

Probing the Boundaries
Innovative Dialogue

The Patient

Probing the Interdisciplinary Boundaries

A Persons Project

Edited by

Aleksandra Bartoszko & Maria Vaccarella

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**The Patient:
Probing Interdisciplinary Boundaries**

Probing the Boundaries

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Probing Interdisciplinary Boundaries**

Edited by

Aleksandra Bartoszko and Maria Vaccarella

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Introduction

Aleksandra Bartoszko and Maria Vaccarella

The good physician treats the disease;
the great physician treats the patient
who has the disease.
(Sir William Osler)

Was he a doctor, or a patient?
Neither category seemed valid,
nor for that matter mutually exclusive.
(J.G. Ballard, *The Atrocity Exhibition*)

This volume focuses on the patient. But who is a patient nowadays? An individual? A collective identity? How is the cultural concept of “the patient” created and circulated? And by whom? In the attempt to answer these and other questions, this volume shows that the patient, even if alone or isolated, is always part of a larger network. Illness as a social reality, while affecting individual bodies, concerns the social body as well. The patient’s suffering results not only from surgery and medication, but from the subjective experience of illness, isolation or stigmatization as well.

Along with medical improvements, social relations and body ideologies have vastly changed over the past decades. An increasing medicalisation of life has induced people to readjust the image of themselves as humans and as social actors. The boundaries between the concepts of health and illness have been put into question and negotiated, just like practices of caring, healing and helping have been continuously interwoven. The increasing access to both professional and lay sources of information has amplified the healthcare recipients’ self-awareness and their demands on the health personnel.

Medicine, like any other science, has an ideological impact. Hospitals and clinics provide contexts in which social structures and ideologies may be reinforced or resisted. Physicians’ expertise and personality influence the nature of their relationship with and experiences of their patients. Therefore this volume deals with patienthood as well as with physicianship.

This eBook brings together the papers presented at the first global conference on “The Patient”, held in Salzburg, Austria, in November 2008. The project on “The Patient”, of which the conference in Salzburg was only an initial expression, stemmed from another well-established ID.net project, “Making Sense of Health, Illness and Disease”. At the sixth conference on these themes in Oxford in 2006, ID.net Network Leader Rob Fisher asked

Kimberly Myers and Harold Schweizer to launch a new annual meeting focused on the liminal identity of the patient. Kimberly and Harold were the ideal initiators of this new enterprise: they had already co-edited a volume on “The Patient” from a symposium Harold had hosted at Bucknell University and they had taken part in the “Making Sense of Health, Illness and Disease” project. Delegates were asked to submit their papers substantially as presented, so that this volume would stand as a snapshot of the conference. Thirteen of the papers have been selected by a peer committee and are to be developed as chapters in a book edited by Kimberly Myers.

The purpose of this eBook is not only to collect studies of different patient identities and experiences, but also to explore *the totality of patienthood*, in the ultimate attempt of uncovering *the core of patienthood*, perceived both as a condition and as a process. We believe that this interdisciplinary collection is a testament to this complex perspective, highlighting most of the topical areas of patienthood: (1) attitudes towards the body; (2) professional and lay images of health and illness; (3) patient’s self-definition and identity; (4) attitudes towards the health personnel; (5) patient’s attitudes towards other patients; (6) health personnel’s attitudes towards patients; (7) the concept of treatment; (8) the concepts of cure/care; and (9) attitudes towards the hospital as a social institution.

What comes out of this greatly varied collection is the need for a humanistic rethinking of the patient’s experience. Being part of the larger project “Probing the Boundaries”, this anthology blends disciplines and perspectives. Cross-cultural and cross-disciplinary discussions will lead the way to a new understanding of patienthood. Contributors to the conference and to this collection come from Europe, North and Central America, the Middle East, Africa and Australia and their areas of expertise include medicine, philosophy, literature, film studies, anthropology, linguistics, psychology, rhetoric and nursing science.

The challenging identity shift in the process of becoming a patient is explored here in literary and film contexts, in the papers of Sue Asbee, Karen Caesar, Maria Vaccarella, Marina Guiomar, Jean Rossmann, Amir Cohen-Shalev and Esther Lee Marcus, Judith Musser and Gian Pietro Leonardi. Particular attention is devoted to the construction of metaphors in all of these studies, thus suggesting a cognitive use of metaphorical language in the process of making sense of illness experiences. The patient-caregiver interaction is addressed from the point of view of doctors, alternative practitioners, nurses and spouses, in the works of George Simms, Gabriele Kitzmüller, Geir Lorem, Lorna Lees, Ondine Spitzer, Mary Buchinger Bodwell and Ted Miller, Diane S. Morse, Amnon Lahad, Hannah Kedar and Dorith Shaham. They all investigate and complicate the definition of roles and practices, often on the basis of valuable personal experiences. And the multifaceted experience of being a patient is also regarded as an

epistemological and communication issue, in the analyses of Fenia Tsobanopoulou, Carie Lambert, Torunn Wibe and Laura Slaughter, Aleksandra Bartoszko and Lisa Roney. These investigations illustrate the cultural dimension of pain perception, health standards and patient models.

The nine parts of this volume correspond to the workshops of the Salzburg conference. It starts with George Simms' reflections on the liminal identity of physician-spouse-caregiver. He examines the cognitive, relational, and spiritual challenges that result when an illness revises and restructures both the patient's and the caregiver's daily life. He sets an example of the perspective shift from the professional and medical stance to a more personal and vulnerable one. Mary Buchinger Bodwell in Part VII further explains why testimonies of this kind, specifically when physicianship overlaps patienthood and/or caregiverhood, play a significant role in medical training. She underlines how an improved understanding of this transition is a crucial component of successful healthcare communication.

Part II gathers chapters questioning the definition of patient, health, illness and disease ; (use a semicolon instead to distinguish parts) and the discourse of normality and subjectivity is discernible in the three texts. Even if not explicitly, all chapters expose the labelling power of diagnosis and its influence on the process of stigmatization. They also underscore the identity transformation in the context of mind and brain disorders. This transformation has an individual and bodily anchorage, but also an institutional and structural one. Gabrielle Kitzmüller explores the experiences of living with aphasia after a stroke and the encounter between these patients and their professional caregivers. The chapters of Geir Lorem and Lorna Lees both uncover the hidden power relationships in the psychiatric setting. Giving the example of hallucinating patients and their struggle for social acceptance, Lees presents theoretical reflections on normality and normativism and ultimately on the relativity of medical diagnoses. Lorem and Lees underscore what Kitzmüller is appealing to - the need for a greater insight into the patients' psychological and personal dimensions in the process of caring and healing.

Part III is devoted to literary works in which the patient experience is creatively articulated. Both Sue Asbee and Karen Caesar explore the works of Margiad Evans. Asbee focuses on the identity shifts that occur when entering the patient condition. She argues that Evans' presentation of epilepsy as a source of creative inspiration and a mystical sense of union with nature is an effective way of coping with the feared loss of identity. Karen Caesar's study points out the intimate and almost sexual tension in the doctor-patient relationship, as described by Evans in a complex partly autobiographical writing. Maria Vaccarella focuses on the interrelation of personal experiences and social significance of a woman's illness, specifically in the case of Frances Burneys' mastectomy letter. The

representation of women's relationship to their body and their illnesses is further investigated in Burney's fictional writing.

In the following chapter Marina Guiomar explores the relation between words, objects and bodies. In particular, she draws on theories of writing and reading connected to the mind/body dualism. She calls attention to the challenge of body representation in literature, particularly in Blaise Cendrars' work. Fenia Tsobanopoulou's study yields a philosophical insight into epistemological aspects of pain and suffering at the core of patienthood. She presents pain as tightly connected to the linguistic and the social contexts and ultimately suggests perceiving the patient in light of personhood, identity and humanity. She also refers to anthropological theories of the difference between illness and disease, and like Lees in Part II and Bartoszko in Part VIII, she highlights the significance of the subjective health experience.

Part V brings together papers that draw attention to the institutional context of patienthood, particularly its potential depersonalising or alienating effect. Jean Rossmann's literary analysis investigates the depiction of an alienating hospital and of dehumanizing medical technologies. Amir Cohen-Shalev and Esther-Lee Marcus further Rossmann's exploration of the "art of dying" from the perspective of film studies. They emphasize the value of film techniques and their ultra-realistic treatment of various key topics pertaining to the condition of being a patient who is not only entangled in complex family relationships, but also in a state-controlled medical system. This chapter concentrates also on the utilization of cinema for training of medical staff. The character transformation induced by the medical setting is present in Judith Musser's chapter, too. The texts she analyzes focus on a universal experience of alteration, which unites different actors within the healthcare system.

The following part of the volume is devoted to issues of health communication. Carie Lambert's chapter focuses on the rhetoric of patienthood. She maintains that effective patient-physician relationship begins with good communication and stresses the patient's crucial role in this process. She calls for effective training in patienthood. She also argues that the majority of the patients have unrealistic expectations towards their physicians, which are often fostered by the media, as Lisa Roney also points out in Part IX. Ondine Spitzer's reflection on communication is extended to an epistemological level, thus providing an analysis of the conflicts among different medical paradigms. She highlights power relationships in the field of medicine and the potential damage they may cause the individual patient.

