, my father now worries about his retirement. He worries that he does not have enough money. He worries about little else. I wonder what he means by enough.

Life with my parents taught me two things: power can be abusive and appearances can be deceptive.

Obviously, parents cannot avoid being more powerful than their children. But when I think of my own parents, I am reminded of Thrasytachus in the first book of Plato's Republic. Here, Socrates speaks with Cephalus, Polemarchus, Thrasytachus, Adeimantus and
Glaucon. They discuss the nature of justice. Cephalus proposes that justice consists of telling
the truth and paying one's debts (Plato; I, 331b-c). His son, Polemarchus refines this definition
by saying that justice is giving each man his due; 'helping one's friends and harming one's
enemies." (Plato; I, 332d) Socrates responds that one must be truly knowledgeable to distinguish
true and permanent friends from false friends, temporary allies from transient foes, before urging
that it is never the work of justice to harm anyone, even tested and permanent enemies.

The sophist, Thrasyachus, becomes annoyed. He angrily asserts that "the just is
nothing else than the advantage of the stronger." Those that have power make laws to their own
advantage (Plato; I, 338c-339). In arguing his position with Socrates, he likens rulers to
shepherds who look after their sheep only to fatten them for the slaughter. He says:

...[T]he just is really another's good, the advantage
of the stronger and the ruler, but for the inferior who
obeys it is a personal injury. Injustice on the other
hand exercises its power over those who are truly
naive and just . . . [T]he just is everywhere at a
disadvantage compared with the unjust.

(Plato; I, 343d)

While Thrasyachus originally tries to limit justice to the confines of legal positivism (i.e.,
justice is merely the law as it is dictated by the powerful), his reasoning falters when he
acknowledges that it is the weak who are "naive and just" and it is those who abuse them who are
unjust. He further admits that even for the strong to rule unjustly, a degree of justice must exist
for individuals to obey the rule of law (Plato; I, 352). Consequently, Thrasyachus' original and
seemingly unethical stance becomes imbued with strains of an ethical understanding of justice.

As I look back on my relationship with my father, he adopted a stance not unlike
that of Thrasyachus. He had an absolute power over me when I was young. He created rules
which I perforce obeyed. His justice was a paternal authority of the stronger adult over the weaker child. He believed that his sometimes tyrannous behaviour was just. But ironically, my father, like Thrasymachus, exhibited an awareness of justice, per se, that was quite different from the one he professed to follow. In speaking of the concepts of equality and fairness, my father acknowledged their existence, even if only theoretically. Further, I believe that my father’s chat with me in my teen years was a warning that I would never find justice within the domain of my family. He explicitly outlined a familial structure of injustice and inequity in which he took an active part. By exposing the rules which governed his behaviour, he implicitly told me to seek my right elsewhere.

The intimate realm of my family taught me indelible lessons about the exercise of power. The absolute quality of parental dominion allows little or no room for appeal. The responsibilities associated with parenting can easily be put aside in favour of indifferent or even malicious care. Children can thus come to embody Thrasymachus’ "naive and just" men who sacrifice happiness in obedience to their masters. More importantly, my early life taught me about the power associated with class. Among the wealthy, authority is often viewed as a right. The exercise of power is normalized. Michel Foucault asserts that power creates its own reality. In *Discipline and Punish*, he writes that power constructs its own rules and laws “from which it extends its effects and by which it masks its exorbitant singularity.” (Foucault, *Disc. & Punish.*; 23) I knew and felt the disdain with which the privileged can view the rest of the world. Wealth can facilitate an arrogant disregard for others. Further, money, prestige and class can protect

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14 In no way do I intend to imply that all wealthy people behave in this manner. Consequently, I use the verb "can" to modify my statements in this regard.
individuals from socio-moral scrutiny. Affluence can buy privacy. In some instances, it can also purchase unwitting, social respect.

The appearance of goodness and beauty is enough for most people to believe in the presence of an intrinsic moral worth that may or may not be there. After a friend of my parents of 15 years broke with them, she told me: "I didn't want to think they were capable of such appalling behaviour. I mean, they're so good looking!"

Here again, I am reminded of Plato and his admonition to be cognizant of the difference between appearance and reality. His allegory of the cave appears at the beginning of Book VII of Republic. It tells of prisoners who live in an underground cave. They are fettered so that they can only see shadows dance on the wall in front of them. These people believe that the world consists of these shadows; that the shadows are real. But, when one man frees himself and turns to see the fire and the puppeteers behind who create these shadows, he discovers a new reality. Moreover, if someone drags this man up the steep path of the cave into the sunlight of the world above, he is temporarily blinded but again discovers a new world (Plato; VII, 514-517). Plato elaborates on this:

The visible realm should be likened to the prison dwelling, and the light of the fire inside it to the power of the sun. And if you interpret the upward journey and the study of things above as the upward journey of the soul to the intelligible realm . . . In the knowable realm, the form of the good is the last thing to be seen, and it is reached only with difficulty . . . In the intelligible realm it controls and provides truth and understanding . . .

(Plato; VII, 517b-c)
The concrete world is thus only *apparently* real. It is only through the education of the human soul that ethereal forms of good can be pursued. Truth lies in the pursuit of these forms. It depends upon a constant re-viewing of the world.

Thus, the absolute materialism of my own upbringing did not understand or tolerate such pursuits of truth. The objective world — the realm of the cave — was more beautiful and valuable than other more esoteric goods. My parents were successful, both financially and socially, but they were often incapable of tending to the more subtle emotional and spiritual aspects of human life. Consequently, as a child, I felt a constant tension between my awareness of the apparent power and opulence of my surroundings and, my puerile consciousness of an ill-defined sense of human goodness.

When speaking about justice, philosophers have traditionally argued that standards of justice are different for family members than for male citizens. For example, while Aristotle views the family as a precursor to the *polis*, he speaks of its structure as being naturally monarchical as opposed to oligarchic, democratic or aristocratic (Aristotle; I, ii). Further, even as John Locke espouses liberal constitutionalism as the ideal form of government, he likens fathers to monarchs. He writes: "... *parents in societies*, where they themselves are subjects, retain a *power over their children*, and have as much right to their subjection, as those who are in the natural state." (Locke; VI, §71) The bond between parents and children is one of duty and obedience. Fathers are obliged to materially provide for and to educate their sons and sons in return honour their fathers. Even a contemporary writer, such as John Rawls in his treatise, *A Theory of Justice*, distinguishes between the domain of the family and that of the larger political community. The family, unlike the rest of society, is governed by a sense of fraternity and a
bond of love (Rawls; 105, 463). Due to her "peculiar situation and limited understanding," the child yields temporarily to the higher moral authority of the parent. The family retains a definitive hierarchy in which each member has rights and duties (Rawls; 467). Over the period of years, the child learns the capacity for fellow feeling and justice from within the family. This, in turn, allows her to possess a more complex moral association with others. It is at this point that she is ready to take on the role of a participatory citizen (Rawls; *passim* 462-472). When she becomes an adult she thus moves beyond the intimate monarchical rule of her family into the larger social realm of a democratic community.

Michael Walzer's book, *Spheres of Justice*, promotes a pluralistic notion of justice within egalitarian or democratic regimes. He proposes that separate spheres of justice exist within any given community. For example, the family can be regarded as one such sphere and the realm of medicine, another. He writes:

> What a larger conception of justice requires is not that citizens are ruled in turn, but they rule in one sphere and are ruled in another — where "rule" means not that they exercise power but that they enjoy a greater share than other people of whatever good is being distributed . . . . (Walzer; 321)

Society is thus composed of a variety of arenas in which individuals participate and benefit at different levels. The standards of justice for one area do not necessarily carry over into another. Moreover, as citizens we should be able to tolerate temporary losses of power in any given area. The academy, the military and the health care system all subject individuals to some degree but "the experience has a fixed duration . . . . And we are protected by the autonomy of the various institutional settings in which it occurs." (Walzer; 290) In contrast to Foucault, Walzer asserts
that professional knowledge is not in itself dominating because it is confined and delimited to certain spheres. Further, the power of parents, teachers and doctors is circumscribed by the fact that they are members of a larger egalitarian community which "disciplines" and censors their activities (Walzer; 289-90).

In thinking about my own family, it is clear to me that its justice was monarchical and even sometimes tyrannical. I certainly knew that I was situated at the lower tier of a hierarchy. Interestingly though, as I gained the social and political autonomy of adulthood, it was not clear to me that I put aside the subjection of my familial realm. It did not seem as though the disempowerment I experienced as a younger, disfavoured, female offspring limited itself to the intimacy of my family. It seemed to reverberate elsewhere in my life. As a result, while I am sympathetic to Walzer's defense of difference and pluralism in liberal democracies, I am critical of his belief that the loss of power in one arena does not affect status in another. Susan Moller Okin criticizes Walzer for similar reasons. She argues that Walzer's spheres perpetuate forms of historical patriarchy — that they, in effect, protect those who are traditionally dominant in a culture. For example, the sex differentiated roles of the family permeate the rest of society (Okin; 68-73). Like Okin, I am unconvinced that the relative impotence of one sphere remains delimited from other spheres. As I will show later in this chapter, my own experience has taught me that the justice (or injustice) I experienced within my family structure carried over into the treatment I received as a patient. The fact that my family no longer recognized me encouraged my physicians to treat me as though I were legitimately

15 Determining the extent to which any family navigates the boundaries between monarchical, despotic and democratic rule is an interesting task. However, such an investigation is beyond the scope of this project.
dispossessed. I became unworthy of considerate medical care precisely because my parents felt as though I were unworthy of parental care. The spheres of my family and of the health care system were thus not distinct. My beleaguered status within my family, as well as my family’s social position, affected my treatment as a patient. As a result, I contest Walzer’s assessment that temporary losses of power are tolerable, because they are not self-contained and revererate beyond the particular incident, over time and in other social spheres.

Theorists generally agree that the family is the first school of moral justice. And as a political scientist, I am acutely aware from whence I have sprung. As a child, I knew and enjoyed the commodiousness of upper class life. However I also experienced the subjugation of its rampant sexism. My family’s gendered stance was certainly idiosyncratic in its ferocity but its seminal impulses were patrician and patriarchal in origin. While I was aware of the absolutism of parental authority, I was acutely conscious of the potency of my parents’ (and others’) affluence in fashioning the socio-political environment as well. I witnessed a singularity of power which masked itself in the acquisition of physical objects of beauty and in the creation of social mores. My girlhood confirmed the Foucauldian claim that power creates its own truth. But, while I believe that this is true, the Platonist in me resists Thrasymachus’ notion that justice

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16 This was particularly true in my own case in that my father served on the board of one of the city’s major hospitals. His own father had also been a physician who had been a medical professor in London England and whose professional reputation transcended incredibly large geographical distances.

17 Increasing evidence suggests that socioeconomic status affects access to medical care. In the United Kingdom “access to the National Health Service has not eliminated disparities in health according to socioeconomic status.” In a study of London civil servants, the mortality rate from coronary heart disease of unskilled clerical workers was 4 times that of skilled administrators with the same affliction. “… [N]either biomedical risk factors nor limited access to medical care can account for most of the differences…” Universal access to medical care does not seem to ameliorate the correlation between health and income (Pincus et al.; 406-411).
is simply the advantage of the stronger. To some extent, my work is simultaneously Foucauldian, Platonic and feminist in its approach. My hope is to engage in a dialogue with medicine. By composing both experiential and theoretical arguments, I hope to expose and dissect the nature of power as it is embedded in medical culture and practice.

First Encounters

When I was little, I can remember hiding under the bed when the pediatrician made house calls. He would lift up the bedcovers and peer in at me, coaxing me to come out. I felt far too naked in my pyjamas.

One morning, when I was twenty, I went to the doctor for what I thought was a minor infection. He told me that I had a cyst that needed further examination. By the end of the afternoon, I was in a cool, darkened room at a downtown hospital, having my abdomen scanned. Technicians muttered to themselves behind incandescent monitors in the corner. They left the room and two young doctors, whom I had never seen before, came in carrying binders and clipboards. They told me that I had a cyst. I nodded obliquely. "Well," they wondered aloud, "Did I know when my doctor had booked the surgery?"

A wave of giddiness surged through me. "Surgery?" I asked.

One of them sat down on a stool beside me. "That," he said, pointing instructively at a screen, "Is a tumor that needs to come out."

I felt as the room receded from me. I felt weightless. "Really?" I demanded, "Are you sure?"
"Oh, yes." One of them said. "We'll talk to your doctor right now. You need to call him this afternoon."

I spoke to my doctor the following morning. His tone was kind and reassuring. He confirmed that I would need surgery within the next few weeks. "But while it was urgent, it was likely not life-threatening." I bartered with him and we agreed that I could be operated on during the Christmas break. Before, I hung up the phone, he reminded me that he knew my mother had been successfully operated on for a similar problem a decade before. He offered "I'm sure she'll be of great help to you in all of this."

I swallowed a little. "Well actually, I wasn't planning on telling my parents about it."

I could hear an intake of breath at the other end of the line. "What? I don't think you understand the seriousness of this. Your family must know. — I know them. They would want to know."

I tried to clarify myself without divulging too much. "It's a little complicated." I said. "I haven't lived with them in several years and, well . . . . Well, we've drifted apart. We really don't get along."

He enunciated, "Let me be very clear. I expect you to have spoken to your parents by the time I see you next week. Whether you get along with them or not." He hung up the phone.

I felt lost.

The next week, we discussed the impending surgery and my parents again. I didn't want to seem disloyal to my family. I didn't want to bad-mouth them to a man I hardly
knew. I tried to reiterate that I didn’t think it was wise or necessary to tell my parents anything. He laid down the bottom line, "I simply won’t operate without your parents being involved. You will need at least 3-4 weeks at home before you will be able to look after yourself again. You have to tell them. You need their help. — I know your mother. Whatever your differences, she is a good woman." He put his hand on my shoulder. "Just call her."

I left his office. As I walked home, I felt waves of emotion surge through me. I wanted to be able to call my parents. I needed them. But I also knew that when I had asked for help in the past, they had been unwilling. I didn’t want to be rejected. But the surgery and the doctor’s ultimatum loomed in front of me. Perhaps, I thought, it was worth a try.

The next day, I rang my mother. I heard her high authoritative voice answer the phone. "Mummy?" I said. I heard a muffled response. "Mummy, I need a moment. Do you have a bit of time to talk?"

"Not really," she huffed. "What is it?"

"Well, it’s important. If you don’t have time, I’ll call you back."

"No. Just tell me."

"Well. I saw Dr. P a couple of weeks ago and apparently I need to have an operation." I hesitated. "It’s booked for around Christmas. — I just thought you might want to know." I waited for a response. There wasn’t any, so I went on. "I was wondering whether I might be able to come to stay with you afterwards? — It’d only be for a couple of weeks."

Her voice was firm, "The answer is no. If it can wait for another six months or so, well then, maybe. But no, not at Christmas. It’s your father’s busy time of year."
I felt as though I had been punched in the stomach. I stuttered, "I... I'd stay out of the way. And I promise, I'd be gone after two weeks..."

"No. My answer is no. — And one other thing." I could hear her bracelet chink against the phone. "Don't think we'll pay the extra-billing, because we won't." The phone clicked down.

I fell back against the wall by my bed and gazed out the window in silence. I didn't want to cry.

Later in the week, I called the surgeon. Before I could say anything, he bellowed at me, "What the hell have you done?! I talked to your mother yesterday. — What have you done that they won't take you home?!"

My words caught in my throat. What did he mean that he had spoken to my mother?! "I haven't done anything."

"Well, you sure must have. — She said they'd think about taking you in July."

I asked confusedly, "I thought I had to have this operation sooner rather than later? Can it wait until then?"

"No, you shouldn't wait until summer. — But I'll tell you this. I'm sure as hell not going to operate without you having a place to stay."

"What if I had a place to stay that wasn't my parents'?"

"Well, I suppose so. But, I'd have to have proof that you're convalescing somewhere safe."

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18 At that time, in early 1986, doctors could still bill extra charges on top of the province's standardized payment schedule (OHIP). This practice was halted later the same year.
"I think I can do that," I said.

"Really, the best thing would be if you'd sort this thing out with your parents."

"But you'd accept an alternate place?"

"Yes, I'd accept it."

Three weeks later I arrived at the hospital, having arranged to stay with the
mother of friend. I felt hollow as I went through the admitting protocols. On one of the forms, I
wrote down the name of a close friend as my next-of-kin. The anesthetist came to see me. The
nurses prepared me for the O.R. A couple of friends came to visit and chat. They gave me
books and a stuffed animal. The surgeon came to the ward late in the evening. He sat on the
edge of the bed. He brusquely explained the operation and asked for my consent. He seemed
uncomfortable and a little irritated. I signed the sheet. As he stood to leave, he turned, patted my
leg and said emphatically, "You are going to be very sick tomorrow."

The next day I awoke from the surgery feeling as though I had been run over by a
streetcar. In seemed as though I was immersed in a sea of pain and semi-darkness. Dr. P bent
over me, "I've called your parents to tell them how it went. — You're going to be okay." A
confused anger rose briefly in me. Why did he call my parents? I fell back to sleep.

Hours later, I roused again in my room. I felt pierced by pain and loneliness. My
parents weren't there. . . . My hopes withered within me. My being ached with sorrow. My last
sinewy tie with my parents was dead. I knew now that I was truly on my own. I closed my eyes
and sunk back into the pain that engulfed me.

Sometime later a surgical resident came to see me. I felt barely conscious.

"Well," he said. "I'm glad you're finally awake. You sure took a long time to wake up."
"I did?"

"A bit longer than normal — but nothing to worry about." He pointed to the sutures on my stomach, "It was a bit more complex than we thought. We opened up you here and here. We did a full abdominal."

I looked down at my swollen belly.

"But it went well." He replaced the covers. "Now, you know you’ll be here for about a week or so?" He got up to leave, "Okay — I’ll see you tomorrow."

I shut my eyes.

I became clearer over the next several days. Friend after friend came to see me. I felt overwhelmed by kindness but nonetheless, still very much alone. Dr. P came to discharge me. I hadn’t seen him since the day of the surgery. He advised about what I should and shouldn’t do. We made an appointment for a few weeks later. Finally, he leaned over me, scowling, "You’ve got to mend this thing with your parents. I mean, I understand about teenagers. — I have kids of my own. — But you’ve got to start treating them better. Show them a little respect."

I wanted to yell at him and cry simultaneously. I did neither. I mumbled something like ‘I’ll try’ and he left.

My first experience of medicine was thus one of a benevolent disregard of my own wishes. My doctor was capable and well-intentioned, but his actions left me feeling impotent and isolated. Although I was a young adult, he treated me as though I were a child. He consistently ignored my requests to keep my parents out of my medical care. He breached my
confidentiality over and over again by contacting them. He believed that he was acting in my best interest. But he wasn’t. By speaking to my family without my consent, he made it clear that his concern lay with them and not with me. I felt betrayed. But I also knew that there was little I could say or do to alter his opinion. While I depended on his medical and surgical expertise, I became circumspect about his care. I was ill and I needed him, but I didn’t trust him.

The frailty I felt when confronted by my morbidity was exacerbated by the psychological recklessness with which Dr. P pursued his benevolent and paternalistic purpose. He made me feel inconsequential. My decisions were not worthy of regard. Furthermore, he raised my expectations about my parents just enough so that they were horribly dashed when I was physically and emotionally most vulnerable. I felt completely helpless and utterly alone. Instead of being grateful for his clinical skills, I believed myself to have been maligned and misunderstood.

To Dr. P I appeared as a miscreant daughter of an upper class family. To myself, I was an able student and an avid athlete. I consciously channeled the tumult of my parents’ disaffection for me into over-achieving endeavors. Perhaps, I thought I could regain my family’s love through being exceptionally bright, exceptionally swift and exceptionally strong. In short, I tried hard so that my mother and father would stop hating me; I wanted them to admire me. Although I may have seemed like a delinquent to the medical staff, I didn’t see myself as one. Nonetheless, I quickly learned that my words and actions were not valid measures of who I was. Instead, I was defined by my parents and their social rank. Since they rejected me, my doctor saw me as aberrant. As one doctor would say to me years later, “Even the parents of murderers visit them in jail.” Having worked so hard to maintain my self-respect in the face of daunting
parental antipathy, I lost my credibility as soon as I entered the clinical environment. I was stripped of a portion of my agency not only because I was ill and lacked medical expertise, but because I was without the support of my upper class family.

Although my physician formally obtained my consent for the operation, he did not bother to obtain my permission when he telephoned my parents to discuss my medical treatment. In short, he didn't maintain my confidentiality. In a medical journal of the same year, the author states that the purpose of confidentiality is to protect the physician-patient relationship.

Confidentiality is important because it protects privacy, which is bound up with self-respect and personal integrity, and it makes possible, within the professional relationship, an exchange of information of an intimate kind aiding communication and providing a basis of trust between physicians and their patients' care. (Murray; 230)

Maintaining a patient's confidences is thus central to build a trusting relationship. While physicians may reasonably seek to include family in discussions of disease and therapy, ethically they need to inform a patient prior to doing so. The ill individual thus agrees to expand the sphere of clinical confidentiality with regard to his/her own ailment. For a doctor to ignore the need for a patient's consent in releasing intimate information to others is to denote a lack of respect for that individual. Moreover, legal statutes often require that physicians maintain the confidentiality of their patients. Interestingly, in a recent study of family practice units at McGill University, researchers discovered that most professionals were relatively ignorant of confidentiality issues and laws. They caution: "Considering that confidentiality has been cited as
a reason for not seeking health care, we must be able to reassure patients that their medical records are confidential." (Shrier et al.; 712)

While Dr. P was understandably concerned about my post-operative care, he exercised poor clinical judgement in breaching my privacy. While he sought to garner the support of my family during my recovery, in actuality, he left me vulnerable to their abandonment. Further, he jeopardized the trust which I should have felt for him as my surgeon. It became clear to me that I was not an equal to him nor to my parents. While his intent was benevolent, he used his authority in manner which overwhelmed and hurt me. In the end, he exacerbated my suffering and attacked my self-esteem. While in his care, I didn’t feel as though I were a rights bearing individual. Despite the munificence of socialized medicine, I felt as though I lost a portion of my citizenship in becoming his patient.

**Hysteria**

About six months after I had my first surgery, I tree-planted in the Canadian forests as a summer job. As I worked, my normally athletic body lagged. Meals didn’t stay down. I felt pained and giddy. I collapsed twice and my foreman sent me to town to be checked by a doctor. I was admitted to a local hospital for overnight exploratory surgery. I assumed that the cause of my malaise was relatively minor and that I would be back to work in a few days.

I awoke from the anaesthetic having difficulty breathing, moving, speaking and seeing. My left side was paralysed, my speech was slurred and my eyesight, blurry. Eventually the doctors told me that they thought I had had a small stroke. Incredulity swept through me; robust twenty year olds didn’t have strokes! However, my physicians assured me that they did.
When they mitigated their diagnosis by telling me that because I was young, I would recover quickly and completely, I thought that I would walk back to a normal life within a couple of weeks. I was wrong.

Weeks dragged by. My strength returned slowly. I made inconsistent gains. One day I would be able to move my leg a certain way and the next day I wouldn’t. Some days I could sit up in a wheelchair for a couple of hours, other days I passed out. The physiotherapist and doctors were kind, but scolded me for my lack of effort. I became embarrassed and frustrated by my seeming ineptitude. I grew frightened and disheartened by my body’s capricious disobedience. I tried to make myself better. I tried to force my muscles to work, the way I often had done when I played competitive sports, but they seemed to abjure my efforts. The doctors often told me that stroke patients recovered differently than I seemed to be. I wanted to be a good patient and I tried to shape my recuperation to their expectations. I tried to be the model stroke patient but my care-givers gently reprimanded me with phrases such as: "CVAs don’t move that way," or "Your reflexes seem to vary slightly every day," or "You could move that muscle yesterday." The medical staff treated me with benevolent but puzzled concern.

The absence of my immediate family made matters worse. My next of kin on my hospital admission sheet was a friend at home. Without my knowing, she discovered that my parents and brother were holidaying in Spain. She called them but they were uninterested in my plight. Finally she called an uncle of mine whom I had never met. He flew in to see me for a day. As a doctor, he became concerned that I might die. He telephoned my father, but my parents still refused to come. Consequently, although I was seriously ill, no family attended me. I was unsurprised by their absence. In fact, experience taught me that I wanted nothing to do
with them. The staff’s and my friend’s insistence on their involvement disheartened me. My parents did not see me as their child. I understood this but I struggled to explain their lack of affection to those around me. I couldn’t point to any single moment in which I had irrevocably dislodged their love. Our estrangement was not an adolescent by-product, it had fermented throughout my life. Given my parents’ social standing, this explanation was simply not credible. It made no sense that parents — particularly rich, well-educated parents — would abandon offspring without substantial cause. As a result, their absence condemned me. The spectre of a delinquent haunted my medical persona. Consequently, my physicians treated me with a bewildered kindness that masked a disbelief in my psychological and social stability.19

Despite such misgivings, the medical staff devoted a great deal of time and resources to my care. Accordingly, they pursued a place for me in a rehabilitation hospital. They wanted to move me to a facility that could provide better diagnostic and therapeutic resources. They explored a variety of options and decided that even if my parents remained uninvolved in my care, it would be better that I return home to a city where I had friends. The hospital approached a local businessman for help and, he offered to fly me across the country in his private jet. Within a week, an ambulance crew loaded me on a stretcher and into a small plane. Later the same day, another ambulance greeted me when the jet landed. Against my wishes, the hospital informed my parents of the time and place of my arrival, but they didn’t

19 Furthermore, one of my physicians trained under my grandfather during his medical training in England. This only enhanced his distrust of me, in that he could not imagine the family of his old mentor abandoning a relative.
meet the plane, nor did they appear when I was admitted. The clinical staff who accompanied me could barely disguise their disapproval.

In memory, trepidation and uneasiness coloured my homecoming. Returning to my own city made me acutely aware of my losses. I measured myself against recent memories of myself walking, training, studying and working in the familiar cityscape. I felt deeply humiliated. Only weeks before I had bragged to my friends of the small fortune I would make tree-planting; of how these sums would be used to travel the world or attend graduate or law school. My arrogant belief in my own dreams was shattered; so too were my naive dreams of making my own irrefutable mark on the world. I had assumed until this point that I was destined for great things. My admission to a large urban hospital coincided with a personal crisis of confidence and vision. The veil of my youthful illusions was lifted: I saw that I was still quite weak and ill, that my ailments were tinged with mystery, that I was without familial support and that I was close to penniless. In short, I was deeply afraid.

One of the first rules I learned as I child, was not to show fear. I thus approached the medical staff in the new hospital with a bravado of good nature. Furthermore, I felt so threatened by my situation that I very much wanted them to like me. I felt I needed them to like me. I maintained a rictus of fear throughout most of my stay in hospital. Given that hysterics are meant to demonstrate an inappropriate indifference to their symptomatology — *la belle indifference* — my jovial presentation could only have abetted the rising suspicion that my ailments were psychological in origin rather than purely physical.

Clinicians seemed circumspect in their dealings with me. They told me little except that they doubted the veracity of the report of the CT scan findings of a few weeks earlier
which indicated a "perfusion" in the right hemisphere of my brain. While the staff physician and senior resident both examined me, when I questioned them, they never spoke to me about a diagnosis and/or plan of treatment. They simply patted my leg and told me I would get better; that I just had to try harder. I did, however, see a physiotherapist everyday. And while I worked arduously at regaining my strength and learning to walk, I never quite managed to eliminate my hemipareisis. In addition, I was utterly exhausted. Again, the nurses and therapists chided me for my seeming lack of effort. Other than gentle chastisements, an overwhelming clinical silence pervaded most of my hospital stay. I began to get intense migraines from the stress of appearing congenial while feeling completely helpless, terrified and alone. I knew I was somatizing my emotional strain but I couldn’t stop myself. I simply couldn’t check my galloping fear and growing alienation. And again, my need for medications to ease my increasingly frequent migraines only added to the burgeoning notion that my complaints were intrinsically psychological.

Without warning, a psychiatrist showed up in my ward room one day. He introduced himself as Dr. R and asked me to follow him down the hall for an interview. The sense of being ambushed was overwhelming. I immediately knew that he wasn’t there to offer support but was instead there on a reconnaissance mission to determine the extent of my emotional disequilibrium. His manner was coy and effete. He seemed oblivious to the difficulty that I had in standing and walking. He questioned whether it was really necessary that I use a cane to assist myself. I remember little of our interview except that he suddenly asked me what I

20 hemipareisis: weakness affecting one side of the body
fantasized about during sexual intercourse. This question stunned me. I suddenly had the urge to be violent. I wanted to scream that my current concern was whether I would recover my former self and that I was not particularly concerned about my sexual practices or gender identity. Yet, despite my misgivings I answered it, suspecting that if I refused, my noncompliance would condemn me. Nonetheless after a few more similarly phrased questions, I terminated the interview. I felt violated and misunderstood. Moreover, I believed if I continued, I would become an accessory to Dr. R’s psychological assault.

When I left hospital, my chart’s diagnosis concluded: "Right CVA. Conversion Reaction." A social worker handled my discharge. She revealed that throughout my stay that my physicians had been in contact with my parents. My mother had indicated that she wanted nothing to do with me, that I had consistently lied to her and stolen from her. Moreover, she claimed that I had perennially done badly in school and that I had manufactured illnesses in the past to garner her attention. My clinicians and parents agreed that it was time for "tough love," and I would have to stop depending on my parents for support. I was to leave to spend three weeks with an old friend of the family, who had also been apparently warned not to offer me protracted assistance. Ostensibly, I did not need further medical follow up or rehabilitation. This would only reinforce my attention-seeking behaviour. What I needed was to get a job and to pull my proverbial socks up. Given my poor academic record, the social worker suggested that I seek

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21 CVA stands for cerebral vascular accident, or stroke. Right CVA locates the stroke as having happened in right hemisphere of the brain.

Conversion Reaction was a replacement for the term "hysteria" in reference to psychosomatic disease, from the 1980s until the mid 1990s. The current term (1998) is Histrionic Personality Disorder.
some form of work, such as "becoming a bus driver." The message was very clear: I was to stop being a neurotic, upper class brat.

The social worker’s invective tone battered me. I not only felt abandoned and betrayed but vilified. I knew I had never stolen from anyone. I knew also that I was a pretty good student. I offered to provide her with transcripts to prove my scholastic record. I reiterated that I expected to go on to professional or graduate school. She responded by saying that perhaps I should re-think my future as I obviously wasn’t "strong" enough to undertake such endeavors. It was clear that she alluded to my lack of psychological and moral strength. I felt that it was futile to defend myself.

In short, I discovered a coercive element in the clinic. I experienced this coercion in a number of important ways. Foremost, I encountered the enormous psychological and social power of a medical diagnosis. Both "cerebral vascular accident" and "conversion disorder" were labels which supported complex and burdensome matrices. Further, a formidable silence pervaded much of my clinical stay. This lack of communication and dearth of information resulted in a deeply felt alienation. Utterly alone, I lacked power. My physicians’ consequent breach of my confidentiality represented not only the disdain with which the clinic viewed my personhood but also the abject nature of my powerlessness. Finally, and not insignificantly, I realized that my physicians and I cleaved to different so-called "truths." The objective conclusions as laid out in my medical chart diverged so greatly from my own understanding of myself that I barely recognized them. In a sense, medicine taught me (in
manner that theoretical political science could not) about the corporeality of Plato’s concern for justice amidst the convoluted inter-penetrations of appearance and reality.

When I was first diagnosed with a CVA, I tried to identify myself as a stroke patient. I tried to view the specifics of my symptoms as part of a larger pattern of clinical classification. A diagnosis offered a stable point of reference amidst the turmoil of sickness. I clung to the certain clarity it offered in the tumult of my distress. By identifying myself as a CVA patient, I could thereby envision myself no longer being a CVA patient. By affiliating myself with a specific disease category, I sought to subjugate my sickness and become well again. But when, I physically and emotionally could not do this, I felt myself to be a failure. Years ago, when I was waiting in a hospital corridor, a middle aged women turned to me and confessed that she had "failed chemotherapy." Her words carried all the weight of expectation and promise that a diagnosis and treatment brings. Having assumed the burden of her disease, she accepted responsibility for not having successfully responded to therapy. While I was shocked by her statement, I understood her self-abasement, for I too had spent much of my time when under medical care as a clinical failure. My attempts to mold myself into my doctor’s description of a disease consistently failed. Despite my efforts to adhere to the prevailing diagnosis, I often found that my symptoms, behaviour and self-conception fell outside the parameters of the disease or syndrome with which I had been anointed. The ambiguity of my diagnosis further obfuscated the course of my therapy. As a result, the only clear and consistent theme which emerged from my treatment was that I was uncooperative. And that by failing to fit into the parameters of my diagnosis, I became somehow inimically responsible for my own
illness. I was, thus, suitably diagnosed with having a conversion reaction, which is equivalent to becoming a type of clinical outlaw.

My peripheral status was all the more evident in the fact that my physicians did not speak to me. Their silence had important ramifications. By depriving me of information, it denuded me of the essential power which attends knowledge. I lacked the means with which to construct a dialogue. Consequently, my reason and opinion were suppressed. As a result, I lost a critical portion of my agency in the hush that governed my medical care. Moreover, my physicians' tactical silence indicated that I was unworthy of consultation and exchange. Despite my age, the clinic viewed me as if I were an incomplete being, not fully endowed with the right and/or ability to formulate consent. As a result, my physicians did not protect my privacy. They confided themselves, not to me, but to my parents, who not only had little concern for me, but palpable antipathy. Together, they created an environment of hostility and suspicion. In a time of great physical and emotional distress, I thus found myself bereft of fundamental psychological, social, and political supports.

According to the physician and ethicist, Jay Katz, this type of assault on a patient's personal agency is not that unusual in the clinic. In elaborating on doctor-patient relationships in general, he writes that doctors have relied both on subtle and overt forms of coercion for centuries in their clinical practice. His point is that the historical and cultural mores of medicine do not easily support notions of equality (Katz; passim). More importantly, until very recently, medical therapeutics were so ineffective in themselves, that a patient's faith in the ascendancy of a physician was often the only power that could make a patient well.
Authoritarianism is deeply imbedded in professional practices. Fears about the awareness and acknowledgment of uncertainty loom large in physicians’ and patients’ psyches and the retreat from honest conversation is a powerful social reality. These forces that conspire against disclosure and informed consent cannot be taken lightly. They speak to the fact that the idea of informed consent does not now govern the relationship between physicians and patients, that time has not yet come. (Katz; 227)

While Katz attempts to delineate the inability of clinical relationships to support the modern presumption of informed consent, his overall thesis outlines a clinical culture which shrouds itself in silence; which distrusts patients’ decision-making capacities (Katz; 208); and which cannot tolerate ambiguity and uncertainty (Katz; 164). Physicians are thus ill-prepared to cope with psychologically autonomous patients. And while formal rules exist within the clinic to protect patient self-determination, such protections are often not realized.

The fact that medicine both consciously and unconsciously blankets itself in silence means that a linguistic and conceptual gulf forms between physicians and patients. The medical persona distances and objectifies patients which inevitably leads to a diminution in their autonomy. In the next chapter, I elaborate more explicitly about the distinction which develops between the professional characterization of disease and the lay experience of illness. I outline the differing and often conflicting narratives of doctors and patients which emerge about human ailment. Two versions of truth materialize. Two voices and reasons compete over the shared experience of sickness. But inevitably, it is the doctor’s truths which have the greater power in the subtle antagonisms of the doctor-patient relationship. It is the physician’s will which usually
prevails for medicine yields a weightier authority when confronting the complaints and frustrations of the ill.

All of this brings me back to Plato's allegory of the cave which I mentioned earlier in the chapter. While, I think that it is clear that Plato believes that the man who frees himself and crawls up to the "light of the forms," possesses the greatest truth — he is the philosopher — it is not clear to me whether those of us who are still chained below in the nether worlds are capable of discerning the philosopher from the lunatic or the fraud. How can we know whether the man who comes to relate to us the "truths" of the forms has in fact seen them? Perhaps, he has only crawled part way up the tunnel and the rest is a figment of his imagination? Or perhaps, what he tells us is true, but there may be a cosmology further beyond, which affords even greater vistas and light which has yet to be discovered and, thus the philosopher's light of the forms are not completely true? Further, what if we don't believe the philosopher? What if he cannot persuade us that the shadows that we take for reality are in fact fictions of the puppeteers behind us? Plato certainly foresees this conflict. He clearly outlines that both the philosopher and the cave-dwellers are independently wedded to their vision of reality. In fact, the cave-dwellers must be forcibly 'dragged up the rough, steep path in to the sunlight' by the philosophers (Plato; VII, 515e). They do not willingly abandon their dark grotto. The philosopher (who could be regarded as the physician of the soul) employs coercion in his efforts to remedy the people's illusions. Force seems to play an integral part in enlightenment (i.e., in spiritual healing). But where does this leave us? Does this mean that physicians should use coercive methods in their efforts to rid patients of disease?
I am not convinced that it does. Plato's *Republic* is a text so laden with ambiguity, that I'm not sure that he intends for the philosopher to be a coercive persuader of souls. I'm not convinced that the philosopher has a political role. Book X, for example, recounts the Myth of Er in which Odysseus renounces his former life of honor and politics, and chooses, as his next human incarnation, the life of "a private individual of who d[oes] his own work." (Plato; X, 620c) I believe that the philosopher is not a possessor, but a lover of knowledge. His, is not a knowledge that is expressed in doctrine but, rather, in exploration and revelation. Moreover, Plato writes, in describing the trial of his mentor Socrates, that 'the unexamined life is not worth living.' Further, he asserts that a man who is interested in justice should lead a private, not a public, life. Plato's writings reveal the tragic outcome when truths compete for ascendancy. Socrates is, after all, condemned to death for his thoughts (i.e., for corrupting the youth and disbelieving in the gods of Athenians).

I am aware that my use of Plato is idiosyncratic in these circumstances. My discussion does not adhere to traditional interpretations of his text. Nonetheless, I believe that Plato expresses the deep ambiguity of the search for truth. The potential for conflicting interpretations and so-called "truths" exists throughout his writing. *Republic*, in particular, elucidates the enormous (and perhaps, irreconcilable) tension between power and knowledge in human affairs. For me, the allegory of the cave points to the potential in all of us to discover the truth; to move beyond the dark cave of our illusions. And, with regard to medicine, I sometimes wonder whether human illness is itself an opportunity to break the chains of myths which bind our lives; and it may be the patient or the physician who gropes through the umbra to the light of knowledge and discovery at the end of the tunnel. Finally, and perhaps most importantly, Plato's .
allegory attracts me because it represents a shift in vision. The oscillation between the fiery light of the cave and the stark sunlight of the forms seems to parallel my own experience of the shifting and divergent realities of illness and disease. The dichotomous strain between shadow and sunlight is analogous to the opposition of subjectivity and objectivity in the medical environment.

**Intubate or Die**

Several years later, I arrived at an emergency ward in extreme respiratory distress. My breathing was shallow and slow. I struggled for every breath. Within seconds, I was propped up with an oxygen mask hissing against my face.