Empathy is a major theme in Part VII, which focuses on pedagogies and teaching of future practitioners. Mary Buchinger Bodwell gives her report on the situation of medical students' communicative and empathic skills and shares her reflections from her practice as a communication instructor in a medical college. She also underscores the importance of the

humanities in medical training, not only for communication purposes, but also as a tool for changing the central narrative of modern medicine that has reduced the patient to a problem that needs to be solved. Ted Miller, Diane S. Morse, Amnon Lahad, Hannas Kedar and Dorith Shaham present a quantitative study of empathic training. Their study shows that physicians and students distinguish between empathic and non-empathic practitioners. All subgroups place a high value on empathy. This is a particularly interesting finding, which illustrates the gap between theory and practice in medical setting, since previous studies had demonstrated a significant decline in students' empathy over their years in medical school. The authors argue also that the empathic behaviour is culturally bound and cultures differ in the way empathy is expressed and in the value they attribute to caring.

The cultural dimension of patienthood is featured in the eighth part. Both Aleksandra Bartoszko and Gian Pietro Leonardi emphasize the importance of cultural factors in perception, reception and representation of patienthood. Bartoszko underlines different perceptions of the concepts of health and illness by medical experts and lay people, engendered by their life style and possibilities. Additionally, she attempts to answer the question: how and why does somebody avoid becoming a patient? Leonardi presents a literary character with AIDS, who meets with a number of cultural collisions - familial, medical and societal. The gender dimension of disease is essential in both chapters.

Lisa Roney's study concerns the public dimension of patienthood. In particular, she warns of the dangers in accepting the media's selective and distorted view of "heroic" patient. She underlines the extent to which such rhetoric creates unreal images of the illness experience and hinders an effective health communication in the end. Lastly, Harold Schweizer's moving piece of poetic prose effectively encapsulates issues in the patient condition, which emerged throughout the conference.

We are sure that this selection of papers, which addresses the patient category from various and revealing perspectives, will spur further interdisciplinary discussion on this theme.¹

¹ We would like to thank the organizers of and the participants to the conference in Salzburg, and all the contributors to this volume. We also appreciate the kind help and comments from Danijel Loncar from University of Zagreb, Croatia; Halvor Hanisch, Inger Marie Lid, Astrid Bergland and Grete Alve from Oslo University College, Norway; Luca Caddia, independent scholar from Rome, Italy; Paolo Simonetti and Emanuela Zirzotti from 'Sapienza' University of Rome, Italy.

PART I

Suffering, Empathy and Healing

The Liminal Identity of Physician-Spouse-Caregiver in Severe Chronic Illness

George R. Simms

Abstract

In her monograph *Good Days, Bad Days; the Self in Chronic Illness and Time*, Kathy Charmaz characterizes chronic illness as an intrusion, an invasion, and an immersion for the patient, depending on the severity of the disease process. This paper focuses on the most severe expression of chronic illness - namely, immersion.

Trained in the fields of medicine, psychology, theology, and ethics, I enjoyed for many years a thriving career in academic and clinical medicine in which I was, I felt, meeting the needs of my patients holistically. All this changed seventeen years ago when my wife suffered two strokes, a vascular brain tumour, and five brain operations. That experience made me realize that none of my professional training had really prepared me for what I encountered as a human being. All at once I found myself in a disorienting state of liminality in which I had to be simultaneously a physician, a caregiver, and a spouse.

Using the works of Kathy Charmaz, Victor Turner, Eric Cassell and Viktor Frankl as a theoretical base, I examine the cognitive, relational, and spiritual challenges that result when an illness completely revises and restructures daily life for both the patient and the caregiver, whose role is at once less clear-cut and immensely more complex.

Key Words: Chronic illness, stroke, caregiver, liminality, Logotherapy, suffering.

My entire professional career has been given over to bringing together the disciplines of medicine, human behaviour and spirituality in the service of patient care. My guide in this life-long project has been the work of Paul Tournier who fifty years ago introduced into the medical literature the concept of "*Medecine de la Personne*," that is, "medicine of the whole person."¹ It was his conviction - and it is mine - that in order to best help your patients - particularly those with chronic illness - it is essential to understand them biologically, psychologically and spiritually. To this end, in addition to training in medicine, I took advanced degrees in human behaviour and theology, and have attempted to meld these three disciplines into an approach to patient care that might be called "whole person medicine."

This integrated approach to clinical medicine served me well until seventeen years ago when my wife suffered two strokes, a vascular brain tumour and five brain operations - all of which left her neurologically impaired, and changed our lives completely. Out of that catastrophe came the realization that all my professional training, as good as it was, was insufficient to meet the challenges I now faced as a physician, a caregiver, and a husband.

In his seminal book *Dramas, Fields, and Metaphors*, cultural anthropologist Victor Turner used the term “liminality” to describe a state of mind, which accompanies every change of state or social position, or certain points in age. He called these changes “transition rites” and divided them into three phases: separation, margin (or *limen* - the Latin for “threshold,” signifying the great importance of real or symbolic thresholds at this middle period of the rites), and re-aggregation.² It is the thesis of this paper that the greatest suffering engendered by severe chronic illness - both for the patient and the caregiver - is the inability to move beyond liminality. Liminality needs to be examined, fleshed out, and talked about because, of all the problems of serious illness, the constant sense of uncertainty is the worst.

Turner’s first phase, separation, involves symbolic behaviour signifying the detachment of the individual from an earlier fixed point in the social structure or from an established set of cultural conditions (what he called a “state”). During the ensuing liminal period, the individual becomes ambiguous, neither here nor there, betwixt and between all fixed points of classification; he passes through a symbolic domain that has few or none of the attributes of his past state. In the third phase, the passage is consummated, and the individual re-enters the social structure often, but not always, at a higher status level. In cases of serious illness, it is often the opposite.

When I look back on the journey of my wife’s illness, I can see that I have traversed each of the phases Turner describes. The initial separation took the form of an intellectual understanding of the underlying pathophysiology of my wife’s condition. I knew that she had sustained a life-threatening neurological event, that she was severely impaired, and that things would now be different. What I was not prepared for was how different things would be, and how emotionally and spiritually disoriented I would become. Once the implications of that burden became clear, and I realized that I had been forced into an unfamiliar role as simultaneous husband, caregiver and physician, I began to reel inside. To be sure, I was not her attending physician. But I found that, as a primary care physician by training, I could not divorce myself from the bio-psycho-social dimensions of her illness. It was at this point that the convergence of the three roles - husband, caregiver, and physician - ushered me into Turner’s second phase, liminality. I was her husband. But I was also now a nurse, a cook, a house maid, and a physical therapist. Added to all this, I was the silent physician

watching a tragedy unfold before my eyes and knowing what the long-term implications would be for her and for me. It was then that I realized what the English poet John Keats meant when he wrote: “Until you have been sick, you understand not.” From the inside, it all looked different.

What I have described - that is, the liminality imposed on caregivers in intimate relationships - is nothing unique. This is what happens in chronic illness. Kathy Charmaz, in her book *Good Days, Bad Days*, divides chronic illness into three functional categories: chronic illness as *interruption*, chronic illness as *intrusion*, and chronic illness as *immersion*.³ Examples of chronic illness as interruption are migraine headaches and severe menstrual cramps. Here the pain is significant - even disabling - but time-limited. While it lasts, it is miserable and may cause a temporary suspension of daily activities. But it predictably comes to an end, and life then resumes its normal pattern until the next recurrence. The point is, there is a beginning and an end, and pain-free intervals during which life is completely normal.

An example of chronic illness as an intrusion is a progressive neurodegenerative disease process - for example, Multiple Sclerosis or Parkinson’s Disease. Here the symptoms come more frequently, last longer, and are more disabling. There are symptom-free intervals which may last days, weeks, or even months. But they are progressively shorter in duration, and are usually accompanied by increasing anxiety over how soon the next episode will appear.

Immersion in chronic illness is fundamentally different. Here one’s body has been taken over by the disease process itself so that life is no longer about symptom-free intervals of enjoyment, but about symptom management and survival. For my wife, life has been reduced to living in a wheel chair, emptying her bladder every two hours, living with paralysis, concentrating on simple motor tasks, and struggling with the embarrassment of marked cognitive reduction. For me, it has meant getting her up and dressed in the morning, getting her washed and settled before I leave, planning my day so that she is not left alone too long, doing the household chores she can no longer do (which is virtually all of them), preparing meals, transporting her in her wheel chair when we go out to eat, getting her ready for bed, and getting up with her during the night for toilet needs. Most challenging to me are avoiding social settings that heighten my wife’s anxiety and confusion, and living patiently with her near-complete dependency.

Many of the losses of chronic illness are only relatively important. By that I mean, they are relative to factors unique to the couple: their age, their individual attitudes and personalities, and the length of the relationship. For many older couples worn out by the “slings and arrows of outrageous fortune,” immersion in a chronic illness is but another distasteful, but necessary, burden to bear. There is little left to talk about, there are no more dreams, there is no sexual energy left, and often no interest in things spiritual.

But for those afflicted at a younger age, as we were, things are different. The mind is still keen and alert, the sexual energies are still strong, and there is a deep need for companionship.

There is nothing more agonizing for the stroke patient than changes in cognitive function and emotional instability. Short-term memory loss makes it impossible to retain and recall new information; confusion makes social interaction difficult; aphasia impedes the ability to coherently express one's thoughts; and finally the loss of the "executive functions" of the brain cripples one's capacity for abstract thinking, computation, and complex decision-making. All these losses afflict the stroke patient grievously. For example, my wife - who was a nurse, spoke three foreign languages, and owned her own business - can no longer add two and two and get four. Like many stroke patients, she has experienced a moderate-to-severe depression, which is difficult to manage, and may last for the rest of her life. Other stroke patients have it even worse, experiencing volcanic emotional outbursts interspersed with the depression.

All these changes are of prime importance because relationships, if they are to survive and grow, must be grounded in meaningful communication. When that communication is lost, nothing can take its place. Care-giving, as loving and kind as it may be, is no substitute for meaningful exchange between two people who have learned to love one another through the mutuality of their words. To lose that capacity, as we did, is a form of death. The work now becomes how to adjust to a new reality, and how to develop strategies to compensate for the losses. For the caregiver, as well as the patient, this process involves a great deal of suffering.

Pain and suffering are closely identified in most people's minds: the greater the pain, the more it is believed to cause suffering. Bioethicist and internist Eric Cassel, however, in his landmark monograph *The Nature of Suffering*, rightly points out that pain and suffering are phenomenologically different; and, indeed, in medicine we regularly make the distinction between pain and suffering - pain being the physical manifestation of the disease, and suffering the psychological and spiritual manifestation of the illness. One can have pain without suffering, suffering without pain, and suffering with pain. Pain caused by childbirth, kidney stones, or sciatica - though often excruciating - rarely causes suffering, because the pain is well-defined, usually short-lived, and responsive to pain medication. On the other hand, pain that is virtually overwhelming and that the patient believes cannot be controlled, pain that is not overwhelming but continues for a very long time and thus seems endless, and pain of unknown source all cause great suffering.⁴

In general, suffering occurs when the personhood of the individual is threatened. By "personhood," I mean that composite of a human being that takes into account more than just the mind and the body. We are more than

our genes, our biology, and our psychological proclivities. Persons have personality and character; they have life experiences. A person has a relationship with himself or herself and is a social and political being. A person has a family, cultural background, and various roles. Persons do things; they have regular behaviours, secret lives, and a perceived future. Disease is merely a pathological alteration of structure and function at the cellular and sub-cellular levels of one's body. Illness, by contrast, is the person's response to that alteration. In other words, it is the body that becomes diseased but the person who becomes ill, and it is illness that causes suffering. Ultimately, suffering is unique to each person, reflecting the totality and complexity of her or his humanity.

The suffering of the caregiver comes when he or she is forced to witness the unrelenting distress of the loved one, when family and social roles are suddenly and involuntarily reversed, when one's personal identity is threatened, and when the future looks uncertain and foreboding. This is what every caregiver faces, and what I faced seventeen years ago. The question now becomes: Is melioration of this kind of suffering possible? Can one get beyond the suffering of liminality in the face of a condition that has not - and will never - change? There was a time when I did not think so. But I have since come to feel otherwise.

Thirty-five years ago I had the good fortune of studying under the Viennese psychiatrist Viktor Frankl. I was a young physician in those days, and was burdened by a large number of dying patients in my practice for whom everything had been done and nothing worked. They were terminally ill and without hope for recovery. And I had no hope to give them. This fact weighed heavily on my mind and drove me to seek help. In working with Dr. Frankl, I was introduced to the principles of Logotherapy - which I will discuss more fully in a moment - and in particular, the three different ways he determined one could find meaning in life: first, by way of achievement and accomplishment; second, by experiencing something of personal significance, such as a cause or a work, or by loving someone; and the third, by suffering. For Frankl this was not just a theoretical construct. He knew plenty about suffering. As an Austrian Jew in the Second World War, he was stripped of a promising academic career at the University of Vienna, deported to Auschwitz where he spent the next three years of his life and saw his father, mother and wife die in the gas chambers. It was there that he worked out the basic concepts of his book *Man's Search For Meaning*. It is in the second part of this book that Frankl posits the concepts of Logotherapy. Logotherapy has been called the Third Viennese School of Psychotherapy to distinguish it from Sigmund Freud's Psychoanalytic Society and Alfred Adler's Individual Psychology. The word Logotherapy comes from the Greek word "*logos*" which denotes "meaning." According to Logotherapy, the primary motivational force in life is neither the will to pleasure nor the will to

power, but the will to meaning. The inability to find meaning in life is what Frankl called an “existential vacuum,” and sets the stage for what he described as “noogenic neuroses” - that is, neuroses that have their origin not in the psychological, but in the existential dimension of human existence. By “existential,” Frankl does not mean traditional religiosity, but rather a core understanding of one’s own existence. For Frankl the real aim of human existence is to be found in self-transcendence - that is, uniting with something bigger than oneself - and not self-actualization, or merely becoming the best one can be as an individual. From a logotherapeutic perspective, self-actualization cannot be attained if it is made an end in itself; it occurs only as a side effect of self-transcendence.

In Logotherapy what matters above all else is the attitude we take toward suffering. If one can find a meaning to his suffering, it becomes enduring - and even perhaps ennobling. In short, suffering ceases to be suffering at the moment it finds meaning. There are situations in life - and I think here of terminally and chronically ill persons - when one is cut off from the opportunity to do one’s work or to enjoy one’s life. At this point, suffering becomes unavoidable and life can become unbearable. But by framing the situation as a challenge to suffer bravely, one discovers meaning for each day, and life retains meaning literally to the end.⁵

Armed with this powerful insight, I returned to my dying patients with a hope I had never had before, and began exploring with them ways in which they could find meaning in their individual suffering and dying. It was, for me, a true epiphany that transformed my role as a physician, and later was to give me insight into my journey with my wife’s illness. I am persuaded that more suffering exists than any of us ever knows. And it exists right before our eyes, in the lives of those we think we know best. Just as people with chronic pain learn to keep it to themselves because others lose interest, so too those with chronic suffering - both patient and caregiver. Frankl’s principle of meaningful suffering, when it works, offers a positive, quiet consolation to those whose suffering would otherwise leave them in despair.

But one of the hardest lessons I have learned as a hospice physician is that while some people are able to move on from their suffering, others are not. Some people live in peace and die in peace, while others appear to live in anger and die in anger. This seems not to have so much to do with religiosity (though it may for some) as it does a sense of what Cassel calls “resilience,” and what Frankl would view as finding meaning in the midst of suffering.

At the end of this paper, and after seventeen years on this journey, what can I say that might be of help to anyone here who is a caregiver, or knows a caregiver personally? I submit a few thoughts for your consideration. First, caring for a chronically ill spouse, relative or friend is a full-time job that carries with it high levels of stress and distress. Caregivers have statistically higher rates of death, depression and cardio-vascular disease

than their non-caregiver cohorts. Thus being a caregiver is not good for your health. Everyone needs to know this so that steps can be taken to minimize the long-term effects of the stress - steps including sufficient rest, good nutrition, time for inner solitude and reflection, and a strong support group. Second, liminality, is a phase that one has to go through in cases of serious illness. But to remain trapped in a limited existence is a curse, and the true source of long-term suffering. Inasmuch as it is possible, one should strive to embody a new reality, to reach new levels of integration within oneself and the situation at hand. Third, each person responds to these changes in different ways. What worked for me might not work for you. Viktor Frankl always taught that it is not our job to tell people what their meaning in life is. Rather, it is our job to help people find their own meaning. Each of us must be given the opportunity to embark on this search within the context of our own lives, and encouraged to make meaning in ways that suit us intellectually, emotionally, and spiritually.

My own struggle with liminality ended when I was able to place my wife's illness - and my response to the seeming injustice of it all - in a larger context of transcendent meaning. Not that I understood the meaning - for I still do not - but that I was eventually able to accept the mystery of it, let it go, and ask the more important question that C.G. Jung once posed - namely, "*Nicht warum, sondern wozu?*" That is, "Not why, but to what purpose?" In other words, not the initial, understandable question: "Why did this happen to me?" but rather: "Now that it has happened, what does it mean, where is it taking me, how am I to understand the purpose behind it?" This question, which was posed to me by a Jungian analyst in Zurich, Switzerland fifty years ago, has been the leitmotif in my work with chronically ill and dying patients - and has been the guiding light in my personal journey as husband, caregiver, and physician.

Notes

¹ P Tournier, *Paul Tournier's Medicine of the Whole Person*, Word Books, Waco, Texas, 1973. P Tournier, *The Healing of Persons*, Harper & Row, New York, 1965.

² V Turner, *Dramas, Fields, and Metaphors*, Cornell University Press, New York, 1974, pp. 231-232.

³ K Charmaz, *Good Days, Bad Days*, Rutgers University Press, New Brunswick, 1991, pp. 9-106.

⁴ E Cassell, *The Nature of Suffering*, Oxford University Press, New York, 1991, pp. 35-43.

⁵ V Frankl, *Man's Search for Meaning*, Pocket Books, New York, 1963, pp. 149-213.

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PART II

Stigma and Brain/Mind Disorders

The Aphasic Patient, the Caregivers and the Health Systems

Gabriele E. Kitzmüller

Abstract

Background: Stroke, as a life threatening and disabling disease, is increasing in the aging population of the western part of the world. About one third of the stroke survivors will experience speech difficulties, which hinder effective communication.

Aim: The aim was to illuminate the experiences of living with stroke and aphasia and the experiences of meeting professional caregivers.

Method: Eighteen narrative interviews with aphasic persons and their closest relatives were analysed with a phenomenological hermeneutical approach.