Since a few months after my first operation I had had unexplained bouts of paralysis which affected everything from my eyesight, swallowing and speaking to my walking. No one knew why, but I seemed to be chronically tired and intermittently paralysed and ill. Many clinicians strongly suspected that I was hysterical; that my illness was an unconscious manifestation of a longing for affection. To them, I wasn’t really ill; it only seemed as though I was ill.

About a month prior to my respiratory crisis, I had had what appeared to be a minor spinal injury. After falling while camping, I had had fiery pain in my arms, neck and head accompanied by loss of movement and sensation. I had been hospitalized but the scans only revealed a hyper mobility of my cervical spine.\textsuperscript{22} Given my previous medical records of

\textsuperscript{22} A scan several months later revealed that I had what seemed like a healed fracture in my thoracic spine. My thoracic and lumbar spines were not investigated after the fall.
unexplained weakness and the lack of any substantial radiological evidence of damage, I was sent home in a wheelchair to await an opening in a spinal rehab unit.

The young doctor who attended me knew all this. We knew each other by name. Dr. G quickly whisked me into a private area of the unit. He crouched low down beside the stretcher and looked up into my face. "You're going to need to be intubated. — We're going to have to put you on a ventilator. It's a machine which breathes for you." He paused. "Do you understand?"

I nodded. I understood — but I wasn't sure I wanted to be put on a ventilator. I had spent the past few years getting sicker. There were times when I seemed to improve, but they were offset by longer and deeper plunges into pain and illness. The physicians may not have known what was wrong but I knew that I was slowly getting worse. And, this struggling to breathe was perhaps one of the worst times I had yet had. I wasn't sure I could face more. I loathed hospitals. I feared them. I feared their pain and isolation. I feared the clinical disbelief that accompanied my admissions.

"Now, I should tell you, if in fact you do have cervical injury, there is a possibility that you may never come off the ventilator — that you may always need it."

The thought of being permanently ventilated terrified me. I shook my head 'No.' He took one of my hands in his. "You don't want to be ventilated?"

I shook my head again.

He intoned, "I think you know that you might die without it."

I nodded.
"I want you think about this? Are you sure?" He kept his eyes on me. "I don’t think you should decide so quickly. You’re young, remember. You should give yourself a chance — please don’t decide yet."

My breathing was slowing, but I was still straining to inhale. I was exhausted. The world was becoming blurred and confused. But I was still fighting. I wanted to live.

"Do you know what you want to do?"

I shook my head. I wasn’t sure.

"Okay at least let me help you?"

I nodded.

"I want to move you to intensive care. But not here. I don’t think they’ll look after you very well here. I want to send you to T.W. Hospital."

Part of me didn’t want to go to any hospital. I wanted to just go home. Another part of me wanted to live. I nodded reluctantly.

"Okay, Let’s go!"

Once again I was rushed through city streets in the back of an ambulance. When I arrived at T.W. I was taken into a room and laid flat. I felt the darkness close in. My body sank heavily underneath me. My chest caved in. I pulled at each breath slowly and determinedly, feeling as though I were drowning under a weight of sand. I remember that a man and a woman slid their stethoscope pads across me. I couldn’t speak. They put me in a hallway, then in another room. Everything was blurry. I sucked at the air; a fish out of water.
The next thing I knew I was being bagged.23 My eyes cleared a little and I saw people above me. I didn’t want this. I didn’t want to be there. I heard a voice say "Let’s intubate." A panic coursed through me. What if I didn’t ever come off the ventilator? Then I’d be stuck in a place like this forever! I tried to move me head away from the hands in my face. "Don’t do that!” A young woman shouted at me. "No! Don’t do that!"

I shook my head again. I heard another voice say, "Maybe she doesn’t want it."

The woman leaned over me again. She pressed her face towards mine, "Look, I’m Dr. B!” She shouted, "Intubate or die!"

The political theorist rose up in me: was she really offering me a choice? I wanted my options better expressed. I was afraid of the ventilator. I was afraid of doctors and hospitals. I was afraid of dying. I faced a terrible decision — I stopped struggling.

Instantly hands were upon me. A tube bored through into my right nostril. A needle sunk into my throat. I wanted to scream. I became aware of a searing pain in my nose and throat. The tube was taped to my face. I was in agony. My being was shot through with terror and with pain. I was crying. I could feel the tears puddling in my ears as I lay flat on the stretcher. I was in hell. I wanted to go home. I really wanted to go home.

Through the veil of my anguish I heard someone say "She’s bucking the vent — I can’t get it set right.” Dr. B stood by the side of the stretcher, "You’ve got to stop trying to breathe. The machine does it for you. Just stop breathing."

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23 "Bagging" is a procedure in which a mask is placed over the mouth and nose of a patient. The mask is attached to a rubber balloon. When the balloon is compressed manually, air is forced into the patient’s lungs.
I didn’t want to stop breathing. I didn’t want to stop trying to breathe. I wanted to go home. I didn’t want to be in hospital. If I let go, if I gave myself over to the machine it would mean that I submitted to being there. It meant that I had given up. More importantly, it meant that I trusted them and I didn’t.

"Okay well let’s get her up to the ICU and try another vent."

The ICU seemed to hum with machinery. My partner and a friend stood above me. I continued to try to breathe against the vent. I couldn’t stop myself. I felt desperate and inconsolable. I lay on my back encased in a neck brace. Pain seared through my arms, neck and head. It tore at my throat. Tears slipped down the sides of my face.

Nurses periodically fiddled with my tubing. I dreaded them suctioning my airway. After an x-ray, I was rolled onto my side. I could stare out at the wall, at the machines and at my friends. I could move my arms a bit and I could write barely legible notes on scraps of paper. I couldn’t talk. Hours passed slowly. I didn’t know whether it was day or night, the ICU seemed incessantly active and bright. Thankfully, someone put a walkman over my ears. I shut my eyes and tried to hide in the music. I drifted in and out, gripped by pain. I clutched at the strains of music filtering through the earphones.

A day or so later, I became conscious of nurses gossiping at the foot of the bed. They shuffled through the papers of my chart. They muttered and pointed. I tried to listen but I could only catch fragments of words. I could guess at what they were saying. No one knew

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24 "Suctioning" is a procedure in which the ventilator is temporarily disengaged from the tube going into the throat and lungs. A smaller, thinner tube is inserted down into the lungs and fluid is suctioned out of the airway. Once complete, the thinner tube is removed and the ventilator is re-attached.
why I wasn't able to breathe. Perhaps, I was putting it on. Perhaps, I was faking. Perhaps, I wanted attention. It was too painful to contemplate; I tried to ignore them. Another day passed, maybe it was two. I wasn't sure.

A doctor came by. She bent down and told me that there was no reason that they could find for why I couldn't breathe. My neck injury wasn't serious enough. She was going to turn the vent off and remove the tube from my throat. She quickly extubated me. I soared with relief that the tube was gone. The infernal pain of it in my nose and throat was gone. But within a few seconds, I was fighting for air. I sucked at the oxygen mask hissing on my face. My breaths were slow and shallow. I felt my whole being grapple for each breath. I looked up at her and saw her face fill with confused concern. "Oh," she said. "It'll take a few minutes for you to get used to being without the machine. You'll work it out." She turned to the nurse, gave her instructions and left. I gasped on.

I maintained normal oxygen saturations with extreme effort. I felt the hostility of the medical staff as they watched me in disbelief as I struggled to breathe. I felt utterly helpless and alone. I longed to be shielded from their disinterested observation. Their incredulity at my agony tortured me; better to die gasping at home alone in my own bed than like this.

I began to tire. I fell asleep to nightmares of mountain climbing at too high an altitude. My head pounded as I staggered through glacial snows. I cursed myself for not

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25 Oxygen saturation denotes the amount of oxygen that the blood hemoglobin carries. It is measured through the skin by a sensor placed on the earlobe or fingertip. Normal oxygen saturations run between 92-98%.
bringing oxygen cannisters on the final push to summit. Fields of glinting ice sheared through my eyes and into my skull. My head hurt. I wanted to be sick.

I awoke to a nurse and doctor slapping my face over and over and shaking me "Stop that!" Stop that!" They shouted.

I looked up at them in puzzlement. My head still pounded.

"That’s better. Her saturations are back up." One of them warned a finger at me.

"Don’t do that. Keep breathing.

I watched them talking to one another at then end of the bed. I looked at the ceiling. I wanted to get up and run out of there. I wanted to cry but held myself in check. I turned the walkman back on and drifted back into the music.

Again I was on the mountain top, feeling sick. I put one foot in front of the other. I kept climbing. I wasn’t sure I would make it down. My head hurt. I couldn’t see properly. The sun and snow were blinding. I sat down to hold my head in my hands. The sky swirled around me.

"Hey! Hey! Breathe!" A nurse gripped my head in her hands. I heard the wailing of an alarm nearby. My oxygen saturations had sunk to 75%.

I looked up at her. I was trying to breathe. I thought I was breathing better; not great, but better.

"Stop holding your breath!" She lectured me. "There’s nothing wrong with you."

I wanted her to go away.

"Now keep breathing or I’ll have to get the doctor back in here!"
I shook my head; I didn’t want to see any more doctors. I’d had it with all of them. I wanted to be anywhere else.

I lurched back onto the mountainside. And again back into the ICU. And back again onto the steep slope. I bounced back and forth between the glacier and the inhospitable glower of the ICU. I remember little except for the searing pain in my head and body.

Eventually, I was moved ‘to the floor.’ My breathing was apparently stable. I found myself one last time on the barren mountain peak. I bent over to catch my breath and threw up on my boots.

I awoke in a ward room, with an oxygen mask against my face, vomiting onto my chest. I tried to roll myself but couldn’t. The call bell was by my hand. I pressed it and waited. No nurse came. My chest gradually dried.

Hours later my partner swung through the doorway.

I whimpered and cried "Get a gun," I said. "And just shoot me — I want to die!"

"No, you don’t. No, you don’t. I’ll get you cleaned up and feeling better."

"Just get a gun — I want to die!" And I meant it.

My desire to die was desperate and absolute. I saw no way to relieve my suffering. While the hospital had likely saved my life, it also caused me enormous physical and emotional pain. I wanted to leave, but was too ill to even sit up. At times, I regretted to agreeing to be intubated. Perhaps, I felt, it would have been better if I had died. Alive, I not only had to cope with my incapacity but I also had to face the further insult that few believed I was legitimately ill.
I felt trapped and I lingered over the decisions that had brought me to hospital. Had I been right to allow my partner to call for an ambulance? Perhaps, I should have stayed at home. I knew quite clearly that my reception at any hospital might not be cordial. No one knew quite what was wrong with me and they were tired of trying to figure it out. I was well aware that I was becoming a medical pariah. And yet, at that point, I wanted to live. I wasn’t quite ready to give up; to die with my boots on at home. And so we called an ambulance.

Dr. G’s reception was not hostile. He treated me with respect and laid out my options. As he outlined all the possibilities, I grew frightened. I remember thinking that I just wanted to go home; that maybe going home to die was preferable to being possibly intubated for life. His bias for living was readily apparent. But so also was his concern. He seemed to recognize my bi-polar fear of dying on the one hand and of living utterly dependent on a machine on the other. In spite of my generalized mistrust of medicine, I trusted him. In the end, I consented not to be intubated immediately, but to commit myself to his judgement and care. I momentarily put aside my dread of hospitals and of their objectified view of me. I chose to submit to Dr. G’s suggestions because he recognized me. He spoke to me as though I were worthy of consideration. In short, he treated me as though I were valuable.

My arrival at TW hospital was punctuated by the fact that no one spoke to me other than to examine me. People moved efficiently about me but never addressed themselves to me. My partner was asked to leave. I felt terribly alone. In the end, the only treatment option was offered to me in extreme crisis as: ‘intubate or die.’ While Dr. B felt justified in intubating and ventilating me, I felt threatened and even assaulted. In 1994, the law in such matters was clarified in Ontario. The *Ontario Consent to Treatment Act* states that a health care practitioner’s
duty to obtain consent from a patient is superseded in cases of emergency (Bloom & Bay; 170-171).

If a patient is unknown to the clinician, as is often the case in emergency medicine, and if no readily interpretable advance directive is available, the clinician must use a best-interest standard, that is, doing what a reasonable person would want under the same circumstances. In these instances, emergency physicians must make treatment decisions based solely upon medical information without regard to the patient's actual wishes.

(Palmer & Iverson; 729)

Legally, Dr. B may not have needed to obtain my consent. However, I believe that ethically she could have obtained my consent in the minutes which preceded my losing consciousness.

Furthermore, my partner had apparently clearly outlined my fears of intubation to her when I first arrived. Unlike Dr. G, Dr. B never acknowledged me or my apprehensions concerning ventilation.

When I contemplate my consent to be intubated that night, I characterize it as a "thin" form of consent. My decision was my own but it was made in fear and without trust. I had few resources to call upon in making my decision other than my own dread and the sparse information I received from clinicians. I also had little time. Physical suffering and grim fantasy overwhelmed me. Foremost, my reluctance to be intubated was based on a trepidation that my suffering would not necessarily end or might even worsen. I deliberated from within an intimate realm of suffering to which objective reason had no access. The first emergency physician, Dr. G, seemed to grasp the tension between my fearful pain and my desire to live. He spoke to me, and tried to calm me. In short, he attempted to reassure me of his and of my own competence to
come to the best decision. Dr. B, on the other hand, chose not to speak to me. I knew that I was extremely vulnerable. I knew I could die. I also understood that to consent to treatment would mean that I consented to remain extremely vulnerable and give myself over to the care of the physicians around me. I needed to trust that the physician who intubated me would see me through whatever anguish lay ahead of me. Given that Dr. B made no attempt to communicate with me, I had no basis to trust her. In retrospect, I believe that if she had made even the slightest attempt to establish a rapport with me while I was conscious she may well have obtained a more substantial act of consent from me (and one that I would not have doubted later).

Relationships thus affect the quality of consent in health care decisions. Legalistic and procedural approaches to consent do an injustice to the complex vulnerability and interdependence which a patient confronts when making a medical decision. Traditional liberal notions of a rational and independent self have limited relevance in moments of actual crisis. Feminist theorists have long been critical of this atomized portrait of the autonomous self. In the medical world, as in many aspects of life, an individual is not always "in control" and thus must choose when and how to acquiesce to another's offer of assistance. The decision to undertake treatment is both a rational one based on accessible information and an act of faith in another human being. To consent to medical care is an act of autonomy which places an individual in relationship with another individual. Consent and respect for autonomy happens between people and not in isolation. The feminist theorist, Jennifer Nedelsky, speaks of a form of autonomy which is embedded in and depends upon a web of relationships. She writes:

If we imagined that autonomy and its attendant responsibility corresponded to situations where we
were in control, we would either have to imagine a situation of isolation or deny, denigrate or undermine the autonomy of others.

(Nedelsky; 1995, 55)

It is this type of understanding of autonomy which may well have facilitated a more comprehensive act of consent on my part. Even a small attempt at establishing a relationship with me might well have alleviated my overwhelming dread and allowed me to make a positive act of consent rather than a technical one.

One medical author writes that

[informed consent within the doctor/patient relationship should be less of a mechanical recitation of procedures, interventions and risks and more of a partnership, alive, evolving and requiring constant assertion of its terms of reference.

(Arboleda-Florez; 67)

My own frame of reference was that the clinic itself posed a threat along with my illness. My immediate fear of being permanently ventilated was compounded by an all pervasive dread of hospitals. Like most patients, I feared the anonymity that each hospitalization brings. I loathed having my personal identity superceded by a chartful of symptoms and psycho-social analyses of my parentless state. The clinic tended to flatten me into a two dimensional medical portrait with which I could not relate. In short, I hated becoming a disease. Furthermore, the fact that doctors often fell back on a diagnosis of "conversion disorder" (hysteria) when they could not pinpoint the cause of my physical distress, frightened and angered me.

I felt much like Tolstoy's character, Ivan Ilyich when he is repeatedly told by his physicians that there is nothing wrong with him although he knows he is dying. The doctors' denials torment Ilyich.
What tormented Ivan Ilyich most was the pretence, the lie, which for some reason they all kept up, that he was merely ill and not dying, and that he only need stay quiet and carry out the doctor's orders, and then some great change for the better would result. But he knew that whatever they might do, nothing would come of it, except still more agonizing suffering and death. And the pretence made him wretched. . . . the awful, terrible act of his dying, was, he saw, reduced by those about him to the level of a fortuitous, disagreeable and indecent incident . . . .

(Tolstoy; 142-143)

Of course, Ivan Ilyich is dying. It seems as though his physicians might know that he is direly ill but they are powerless to help. So instead, they lie to him, telling him his complaints are trifling and that he will eventually get well. In my own case, my doctors were also powerless because they simply could not divine what was wrong. Rather than thinking that I was truly ill, they came to believe that I was manipulating them. Consequently, although I struggled to breathe and move, they pretended that I was fine. I looked to them for assistance but instead received thinly veiled contempt.

During previous clinical encounters, I had known and felt the bewildered disdain with which the doctors treated me. And like Ivan Ilyich, I experienced the psychological despair and torment of having my concerns swept aside under the rubric of medical care. I loathed going to see physicians primarily because I found such visits humiliating. Submitting myself to a physician's care became a process of self-abasement. At times, I felt that I was so incapacitated and ill that I either had to submit myself or die; but, by turning to a doctor for assistance, I also knew I was yielding power to an individual who in all likelihood would not believe me.
Throwing myself on the mercy of someone who simply did not trust me — who did not trust that I was legitimately ill — become a dichotomously life-saving and self-mortifying act.

What I most feared about hospitals came true during that admission to the ICU. While I was prepared to be viewed with distaste when I arrived at hospital, I shuddered at the thought that I might encounter outright hostility or abuse. My circumspection about hospitals could only support vague and unvoiced concerns that I might one day be imperiled by clinical distrust. I understood that my ignominy in medical circles compromised the quality of care I received, but I hoped that it would never mean that I would be physically mistreated. Dr. B's brusque form of consent was only the first in a series of steps that brutalized me both psychologically and physically. More significantly, the decision to approach my respiratory difficulties as willful attempts to garner attention proved to be torturous for me. Once the tube and ventilator were removed I was in agony. Not only did the staff choose to ignore my suffering but they actually physically took part in it by manhandling and shouting at me. They withheld their skill and concern and replaced them with hostility and threats. In retrospect, I felt much like a drowning man within the throwing range of a lifeline but whom people ashore quite consciously choose not to throw it to. It terrified me to know that I was not only unworthy of medical trust, but also of medical rescue.

Consequently, within a few days of my admission, I was quite willing to kill myself rather than face the impassive judgement and treatment of the clinicians around me. Physically, I could no longer fend for myself. While I could move my hands and arms a bit, I could no longer roll or sit up. My bladder and bowels required assistance. I was utterly dependent. I couldn't imagine relying on people who regarded my ailments as illegitimate. I
could no longer bear the disbelief which surrounded me. It seemed untenable that I continue to subject myself to individuals who dispassionately watched me smolder with pain. Furthermore, it was not clear to me that these very same individuals who swore themselves to saving lives would in fact save mine.\textsuperscript{26} Suicide seemed a better option than living immobile, immersed in pain and either being ignored or maltreated by those whose charge it was to look after me. If I could have walked out I would have, but I couldn't. I was stuck. In the end, it seemed that it would be better to die than to become a virtual prisoner of a medical system which I felt was torturing me.

\textbf{The Talking Cure}

About three years after I had my first bout of paralysis, I was operated on for an appendicitis and awoke once again from the anaesthetic with severe weakness. For the past year, I had been seeing a psychotherapist who specialized in psychosomatic disorders. Specifically, he used hypnosis and analysis as a framework with which to help me cope with my ongoing fatigue and residual weakness. It seemed we had made much progress over the past several months. I began to feel comfortable with the therapeutic process; I spent much of my week either preparing for, reflecting on or, attending therapy sessions. Finally, I had a venue through which I could explore much of my familial relations and the significance of my ongoing disability. I decided to accept the diagnosis of conversion reaction (hysteria, histrionic personality disorder) and threw

\textsuperscript{26} In recalling my time in the ICU, my partner would say to me later, "And what if you had died? What would they have said then? 'Oops, we made a mistake!' Or would they have said, 'Quick, get out the case books! We have an amazing case of conversion disorder! She actually willed herself to death!'?"
myself into the psychological strategies that would make me well again. Needless to say, when I woke from the anaesthetic and found myself returned to an invalidic state, my surprise was enormous. I felt myself to be a failure. More importantly, my cynicism about the diagnosis and the efficacy of its treatment re-asserted itself.

As I recovered on the surgical ward, I could see the incredulity in the faces of the staff who cared for me. They knew that they had taken appropriate precautions to protect me from having another "stroke." Pre-operatively, a cardiologist had examined me and declared me fit for surgery. The anaesthesiologist had monitored my vitals with vigilance. And yet, I awoke in post-op with profound weakness. My psychiatrist visited the ward and demanded further medical investigations. Another MRI was ordered. But the scan proved to be negative. No one understood what had happened. While my physicians remained largely congenial, they were obviously confused. As the object of their bewilderment, I grew afraid. Not only was I utterly dismayed to be paralysed again but I also felt imminently threatened by the mysteriousness of my affliction. If no one knew what was wrong with me, no one could prevent it from happening again. I began to comprehend medicine's powerlessness in the face of uncertainty. Furthermore, I understood that if the cause of my illness remained unknown, my doctors would once again turn...
to my psyche as the root of my problem. Unfortunately, I was no longer completely convinced that a purely psychological approach to my symptoms was going to restore my health.

My skepticism rooted itself, not so much in an intrinsic distrust of psychiatry and psychotherapy, but rather in a disbelief in the accuracy of my psychosomatic diagnosis and in the merits of its treatment. Throughout my tenure as a patient, I doubted that I was truly hysterical. As much as it seemed highly likely to my physicians, it seemed highly unlikely to me that I was ill simply to garner secondary gains and attention. Nonetheless, I knew that the psychological sciences had much to offer me (if only to help me cope with a chronically difficult situation).

Given that the clinic offered me little else as a chance for recovery, I plunged into the therapeutic process. The self-exploration of psychotherapy benefitted me in many ways — after all, I pursued psychotherapy for a period of seven years. It allowed me to give voice to the injuries of my familial past and to vent my frustration with my ongoing illness. However, it also exposed me to a myriad of assumptions and techniques which I found belittling. Psychotherapy as a form of medical treatment did not avoid the pitfalls of other clinical approaches. Foremost, despite its focus on personal narrative, its analyses could be used to objectify me as a patient. Secondly, it employed broad, generalizing theoretical frameworks within which to interpret my life-story. Ultimately both of these aspects of psychotherapy diminished rather than increased my sense of personal agency.²⁹

²⁹ It is not my intention (here, or elsewhere in this paper) to take on a detailed critique of psychiatry and psychotherapy. I am fully aware that I am not in a position to comment on the teachings and internal logic and coherence of the psychological sciences. However, I do want to examine them with regard to aspects of my own and others’ medical care. I am interested in psychotherapy’s use within the practice of the medical sciences. Specifically, I am interested in instances when physicians apply psychological theories to disease and the sometimes deleterious effect that this has on patients. In sum, I delve into the psychologizing of disease as an aspect of medical coerciveness.
As I will discuss in a subsequent chapter, Sigmund Freud pioneered talk therapy as a treatment for hysterical illness. Today, talking to a psychiatrist is still seen as an intrinsic part of managing psychosomatic disease. On the surface, the subjective voice seems to predominate in this type of psychological approach. The patient’s life story appears to have the most relevance in unearthing the "truth" about the patient’s symptoms. However, what is less readily obvious, is that the patient’s story is largely interpreted by the clinician, who tries to fit life events into a complex theoretical matrix. Philip Slavney, a doctor who writes about the effective diagnosis and treatment of hysteria, states:

> Although the patient provides most of the information on which the story is based, the author of that story is actually the psychiatrist, for it is the latter who decides what will be used, what held in reserve, and what ignored. The information provided by the patient is only the starting point, and because it is often fragmentary, the author/psychiatrist must supplement it with material derived from clinical experience, theoretical assumptions and cultural themes if the requirements of the narrative form of the story are to be met. The psychiatrist defines the context that unites the story’s elements into a meaningful whole. Without that context there would be no story; only a series of episodes that neither accounted for the present illness nor afforded a vehicle for the psychotherapy that grows so naturally from this type of reasoning.

(Slavney; 165-166)

The patient’s chronicle thus becomes the object of medical scrutiny. Its validity and usefulness is measured by how it parallels the psychological models of either hysteria, conversion reaction, or
histrionic personality disorder. The elements of the patient's chronicle which confirm the diagnosis of hysteria become the focus of the physician's attention. Ironically, in attempting to weed out histrionic behaviour, the doctor creates a psychological drama of the analysand's memories and fantasies. The purpose of the therapeutic process is so goal-driven by the desire to restore normal physical functioning through its psychiatric hypothesizing that it undermines patient's autonomous understanding of his/her own life. Subjective narrative and logic is thus easily subsumed by medical paradigms. In this sense, psychological approaches to psychosomatic disease can dominate patients by imposing categorical meaning on their personal stories. Empathy can be subsumed in the attempt to eliminate troublesome somatic symptomology.

For example, in my own case, the clinical significance of my parents' abandonment of me changed over time. Originally, my physicians regarded me as a wayward offspring of a reputable family. Within a year or two, my mother and father became monstrous ogres, instantiations of an evil from which I would never recover. While I was no longer seen by clinicians as a delinquent, I now became the overly traumatized child of psychologically deranged parents. Rather than being seen as someone who survived a lack of parental affection and concern, I was seen as being someone who was familially and fundamentally neurotic and unbalanced. For my own part, I knew that I suffered greatly from my parents' absence. I knew that I tried to over-achieve in many areas of my life in order to compensate for my feelings of

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30 All of these are names employed for very similar (if not the same) disorder. Hysteria was used prior to the DSM III (1980), conversion reaction then became the appropriate terminology. In DSM IV (1994), histrionic personality disorder is now the official medical diagnosis.
unworthiness; that I looked to others for approval and; that I longed for the affection and
intimacy of a real family. Nonetheless, I also possessed a confident awareness of my own
successes and capacities. In the end, I just couldn’t believe that my whole existence should be
defined by my mother’s and father’s disapprobation of me.

In an effort to escape from the clinical stereotyping of my past, and thus of my
selfhood, I once lied about my parents when I was admitted to a hospital in which I had never
been treated. I told the staff that my parents were dead. At the time, I felt it would be easier than
attempting to justify their conspicuous absence. The concomitant shock, disapproval and
suspicion which arose every time I was asked to explain my parent’s disinterest was profoundly
frustrating. I had long ago acclimated myself to their antipathy but continually having to satisfy
others’ (particularly clinicians’) curiosity grew very tiring. This was especially true when I
experienced very serious problems such as respiratory failure. I couldn’t help but feel, as I lay in
intensive care, that my physicians’ foci should be less on my familial background and more on
the immediate crisis at hand. Unfortunately, my attempt to avoid clinical scrutiny about my past
failed. Inevitably, the medical staff discovered, through the faxing of my previous medical
charts, that I had lied. (I can only say that my stupidity in even thinking I could avoid my
familial stigma was the result of poor judgment and extreme physical suffering.) Consequently,
my doctors viewed me with even greater leeriness, for I was now an egregious liar. The clinic
had even more reason to distrust me.

As long as I didn’t fully recover my muscle strength and/or, continued to have
relapses, my psychotherapy came under constant suspicion. As I stated earlier, I began to doubt
its efficacy. My psychiatrist, on the other hand, began to doubt my integrity. Perhaps, I wasn’t
telling him all that I should. Didn’t I have more memories to share? Was I sure I wasn’t adopted? Was I sure that I hadn’t had a sexual relationship with my father? The solution was apparently to do more hypnosis and to increase the frequency of my visits. As I delved into the grey shadows of my past, I learned a great deal. But still, it wasn’t enough, because I wasn’t getting better. A year passed. And another. And another. And another. As I discovered more and more about myself, I continued to have muscular paresis and serious relapses that landed me in hospital. Perhaps, my therapist suggested, I simply didn’t trust the process enough. He concluded that I was a poor hypnotic subject because my paralysis didn’t disappear while in a trance. I argued in return that hypnosis wasn’t considered to be a reliable approach to hysteria in the medical literature. Nonetheless, we persisted. I kept a dream diary and a therapeutic diary, as well as one for my own purposes. Throughout, he continued to probe me for more memories. I felt dried up. There was nothing more I could tell. This apparently, for him, confirmed my lack of trust. At times, I felt tempted to fabricate stories in the vain belief that if I imagined them they might have an iota of relevance. Throughout the process, the persistence of my physical symptoms was evidence of the fact that I was withholding crucial narrative and insight about myself. My doctors intimated that not only was I failing to heal myself but, I was failing to take part in healing myself; (i.e., that I was non-compliant with prescribed treatment). The clinic not only viewed me as a hysterical and a failure but, now also potentially as a conscious malingering who refused to get well.³¹

³¹ Ironically, while my psyche continued to be viewed with great suspicion, the barrage of psychometric and psychological tests which I underwent indicated that my psychological picture was not that of conversion hysteria. (Atkins; medical chart) After having undergone two rounds of testing over a four year period, my physicians told me that, ‘given [my] high level of intelligence, it was quite possible that I was manipulating the tests in my own favour’ and thus, the psychometric results were deemed irrelevant.
The increased vilification of my character, along with my declining physical health eroded my confidence even further. At times my feelings of being inadequate became overwhelming. Over the period of a decade, my overall strength declined. I had four or five bouts of respiratory failure which required intubation and ventilation. For months at a time, I desaturated at night and required oxygen. I had trouble swallowing and speaking. I repeatedly got pneumonia. My joints hurt. For weeks at a time I was bed-ridden. Sometimes it took all my strength to get up and into my wheelchair to go to some new medical specialist (e.g., rheumatology, respirology, etc.) who told me that s/he couldn’t help me; that my problems were neurological. But we all knew that the neurologists thought I was hysterical; that my complaints weren’t real. Seeing a doctor became a futile and exhausting endeavor. I thus withdrew. Much of the time, I was in pain and completely enervated. Suicide began to seem like a reasonable option. My partner and I spoke to each other about the possibility of euthanasia. In my despair, I once confessed my suicidal thoughts to the psychiatric resident who was assigned to me during a hospital stay. He concluded that my euthanizing ideations were an even greater indication of my attention seeking personality. Unfortunately, he did not seem to grasp that my contemplation of suicide might be the reasonable result of becoming sicker and sicker without being offered appropriate help. I was losing hope.

As I felt my life slowly ebbing from me, both my partner and I became depressed, angry and tired. Our interactions with medical staff were often caustic. According to the clinicians, our irritability demonstrated an essential and anti-social malevolence. One doctor actually suggested that my partner was poisoning me with unknown substances just so we could
enjoy watching the physicians puzzle over the severity of my symptoms. \(^{32}\) (Little did it occur to her that my illness began a full five years before we even met.) In short, my relationship with the clinical establishment became one of such deep suspicion and antagonism that whenever I collapsed into respiratory failure, my partner and I would wonder whether it was worse to allow me to suffocate to death or, to call an ambulance and have me re-immersed (at a time of complete vulnerability) in an environment of abiding hostility.

Ultimately, the psychologizing of my illness yielded little clinical benefit. While I certainly profited from the insight that psychotherapy afforded, it did not alleviate my physical symptoms. As a result, in some ways, it contributed to my sense of failure. In focusing on the apparent power I had to heal myself, it created enormous self-doubt when I failed to do so. The loss of confidence was damaging in that I needed as much emotional strength to cope with my physical deterioration. While my first therapist encouraged me to yield myself to his care, I found that he was a poor substitute for the emotional sustenance of an actual family. Psychotherapy promised me more than it could, in fact, deliver. It encouraged me to be psychologically vulnerable without provide substantive means to support that vulnerability. This left me doubly exposed. As I became critically ill, my second psychotherapist — I left my first therapist after 4 years — confessed that there was little he could do to alter the clinical perception of me although he believed that I was not hysterical. ('Other medical specialists,' he said, 'Don't hold psychiatrists in very high esteem.') I finally withdrew from psychotherapy when my

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\(^{32}\) This physician suggested that my partner was suffering from Munchausen's syndrome by proxy; i.e. an extreme form of hysteria in which a care-giver surreptitiously makes the patient ill in order to garner sympathy for them both.
physique was so depleted that the comfort I derived from the sessions was overawed by the exertion it took to get to them.

Unfortunately, while psychotherapy soothed me in some ways, it offered me a false hope. Not only did it not provide me with tangible, physical results, it contributed to my declining self-esteem. It made me acutely aware of my own (and of my psychiatrist’s) impotence. Further, by employing my familial and social history as evidence of my innate psychological instability, it denigrated my sense of personal agency even further. In the end, my experience of psychiatry proved disappointing. Moreover, I began to view it as a potentially coercive aspect of my overall health care, particularly when it tried to criminalize my own and my partner’s personae.

Looking Forward — The Next Chapters

My own experience of the clinic has led me to be interested about the nature of power as it is exercised in medical practice. As a political scientist and as a patient, I am all too aware that the invocation of patients’ rights under the guise of bioethics cannot adequately mediate the complexity of medical relationships. While the power of the clinic to cure is awe-inspiring, its tendency to subjugate patients is worrisome. Medicine possesses a puissance that is grounded in both its tangible and psychological authority to combat disease. Physicians’ approaches to disease are often couched in battle imagery. But while doctors appear to be taking on an abstract disease entity, they frequently censor and violate patients in their attempt to vanquish the enemy. Patients thus often feel belittled and impotent when they submit to medical treatment. The curative act is not necessarily a definitive or pure act of goodness. It overtly and
covertly violates the subjectivity of the patient. As a result, I want to draw attention to and explore the coercive elements of medicine — to unveil the obscure malevolence which lies beneath the obvious munificence of medical diagnosis, treatment and cure.

In the next chapter, I look at the distinct narratives that emerge out of illness. I address, in particular, the enormous gulf between medical accounts of disease and patients' narratives of illness. The divergence of chronicle is poignant primarily because medical sciences exert tremendous power over patients. The objectified intent and discourse of the medical chart supercedes the subjective understanding and expression of the patient. In an interview referring to the prerogative of science and medicine, Foucault speaks of the regime of scientific statement. The politics of scientific statement is "... not so much a matter of knowing what external power imposes itself on science, as of what effects of power circulate among scientific statements, what constitutes, as it were, their internal regime of power..." (Foucault, FR; 54-55) Foucault's main point here is that contemporary conceptions of truth are centred in techno-scientific rhetoric and convention. Science and politics interpenetrate one another. With regard to the clinic, medical science possesses a monologic and unchallenged power. There is little room for theoretical conflict because the procedural objectivity of science generates what is apparently "true." The singularity of medical "truth" dominates patients.

In confronting the realm of sickness and medicine, we are perennially faced with a tension between the objectified account of the medical chart and the subjective story of the ailing individual. The enormous descriptive discrepancy which separates these two types of narratives indicates the gulf of understanding which exists between physicians and patients. The divergence of reason and narrative characterizes the break down in relationship which often
exists between patients and practitioners. But while patients may try to resist the objectifying gaze of their health care providers, the clinic’s curative ability rests largely on its objectifying (scientific) capacities. The subjective voice of patients has an integrity which is thus suppressed in the medical environment.

In my third chapter, I examine hysteria as an extreme but trenchant example of the dissonance between doctors and patients. I address the issue of psychosomatic disease as a trenchant example of not only the gulf which separates clinical and lay interpretation of illness, but also of the coercive force of medical scrutiny and diagnosis. According to medicine, hysteria is primarily a disease of appearances. The patient *appears* to be suffering from a serious ailment, but is, *in fact*, not. Scientific tests cannot prove that a disease process exists. The patient, on the other hand, suffers genuine physical complaints and *knows* that an illness is present. Hysteria thus presents a remarkable inter-penetration and clash of appearances and truths. On the one hand, the patient experiences symptoms which s/he believes are real. On the other hand, the physician (after much clinical investigation) believes that the patient’s complaints are illusory. Hysteria thus produces a situation in which doctor and patient try to grapple with an illness from explicitly and diametrically opposed perspectives. Yet, inevitably, the clinical judgement achieves ascendancy. The subjective truth of the patient must yield to that of the practitioner if a cure is to be hoped for. The patient abandons his understanding of reality (even though his/her body indicates otherwise) and tries to adopt the objective reasoning of the clinic. In this way, the patient is forced to deny his/her self in order to receive medical care. This renunciation constrains the individual at a most fundamental level. However, if the patient does not recover, his/her truth is never fully suppressed. Plato’s parable of the cave is illustrative here. Medical science can
provide truths about the objective world, but it cannot furnish truths for a realm which it does not know or see.

Ultimately, it is medicine’s tendency to dominate while doing "good" which thus intrigues me. Although it provides effective treatments for human ailments, it also exerts a coercive force. As a political scientist, I remain concerned about the clinic’s clumsy and sometimes misguided exertion of power over patients. In my own experience, it is the coercion of medical processes under the guise of benevolent egalitarianism which troubles me. Moreover, the preachings of bioethicists and the language of rights’ do little to alter the asymmetrical power balance in clinical relationships. If anything, they simply mask the coerciveness of medical observation and diagnoses.\textsuperscript{33} I wonder whether the force of medical intervention will ever be able to successfully accommodate the reason and narrative of patients. Plato’s belief in the dialectic of reason along with feminists’ use of the subjective voice are instructive here in that they goad me into pondering whether dialogue, rather than scientific monologism, can be implemented as an approach to human ailment.

My final chapter resumes the subjective narrative of this chapter. It resolves some of the mysteries of my medical journey. But it also raises questions about the political nature of health care provision. It discusses the power matrices that are imbedded in medical practice and attempts to raise the possibility for political change in the clinical environment.

\textsuperscript{33} I am concerned when I see six week "ethics" courses offered to doctors at prestigious universities; i.e. the graduates of which return to their communities to become the prevailing experts in the delivery of ethically sound medical care. I think that these type of endeavors are a reflection of medicine co-opting a philosophical mandate.
Chapter II
Narrative Divergence

Introduction

The first thing I remember is not being able to see. My eyes were open; at least it felt that way. But I couldn’t be sure because I’d just woken up. My eyes shifted heavily. I shut them and waited a little. A voice urged me, "Dear! It’s time to wake up now." I opened my lids again and saw only opaque shadows moving above me. "Wake up dear! Wake up! -- What’s her name?!" I heard my name over and over, sometimes gentle, sometimes insistent. "Open your eyes!"

Jesus, I thought, my eyes are open. And then I realized I couldn’t see clearly. The world was underwater; blurred and unfocused. And then I felt hands laid upon indistinct parts of my body. "Hhhaa!" I called out, my tongue lolling heavily in my mouth. "Aaaah plann nn seeee." My tongue laboured in the cavern of my mouth. Hands deftly bound my body with sheets and slung it through the air onto another stretcher. I smelled the hiss of oxygen on my face.

Sometime later, a male voice persisted through the gloom, "Squeeze my fingers."