Results: People with aphasia were living with the major consequences of their brain damage. Aphasia¹ was experienced as the most burdensome. It was difficult to return to work and many families lost their friends and their social network. The aphasic person often felt stigmatized, and self-confidence as well as identity was threatened. The informants' psychological needs were underestimated during institutionalisation. Anyhow, most patients commented positively on their experiences with the professional staff in spite of the experienced lack of knowledge about aphasia. Informants reported that their illness had altered their outlook on life in a positive direction.

Implications: The results call urgently professional staff in the health and social care sector to include psychological aspects based on better knowledge about living with aphasia.

Key Words: aphasia, stroke, brain damage, caregiver, identity, Giorgi, phenomenological hermeneutical method.

1. Introduction

Stroke is the most common disabling disease in the aging population of the western part of the world and it is increasing.² Stroke is life threatening, and is the third most common cause of death in the western world.³ One third of the stroke survivors will experience speech difficulties which hinder effective communication.⁴ Aphasia often adds other disabling consequences, for instance hemiparesis.⁵ Living with aphasia can enhance isolation⁶ and the connection between aphasia and depression is well-documented.⁷ People with aphasia often experience low self-esteem.⁸ As a disability, which disturbs communication, it can deteriorate a person's coping potential and quality of life.⁹

2. Aim

The study's aim was twofold: to illuminate the experience of living with aphasia caused by stroke or other serious brain damages and to illuminate patients' and families' experiences of meeting professional caregivers within hospitals, rehabilitation units and social welfare systems.

3. Methods

The informants were recruited by the local leaders of the local Aphasia associations in Norway and nearly all of them were members of the association. In 2005 thirteen persons with aphasia and in addition four of their spouses and a son, living in different areas of Norway, were interviewed. Most of the eighteen narrative interviews were held at the informants' homes and were audio taped and transcribed. The informants were asked to tell about their life before and after the stroke and to describe their encounters with health professionals. The study's method and analysis was based on Giorgi's phenomenological research method, as gaining understanding of the phenomenon "living with aphasia" from the informant's point of view was the most important aim.¹⁰ Giorgi's four analytical steps guided the analysis: 1) reading the whole text to gain a main understanding, 2) discriminating meaning units with a focus on the phenomenon being researched, 3) expressing the insight contained in the meaning units more directly 4) finally synthesizing the transformed meaning units into a consistent statement regarding the subject's experience.¹¹ Giorgi's method was combined with Gadamer's hermeneutical theory which guided understanding thorough the interview settings and the reflections about pre understanding and context.¹²

4. Ethical Considerations

The study was approved by the ethical committee for medical and health related research of Northern Norway. At the time of the interviews several of the informants were still afflicted by the consequences of their brain damage. Therefore it was necessary to conduct the interviews in a considerate manner.

5 The Informants

The participant's age varied from 30-68 years, but all of them were under 60 years of age at the time of the incident. All informants lived at home and were able to give their informed consent and to communicate well enough to avoid misunderstandings or unanswered questions. The time of onset of their illness varied between two to ten years, with an average of five years. Ten informants were married, six had youngsters, and twelve were employed at the onset of illness. All of them suffered from other consequences of their brain damage as well as aphasia, such as paralysis,

hemi paresis, loss of memory, concentration and orientation, epilepsy, pain, reduced sensibility in parts of the body, apraxia, loss of ability to write, read and to do arithmetic or suffered from hearing- or sight impairments. Eleven informants suffered from Broca's aphasia, one from Wernicke's.

6. Findings

a. Living with Stroke and Aphasia [Main Theme I]

- Sub-Theme 1: Experiencing Problems in Communication

Some informants had lost their speech completely for days and weeks after the attack. All of them had regained speaking ability at the time of the interview, two to ten years after the incident, but most of them expressed that they were still struggling with aphasia. An uninformed listener would most likely not be able to hear that seven of them still had aphasia and this posed a problem. Having aphasia that cannot be seen or heard meant that they were treated as if they were not disabled whilst having to concentrate hard on finding the right words. They were easily exhausted and some felt isolated. Struggling with words they could not find, threatened their self-esteem and some felt themselves looked upon as mentally retarded. They used words like: a silly person, an idiot, an imbecile, a moron to describe their experience of encountering with other people's assumed view. Pål repeatedly stated that there was nothing wrong with his intelligence. Bernt had experienced that people he knew, avoided meeting him when they saw him in the streets and he interpreted his experience as follows: "The first years of my life after brain damage I spent in hell. People like me, are taken as vegetables."

Petter, who lived with Wernicke's aphasia, had experienced that he suddenly spoke a language that nobody could understand and which he thought was completely the same as before. John expressed himself like this:

I thought I could speak. For me everything I said was clear speech. Nobody told me that they couldn't understand me. But I noticed that I didn't get through and I got angry and began to curse. I became a difficult patient and felt completely useless. I hoped that the undertaker would come and collect me soon.

Petter's wife estimated that it took about six month after stroke before he could make himself understood. Petter expressed that he still did not understand that speech ability was back as life still was a struggling experience for him six years after stroke:

I ought to be grateful to health systems who saved my life, but they couldn't help me back to my world [...] life is horrible, it is completely changed.

Petter felt that the red thread in his life was torn over, everything seemed to be disconnected. The best thing he could do was to travel abroad where he did not have to care about his speech. There he felt free and equal with his wife and other people.

It was difficult for informants with aphasia to communicate with more than one person at time, which excluded them from various social gatherings. When they tried to participate in conversations they failed, because others had changed the topic when they were ready to answer. Nearly all of them considered aphasia to be the worst threat to their life quality, even those who had other serious disabilities.

- **Sub-Theme 2: Living with Aphasia Affects Mood**

Nearly all of the informants with aphasia spoke of periods with depression. Pål expressed:

I talked to another patient at the rehabilitation-unit who had become my friend: why not kill ourselves, get through with it, there is no point with life anymore [...] my friend had experienced the same kind of depression [this friend was 35 years old, had severe aphasia and his right arm was paralyzed].

When depressed, Mette found it intolerable not being able to stop crying. Kim was religious and he had longed to see a priest after the stroke. He was unable to convey his wish and nobody asked him what he needed either. Kim told:

I felt that I was falling down, deeper and deeper down. I had a longing for God that nobody could see [...] I got lonely and filled with grief. I dried out physically and mentally.

- **Sub-Theme 3: Being Aphasic in Relations**

Two of the informants divorced shortly after the onset of their illness and another moved out, but was still married. According to Aphasia association groups it is a well-known phenomenon that couples often break up in connection with aphasia. One couple explained that aphasia threatened their relationship, as communication was difficult and sometimes impossible. Some informants with aphasia realised that it was difficult for others to live

with them as they experienced that their moods shifted from being angry to being depressive or extremely sensitive. Other informants did not realise that their personality had changed but were told so by their relatives and found that difficult to accept. Two of the females with aphasia said that they did not appreciate that their husbands talked on their behalf since the husbands sometimes misunderstood their intentions. The participants who had spouses at the onset of illness said that they would not have managed without them but they were well aware about the influences their disabilities had on their spouses' lives. Mick expressed it in this way:

It has been very hard for my wife. It was easier for me than for her. To have a husband with stroke means to loose the person you knew before [...] it is another life.

Spouses related that their life had become more difficult and they experienced long periods of sick leaves. Roles had changed in their everyday life and obligations and burdens had increased. Some had to struggle with representatives of the health care systems and the disease threatened their economy. All except one developed chronic health problems soon after their spouses' onset of illness. Eva made this statement: "Suddenly I had not only one child but two 'children' to care for." And her husband Hans added: "And I was the worst one." Eva described her sorrow about some kind of "loosing" the man she loved: "He would never be the same," she said.

It was also problematic for the informants to care for their children. The informants with aphasia talked about difficulties with being respected as a parent. Their children would not listen to them, and some of them distanced themselves from the parents with aphasia. The first time after the stroke the children were frightened of loosing their parent, later they were frightened and angry about the changes. Some of the children became aggressive or depressive and their achievements at school declined. Others moved away earlier than usual and some needed psychological help, but did not receive any. For the spouses it was problematic to share the limited time between work, caring for a sick partner and child care. The interview texts also revealed loss of friends, colleagues and other members of their social network that had been there before the stroke. Some relationships became difficult due to communication problems, other friends disappeared simply because leisure activities could not be shared anymore. The spouses too had to face the same difficulties loosing friends and network.

- **Sub-Theme 4: Not Being Able To Work**

Aphasia also obstructed the participant's professional careers. Only three out of eleven who were employed before the onset of illness, went back to work, two of these in less demanding positions and then only in part time

jobs. One returned to his initial full time job, which he explained was possible only due to extraordinary goodwill from his employer and colleagues. Male participants grieved about losing their professional positions. It was hard to realize and to accept that it was impossible to go back to work, and many expressed bitter disappointment about professionals in vocational rehabilitation as they considered them to be ignorant about aphasia. The informants expressed that they had not received the help and support they had expected. Two male informants still struggled very hard to get back to work many years after their stroke in spite of severe aphasia and other disorders. The male participants' identity seemed to be closely connected to their positions in work life. One of the informants presented himself with his name and profession and in the first part of the interview he talked as if he still kept the former position. Hans, who was the only one who was back to full time work, made this statement:

I told them at the hospital, if you can't block this vessel [he had a life threatening angina on top of his brain damage] you may just as well hand me a rope, because then my professional life is finished and to get back to work is my greatest target. I don't want to receive disability benefits for the rest of my life.

It seemed easier for the women to compensate for lost positions at work. They concentrated on family, children and the leisure activities they still could manage. For nearly all informants it was very important to participate in and work for the local Aphasia associations. It was seen as meaningful and provided opportunities to create new social relations as the loss of former friends and colleagues represented a challenge to be dealt with.