I squeezed his index and middle fingers.
"Squeeze them!"

What! Squeeze them? I just squeezed them! The fingers of my right hand reached out, groping for his hand. They searched the blanket and lunged at the dark shape in front of me.

"No. No, with the other hand. Your left hand. Squeeze with your left hand!"

My left hand. . . Where was my left hand? . . . Finally, I felt his hand in mine. Thank god. I squeezed with all my strength.

"Now I want you to do it harder than that. Do it harder!"

At the same time, I wanted to yell, 'Not my hand, you idiot! My eyes! I can't see. It's my eyes!' I swore vehemently within me. I grasped his fingers simultaneously trying to twist my body away from his vociferous authority.

"Okay. Sit up." His dark form hung over me.

I threw my head forward but my chin rolled heavily to one side and my chest sagged heavily against the mattress. Profanities welled up inside me. I grabbed at the bedrail with one hand and pulled. I slid awkwardly onto my right elbow.

The masculine voice decreed from above, "Sit up."

I tried again but my torso rolled softly away. A man's forearm gathered me at the shoulders and drew me in a sitting position.

"Raise your left arm. . . . RAISE your left arm!"

I felt something cool and dead-fish-like lying on my right thigh. I pushed it away.

"Don't use your other arm, raise it yourself!"
Desperately, I reasoned 'Other arm? Other arm. Yes. Two arms. I have two arms.' I knew that I should know that I had two arms. I should have seen and felt them. Panic seared through me.

A warm palm touched me. I felt the pad of his thumb against my wrist. He lifted the arm in front of me. I could feel it. "That's right. That's right. Hold it higher. . . . Try again, hold it up. . . . Now shut your eyes and keep it there."

With my eyes closed it disappeared.

"Okay now, you can open them."

I looked but the shadow-arm-thing wasn't there. The thing, my arm, was down by my leg, near the sheet.

"Okay." He straightened up. "Oh yea, I'm Dr. A. I'll be looking after you." He patted the bed with his notebook as he turned to leave," I'll see you later."

A few hours later, more physicians arrived. Without introduction, they stood around my bed, the sheets pulled back, my body laid supine before them. Again insistent voices asked me to move, sit, see, feel, speak. Their silent scrutiny unnerved me. The uncooperative oddity of my body embarrassed and frightened me. My body had lost grace, a grace and power that I had presumed would never elude me. And now I lay sandbag-like, fighting the weight of inertia that seemed to encase my limbs. I desperately wanted to believe nothing was wrong. If I wished and worked hard enough, the veil of incapacity would suddenly lift and all would be well again.
I wrote these passages approximately two years after I suffered an apparent stroke at age twenty. The hospital chart describes the same event:

Approximately within 12 hours post-anaesthetic it was noted she had onset of left weakness. . . . Repeat CT of the head approximately one week later showed luxuriant perfusion in the right parietal area. No clear infarct was seen.

My description contrasts sharply with that of the medical record. The form and content of each of these narratives could not be more distinct.¹ My own description is one which Arthur Kleinman calls an "illness narrative." It embodies an attempt to both explain and simulate my experience during the first few hours of my infirmity. Conversely, my medical chart is composed from a variety of sources: nurses, therapists and physicians (among others) who notate clinical observations, test results, problems and abbreviated details of my life. It is the manifestation of what Foucault aptly calls the clinical gaze (Foucault, Birth.; passim). In our society, people who become ill, more often than not, become 'patients' of the medical system. In this sense they are subjugated not only to whatever ails them but also to those who care for them. Despite the immediacy and poignancy of patients' experiences and narratives, the dry observations of charts dominate patients' lives when they are ill. The language of the medical record supersedes all other discourse. It discloses information about a patient and it consequently directs (and records) treatment. As medicine becomes increasingly driven by seemingly objective tests and imaging, the subjective world and testimony of the patient recede. The medical narrative diverges more and more from the illness narrative. Its words transform and overtake those of the patient.

¹ For example, I felt the paralysis immediately upon waking from anaesthesia whereas the clinicians noted it as occurring within 12 hours of my waking.
Despite the clinical intention with which they are composed, charts are political documents. As such, they can come to represent a power exercised over others for an apparent good.

**The History of the "Gaze"**

To my knowledge, no one has attempted a history of medical record-keeping. Michel Foucault perhaps comes closest to a chronicle of medical iconography in his work *The Birth of the Clinic*. His book professes that the origins of medical observation and discourse lie in the latter half of the eighteenth century. While Foucault presents a compelling argument, the nineteenth century could also be considered a seminal moment for the modern chart.² The advent of the "germ theory" of disease, between 1870-1900, meant that record-keeping played a pivotal role in the diagnosis, treatment and social control of sickness. By the twentieth century, charts became central to patient care. Physicians’ ability to probe the body with chemicals, needles, scalpels, scanning equipment, etc. required increasingly more sophisticated methods of notation and interpretation. Consequently systematized approaches to information gathering and recording appeared. Today, computerization hopes to further revolutionize medical record keeping by aiming to produce ‘paperless’ charts.

In *The Birth of the Clinic*, Michel Foucault writes about the eighteenth century roots of clinical thought. Specifically, he analyzes medicine during and after the French Revolution.

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² The medical historian, Pauline Mazumdar, directed me to Karl Wunderlich who undertook a study of patient temperatures in 1871. His notes might well have been the first effort to produce clinical data. She suggested that Wunderlich might be thought of as the first physician to undertake charting in the manner that we understand it today.
While the new state originally dictated that hospitals were no longer required in a nubile realm of political liberty, physicians nonetheless continued to develop medical science both despite the prohibition and, because of the new regime (Foucault, Birth.; 32-36). In the end,

... in liberty, disease was to formulate of itself an unchanging truth, undisturbed, to the doctor's gaze; and society, medically invested, instructed and supervised, would by that very fact, free itself from disease.

(Foucault, Birth.; 51)

The purity of the new republic's political ideology apparently foreshadowed the inevitable physical purity of its people. The new political consciousness provided the climate for two critical events in the development of positivist medicine: (i) the emergence of a way of seeing and speaking specific to physicians and, (ii) the breaching of the social interdiction against post mortem.

Foucault refers to the emergence of the new form of perception and language as the "speaking eye." (Foucault, Birth.; 114) According to his analysis, physicians began to possess an articulate vision which both 'sees' and 'speaks.' It was the collapse of Speech and Gaze into one action that allowed medicine to simultaneously observe and classify illness. "The clinical gaze has the paradoxical ability to hear a language as soon as it perceives a spectacle."

(Foucault, Birth.; 108) The ability to speak disease into existence was pivotal in the history of medicine. The merging of two functions into one all-knowing act of language and sight meant that medicine experienced a power over disease (and patients) that it heretofore lacked. "The gaze is passively linked to the primary passivity that dedicates it to the endless task of absorbing experience in its entirety, and of mastering it." (Foucault, Birth.; xiv) The simultaneity of perception and language receded the individual patient to the periphery of medical knowledge.
Disease is perceived fundamentally in a space of projection without depth, of coincidence without development. There is only one plane and one moment. (Foucault, *Birth*.; 6)

As Foucault’s conceptualizes it, the "gaze" reduced symptoms into signs which were in turn to be read as disease. A collection of observable signs replaced the human body. Illness preempted the individual. The patient became a text to be read, absorbed and judged (Foucault, *Birth*.; 121-2). This text was housed physically and temporally within the medical clinic — for it did not exist outside it. Medicine’s discursive sight thus relied heavily on the availability of a space within which it could practice. Hospitals provided both the actual and conceptual space for physicians to observe, record and talk. The clinic served as a locale in which sickness could be observed uncontaminated by the natural and social worlds. It acted as a haven from outside influences which might adulterate the appropriate progression and study of disease. It thus furnished a free and endless domain in which the absolute truth of an illness could be allowed to surface on the body of a patient. And invariably, the body was that of an impoverished man or woman.

. . . [I]t is the interest paid by the poor on the capital that the rich have consented to invest in the hospital; an interest that must be understood in its heavy surcharge, since it is a compensation that is of the order of objective interest for science and of vital interest for the rich. The hospital became viable for private initiative from the moment that sickness, which had come to seek a cure, was turned into a spectacle.

(Foucault, *Birth*.; 85)

A poor patient could not refuse to submit to the authority of the clinic without offending society. For the community had a vital interest in the diseased body; in its capacity as an object to teach about human infirmity.
By the early 1800s, the diseased corpse offered physicians a unique glimpse of human frailty. Foucault believes that the defining moment of modern medicine arises from the moment the clinicians could legitimately experience the anatomical gaze. (Foucault, Birth.; 146)

In the new liberty of the French Revolution, the state no longer objected to autopsies. Consequently, post mortems became common practice within teaching hospitals. "Death, which, in the anatomical gaze, spoke retroactively the truth of the disease, makes possible its real form by anticipation." (Foucault, Birth.; 158) Death was the fruition of disease. It was a surveyable landscape from which to observe the ultimate signs of human malaise. The dead body provided a dissected and tangible portrait of the course of disease in the living. Visible symptomology thus receded in importance as patients and diseases were reclassified according to normally invisible signs of pathology. Death became the locus of fixed truths and doctors were the arbitrators of these truths.

The development of the clinic and its morbid gaze thus meant that increasingly the material individual was lost in a conceptual grouping of signs which in turn was overtaken by a larger category of disease. The patient thus became a medium of discovery and articulation for medical science.

The locus in which knowledge is formed is no longer the pathological garden where God distributed the species, but a generalized medical consciousness, diffused in space and time, open and mobile, linked to each individual existence, as well as to the collective life of the nation, ever alert to the endless domain in which illness betrays, in its various aspects, its great, solid form. (Foucault, Birth.; 31)

The ill individual became the communicative body over which the physician hoped to gain mastery. Ironically, with the growth of political liberty, sick individuals began to be dominated
by a medical nosology that required less and less of their participation. They were subsumed by a system which understood them to be important only in the manner in which they evidenced the frequency of pathological facts.

The potency of the clinic relied on a command of observation, perception and language which was unique to itself. "...[T]he gaze that sees is a gaze that dominates, and although it also knows how to subject itself, it dominates its masters." (Foucault, Birth.; 39) A political alliance thus formed between parole (speech) and regard (observation) which promoted a positivist approach to human ailment. It resulted in a culture in which facts dominated experience. Only that which could be observed, notated and classified existed in the new medical cosmos. The subjectivity of illness disappeared in the clinic. The gaze subjected itself only to the facts which emerged through a multiplicity of signs occurring in the bodies of both the living and the dead.

Ironically, this positivism of the eighteenth century cast a pall on the medical culture of the early nineteenth century. The clinical gaze demanded facts. Unfortunately, little evidence existed that physicians could, in fact, heal illness. Despite the availability of drugs which could induce nausea, diarrhea, perspiration and the relief of pain, symptomatic pharmacopoeia could not be proved to cure. It was felt by many that the body would heal itself in time, or die — with or without medical intervention (Rosenburg; p. 4). The clinic adopted a less aggressive posture toward sickness. Aware of their apparent impotence, practitioners focused on therapeutic intervention in which treatment was administered more for the patient's and family's relief that something was "being done" than for its curative nature. During this
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period, medicine thus possessed an empirical consciousness that was *dubiously* aware of its incapacity.

The clinic's penetrating glance would finally be rewarded in the latter part of the century with the rise of bacteriology. Between 1870-1900, bacteriologists made a number of discoveries which led to the creation of the "germ theory" of disease. Two schools of study emerged: one in France under Louis Pasteur and the other, in Germany, under Robert Koch. Both groups of scientists undertook remarkable experiments during this period with a variety of bacteria. They achieved stunning results. Pasteur developed the anthrax vaccine in 1881 and rabies vaccine in 1885. Koch's experiments resulted in the discovery of the tuberculosis bacillus in 1882 and the cholera bacillus in 1883. Klebs and Loeffler identified diphtheria in 1883 and 1884. The postulate that germs were largely responsible for disease revolutionized medicine. With the aid of bacteriological science, doctors adopted a more assertive approach. No longer satisfied with the dissecting gaze of their predecessors, physicians stimulated the body with vaccines and inoculations. The body's immune response to injections of attenuated bacteria, in turn, vanquished malady-causing microbes. Illnesses that had ravaged populations could now be identified and conquered by physicians. Consequently, medicine achieved greater potency, greater positivism and greater prestige.

New medical power relied heavily upon coordinated efforts between practitioners, bacteriologists and public departments of health. Doctors needed to be educated about scientific

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endavors. Once educated, they required the proximity of laboratories that could both test patient swabs and produce serum for their practices. Government departments often had to fund and oversee the distribution of vaccines. Quality control was essential. Serum tended to lose its effectiveness if stored for any length of time, or if exposed to extreme temperatures or light. Death could easily result from impurities. Boards of health closely oversaw the production and administration of antitoxins. They required that doctors submit reports not only on the outbreak of diseases such as cholera, diphtheria and tuberculosis but also on the course of treatment adopted for such cases. Local jurisdictions often conducted annual surveys and compiled statistics on physician behaviour. They required physicians to document outbreaks and frequencies of diseases. Doctors also had to accurately report about the efficacy of the new vaccines. Officials sought compliance with laws demanding the use of serums. "Only under pressure from public health authorities and the public would the doctors agree to try diphtheria antitoxin or report TB cases." (EHrenrich & English; p. 88) Given that bacteriologists developed antitoxins which battled the most prevalent diseases, governments were inevitably drawn into germ theory medicine. Public health was after all their concern. Consequently, specific bureaucracies arose to cope with the developments in science and medicine. These offices

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5 As was the case in St. Louis when doctors unwittingly administered contaminated diphtheria antitoxin to a group of youngsters who then all died (Ziporyn, 1988; 57).

6 "Traditional sanitary measures were carefully enforced by Philadelphia's Board of Health. In conjunction with other interests in the city government, the board succeeded in getting streets paved and having proper drainage installed. The waste removal service for much of the city was improved, and through constant surveillance of all parts of the city, particularly in the summer time, by the police force, acting as supplementary sanitary inspectors, breaches of sanitary law were identified." (Liebenau; p. 218) Interestingly, the 1900 Annual Report of the Provincial Board of Health of Ontario (printed 6 years after the discovery of diphtheria antitoxin) attributes the decline in the frequency of contagious disease to the use of germicides and to water supply cleanliness. The Board kept rigorous track of rural and urban communities' laboratories, vaccine supply, sewer construction, isolation and decontamination techniques.
required medical notations and reports in the aid of the creation of statistics about communities' health. Further, they used the medical record as a method of constructing and enforcing particular clinical practices. Thus the purposes of medical discourse moved beyond the scope of the clinic and became one of legal obligation to the public domain.

The wide acceptance of germ theory also signaled the convergence of science and medicine. Medical positivism found fertile soil in scientific thought. To be successful, a doctor had to perform two roles: that of the practitioner and that of the scientist (Russell; 107). The enormous achievements of the bacteriologists turned the laboratory into a sacred space. "The laboratory was the temple of objectivity from which science could survey the world of man and nature — a kind of 'germ-free zone' separated off from the filth, commercialism and cheap sentiment of the world." (Ehrenreich & English; 77) Metaphorically, medical science came to stand for that which was clean and pure. The reduction of sickness to a stain of bacillus took an evangelical quality. The locus of study was removed from the body itself and moved to a more perfect realm: the laboratory. Medical facts emerged in the absence of the incarnate patient. Physician observation and discourse took place (for the most part) separate and apart from the ailing body. It is at this juncture that medical discourse moved away from the sullied dependency on symptomology7 and into the righteous reliance on quantifiable fact.

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7 Here I define symptom as a subjective complaint or sign made by the sufferer.
The Modern Record — SOAP

Today, at the end of the twentieth century, the increased use of laboratory sciences as well as technology has meant that medicine is even further removed from the body. While physicians still examine patients, they likely trust tests and/or scans to provide the most meaningful information. Diagnoses are made on the basis of lab results, electrical tests and, radiological and magnetic imaging. In this context, medical charts notate fewer and fewer symptoms and more and more clinical data. Temperatures, blood pressures, and, respiratory and heart rates are constantly monitored. They are all written down and logged on graphs. Blood is tested, not just once, but often on an hourly or daily basis. Innumerable parts of the body can either be biopsied or analysed at the cellular level (e.g., muscle tissue, bone, organs, blood, urine, semen, cerebro-spinal fluid, etc.). Numerous subsidiary professions have arisen to meet medicine’s increased technology (e.g., physiotherapists, occupational therapists, nutritionists, technicians, psychologists, etc.) Furthermore, different physician sub-specialties look after compartmentalized areas of the body. Consequently, an array of personnel and documentation compose the clinical experience.

Understandably, a distinct system of record-keeping must be adopted to keep details in order. One medical textbook states: "Because of the medical record’s complexity . . . . [It is] a road map of potential patient care problems. The record should be well organized, easy to read, and accessible to all." (Mastering Documentation; 3) A hospital generates an enormous number of reports during any one stay. Various types of chart-keeping methods proliferate modern health care. The most common are POMR (Problem-Oriented Medical Records), PIE (Problem, Intervention, Evaluation), Focus and CBE (Charting By Exception). The majority of
approaches organize information around identified problems and not necessarily by symptom. Most of them incorporate the SOAP(IER) technique which stands for Subjective, Objective, Assessment and Plan (Intervention, Evaluation, Rehabilitation). Subjective is the section reserved for transcribing the statements and complaints that a patient makes regarding an identified problem. Objective encompasses the apparently dispassionate observations of the health care worker. It is the current manifestation of Foucault's eighteenth century gaze. It is the naming of things in a clinical and disinterested manner. Assessment is intended to be the evaluative area of the record, providing a summary of the situation and a conclusion. Plan outlines the treatment plan or intervention. This method can thus identify and record any number of problems on any given patient. New advances in charting propose an "integrated" method in which each health care professional comments simultaneously on each of the problems identified by SOAP(IER). Finally, in addition to hourly handwritten notes in SOAP(IER) format, a medical record contains a variety of other papers, such as a medication administration records, graphs, laboratory, pathology and imaging results, consultation notes from other specialists and, discharge planning notes (among many others). Hospitals increasingly use computerized databases to track all of this information. The medical narrative, for the most part, is barely chronological, rather its structure consists of a gathering of objective findings into a visual format. This format is arranged so that apparent trends in the data can be easily reviewed, analysed and discussed.

The communication of information has become paramount in health care. Ironically, the emphasis is not on communication between patient and practitioner, but between health care professionals. And for the most part, nurses, not doctors, create the majority of chart
entries. Medical discourse is no longer the sole domain of the physician. It has become somewhat removed from the proprietorship of the doctor. All those who come in contact with a patient must document the interaction. Medical language serves the larger community of health care. On the other hand, while the chart is often a primary means of communication between staff, the physician retains primary authority over the record, and thus over the patient. S/he possesses the unique ability to write orders. Orders consist of physician directives. They have absolute power in the chart. They preside over other health care personnel and patients alike. There is no greater potency in the hospital — except, perhaps, for the law.

For both scientific and legal reasons, everything must be written down. Notating is not only necessary for the communication of scientific fact but also legal fact. In this sense, the record stands as both a professional and a legal narrative. Its discourse is self-consciously aware of the possibility of judicial intervention.

"You write defensive explanatory notes in the chart with one eye on peer review, the other on a potential jury trial."
(Winterhouse in Kleinman, LN; 217)

Textbooks on medical documentation almost always highlight the possibility of malpractice suits. The general provision is 'that if it isn’t written down, it didn’t happen.' According to the law, medical records do not interpret events, they witness them. The medical narrative is thus

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8 "As was demonstrated in a study in 1972 in Scientific American, the deterioration in the physician-patient relationship has in large part been responsible for the changing attitudes of the public, who are now more willing to sue physicians when something goes wrong." (Sharpe; v)

9 In law, the convention of the chart acting as witness has proved to be tautological. If patients suffer incompetence at the hand of their physicians, they may seek recourse in the courts. The chart becomes pivotal at this point, for it is, legally, the primary and objective witness. In reality, however it is composed by the clinicians who treat the patient. The plaintiff’s lawyer must thus treat as fact the very record whose author is suspect.
not only a scientific endeavor but also a legalistic one. The notation of scientific and
technological fact passes from the realm of the clinic and lab to that of the evidentiary fact of the
court. Documentation possesses an authority in itself. It is a potency that exists independent of
both the observer (the physician) and the observed (the patient).

In the modern medical record, Foucault's positivism has been carried out to its
fullest purpose. Medicine's gaze finds its dispassionate voice in the chart. From the advent of
the post mortem through the rise of bacteriology and the consequent need for statistical record
keeping to the increased use of technological and clinical data, the chart has become increasingly
more complex. Moreover, it has moved further and further away from the realm of the subjective
account of the patient in anamnesis.\(^\text{10}\) The chronicle of illness has been overtaken by objectified
facts and discussions of disease.

The Idiosyncratic Language of the Chart\(^\text{11}\)

Not surprisingly, the record exhibits a particular vocabulary that remains quite
distinct from that of the general population. Foucault writes:

> The clinic — constantly praised for its empiricism, the modesty of its attention, and the care with which
it silently lets things surface to the observing gaze without disturbing them with discourse — owes its
real importance to the fact that it is reorganization in depth, not only of medical discourse, but the very
possibility of discourse about disease.

(Foucault, Birth., xix)

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\(^{10}\) Anamnesis quite literally means the 'recalling of things past.'

\(^{11}\) My familiarity with the language of chart-keeping comes not only from reading my own medical
records but also from the chart review which I conducted during my master's research on resource allocation in an
urban cardiac unit.
In the clinic, intimacy becomes transformed into distance and judgment. The reduction of illness to disease and, in turn, to fact requires judgment. This judgment determines what is important or real in medical terms from what is unimportant or nonexistent. "The [medical] glance is silent, like a finger pointing, denouncing." (Foucault, Birth.; 121) The denunciation is without rancour but is nonetheless hostile to the contextuality of the world outside and prior to disease. Its recorded perceptions are largely inaccessible to lay people and are both consciously and unconsciously shrouded in secrecy. Latinate words and acronyms appear throughout (as they have done for the past two hundred years). Scientific and technologic terms appear as well. Consequently, the language of the clinic diverges from that of the general populace. The privileged learning of the clinic not only dominates through the power of its gaze and the strength of its positivist culture but also through a language which is largely incoherent to non-medical persons.

Although Latin is a "dead" language, it remains a vital part of much professional vocabulary. Law, medicine, the academy and the church all employ Latinate phrases. Historically, it is a language which has been associated with knowledge and power. For centuries ordinary people could not read books or understand religious services because they were composed and spoken in Latin. Only those with the appropriate learning and social standing could comprehend the law, anatomy and written texts. The continued use of Latin in medicine is thus a remnant of a period in which social hierarchy was paramount and when the withholding of knowledge from common folk was an acceptable practice. The continued use of Latinate short

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12 For example, a defining moment of the Roman Catholic church in the twentieth century was its decision to begin to conduct mass in secular languages rather than in Latin.
forms, words and phrases in the clinic form an effective barrier between physicians and patients. It encourages a privileged type of discourse.

And even when clinicians use English, ordinary words can become transformed within the medical setting. Scientific and technical language can obscure the everyday meaning of what is being discussed and recorded in patient’s chart. Moreover, short forms abound in the clinic. For example, *b.i.d.*, *t.i.d.* and *q.i.d.* are acronyms for two, three and four times daily. *P.O.* and *N.P.O.* stand for ‘by mouth’ (*par os*) and ‘nothing by mouth’ (*non par os*) respectively. Understandably, these initials are largely incomprehensible due the fact that they are derived from Latin. Nonetheless, English short forms exist which remain unintelligible to the lay person. For example, *R/O* means ‘rule out;’ *SOBOE* translates as ‘shortness of breath on exertion;’ and, *CHF* replaces ‘congestive heart failure.’ These are examples of some of the innumerable ways of expressing medical terminologies in shorthand. These methods save time for the professionals who both record and read notes. However, in creating a narrative which is abbreviated in both form and content, physicians fashion a chronicle which is endowed with an altered significance from the patient’s perspective.

For example, to indicate that a question has been asked and responded to in the negative, doctors employ the word "denied." (Doctor: "Do you have pain?" Patient: "No." — This interaction is noted in the chart as: *Patient denies pain.*) Outside the clinic, "denied" implies a host of things. The phrase "Patient denies pain" could be interpreted as the patient *will not admit* to pain, and is thus suspicious or untrustworthy. Or perhaps it could be seen as the patient...
is in denial, and thus cannot know or articulate him or herself accurately. Other terms such as "insufficiency" and "failure" also occur regularly. These usually are meant to mean less than normal or a cessation of function. Nonetheless, they could imply a lack of character or will, if not on the part of the patient, on that of the body.

Further, violent metaphors abound. Sometimes it is not clear whether the doctor conducts an all out attack on the disease or the patient. For example, in discussing cancer therapies, Susan Sontag writes:

Treatment . . . has a military flavor. Radiotherapy uses the metaphors of aerial warfare; patients are "bombarded" with toxic rays. And chemotherapy is chemical warfare, using poisons. Treatment aims to "kill" cancer cells (without, it is hoped, killing the patient). (Sontag; p. 65)

Moreover, the brutal language of the gaze can also unwittingly portray the patient as unreliable, unable and guilty. To return to Foucault, medical language has an aura of righteousness. As a result, the patient can seem to fall under suspicion, or even outright hostility. This happens when the idiosyncratic language of the text manages to colonize the patient’s experiences through its objectifying, alienating and sometimes violating terminology. The dispassion and militarism of the medical effort to fight disease progresses until it is metaphorically transferred onto the ill individual. The patient becomes the disease who is also the identified enemy. It is at this point that medicine oversteps its valid purpose and commits a moral-political harm.

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13 Of course, "being in denial" comes from psychology and psychiatry, medicalized professions themselves.

14 I believe that a whole paper could be devoted to the unconscious metaphor and sometimes quite deliberate descriptions of charting language. The inherent violence of medical narrative becomes apparent during even the briefest perusal of medical records.

15 Please see Appendix A in which I show examples of a consultation sheet in which notable, but not exceptional language appears.
Of course, there is a valid reason for the brevity and apparent dispassion of the medical record. Foremost, the medical narrative has a specific and purposive relationship to medical observation. To a large extent, observation and the need to elicit and record information structures much of the notation. As a result the chart serves the clinic's objectivity.

The aim of medical discourse is always to eliminate or control the purely personal and subjective, whether its source be patient or physician, so that the physical anomalies that characterize a [disease] can receive the attention their successful treatment requires. (Hunter; 52)

The identification of disease necessitates a distancing from the subjective self. It requires a re-narration of the patient's story so that it can be notated and interpreted by scientific standards.

The medical chronicle overreaches the patient's account in order to produce a case which permits diagnostic generalizations. Narratives about disease are constructed through the apparent neutrality of positivist methodology. In the end, however, the efficacy of clinical objectivity demands a discourse that distances and dehumanizes the very people at whom its services are directed: the ill.

In its scientific and technological rigour, medical discourse has removed the embodied patient from its view. Not only has the actual person long disappeared, but so has the body. It is reconstructed as a database of facts. And hospitals employ computers to compile, maintain and retrieve these databases. Thus, the production and notation of evidence happens

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16 On a more personal scale, one socio-linguist postulates that physicians sometimes employ dispassionate vocabulary because they "have a compelling need to maintain emotional equilibrium in the face of illness and death." (Ainsworth-Vaughn; 183)
largely in the absence of the patient. Although physicians may still conduct physical exams and interview patients, their medical narrative is removed from the subjectivity of the ailing self. The symptomology of the body is no longer considered to be an intimate self-conscious state rather it is viewed as an object of evidentiary investigation. When consulting with one another, specialists tend to depend upon the chart as a guiding reference rather than relying on the diseased body or ill person for direction. Clinicians analyse, discuss and treat with little or no contact with patients. The medical record supersedes the actual patient. The body is no longer at the centre of the gaze, it is instead peripheral. From an extreme perspective, it would seem almost possible for a chart to exist without an embodied individual. The medical narrative thus possesses a prima facie force all its own. It represents both a scientific and legal consciousness that depicts the patient as other. Given modern medicine’s extraordinary, scientific ability to treat disease, the objectivity of the discourse predominates. The physical suffering that initiates the discussion can thus become obscured. Medical narratives that define and determine care thus exist separately from, and outside, the experience of patients.

**Devotions on Emergent Occasions**

Despite the current preeminence of techno-medical discourse, patients have nonetheless created narratives about their experiences of illness and health practitioners for centuries. Inevitably, mortal ailments plague all lives, regardless of class, gender or power.

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17 This may seem to be a harsh criticism but it is one derived from my own experience in which many, but not all, consultants have presented themselves with their heads bowed over the chart in hand and given me only a perfunctory physical exam. On the rare occasion, I’ve even received changes in orders without having ever met the prescribing physician.
Consequently, it proves to be a universal theme. And sickness is the source of inspiration for many works of art. Whether in paintings, plays, films or books, humans try to capture the peculiar and sometimes absorbing sphere of ailment. Innumerable pieces depict the exigencies of illness (everything from Goya’s painting Diphtheria to Mann’s The Magic Mountain). And despite the clinic’s apparent deafness to patients’ voices, patient narratives abound.

For example, in 1623 John Donne composed Devotions on Emergent Occasions in response to an illness he suffered during the winter. This work was (and remains) extremely popular. It details Donne’s illness and recovery and, his consequent reflections about man and God. His meditations combine intimate emotions with larger moral observations. Sickness, for Donne, reminds man of his feeble mortality amidst God’s immortal cosmos. He suggests to the reader that though we have physicians, "...we shrink in our proportion, sink in our dignity in respect of very mean creatures who are physicians to themselves." Animals are often capable of enduring and healing themselves, while humans "must send for the physician." We must therefore trust in external forces: in the apothecary and (more importantly) in God.

According to Donne, to be ill is to be reminded of humanity’s small, mortal stature. The community of man exists with the constant and inevitable threat of being cut down. "Any man’s death diminishes me because I am involved in mankind, and therefore never send to know for whom the bell tolls, it tolls for thee." Death and disease thus possess moral dimensions that far exceed the secular suffering they induce.

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Another man may be sick too, and sick to death, and this affliction may lie in his bowels as gold in a mine and be of no use to him; but this bell that tells me of his affliction digs out and applies gold to me, if by this consideration of another's danger I take my own into contemplation and so secure myself by making my recourse to my God, who is our only security. (Donne; Meditation XVII)

Donne’s own illness leads him to contemplate his relation and devotion to men and other creatures and, ultimately, to God.

By contrast, Katherine Mansfield finds illness to be a fearsome and lonely prospect. She contracts tuberculosis in 1920 and dies of it in 1923. While her journal entries reveal a morbid humour, as when she depicts herself and another consumptive patient coughing through the night "like two roosters calling to each other at false dawn," they also disclose enormous suffering. Mansfield writes: "There is no limit to human suffering. . . . Suffering is boundless, it is eternity. . . . One must submit. Do not resist. Take it. Be overwhelmed. Accept it fully. Make it part of life." She attempts to reconcile her terrible pain with her enjoyment of life. "Life is a mystery. The fearful pain will fade. I must turn to work. I must put my agony into something, change it." Both she and her physician, Dr. Sorapure, believe that her illness can transform her spiritually. He hints that her 'ill-health will allow her to repair' into something greater. Together they hope that she will encounter a metamorphosing revelation which is similar to Donne’s and which will help make life more viable. Nonetheless, Mansfield opines that despite her belief that her suffering can be overcome, it continues to be unbearable. Alone, and in pain, she writes that she must perforce be her 'own doctor' in enduring her physical and mental anguish. Her only solace is that her pain can perhaps provide her with a form of spiritual transformation.
Virginia Woolf also experiences isolation when she is confined to bed with a bout of influenza during the 1940s. Although her life is not threatened, Woolf nonetheless expresses a metaphysical moodiness. While her essay, "On Being Ill," lacks the agony of Mansfield's journal, it successfully captures the lonely melodrama of illness. For the stricken individual, the mundane aspects of life recede. Business affairs no longer seem important. Some friends appear toadish, while others become magnificently beautiful. Sickness alters memory and the perception of time. It dislocates the senses. All that is ordinary is transfigured. Even the purpose and structure of language mutates and becomes enigmatic.

In illness words seem to possess a mystic quality. We grasp what is beyond their surface meaning, gather instinctively this, that and the other — a sound, a colour, here a stress, there a pause — which the poet, knowing words to be meager in comparison with ideas, has strewn about his page to evoke, when collected, a state of mind which neither words can express nor reason explain. (Woolf; 21)

The plodding cadences of prose are superseded by the 'beating wings' of poetry. For Woolf, only the poets can appropriately capture the mysticism associated with the body in pain.

Restricted to one's quarters, the ill person looks to healthy existence as a passenger looks to a "remote and fair" shore from the deck of a "ship far out to sea."

The poesie of illness is perhaps most apparent in the writings of the Romantics. In particular, John Keats, a physician as well as a poet, spends much of his time writing about the bittersweet transience of earthly life. The loss of his father at a young age, as well as the untimely death of his brother Tom to tuberculosis, produces an uncanny sensitivity to the suffering of the sickbed. In *Epistle to John Hamilton Reynolds*, Keats writes to his ailing friend:

"Do you get health -- and Tom the same -- I'll dance,/ And from detested moods new Romance/
Take refuge -- . . . " He composes this piece while nursing his ill brother in Teignmouth. The burden of disease and the threat of death darken the poet's mood. "But I saw too distinct into the core/ Of an eternal fierce destruction,/ And so from happiness I far was gone." A tension between mortality and immortality reverberates through much of his poetry. Even when he sings the praises of the Nightingale, the bird's song reminds him that

I have been half in love with easeful Death,
Call'd him soft names in many a mused rhyme,
To take into the air my quiet breath;
Now more than ever seems it rich to die,
To cease upon the midnight with no pain,
While thou art pouring forth thy soul abroad
In such an ecstasy!

Keats' intimacy with mortality is made all the more poignant by the fact that he becomes consumptive and dies at the youthful age of twenty-six. While he writes little about his final months with TB, his poetry and letters abound with a consciousness that is deeply allied with that of the ailing sufferer.

Illness narratives leading up to the late twentieth century tend to focus on human ailment as a mortal threat and as an opportunity for spiritual reflection. The deep sense of

19 Apparently, the last lines of poetry that Keats writes are as follows:

This living hand, now warm and capable
Of earnest grasping, would, if it were cold
And in the icy silence of the tomb,
So haunt thy days and chill thy dreaming nights
That thou wouldst wish thine own heart dry of blood
So in my veins red life might stream again,
And thou be conscience-calm'd-- see here it is--
I hold it towards you. (Bate; 626-27)

The imagery of the outstretched hand evokes an intense awareness of mortality. By this stage of his illness, Keats knows that he has tuberculosis and that he is going to die.
suffering and isolation associated with ailment creates the possibility to reconceive an individual's place in the social and metaphysical cosmos. Donne, Mansfield, Woolf and Keats all express a spiritual longing or awakening. In the midst of pain, they discover a mystical tie to God and/or the universe. Thus, in spite of its physical manifestations, illness evokes an invisible transfiguration of the soul. The suffering of the body provides an uncontrived opportunity for ontological contemplation. Illness provides the possibility that the ailing individual will discover a more meaningful understanding of what it is to be human and, through the creation of art and narrative, share this insight with the rest of the human community.

**Illness As Metaphor**

While illness narratives of the late twentieth century certainly express the spiritual confoundment of earlier accounts, they also display a consciousness of the social meaning of physical dysfunction. They seem to express an awareness of the cultural and political significance of ailment. Even Virginia Woolf's account of the 1940s seems to hint at an emerging awareness of the social dislocation and isolation of illness. Instead of experiencing a sense of metaphysical community, patients of the twentieth century begin to report a sense of social alienation in their chronicles. The modern patient is conscious not only of physical infirmity but also of political weakness in a society which upholds the values of free, equal and independent individuals. Suddenly, the patient is no longer quite as equal as before. The impotence of disease is no longer merely physical but also political. The ill individual becomes subject not only to physical symptoms, but also to the social imagery and medical institutionalization of disease.
Susan Sontag's *Illness as Metaphor* is a case in point. Originally published in 1979, Sontag's treatise explores the metaphorical hold that certain diseases have in the public imagination. The author sees sickness not only as an intimate physical and spiritual event but more notably as a situation which evokes complex social sentiment. Sontag's own experience of cancer thus becomes an occasion for intellectual observation and criticism of medico-social culture.

The image of the ill person and its attendant metaphors are potent forces in any given culture. Susan Sontag categorizes them as "punitive or sentimental fantasies." (Sontag; p. 3) In two works, *Illness as Metaphor* and *AIDS and Its Metaphors*, she attempts to decipher disease meaning and myth in Western society. Specifically, she examines tuberculosis, cancer, and AIDS. She compares and contrasts the personae of consumption and cancer, and explores cultural perceptions about AIDS. Her point is that the landscape of illness is fraught with metaphors that often contribute to, rather than alleviate illness suffering. Diseases become imbued with distinct "personalities" that tend to overwhelm victims. The patient's body, psyche and person are viewed to be latently "tubercular" or "cancerous." Consequently, the cultural weight of an ailment can eviscerate the personal significance of illness in an individual life.

According to Sontag, people romanticize tuberculosis.²⁰ Typically, it is a disease characterized by an excess of love. Victims' fluctuating symptoms spur the belief that it occurs in only those with passionate spirits. The Romantic poets encourage images of the soulful and beauteous consumptive pining away in a garret (Sontag; 20). And, despite the nineteenth century

²⁰ It should be noted that Sontag writes this in the late 1970s when the incidence of tuberculosis was relatively low in the western world. With the worldwide resurgence of TB in the 1990s among the poor, homeless and ill, I wonder whether the metaphorical image of the disease is changing.
aristocracy's embracing of the artistic sentiments surrounding TB, it nonetheless possesses an aura of deprivation, whether it is due to a lack of finances or an inadequacy of climate. Further, the final, mortal hemorrhage is sometimes considered to be painless. In consumption, death becomes the culmination of a spiritual journey of illness and, it is therefore metaphorically embellished as transcendent and relatively easy (Sontag; 14-15).