- **Sub-Theme 5: Values and Targets in Life Could Change**

All of the informants reported that they experienced serious and impending threats to their lives and their identities, which had shaken their existential foundations. Some of them said that they discovered values in life which they were not aware of before, for example:

Before the stroke I was focused on money and wealth, now I have other values, I work for people [...] I also have a deeper faith, I am closer to God. [Kim]

I appreciate many things now, which I took for granted before. It is important to give and receive love. You don't know how long your life is. [Rita]

The suffering had led to a deeper understanding of their lives and existence. They had revised their earlier values and targets in life for values that clearly had become more important. None of the spouses expressed such changes.

b. Encounters with Health Professionals [Main Theme II]

- Sub-Theme 1: Experienced Qualities and Insufficiencies

The informants had met health professionals in hospitals, rehabilitation units and in home care. They considered most of the professionals as kind and friendly and half of them had no complaints about care or treatment. They reported positive experiences, which greatly influenced on their well-being. Staff's qualities such as patience, humour, trustworthiness, encouragement, compassion, enthusiasm, communicative skills and allowing participation were appreciated. Petter gave this example:

A helper's qualities were important; she had to be attentive and listening, not talking too much herself. It was important that I was allowed to talk and to ask [...] humour was important and that people weren't superficial [...] that they spoke to me in spite of not understanding my replies [...] it was important that they touched me and looked at me... although I couldn't see them [Petter was blind at that time] I heard immediately if they turned away from me.

It was emphasized that health care workers knew far too little about aphasia. This led to communication problems and misunderstandings, and the informant's needs often remained hidden and unattended to. Only the speech therapists used picture books or other technical aids to help the patients to express themselves. Other professionals did not use such things, so communication about activities in daily living became difficult. Hospitals with primary nurse systems seemed to provide better conditions for the aphasic patients. In such settings it was assumed to be easier for the health workers to realise the patients' needs. The aphasic patient's coping ability was promoted by engaged health workers actions of motivating and praising. The professional health workers' personalities, knowledge and skills could influence on coping and outcomes. Bernt gave an example:

One of the best helpers I met at the rehabilitation unit. I tried to swim for the first time after the stroke, but it went wrong... I couldn't hold my balance and turned around [...] but she was phenomenal, she didn't give up on me [...] and after six weeks I could swim again.

It was appreciated when health professionals did not focus on the patient's disabilities, but on their capacities and on issues that made life easier for them. Kim described how aphasia and paralysis made him depressed and lonely. The psychologist could see his loneliness and helped him to buy a dog. Since the dog entered Kim's life, the depression vanished. Unfortunately it seemed that this psychologist was one of the few who cared for the patient's mood. Other informants commented negatively on what they perceived as the psychologists' main interest: diagnosing their disabilities. Other categories of health care workers did not focus enough on the patient's psychological needs but left them to themselves abandoned with their depressing thoughts and fears.

Health personnel that were experienced as being arrogant in a paternalistic manner were the worst encounters, especially when they made wrong prognosis or decisions concerning the informants' future without consulting them. Such impediments to coping left the informants depressed, resigned or filled with anger. Mick was very angry about his prognosis which had turned out to be completely wrong:

[...] he was arrogant and unkind. He said to me: You will never regain your health [...] I was so angry, furious [...] I will never forget him for the rest of my life.

Also the spouses shared this anger about wrong prognosis, as Eva expressed it:

[...] she told me that his brain damage was huge and that he never would be able to come home again, she recommended me a institutional place for my husband. [Eva's husband was almost completely restored three years after]

The spouses also reacted negatively when their husbands or wives were treated like children or disabled persons who could not make their own decisions. They stressed the fact that they received too little information and that there was a lack of knowledge about aphasia in the health and social systems. The fact that they and their children did not get any support made it more difficult for them to give support to their sick spouses and resulted in severe problems with their own health. Sometimes hospital discharges were not planned at all, exposing them to burdening tasks they hardly could manage without help.

Anyhow there were also many god impressions, which left traces forever. To be taken care of in a considerate manner was one of them. Pål told:

[...] she was strict, but she looked after me in a good way. She gave me the best food you could get. She cared for me like a mother, a really good mother.

- **Sub-Theme 2: Experiencing Professional Staff's Lack of Interest in Previous Life History and Preferences**

It was quite unusual that the health care workers asked the spouses about the patient's life history, preferences and habits, in spite of the fact that nearly all of the informants had total or severe aphasia the first days and weeks after onset of illness. Therefore health care workers did not get any information about what the patients were used to and wanted, as they could not inform about these things themselves. No questions were asked about the patient's food habits and preferences which could result in bad appetite and loss of weight, but the informants did not complain about such things. They excused health workers having too limited resources in relation to what they had to do. In contrast the spouses gave negative comments on these issues and did not make excuses. Only some of the speech therapists considered informants' life histories as starting points. This was highly appreciated both by the patients and their families.

c. Informants Opinions on How the Health Care System Worked for Them [Main Theme 3]

Conditions of geographic and systemic order often caused difficulties for the informants and their families. Many of the informants were referred between several hospitals, especially when they needed any operation or complex rehabilitation. Petter who needed both, had to travel more than 1000 kilometres to reach the help needed. He stayed in five different institutions, far away from his family. One can imagine what it is like to change environments so often suffering from a serious illness which has made one blind, speechless and confused. Visiting him was nearly impossible for his wife who had two small children to take care of at home. In many of the local hospitals there were no speech therapists and no psychologists available. Therefore most informants did not receive help for their speech problems or their psychological needs during hospitalization. Some of the informants underlined that the specialization of health systems made rehabilitation very difficult for them. Martin's brain damage and aphasia were caused by a heart arrest. Martin stayed in a ward that specialised in heart problems for many weeks. According to Martin and his wife the staff seemed to have little knowledge of the impacts brain damages can have and they were not aware of the fact that he had aphasia. The staff tried to collaborate with a neurologist at the same hospital, but this collaboration failed. Hans made this statement about not getting any help with his brain damage and aphasia:

At the coronary ward they didn't know anything about aphasia. I could only shout and moan and I was drugged down with wrong medicines so they didn't understand that I had aphasia. Fortunately I am big and strong, otherwise they would have killed me with those medicines.

Most of the informants and their spouses reported tremendous difficulties in acquiring help from the social security and the vocational rehabilitation services due to lacking knowledge about aphasia. They were more often met with resistance rather than a helping hand, which contributed to low self-esteem and a feeling of worthlessness.

7. Final reflection

This paper provides a description of how participants in this study experienced living with aphasia and their encounters with health workers within the Norwegian health care system. If there are some issues, which can be generalized, it must be on a general level, focused on main theme one: "Living with stroke and aphasia." The fourth level of analysis according to Giorgi is still preliminary, but it seems that the patient with aphasia is threatened by social isolation due to communication problems, mood changes and lowered self-esteem. Nevertheless it is possible that the experience of severe illness and disability can open up for a better understanding of important values and targets in life. For health professionals it is important to consider the difficulties aphasia may contribute to and to find interventions, which can make life easier for the aphasic patient and his family.¹³ A closer understanding of the phenomenon "aphasia" may hopefully help us to prevent statements as follows:

My brain damage gives me a lot to think about. I shouldn't be forced to fight the health system, they should instead reach out a helping hand. [Hans]

Notes

¹ Aphasia, definition: (from Greek, *aphatos* : "speechless") loss of the ability or disability to produce and/or comprehend language, due to brain injury. Broca's area, governs language production, Wernicke's governs the interpretation of language.

² R Bonita, 'Epidemiology of Stroke', *Lancet*, vol. 339, 1992, p. 432.

³ *ibid.*

⁴ B Indredavik, 'Hjerneslag', in *Når livet blir annerledes, Lærebok i Rehabilitering*, LW Lande & K Vardeberg (eds), Fagbokforlaget, Bergen, 2004, pp. 125-146.

⁵ *ibid.*

⁶ MT Sarno, 'Quality of Life in Aphasia in the First Post-Stroke Year', *Aphasiology*, vol. 11, July 1997, pp. 665-679.

⁷ RG Robinson, Y Murata & K Shimoda, 'Dimensions of Social Impairment and Their Effect on Depression and Recovery Following Stroke', *International Psycho-Geriatrics*, vol. 11, April 1999, pp. 375-384. TB Hafsteinsdottir & M Grypdonck, 'Being a Stroke Patient: a Review of the Literature', *Journal of Advanced Nursing*, vol. 26, 1997, pp. 580-588. S Parr, 'Coping with Aphasia: Conversations with 20 Aphasic People', *Aphasiology*, vol. 8, May 1994, pp. 457- 466. S Brumfitt, 'Clinical Forum, Losing Your Sense of Self: What Aphasia Can Do', *Aphasiology*, vol. 7, June 1993, pp. 569-591.

⁸ M Herrmann & CW Wallesch, 'Psychosocial Changes and Psychosocial Adjustment with Chronic and Severe Non-Fluent Aphasia', *Aphasiology*, vol. 3, June 1989, pp. 513-526.

⁹ S Parr, 'Psychosocial Aspects of Aphasia: Whose Perspectives?', *Folia Phoniatica et Logopaedica*, vol. 53, May 2001, pp. 266-288. S Parr, S Byng & S Gilpin, *Talking About Aphasia*, Open University Press, Buckingham, 1997. S Parr, 'Coping with Aphasia', pp. 457- 466.

¹⁰ A Giorgi, 'Concerning the Application of Phenomenology to Caring Research', *Scandinavian Journal of Caring Sciences*, vol. 14, January 2000, pp. 11-15. A Giorgi, 'An Application of Phenomenological Method in Psychology', in *Duquesne Studies in Phenomenological Psychology*, A. Giorgi (ed), Duquesne University Press, Pittsburgh, 1975, pp. 82-103.

¹¹ A Giorgi, 'Concerning the Application of Phenomenology to Caring Research', pp. 11-15.

¹² HG Gadamer, *Universaliteten i det hermeneutiske problem*, Kleine Schriften I, Philosophie, Hermeneutik, Tübingen, 1976. HG Gadamer, *Wahrheit und Methode*, J.C.B Mohr, Tübingen, 1965.

¹³ G Kitzmüller, 'Hvordan kan afasipasienters positive erfaringer i møte med helsepersonell påvirke mestring?', *Nordisk Tidsskrift for Helseforskning*, vol. 2, 2007, pp. 42-55. K Sundin, A Norberg & L Jansson, 'Understanding Between Care Providers and Patients with Stroke and Aphasia: a Phenomenological Hermeneutic Inquiry', *Nursing Inquiry*, vol. 9(2), 2002, pp. 93-103.

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The Suffering of Psychosis: The Patient Experience as Seen from the Helper's Point of View

Geir Fagerjord Lorem

Abstract

Psychosis has pervasive effects on a person in terms of suffering, loss of freedom, and life opportunities. Psychosis is often connected to lack of insight, which also makes the patient perspective a potential problem. Yet, studies show how patient goals, values and own perception of improvement are important aspects. This study was initiated to elaborate how patient experiences and participation were perceived by clinical personnel. The idea was investigating how the notion "lack of insight" affects perception of the patient's own perspective, participation and empowerment.

The study was a qualitative inquiry based on in-depth interviews with 11 mental health care workers with experience from psychotic patients. The selection was strategic and informants were recruited from various institutions and professional background. Topics as the meaning of lack of insight, awareness of illness, patient strategies, as well as how it affected treatment, cooperation, and patient participation were covered.

The informants were unanimous that people who lack insight may still have a strong awareness of suffering. They indicated that key aspects of patient suffering was not picked up by medical language, and that these aspects regarded as significant by personnel for understanding the patient's choices, behaviour and suffering. Despite interest in patient experiences, the patient opinions and non-adherence were still seen in contrast to clinical assessment and advice.

The study indicates a need for a clinical language to address the suffering and patient experience more directly. The author suggests that this can be done by an attention to patient awareness of illness as well as a shift of focus from symptom to problem descriptions, with particular weight on patient goals, value, and everyday life. Training and attention to the relevance of patient descriptions and narratives is important among clinical personnel in order to secure the patient perspective.

Key Words: Schizophrenia, insight, patient perspective, assessment of illness.

1. Introduction

Psychosis has pervasive effects on a person in terms of suffering as well as loss of freedom and life opportunities. This paper will mainly focus on schizophrenia, which is characterised by continuous signs of psychosis lasting for more than six months. Its characteristics are delusions, hallucinations, and disorganised speech and behaviour as well as social and occupational dysfunction.¹ Psychosis is often connected to lack of insight, which also makes the patient perspective a potential problem.

Usually, to have insight means to have thorough knowledge or skills in that area. In this context, insight is used in the more limited sense, viz. insight into the illness or sense of reality. Grisso and Appelbaum argue that insight must be seen as a multidimensional concept that includes the ability to communicate a choice, understand relevant information, and accept the situation and its likely consequences as well as the ability to handle the information in a rational manner.²

The purpose of raising the question of insight is clinical, and entails trying to identify problems in order to improve patient insight. Grisso and Appelbaum are, however, critical of the opinion that psychotic patients do not have insight as such.³ First, it is an assertion that can be empirically proven wrong; second, it reduces a complex issue to a question of agreement between patient and doctor. Disagreement may in this connection be caused by delusions; however, differences are also likely to be based on different perspectives, values, and treatment goals. These aspects, which are essential to user participation, become problematic due to the question of insight.

The impact of insight into illness is widely discussed.⁴ The level of insight has a direct impact on the patient who is suffering from psychosis. This involves the opportunity to give informed consent, which is the basis of user participation. Participation is meant to promote a meaningful role for the patient so that he or she can take active part in treatment by being able to make choices that affect his or her own situation. Lack of insight will, however, affect informed consent negatively and thus compromise user participation.⁵ It also influences the communication between patient and therapist.⁶

2. Aims and Objectives

This study was initiated to elucidate how clinical personnel perceive patient experiences and participation. The objectives were to describe and analyse mental health care workers':

- perception of patients' insight and competence to give informed consent to treatment,
- experiences when lack of insight has become an issue in a clinical context, and

- perception of patients' suffering and experiences.

The idea was to investigate how the notion "lack of insight" affects perception and assessment of the patient perspective, participation, and empowerment.

3. Methods

The study is a qualitative inquiry based on in-depth interviews with 11 mental health care workers. They had a minimum of one year of praxis with adults suffering from psychosis. The selection was strategic and informants were recruited from various institutions and professional backgrounds (psychiatric nurses, psychiatrists, and psychologists). The interviews were conducted in 2007 by the author. A thematic guide was used. Topics such as the meaning of lack of insight, awareness of illness, and patient strategies were covered, as well as how these aspects affected treatment, cooperation, and patient participation. The interviews were recorded and transcribed. The analysis of the transcribed text was conducted in NVivo 8.0 in several steps: (i) The text was read to acquire an overview. (ii) Units of meaning were identified and coded. (iii) Categories were established by focused and axial coding. (iv) Comparisons were made both externally with other literature and research, and internally by comparing different informants, codes, and contexts.⁷

4. Awareness of Suffering

It may sound naive, but I don't think I have ever met a patient that hasn't in one way or another understood that something is wrong. [104]

When the informants spoke of suffering, they not only recognised the patient's immediate awareness of his or her own situation, but also tried to articulate "what it must be like" to have the subjective experience of mental illness.

It [the suffering of psychosis] is a mere jumble of misery that has no proportions [...] there is no filtering of the suffering, no limitation. [101]

Table 1: Awareness of Illness

	Characteristics	Description
	Immediate experience and misery without proportion	Suffering strikes without filter or protection. Feeling unpleasant, or experiencing pain.
More inner	The perception that “something” is wrong	Perceiving the breakdown of everyday life, without necessarily having the ability to account for or do anything about it.
	Fear and anxiety	Both suffering and immediate awareness that something is wrong. Anxiety interferes with daily activities and affects the way the environment is perceived by the patient.
	Confusion and chaos	Difficulties concerning understanding and accounting for own perceptions and experiences.
	Unmanageable problems	Practical activities and seemingly simple tasks can become problematic. Normal life functions break down.
	Losing sense of reality	In this context, the patient’s own experience that reality “slips” and the uncertainty, confusion, and fear that may follow. It is particularly evident when the patient is scared.
More outer	Loss of control	Experience of loss of control over oneself and influence over own situation (being forced). Loss of self-control often implies control being taken away by force.
	Isolation and loneliness	Isolation in the sense of being excluded from others, and the loneliness that arises from solitary life. Absence of family life, friends, and participation in society.

All informants were asked about what they thought was the worst aspect of suffering from psychosis. They all pinpointed what they perceived to be the most severe part of patient suffering, although they emphasised

different aspects such as problems that become unmanageable, fear, anxiety, chaos, loss of control, and loneliness (see Table 1).

The informants were unanimous, with one exception, that people who lack insight may still have a strong awareness of suffering. This awareness could be problematic as such. Problems concerning a rational and articulate attitude towards illness and reality were described; however, the informants nevertheless recognised in the patients an immediate, bodily, and emotional understanding of their situation and experiences, called being “conscious” or “aware of illness.” It is also sometimes referred to as “feeling ill.”

This awareness is connected, often, to the immediate perception of something being wrong, but even more to having insight into everyday, practical matters of functioning:

Patients seldom use their diagnosis actively. What they do speak about is their level of functioning. And speaking about that, I think that many patients in fact have a good overview of what they can cope with, what they can't deal with, and what kind of assistance they need and so on. [104]

The personnel thus recognise a different concept of insight based on the awareness the patients have of their own situation and experiences. This is done without overlooking the cognitive problems of communicating, acknowledging, and articulating the problems. Furthermore, the practical perspective that the clinicians emphasise is described as a more viable way to establish a common understanding in order to discuss problems with the patient. It stands in more direct relationship to the suffering and thus the experience of the patient. It gives a context in which to speak about the suffering, but also about treatment, drugs, and activities.

Speaking about insight becomes very medical to me, and it doesn't meet the patient very often. But speaking about the level of functioning and insight into that, here one can meet the patient. [104]

There are several points that are interesting.

First, the personnel have an empathic, understanding perspective of the patient suffering. This means that they seek to understand the situation from the point of view of the patient. They are interested in the experiences with the illness and try to see themselves in the position of the other. This may be easier when speaking about isolation and loneliness, but their descriptions of the more elusive aspects of psychosis include efforts to

understand the patient perspective. In a certain sense some say that it is not unlikely for others to react in a similar manner given the same circumstances. Hence, they try to see the experience of psychosis in general terms or to recognise a common human perspective of the suffering.