Conversely, cancer remains an ugly disease within the popular imagination. It often occurs in unmentionable digestive or sexual organs. Sontag refers to these as the "lower organs." The disfigurement and/or excision of colons, prostates and uteruses cannot be easily romanticized. And like tuberculosis, both physicians and lay people believe in a cancer-prone personality. In medical journals, the "modern bogey of the cancer-prone character" is "someone unemotional, inhibited, repressed." (Sontag; 39, 47) Cancer patients are desexualized and disfigured. Ironically, despite (or perhaps because of) the relative impoverishment of cancer patients' psyches, their malady occurs most often in an environment of material excess. The rich diet and heavy pollution of post-industrial countries produce and harbour innumerable carcinogens. Finally, unlike TB, both treatment and death are dramatized to be torturous. "[T]he person dying of cancer is portrayed as robbed of all capacities of self-transcendence, humiliated by fear and agony." (Sontag; 17)

In analysing the metaphorical baggage surrounding sickness, Sontag proposes that allegories of ailment are dangerous on two counts: (i) they mediate an individual's encounter with illness and the medical system, thereby thieving the patient of a personal understanding of illness and, (ii) they make illness a primarily psychological event which blames the victim and can distract from valuable therapies (Sontag; 47, 56). In referring to Bichat (an eighteenth
century anatomist), she writes: "Disease [for him] is the will speaking through the body, a language for dramatizing the mental: a form of self-expression." (Sontag; 44) Sontag critiques this type of psychological theorizing. Discussions that focus on emotional origins place the onus of dysfunction on the patient, inducing an enormous amount of guilt. They also tend to remove the individual from the community of human sympathy. Such paradigms are disrespectful and dangerous. Katherine Mansfield is a case in point. "The weakness was not only physical. I must heal my Self before I will be well. . . . This must be done alone and at once. It is at the root of my not getting better." Apparently the novelist believes her condition to be so much the result of her psyche that she abandons medical treatment, no doubt hastening her death (Sontag; 47). It is thus not only for emotional reasons but eminently practical ones that Sontag condemns the sentimentalization of disease.

Sontag writes out of a rage engendered by her own experience. Interestingly, she does not admit to being a former cancer patient until the writing of her companion volume, *AIDS and Its Metaphors.*21 Her illness narratives are distinct. Written in a highly intellectual and distanced prose style, her books are an articulation of her resentment of the images and language associated with disease. She states clearly that common metaphors of illness discourse not only diminish experience through false stereotyping but also exacerbate both physical and psychological suffering. Moreover, Sontag views medicine as a highly practical discipline. Antibiotics, not hygiene nor economic prosperity, have lessened the incidence of tuberculosis.

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21 "Twelve years ago, when I became a cancer patient, what particularly enraged me -- and distracted me from my own terror and despair at my doctor's gloomy prognosis -- was seeing how much the reputation of this illness added to the suffering of those who have it." (Sontag; 100)
Radiotherapy, not psychotherapy, ameliorates cancer patients’ conditions. In a sense, hers is a deeply conservative critique which does not acknowledge anything but the mechanical capacities of physicians. Medicine’s attempts to provide ministrations to the psyche and the soul has no place in her understanding of clinical practice and disease conception.

For Sontag, physicians and case-historians often employ pre-meditated fantasies to articulate facile epiphanies about illness. Obliquely put, transcendence is a deeply personal and even private matter. Furthermore, she asserts that perhaps the most damaging illness allegory is that of violent or self-righteous imagery. (This remains particularly true of AIDS.) She concludes:

We are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties nor the enemy. We — medicine, society — are not authorized to fight back by any means, whatever. . . . About that metaphor, the military one, I would say, if I may paraphrase Lucretius: Give it back to the war-makers. (Sontag; 183)

The fight here is to preserve the individual patient’s identity and respect, as well as a subjective perception of meaning that prevails over enculturated stigma, disrepute and mawkishness about disease.

A Leg To Stand On

In her discussions, Susan Sontag explicitly attacks the writings of the physician, Oliver Sacks, for using "catastrophic neurological illness as the material for . . . portraits of suffering and self-transcendence, diminishment and exaltation." (Sontag; 125) For her, his writings typify formulaic epiphanies about human suffering. However, although Sontag objects
to Oliver Sacks collections of medical tales, he writes not only about patients but also about his own journey through illness. As such, he is a wonderful raconteur of his own physical and psychological debility. His volume, *A Leg to Stand On*, tells of a severe leg injury that results from a mountaineering accident. He rips his quadriceps muscle from his thigh after falling from an elevated ledge. After reconstructive surgery, his leg feels remarkably different; at times he can't even find it. The medical staff ignore and even deny his bizarre symptomology and Sacks is left in limbo. Terrified by his physical impotence and by his physician's oversight of the strange sensations emanating from his limb, he feels utterly alone. In the end, although Sacks is by profession a doctor, his story focuses less on physical suffering than on the alienating psychological culture of being a hospital patient.

Physical incapacity by necessity results in a loss of personal agency. The hospital, however, exacerbates this powerlessness.

One's own clothes are replaced by an anonymous white nightgown, one's wrist is clasped by an identification bracelet with a number. One becomes subject to institutional rules and regulations. One is no longer a free agent; one no longer has rights; one is no longer in the world-at-large. It [is] strictly analogous to becoming a prisoner, and humiliatingly reminiscent of one's first day at school. One is no longer a person — one is now an inmate.

(Sacks, *Leg.*; 46)

Practical aspects of care require that the sick person assume a posture of passivity. Others must act for the self when and where activity is no longer possible. The sick bed and room simultaneously protect and rule by enforced seclusion. Unable to master the chores of living and

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22 Sacks' description of hospital life harkens back to my discussion earlier in the chapter of the carceral tone of clinical language.
isolated from the populated, healthy world outside, Sacks must simply linger. Quite literally, he lies in wait for the healing attentions of both nature and the physician to take their course.

Sacks' desire to speak with his care givers about his condition dominates much of his thought while reclined in bed.

I became all of a sudden desolate and deserted, and felt -- for the first time, perhaps, since I had entered the hospital -- the essential aloneness of the patient, a sort of solitude which I hadn't felt on the Mountain. Desperately now, I wanted communication, and reassurance, . . . I myself needed to communicate above all to my physician and surgeon: I needed to tell him what had happened to me, so that he could say, "Yes, of course, I understand." (Sacks, Leg.; 88)

He wants desperately to tell his story. However, he discovers that while he wants to engage in a dialogue about his treatment, the surgeons only wish to discuss the "salient facts." The conversation is peremptory and impersonal (Sacks, Leg.; 47). The patient feels thwarted and upset. To make matters worse, when, after surgery, Sacks can no longer sense his leg, the attending physician denies that anything could possibly be wrong.

[My physician] would reassure me, help, give me a foothold in the darkness. But instead, he did the reverse. By saying nothing, saying "Nothing," he took away a foothold, the human foothold, I so desperately needed. Now doubly, I had no leg to stand on; unsupported, doubly, I entered nothingness and Limbo. . . . I was thrown into a further hell -- the hell of communication denied. (Sacks, Leg.; 109)

The medical denial of his reality dislocates and unnerves the patient even further. "As a patient in hospital I felt both anguish and asphyxia — the anguish of being confronted with dissolution,
and asphyxia because I could not be heard." (Sacks, Leg.; 209) Sacks’ suffering arises out of an essential conflict in perception which occurs in medicine when the experience of the ill self clashes with the objectivity of the clinical gaze.

The divergence of perceptions and of narrative becomes most apparent in the interactions between doctors and patient. In one scene, surgeon and students enter Sacks’ room without greeting him. Instead, they refer either to the chart on the end of his bed, or to the nursing Sister beside, or to the leg bound in the cast. When Sacks stammers something about the unresponsiveness of his quadriceps, he is dismissed with a wave of the surgeon’s hand. The medical team soon sweep out of the room. Later, when he is recuperating, Sacks glimpses at the chart which so often mediates the time he has with his care givers. He reads "Uneventful recovery." It is at this point he realizes the tremendous discord between his own chronicle and that of the staff. For him, recovery has been utterly remarkable (Sacks, Leg.; 154).

Sacks’ narrative sketches the particular, acute pain of the patient. He talks little of physical discomfort, but rather emphasizes the enormous psychological pain of hospitalization. The antiseptic clinic may undertake mechanical cures, such as mending bones and performing surgeries, but it often neglects and, even bridles, the human spirit.

To be deaf to metaphysical implication is one thing, but to be deaf to anguish is another; and this was my indictment of classical neurology. It explained my doubling of despair when I was a patient and complained like Head’s patients that my leg felt "unreal," only to be told by my doctors: "That’s not our business." . . . classical neurology has no room for such matters, and will not admit them, except as occasional, colourful "figures of speech."

(Sacks, Leg.; 209)
The absence of the patient’s voice in the clinic not only deprives medicine of critical information in the healing process, it impoverishes its practices. Patients who feel passed over or muzzled, know its coercion. The medical narrative perceives, interprets and speaks in a manner which denies the perceptions, interpretations and language of subjective suffering. Sacks’ narrative demonstrates that the clinic’s dominance of the subjectivity of the ill self (in its need for apparently objective findings) is a coercive act whether or not it is overtly recognized as such or not.

At the Will of the Body

Unfortunately, the domination of the patient by medicine’s highly technocratic, Foucauldian gaze occurs all too often. The Canadian sociologist, Arthur Frank, writes of the distinction between illness and disease in his memoir, *At the Will of the Body*, "We may be victims of disease, but we are not victims of illness. . . . Because we can choose how we experience illness, we can be more than victims." (Frank, *Will.*; 138) Disease is an imposed medical category, whereas illness is a circumstance. Further, illness can be an opportunity for the discovery or recovery of life’s meaning. Nonetheless, the clinic both insists on viewing patients in terms of disease categories rather than in terms of illness. Because the clinic demands the splitting of the self into a separate disease entity, its culture can become an obstacle to the reconstitution of the individual.

Like Sontag, Frank objects to metaphors of militarism that colour discussions of disease and treatment. Medical staff and friends speak of his cancer in terms of a battle. Characterizing cancer as a battle turns the body into an external field upon which violent
incursions are made. Treatment aims to colonize the body, to dominate it. As a result, the patient loses the capacity to be intimate with the illness experience. Echoing Sontag, Frank and his partner refute such language.

But our talk never suggested that we were fighting cancer. We never thought of "the cancer" as a thing to be fought. . . . Cancer is not some entity separate from yourself. . . . The tumors may have been a painful part of me, they may have threatened my life, but they were still me. . . . I could never split my body into warring camps: the bad guy tumors opposed to the naturally healthy me. There was only one me, one body tumors and all. Accepting that I was still one body brought me a great sense of relief.  

(Frank, Will.; 84)

Unity remains paramount. Trust in the sanctity of his whole being endows both strength and coherence to his agency as a human being. This singularity of focus (and not images of bombardment and dissolution) provide the necessary means for his repair.

Despite the best of intentions, Frank cannot, however, avoid the stigmatization that seems to be associated with his disease. "... I experienced the visible signs of cancer as defects not just in my appearance, but in myself." (Frank, Will.; 92) He has difficulty enunciating the word ‘cancer.’ He tries to mask the presence of an intravenous line in his chest through layers of loose clothing. Finally, the loss of his hair to chemotherapy labels him decisively as a patient — it marks him as someone who has been colonized by disease — and he dons a hat to cover this last sign. Somehow he cannot avoid turning himself into an object of stigma. While Frank does not discuss metaphors in any detail, he hypothesizes that cancer is so strongly mythologized in society that the sufferer cannot evade being cast within its allegory of evil.
To fall prey to stigma means that the individual transmutes into the disease itself. The disease overtakes the persona. In this sense, the patient becomes the locus of management rather than of the illness experience. A diagnostic grouping may be useful for treatment but it is not efficacious to care. This dichotomy reveals itself when Frank first goes to his doctor and discovers that tests, and not communication, form the basis of the medical exam. To his greater surprise, his physician does not even touch him.

As I remember it, no "hands on" examination was done; the lab tests were presumed to tell all. At that point two physicians were telling me that nothing much was wrong. I wanted to believe them, but my body insisted otherwise. (Frank, Will.; 25)

It is only when he shops for a third opinion that he is finally palpated. This physician feels a mass and, just by the way he looks at and speaks to him, Frank feels better even though he now faces the prospect of a tumour. He writes that ". . . [h]e was almost alone in expressing optimism about me, not as a case but as a person." (Frank, Will.; 26) When cancer is confirmed in the laboratory, the specialist is an excellent technician but a lousy communicator. The new oncology patient calls it "a triumph of science and a lapse of humanity." (Frank, Will.; 27)

Poverty of communication is so pervasive that it seems to be a constant and malignant side-effect of the clinic itself. "The gap between what I feel and what I feel allowed to say widens and deepens and swallows my voice." (Frank, Will.; 13) And like Sacks, Frank feels isolated and silenced. His voice is not important to those who treat him. Ironically, the hospital conducts psychosocial surveys of its patients, inquiring about problems and stress within the family or at home. Although the questions in themselves indicate a level of caring, the
environment in which they are asked — behind a "privacy" curtain in a public ward — is hostile to any honest response.

If we had expressed our problems and emotions in that very public setting, we would have been extremely vulnerable. If we then received anything less than total support, it would have been devastating. The nurse showed no awareness or appreciation of how much her questions required us to risk, so we gave only a cheerful "no problems" response. That was all the setting seemed able to support. . . . If the staff had had real support to offer, they would have offered it in a setting that encouraged our response. (Frank, Will.; 69-70)

The spatial layout of hospitals inhibits any valuable exchange between staff and patient.23 Even when team members try to employ psychological approaches with patients, they often fail because the theoretical models are rather "like horoscopes — broad enough to fit anyone, but just specific enough to allow individuals to believe their own lives are being described." (Frank, Will.; 109) Through the psychologizing of disease the patient can thus feel responsible for the anti-social behaviour of sickness. A pernicious belief emerges that ill health is evidence of emotional weakness. Thus, even in the well-meaning psychological management of disease, constrained and inappropriate paradigms can replace insights. And because clinicians rely on disease models, ill people become embodiments of lab results, scanning images and psychological propensities.

23 Not only space but time places a terrible constraint on the relations between patient and hospital staff. A friend of mine who died of cancer in March 1996 writes of her first day of chemotherapy: "Sailing along beautifully (with the occasional tiny low point), . . . . But today appeared a certain Wendy Bailey — nurse clinician — who was supposed to talk to me about my prognosis. However she'd been away at a conference for 13 days and was trying to cover in one session what should have been done in four. . . . Very down. After session." Journal, Rea Wilmshurst, 21 February 1995.
A theme of powerlessness runs through Sontag's, Sacks' and Frank's stories of hospitalization. The authors speak of a sense of diminishment that is reminiscent of the inefficacy of childhood. Encumbered by physical infirmity, they suddenly discover that they are diminished socially and politically. They feel less relevant even though they are at the centre of medical activity. They experience a loss of personal agency which induces a carceral sense that they are prisoners of both social metaphor and medical objectivity. Medical language and paradigms overtake the patient's voice and subjective sense of self. An absence of communication is thus a common motif in these accounts of patienthood. Yet suffering can be only endured when it is shared with others. For Sontag, Sacks and Frank, discussion forms the basis of caring and recovery. "Care is inseparable from understanding, it must be symmetrical. Listening to another, we hear ourselves." (Frank, Will; 48) Proper caring allows expression of both pain and need. During her illness, Sontag becomes enraged by the stereotypes which obstruct the actual experience of being ill. Sacks feels discredited and belittled by the refusal of his care givers to either speak or listen to him. He needs the affirmation of dialogue. The alienating silence of the clinic causes him undue suffering. Frank also criticizes medicine's hushed veil. He writes his memoir to give expression to all that which he wanted to speak when he was ill. He views sickness as a "dangerous opportunity" to gain potential insight into life and establish closer relations with family and friends (Frank, Will; 7).

24 The theme of the re-emergence of childlike helplessness appears in other narratives. Author and stroke patient, Robert McCrum, writes in his diary: "It occurs to me that as a patient I am regressing to a state of childhood in some ways, surrounded by parents, waited on hand and foot. I feel like a child, and helpless like a child." (McCrum; p.75)
Each author discovers that ill health occasions a vulnerability, necessitating dependence on and care from others. However, the relationships between doctor and patient are one-sided to the extent that they allow the sick person little effective voice in the administration of care. They become situations of dominance. True caring requires communication between donor and recipient. And it is the longing for expression as well as the absence of such care which reverberates through most patients' lives. Thus, the possibilities that are attached to the pain of patiethood can be obliterated by the clinic's denial of suffering.

**Storytelling As An Antidote to Pain & Suffering**

When people become ill, they need to tell stories. In the quest to apprehend and accept suffering, individuals recount both the mundane details and the numinous revelations which occur to them during the course of their illness. Anatole Broyard, in his memoir of cancer, writes that "storytelling seems to be a natural reaction to illness." (Broyard; 20) He argues that creating stories "rescues him from the panic inherent in creation and the suction of infinity." (Broyard; 21) His poor health offers new sensations and adventures. He becomes literally and metaphorically 'intoxicated by his illness.' The sensations of ill health are all engrossing. They offer novel opportunities and adventures. Consequently Broyard writes to give voice to his explorations. For him, story-telling is the act of reconstituting the self and of forming new connections with the external world.

In a socio-linguistic study of doctor-patient interactions, Nancy Ainsworth-Vaughn concludes that patients need to tell stories for two central reasons: (i) to reduce the social space between physicians and patients and, (ii) to assert a self which is suppressed in institutional
discourse. She also concludes that patients use their narratives as a form of persuasion during diagnosis (Ainsworth-Vaughn; 148, 150). Speaking or writing about illness is thus an *act* of personal agency. It is an attempt to exert influence in both the illness process and in clinical encounters. The reassertion of the subjective voice in the midst of disease is multi-faceted. Patients tell stories because they need to reassert themselves in the midst of suffering which is simultaneously physical, spiritual, social and political.

The psychiatrist and medical anthropologist, Arthur Kleinman calls these assertions "illness narratives." His book, *The Illness Narratives*, outlines the extraordinary importance of such stories to both the patient and the would-be-practitioner. Specifically, he examines the effect of chronic illness on the lives of those afflicted as well as on those of the people who look after them. Like Frank, Kleinman concludes that there is a moral dimension to the story-telling associated with ill-health.

> Meaning is created in the context of serious illness out of the very stuff that makes up our personal and cultural dilemmas . . . Meaning is inescapable: that is to say, illness always has meanings. The experience when ill need not be self-defeating; it can be — even if it often isn't, an occasion for growth, a point of departure for something deeper and finer, a model of and for what is good. (Kleinman, 144)

The reconciliation of sickness events with a particular life history is absolutely integral to the patient's existence. The desire to interpret or reinterpret the assumptions which govern a life is central to human sickness. It is a primary feature of being ill.

Another physician, Robert Coles, also asserts the importance of stories in the experience of illness. In one of his books, he writes about his "conversations" with a young
polio patient. Here, he discovers not only the power of personal narrative but also the power of fiction. The patient, Phil, rereads Mark Twain's *Huckleberry Finn* and experiences an epiphany. The central characters of Jim and Huck speak to him; ‘they straighten him out.’ (Coles; 36) Phil begins to contemplate the ‘worries and terrors’ of his own life.

His complaint went deeper; like Job, he was puzzling in the most profound way possible and wanted to find his voice, use it to make a plea, his own cry, though he had already begun to regard the world as largely indifferent to him and his situation. (Coles; 37)

In the midst of illness, the spawning of a ‘voice’ with which to express ontologic anxieties promotes a resurgence of individual agency in a patient. This, in turn, encourages healing. Stories are thus a reclaiming of power.

Perhaps one of the more impressive testaments to the potency of narrative is Jean Claude Bauby’s memoir, *Le scaphandre et le papillon — The Diving Bell & the Butterfly*. Once a famous Parisian editor, Bauby can now only move his right eye after a devastating stroke. He is essentially "locked in" "comme un bernard-l’ermite sur son roche." — *like a hermit crab dug into his rock* (Bauby; 9). His assistant painstakingly recites an alphabet of letters while Bauby blinks to indicate which letter he wants. Throughout the long summer months, the author composes the chapters of his chronicle in his head, editing and re-editing them before he arduously blinks each letter out. He is perhaps most lyrical when he concludes his work. He describes his seated assistant reading the chapters aloud to him. As he contemplates his writing, he feels a calm descend even as he wonders whether there is enough material for a book. Bauby leaves us with a final glimpse of the open mouth of a handbag beside him:

(Baurby; 137)

Her purse is half open, and I see a hotel-room key, a metro ticket and a hundred-franc note folded in four, like objects brought back by a space probe sent to earth to study how earthlings live, travel and trade with one another. Does the cosmos contain keys for opening up my cocoon? A metro line with no terminus? A currency strong enough to buy back my freedom? We must keep looking. I’ll be off now. (Leggatt; 139)

The images are haunting. It is unclear who in fact becomes the metaphorical alien who probes the earth. Is it Baurby? Or, is it the reader? No matter. The message of important is that Baurby defiantly strives for his freedom, whether it is in choosing to ‘drool on cashmere sweaters’ rather than on hospital gowns, or whether it is in his courageous efforts to write of his extraordinary view of the cosmos. Even if he remains pensive and confused, it is clear that he has found some liberty in the telling of his story.25

Divergence and Domination

Both Kleinman and Coles believe that physicians should not only heed patient’s narratives but also participate in the search for meaning which precipitates them. Unfortunately,

25 Baurby died shortly after writing this memoir. He did not see it published.
doctors generally do not recognize the worth of illness narratives, let alone legitimize them. Instead they reconstruct the patient's and family's experience in spare scientific language in which meaning can only be expressed in terms of biomechanical observation. Despite the fact that doctors 'take the histories' of their patients, in an era of increasingly technological medicine, they are not inclined to give such histories much weight. The anamnesis has become a formality. It might identify specific problems but it does not disclose what is 'actually' going on. The evaluation of scientific fact is the only credible narrator of events. As a result, "... in contemporary biomedicine and the other helping professions there is no teleological perspective on illness that can address the components of suffering relating to problems of bafflement, order and evil..." (Kleinman, IN; 28) In situations which generally lie beyond medical capacity, physicians have little knowledge or awareness of the normative relationship between the body and the self. A moral dimension is thus missing from evidentiary accounts of disease. Further, even if a clinician wants to explore the more nebulous realm of illness meanings with patients and/or integrate such meanings into a healing relationships, there are no cultural or environmental supports for this type of endeavor in the clinic. And, while this may not be an overwhelming issue in acute illnesses, Kleinman concludes that it can become one in terminal and chronic cases over which the doctor can exert little control.

Understandably, mastery is an essential part of medicine. Both physician and patient need to believe in medicine's competence. Terminal and chronic illness challenge this faith. If a physician can no longer halt a disease, or can no longer identify and control an ongoing condition, the patient loses confidence, particularly if only mechanical assistance is being offered. In turn, the physician feels inadequate because both medical education and culture
do not supply the necessary skills to cope with situations which human knowledge cannot
control. Consequently, attention remains focused on technical details rather than on the illness
experience. ". . . [T]he health professional's creation of a narrative may function as a kind of
second guessing that protects against feelings of inadequacy and even failure." (Kleinman, IN; 51)
The clinic's positivistic approach which perceives and responds to illness only in terms of
visible signs and categories is largely unable to cope with uncertainty. The medical gaze requires
material evidence to be effective. It perceives only fact. Its interpretations are essentially
evidentiary in nature. As a consequence, medical narratives are epistemologically averse to non-
tangible issues such as suffering and meaning. Even when they transcribe patients stories, they
selectively focus on details which results in "the dangerous fallacy of over-literal interpretations
of accounts best understood metaphorically." (Kleinman, IN; 52) Inevitably, medical records
denote only that which can be itemized, anything else which does not fit into an evidentiary
framework of observation and description is excluded.26

Physician and patient stories consequently diverge. While medicine collects data, patients construct biographies.

Each patient brings to the practitioner a story. That story enmeshes the disease in a web of meanings

26 This fundamental flaw of positivism reminds me of the Soviet neurologist, A. R. Luria, and his account of the
mind of a mnemonist:

S., however, had told us many times: "I can only understand what I can visualize." . . . .
He was unable to grasp an idea unless he could see it, and so he tried to visualize the
idea of "nothing," to find an image with which to depict "infinity." And he persisted in
these agonizing attempts all his life, forever coping with a basically adolescent conflict
that made it impossible for him to cross that "accursed" threshold to a higher level of
thought.

(Luria, Mind; 130-33)

Medicine is caught in a similar trap. It cannot move beyond sensate thinking. Because of its dependence on
observation, medicine has great difficulty dealing with abstraction.
that make sense only in the context of a particular life. . . . Practitioners are attracted to and repelled by . . . . these narratives . . . . They are attracted by the potential to understand how a person and the person's world affect and are affected by a disorder. . . . They are repelled by the fear that the story will entangle them in confusion, which may cover the traces of disease (thus making diagnosis more difficult) or interfere with the working out of a disease-specific treatment. (Kleinman, IN; 96)

Clinical and lay stories do not easily mix. The divergence of narrative represents essential differences in intuition, reasoning, purpose and interpretation. The doctor looks at illness in terms of specific signs that can be generalized into a corpus of facts. The agglomerate evidence points to a prevalent disease-type. Consequently, the patient symbolizes an idealized "case" or example which can be applied to the rest of humanity. On the other hand, the patient perceives the illness to be a series of particular events. Each symptom uniquely signifies a personal transformation. The singularity of the illness experience cannot be extinguished by diagnosis. Medical categories cannot appropriately represent the confusing complexity of lived experience.

Thus, practitioners and patients perceive and interpret sickness oppositely. A central antagonism emerges in their stories: doctors need to work with generic ailments while patients need to preserve and find meaning in the singularity of suffering. This does not imply that patients remain mired in the particular. On the contrary, keen attention to the unique aspects of illness can lead to epiphanies of meaning that can be shared broadly. "The ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability." (Frank, WST; xi)
In *The Illness Narratives*, Kleinman writes about the tension between the practitioner's selective attention to detail and the patient's complete observation of sickness. He outlines the distance in both the origin and expression of illness experience between practitioners and patients. He criticizes clinicians for becoming increasingly incapable of understanding and addressing issues of narrative which are so important to patients and families. The solution, he suggests, lies in a recapitulation of the medical relationship. Instead of being pure positivists, doctors should engage in the patient's life. True healers need to listen intently to people's stories. Stories provide metaphorical truths about human experience. The patient's biography must become a part of the practice of care (Kleinman, IN; 237). Kleinman calls this "empathic witnessing." With empathic witnessing, the practitioner no longer acts from a removed vantage, but instead becomes a true member of the patient's community and embedded in the contextual circumstance of illness.

... [W]e should also say that illness and care are far too important to be left solely in the hands of medical professionals, especially those who configure these innately human issues in a framework that constricts our humanity. ... [the physician] is there in the experiential realm of suffering together with his patient and the members of the family. ... in the worst moments, he participates in the moral equivalent of what the illness experience means for a patient and family... the experience of the healer can be a quest for a kind of human wisdom, a model of forbearance and courage, a form of goodness, a lesson in the essentials of humanity.  

Kleinman, IN; 267)
Attention to narrative (and all that it entails, including perception, language and meaning), exhumes the long buried moral dimension of the clinic. Illness has meaning that is far more than biomechanical. It endows human life with a perspicacity that normally eludes observation. In the end, the biography of a life is far more important than the actual events composing it. And Kleinman, among others, urges physicians not only to recognize biography but also to participate in it.

While the bridging of the cultural and discursive gulf so strongly evident in the clinic would likely promote the well-being of all its participants, accomplishing such a task is not simple. The historical, political and educational climates encourage the communicative gap between physicians and patients. Medical schools breed individuals who have been taught to focus on fact rather than intrinsics. The grueling, regimented hierarchy of medical training erodes students’ self-esteem. Required residency programs impose long hours and intense stress. The Harvard anthropologist, Melvin Konner, found his clerkship at a Boston area hospital to be so brutal that he abandoned the idea of becoming a doctor.

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27 Howard Brody, Robert Coles and Rachel James also point to narrative as potentially a moral force in medicine.

28 An obstetrical resident at a Florida hospital writes: "I'm working 110 to 120 hours a week, and I'm on call every other night or every third night. I start doing C-sections early in the morning, and I'll do six or seven during the day and continue with them all night long. . . . Despite the fact it's a university hospital, we're really not taught by attendings. They're not around much because they're too busy with other things, so I'm really learning obstetrics from more senior residents, which means I'm getting my medical training from people who have been at it a year or two longer than I have." (Pekkanen; 5-6)

Unfortunately, the loneliness of the clinic is not confined to patients alone. High rates of addiction, depression and suicide are well documented among physicians. Doctors remain isolated by their status in medical hierarchies, by their sole responsibility for patients, and most importantly, by their positivistic need for emotional detachment. Their segregation is furthered by both a language and culture which prohibits any proximity to those under their care.

I think back to the years of [medical school] lectures in which the emphasis was so heavily on understanding the workings of the body in health and disease. The diagnosis was everything! . . . We were so busy trying to figure out what was wrong and what should be done that there was no time or energy left to understand how an acute medical problem fit into the life of a patient. . . . I suppose our professors were just as uncomfortable as I am in dealing with the realities of patients . . . . It came as quite a shock to me to discover that my common sense was not developed enough to help my patients through the chaos of their emotional response to illness. (Hilfiker, Healing; 53-54)

Consequently, physicians cannot share either the joys or misgivings of their profession with others surrounding them. Constantly confronted by the limits of their own knowledge and capacity, by the uncertainties which plague mortal life, as well being isolated from their

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30 Dr. Roger MacDonald, a recovering alcoholic, tries to reformulate his professional conduct vis a vis his patients: "You know I've learned a lot from AA and Al-Anon. Take one day at a time. I think I'm taking a lot longer with patients now than I used to, trying to listen to them, be with them a little. It's a lot more fun for me, and probably better for them." (Hilfiker, Healing; 204)

31 David Hilfiker writes about many of these problems in his articles and books. Ignorance, uncertainty and isolation invariably lead to the emotional incapacity and breakdown of doctors. He writes about his own mental breakdown as a result of these stressors in his books: Healing the Wounds: A Physician Looks at His Work and We Are Not All Saints.
immediate families by busy call schedules, practitioners are deprived of essential human
communion. They reside in an emotionally bereft world. Medical jargon and inflated social
status prevent them from communicating with their patients. Professional silence prohibits their
sharing with colleagues and families. They remain denied of biography in the most essential
sense: they are denied of a ongoing narrative of themselves. They work (and often live) in an
environment which cannot support intimacy let alone appropriate exchange.

Over the years, the habit of disassociation became
so ingrained in my personality that it invaded every
nook and cranny of my life. I simply expected all of
us to live that way as a matter of course. It wasn’t
that I consciously valued that attitude toward life;
but so powerful was its attraction, so difficult was it
to switch out of it, that I found myself living with it
more and more. What had begun as a technological
tool became over the years a dominating force in my
life. (Hilfiker, *Healing*; 131-32)

Human alienation prevails to the extent that even those physicians who wish to connect more
intimately with their patients and colleagues find that the constraints of time, tradition,
education and culture inhibit most attempts at relationship. In the end, the positivistic and
technocratic medical gaze divides the totality of the body into evidentiary fragments which fail
to yield the more profound sustenance of meaningful narrative.

A solution to the clinic’s callous tendencies lies perhaps in the incorporation of
empathic witnessing. But while empathy’s constructive role in human relations seems clear, the
type of witnessing which would apply to caring for the vulnerable is more opaque. Usually, the
consciousness associated with witnessing arises from two realms: the juridical and the religious.
Legally, witnesses are observers who provide testimony to be judged in court. They fall under
the rubric of law and can be deemed to be dubious or credible. Alternatively, in religion, individuals witness divine acts. Subsequently, they recount stories about their numinous experiences which often become parables of learning. This second type of witnessing appears closest to the proposed empathic witnessing. It contains the narrative and moral dimension which Kleinman hopes to introduce into medical practice. Unfortunately though, neither model of witnessing proves adequate in the medical realm. The primary fault lies in that witnesses only experience agency in story-telling, but not in action or decision-making. They are judged but do not have the power to judge. Given that medicine decodes and treats sickness, doctors cannot be witnesses alone when they are required to be judges, juries and, sometimes metaphorically gods, with regard to disease. The clinic’s positivist stance cannot tolerate the passivity of a raconteur, however inspiring the plot. In the end, clinicians cannot be empathic witnesses while they remain arbiters of power within the clinic.

The possibility for physicians to become empathic witnesses thus appears remote. Kleinman ignores the political climate within which clinical relationships take place. He focuses on problems of language and morale without recognizing the larger sphere in which they occur. Ultimately, the inability to listen to patients and partake in the construction of meaningful biography is not simply an issue of attitude, it is more fundamentally one of epistemology and power. The medical nosology simply does not comprehend details which cannot be categorized. It limits itself to sensate understanding; knowing only that which can be materially observed. Its focus obscures all other forms of perception, interpretation and narrative. Accordingly, as Sontag and Frank both assert, the clinical environment cannot support psycho-social and spiritual intervention. More importantly, practitioners cannot and
should not appropriate the language of biography and morality when their impoverished communicative circumstances remain unchanged. Kleinman’s well intentioned advice to physicians to stop being aloof observers and become engaged witnesses thus seems almost futile when examined in the context of the powerful spatial, perceptual and verbal constraints of the clinic.

Alternatively, Foucault pays tremendous attention to political culture. The exercise and manifestation of power, particularly in the form of thought and discourse is central to his writing. Instead of regarding medicine as a benevolent and sometimes ill-advised endeavour, he sees it as a social institution exerting force on both its practitioners and its patients. "It judge[s] immediately and without appeal." (Foucault, FR; 155) In the Foucauldian panorama, the formation of parole (speech) and regard (observation) into one oppressive gaze has its roots in the legality of the autopsy and, in the subjugation of the poor in the hospitals of eighteenth century France. While Foucault outlines the dominance which pervades the clinic, he refuses to condemn its oppressive weight. Instead he likens it to a mortal desire to outmaneuver death.

[F]medicine offers modern man the obstinate, yet reassuring face of his finitude; in it death is endlessly repeated, but it is also exorcised; although it ceaselessly reminds man of the limit that he bears within him, it also speaks to him of that technical world that is the armed, positive, full form of his finitude. (Foucault, Birth; 198)

Foucault’s critique therefore stops short of indictment. Positivism requires an object upon which it exerts mastery. Alienation and domination are the inevitable products of the discipline
of observing and categorizing illness. And medicine, in employing a distinct and discrete language which oppresses and silences, remains true to its origins.

While Foucault dissects the anatomy of power in medicine, he avoids comment on the suffering which it occasions. When patients are subjugated, they suffer injustice. And given that they are physically and emotionally vulnerable, their subjection is even more keenly felt. When ill people become categorical diseases as manifested in laboratory tests and radiological scans (and not even in the symptomology of their bodies), when they lose their names to serial numbers and their clothes to uniform blue gowns, when their voices speak but remain unheard and when their epiphanies are irrelevant (most tragically for the dying), they lose themselves. Humans who have no access to subjective perception and expression, no longer have personal agency. The feminist mantra that the personal is political is nowhere more true than in the clinic. Within this institution, individuals experience a depletion of political power that is felt acutely at the most intimate and spiritual of levels.

For example, the patient narrative which appears at the opening of this chapter is my own. I wrote it within a couple of years of experiencing an inaugural bout of weakness and paralysis. Understandably, the illness itself astonished me. However, I was transfixed not only by my physical powerlessness but also by the impotence of my being within the culture of the hospital. Lacking the knowledge that subsequent hospitalizations would bring, I nonetheless inferred that I had not only crossed a great physical and emotional chasm when falling ill, but that I had also traversed a socio-political divide in becoming a patient. As a human being I experienced an ontological crisis. My sickness induced a profound questioning of my very being. And my narratives (both spoken and written) attempted to capture the enormity of the
existential crisis brought on by hospitalization. They sought to express the alienation I felt as a patient. Patienthood, as well as illness, created a breach in my being. To paraphrase Rousseau, in becoming an object of the medical gaze, my existence was defined by the perceptions and opinions of others. Clinical action and discourse treated me perennially as an object and my subjectivity disappeared. I felt disempowered physically, spiritually and politically. While my dysfunction drove medical care in the form of tests, examinations and scans, I had little or no say in what, where and how my care would be performed. This was most obviously expressed in the many scenes in which groups of physicians gathered around my bed and addressed themselves to my body (and subsequently to procedures, scans and lab results) but not to me. My identity was superseded by a disease-type and by notations made in the medical chart. I was intensely aware that the story of the medical record varied widely from my own, and yet, it nonetheless defined and ruled my existence. Its tyranny was complete.

As lay experiences and accounts become increasingly distanced from those of formal medical understanding and charting, a fissure forms not only between the patient and practitioners, but in the self. An embattled situation develops as the patient tries to reconcile the illness experience with the description and dictates of attending clinicians. Individual patients often attempt to bridge the discursive gap by adopting medical terminology to describe their own lives. Instead of living within the experience of illness, they try to become observers of themselves. But by appropriating the clinic's positivist posture, they experience a split from

32 "...[T]he man accustomed to the ways of society is always outside himself and knows how to live only in the opinion of others. And it is, as it were, from their judgment alone that he draws the sentiment of his own being." (Rousseau, 1754; p.81)
within: they cannot be both subject and object. Furthermore, the clinic is unsuited to accommodating patients who wish to partake in the construction of the medical narrative itself. Consequently, patients conflict with themselves and with their environment. Already weakened by infirmity, inevitably they yield to the puissance of medical authority and narrative. Nonetheless, an underlying tension remains: illness and disease create separate stories between which the individual is constantly torn.

The predominance of medical narrative creates a disturbing aspect in the clinic: a widening chasm which separates the well from the unwell. While the politic of this abyss may be comprehensible, it is not without consequence, particularly when viewed from the perspective of an over-wrought doctor or a vulnerable patient. In medicine, shared events produce discrepant chronicles and opinions. Two narratives emerge which depict divergent interpretations of human mortality. The positivistic and technological one predominates. The lay voice, the one which expresses emotion, spirit, morals and, ultimately, weakness has little choice but to submit. Nonetheless, the inherent pain associated with vanquishment cannot be

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33 My friend, Rea Wilmshurst, who died of cancer, kept a journal itemizing her facts: when she had a bowel movement, when she vomited, logs of her meals, when and how much she urinated, how long she slept, among many other details. She kept her notes precisely to share with her doctors. But her surviving partner informs me that her care givers almost never asked her such questions, let alone sat down with her to glean her observations. And from the perspective of an acquainted reader, her diary would be so much more valuable if it housed far more of her own narrative.

Ian Hacking sees the appropriation of medical terminology in a different light in his book on multiple personality disorders. Here he outlines how psychiatrist and patients worked together to build a diagnostic-type that is unrecognized outside North America. According to Hacking, by inferring to one another and self-referencing that a disorder might exist, the category of MPD was created. My only comment about this is that I view psychiatric diagnoses to be distinct from physical medicine ones. A slightly variant culture exists in psychiatry. Given the non-tangible concerns of mental health, psychiatry must take a far less rigid stance than other clinical subspecialties. Because it cannot adhere to positivistic procedure, I believe that diagnostic categories in this field are far more fluid and influenced by external culture than elsewhere in medicine.
dismissed. Ailing persons suffer illness and then suffer doubly again from the impotence and censure of becoming a disease.
Chapter III
Hysteria

Introduction

When an individual makes a doctor's appointment, s/he presumes that the attending physician will either be able to comprehend, help or cure symptoms which interfere with normal living. Medicine, thus, offers the hope of a return to health. Seldom does the patient entertain the possibility that perhaps the health care professional will not know, will not understand and will not help alleviate pain and suffering. But, what if, as so often happens,¹ the doctor can find no reason for the crippling back pain, the overwhelming fatigue, the loss of voice, the shortness of breath? What if all the laboratory results come up with nothing and the scans are negative? The patient does not have a slipped disc, cancer, leukemia or asthma. At this point, the doctor cheerfully says to the patient: "Good news! There's nothing wrong with you! Go home." Usually, the patient goes home and tries to get on with life. But if the problem persists, the person encounters a conundrum: she or he cannot legitimately adopt the

¹ Some medical journals report that up to 1/3 of patients present with psychosomatic problems when visiting a general practitioner. Others say that between 5-20% of patients have unexplained physical symptoms. These individuals are presumed to have somatoform disorders (Rief, 529; Kroenke, 263).
sick-role because, according to the physician nothing is wrong, and yet subjectively, a great deal is wrong. Normal life is not possible. In this scenario, the divide between medical understanding and lay experience becomes acute and often unbreachable.