Second, the firsthand experience with suffering is always understood in interaction with the environment. It is not seen as a mere inner or mental state, but in interaction with how the outer circumstances affect the patient. This is particularly evident with regard to loneliness that has to do with the relation with others, but loss of control, breakdown of everyday life, and fear also cannot be understood except in the context of how the surroundings become unmanageable to the patient. Inner and outer thus cannot be seen as qualitative distinctions, but as a question of degree in describing the individual's interaction with the environment.

Third, the suffering mainly focuses on social and everyday life activities. The informants thus connect the suffering of the patient mainly with the social and occupational dysfunction of the patient (part B of the diagnostic criteria in DSM-IV) and not with the characterising symptoms of schizophrenia (Part A). The data indicate that symptoms like delusions and hallucinations (from Part A) are also evaluated in terms of how they affect the life of the patient. Hearing voices, for instance, is mainly described as a problem if the patient cannot cope with it. The problem description is a question of functioning and not necessarily of the presence of symptoms.⁸

Fourth, the informants were unanimous that the patients at some level have awareness that something is wrong even though they might disagree about the character of the problems: "Sometimes I think that they think everything is fine and that it is we who are ill and not them (Informant 105)." Another informant pointed out an ambiguity in the patient's awareness, viz. both the awareness of a problem and the shortcomings in dealing with it. This indicates that the failure to uphold basic life functions goes deeper than simply being a question of insight.

In summary, if the suffering is immediate to the patient, so the empathic contact seems to be immediate, too. This indicates not just a will to understand on the part of the clinicians, but also recognition that there are aspects of the suffering that transcend what is possible to express in words. It is also interesting to observe how the suffering is understood as part of the interaction between environment and patient.

5. Assessment of the Patient

The informants, when asked directly, stated that insight is to know that you suffer from an illness and to know what the illness is and how best to relate to it. This concurs with the textbook definitions; however, when speaking about situations in which insight becomes an issue, they added more aspects and complexity to the phenomenon.

The interviews contained many descriptions of practical situations. The author has looked into the kinds of situations in which insight becomes an issue, and asked why the clinicians have evaluated them either positively or negatively (in a few situations their evaluations are regarded as indecisive or either/or).

What we see is that the informants understand the awareness of suffering mainly in terms of the patient's experience and how it affects life. This is also perceived as a better way to talk about problems with the patients. This pattern is seen also in the assessment of patients (see Table 2).

Table 2: Assessment of the Patient

Category	Positively evaluated	Neutral or indecisive	Negatively evaluated
Adherence	Following medical advice	Waiting and seeing	Not following medical advice
	Compliance		Adherence as a patient strategy
	Recognising problem or illness		Not recognising problem or illness
	Seeking help and treatment		Refusing treatment
	Coping with illness and everyday life		Escaping problems/not coping
	Quitting alcohol or drugs		Abuse of alcohol or drugs
Intentional acts	Ensuring basic needs are met		Not ensuring basic needs are met
			Self-destructive behaviour
	Practical attitude		Lack of rationality and understanding
			Purposeless action
			Not relating to consequences of actions
Behaviour	Being involved or being active	Resting/travelling	Being passive
			Aggressive behaviour
			Lack of self-control

			Abnormal appearance
		Uneasiness	Restlessness
			Instability or ambivalence
			Unworthy behaviour
Rationality	Learning from experience		Not taking experience into account
	Complying with self-limitations		Not complying with self-limitations
			Lack of self-insight
			Lack of situational awareness
			Delusions
			Being stubborn
Social life	Reliable/keeping appointments		Not relating to others adequately
	Strengthening social network	Withdrawal (voluntarily)	Failing in care of others

We may say that the informants offer a more complex and nuanced picture of insight in comparison to the “textbook” definition. The overall picture is that insight is seen in relation to how a patient deals with his or her own situation. It is interesting to observe the role that adherence is given. Here the patient opinions and actions are assessed directly on the basis of medical advice and knowledge. Here we also see a more clear structure between what is seen as positive and negative in contrast to the other categories. However, the other categories are just as important. Intentional acts concern the patient strategies, behaviour is mainly how the patient appears to others, rationality is the understanding, and communication and social life emphasise participation and interaction (see Table 2 for details).

Loss of function is preferred as the explanation for the core of the suffering. Level of functioning is seen to relate in a more direct manner to what can be improved clinically. Informants also claim that talking in terms of “loss of function” enables them to communicate better with the patients. We can interpret this as part of a pragmatic concern; however, there are problems:

First, non-adherence is perceived as not having insight. This occurs because not complying with medical advice is perceived as not taking care of one's own best interest. This is no surprise. We see this trend both generally and particularly in relation to mental illness.* Grisso and Appelbaum warn against what they see as an oversimplification of the problem.* First, the statement that psychotic patients lack insight is possible to empirically disprove. Second, they also warn against what they see as reducing the question of insight into a question of the patient agreeing with the doctor's opinion. They say that the question of insight is far more complex than that, and that these attitudes may serve to conceal underlying reasons for the disagreement. It is also problematic because the medical language defines not only the problem but also its solution, which does not necessarily take personal values, goals, and perceptions into consideration. It may also obstruct the opportunity for the patient to make personal experiences and decisions about treatment, even though experience with improvement and worsening may be the most important factor in adherence.*

Second, negatively evaluated criteria are given too much weight. This can be seen as part of the perspective of these informants. Their interest is trying to improve the life of the patients. Focusing on the negative becomes, in a way, part of problem solving; it also focuses on the practical aspects of the suffering that can be dealt with. The problem is that it also establishes an asymmetric relation between the positive and negative assessment of the patient. For instance, the opposite of being aggressive could be being calm. However, from the descriptions, it seems to take less aggressiveness to be assessed as aggressive, than it takes calmness to be perceived as calm. It becomes easier for the patient to be assessed negatively and in pathological terms than to be re-assessed as normal and stable.

Third, some criteria seem to lack a positive counterpart altogether. The adherence indicates symmetry between what is assessed as positive or negative; however, some features like being stubborn seems to lack logical counterparts. For instance, the opposite of stubbornness may be docility, passivity, or submissiveness. These are aspects that may also be assessed as negative. Others, like abnormal appearance, purposeless action, and self-destructive behaviour, seem to lack *practical* counterparts. Having a normal appearance is not noticed, nor are actions or intentions that are intentional and goal oriented; they do not stand out to be noticed as the abnormal or bizarre do.

Fourth, the problem orientation is directed towards how the patient deals with the environment, spanning from an abstract/rational manner to practical actions and behaviour. This concurs with the perspective in which the suffering was described.

In summary, we see a tendency on the part of the clinicians to view insight in terms of the practical skills, coping, and life situation of the patient

as such. It involves a practical opportunity to improve life conditions as well as the level of insight the patient has into his or her own situation. This can be seen as a practical effort that tries to avoid the oversimplification that Appelbaum and Grisso criticise.* The problematic aspect is the risk that the assessment may disfavour the patient.

6. Medical Language

The role of medical language seems to present clinicians with a dilemma. When asked directly, the informants indicate that key aspects of patient suffering are not picked up by medical language and that these aspects are regarded by the informants as significant to the understanding of the patients' choices, behaviour, and suffering. Despite an expressed interest in and empathy for patient experiences, patients' opinions and non-adherence were still seen as conflicting with clinical assessment and advice.

All informants demonstrated a nuanced and critical attitude towards their own professional roles and concepts. The informants articulated ethical concerns as well as a critical and considered attitude towards psychiatric knowledge, concepts, and institutions. Moreover, all informants emphasised the patient perspective. There was no indication that this interest and self-criticism were not genuine.

It is reasonable to ask whether this dilemma occurs because there are no other professional alternatives to the established language and therefore informants fall back upon it when describing or assessing patients' situations. Following this line of thought, the medical language should further emphasise how the pathology of illness directly influences patient experience, suffering, and everyday life. In the case of schizophrenia, emphasising the social and occupational dysfunctions could do this. This is not without problems.

First, these descriptions of suffering are too general to serve as a basis for a nosology (the systematic or scientific classification or investigation of diseases). For instance, loneliness does not characterise schizophrenia as such even though it is a common feature of schizophrenia.

Second, subjectivity poses a problem for the diagnostic manuals, and thus subjective descriptions are avoided altogether. This strategy of the DSM manual has been challenged by writers who think that firsthand experiences can be addressed more directly in diagnostic descriptions and that psychiatric diagnoses are dependent upon the patient experience as such. It has therefore been suggested that the strategy is more problematic than the subjectivity itself, and that phenomenology may address these aspects more adequately than the common sense assumptions do.*

Third, the concept of illness will be re-thought; however, this is a discussion in progress. Illness is characterised not only by the experience of being ill, but also by the breakdown of everyday life.* Fullford argues that we

react to psychosis as pathology due to the action failure that accompanies it.* In this manner, the informants try to see the everyday life of the patient as a direct consequence of the pathology. Fuchs tries to describe how schizophrenia affects intentionality in a very specific manner and may be seen as an example not only of trying to describe the experience, but also of using these descriptions as characterisations of particular disorders like depression and schizophrenia.*

Fourth, we see a shift of focus when treating chronic conditions. The informants' focus is not solely on curing disease, but also on improving life condition. What we see here is that when the disease is partly incurable, improving life condition turns attention from the removal of symptoms towards how to live with them. When the goal is social remission (living with symptoms), social and occupational functioning become more important.* Not all patients suffering from schizophrenia experience it as a lifelong disease, but many do.* This should call for a further emphasis of these aspects of the descriptions - at least - to clarify the treatment goals when total remission (being symptom free) is not attained.