Within medical nosology, a distinction exists between illnesses which are thought to be "organic" (i.e., originating in the body) and "functional" (i.e., originating in the psyche). As such, physicians categorize patients according to whether they can find physical evidence of disease. So, when an individual is sick without apparent medical cause, a referral to psychiatry is often made because a functional diagnosis seems appropriate. In the past, such illnesses were known as "hysteria" or "Briquet's syndrome." Today, hysteria, per se, as a diagnostic category no longer exists. The Diagnostic and Statistical Manual of Mental Disorders IV speaks instead of "histrionic personality disorder" "somatization disorder," "conversion disorder," "hypochondriasis" and/or "malingering" in categorizing such ailments.

Yet despite the fact that hysteria has disappeared from the official parlance of the clinic, it remains an object of avid interest in many circles. The historian, Mark Micale, refers to this academic prurience as the emergence of 'new hysteria studies.' Conceptually, hysteria has never gone away. Most obviously, it remains alive today in the characterization of somatoform disorders. More subtly, many scholars claim that its dramatic profile has re-emerged in the diagnosis of 'dissociative identity disorders' (multiple personality disorders); in tales of ritual, satanic abuse and of alien abductions; in the controversy between 'recovered memory' and 'false memory' advocates as well as in the diagnoses of 'chronic fatigue syndrome' and 'Gulf War syndrome.' (Hacking, RTS; passim; Showalter, Hyst.; passim) As the feminist theorist, Elaine Showalter, adroitly states: "... [H]ysteria has not died. It has
simply been relabeled for a new era . . . . Contemporary hysterical patients blame external sources — a virus, sexual molestation, chemical warfare, satanic conspiracy, alien infiltration — for psychic problems." (Showalter, Hyst.; 4) Histrionic people, in short, resist psychological interpretations for illnesses and dysfunctions. They seek, instead, extrinsic causes for personal problems.

Alternatively, there are other physicians and academics who adopt a different stance on the disease. In their eyes hysteria is not a psychic phenomenon but rather a categorical one. People suffer from ailments for which we, at given times and places, do not have names. Our ability to classify distinct malaises depends, to a large extent, on social norms and cultural beliefs. Further, the process of diagnosis is one of grouping bodily signs into categories that seem to make sense pathologically and seem to match the community's social resource pool. Diseases are thus not concrete entities, but rather fluid concepts which change according to the limits and dictates of social and medical knowledge. Hysteria and its counterparts thus serve as amorphous categories for lumping together symptoms which are not fully understood by a society at any given time.

The debate between those who believe that hysteria is alive and well as a human psychological trait and those who believe that the diagnosis is a manufacture of clinical hegemony falls fundamentally and confusingly into the debate about the nature of the mind-body connection. It is mired in the controversy between those who conceptualize the psyche and soma as an interconnected and amorphous entity and those who see a clearer distinction between that which is physical and mental in human life. As a result, discussions about hysteria provoke intense passion. In speaking and writing about hysteria it seems that individuals must
ally themselves with one camp or the other. Unfortunately, this does not create much clarity with regard to the overall meaning and significance of hysteria within clinical practice.

My own position in the contention over this disease lies somewhere between the two extremes. I believe that, in as much as hysteria and its heirs are diagnostic codes that medicine continues to apply to patients, hysteria does exist. But with regard to the relationship between mind and body, I am willing neither to fully endorse psychosomatic disease profiles nor dismiss them. It seems to me that no division can truly exist between the psyche and soma. Thus, in my view, all disease and syndromes are both functional and organic. Unfortunately, disease categories do not adequately address the latent mind-body holism that I believe is inherent in human beings. While somatoform diseases theoretically attempt to bridge the mind-body divide, they nonetheless remain an expression of objective scientific classification. And, as I discussed in the previous chapter, the division between objectivity and subjectivity in medical diagnosis creates a sense of dissonance between the experiences of practitioner and those of the patient. In the case of hysteria, this becomes quite extreme as the subjective symptoms of the patient remain inaccessible to the objective scrutiny of the clinician. In this chapter, I argue that this dissonance greatly undermines medicine's attempts to treat psychosomatic disease without resorting to stereotypes which undermine patient autonomy.

Consequently, my examination of hysteria in this chapter purposely tries to avoid the medical and academic controversies which surround the confusing interpenetration of mind and body. Although, it does tend to focus on the presence of somatoform disorders as the most commonplace persistence of hysteria in the modern day clinic. I am interested primarily in the way in which medicine — and society — mobilizes against those who are diagnosed with
hysterical disorders. Consequently, this chapter explores the historical evolution and conception of hysteria over time. It looks at the gender and sexual stereotyping that has been typically associated with psychosomatic diseases. These presumptions about gender and sexuality have traditionally marginalized and disempowered hysterical patients. In being viewed as less than fully enfranchised human beings, these individuals fall prey to truistic characterization. Hysteria is thus a disease which encompasses the limits of medical knowledge and effectively articulates the way in which disease categories are both scientific and social constructs.

Hysterical disorders starkly elucidate the possibility for dichotomous tension between patient and doctor—between subject and object—in the clinic. And as such, hysteria serves as a dramatic portrait of the exercise of power between patients and practitioners in medicine. Consequently, despite the best of medical intentions, I posit that hysteria can easily have devastating consequences for those who have the misfortune of acquiring its label.

The History of Hysteria

The history of hysteria extends over a number of centuries. The term "hysteria" comes from Ancient Greek, meaning "uterus." And the term which has replaced it in current medical parlance, "histrionic," comes from Latin and means "actor." Across time, its etiology has been located in the womb, in religious heresy, in the nervous system and finally in the psyche. It has been treated socially, surgically, psychoanalytically and behaviourally. Perhaps the only consistent themes which emerge through time with regard to its definition and treatment are the drama of its physical presentation and its ongoing connection with antisocial behaviour.
Hysteria traces its origins to the ancient worlds of the Middle East and Greece. Apparently, an Egyptian medical document of 1900 B.C. attributes odd behaviours in women to the displaced movement of the uterus upwards into the chest. Physicians remedy this by burning herbs and incense near the vagina to entice the organ to drop back into place. The Greeks and Romans modify this view. They believe that the illness is the result of a "starved" womb. The woman is afflicted because she is not fulfilling her reproductive role. A cure is thought to be found in immediate marriage and in the bearing of children. In the ancient world, then, the disease is eroticized. The re-sexualization of the hysterical woman prevents her reproductive organs from becoming restless and wandering through the body (Micale; 19). She is thereby restored to health.

In the Middle Ages, Europeans tend to view all illness as a form of divine curse and St. Augustine writes about ailment as a manifestation of evil. However, hysteria is particularly attributed to satanic influence. During this time, hysterical women are shunned and despised. Accordingly, physicians believe that witchcraft is the likely origin of symptomology. The *Malleus Maleficarum* of 1494 is perhaps one of the best known tracts which advocates the punishment of bewitched and demonically possessed women. The church exorcized, excommunicated, tortured, executed and (sometimes) sanctified hysterics. In 1603, Edward Jorden, an English physician, describes the case of Mary Glover, a woman who exhibits neurological symptoms that become increasingly dramatic when an apparent witch casts a spell upon her and, as a result, church authorities become involved in her case. Jorden tries to argue that Glover's symptoms do not belong to the religious realm but rather to the pathology of medicine (MacDonald; passim). In the medieval era, the correlation of hysteria with aberrant
social behaviour is thus fortified by its association in the popular imagination with the presence of demonic artifice.

In the seventeenth and eighteenth centuries, physicians return to thinking about the disease as one that originates through the contagion of the uterus. Ironically, the disease is now conjectured to be the result of excessive, rather than impoverished, female sexual desire. However, other new etiological theories also appear which attempt to construct a link between the brain and physical symptoms. Most famously, Thomas Sydenham describes hysteria as the result of an extreme spiritual imbalance between mind and body. He suggests that the illness arises out of the acute emotionality of women. While he focuses on women, he also identifies "hypochondriasis" in men. Nonetheless, despite his hypothesizing, hysteria's erotic characterization reemerges during this period even as its diabolic imagery recedes. Therapeutic surgeries on the reproductive organs consequently emerge and manifest a refocusing on sexuality as the conceptual basis for hysteria. The use of hysterectomies and female castrations during this era also points to doctors' very concrete attempts to construct a link between the realm of the emotions and the symptomology of the body.

The therapist, physician and feminist, Judith Herman, refers to the nineteenth century as "The Heroic Age of Hysteria." Pierre Briquet, Pierre Janet, Jean-Martin Charcot and Sigmund Freud all undertake major studies and write about hysteria. Pierre Briquet composes a treatise about potential therapies in which he emphasizes the central role of emotion in the disease. Janet expands this premise by arguing that hysteria is a form of mental illness. He

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2 Jeffrey Masson has transcribed some of these medical cases in a rather horrifying and almost unreadable text entitled: *A Dark Science: Women, Sexuality and Psychiatry in the Nineteenth Century.*
asserts that physicians need to bypass physical signs and symptoms and instead focus on the altered states of consciousness which are associated with the ailment. "Janet propose[s] that these psychological phenomena [are] the result of emotional traumas that [weaken] the synthesizing abilities of the healthy human psyche." (Micale; 26) These psychological lesions consequently reverberate through the individual’s life and become manifest in his/her body and behaviour.

Across the ocean, in North America, physicians also confront the problem of the ‘female malady.’ The American clinician, S. Weir Mitchell develops the rest cure as a remedy. His treatment relies upon the exercise of absolute authority by the doctor over the hysteric. The physician removes the afflicted woman from her family and puts her to bed for six weeks. She is not allowed to read, move, sit up or get up. During the first two weeks nurses feed her 4 ounce servings of milk every two hours (Bassuk; 142). She is reduced to an infantile state. Gradually, her doctor prescribes her more and more activity. If her symptoms reappear, she is returned to bed. After 6-8 weeks, Mitchell pronounces that the patient is cured and returns her home where she resumes her domestic duties.\(^1\) Mitchell’s treatment focuses on the need to restore the woman to her functionality within the family.

Perhaps, the most legendary examination of hysteria is undertaken by Jean-Martin Charcot at the L'Hôpital Salpêtrière in Paris during the late nineteenth century. A mentor of Freud’s, Charcot makes a career of studying the disease. The Salpêtrière houses probably the largest population of hysterical women in history under its hospital roof. Here,

\(^1\) Charlotte Gilman Perkins writes about her experience of the rest cure in "The Yellow Wallpaper." She feels that its passive and infantile regimen nearly drive her mad.
Charcot fashions a radically new approach to the disease in which he attributes hysteria to a dysfunction of the central nervous system. He firmly believes that its origins lie not in evil spirits, nor in psychology, but in some unseen pathology of the body. Charcot identifies an hysterical pressure point on the abdomen, which, when pressed, induces a fit in his patients.

Quixotically though, the grand theatre of his clinic creates controversy about both his diagnostic methods and his medical analyses. The disproportionately large number of hysterics situated in Paris, in relation to other European cities of the time, incites suspicions as to what Charcot is in fact ‘seeing’ in his patients. Many of his hysterics are indigent women, and concern arises as to whether some of them are consciously or unconsciously performing hysteria for their food and shelter and to satisfy both their own and Charcot’s egos. In her work, *The Female Malady*, Elaine Showalter goes into considerable detail about the spectacle of hysteria and Charcot’s experimentations with hypnosis. She writes:

> Because the behaviour of Charcot’s hysterical stars [is] so theatrical, and because it [is] rarely observed outside of the Parisian clinical setting, many of his contemporaries, as well as subsequent medical historians, [suspect] that the women’s performances [are] the result of the suggestion, imitation, or even fraud. (Showalter, 1987: 150)

It seems likely that a symbiotic relationship exists between the French physician and his patients in which he needs them to sustain his teaching clinic and notoriety while they in turn need him for their sustenance and self-respect. In the end, the clinical theatre of the Salpêtrière points to the extremely interesting and often confounding relationship which arises between clinicians and patients in the diagnosis of hysteria.
The most influential nineteenth century investigator of hysteria is Sigmund Freud. He proposes that the roots of the illness lie in an individual converting traumatic psychic phenomenon into somatic symptoms. In *The Aetiology of Hysteria*, he claims that the patient's efforts to suppress the sexual traumas of childhood produce a multiplicity of symptoms ranging from seizures to anaesthesia. Later, Freud modifies his trauma theory with the belief that semiconscious sexual fantasies (as opposed to traumas) become expressed in bodily symptoms. Judith Herman calls the discussion in Freud's text "brilliant, compassionate" and "eloquently argued." (Herman; 13)

Freud's treatment, while sexually based, focuses on the 'psychoanalysis' of patients. The analyst probes the patient's psyche looking for evidence of sexual themes. Perhaps one of the most famous of these talking cures was Freud's collaboration with Joseph Breuer in the treatment of Anna O. Here clinician and patient work together to unearth the richness of memory and unconsciousness. Unfortunately, Freud's other famous case, that of Dora, was less apparently successful. Analyst and analysand are combative and Dora leaves his

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4 While Freud wrote many descriptions of hysteria, a nine point analysis of hysterical symptoms appears in the *Collected Works Volume II*:

1. The hysterical symptom is the memory symbol of the operation of certain (traumatic) impressions and experiences.
2. The hysterical symptom is a substitute, produced by 'conversion,' for the reactivation of these traumatic experiences by association.
3. The hysterical symptom is, like other mental products, the expression of wish fulfillment.
4. The hysterical symptom is the expression of both a masculine and a feminine unconscious sexual phantasy. (pp. 55-57)

5 As a consequence, the twentieth century psychoanalyst, Jeffrey Masson, will criticize Freud for abandoning his patients and not validating their early childhood sexual experiences. Both Masson and Herman feel that Freud bows to social pressures when he revises his theory of hysteria.
care prematurely. Nonetheless, psychoanalytical theory is founded almost exclusively on

Freud’s conception of hysteria as the perverted and somatized expression of erogenous desire.

But the most important result arrived at by such a consistent pursuit of analysis is this: whatever case and whatever symptom we take as our starting point in the end we infallibly come to the realm of sexual experience. (Freud, CP I; 193)

Unlike Charcot, Freud places sexuality at the core of his understanding of hysteria as a nervous disorder. He writes: "Detailed investigations during the last few years have led me to the conviction that factors arising in sexual life represent the nearest and practically the most momentous causes of every single case of nervous disease." (Freud, CP I; 220) It is in Freud’s theories that we see both the fulfillment of ancient erotic conceptions of the disease and the basis for twentieth century explorations of the human unconsciousness.

The Great War of 1914-1918 produces a new type of hysteric. Mental breakdowns of men on the battlefront become commonly known as "shell shock" because originally it appears as though the soldiers are suffering the after effects of explosive bombs and artillery. It is soon discovered that many men who suffer from inexplicable paralysis, shaking, crying and muteness have not been exposed to any physical injury. Two schools of medical thought emerge: (i) the men are simply moral cowards and, (ii) the men suffer from the devastating psychological toll of "unremitting exposure to the horrors of trench warfare." (Herman; 20) For doctors who believe that the soldiers are finding a way to shirk their duties, public humiliation, physical and psychological punishments become the mainstay of treatment. For other physicians, such as W. H. R. Rivers, who "cures" the renowned poet, Siegfried Sassoon, psychoanalysis becomes the principal remedy. These two different approaches
forecast the dichotomous strategies that will be used to combat the disease for the rest of the century: (i) behavioural and, (ii) psychoanalytical.

The psychoanalytical approach to hysteria gains more prominence both during and after the Second World War. Doctors treat war neuroses with talk therapy in close proximity to the front. They discover that soldiers mend more quickly when traumatic events are recalled through hypnosis and the use of narcotics such as sodium amytal. Further soldiers return to active duty more quickly particularly when physicians encourage their ties of love and fealty to their immediate soldiering comrades. Yet, despite this more apparently humane treatment, the belief remains strong in the clinic that these hysterical men are "suffering from some persistent form of wickedness, perversity, or weakness of will." (Kardiner; 406) Moreover, little attention is paid to the long term effects of this type of psychological trauma. As a result, the veterans of the Vietnam conflict in the 1960s and 1970s will turn to self-help or "rap" groups which attempt to more permanently cope with the neurotic results of longtime combat exposure.

Despite the rise of psychoanalysis as the apparently primary mode of treatment for hysteria, confusion still exists as to its origins and remedies. In the 1960s and 1970s, the French psychoanalyst, Jacques Lacan, creates a discourse about power and sexuality in hysteria. In this context, hysteria becomes a wonderful tool for exploring the dynamics of psychoanalysis and issues of gender in both society and the clinic. Feminists take up this critique both attacking and honouring hysteria as a form of primarily female rebellion against male social oppression.6

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6 I will explain both the Lacanian and feminist approaches to hysteria in a bit more depth later in the chapter.
Amidst the debates, hysteria *per se* understandably disappears from the diagnostic manuals and is replaced by "conversion reaction", which becomes in the 1990s "histrionic personality disorder." Perhaps, it is hoped, that these will be less contestable terms. Finally, in an effort to improve treatment efficacy, clinicians increasingly incorporate behavioural modification techniques with psychotherapeutic approaches in the 1980s and 1990s.

Historically then, hysteria has thus always been associated with some form of social dysfunction in the afflicted individual. As well, the manner in which it diagnosis is imbued with sexual metaphor has not really diminished over time. Today, clinical approaches to these disease inherit many of the prejudices of early social, religious and medical conceptions. Amidst the confusing and interpenetrating interpretations of hysteria, the attempt to maintain an objective clinical stance with regard to its dissembling symptomology remains a consistent theme. The exercise of a stabilizing authority (whether, social, religious, military or medical) seems to be paramount in attempts to subdue this disease. Its modern manifestations cannot escape the insinuation of sexual, social and political themes despite innovative and often contradictory theoretical and treatment approaches to the disease.

**Gender and Sexuality in Hysteria**

New diagnostic terminologies do not obviate the sexualization of hysteria in the clinic. Historically, both gender and sex play a significant role in the conceptualization and treatment of the disease. From the early Greeks to the modern era, medicine perceives that women are primarily at risk. For the minority of men who suffer from the ailment, they are often seen to be effeminate and even morally corrupt. Consequently, hysteria inevitably
involves judgements about the gender and sexual inclination of those who are labeled with the disease. Whether, male or female, the patient often cannot dispel the aura of sexual misconduct or perversity which is attached to conversion and somatoform disorders.

Historically, medicine has little knowledge of female psychology or anatomy. Much of what is supposed to be true about the human organism has been gleaned from research on men. Theorizing about feminine biology is thus often an extrapolation from male anatomy. As a result, what is female, or different, is often pathologized. The French psychoanalyst and feminist, Luce Irigaray writes: "As a particularly ‘honest’ man friend told me not so long ago, not without some astonishment at his discovery, ‘It’s true, I have always thought that all women were mad.’" (Irigaray; 35) There is good evidence that physicians perceive women’s maladies to be largely the result of emotionality and thus they give little credence to women’s suffering (Smith; 31-32). If doctors understand little about women and/or believe that their ailments are psychosomatic, then it seems likely that these doctors will treat women as either aberrant or hysterical or both. It is not surprising then that the persistent association of the female sexuality with emotional lability means that women seem to be diagnosed with hysterical disorders more often than men.

While physicians know that men, particularly combat soldiers, suffer from psychosomatic diseases, they are unwilling, for the most part, to diagnose them explicitly as hysterical.

. . . [M]edical writers creatively, and most likely unconsciously, [deploy] a series of strategies of resistance that allowed them to discuss the subject of hysteria in adult males while avoiding, or at least minimizing, the psychological and sexual
ramifications of the idea. Included among these strategies [are] the use of alternative, technical sounding terminologies to diagnose male patients, the ascription of unknown organic etiologies to cases involving men, limitation of the label to adolescent boys or effeminate men, and the illustration of the diagnosis with cases drawn from socially and ethnically stigmatized populations. (Micale; 165)

As a result, doctors employ terms such as neurasthenia, shell-shock, combat fatigue and nervous exhaustion to describe men whose symptoms did not fit known diagnostic categories. Nonetheless, all of these expressions indicate a form of hysterical reaction as far as medicine is concerned.

On the whole, two types of male hysterics emerge from the literature. The first tends to be those who suffer from some sort of combat trauma and the second tends to be those who are socially marginalized such as poor, immigrant or homosexual men. A contemporary example of military hysteria comes from the Gulf War. In the 1990s, veterans from this war suffer from a multiplicity of symptoms ranging from impotence and fatigue to respiratory and motor problems. These are placed under the rubric of "Gulf War Syndrome." Many, including the feminist scholar, Elaine Showalter, attribute this malady to some sort of hysterical reaction. Medicine has yet to discover a physical basis for the soldiers' symptoms and thus British and American governments perceive that Gulf War syndrome as less a real manifestation of physical trauma and than a manifestation of psychological stress from soldiering in a potential chemical war battle zone. Many veterans are thus ineligible for compensation or benefits from their
respective governments. Alternatively, civilian men who suffer have hysterical disorders tend to be young, effeminate and/or immigrants or poorly educated. As one psychiatrist tells me, somatizers are seen to be less sophisticated than their contemporaries and tend to come from non-industrialized regions. A good example of this type of stereotyping appears in *DSM-IV*: "Somatization Disorder occurs only rarely in men in the United States, but the higher reported frequency in Greek and Puerto Rican men suggests that cultural factors may influence the sex ratio." *(DSM-IV; 447).* With regard to conversion disorder the manual reports that it is found more commonly in rural populations and developing regions *(DSM-IV; 455).* It seems likely that, in order to protect men from a desexualizing diagnosis, the *DSM IV* no longer explicitly speaks of hysteria but rather refers to histrionic personality disorder, and somatoform disorders. These categories can be more appropriately applied across genders.

In her book, *Trauma and Recovery*, Judith Herman makes the interesting and engaging argument that the increased awareness that men suffer from psychological trauma has encouraged the recognition of traumatic stimuli in women. The recognition of war neuroses allows society to more clearly apprehend the post-traumatic symptoms of women who suffer from domestic oppression, silence, sexual abuse and rape. Herman argues that the creation of social and psychological spaces to recount the wounds and persecutions of women in a male

\[\text{Ailments such as Fibromyalgia and Chronic Fatigue Syndrome also suffer from this characterization. For example, individuals suffering from these syndromes in 1999 cannot qualify for disability benefits in the province of Ontario without the presence of one other major psychiatric or medical diagnosis. Without proof of the organic or functional basis of these illnesses, authorities tend to see these disorders as justification for neither physical nor psychiatric disability. It is in policies of this type that medicine and society express their deep ambivalence toward ailments which seem to lie confusingly between organicity and functionality. As it stands, it seems that they are perceived as illegitimate and therefore ineligible for support.}\]

\[\text{Given a North American propensity to stereotype "Mediterranean" men as more emotionally labile than their male counterparts elsewhere, perhaps this contributes to the clinic’s perception that these individuals somatize more easily.}\]
dominated society is politically and scientifically significant. She refers to the National Institute of Health’s 1975 creation of a research centre on rape. She writes: "As in the heroic age of hysteria, long and intimate personal interviews [have become] once again a source of knowledge." (Herman; 30) Only through these types of exercises is it determined that domestic and sexual violence is akin to combat trauma. But even Herman admits that these advances in psychological recognition are tenuous. "To hold traumatic reality in consciousness requires a social context that affirms and protects the victim and that joins the victim and witness in common alliance. . . . For the larger society, the social context is created by political movements that give voice to the disempowered." (Herman; 9) If political will is weak or absent, then the victim is silenced and devalued. The credibility of the hysterical comes to be questioned.

Throughout the history of the field, dispute has raged over whether patients with post-traumatic conditions are entitled care and respect or deserving of contempt, whether they are genuinely suffering or malingering, whether their histories are true or false and, if false, whether imagined or maliciously fabricated. (Herman; 8)

The legitimacy of the psychological impact of combat, as well as domestic and sexual, trauma fluctuates according to medical and social beliefs. The study of hysteria is thus politically charged. Its recognition tends to revolve around political and moral controversies which focus on gender and sexual stereotypes. The re-occurrent social inference is that good men (i.e., good soldiers and manly men) and good women (i.e., women who don’t invite rape) don’t suffer from confusing and ill-defined somatic complaints.
Historically, presumptions about gender tend to be tied to judgements about sexuality. Because hysterics do not necessarily fulfill their gender specific roles and obligations, their sexuality also comes to be questioned. Medical portraits of hysteria often include discussions of sexual dysfunction and deviance. In this sense, the DSM-IV's histrionic personality disorder is decidedly an etiological descendant of the ancient Middle Eastern and Greek ruminations on the centrality of sexual desire in hysteria. The medical text states: "[t]he appearance and behavior of individuals with this disorder are often inappropriately sexually provocative and seductive." (DSM-IV; 655) Beginning with Freud and moving into the twentieth century, modern conceptualizations of hysterical disorders come to embody a variety of theories; nonetheless most of them inherit a preoccupation with sexuality from their temporal and conceptual predecessors.

The nineteenth century writings of Sigmund Freud, in effect, legitimate the sexualization of patients for whom systems of medical classification have no explanation. His original theory of hysteria is called the seduction theory. Here, Freud outlines that the root cause of somatization lies in early childhood sexual trauma. This trauma acts as an emotional and unconscious touch point in the adult life of an individual. During psychoanalysis Freud's female patients reveal that it is most often middle aged men (fathers, brothers, uncles, etc) who inflict these sexual-psychological injuries on children. Interestingly, despite its sexual overtones, the seduction theory falls squarely within the tradition of medical disease modeling

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9 It is only recently that psychologists, academics, feminists and gay activists have drawn our attention to the distinctions between sex, gender and sexuality. Sex is a biological or anatomical characteristic. Gender refers to the identification with masculine or feminine attributes in an individual. And sexuality delineates the inclination of an individual towards heterosexuality, bisexuality or homosexuality.
in that it tries to locate the origin of hysteria in some identifiable event (Evans; 73). But Freud is discomfited by the apparent perversity which underlies his theory and thus, he comes to assert that the trauma is effectively self-induced through the suppression of sexual fantasies or desires on the part of the patient. "The hysterical - who, in line with Freud's revised theory, has now traded places and become the seducer and not the seduced..." She becomes an allameuse, or in other words, a sexual tease (Evans; 77, 78). Accordingly, hysterics shrink unnaturally from the demands of sexuality. As a result they either behave too provocatively or are too inhibited in front of men. Given this perspective, Freud decides that his fourteen-year-old analysand, "Dora" (Ida Bauer), recoils inappropriately from the sexual advances of the middle-aged Herr K. Further he does not see Herr K's actions as objectionable. Instead, he concludes that he would consider any person hysterical if s/he finds discomfort in a situation which, in Freud's own view, should elicit sexual excitement (Freud CP III; 37). Freud concludes that Dora's somatic complaints are the result of her unwillingness to engage in sexual play despite her strong unconscious and natural desires to do so. Her trauma, in effect, manifests itself in her conversion of unfulfilled and guilt-ridden erotic desires into physical symptoms.

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10 Here, Freud imposes the erotic values of middle-aged males (himself, Herr K. and Ida's father) upon an adolescent female. The medical sociologist, Brant Wenegrat writes:

Few cases in the psychoanalytic literature show such a complete failure of rapport between analyst and patient as evident in Ida's case. Freud [finds] nothing remarkable about Herr K.'s attentions. His theory of sexuality [leads] him to assume that if Ida [finds] these disgusting, as she claim[s], then it must be because her sexual drives [are] subject to repression. . . . Nor [does] Freud consider what it mean[s] to be traded for her father's satisfaction or what it mean[s] to her to have Freud, whose fees her father pays, tell her there [i]s nothing wrong. (Wenegrat; 67)
Because hysterics misconstrue their sexual roles, "the hysterical fit is an equivalent to coitus." (Freud, CP II; 104) In analysis, memories of childhood sexual abuse are not literally true but rather forms of 'pleasurable, auto-erotic gratification,' akin to what is now referred to as sado-masochistic desire (Freud, CP II; 173). Consequently, no girl or woman is 'innocent' in terms of her state of mind (Freud, CP III; 61). Females are simultaneously corrupted and corrupting. They are both consciously and unconsciously manipulative, and an analyst requires the utmost vigilance in not succumbing to the sexual advances of the analysand.

The critic, Martha Evans writes: "...Freud's theoretical manipulation of hysteria depends precisely on the fantasy of a feminine patient and a masculine authority figure." (Evans; 75)

Both her unconscious drama as well as her erotic desire woo the analyst at his own peril.

In general, whether yielding to anger or to desire, the analyst, represented as playing the male role in this romance, appears to feel undone by the hysteric, who perpetually attempts to dislodge him from his place as an authority. (Evans; 78)

As the protector of clinical ascendancy, the analyst must repel the sexually perverse, but nonetheless powerful attractiveness of the hysteric. Clinically then, the hysteric possesses the qualities of not only a sexual but an intellectual seductress for the analyst. Thus the psychoanalysis can come to embody the metaphors of a heterosexual liaison.

Interestingly, it is the erotically charged dynamic between hysteric and analyst which comes to fascinate the twentieth century French psychoanalyst, Jacques Lacan. His studies, as well as those of the French school of Freudian thought, focus on the transference which occurs between clinician and patient. The hysteric claims the position of object vis a vis men because this gives her power in rejecting male advances.
The hysteric... emphasizes the partner or Other, making herself into the object of the Other's desire so as to master it. The other is the desiring subject in the hysteric's fantasy... Indeed, the hysteric orchestrates things in such a way as to ensure that the Other's desire is kept unsatisfied, leaving the hysteric a permanent role as object. The Other as desiring subject here is but a puppet: it is the Other whose desire is kept unsatisfied by the hysteric in order for the hysteric to be able to maintain her role as desired object, as desire's lack. (Fink; 123).

The hysteric thus enjoys seeing herself as object so that she can imaginatively construct the man's attraction for her. In this sense, she internally adopts the male's sexual posture while remaining an object of his desire. The French feminist, Julia Kristeva, writes:

Sexualité phallique d'une part, autosensualité en miroir-reduplication de l'autre - l'hystérique n'est donc d'aucun sexe, et se comble d'angoisse de ne pas en être. Lorsqu'il est un femme, sa frigidité ne l'empêche pas de se livrer à une perversion sensorielle, sadomasochique. Il devient la victime de vrais pervers, ou bien il se procure lui-même les symptômes de diverses douleurs, paralysies, degoûts ou vomissements. (Kristeva; 114-115)

*With phallic sexuality on one hand and autosexualty as a mirror reduction on the other, the hysteric is of neither gender, and is filled with the anxiety of being genderless. When the hysteric is a woman, her frigidity does not prevent her from engaging in a sensory and sadomasochistic perversion. She becomes the victim of true perverts, or better she is afflicted with the symptoms of various ailments, paralyses, skin eruptions or fits of vomiting. (Guberman; 73)*

In this sense, the hysteric is open to (and even invites) sexual abuses. Moreover, her perverse sexual desire manifests itself in somatic symptomology.
Understandably, homosexuality, as well as nymphomania and frigidity, falls under the rubric of sexual perversion. From a clinical perspective, currents of homosexuality appear in both male and female hysterics. In this context, male patients may well appear overly aggressive in order to counter their latent effeminate tendencies. (Of course, overtly feminine homosexuals are also more likely to be hysterical.) The relatively high incidence of soldiers who suffer from hysterical disorders reinforces the profile of the gay man who is outwardly macho but inwardly cowardly. In speaking of women, Freud states that if female somatizers are not coquettish, they may well be boyish in character and either covertly or overtly competitive with men (Freud, *CP II*: 104). He postulates that a woman may suppress her heterosexual libido and redirect it towards members of her own sex (Freud, *CP III*: 73-74). Female hysterics can be both simultaneously vamps and/or lesbians. Women who spend a great deal of time with women are suspect especially if they are not seen to be seeking the erotic affection of males. Furthermore, women patients might even be using their physical ailments as a way of enticing other women's amorous attentions. Hysteria and its heir, histrionic personality disorder, are diagnoses which structure the clinic's perception so that it is oriented on sexual abnormality. Whether male or female, straight or homosexual, hysterics are seen to live either in defiance or in the absence of traditional sexual norms.

Psychoanalytically and clinically, then, hysterics are not only sexual phenomena but sexual perverts. Given that the disease-type predominates in females, a woman who experiences diagnostically confusing illness can easily be considered to be experiencing sexual dysfunction. In this way, the erotic reification of women (especially those who suffer from unknown illnesses) finds its way into modern medical text books. The neurologist, Michael
Weintraub states that females who exhibit unexplained or bizarre symptoms and appear coquettish and seductive are immediately suspect (Weintraub; 17). As a result, their physical symptoms are not taken seriously. One psychoanalyst writes of her training at the Meninger Clinic in California during the 1960s:

A serious discussion took place over whether a woman could be designated as hysterical regardless of other symptomology, if she reported that she experienced orgasm during sexual relations. At a less formal level, I sometimes heard male therapists and diagnosticians seriously offer one sure sign that a given woman patient should be diagnosed as hysterical: that the male examiner became physically aroused in her presence. (Lerman; 63)

Thirty years later, the remnants of this type of thinking can be found in DSM IV’s description of histrionic personality disorder as a syndrome which is linked to sexual seductiveness. It seems that the clinic cannot avoid weaving judgments about sexuality into the fabric of certain somatoform diagnoses.

It is not hard to see that clinicians may easily perceive women who assert their own sexuality as perverted or hysterical or both. Sexual tendencies and practices in females such as egocentricity, exhibitionism, emotional lability, masturbation, sexual provocativeness, as well as frigidity, suggestability and dependency can all indicate psychosomatic propensities (Lerman; 63). At a conceptual extreme, it is difficult to postulate what a woman must do, in order to not be considered hysterical. On the one hand, Ida shies away from Herr K.’s kisses and is thereby hysterical. On the other hand, a woman who makes herself attractive, wears make up, a tight skirt and high heels can also be viewed as hysterical. Alternatively, a woman
who loves another woman is also hysterical. This apparent contradiction in sexual stereotyping can lead some feminists to conclude that

[b]ehind psychotherapy’s guise of treatment, just as surely as beneath pornography’s protestations of liberation, lies the sexual sadism that is at the core of misogyny. Here in its medical form. Women’s bodies are dirty, women’s minds are polluted by their bodies, women’s sexuality is diseased, sex is evil because women are sex.

(MacKinnon in Masson; 86)

From this perspective, female gender and sexuality are irrevocably interlinked in the clinic. It seems advisable to warn women therefore that displays of sexual independence may well point to latent emotional instability and psychological dependency for physicians.

In sum, the gender and sexual characterizing of hysteria and histrionic personality disorder can easily be stereotyped. Women are mainly hysterical. The few men who are histrionic or suffer from conversion disorder are more likely to be effeminate, gay and/or unsophisticated. Furthermore, in the literature, somatizers deny their sexuality. Ironically, they also are sexually provocative. As a result, women simultaneously lure and shun men. They are both frigid and orgasmic. Somatizers are sexually manipulative while being sexually naïve. Further, while all are hetero-erotically enticing, they also are homo-erotically oriented. It seems that hysterics are sexually dysfunctional in such a variety of oppositional modes that the diagnostic criteria could be potentially met by a wide spectrum of individuals. It seems not to matter what form sexualized behaviour is seen to take in psychosomatic patients, only that it does not apparently adhere to publicly held norms. Moreover, if a physician encounters an individual whom s/he views as a sexual object who threatens the nosological
order of the clinic and the gender roles of the community then that individual may seem to be converting psychic phenomena into somatic symptoms. When subjective physical symptoms are clinically undecipherable then the patient’s social behaviour is questioned and in the case of hysteria this can manifest itself as apparently objective judgements about both gender and sexuality. - Incongruously, the guise of medical objectivity here is made all the more interesting in that one supposes that a physician can only judge sexual propensities in large part through his/her own subjective, erotic response to the patient.

**Alice James — A Victorian Hysteric**

Alice James is born into a Calvinist and intellectually gifted, Bostonian family during the nineteenth century. Two of her brothers, William and Henry, become famous authors. Throughout her life, Alice is plagued by a variety of obscure and debilitating ailments which essentially render her an invalid for much of her adulthood. Family members and physicians variously suppose that she suffers from neurasthenia, gout, rheumatism and hysteria. Yet, when she is physically able, Alice hosts intellectual salons in Boston and in London and maintains a journal and detailed correspondences with her family and friends. Nonetheless, her life is punctuated by her re-occurrent illnesses. In reading her journal and letters, it becomes apparent that her world is composed of her tie dependency on her care givers, her battle with an uncooperative body and her ongoing pursuit of medical assistance. In some sense, her life is typical of somatic patients and her writings reveal not only the physical, but also psychological and political, ramifications of having an hysterical illness.
James’ biographer, Jean Strouse, claims that ‘Alice envies men and resents the disadvantages femininity entails.’ (Strouse; 167) Throughout her book, Strouse infers that James’ equivocal feelings about being a Victorian women is somehow inexorably the cause of her mysterious ailments. Henry, James’ brother, writes: "In our family group, girls seem scarcely to have a chance." (Strouse; xiii) Expected to be a paragon of virtue by her ministerial father, Alice never fully embraces this role. Intellectually, she appears to be on a par with her more famous brothers and is appreciably dissatisfied with the homely purpose she is expected to fulfill. Elaine Showalter, among other feminists, would probably agree that James’ illnesses are likely an unconscious response to the stifling social expectations with which women are cursed in the late nineteenth century. Hysteria can thus be seen as Alice’s escape from the trappings of traditional gender stereo-typing.

From a twentieth century perspective, Alice James’ sexuality also comes under suspicion as a result of her close bond with her care-giver and companion, Katherine Loring. Strouse implies that the James’ psychological dependency on Katherine is striking. The reader infers that perhaps this reflects the patient’s antipathy for men and an unnatural attraction toward women. However, from my own perusal of her letters and diary it is not particularly evident that Alice dislikes men. Even if Alice were a man-hating lesbian it seems unreasonable that this should mean that her illnesses are political manifestations of problems with her gender and sexuality identity. I suggest that what Strouse and others fail to consider is that women are generally the primary care-givers of the ill. It seems only natural that strong bonds form between such women and chronically sick patients. Men, traditionally, do not inhabit the domestic realm, caring for ailing friends or relatives. Even today, women do most of the
majority of housework and childcare. They also tend overwhelmingly to the sick and to aging parents. Even if it were true that women hysterics desire or form intimate female bonds, it may not be the calling of innate lesbian desire, but instead the manifestation of a natural need for meaningful contact with other human beings. For the most part, ill individuals inhabit the private realm and it is reasonable that they might form deep friendships (and perhaps, love-interests) there. In my opinion, it is perhaps a little glib to link apparently questionable, female, somatic complaints with aberrant "homosexual" desire.

In addition to gender and sexual stereotyping, James' life provides another example of hysterical generalization, that of "la belle indifference." According to hysterical and psychosomatic diagnostic theories, if the patient isn't constantly complaining of physical symptoms, she or he may well be displaying la belle indifférence. If somatizers appear to be coping too effectively with disability, they are seen as suspiciously indifferent to the gravity of their situation. Interestingly, because James finds little solace and, much denigration, in her medical interactions, she tends to act without medical advice and without seeming concern for the consequences. Moreover, rather than mire herself completely in the realm of her physical dysfunction, James reads, writes and maintains close ties with her family and friends. She explores imaginary landscapes and engages in adventures in the manner of "Stanley slaughtering the savages." (James; Diary; 10 October 1890) She writes:

If I can get on to my sofa and occupy myself for four hours, at intervals, through the day, scribbling my notes and able to read the books that belong to me, in that they clarify the density and shape the formless mass within, life seems inconceivably rich. . . . (James, Diary; 5 May 1890)
Theoretically, James' capacity to find life "inconceivably rich" could be interpreted as a manifestation of pathological nonchalance. Yet, I suggest that while medicine may view her propensity for introspection and pleasure as a sure sign of her unconscious desire for invalidism, it also signals an ability to accept her physical limitations and revel in her other faculties. Without organic evidence of disease, the clinic regards James' personal life and writings as prototypical hysterical material, however if it considered her illness to be more legitimate, then it might see her persona as stoically insightful.

Her journals divulge that it is the imposition of the diagnosis of hysteria that increases the suffering in her life by isolating her emotionally, socially and medically. The diagnosis does little or nothing to comfort or heal her. Consequently, James' relationship to the clinic is a complicated and ambivalent blend of desire and antagonism. She writes in her diary: "I suppose one has a greater sense of intellectual degradation after an interview with a doctor than from any human experience." (James; 27 Sept 1890) She discloses to her brother William in 1886:

It may seem supine to you that I don't descend into the medical arena, but I must confess my spirit quails before any more gladitorial encounters. It requires the strength of a horse to survive the fatigue of waiting for the great man and then the fierce struggle to recover one's self-respect.

(James, letter to William, January 3-7 1886)

After almost thirty years of illness in which she has found little respite from suffering, James has no belief in her various doctors. Her mistrust of the curative power of physicians along with the erosion of self-esteem which accompanies their visits contribute to her sense of their pernicious worthlessness. As a result, she tries to avoid unnecessary medical contact. Because her
physicians remain either professionally contemptuous or aloof, she finds little therapeutic value in their physical presence. Her ideal doctor is one who spends only little time with her and prescribes what she wishes from a distance (James; letter to Aunt Kate 15 November 1887).

James' relationship to her doctors becomes utilitarian: she uses them for what she feels is her best advantage. She doesn't seek cure or even compassion but rather, symptomatic and pain relief. She must derive her care from wherever and, in whatever manner she can. As a result, without a functioning relationship to a doctor (or what clinicians would call "appropriate medical supervision"), she at one point becomes so addicted to morphine that she cannot sleep for several months. In this sense, she embodies the caricature of an hysterical: manipulative and seemingly emotionally unstable. But these faults are not entirely of her own making. Nor are they necessarily the inevitable result of her hysterical personality. Instead, they indicate the complete collapse of the therapeutic relationship between her herself and her physicians.

Hysteria forms a breach between her subjective world of intellectual independence and physical pain and the male-dominated, objective legitimacy of the clinic.

Paradoxically, James experiences a powerful moment of cohesion with medicine when she is diagnosed with terminal breast cancer in 1891. She is almost exultant at the doctor's pronouncement that she is, in fact, medically ill.

Ever since I have been ill, I have longed and longed for some palpable disease, no matter how conventionally dreadful a label it might have, but I was always driven back to stagger alone under a monstrous mass of subjective sensations, which that sympathetic being, "the medical man" had no higher inspiration than to assure me that I was personally responsible for, washing his hands of me.
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with a graceful complacency under my very nose. (James, Diary; 31 May 1891)

To anyone who has not been there it will be hard to understand the enormous relief of Sir A. C.'s uncompromising verdict, lifting us out of the formless void and setting us within the very heart of the concrete. (James, Diary; 1 June 1891)

For James, any diagnosis, even a terminal one, is better than no diagnosis. Having a tangible illness, however grave, comforts her. Ironically, at the point when most humans find themselves abjectly alone facing death, James finds community and respectability in her mortality. She regains a legitimate membership in both the social and medical world. It is the certainty of cancer, even terminal cancer, which buoys her sense of personal power and authenticity.

Alice James is a quintessential hysteric. Diagnosed at the height of the hysteria epidemic of the last century, much of her life and writings depict the typical profile of one of these problem patients. She manages to avoid her feminine responsibilities through her illness. She seems to avoid amorous contact with men and has an overly intimate relationship with her female companion. Moreover, she seems to exhibit an intellectual and spiritual contentment with her invalidic state. Finally, James simultaneously seeks out and shuns medical assistance, all in an apparent attempt to garner attention for her self-induced malaise. She fits neither social nor medical expectations.

However, Alice James is also a portrait of deep suffering. In the midst of her illness, her prose illustrates her poignant desire for dignity. Hysteria diminishes her physically and socially and, plagues her psychologically. As long as she remains ill without cause, her
personhood remains in question. Others doubt her and she doubts herself. Hers is a life filled with the "formless void" of ambiguity. And it is barely tolerable. Hysteria, as a disease, disempowers her. Her friends and family vacillate between sympathy and condemnation for her hysterical lifestyle. Her physicians patronize her and James begins to revile them. Ill and cast adrift in the uncertain and ambiguous realm of hysteria, Alice James suffers both physically and psychologically. If given the choice between a life lived in ignominy and a death endowed with respect, James undoubtedly chooses the latter. It is not surprising then that she embraces the social, cultural and medical legitimacy of a cancerous death after a life of social and medical disrepute.

The Fluidity of Disease Modeling

Conceptually, clinicians employ hysterical diagnoses when they can find no organic cause for an individual's complaints. Patients who have symptoms which do not fit into well understood physiological patterns easily fall under the rubric of "not yet diagnosed" (N.Y.D.) and/or somatoform or histrionic disorders. In this sense, they challenge conceived notions of what it is, in fact, to be "diseased." Hysterical symptoms are ones which do not fit comfortably within traditional medical conceptions and classifications. They represent the realm of uncertainty with regard to diagnosis. While subjectively the symptoms remain very real for the sufferer, objectively they offer no clinical evidence for their existence. As a result hysteria exists in an ambiguous diagnostic realm – lying somewhere between the boundaries of the physical, mental, spiritual and cultural spheres of human existence. It is thus a disease of ambiguity. Controversy and discomfort often characterize hysterical diagnoses.
Historically, the medical nosology for diagnostic cataloging finds its origins in botanical and biological systems of classification. It is an attempt to impose order and coherency on apparently random physiological events. Diagnosis' main purpose is to provide groupings of symptoms and phenomenon that are efficacious to medical treatment. Diseases, then, are not concrete objects, but are instead ephemeral models which are used to try to combat sickness and prolong human life.

Disease classifications are even further removed from concrete objects than animal or plant classifications. At least an individual oak tree being classified is a tangible "thing"... (Ziporyn; 88)

Consequently, the abstract modeling of disease constantly shifts and changes. Through the centuries, medicine has employed a variety of frameworks with which to understand the human body and its illnesses. Humoral systems of medical knowledge produce different diseases than do paradigms of germ theory and/or more technologically based models. Moreover, in modern medicine, different sub-specialties often comprehend diseases differently. For instance, immunological medical theory is quite different from rehabilitative medical theory. Definitions of disease thus change according to the context in which they are formed and employed.

Society, culture and technology influence the construction and reconstruction of disease in both time and place. And examples of the fluidity of disease groupings can be found in a number of disease-types. Typhus and typhoid were once thought to be the same phenomenon. Their symptomology coincided. However, the rise of laboratory medicine meant that physicians could distinguish typhoid from the more general grouping of typhus. Within this construct, typhoid is understood to be caused by specific bacilli, whereas typhus denotes any
number of anthropod-borne infections. Similarly, until 1931, doctors did not recognize polio as a disease that could affect children and adults. Previously, it had been known as ‘infantile paralysis’ because it infected only infants. The epidemic which occurred in children and adults from the 1930s-50s changed this medical perception. Physicians now understood that polio affected all age groups. Interestingly, polio’s sudden widespread incidence in older populations was likely the result of changing social patterns. The tendency toward suburbanization, in which people moved out of tight urban living conditions in which they were exposed to the polio bacteria in infancy and consequently developed immunity, to less densely populated communities, meant that individuals succumbed to the bacillus when they were exposed at older ages (Ziporyn; 34). The re-conception of this disease was thus the result of altered urbanization. Another example of disease re-grouping is diabetes. Originally conceived as one event, it has since been classified into two distinct diseases: Diabetes Type I and Diabetes Type II, each requiring very different protocols. With these and other examples, it can be seen that medicine revises its nosological understanding of sickness based on fluctuating scientific, social, cultural and political circumstances. Disease groupings continually evolve.

While historically much of modern medical classification finds its origins in the legalization of the autopsy in Europe at the end of the eighteenth century, different cultures develop differing conceptions of disease through time and across political and social boundaries. During the mid to late nineteenth century, France and Germany developed equally strong but largely separate streams of medical science. Nonetheless, both groups of scientists used post mortem and laboratories to conduct experiments and form new theories about the human body. Moreover, the consequent rise of bacteriology at the end of the nineteenth century also affected
Britain's public and private health practices (which she no doubt exported to her empire through her colonialists). North America, in turn, established new medical schools based on European models. And yet, despite the fact that medical educators and students examined the human body in very similar ways, all of these countries developed and maintained their own characteristic diagnostic patterns.

Significantly, diagnostic differences between nations cannot be accounted for solely by discrepancies in the genetic pool of populations nor by variations in environment. Different countries simply sustain quite different assumptions about human health. Medical classifications thus depend upon cultural beliefs. German physicians, for example, diagnose heart disease far more commonly than their counterparts elsewhere. French physicians are preoccupied with toxicities of the liver, whereas British doctors tend to be concerned about kidney dysfunction (Payer; 39). In Haiti, people believe in "voodoo death," whereas to European and North American doctors this appears as nonsense (Kleinman, 1978; passim). In France, spasmophilia, _per se_, is caused by magnesium deficiency and produces fatigue and muscle spasms. In the U.S., spasmophilia does not exist and similar symptoms might be diagnosed as an anxiety disorder (Payer; 38). Similarly, dissociative identity disorder is a psychiatric assignment in the United States and Canada but not in Europe. The fact that differences exist between nations who develop and continue to practice medicine, shows that social values have a significant impact on apparently nonpartisan medical thinking.

Medicine's objectivity is thus embedded in the subjectivity of culture. From a critical perspective, Michel Foucault's writings which point to the confluence of the clinic's scientific positivism and social and academic matrices of power do not seem widely off base.
The creed of the scientifically demonstrable fact is something of a necessary professional myth. Objectivity is a fundamental aspect of medicine's quest for knowledge of and power over illness. Unfortunately, it does not denote the actual fluidity of disease typing. Discrepancies exist. Even when addressing something as apparently concrete as physical infirmity, diagnostic categories are not only influenced by, but are the products of social and political environments. It is thus not surprising that the more abstract conceptions of mental and emotional illness are subject to even greater cultural bias. Here, categories are often based upon culturally specific notions of human behaviour. Functional diseases are even less concrete than organic ones. These types of illnesses do not produce neutral categories. In particular, psychological disease conception relies on the ambivalent interface of both scientific discovery and temporal and cultural context.

In his two books, *Rewriting the Soul* and *Mad Travelers*, Ian Hacking outlines the basis for what he calls "transient" mental health diseases in both Europe and North America. Hacking's central argument in these two texts is that forms of madness depend upon specific cultural circumstances. For example, doctors diagnose *fugueurs* (compulsive travelers) only in nineteenth century France. The philosopher hypothesizes that these *fugueurs* do not really appear in the U.S. because of the American nineteenth century association of madness with slaves' desires to escape their masters. Further, these *fugueurs* (all of whom were men) emerge at the inception of the tourism industry in Europe and just prior to the cessation of intense governmental scrutiny of internal travel in France. Hacking reasons that hysterical

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11 By "transient," Hacking means diseases which appear for a limited period of time in human history and then disappear.
fugue fitted perfectly into the neo-manicheism of French social imagination at the time: of virtuous, romantic tourism on the one hand, and of vicious, criminal vagrancy on the other (Hacking, 1998; 81). He argues that disease classifications do not solidify unless they fit a specific social context. Practitioners and patients form a symbiotic relationship in which the meaning and significance of a disease can be easily understood and accepted by both parties. By extension, a disease disappears — as did hysterical fugue — because it maintains neither medical nor social validity. It dies because it can no longer sustain interest or inquiry. Hacking concludes then that it is perfectly reasonable that the nineteenth century disease of hysteria has fragmented into a variety of other illnesses and syndromes in the twentieth century. Somatoform disorders, fatigue syndromes, alien abductions and dissociative identity disorders speak to the present cultural imagination far more readily than do neurasthenias, glove paralyses and hysterical fits.¹²

Moreover, even within any particular time and place, medicine’s own professional culture which also affects the construction of disease categories and the interpretation of bodily signs. A clinician’s diagnostic judgement is thus not only influenced by broader social norms but it also arises out of a manifestly scientific tradition. Hierarchy and the ethos of objectivity typify the clinical environment. Medical training as well as hospital architecture dictate much of physicians’ interactions with other health care workers and with patients. While Foucault’s clinical gaze is most distinctly nineteenth century and French in its

¹² It is important to note that although medical knowledge metaphorically progresses through the ages, it does not necessarily gain greater specificity in its ability to understand sickness. Instead, it re-arranges symptoms to fit disease types which mutate through time and across cultures. There are probably no more numerous ailments now than there were two thousand years ago, just differing abstractions of human afflictions.
origins, the gaze itself can be universally applied to most medical institutions. Despite varying ways of speaking and seeing, medicine has a way of being that is endemic to its practice.

The psychologist, Paula Caplan, who assisted with the compilation of the DSM IV – the bible of mental diagnoses – writes acerbically:

When I have worked on mental health teams, I have observed repeatedly that the conclusions about causes of patients' problems and recommendations for treatment depended a great deal on which team members had official power and authority or who had the guts to speak-up. (Caplan; 19)

Here, Caplan refers to the inherent power structure which exists within most teaching hospitals. Although health care providers theoretically work as a team, certain members of that team have significantly more authority than others. Firstly, physicians for the most part are trained to see themselves as above all other health professionals. Secondly, medical and post graduate students are arranged hierarchically beneath attending physicians in which hazing rituals are still quite common and the majority of students report that they have been subjected to harassment and abuse by their clinical supervisors (Rachliss; 180-181).

...[T]here is no effort to teach an intern, who is seeing patients as a physician for the first time, how to see patients with a caring, sensitive and empathetic manner. Worse, the lack of sleep, and the huge volumes of work combine to begin a process of depersonalization of the patient and dehumanization of the doctor that is continued in residency. (Smith; 123)
The sheer physical and psychological rigours of medical training\textsuperscript{13} mean that student doctors have few chances to learn interpersonal skills. Despite ongoing discussions about collaborative practice models within hospitals, there are strong constraints which prevent individual team members from acting independently and/or outside of the parameters of the political architecture of the clinic.

The other aspect of clinical culture which impacts on diseases and diagnosis is the pretext of objectivity. Scientific methodologies have no doubt advanced medicine's capacity to treat human ailments. Grounding therapies in objective observation both simplifies and facilitates the pursuit of human health. Physicians thus focus on attributes in patients which can be categorized and quantified. As I argue in the previous chapter, doctors are professionally more comfortable with tangible evidence. If something can be seen, heard, touched, smelled or, even tasted only then does it becomes clinically valid. Patients' complaints need to be confirmed by some form of sensate process in order for a physician to feel potent and able to proceed to treatment. Symptoms cannot remain abstract things, they need to become concrete objects. Physicians thus tend to see themselves as scientific technicians and objectify patients as representations of disease categories. The clinic's puissance depends on its objectifying gaze.

Paradoxically, this culture of scientific positivism is not entirely absolute. What tends to be overlooked in the need for the objective findings, is the presence of the individual

\textsuperscript{13} "As [medical students] move through the various areas of clinical medicine, students must continue to study while being subjected to a work load that would make a galley slave tremble. The milieu in which a medical student labors encompasses a complete hierarchy of medicine: interns, first through forth year residents, research fellows and professors. Medical students are given a lot of work but little real responsibility, and they get no respect at all. Little wonder that they begin to develop the attitude that someday they will be at the top of the totem pole, will have paid their dues, and will deserve all that will justly come to them." (Smith; 121-22)
clinician's subjectivity in the diagnostic process. This subjectivity persists in spite of the fact that physicians are participants in a system which tends to degrade their own — and their patient's — capacity for personal agency. Rigorous attempts to standardize disease groupings aside, the interpretation of both nosology and patient behavior ultimately depends upon the personal and social bias of the diagnostician.

The process of diagnosis, whether informal or formal, is inevitably linked as much — if not more — to the personality, theoretical orientation, and cultural circumstances of the therapist (or whoever is the assessor) as it is to the personality and circumstances of the patient. (Lerman; 5)

Determining whether a patient has a disease-type which can be treated requires that the clinician interpret symptomology which is the result of not only diagnostic definitions, but of moral, cultural, familial and personal value-systems. Here, the objectified climate of the clinic depends once again on the psychological, social and professional plasticity of the individual physician.

The feminist theorist, Kate Millett, in writing about her own experience of mental illness, concludes: "Diagnosis is based upon impressionistic evidence: conduct, deportment, and social manner. Such evidence is frequently misinterpreted. Further, it may not even be experienced by the afflicted party, but instead may be observed by others who declare such a one afflicted." (Millett; 311) Millett's insight is an important one. The objective observation of the clinic is one which is gleaned through subjectivity of the clinician. The doctor views the patient as object from his/her own subjectivity. Conversely, the patient, as subject, may or may not in fact experience what is apparently objectively observed by the practitioner, as subject. In the clinic, then, the subjectivity of both physician and patient becomes obscured by a
facade of objective diagnostic modeling. In the pursuit of health, physician and patient become embroiled in a dynamic of interpenetrating subject-object relations. Disease categories function as an artificially contrived but necessary stabilizing force in this melee. It is important to remember that in their effort to provide cogent models, disease models do not obliterate this dynamic but rather mask it.

In the end, despite the projection of disease as a tangible object, it remains an abstract and enigmatic form—a product of not just scientific fact but of social, historical, cultural and personal persuasions. Nonetheless, the stability of disease typing provides tremendous benefit to both the ill individual and the physician. Medicine's use of categories simplifies diverse bodily signs into interpretable symptoms. This simplification is a fundamental power in its capacity to treat illness. It codifies symptoms so that they can be potentially treated and ameliorated. Plans can be made and courses of action taken. Hopes and fears are focused on a tangible entity. Together the lay person and the practitioner attempt to resolve what Alice James refers to as the amorphous void of illness and replace it with the clearer certainty of disease. In this sense, they both dislike ambivalence. They desire solutions to what may be bewildering and overwhelming problems disease categories provide such solutions.

However, because disease categories are fluid forms which are designed to illuminate culturally specific worlds, the penchant for certainty can be problematic. The drawback of physicians' (and some patients') discomfort with uncertainty is that diseases become reified (i.e., they are viewed as concrete objects and not as abstract models). This results in a false sense of righteousness when doctors minister to human beings. The
maintenance of a trusting and therapeutic relationship is not the goal in these instances. The aim
is to achieve certainty through diagnosis. The fault of this is that in forcing certitude on
ambiguous and unfathomable situations, medicine can coerce complex human beings into
simplified paradigms.

As I argue in the previous chapter, diseases tend to characterize individuals. Through the process of diagnosis, medicine colonizes patients with its own nosological theories
and values. Susan Sontag criticizes this metaphorical aspect of disease frameworks in her
discussions of tuberculosis, cancer and AIDS. I think she would agree that diagnosis is not a
neutral act. As it ministers to the patient it also harbours a host of presumptions and
characterizations that tend to flatten the patient into a two dimensional representation of disease.

Furthermore, at a less metaphorical level, diagnoses possess social import and can determine a
person's mental and legal competency. Diagnostic categories define eligibility for health and
life insurance. They arbitrate not only whether someone will receive treatment but that person's
access to pharmaceuticals and other remedies. They define what type of sick role an individual
can adopt. Moreover, being diagnosed with a mental illness likely limits the social and
professional status that the sick individual can obtain. To some extent, the diagnosis of a mental
disorder, over that of a physical one, perhaps has even more capacity for injury. Mental
diseases – of which hysterical disorders are a marginal part – carry enormous stigma. As
theories of psychological abnormality, they easily create self-doubt and social ostracism for the
patient. There is thus a political dimension to clinical categorization. Disease labels which may
originally appear as beneficent tools, can supersede individual identities with diagnostic
personae that, depending on the contexts of time, place and the personal foibles and experience
of the diagnostician, diminish patient’s agencies even as they try to promote medicinal remedies.

First person accounts of illness point to this fundamental problem in seeking medical assistance. My own, Sontag’s, Sacks’, Frank’s and others’ narratives articulate a sense of dissonance around the clinical characterization of symptoms. An impoverished sense of personal agency seeps into these stories which cannot fully be attributed to the loss of physical health alone. The distinction between objective, scientific accounts of disease and subjective biographies of illness are readily apparent. The differences in language reveal much about the conflicting ideologies of the individuals involved. While each individual’s discourse represents something of their own personal politic, the clinic’s discourse as it manifests itself in diagnoses exposes something about the structure of medical thought and power. In the case of hysteria, this distinction is extremely stark for patients whose symptoms and experiences cannot even be interpreted by the clinic. They have no reality as far as the clinic is concerned because they do not adhere to understood principles of medical knowledge. Subjective knowledge stands in complete contrast to objective knowledge. I believe therefore that hysteria is a phenomenon that embodies the tensions between objectivity and subjectivity in the medicine. It is fundamentally an expression of the contention between practitioner and patient in the pursuit of knowledge and power over illness.

Hysteria reveals that human beings are not easily, nor accurately catalogued. "The misfit between human problems and official diseases is serious enough to be considered a major syndrome — possibly even a disease — afflicting high-tech, high-cost, medicine." (Ehrenreich; 110-111) Hysteria’s diagnostic heirs, such as somatization and conversion disorders, constitute
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attempts to catalog a form of illness behaviour that has no scientific explanation. These facetious disorders lie uncomfortably between the realms of physical and psychological medicine. They do not "fit" into the diagnostic boxes which make treatment more efficacious.

Although it is methodologically hazardous to make retrospective diagnoses, studies reveal that between 60 and 80 percent of hysterical patients suffer from physical illnesses that are overlooked at the time of original diagnosis (Speed; 148). One psychoanalyst, Alison Orr-Andrawes, has re-evaluated Freud's prototypical case-study of hysteria, that of Ida Bauer (Anna O.), and has found psychiatric explanations inadequate. Ida, she supposes, suffered from mild epileptic seizures which would account for some of her bizarre symptomology (Orr-Andrawes; passim). In 1965, two physicians undertook a review of eighty-five patients who were diagnosed as somatizers between 1951-55 at the National Hospital in London, England. They discovered that the majority of these individuals had physical illnesses which were undiagnosed. Twelve patients had died in the interim, four of suicide and eight of a variety of causes ranging from cancer to vascular and brain diseases (Slater & Glithero; 9). Of the remaining patients, only twenty-one, less than a quarter of the original group, still had symptoms for which no organic cause could be found (Slater & Glithero; 11). The authors thus contend that certain organic diseases may predispose patients to behave hysterically. Multiple sclerosis, epilepsy and myasthenia gravis are among the several diseases which physicians think have strong correlations with hysteria (Mai; 104, Weintraub; 121).

Rather than either proving or disproving hysteria's existence, these retrospective ruminations on hysterical case studies are intriguing because they seem to overlook the possibility that the diagnostic criteria which define the disease may be at fault. Instead, they presume that
hysterical behaviours find expression in other disease forms. The researchers pathologize the patients for the apparent inconsistencies in diagnosis rather than re-examining the basis for diagnostetic criteria in general. For me, it is the researchers' inability to point to paradigmatic problems in hysteria’s representation in the clinic that is relevant here. These studies denote some of ambiguities of the nosological understanding of hysterical disorders. They capture the deep ambivalence of these diagnostic types.

In my opinion, hysterical disorders then are not only a manifestation of certain behaviours and unsubstantiated symptoms but their existences are a result of gaps in medical comprehension. They are diseases that occupy the spaces between diseases types. Hysteria is thus not only a manifestation of certain human dysfunctions but also an representation of the way in which medicine’s nosology grapples with issues of uncertainty and unfathomability. From the perspective of clinical absolutes, it is the clinic’s ongoing struggle with that which it does not fully comprehend which is perhaps the most instructive aspect of hysteria’s metaphorical and categorical persistence in diagnostic processes. Hysterical disorders embody the fluidity inherent in disease typing and of the concomitant desire for stable categories in medicine’s fight against amorphous human illness.

Misanthropy and Treatment in Hysteria

Although, in theory, the person who suffers unexplained sickness does not do so willingly, a great deal of suspicion surrounds these mysterious cases. Physicians have trouble believing symptoms exist for which they can find no medical cause. They do not like treating them. In medicine, an ambiguity exists as to whether somatic patients deliberately get sick to
garner attention and challenge physician authority (malingering), or whether in fact, they cannot help being ill (histrionic personality disorder and somatoform disorders)(Ford; 249). Even when viewed from the latter perspective, they are seen as mentally and emotionally unstable because their illnesses are psychogenic. By extension, doctors have difficulty believing the people who complain about "unreal" or unconscious problems. On the patient's side, frustration mounts at the apparent disbelief and lack of concern for what may be overwhelming discomfort and difficulty. For the physician, although a number of possible (but not necessarily efficacious) treatments exist for somatoform disorders, s/he feels powerless to help ameliorate complaints that cannot be identified. In sum, the subjective and objective realities are at odds with one another in these situations. They simply contradict each other.

Never is the chasm which can sometimes characterize the doctor-patient relationship more profound than instances of unexplained illness. Inevitably, a failure of rapport between doctor and patient occurs when medicine cannot explain physical suffering. Given the clinic's positivist culture, it is not surprising that it harbours great skepticism with regard to individuals that it cannot adequately quantify, explain or diagnose. Obviously, the clinical eye cannot apprehend these people, for they do not furnish the requisite, sensate proof of the existence of their suffering. As a result, the professional and the lay person find no success in their meeting. The patient feels the physician has failed to know the reality of the illness. And the medico believes that the patient has failed to know her/his self. The British neurologist, Eliot Slater, believes that hysteria diagnosis denotes a disorder of the doctor-patient relationship. Hysteria is a condition of mutual non-communication and misunderstanding between physicians and patients (Micale; 70). Unfortunately, the tension between both parties is seldom resolved by the diagnosis
nor by supplications such as: "There's nothing really wrong with you." or "It's stress-related." The doctor blames the patient for the ailment and can feel that his or her competency is being ridiculed. Conversely, the patient indicts the care-giver for a lack of sympathy and action. They often vilify one another and grow increasingly frustrated. When hysteria manifests as a somatoform disorder, it represents an extreme example of the dissonance which can exist between practitioner and patient in the interpretation of bodily signs. Somatic disease forms can come to embody the divergence of subjective and objective narrative of which I speak in the previous chapter. As a result, these modern hysterias present the potential for a collapse of the therapeutic relationship between doctor and patient, resulting in the very real possibility that treatment can descend into frustrated coercion disguised as therapy.

In becoming ill, sick persons fail to meet communal expectations. If no tractable medical reason can be found for their withdrawal from society, then they are viewed as pariahs. Men are poor soldiers and women are inadequate wives and mothers. They circumvent both their private and public duties. The nineteenth century physician, S. Weir Mitchell, describes hysterical women as "the pests of many households, who constitute the despair of physicians, and who furnish those annoying examples of despotic selfishness, which wreck the constitutions of nurses and devoted relatives." (Smith-Rosenberg; 207) Henry James thinks similarly about his sister, Alice. "[T]he extraordinary intensity of her will . . . made the equal, reciprocal life of a 'well' person . . . almost impossible to her - so that her disastrous, tragic health was in a manner the only solution for her of the practical problem of her life." (Strouse; 284) It is as if the hysteric intentionally chooses illness over health in a deliberate attempt to resolve other life issues. More recently, one doctor, in writing about the management of somatizers, states:
The person achieves "secondary gain" by avoiding a particular activity that is noxious to him or her, and getting support from the environment that otherwise might not be forthcoming. (Speed; 148)

Secondary gain is viewed as a fundamental motivation. Insurance payments, disability claims, and familial attentions are all believed to create systems of reward for somatizers. Furthermore, because these individuals are not objectively diseased, they are viewed as garnering these benefits illegitimately. Clinicians agree that somatizers (these include chronic fatigue, fibromyalgia and chronic pain patients) are manipulative, aggressive and dependent. They believe them to be angry people who either use threats of self-harm or willfully become more ill to influence families, friends and physicians (Wenegrat; 71-72). This type of medical belief in the purposiveness of histrionic behaviour creates tremendous tension and resentment in the clinical encounter between doctors and patients.

Interestingly, clinicians are not the only ones to perceive hysteria as socially subversive. A number of feminist writers take a conceptual stance that is very close to the clinical one but with a slight twist. Some feminists acknowledge the latent anger of hysteria but hypothesize it to be a form of revolt by the powerless female against the socio-politically powerful male. They believe that women during the nineteenth century who take their beds, do so as a form of social resistance. Victorian women use their symptoms to avoid the strict social and sexual roles that are forced upon them (Bassuk; 147). Illness represents a type of passive-aggressive opposition to the demands of a phallocentric world. Elaine Showalter writes:

[H]ysteria and feminism do exist on a kind of continuum. . . . If we see the hysterical woman as one end of the spectrum of a female avant-garde struggling to redefine women's place in the social
order, then we can also see feminism as the other end of the spectrum, the alternative to hysterical silence, and the determination to speak and act for women in the public world. (Showalter; 161)

Thus, the feminist psychologist, Luce Irigaray, conjectures that hysteria embodies a culturally induced phenomenon. Women are subjugated and controlled by men and refuse to partake in their own subjugation by falling ill.

...[T]here is a revolutionary potential in hysteria. Even in paralysis, the hysteric exhibits a potential for gestures and desires... a movement of revolt and refusal, a desire for/of the living mother who would be more than a reproductive body in the pay of the polis... (Irigaray; 47)

Of course, this type of feminist interpretation of hysteria endows the disease with a noble and heroic stature that is generally lacking in medical circles. But it also politicizes hysteria. The ailment becomes a mode of political rebellion expressed in somatic symptoms, resulting in the domestic, economic and social disruption of a traditionally paternalistic and objectified world.

While I am sympathetic to the revolutionary rhetoric of this interpretation, I feel that it contributes to the already divisive tension which characterizes doctor-patient relationship in diagnoses of hysteria. One of the problems with this view is that if doctors presume that est femineo generei pais una uterus omnium morborum, then women become the loci of disease individually and collectively. They therefore need to be controlled and censured. It follows that individuals who are out of the ordinary and who are inappropriately politically active could conceivably find themselves under medical supervision for emotional and mental illness. "At this point, it is clear that a link has been made between women and psychiatrists as moral guardians. The latter are needed by patriarchal culture to keep women within their narrow role boundaries."
Women, because of their innate weakness, can easily become viewed as a source for social ills. And, when they inadmissibly fall ill, they manifest the very corruption that lies within them. Showalter's argument that women might willfully fall ill as means of political protest might give credence to the belief that women have dangerous and immoral natures.

More importantly, the idea of social insurrection has now been taken up by clinicians. They suppose that women are more likely to become mentally ill and hysterical precisely because they feel powerless (Wenegrat; 47). Diagnostically, hysterics embody impotence. Doctors perceive women and men, who are sick without apparent cause, as pathetic. Their supposed "sick" rebellion is ultimately seen as self-destructive and counterproductive. Psychosomatic illness represents the affected person's inherent psychological and social incapacity. Medical clinicians can thus assume that hysterics are weak and ill and that their behaviour should be censured because of its inappropriate challenge of political and medical authority.

As a result, I question whether hysteria actually serves women's rebellion, or whether it is in fact a reflection of men's oppression of women and of objectivity's subjugation of subjectivity. The primary difficulty of presuming women become ill and hysterical as protest or gender ideology is that it essentializes what is feminine socially. Furthermore, it never properly examines the procedures for diagnosing women (or men) as emotionally unstable. It is not cognizant of the cultural and nosological matrices which support such diagnoses. It does not provide a critique of the criteria associated with hysterical disorders but instead takes them as objective facts. Moreover, this perspective does not take into account that if hysteria is an act of powerlessness, its medical classification as psychogenic disease and/or personality disorder tends
to support and promote this powerlessness by portraying those who fall prey to it as unreliable. In this sense, the feminist and clinical views coincide. They reify histrionic behaviour: the feminists politicize it and the doctors pathologize it. The subjective discourse of the patient is thus superceded by abstract, over-awing forces.

Nonetheless, despite medicine's continued skepticism, hysteria as it is expressed in somatic complaints remains a formidable challenge to physicians. Patients with unexplained complaints continue to present themselves to physicians for assistance. Somatizers comprise a significant portion of any medical practice' population. Chronic fatigue syndrome, Gulf war syndrome, fibromyalgia, and environmental sensitivities all lie in an uncomfortable nether world of being scientifically unsubstantiated conditions. Somatization, conversion and facetious disorders also all rest in this same impenetrable region. A constant tension exists about their legitimacy as diseases. Elaine Showalter, for example, expressly states that they are modern day equivalents of hysteria. Conversely others believe them to be legitimate diseases whose organic origins have yet to be discovered. Given the significant fraction of patients who fall under these designations, doctors pursue a variety of approaches for these disorders. Some of these include psychotherapy, cognitive-behaviour treatment, hypnosis, sodium ambytal (and other drug therapies) and family therapy. Unfortunately, these approaches are not uniformly successful and ongoing debates exist about how to best manage these problematic patients.

The efficacy of medical intervention in acute cases of somatization is much higher than that of chronic or intractable somatization. Often through hypnosis, suggestion or ambytal interviews, patients who present with acute symptoms of blindness or paralysis can have their symptoms relieved almost immediately. However, for longer term somatic patients the prognosis
is more bleak. Psychotherapeutic and behavioural approaches seem to be the norm but are not always effective (Guthrie; 273). As one medical author states:

... [W]hen investigations prove negative, management is commonly limited to reassurance about the absence of disease and occasionally referral to a general psychiatrist. In our experience such referrals are unpopular with patients and rarely result in effective treatment. In fact there is scant provision in either medical or psychiatric services for the patient with somatic complaints who has neither physical disease nor severe mental illness.

(Mayou & Sharpe; 561)

Unfortunately, due to the underlying tension between doctor and patient in these instances, treatment is seldom embraced by either party with much enthusiasm. The patient usually does not like having his/her symptoms explained as emotional and the clinician often finds pursuing psychological approaches both time consuming and unreliable.

Interestingly, I have found one account of a successful cure of chronic hysteria through psychotherapy written by a patient. The book, *The Words to Say It*, by Marie Cardinal, describes the cessation of chronic uterine hemorrhaging through treatment with psychotherapy. The course of treatment follows the strict principles of Freudian analysis. The patient sees the analyst daily in an office at the end of a cul-de-sac over a period of years. Here, she lies on a couch and narrates a stream of consciousness to a doctor who rarely, if ever, speaks. The physician remains dark and aloof. The overall tone of the work is mysterious. It seems that the analyst’s authority over the narrator plays a significant role in her apparent cure. In gratitude for her recovery the author dedicates her book "to the doctor who helped me be born." It is as if the
patient has found a remedy in a psychological submission to the analyst and deep immersion in her unconscious processes.

Despite this text, a cautionary note should be found in the fact that even Freud's seminal discussions of "Dora" and "Anna O" do not present definitive psychoanalytic cures of hysteria. The case of "Dora" (Ida Bauer), for example, appears to be an abysmal failure. It seems that Bauer never achieves a recovery. She is ill for the rest of her life. Moreover, she abandons psychotherapy in frustration. In the other Freudian case, that of Bertha Pappenheim ("Anna O.") Pappenheim has a long and arduous recovery from her illness, punctuated by serious relapses which occur after her apparently successful analysis with Freud (Micale; 64). While she eventually is well in later life, becoming a social activist and writer, it is not clear that her recovered health is truly the result of psychotherapy. Despite the influence of Freud's studies and of psychoanalysis in general, there is still some doubt as to the efficacy of analytical treatment for somatic disorders.14 Medical journals equivocate that a patient may be too ill, or simply may not want to recover.

I am willing to conjecture that psychotherapy probably offers a remedy to some patients. Perhaps patients are cured by a belief in the cure itself (i.e., psychotherapy works as a placebo). What is clear, however, is that a cure by psychoanalysis can only result when the illness is in fact truly functional and also when the patient believes two things: (i) that symptoms are psychosomatic in origin and (ii) that the analytical approach is efficacious to recovery. Logically,

14 There are also ongoing debates as to whether traditional analytical treatment is worthwhile or whether short-term, more cost-effective courses of psychotherapy are of better use to patients and practitioners.
those who do not feel that symptoms are psychosomatic will not be cured by, nor can they be coerced to undertake successful psychotherapeutic treatment.

The second most common approach to somatic patients is the adoption of behavioural management techniques. The aim is to get patients to abandon their illness behaviour through inducements and negative reinforcements. Ideally, the physician and patient make a contract in which the patient agrees to certain rewards or constraints depending on whether s/he exhibits their physical symptoms or not. For particularly intractable cases of somatoform disorders it is thought that individuals are best treated in special in-patient programs where the medical staff can monitor their conduct and respond immediately to any regression by withdrawing rewards. These privileges can be multi-faceted from access to radio and television or to family members and friends. Behavioural modification programs hope to induce recovery through the patient’s desire to re-attain creature comforts by abandoning the sick role.

Despite the best of intentions, I believe that there are fundamental problems with both psychoanalytic and behavioural approaches to somatization. Firstly, the labeling of psychosomatic disease appears unlikely to help patients because of its stigma. Secondly, therapies for somatic diseases are contentious and do not offer clear evidence of their effectiveness. Thirdly, in my opinion, some of these treatment methodologies seem to jeopardize the therapeutic bond between physician and patient. In most cases, patients must adopt the position that they do not fully know themselves – that they in effect are psychologically defective. This seems potentially damaging to basic self-esteem. Somatic individuals must submit themselves to the authoritative analysis of psychiatrist or they must embrace a regimen which constrains their autonomy in the hope of relieving their physical symptoms. Medicine places somatizers in a double-bind: they
must deny themselves and submit to medical authority or risk suffering more clinical and social
disdain. Either way, it is hard for them to win. Finally, the ambiguous nature of
hysterical/somatic diseases creates ambivalent responses in attending clinicians. Without a proper
understanding of the origin of symptoms doctors do not really know what type of action to take
nor what type of posture to adopt in their interactions with patients. These apparently facetious
disorders lie in the uncomfortable realm of uncertainty with no clear guidelines for patients or
physicians. This inevitably results in enormous frustration no matter what the therapeutic
approach.

As a result, I want to address the fact that there is often an essential misanthropy
with which physicians view hysterics. A resentment invariably forms against the ill individual.
One physician writes:

\[\ldots \text{[M]any physicians\ldots demonstrate disdain for the patient by performing demeaning indignities such as placing a surgical clamp on "an anesthetic breast." The physicians may also give up on the patient as not worth the effort because he or she is obviously faking. This reaction is usually sub-conscious and is basically a response to the frustrating and hostility-provoking behaviour of many patients.}\]

(Weintraub; 117)

Doctors envision themselves as engaged in a power struggle with patients who apparently refuse to
get well. They interpret continued illness as a form of resistance and insubordination. The
diagnosis of psychosomatic disorder places the physician in conflict with the patient. Instead of
conducting a battle against a tangible disease, the doctor conducts a campaign against the sick
individual. In hysteria, medical militarism turns the patient into an enemy who must be
vanquished for the clinician to succeed.
In the past, doctors felt that it was necessary to control hysterical patients. Doctors also sought to punish women when they were hysterical. They suffocated them, beat them and threw ice water on them to stop their fits. They also tried to humiliate them in front of their friends and family (Smith-Rosenberg; 211). In Charlotte Perkins Gilman's fictional account of her own experience of hysterical cure, the female protagonist goes mad as the result of her medical confinement. "The Yellow Wall-paper" describes a woman who is restricted by her physician-husband from engaging in household or social activities in order that she may recover from nervous prostrations. She is confined to a bedroom upstairs that was once a child's nursery and, consequently, struggles to maintain her sanity. The windows are barred (to prevent children from falling out) and the room is covered with a peeling yellow wallpaper. The narrator becomes fixated on the wallpaper. At first she despises it, then is disgusted by it and finally maddeningly consumed by it. Her husband dismisses her concerns about the walls. He becomes resolute in his determination to not give in to her nervous whims (Gilman; 41). He structures her daytime hours through the servants, disallowing her letter writing and social activity and, largely ignores her otherwise. At one point he threatens her by suggesting that she will have to go to see S. Weir Mitchell in the fall if she doesn't get well. Unfortunately, she doesn't respond. By the end, the protagonist becomes odder and odder, secluding herself in her yellow prison until she has become quite insane. In this story, Gilman's implies that the medical prescription has been worse than the illness itself. Afterward, when she hears that Mitchell changed his treatment of nervous women as a result of reading her story, she says, "If that is a fact, I have not lived in vain." (Gilman; 16)

One medical historian notes: "Indeed, much of the medical literature on hysteria is devoted to providing doctors with the means of winning this war of wills [against patients]."
Freud supposes that patients seek revenge by showing their physicians to be inept at curing them. He advises therapists take on an "attitude of superiority and contempt" when dealing with hysterics (Freud, *CP III*; 23). He outlines that repression in such individuals causes them to be incapable of judgement. Further, in discussing the analytic process with hysterics, Freud states that when someone says 'no', she or he really means 'yes.' (Freud; *CP III*; 71) Even when narrating their own subjective experiences then somatizers are to be discredited. They do not fully know what they mean.

This form of psychotherapeutic refutation continues to find expression in the modern day clinic. One psychiatric patient writes:

> A Murphy's law in psychiatry is that a doctor's understanding of your condition is true in direct proportion to the vehemence of your denial. They convinced me that I needed to give away some control . . . , and that my reluctance to do so was a symptom of the illness which landed me there in the first place. 

(Supeene; 38)

In my opinion, little could be more aggravating or perilous to the psyche than to be treated as invalid ontologically.¹⁵ Medicine denies psychosomatic and mentally ill patients an essential potency in refusing them the capacity to reason without contradicting themselves. Theoretically, the more a patient denies unconscious motivation for being ill, the more likely she or he is to be unconsciously motivated to be ill. When a person says one thing but the clinic takes it to mean another and, when that person is painfully sick but the clinic presumes that the sickness doesn't exist, the clinic refuses that person a fundamental reality and agency. Thus, the essential problem

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¹⁵ Perhaps not coincidentally, *invalid* is a term in English which denotes both 'lack of legal power' as well as, 'someone who is ill or disabled.'
of a diagnosis of psychosomatic disease is that it can never be properly refuted. And the patient becomes trapped in a medical theory (and subsequently, a therapy) that has no possibility for contradiction. And while self-reflection engendered by psychotherapy is no doubt useful for human beings, its denial of the analysands utterances in cases of hysteria seem destructive, if unethical.

With regard to behavioural approaches to somatization, current medical texts emphasize a contractual relationship with patients. Unlike their earlier cohorts, journals now advise against the use of overt disciplinary methods when dealing with psychosomatic disease because it contravenes popular expectations and may drive the patient to further resent the practitioner. Nonetheless "the therapist with considerable experience and perspicacity will know when and how to apply a disciplinary technique." (Abse; 35) In an article published in 1996 on the treatment of conversion disorders, the author clearly explains that patients must be in hospital so that the physician can completely control the environment. Further, individuals must be confined to wheelchairs so that they cannot continue to act out symptoms. Finally, physicians are to dupe patients by giving them pseudo scientific explanations for their illnesses (Speed; 149-50).

Ride passes/outings/LOAs are to be rarely offered, and only at the discretion of the attending physician. During a behavioral treatment program, it is crucial to maintain control of the involved behaviour, and this can be only in the hospital. Passes of all types may at times be used as reinforcement for significant improvements ("healthy behaviours") late in the treatment program just before discharge.

(Speed; 153)

Ostensibly, absolute mastery of the somatizer is necessary for successful treatment. Medicine does not work cooperatively with patients in these cases but rather intends to deceive and manipulate
them. Hysteria means that the doctor must dominate the patient. Despite the presence of a "contract" in these instances, the pretense of the therapeutic alliance between patient and physician thereby disappears. While doctor and patient remain theoretically equal, in reality the relationship is lop-sided. The clinician retains the power to punish and reward (through prescriptions and orders) while the patient must acquiesce to the "contractual" demands (even if this may not be psychologically or physically possible).

The desire to dominate somatic patients is explicit in medical literature. Journals specializing in psychiatry, neurology and rehabilitation describe behavioural modification techniques that overtly punish and incarcerate patients who do not comply with medical orders to get well. One recent article (1997) outlines the "management" of children with conversion disorder:

During the first week, the patient [a ten year old girl] was extremely resistant to therapies and perseverated on her pain and weakness. She made no gain in motor function. It was determined that she was receiving reinforcement for her sick role from family and friends through visits and phone calls. Once this problem was identified, all visits and phone calls were restricted except as rewards for achieving daily goals. (Gooch et al.; 265)

When this child later experiences a decrease in function, 'upon hearing that she might have to return to the hospital for another inpatient stay, her symptoms subside.' (Gooch et al; 266)

Physicians place ailing patients in hostile environments, which imperil them psychologically and physically. One case of note occurred during the 1980s when an eight year old boy died of a
bowel obstruction while an inpatient at the Hospital for Sick Children in Toronto, Canada.\textsuperscript{16} He had gone untreated because doctors assumed his nausea was hysterical and forced him to clean up his own vomit. Despite this type of tragedy, doctors continue to practice coercive therapies on psychosomatic patients. Currently, two Canadian physicians, Teasell and Shapiro, run an inpatient rehabilitation program in London, Ontario. They employ a strategy very similar to the rest-cure (which nearly drove Gilman mad) as a form of aversive therapy for their conversion disorder patients. 'If patients continue to not make gains or remain resistant, they are subjected to "deep rest," which consists of confining the patient to bed and withdrawing all privileges and stimulation. Rarely, is this form of treatment required for long periods.' (Gooch et al; 265) Even today, the punitive intent and methodology of the treatment of hysterical patients is abundantly clear.

Ironically, the clinical approach to treating forensic patients is strikingly similar to that used with psychosomatic patients. In prison psychiatric settings,

\texttt{[a]s patients progress through the system, they are granted increasing privileges such as greater freedom of movement within the confines of the hospital, increased liberty in setting their own personal schedules, permission to keep certain items that are prohibited from patients at lower levels, and access to specialized activities and social functions. This system is viewed as a mechanism to promote the highest level of adaptive functioning for patients while still maintaining the integrity of the security of the hospital.} (Marques; 83)

The parallels are not only in the adoption of behavioural modification therapies, but also in the essential cynicism which characterizes the doctor-patient relationship. Neither forensic nor

\textsuperscript{16} This child's name was Stephen Yuz. While I have looked for information or articles in medical journals on this incident, I have found none. The two residents in charge of his care were eventually held responsible for his death in a public inquiry a few years ago.
hysterical patients can be trusted to behave appropriately without external constraints. Both are seen as socially threatening, the former to the physical safety of the community and the latter to the nosological stability of medicine. As a result, the doctor maintains a professional distance and prerogative when treating these patients. The practitioner manipulates the clinical environment in such a way that it repudiates and suppresses the patient’s manifestation of his/her sickness. As such, the clinic denies the sanctity of an afflicted person’s perception and narration of reality. Behavioural modification therapies provide little in the form of empathy or legitimation. They instead exert control over the patient.

While clinical supremacy may be appropriate in a forensic environment, both for the security of the community and of the criminals themselves, it seems hardly appropriate for people who are merely ill when they apparently should not be. It would seem that the clinic, either covertly or overtly, believes that psychosomatic patients are medical criminals. With no biological explanation for their ailments, they commit two offenses: firstly, they shirk their social duties and secondly, they defy medical knowledge. At times, the hostility with which physicians view psychosomatic patients seems understandable, albeit extreme. For example, if a person refuses to work, coughs persistently throughout the day and occasionally spits up blood, he will be excused for his actions if he is thought to have tuberculosis, but he will be disdained if he is thought to have nothing wrong and, ‘is making himself sick’ to gain sympathy and/or to avoid chores. Conceptually, doctors’ antagonism for patients they disbelieve is comprehensible. These individuals’ symptoms fall outside the nosological understanding of the clinic. In this sense, somatic patients lie beyond the reach of statistically validated therapies. This can only feel enormously frustrating for clinicians.
However, theoretically and politically, I believe that treatments for hysteria may well deny patients reason, narrative and autonomy. Moreover, they seek to deny and dominate patients' apprehension and narration of themselves, which seems not only unethical, but counter-intuitive to the construction of a healthy personality. In addition, behavioural programs oppress patients; again with varying scientific support for their efficacy. In all cases, patients disappear from medical view once they are discharged from psychotherapy and behavioural modification programs and, they are unlikely to seek medical assistance again given the coercion they experience when they are 'helped' by physicians. As a result, people whom doctors assume are cured may well in fact continue to suffer silently and invisibly. If people seem to get well under these regimens, perhaps it is because they no longer articulate pain and fatigue for fear of recriminations or punishment. They pretend to be better than they feel. (They, of course, could also be suffering from illnesses which fluctuate with stress and rest.) As well, they could simply adhere to the demands of the physician in order to evade an intolerable and invasive medical authority through eventual discharge from therapy. The deception and coercion of these treatment modalities would seem to encourages, in turn, fraud and resentment. They harbour the potential to destroy any capacity for trust between ill persons and their doctors.

While clinicians may have faith in their dominance of hysterics, patients have a somewhat different view. Suffering from their own illnesses, they must confront the hostility of the practitioners they encounter. They negotiate a clinical environment which appears to be a refuge, but which may, in fact, be misanthropic. One patient says of her experience on a psychiatric ward:
Patients want and need to trust clinicians. However, medical personnel may not seem to be trustworthy, in the sense that they may or may not treat patients with compassion and consideration. Physicians are overtly polite to patients, but their "niceness" may disguise a type of maleficence from the patient's point of view. Somatic individuals thus find themselves constantly trying to cope in an ambivalent environment, hoping to trust their doctors but being ever vigilant to the threats that such doctors pose. Moreover, in adopting a defensive posture, patients only open themselves to further rejection by medical staff.

The misanthropy and distrust that can characterize physician-patient relations in cases of somatoform disorders reveal some of the difficulty of treating modern day hysterias. These disorders disrupt the interchange between professional and lay person. The rhythm and trust of the therapeutic exchange can be disrupted by the contradictory truths of both physician and patient. While the patient seeks assistance from the clinician and believes that his/her concerns will be treated with validity, the clinician desires to help the patient but discovers that objectively his/her complaints may have little organic validity. The ill individual's presumption about the mode of the doctor's assistance can be misplaced given the conflict of objective and subjective realities. It is this perceptual struggle between doctor and patient along with medicine's comparatively limited capacity to treat these disorders effectively which can result in a break down
of therapeutic relationship. Moreover, I believe that some of the therapies which subjugate patients so profoundly challenge the normative precepts of egalitarian communities. The fact that somatic patients stretch the boundaries of medical knowledge and consequently, medical patience, can result in not only ineffective but also derisive treatment protocols which impinge on the personal integrity and agency of patients. As a result, hysterics therefore experience a constant jeopardy of personal autonomy and security in the clinic.

Hysteria and Domination

Hysteria is a disease that is simultaneously characterized by deep ambivalence and intense controversy. It lies uncomfortably between the realms of physical dysfunction and mental illness. Traditionally, it is associated with perverse sexuality and poor gender identity. It also carries enormous stigma due to the fact that it is not truly a "legitimate" disease for no scientific basis can be found for its symptomology. Concomitantly, its modern day cohorts (chronic fatigue syndrome, somatoform disorders, conversion reactions, etc) exist in a similar realm of medical and social ambiguity. While doctors 'treat' many somatic patients, they have few tools to cope with symptoms whose origins are not well understood. As a result, these ill individuals often experience an extraordinary dissonance and alienation from their physicians even as they receive medical attention. In these instances, the divergence between the subjective world of the patient and the objective realm of the clinic is noteworthy. Hysteria represents an extreme example of the possibility for breakdown in the therapeutic relationship. Patients feel ostracized for their illegitimate illness behaviour while clinicians feel it necessary to break the illusion of the patient's somatic complaints. Elements of coercion and resistance begin to seep both into clinical
discussions of treatment protocols and into patients’ accounts of their illness. Histrionic disorders are thus illustrative of an extraordinary political and psychological consequence of physician-patient conflict.

I am not convinced that diagnosing someone with psychosomatic disease alleviates suffering. Rather, it seems to increase hardship. Alice James’ letters and diaries are eloquent testimony to this fact. Hysteria stigmatizes anyone who is unfortunate enough to complain of symptoms for which no there is no known biological origin. Such patients are seen to be inappropriately adopting the sick role. They seemingly avoid familial and social obligations. Whether such illnesses are seen to be consciously or unconsciously motivated, patients’ psychological stability remains in doubt. Further, their sexuality can be interpreted as perverse and their gender identification can come to be questioned. Socially outcast, somatizers feel guilty for being ill. While they endure physical ailments, they become plagued with self-doubt. They must suffer not only the ontological consequences of being ill, but the psychological torment of disbelief.

Medicine both consciously and unconsciously vilifies psychosomatic patients. Its positivist lense cannot tolerate the apparently non-tangible phenomenon of hysterical illnesses. That which it cannot touch, it does not fully understand. And that which it does not understand seemingly does not exist. Thus ailments which can not be proven to exist within the limited parameters of medical knowledge and technology are simply not valid. And those that suffer from such ailments are, quite literally, invalids. Because hysterical disorders lie between disease types – it is never very clear whether they are physically or psychologically based – they are diseases of ambiguity. Somatic patients consequently no longer receive optimum medical care (Horowitz; 5).
It is as if medicine relies so heavily on its nosological frameworks that it cannot really embrace individuals whose symptoms fall outside its diagnostic criteria. These patients then are metaphorical outlaws.

In addition, medical treatments of psychosomatic disease coerce and demean patients. Physicians dominate them, stripping them of their reason, self-efficacy and biography. Therapeutically, the more patients relinquish personal decision-making and power, the more likely they will be cured. Thus, a diagnosis of hysteria is political in its clinical application and remedy. It focuses on destroying the claims of the afflicted individual. And, its therapies employ psychological manipulation and physical coercion to meet their ends. Personal autonomy is greatly threatened by all illnesses, but never more so than in cases of hysteria, conversion disorder, malingering and psychosomatic disease. When the clinic views hysteric as socially inappropriate, sexually deviant and politically rebellious, it adjudicates human behaviour in a manner that seems to exceed its professional mandate. More importantly, given the ambiguous origins of somatoform disorders, these medical presumptions seem to intrude on the basic personal dignity of patients who do nothing more than remain ill without apparent cause. Classified as having no legitimacy, they appear to be treated in a criminal fashion under the rubric of medical care.

Critically, a diagnosis of hysteria often seems to indicate an extreme malfunction of the association between doctor and patient. When a person seeks aid and comfort from a physician, but receives only disdain, medical knowledge and practices should come into question. Distrust and oppression can come to characterize the therapeutic relationship when a diagnosis of hysteria occurs. Thrust away from the certainty of diagnosis, prognosis and cure, somatizers find themselves adrift in an ambiguity which the physician cannot easily share. Instead, the doctor
Atkins proposes to rehabilitate individuals using rigid therapies that makes things worse by rendering patients impotent, angry and resentful. The doctor reacts with even stricter regimes and increasing animosity. A vicious and acrimonious cycle ensues. Fundamentally, the diagnosis of hysteria can create enmity between doctors and patients.

From a political perspective, histrionic disorders point to the fundamental difficulty of presuming and or even implementing theoretical equality in an environment that is historically and culturally hierarchical. To be sure, doctors and patients are equal in terms of their citizenship in an egalitarian community. However, vulnerable and sick persons who seek assistance from trained and knowledgeable medical professionals cannot really exercise their equality fully in interchanges with their physicians. Where there is an imbalance of knowledge there is a necessarily an imbalance of power, and trust is required to bridge this political gap. When doctors and patients conflict over the origins of somatic complaints, this trust may more easily be broken. The inherent inequality of the doctor-patient relationship thus becomes more apparent. And despite good intentions and the existence of legal and ethical codes, patients tend to lose their personal and political agencies.\textsuperscript{17} As a political scientist, hysteria provides a compelling portrait of the problem of maintaining basic human rights in the clinic where relationships embody enormous imbalances of knowledge and, extraordinary conditions of vulnerability and power.

It is perhaps wise to remember that we are all, to some extent, hysterical. Human complaints of illness will always exceed medical understanding. Psyches will always influence

\textsuperscript{17} Despite laws and ethical codes of conduct which state otherwise, physicians do not see patients as equals. This attitude is expressed linguistically when most practitioners introduce themselves as 'Doctor so-and-so' and then often proceed to call their patients by their first names (Smith; 17). On the whole, physicians seldom seek consultative parity with patients, in either medical decision-making or in treatment.
somas and somas will always influence psyches. Everyone, at some point, will experience symptoms for which their doctor has no name and which will lie somewhere outside the boundaries and delineations of medical knowledge. When I listen to and read about people's stories of sickness, it strikes me that the political lessons of hysteria subtly imbedded in most peoples' encounters with their physicians. As a friend of mine, who has "real" cardiac problems said to me about his latest round of medical tests: "I realize that I am on my own. I still have pain, but they tell me I shouldn't. I'm frustrated and feel guilty about that, but then, there's nothing I can do."
Chapter 4
Conclusion

The Final Narrative

There are moments in every day – I may be driving in traffic, I might be bent over the kitchen sink, or I could be huddled over the weeds in the garden – that the specter of my illness haunts me. Schematic images rise in my memory, creating an odd, nauseous wave in my stomach. I breathe a few quick breaths as a swirl of tension gyres into my chest. And then, almost inexplicably the tumult ebbs and my breathing eases. A giddiness surges in its place. A little spark of ecstasy flares at the thought that, fourteen years after my first signs of paralysis, I am well.

In the midst of my strength, I remain aware of my frailty. A small current of fear runs through my happiness, reminding me of my good fortune and occasionally swamping me with its dread. I know that, despite my health, I may become physically, psychologically and politically enfeebled at any moment.
Three and a half years ago I lifted myself from a bath on a grey, February morning into a third respiratory failure in nine months. Within seconds, as my breathing became slower and shallower, I could no longer speak. My partner managed to shift me from my wheelchair onto the bed.

"Are you okay?" She asked.

I shook my head.

"Oh shit! We’re going to Emerg again aren’t we?"

I nodded.

My partner’s face creased with worry, "You’re sure? You’re sure you want me to call 911?"

I looked at her. I knew exactly what she was asking. Could I bear another ICU stay, another intubation and more arguments about what was wrong with me? Could I bear to be dismissed as I lay immobile and in agony? Could I bear being impugned by the very people I turned to in extremity? I had sometimes said that it would perhaps be better to die than to suffer such torment again. I paused. I considered my options. Should I, I wondered, finally cede and let myself die with pained dignity in our apartment or, should I throw myself on the mercy of physicians who often believed I was hysterical and endure tremendous pain, loss of dignity and then perhaps die anyway? As the room lost focus and the fibers of my body screamed for oxygen, I threw my arm out toward the phone that lay nearby. All I knew was that I wanted to live.

Within minutes I could smell the smokey presence of firemen and hear the squelching of rubber boots. I sucked at the air, losing strength. I felt a grainy dusk descend
through my body. I heard a man's voice ask "She’s paralysed right? She’s willing to be resuscitated?" I managed to nod.

My consciousness stirred as the stretcher banged its way through a hospital doorway. I became more clear with the tearing pain of a tube tunneling into my mouth and throat. I instinctively reached to grab at it and felt my arms pinned to the mattress. I could feel a needle seeking an artery in my wrist. It plunged in again and again and again.

"Damn! I can’t get it." A young intern ceded the vial to a burly resident.

The sharp point probed again. I wanted to wrench my arm away but he held it firmly, almost painfully with his forefinger and thumb. "This isn’t any good. I’m going to try the other side."

Reflexively, I tried to draw my other arm away from him. I discovered that it no longer moved. The paralysis had crept stealthily into it.

Unaware, he threw his weight painfully on top of my wrist. "Look, I know this hurts, but I’ve gotta get blood gases." He spoke to me with apologetic grimness. "We really have to know your oxygen and CO₂ levels." The needle probed over and over and over. I counted perhaps ten tries. My eyes watered, seeping through my eyelids.

"Okay. Okay." He relented. "We’ll stop for the moment and try later."

The hard plastic of the tube rasped against my raw throat. My torso seemed to torque painfully around it.

A green clad woman hovered by the ventilator. "Try to stop breathing. Don't work against the vent! Just let it do it for you."
Quietly, the contents of my stomach floated up my throat and poured out my mouth and nose. It happened again a few seconds later. And then again and again every few minutes over the next several hours. It seemed as though my body was trying to eject every last piece of foreign matter. Another plastic tube was inserted in my nose and down into my stomach. Pink and black bile flowed up it and into a jar.

Soon I could no longer bite down on the tube between my teeth. My jaw was becoming slack and saliva began to spill over my lips. I simply couldn’t shut my mouth.

A catheter was inserted in my bladder and, a new I.V., started in my right elbow. I could feel a cold, stinging sensation in my forearm where the last line had blown. As I faded in and out of pained consciousness, people seemed to be always standing above me. Trolleys and machines clattered and banged as I felt the paralysis settle deeper and deeper. I began to feel like an inert, jellified custard.

In the midst of my stasis, the searing in my throat continued unabated. My muscles felt as though they were trembling uncontrollably although I could see they were quite flaccid. A fibrous tension tormented my body. I felt as though I were caught in a rushing torrent of energy that could find no physical expression. The sensation was not painful in any traditional sense but it nonetheless created a barely tolerable physical and psychological agitation. A primal misery engulfed me. My central impulse was to get up and flee the room like a blubbery child. I wanted to seek solitary comfort in a dark, hall closet that smelled comfortingly of wool coats and mackintoshes.

Instead, I remained a captive of my moribund body. Only my eyes and my left hand remained mobile. I fought to retain a focus length beneath my half-closed lids. With
enormous effort, I could roll the heel of my left hand back and forth and flex its fingers weakly.

With a pen held loosely in my slackened fist I scrawled 'PAIN' on a scrap of paper.

The nurse took the message up into her hand. "I know, I know." She patted my arm. "First, we've got to get you to ICU."

Twelve hours later, I still lay on the stretcher in Emerg. Through my opaque agony, I heard arguments about a lack of ICU beds. Cursing and confusion pattered about me.

A respiratory therapist complained, "I've got patients upstairs. Look, I can't leave her. But, for godsake, find someone else!"

Amidst the administrative chaos, my body continued to pulse out bile while simultaneously refusing to breath with any regularity. Encased in a paralytic tomb, my emotions raced with despair.

Finally, the staff found an ICU bed at a hospital a few blocks away. I was hooked to a transportable ventilator and lifted into a waiting ambulance. A paramedic, a nurse, a neurology resident and a respiratory therapist all crouched in beside me.

I arrived in the earlier hours of morning to an amber-lit, peacefully throbbing ICU. As the admitting nurse flipped through papers by my bed, I heard her sigh, "Oh another dump from T hospital."

An insurgence swept through me. With the pen resting inside my left palm, I scratched on a pad of paper lying under my hand: 'I AM NOT A DUMP.'

She crimsoned a little. "I'm sorry. That's not what I meant." She fumbled with the chart a bit more and then picked at the NG tube that still drained pink and black bile. "Did you take something? It says here that you might be a suicide."
A heat of anger flared in me. I signaled no.

"They don’t know why you’re draining so much. – Well, your tox screen is negative..."

I scrawled ‘PAIN’ on the piece of paper.

"I know, I know." She looked across the room thoughtfully. "I don’t know whether they’re going to keep you intubated. We’ll have to wait and see." She turned back to me. "So they don’t know what’s wrong with you, eh? It says here maybe myasthenia, but then they also want psychiatry to see you.

"Well, we’ll get you settled. I’ll get orders. And then, maybe you can rest. The neurology resident won’t be up for a couple more hours."

During the next twenty-four hours, clinicians gathered at my bedside. They murmured inaudibly to one another, flipping through chart material and staring glumly at the various monitors. One of them finally addressed me, "I think we’ll try to extubate you and see how it goes."

Despite saving my life, the tube and ventilator were my enemy. To me, they inflicted intolerable pain. I welcomed their absence. I discovered that with great concentration and effort, I could breathe on my own. But every breath strained me. My lungs worked more slowly and shallowly than I wished. But, I thought I could sustain myself. My mood grew lighter.

A resident attempted to retrieve blood gases from my wrists and failed once again. Without active muscles in my face and throat, I mutely endured his proddings until I finally wrote on the pad of paper with my left hand ‘NO’.

As the day wore on, I grew tired but was too afraid to sleep. I felt that if I slept, I wouldn’t breathe. I feared dying. I feared the ventilator. I chose to breathe and didn’t sleep.

Into the evening, my chest began to ache. My body felt as though it were running at an accelerated pace. The raging current of paralysis continued to drum through me. I tried to meditate but my chest continued to grab at me painfully. I focused on each breath, coaching myself to draw more deeply and with greater frequency. My body seemed reluctant to obey my will. I felt ceaselessly tired and afraid.

A pale doctor appeared over me in the early hours of morning. "Are you having any pain?" he asked.

I signaled ‘Yes.’

"Can you tell me where?"

I tried to speak, but couldn’t.

"Legs?" He paused. "Arms?" He paused again. "Head? Chest?"

I signaled ‘Yes.’

"I thought so." He rubbed his unshaven cheek. "I think we’re going to try you on nitro. It’s for your heart. I want you to tell me if the pain gets better, worse or stays the same. Okay?"

The pain eased temporarily.

"Okay. We’ll start you on a nitro patch and a morphine drip." He patted my bedrail. "I’ll see you in a few hours, I’m going to get some shut eye."

In the morning, my bed was moved to a crowded ward room in the ICU. In the corner, a young, semi-conscious man moaned. His father mopped his forehead with a towel. At
times, the patient’s torso would twist upwards and his eyes and mouth jerk wide open. Alarms would scream and a ripple of chaos would erupt as his body broke free of various lines and machines.

Opposite me, an older woman wanted food. I could hear her pleading for something to eat. "I’m so hungry! I haven’t eaten since yesterday morning! Please give me something to eat. I’ll even take Jello." Her nurse was circumspect. "Not yet. Maybe in a couple of days." I overheard the staff physician tell someone that she was in liver failure. Surgery had revealed a large tumour elsewhere as well. "When you get to the floor, maybe they’ll let you eat then." Her nurse consoled her.

Later the same day, a female psychiatrist stood by my bed. "You don’t look so good," she commented. She looked around the room. "Gawd, don’t you want to get out of here?"

The question stabbed at me.

"Look, I don’t think there’s much I can do here. They think you might have taken something." She looked down at the binder wedged in the crook of her arm. "I don’t get it. Your tox screen’s negative." She looked back at me questioningly, "So, did you take anything? Did you try to off yourself?" She paused for my answer. "No? Good." She wrote something down. "To be frank, I don’t know what I can do. Do you need anything?"

I needed to breathe. I needed to move. I needed to be anywhere but there. I signaled ‘No.’

"You don’t look like you need me, you look like you need a neurologist. – It’s okay if I don’t come back?"
In the afternoon, my partner was holding my hand when two residents appeared at my bedside. Soon, an older physician arrived along with some medical students. The head ICU nurse introduced herself and perched on a stool near my head. A patchwork of white and green clothing gathered closely around me. The staff physician, Dr. L, leaned toward me "We’re going to give you a tensilon test in a minute. Okay?" He picked up my left arm in his. "I want you to pull toward you as hard as you can. Okay. Good. Now we’ll go ahead." He drew up a syringe, cleaned off a port on my I.V. and injected a clear substance into the tube.

Within seconds, my stomach churned and my face striated with pain. My eyelids opened wide but I lost focus. My eyeballs seemed to roll uncontrollably in my head. "Yeow!" I vocalized weakly.

He lifted up my arm. "Pull towards you." He nodded to everyone. "See that? And look at her heart rate – it’s dropped." He looked at me emphatically. "That," he said, "Is one of the more dramatic responses I’ve ever seen." His face quietened. "Young lady, you have Myasthenia Gravis. You’re going to the TW hospital to get plasmaphareisis." As the crowd dispersed, he paused and placed his hand on mine, "We know what you’ve got."

The head nurse bowed her blonde head toward mine in the bed. "I know you’ve had a rough time in the last few years. But the mystery’s over. It’s gonna be okay."

Dr. L glanced at her, "You’ll arrange the transfer?" He watched me for a second, "And call anesthesiology. She needs to be intubated again. She’s working too hard." He looked at my partner briefly, "Okay – that’s it," and then turned away.
A swelling of joy surged in me. Perhaps, I thought, as I lay mired in the flood of my paralysis, I need no longer be completely afraid. Perhaps, I could begin to trust – to trust, just a little – that I might be cared for rather than rebuffed.

The next day, a bevy of attendants jostled me into the back of an ambulance. The vehicle wended its way through rush hour traffic. Occasionally, I saw the slow flash of lights reflected against the sides of trucks and streetcars as we passed.

TW hospital’s ICU was large and dark. As I was transferred into a bed, I felt a pang of fear as unfamiliar faces advanced upon me. The head of the ICU walked over and introduced himself. "Hi, I’m Dr. K." He picked up my hand and put it in his. "We don’t mollycoddle patients like they do over at W hospital." His brusk manner intimidated me. "I don’t believe in keeping people here any longer than they should be." He pulled back the bed sheet and began to examine me. After several minutes he looked at me, "Let’s pull the NG tube. You don’t need it. – Then maybe a bit later we’ll see how you do without the vent. Maybe tomorrow we can stop the nitro as well."

The speed of his decisions sent a flurry of anxiety through me.

With a nurse’s assistance, he rolled my body on its side. "You’re already getting skin breakdown." Addressing the nurse, he directed. "She’s to be turned every 2 hours and for the first 24 hours only side to side, not on her back." He settled me back onto a pillow. "Oh yea, I want physio and OT to see her.

"Okay. That’s it for the moment. The neuro team should be in to see you sometime." He reached for his clipboard resting at the end of the bed. "Let’s see if we can get you upstairs in the next couple of days. I’ll see you later."
The next morning, the vent was withdrawn and by the afternoon I was extubated. Again, I could breathe but only shallowly and with immense effort. I still couldn’t speak. A neurology resident came to see me. He stood at the end of my bed, reading through sheathes of paper and binders. He left without addressing me. Late that evening, I was transferred upstairs to the neurology ward. As I left the ICU, a respiratory therapist reminded me, "Your volumes are low. Try to breathe more often and more deeply."

My new room was next to the nursing station. I could hear phones ringing and the thump of administrative machinery. Through the open doorway, I caught snatches of conversations. In the bed next to me, a young woman lay recovering from Guillame Barré syndrome. Although still somewhat paralyzed from the waist down, her spirits were high. She had been on a ventilator a few weeks ago but now chatted sanguinely on the telephone by her bed. Her television flashed through the hanging cloth divider. Wafts of hospital and junk food permeated the room. Three or four of her family and friends sat and visited.

The commotion felt barely tolerable. I lay mute and motionless, concentrating on inhaling and expelling air. I stared at the pastel-coloured print of a clown which was screwed into the pale green wall. My throat ached sharply from the memory of the tubes. I was afraid to sleep.

A nurse brushed back the curtain and gaped at me blankly. She was asthmatic – I could hear faint wheezing from where I lay. She told me that she’d be back in while to settle me for the night and then disappeared.

During the next 24 hours, I fought exhaustion. While I had begun to be able to turn my head, this mobility slowly ebbed. The paralysis skulked further back into me. Saliva pooled in my throat, my jaw hung slackly and my eyelids began to sink further. My chest seemed more rigid.
with each hour that passed. Cut off and alone, my desire to live persisted. In my wretchedness, a relentless resolve urged me to try to keep breathing. And then gradually, I realized I was slipping. My being was beginning to seethe with lack of oxygen. In the corridor, I could hear the mundane chorus of nursing chores and accompanying chatter. I tried to move my hand against the call bell and failed. I tried again and heard the bell ring in the distance. It was quickly shut off. I rolled my hand again against the sensor. The bell rang. I heard a voice say "She probably wants to be moved. Can someone tell her I’ll be in a minute?" The bell shut off. I pressed once more. Finally, I heard squeaking footsteps penetrate my room.

"Oh gawd, hon!" I felt the nurse begin to raise the head of the bed. "It’s okay. We’re going to help you breathe. Hold on."

I felt an increase flow of oxygen hiss through the mask resting on my face.

"Hey! I need some help in here! I need the ‘sat’ monitor."

Within seconds a tumult of activity invaded my room. Flourescent ceiling lights blazed through my lowered eyelids.

"Her ‘sats’ are low. Get ICU back up here."

Another voice called out, "Get me a suction kit – her airway needs clearing."

A hand rested on my forehead. "We may need to bag you hon."

Within a few minutes, a woman resident arrived from ICU and readmitted me.

"But." she cautioned, "You’re going to have to stay here a couple of more hours until we can clear beds. In the meantime Dr. T, from hematology, is coming to see you. – You’re lucky, we got him just before he was leaving for dinner. – He’s going to arrange for plasmaphareisis." As she left I heard her comment to someone, "Don’t worry, I’m on the crash team if anything happens."
When Dr. T arrived, I managed to lift my left eyelid just enough to glimpse his rumpled trousers and the bottom of his lab coat. He leaned over the bed and lifted my eyelids with his fingertips. He loomed blurrily over me. "We’re going to put a shunt into your chest here," he indicated. "Then we’re going to strain off your white blood cells and then remix your red cells with fresh plasma. It looks like egg white and comes from other people. There’s a small risk of hepatitis and HIV infection. But the albumin is pasteurized, so it’s unlikely." He paused. "Any questions?"

I tried turning my wrist.

"Can she talk?" He queried the nurse sitting next to me.

"No, but maybe she can write."

"Can she sign her name?" He put a marker in my hand. "Here, if you agree, sign right here on the bottom of this page."

With the pen, I slowly inked ‘CHOICE?’ on the sheet.

"Are there any other choices? That’s what you want to know? I don’t think so.

Plasmaphareisis is it."

I signed my initials.

Within the next few minutes a resident inserted a large IV underneath my clavicle. He attached what felt like a large electrical plug to the shunt and sutured the whole thing to my chest. Soon I was back in intensive care being prepped to be re-intubated. Dr. K again held my hand in his, "It’s okay. We’re just going to hook you back up to a ventilator."

Internally, I screamed with panic. I couldn’t bear the thought of the tube again. If they could just help me breathe without lodging a hard plastic hose in my throat. I wanted
desperately to live but I couldn’t bear the unrelenting pain of the tube. I flexed my wrist over and over trying to get his attention.

He placed a pen in my hand. I tried to write.

After a few seconds, he looked at the pad, "I can’t read it. Try again."

I tried to write more legibly.

"I can’t make it out." He deliberated. "Look, make a mark if you agree to be ventilated."

I didn’t move.

"You mean, you don’t want to be ventilated?"

I marked the paper.

"Oh . . . ." I could feel him massage my hand a little in his. "What happens if you crash, will you let us resuscitate you?"

A mournful ache spread through me. If I was quite literally dying, I would endure the pain. I moved the pen.

"Let’s be clear. You will let us resuscitate you?"

I moved the pen again.

"Okay. Good. Then I want to measure your neck for the tube and I going to leave it right here – on the table beside you – in case we need it."

The threat of the tube gnawed at my psyche. My heart raced with the effort of aspiration. My head throbbed voraciously.
At one point, my nurse leaned down and said, "I've been reading the chart. You're not really sick. Dr. K's over-reacting, he should send you back upstairs." I heard her remark to a nurse at the neighbouring bed, "She doesn't belong in ICU."

Her comment sent a desolate anguish through me. I wanted to flee. Instead, I twined myself inward. I focused on staying alive and prayed for her shift to end.

Interspersed lines from a Roethke poem about a child clinging on to his drunken father reeled round and round my brain: ". . . But I hung on like death:/ Such waltzing was not easy." An old friend came to see me, with the remaining strength in my hand, I hung on to him like death. I was deeply afraid.

Plasmaphareisis treatments began the next day. I felt an immediate change in my body. I grasped that the distinction was imperceptible to those around me but, I knew it. I felt it. The clamps that had seized down on every fibre of my body loosened very slightly. My saliva even tasted different.

Later that day I was transferred to a more chronic area of the unit. Through eavesdropping, I discovered that a comatose man lay to my left and in the opposite corner, a young man lay encased by Guillame Barré. Both of them were ventilated through tracheostomies.

My hearing was becoming extraordinarily acute. Very quickly I could not only tell the footfall of the various respiratory therapists, nurses, orderlies and physicians, I could predict which room they would choose to enter from the subtle variations in the patterns of their treads.

My sense of smell was also heightened. The aroma of various crushed medicines wafted at me across the room. With a new NG tube in place, I knew precisely which medications were being
prepared for myself as well as for the other patients in the room. Scents and sounds allowed me to access and interpret much of my world, even as my eyelids were now almost sealed.

Unfortunately, I could also hear the arguments in the hallway between the physicians about my case. "Her toes curled up yesterday. They aren't today."

"Are you sure?"

"I dunno know. I think so... No I'd swear it."

"She has a lot of clonus."

"Dr. G won't do the evokeds again. She's negative. W hospital probably just screwed up the tensilon."

"I don't believe she has Myasthenia."

"Well, someone does cause she's on the meds."

"Who ordered the plasma anyway?"

"Dr. K did."

"What you bet she took something that we can't trace? They say she's really bright."

My partner overheard a neurology resident discussing my case on the elevator one day. The tone of the discussion was an imbroglio of revulsion, anger, awe and concern.

Every few hours, Dr. K would stop by my bed. He would lift the covers and ask, "Can you move anything? Show me what you can do?"

After the second plasma course, my eyelids lifted slightly. But my pulmonary capacity remained marginal. I worked terribly hard to move small volumes of air. I still couldn't
speak, swallow or shut my mouth. Dr. K remarked, "You look exhausted. Too scared to sleep, eh?" He tried to reassure me, "You can sleep. If you stop breathing, we'll resuscitate you."

Weeks of struggle wore me down. I was no longer sure I could endure the tube in my throat. It terrified me.

The next plasma round improved me more markedly. Dr. K commented that I had more expression in my face. An odd pain began to invade my body. I managed to write this to him.

"I know you probably won't like to hear this. But increased pain is a good sign."
He smiled. "It really is."

A strange despair lurked in me. I wanted to be improving more quickly.

Dr K seemed to intuit my despondence. "I've got an idea. Your eyes seem better. You can focus a bit?" He paused. "Okay. My orders are for the nursing station TV and VCR to be brought in. I'm going to get your nurse here to call your family to bring in as many movies as they can find."

His suggestion buoyed me.

"It's completely understandable that this is getting to you. You've been here a long time." His hand rested on my ankle. "And I'm going to call the pain management team... we're looking at longer term pain control. They're better at that than I am."

A few days later, as I awaited more plasmaphareisis, Dr. K came to say goodbye.

"I've been here for longer than my usual stint. Dr. R is taking over for the next couple of weeks. After that I'll be back. But, I think you may be upstairs by then. He'll take good care of you."
In his usual manner, he held my hand in his. "Before I go, is there anything you need or want?"

He bent his ear to my mouth.

"How long will I be like this?" I managed to whisper.

"Honestly? I don't know. I really don't know."

Two days later, I was transferred back to neurology. My breathing seemed more stable. I could vocalize weakly. My left arm was a bit more mobile and I could turn my head to one side. I still required a feeding tube which, if it was run too quickly backed out through my nose and mouth. I couldn't roll myself or sit up.

Dr. M, the neurologist who had visited me a couple of times in intensive care, stopped in very early one morning. He shut the door to my room. "Look," he said, "I believe you have myasthenia, but most of my colleagues don't. You have a long and complex medical history." He paced back and forth at the end of my bed. "Over the years, practically every neurologist has had contact with your case. I can't treat you for myasthenia if I don't have the support of my colleagues. The one physician who sees myasthenics has refused you as a patient."

He looked stern. "I'm sorry but there's very little I can do in these circumstances. The plasma exchanges will go on for only a couple of more times. I won't be able to reorder them."

Anger and self-pity sluiced through me. My eyes brimmed with tears.

"I'm sorry." He stepped toward the door. "And, if you ever say we had this conversation, I will deny it." He opened it and left.

A certain clinical detachment characterized my stay on the ward. During morning rounds little was said about my condition. Occasionally, I would be asked by some doctor whether I thought I was ready to go home yet. S/he would remind me that my hospital stay had been long
and expensive. Intermittent hostility grew and I dreaded the arrival of any physician by my bedside.

In the meantime, I continued with physio and occupational therapy. Over a period of three months, I began to have more movement. My speaking voice started to return. Finally, after several swallowing studies, it was determined that my feeding tube could be withdrawn. Every so often, when I pressed too hard, the paralysis would slip back and I would have a bit more difficulty. Nonetheless, I was making steady progress.

At the beginning of the fourth month, two residents approached me about being transferred to a rehabilitation hospital. I agreed and signed a consent form. Within the week, a nurse, a physio and a doctor from L hospital came to assess me. I knew and liked all of them. I knew that they also liked me. The doctor summarized their position, "We know you will work hard. We've seen it before. But you're still pretty weak. And as you know, we don't deal with patients who need to be ventilated."

"But, I haven't been intubated in weeks," I protested.

"Yes, I know. But you're breathing still doesn't look that secure. You tire very easily." She cradled a binder in her arms. "We will take you," she emphasized. "But, in a few more weeks, when you're stronger. Be patient."

The following day, a social worker came in to tell me that, "Since you are a poor rehab candidate, I'm here to arrange transfer to a nursing home."

"But I want to go to rehab, I don't want to go into a nursing home."

"Well, L hospital didn't take you. Anyway you signed the consent form."

"I did not!"
"It's on the same form as the request for rehab placement."

"But the chronic care stuff was separate. I didn't check it off."

"Well there's a check mark beside it now." She seemed frustrated and confused. "It will probably take a few weeks for a bed to come up, so it won't happen immediately. Maybe you should talk to your doctor if you don't want to go."

I complained to the female resident who saw me the next morning.

She seemed irritated, "You've been here a long time. You're blocking a bed. We tried to get you into rehab, as you requested. But they won't take you." She persisted, "You've got yourself into quite a situation. But we can't keep you here. You are not a medical case. There are people who are really and truly sick, who need this bed."

Two days later my nurse didn’t come in with my scheduled medication. I asked for my pills. She informed that most of my meds were being discontinued. The aim was to have me weaned from all medication within two weeks.

A dark pool of apprehension rippled through me. Slowly, I was gaining new capacities. I could roll myself in bed. With the help of a long, angled spoon, I could feed myself the mashed potatoes and minced beef which seemed to constitute my hospital diet. I didn’t want to get worse. Yet, even as the fear of increased paralysis re-surged through me, a portion of my psyche tried to calm my agitation. Perhaps, I thought, it would be wise to see whether the medications really helped. I counseled myself to be patiently watchful – to wait and see what happened. Moreover, I knew that I couldn’t expect my physicians to prescribe drugs that they themselves were unsure of.
Within a couple of days the reduced dosages started to take a toll. To both nurses and therapists my body seemed heavier. I found it more difficult to move and focus my eyes. My eyelids began to descend. I tired more easily. A few days later, all chemical therapies were stopped and I felt my body sag more heavily. By the end of the following week, I found it difficult to speak and swallow. One day, shortly after physiotherapy, I struggled to breath and grew frightened. An ICU resident came to see me and offered to move me back downstairs for the night. I feared the pain of an intubation and refused.

The following morning, with my face and body increasingly paralyzed, I asked to see my attending physician. A female resident arrived instead. She stood at the end of my bed.

"I don't think I can take this experiment for much longer." I said. "I would like you to restart my medications."

"Why?"

"I'm getting weaker."

"I don't see it."

"Well, my physio and OT see it. The nurses do too."

"We are not giving you any medications. You're not sick. " She rapped a knuckle against her clipboard. "And doctors prescribe, nurses do not. You may be able to convince others but you will not convince us!"

"Can't you see my face? My eyelids are almost closed. I have trouble seeing clearly."
"I don't believe you." She paused and then spoke again. "Most myasthenics can move their eyebrows even when the rest of their face is a paralyzed. Let's see you do that." She waited.

I tried to wriggle my eyebrows but they remained stiffly glued in place.

"You see, you didn't move them."

"I can't move them!"

"No. It's just that you don't want to move them! And you say that your eyesight is blurred, but it's not."

"It is."

"No, it isn't."

The futility of my plea cascaded within me. "So you won't re-prescribe the drugs?"

"No."

I felt close to tears. A protective emotional shell began to descend about me. "I guess there's nothing more to say."

"No. We're arranging for transfer to a nursing facility as soon as possible."

We stared at one another in a piqued silence. She turned and left the room.

During the afternoon my partner and I decided to take me home. With the help of insurance, we booked private nursing care. The following morning I informed the physicians who made rounds. They seemed concurrently irked and relieved. "We do not think that this is in your best interest. Perhaps, your partner is poisoning you and that is why you are sick. . . ."

An extraordinary pained incredulity swept through me and my resolve hardened. I wanted simply to go home.
Within two days, I lay in my own bed. Even as my family physician (with the support of my regular psychiatrist) agreed to restart medications, I began to explore death and dying societies. I worried about getting too weak to kill myself. The years of illness stacked themselves ominously inside me. I had spent the previous 18 months bedridden, aching with fatigue and paralysis. I sprained my joints when I tried to lift or roll myself. Often I was too weak to eat or speak. My endurance was waning. The image of a quick death comforted me.

Unfortunately killing myself was an enormous psychological and physical feat. One counselor suggested that we find a vet who might be willing to provide injectable medicines which might be more reliable as my ability to swallow and retain food remained uncertain.

After much discussion my partner and I agreed to wait a couple of weeks to see whether I gained any strength with the renewal of my drugs. And, in fourteen days, I made gains. Small hopes began to re-emerge.

Unfortunately, during the third week, I ate strawberries that were infested with cyclospora. I became terribly ill and weak. A mantle of grim despair descended. Even as I became more and more dehydrated and struggled to breath, we knew we would not call a doctor or ambulance. Encased in the shell of my agonized body, I moaned inaudibly to myself. I clung on. The private duty nurse called her supervisor and whispered anxiously that I was dying. It would not be until many months later that my partner confessed that she had believed that she would either come home in the evening or wake up in the morning to a cold corpse.

In the end, I survived the food-poisoning. And, during the next months I continued to improve. The combination of pyrodostygmine and corticosteroids nourished me. I gained movement, muscle mass and physical energy. During the next 4 months, I went from using a
power chair to a manual one. And then, within another 3 months I stood, teetering, on my legs.

Soon, I was taking pained steps. It was the first time I had walked in 4 years. My progress was uneven but steady. I had days which set me back. I tired easily and my joints and muscles often hurt with new efforts. But, I improved.

One evening I was in a bike shop with my children. A hand tapped me on the shoulder. I turned around and before me stood one of the neurology residents from Intensive Care. He couldn’t disguise the astonishment on his face. "I’ve been following you for a couple of blocks. You... you... look amazing," he stuttered. "I can’t believe it!"

"I know. I feel pretty good."

We chatted a bit more and then he finally exclaimed, "Gawd, now I know – now I know we make a difference. I really thought you would die." We shook hands. I thanked him. He walked away, his face lit up by an enormous grin.

**Lingering Impotence**

It is now three years since I lay in ICU. For over a decade I struggled with a mysterious ailment which intermittently and gradually debilitated me. But now, I walk, talk and breathe on my own. At times I even partake in light sports such as sailing or roller-blading. I’ve returned to work. Despite the fact that I tire easily and sometimes find myself back-sliding – this itself has required stronger immunosuppressants – an ineffable grace of health pervades my life.

Physical strength and function endows me with the benedictions of an everyday existence. *Normal feels very, very good.*
Yet, even as I enjoy the freedom and potency that renewed vigour brings, a shadow of impotence lingers in the background: I do not have a disease. Even though I respond to treatment, I do not have typical myasthenia gravis. From a scientific perspective, I am positive on only one of the clinical tests. Moreover, I am positive on the least, apparently objective criteria. While it is apparent to a number of physicians that approaching my symptoms as though I were a myasthenic has been incredibly helpful, they remain unable to garner the support of neurologist to assist in my care. As my family doctor said to me a year ago, "If you get really weak, you need to go to hospital. And then you are on your own. There will be nothing I can do."

I remain in the realm of Alice James' "formless void." I still do not have palpable disease, particularly since most neurologists do not see my illness (or my recovery) as valid. My ailment lies between categories. It is thus unclassifiable. Medically speaking, the only thing that is certain is that I do not fit. The rest belongs to the realm of the intangible. Without the certainty of diagnosis, I remain in limbo. I could be hysterical. Then again, I might not be. I test positive on one test for MG but not on another. It looks as though I have an autoimmune disorder but I do not show a titre of MG antibodies.18

My cerebrospinal fluid is abnormal pathologically, but the significance of this finding is unknown. On the one hand, it could signal morbidity, on the other, it could merely be artifact.19 All signs are unclear.

If I were to have a crisis of any sort or become so paralysed or impaired that I required hospitalization, the remedy to this problem of uncertainty from a clinical perspective

18 Of note, is that only about 60% of myasthenics have MG antibodies. It is postulated that the other 40% may have other antibodies for which a test has yet to be developed.
19 Scientists and doctors may not have tested enough cerebrospinal fluids from the general populace. What appears to be pathological could thus in fact be an as yet unrecognized variation of normal.
would be foremostly to take a psycho-social approach to my symptoms. I would not necessarily receive respiratory support, appropriate nursing care and/or plasmaphareisis. It is likely that my medications would be withdrawn. As one of my primary doctors tells me "You have every reason to fear the hospital, but if you are dying it's the only place you can go." The central dilemma of my medical care has not disappeared, it has merely slipped into the background. If I need help, there is no reasonable assurance that it will be there. Further, there is a strong likelihood that I will be maligned rather than cared for.

Like most patients, the subjective experience of my illness is far removed from clinical perception and discussion. My chart is the keeper of an objective account with which I cannot readily identify. At times, I try to adopt a clinical posture toward my own symptomology. I attempt to understand myself from an objective stance. This is only partially helpful as positivist descriptions do and do not fit my own experience. Moreover, while medical language may confirm certain aspects of my experience, it does not necessarily assist in the structuring of the personal significance of these events. And, it would seem that most patients' narratives hint at this dichotomy, whether they have "real" diseases or not. They also experience a conflict between their personal narratives and those of the medical chart.

In my own case, the written record is one of circumspection and doubt. It delineates a clinical tale which finds my symptoms unfathomable. If, as I have done in the past, I were to attempt to adopt an objective stance to my illness, I must, of necessity, discredit my own experience. I must believe myself to be untrustworthy and perhaps, even unfathomable. This proves to be highly destructive to my self-identity and deprives me of an essential dignity. Moreover, it seems to lessen my personal esteem. In the midst of my struggle for my physical
survival, I lose essential political power. Moreover, my attempt to adopt a *purely* positivist approach to my illness fails—interestingly, this is in a psychological and apparently subjectively driven guise—it does not necessarily bring me health or physical function.

In the end, I choose to credit my self-knowledge. I am willing to continue to take drug therapies for which I do not meet the full criteria. I have learned to accept the uncertainty of not wholly fitting a medical category. I am content to gain and maintain physical function even if many clinicians find the means through which I achieve this objectionable. There is no doubt that the return of my physical health has given psychological peace and stability. Nonetheless I remain vilified for my illness as well as for the methods which now apparently mediate my symptoms. Unfortunately, by continuing to take medications which are technically not meant for me, I’ve become a bit of a renegade. In the pursuit of my dignity and restoration of my life, I’ve become a sort of medical criminal. Despite my physical renewal, I thus perhaps have become even more culpable from a clinical perspective. The conflict between my subjective world and the nosology of the clinic has not been resolved.

My renewed physical strength has allowed me to re-engage with my community in a way in which I could not when I was overtly ill. I experience a freedom in my relative health. But despite my relative physical strength, I remain psychologically and politically disempowered. As a member of social democratic community that provides universal health insurance, I feel that there is no real guarantee that I will receive this coverage. I am less than a full citizen in this respect. This diminution of my personal agency is less the result of overt social policy and more the result of the history of my relationship with medical constructs of knowledge and power. I am acutely aware that despite the reanimation of my physical, psychological, social and political
capacities, I remain profoundly impotent with regard to any medical care that I might need. When I experience any resurgence of my symptoms I know that there is really nowhere I can turn to for assistance. If my life is threatened and I choose to go to hospital, it is clear that treatments which have proven to be of value experientially may well be withheld because they seem to make little sense objectively. From a theoretical perspective, it seems that a reverence for scientific positivism overawes a fundamental respect for my life. For many of the clinicians I encounter it appears to be more important to be objectively and methodologically correct than it is to effect a return of function. The nosological category matters more than the integrity of my existence. As a result, treatment regimes which work may not in fact be pursued. In this way, my subjectivity is not perceived as valuable or credible. As such, I am likely to be denied certain socially entrenched services that mean, despite my restored physical and social function, I am not a full member of my socio-political community.

The Political Significance of Illness Narratives

An examination of my own and others illness narratives reveals a variance of subject-object relations in the clinic. Arthur Kleinman is right in concluding that patients' stories offer transcendent opportunities for both patient and practitioner alike. The construction of narrative is an empowering act of selfhood. Further, it encourages relationship and (what Arthur Kleinman calls) empathic witnessing between doctor and patient. The individuals who tell stories and the physicians who listen to them form a bridge across the gulf of understanding between medico-scientific accounts of disease and personalized descriptions of suffering. However, the honouring of patients' chronicles does not fully address the origins of the chasm between
subjective and objective interpretations of human symptomology. There are strong nosological, historical and structural constraints which all contribute to the deep sense of alienation which many people feel when they encounter the medical system. While doctors who comprehend the personal significance of illness help ameliorate the sense of personal rupture which accompanies being treated for a disease, they cannot fully compensate for the loss of personal power which exists when ailing individuals become patients.

Illness narratives not only reveal the spiritual significance of morbid events but also expose the presence of power and coercion in medical relationships. Accounts of illness not only serve to humanize medical practice, they politicize it. Patients' stories reveal that the intimate powerlessness of a patient is not only the result of the loss of physical, social and economic function but also the product of being transformed into an object of medical observation and discourse. Subjective narratives disclose the Foucauldian notion that the pursuit of objectivity and the exercise of power are irrevocably linked. No matter what the source of illness, a patient loses power in becoming the embodiment of a reified medical concept – that is, in becoming an incarnation of an abstracted disease.

The vulnerability of patients is thereby reflected not only in their physical incapacity but also in their loss of political agency. In seeking remedies from physicians for ailments, individuals must, of necessity, submit themselves to the greater knowledge and potency of medicine. In Spheres of Justice, Michael Walzer's theory of complex equality proposes that this temporary loss of "equality" is reasonable and even reflective of a diverse community. According to his portrait of liberal democratic justice, we should tolerate different potencies within different social spheres. That we may experience powerlessness as a patient is more than made up
by the fact that we experience authority in other social roles (i.e., as parents, teachers, entrepeneurs, etc..) While I am sympathetic with Walzer's refusal to characterize democratic societies as communities composed of carbon-copied equalities as well as with his desire to tolerate difference within egalitarian theories of justice, I am not convinced that his portrait in fact works. Like Susan Okin, I am critical of Walzer's belief in the fundamental separation of social spheres. The vulnerability or privilege of one social sphere tends to carry over into other spheres. Thus, familial, gender and economic station influences the relative power which an individual exercises within a community. Likewise, the diminution of personal agency which sick people experience when they have a disease is unlikely to limit itself to the health care setting.

Walzer argues that the powerlessness of patienthood is constrained by temporal duration. It does not have to be endured for very long and the benefits of medical expertise outweigh the loss of political power. His view can be most successfully applied to acute illnesses in which people recover quite quickly – and even here, I am not fully convinced. – However, it seems less applicable to those who have chronic ailments or to those who are fatally ill. For those people with more prolonged conditions, the impotence associated with being clinically objectified is protracted. Of necessity, the polico-medical culture becomes incorporated into everyday life. This powerlessness becomes a part of the fabric of a chronic patient's existence. It is not delimited. And, for those individuals who are dying, the medical pursuit of positivism which tends to dislocate patients' subjectivity seems a bit unjust. After all, dying is probably one of the most subjectively significant processes. It seems wrong to dismiss the political implications of the reification in medical treatment of patients who are exiting life and are at their most defenseless. Walzer's conception of distinct spheres of justice seems inapplicable in both these instances. Its
tolerance of powerlessness in the medical sphere is thus troubling. It is as if the private and intimate interactions of medicine are being shielded from more broad justice based critiques.

A review of illness narratives exposes the inherent vulnerability of patients in almost all interactions between doctors and patients. Consequently, beyond the obvious personal reasons, I chose to write about hysteria because it serves as an extraordinary illustration of the dissonance which exists between subjective and objective accounts of illness. Moreover, as a disease, hysteria's influence in both social and medical history is remarkable. Despite its various manifestations over time, hysterical disorders persist in medical practice. Today, it is common for physicians to encounter patients with psychogenic symptoms. As such, I believe that somatoform diseases provide an excellent opportunity to grasp the divergence between a patient's experience of being ill and a clinician's objective understanding of symptoms. This distinction points not only to a dysfunction in the therapeutic relationship but delineates the role which medical nosology has in alienating patients. The lacunae which separates self knowledge from scientific knowledge has a fundamental effect on patient well-being. In this respect, doctors cannot truly become empathic witnesses to patients' suffering when their professional, perceptual and discursive framework is so utterly divergent from that of the people they treat.

The characterization and treatment of psychosomatic diseases demonstrates the degree to which somatizers are perceived as "other" even when apparently psychologically focused remedies are pursued. While it would be wrong to dismiss psychiatric approaches to somatic illness, particularly when they are believed to have some efficacy in the alleviation of symptoms, I think it is important to describe the political nature of these treatments. When clinicians and patients conflict about the origin of dysfunction, the medical stance is clear, the patient must be
divested of his or her illusory beliefs either through psychotherapy and/or behavioural modification techniques. In this sense, treatment subjugates the intimate reality of the patient. Nosologically, somatic symptoms are the distorted expression of a troubled subjectivity. Thus, the disease is eradicated by defeating subjective truths. From a critical perspective, it seems as though medicine over-identifies the patient's self with the manifestation of disease thereby completely objectifying the patient in the process. Hysteria is a striking example of the conflict in subject-object relations in the clinic precisely because the subjective reality of the patient is explicitly attacked and subsumed during treatment. Objectivity asserts its primacy over subjectivity.

Finally, in the battle of scientific positivism against idiosyncratic anecdote, hysteria stands as an eloquent representative of the fluidity of disease abstractions. It is a disease that has many manifestations across temporal, social, cultural, gender and class boundaries. Today it can mean anything from chronic fatigue syndrome to histrionic personality disorders. Its fluctuating form represents the constant evolution of medical understanding despite a persona that shrouds itself in the constancy of science. Hysterical disorders represent not only the mysterious and impenetrable interaction between mind and body, but also the clinic's leaden grasp of phenomena that are less than tangible. Somatoform illnesses confront the ability of disease models to readily interpret human malaise. They reveal diagnoses for what they are: incredibly useful groupings of bodily signs which seem to be ameliorated by specific protocols. Hysteria challenges medical norms in the manner of a renegade and thus, like most outlaws, its victims can subjected to the most coercive forms of treatment arising from the desire to preserve the stability of medical objectivity.
Ultimately, patients' narratives are more than transcendent or interesting documents; they are also testimonials to the political conditions of patienthood. They are embattled attempts to assert personal agency in the midst of physical, psychological and political degradation. In reciting their stories, patients disclose the profound subjugation which can accompany well-intentioned and skillful medical assistance. Despite the formal equality that is entrenched in democratic communities and in clinical codes of conduct, patients find that they are less than truly equal in actuality. Politically, they experience a discordance between their perception of themselves as equal citizens and their submission to the objective observation and discourse of the clinic. Patients are obviously physically and psychologically more vulnerable; what is less obvious is that they are also politically weak. This weakness is less the result of social policy than it is a consequence of the intersection of medical knowledge and power. The scientific positivism of the clinic constitutes a formidable political force in the lives of patients.

Chronicles of illness raise essential questions about how we successfully navigate relationships in which there is an imbalance of knowledge and power. Patients' stories not only detail the difficulties of such endeavors but also the successful interactions between doctors and patients. Politically, we should be concerned about how to replicate clinical liaisons which minimize subjective powerlessness. From my own and others' accounts, it would seem that even when medical specialists are highly successful at treating ailments, coercive elements seep into the clinical relationship, alienating the patient from both the physician and from his or her self.
Bioethics: A Cure for Impotence?

In the last 30 years, biomedical ethics has assumed a large role in the attempt to construct more just interactions in medicine. Armed with philosophical concepts such as equality, rights, autonomy and utilitarianism (among many others), bioethicists have tried to address the problem of paternalism in the clinic. They have sought to provide frameworks with which to assess and discuss moral disagreements within medical science. As a relatively new field, it draws upon the interdisciplinary expertise of theologians, philosophers, lawyers and physicians. Its mandate covers a multiplicity of issues from creating guidelines for genetic and reproductive research to authoring dictums which govern truth-telling, consent and confidentiality in the physician-patient relationship. For many, bioethics has effectively addressed, and continues to address, the ongoing moral quandaries that are embedded in the health care setting. But while clinical ethics has certainly created a fissure in the edifice of medical practice by reminding both physicians and patients alike of moral obligations and rights, I believe that it is not able to speak to the structural constraints which contribute to inequities within the clinic.

A perusal of most bioethics texts reveals a two-pronged approach. Firstly, abstract theories of "deontology" and "utilitarianism" are laid out. Authors establish concepts such as right, autonomy, act-utilitarianism, rule-utilitarianism, paternalism and beneficence as tools in the dissection of moral problems. Secondly, case-studies appear to illustrate the depth and variety of ethical conflicts in the clinic. Concerns about human experimentation, epidemiology, suicide, abortion, euthanasia and resource allocation arise out of the stories which are laid out as facts in a case. The bioethicists then sift through the various competing claims and determine which theory or value is the most applicable to each situation.
In an article entitled "Baiting Bioethics," published in 1986, Samuel Gorovitz defends the discipline from a number of criticisms. He outlines a number of complaints: that bioethics methodologies are suspect, that its values are inconsistent, that its principles are too abstracted and that it encourages moral relativism by over-emphasizing certain (liberal) values over other social values (Gorovitz; 357-359). While Gorovitz acknowledges that bioethical approaches need strengthening, he champions modern medicine for saving ethics (i.e., for giving it an authoritative and socially relevant venue). He argues that bioethics' strength lies in the fact that it applies abstract principles to real situations. Moreover, the predominance of liberal tenets is a reflection of the larger democratic world and of the need to counteract the enormous force of paternalism in the clinic. In the end, Gorovitz accepts the inevitable faults of a novel and burgeoning field but believes that bioethics "is an unavoidable activity if we are to maintain moral integrity amid the emerging problems of contemporary life." (Gorovitz; 372)

While I do not dispute that bioethics has made a significant contribution as a formal bridle on medical habits, I am not convinced that it is truly effective in mediating the intimate interaction between doctor and patient and/or the structural problems of the clinic. Firstly, it tends to apply templates of egalitarian and liberal thought to a relationship that remains unequal in terms of knowledge and power. It does not seem that formal equality actually assists individuals in mitigating the powerlessness of patienthood. Secondly, its precepts are ones which seem to be externally imposed without much regard to the contextual environment of the hospital or doctor's office or the patient's experience. Health care settings are often economically, physically and temporally hostile to the values espoused by ethical codes. Moreover, bioethical principles do not seem to actively address the interdependence which exists between doctor and patient. They seem
instead to act as prohibitions rather than facilitators in medical relationships. Nor do they seem to recognize the imbalance of power which persists and remains a part of this professional liaison. Discussions of traditional liberal autonomy do not grasp the complex politic of the doctor-patient interaction.

Feminist discussions of autonomy often highlight the problem that liberal rights do not mediate relationships very well. Traditional liberalism focuses on the individual rather than on the construction and maintenance of just interactions between people. In a number of articles, the feminist legal theorist, Jennifer Nedelsky, proposes that autonomy should be reconceived as relationship. She comments about traditional liberal theory: "The values we cherish have come to us embedded in a theory that denies the reality we know: the centrality of relationships in constituting the self." (Nedelsky, 1989; 9) She advocates a more contextual and less atomized notion of selfhood and autonomy that would allow people to be self-determining within relationship to one another. And, in my opinion, it is this type of reconstruction of autonomy which medical ethicists would be wise to acknowledge.

There are feminist critics who have begun to make inroads into biomedical ethics. Susan Sherwin, a feminist philosopher, calls for change in the focus of medico-moral discussions. In her book, No Longer Patient, she emphasizes a more realistic approach to deliberations in which both patients and doctors are viewed as participants in larger social relationships. Sherwin’s point is that ethicists need to recognize the social construction of the autonomous self. Moral problems and the pursuit of individual agency take place within highly complex political matrices of race, class and gender. She writes: "What feminist ethics claim is that oppression is a pervasive and insidious moral wrong and that moral evaluation of practices must be sensitive to
questions of oppression, no matter what other moral considerations are also of interest." (Sherwin; 57) In sum, medical ethical problems do not occur in cultural or political vacuum. As a result, bioethics needs to develop contextual theories and methodologies which recognize powerlessness and seeks to empower those who are currently psychologically, physically, socially and politically oppressed.

The limits of traditional ethical interventions in medical practice are evidenced by patients' persistent sense of vulnerability when seeking medical care. While established ethical edicts seek to safeguard individuals' liberties from the paternalism of the clinic, they do not always work in the manner in which they were originally conceived. For example, the principle of informed consent seems to be unassailable from a theoretical standpoint. However, the process for obtaining consent from patients can often be treated as an obstacle in rather than a facilitator of the professional relationship. The proliferation of generic "consent" forms is an indication of the extent to which authorizing consent has become a legal, ethical formality in medical practice. It is seen as a hurdle to be surpassed rather than as a substantiation of the individual's trust in a particular physician or procedure. In this sense, the patient's so-called right to be informed of the risks of medical treatment and his/her capacity to accede to any given treatment protocol meets conventional liberal requirements for respecting individual autonomy but it does not really address the substance and quality of that individual's autonomy. Moreover, it is not clear, to what extent that individual is in fact exercising true personal agency given the ongoing imbalance of authority in medical relationships.

There are some medical reformers who propose that egalitarianism is still an obtainable goal in the doctor-patient interaction. These clinicians focus on creating "patient-
centred" practice. The aim is to revise the authoritative encounter between doctors and patients. In this new approach both patient and practitioner share responsibility for goal setting and attainment. The physician's role is to help the patient help his/herself (Toop; 1882). The medical relationship becomes partnership. Some even suggest that doctors and patients will eventually sign contracts ensuring parity between the two participants. This will apparently allow an enhanced ability to pick and choose between physicians and to secure guarantees of certain types of care in advance of treatment. If any of the portions of the contract are not filled, both parties have immediate recourse. All of this is a type of legal restructuring of the relationship in an effort to reduce the physician's hegemony.

Unfortunately, the inequality of the relationship in the doctor-patient liaison is quite elaborate. There are legitimate bases for physicians exercising more power than patients: they possess a specialized form of knowledge which remains largely inaccessible to lay persons. Their authority is accompanied by a professional skill. And in the end, no matter what type of ethical revisions are made to interactions with patients, physicians still retain the proprietary right to prescribe. If doctors were truly our equals in terms of accessing medical knowledge and facilities, we wouldn't need them. We would be able to minister to ourselves. The notion of a contractual interaction then does not do justice to specialized knowledge of clinicians, nor to the particular vulnerabilities of ailing persons. The concept seems merely to mask the inequities of the relationship rather than exposing the subtleties of the interpenetration of knowledge and power.

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20 This contractual relationship was suggested to me by Dr. G. De Marchi during conversations about patient care. He is currently the chief medical advisor for the Ontario Disabilities Support Program.
From my own and others' experience, it would seem that while bioethics has successfully provided legal and ethical guidelines for medical practice, it has not addressed the structural constraints which continue to oppress patients in the clinic. It is all very well that physicians know that they should behave in certain ways, it is quite another thing to support those behaviours within a nosological, cultural and architectural environment which is hostile to true equality. At the end of her book, Susan Sherwin writes of medicine that "it rationalizes the principle of hierarchy in human interactions. . . by insisting that its authoritarian structures are essential to the accomplishment of its specific ends. . ." The medical model tends to support rather than diminish patterns of oppression within our communities (Sherwin; 238). Medical ethicists alone cannot really effect the necessary political changes that are required to reduce the sense of impotence and coercion that can accompany medical care. The principles of bioethics are far too abstracted and ethics programs have been integrated far too effectively into medical institutions to provide the external criticism and substantial reconstruction of doctor-patient interactions.

Inducements for Change

Beyond incorporating ethical committees and hiring philosophers to become members of health care settings, medicine needs to explore more fundamental change in its methodologies. The concern with empowering patients must move beyond the dictums of ethics and become a part of policy development in the provision of health services. Creating structural changes which would induce both patients and physicians to become more cognizant of their rights
and responsibilities to one another seems at least a partial antidote to the positivist hegemony of the clinic.

One such inducement would be to provide a way of valuing the subjective experience of patients. Anonymous, annual patient evaluations could be integrated into health care provision services (both public and private systems). Individuals would be asked to rate physicians primarily on the basis of the quality of the therapeutic relationship. Factors such as trust, listening skills, validation of the illness experience as well as clinical expertise would all be part of these surveys. Physicians would also comment on the skills of colleagues. These ratings would more likely emphasize the scientific and professional aspects of medical care. These surveys would thus bring both subjective and objective analyses together in the form of an annual performance review. In turn, the results of these evaluations would be used to give financial bonuses to physicians. The score would indicate the amount that each clinician would receive as a top up on his/her annual pay – this might constitute a 0-10/15% bonus.

From a user’s perspective, this reform would empower patients by providing an opportunity to provide influential feedback about their illness experiences. Patients would help determine the rate of remuneration for health services they receive. Moreover, they would now have a responsibility to be more thoughtful about interactions with physicians and about treatment protocols in general. By limiting the percentage of pay which is influenced by these reports, patients garner an effective but delimited means of shaping medical practice. They find a political and economic vehicle with which to express their subjective satisfaction with health care services they receive without interfering with professional status of physicians.
From a clinical perspective, these surveys may well be viewed as an illegitimate hindrance on practice. However, this bonus system would bolster the aims of biomedical ethics by materially encouraging physicians to be more cognizant of their interchanges with patients. It would be a realistic inducement to encourage more just forms of behaviour. Moreover, it would credit doctors who spend time with patients. Of necessity, the clinic might temper the dominance of objective thought by giving subjectivity a greater role in treatment. Uncertainty in terms of diagnosis might be better tolerated. Physicians, in short, would become more accountable to the patients who procure their services (either through public or private systems).

It is patients who need to gain power in the clinic. Their narratives attest to the debilitation of physical, psychological as well as political vulnerabilities. Medicine requires more than ethics to change its mode of interaction with patients. It needs fundamental reconstructions which address problems associated with scientific positivism, the reification of diseases and patients, the dehumanizing effects of medical training, and impoverished social, temporal and spatial environments. All of these contribute to patient alienation. Perhaps even a small change such as tying physician’s incomes to measures of performance within the therapeutic relationship might be a small step to eventually effecting greater reforms elsewhere.

**Concluding Remarks**

Patient narratives tend to be impressionistic and even emotionally manipulative documents – and mine is no exception. However, I believe that there are important lessons to be drawn from these stories of illness and disease. Above all, I think they reveal the degree of impotence which plagues individuals who seek medical treatment. A sense of powerlessness
pervades most of these texts. And while they are psychological portraits, they have political implications. People who become ill and obtain medical assistance lose a portion of their agency in the process. While formal codes exist to protect individual liberties in the clinic, they are not really effective at fostering patient self-determination within the confines of the clinical exchange. In becoming patients, individuals discover a form of intimate powerlessness which is reminiscent of childhood. Despite being citizens, they are no longer full political agents when they enter the medical realm.

The feminist notion that the personal is political seems remarkably *a propos* in this case. Doctor-patient relationships are private interactions which nonetheless manifest larger social coercions and oppressions. The divergence between subjective experience and objective perception is a political chasm. The suppression of patients’ subjectivity in order to receive the benefits of clinical expertise is a political act. For some, the coerciveness of the medical gaze is tolerable precisely because it is so powerful nosologically. And, there is no doubt that doctors cure many diseases. In this sense medicine performs the role of a beneficent king rather than that of a despot. But, for others, the line between kingship and despotism is not so clear. In some ways, both the success of biomedical science as well as the enormous privacy of these care-taking relationships shields clinical interactions from justice based critiques. How, I wonder, do we know when the impotence we suffer as patients is just?

I believe that the power imbalance in doctor-patient relationships has broad implications for liberal democracies. For communities which espouse egalitarian principles, the hierarchical nature of care-giving relationships poses an extraordinary challenge. Professional and care-giving relationships almost always consist of an imbalance of knowledge and expertise which
no template of egalitarian moralism can suppress. When we seek help or guidance from authority figures, we are at a disadvantage politically – even though we may be equal citizens theoretically and legally. Children are not as powerful as parents. Students depend on and are evaluated by teachers. Likewise, patients depend on doctors for knowledgeable expertise and access to medical facilities. Hierarchic relationships persist within democracies. Moreover, they tend to exist within a realm of privacy which is only partially visible from the social realm. In the end, traditional notions of liberal autonomy and egalitarianism do not properly describe or even appropriately monitor these interactions. The formal equality of rights is just that, formal and not actual in these situations. The impotence of patients challenges liberalism to reconstruct its understanding of individual autonomies. After all, justice happens between people; it is not an atomistic and isolated event. We need ultimately to look at ways of empowering individuals while in relationship to one another.
Appendix A

REQUEST FOR:
PHYSIOTHERAPY ☐
OCcupational Therapy ☐

DIAGNOSES:
DEMENTIA/DEPRESSION
REPRODUCTIVE DYSFUNCTIONS

PRECAUTIONS:
CARDIAC ☐
DIABETES ☐
METALLIC IMPLANT ☐
PACEMAKER ☐
VASCULAR ☐
OTHER ☐

X-RAY FINDINGS (If applicable)

REASON(S) FOR REQUISITION
to assess and engage in some activity that will exercise her three remaining neurons.

DATE 22-3-94.

Signature of attending physician

COMPLETE IN DUPLICATE AND SEND BOTH COPIES

FORM RE: 22-3-94
PRECAUTIONS/CONTRAINDICATIONS:
- CARDIAC
- DIABETES
- METALLIC IMPLANT
- PACEMAKER
- VASCULAR
- OTHER (specify)

WEIGHT BEARING STATUS:
- FULL
- PARTIAL
- NON
- N/A

X-RAY FINDINGS (IF APPLICABLE)

GOALS FOR TREATMENT/ENGAGE MIND IN SOME WAY
- ASSESSMENT OF WHICH IS MOST APPLICABLE
- TREAT AT THERAPIST'S DISCRETION

DATE 04-3-94

SIGNATURE OF ATTENDING PHYSICIAN

THERAPIST'S INITIAL RESP

COMPLETE IN DUPLICATE AND SEND BOTH COPIES

FORM NO. 215-A3M4161
Divergence and Domination

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