7. Conclusion

We know that patient goals, values, and experiences are important in attitudes towards treatment and clinical personnel. Studies show how patients' goals, values, and perceptions of improvement are aspects that are important to the outcome.* We also know that empowerment and participation are important for any person. A different perspective on suffering entails a different horizon of experience, which leads to a different set of values, goals, and, particularly in relation to symptoms, experience of problems and what it means to get well.* It is important that clinical practice addresses these aspects directly and does not cover them up. The concept of insight may be an important obstacle here.

The informants emphasised that:

- The patient does have an awareness of suffering.
- Explanations and problem solving may thus be anchored in this initial awareness of the patient.
- The informants themselves think that they are too reluctant to follow up this potential in practice.

The study indicates a need for clinical language that addresses the suffering and patient experience more directly. This can be done by encouraging the potential that already seems to be apparent in practice (in its best moments), but it needs to be anchored both theoretically and practically in the nosology. The author suggests that this can be done by an attention to patient awareness of illness as well as by a shift of the focus of descriptions

from symptoms to problems, with particular weight on patient goals, values, and everyday life. This would emphasise not only the patient perspective, but also research on user participation and empowerment. Training and attention to the relevance of patient descriptions and narratives is equally important for clinical personnel in order to secure understanding of the patient perspective.

Notes

¹ DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders*, American Psychiatric Association, Washington, DC, 1994, p. 286.

² PS Appelbaum & T Grisso, 'The MacArthur Treatment Competence Study - I - Mental Illness and Competence to Consent to Treatment', *Law and Human Behavior*, vol. 19, 1995, pp. 105-126. T Grisso, 'The MacArthur Treatment Competence Study. II: Measures of Abilities Related to Competence to Consent to Treatment', *Law and Human Behavior*, vol. 19, 1995, pp. 127-148. T Grisso, 'The MacArthur Treatment Competence Study. III: Abilities of Patients to Consent to Psychiatric and Medical Treatments', *Law and Human Behavior*, vol. 19, 1995, pp. 149-174.

³ T Grisso & PS Appelbaum, 'Values and Limits of the MacArthur Treatment Competence Study', *Psychology, Public Policy, and Law*, vol. 2, 1996, pp. 167-81.

⁴ A Beck-Sander, 'Is Insight into Psychosis Meaningful?', *Journal of Mental Health*, vol. 7, 1998, pp. 25-35. J Dam, 'Insight in Schizophrenia: a Review', *North Journal of Psychiatry*, vol. 60, 2006, pp. 114-120. AS David, 'Commentary on: 'Is Insight into Psychosis Meaningful?', *Journal of Mental Health*, vol. 7, 1998, pp. 579-584.

⁵ T Grisso & PS Appelbaum, pp. 167-181.

⁶ GF Lorem, *Samspill i psykisk helsearbeid*, Cappelen Akademisk, Oslo, 2006. GF Lorem, 'Making Sense of Stories. The Use of Patient Narratives within Mental Health Care Research', *Journal of Nursing Philosophy*, vol. 9, 2008, pp. 62-71.

⁷ K Charmaz, *Constructing Grounded Theory. A Practical Guide Through Qualitative Analysis*, Sage Publications, London, 2006. K Malterud, 'Qualitative Research: Standards, Challenges, and Guidelines', *Lancet*, vol. 358, 2001, pp. 483-488. K Malterud, *Kvalitative metoder i medisinsk forskning: en innføring*, Universitetsforlaget, Oslo, 2003.

⁸ I Leudar & P Thomas, *Voices of Reason: Studies of Verbal Hallucinations*, Brunner-Routledge, London, 2000. MA Romme & AD Escher, 'Hearing voices', *Schizophrenia Bulletin*, vol. 15, 1989, pp. 209-216. MA Romme & S Escher, *Making Sense of Voices*, Mind Publications, London, 2000.

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Hallucinations and the Patient

Lorna Lees

Abstract

Hallucinations are almost universally considered undesirable states, however there is some empirical evidence to suggest that this may not always be the case. Romme and Escher have provided a series of case studies whose hallucinatory experiences have enhanced their quality of life. Current neuroscience suggests that auditory hallucination is the result of a breakdown in the ability of the left hemisphere of the brain to filter out verbal intrusion from the right, an intrusion which is perceived as ego-alien. Jaynes theorised that ego-alien voices are experienced at times of great stress, when the input from the right hemisphere is useful in determining appropriate courses of action. Command hallucinations, such as those that form a central characteristic of schizophrenia, are, Jaynes believes, related phenomena.

With this in mind, it becomes inappropriate to offer a blanket statement of the universal undesirability of hallucinations. The decision as to whether a hallucination is desirable becomes a qualitative assessment rather than a biological claim.

The rejection of the biological disease model by the Hearing Voices Movement is understandable given their empirical claims. It is theoretically possible to replace this reductionism with normativism, requiring only (i) an ability to behave roughly according to accepted social norms, and (ii) that the patient values her hallucinatory state over a non-hallucinatory state. However, the normative position is subject to serious criticisms: auditory hallucinations are valued in one social context and disvalued in another, creating an absurd situation in which a hallucinator might be considered seriously ill in his home country, but if he were to fly to another then he would be considered quite healthy.

This paper will examine the possibility of such a theory and will explore the issues around the attempt to provide one.

Key Words: Hallucinations, mental disorder, disease, subjective experience.

Hallucinations are definable as the experience of something that is not there, an event that is present only in the experience of the individual and not as a fact in the world. In this sense we can talk about acoustic or visual hallucinations, but also bodily hallucinations. This paper will examine the experience of hallucinators and the problems that arise when treating them. It

will also offer a suggestion of a theory of health that might go some way towards easing these ethical concerns.

There are people who experience auditory hallucinations, but who do not consider them to be either problematic or symptomatic. The Hearing Voices Movement seeks to challenge the popular stereotype of auditory hallucinations as being a symptom of illness by providing examples of people who have experienced their auditory hallucinations as a positive experience, or who have learned through therapy or home exercises to render their hallucinations positive. The HVM attacks the notion that auditory hallucinations appear to exist outside of the norm of human experience. Research suggests that auditory hallucinations appear in 2-4% of the population,¹ and that not all of those who experience hallucinations are ever in need of psychiatric treatment.² Since hallucinations are more prevalent than previously thought, and since they are not invariably the sign of a mental illness, the HVM refers to hallucinations as a “form of perception,”³ a variety of human experience - “a faculty or differentiation - something like homosexuality, that is definitely not open to cure.”⁴ Although the voices may not be a sign that there is immediate danger to the patient or those around him, Romme’s suggestion is that the experience of hearing voices is related to a problem in the hearer’s life: the voices are “messengers,” and they are a sign that something is wrong. What is wrong might be as simple as loneliness, where the voices represent the desire of the hearer for social contact or companionship.⁵ In this regard, the voices are no more sinister than a child’s imaginary friend, although Romme makes it clear that the two ought to be carefully differentiated in case the voice heard is the voice of someone familiar to the hearer and is saying things that the real owner of the voice would not. Reality testing excluded, the voices are simply fulfilling a need in the hearer, and they do necessarily not pose a threat.

Alternatively, hearing voices might signify a more worrying underlying problem. Romme suggests self-aggrandisement and self-injury⁶ as two possible events surrounding the experience of hearing voices that are signs of something wrong on some level of the voice-hearer’s self. Self-aggrandisement might be a person’s “looking for a super-solution to his own inner chaos,”⁷ while self-injury is usually accompanied by a feeling of depression, dissociation, guilt or a traumatic experience.⁸ Even taking into account the potentially traumatic reasons why voice hearers hear voices, the voices themselves may not, according to Romme and the Hearing Voices Movement, need to be treated. They may be a coping mechanism, a means of alleviating the problem. This notion is clearest when we think of those people whose voices keep them company. Extreme loneliness is not a disease but rather an unfortunate social lacking in the person who experiences it. That person could continue to be unhappy, or he could listen to the voices that talk to him when no one else does and take a measure of comfort from them.

Also a problem in terms of hallucination is the question of rationality: there seems to be an element of choice to the beliefs of a person who hallucinates, in that he or she may prefer the beliefs that arise as a result of the hallucinations to the more mundane explanations offered by others. Stone and Young suggest⁹ that patients who have Capgras delusions may ignore the evidence that it is entirely unlikely that their loved ones have been replaced by automata in favour of other kinds of evidence, such as the patient's own absolute conviction that their loved one has been replaced by an impostor. It seems that such wilful ignorance should, at some stage, become apparent to the patient: the most tolerant observer would become frustrated with a clear refusal on the part of the sufferer to accept what is patently obvious to those who are not deluded. There are an infinitesimal number of cases outside of Hollywood movies where one person has been replaced by another, who just happens to be identical in every possible way. The chances of that happening to someone outside a movie script are so tiny as to make the suggestion ludicrous. Most hallucinators, however, choose to hold onto the beliefs formulated as a result of these hallucinated experiences: why do they do so, and how can we consider them to be uncontroversially sane and rational in the light of it?

Gold and Hohwy¹⁰ make the claim that schizophrenic delusion ought not to be considered in the light of traditional notions of rationality. Delusions that arise as a result of schizophrenia are, they say, "brought about by a violation of a constraint on rational thought we call egocentricity,"¹¹ and they wish to consider schizophrenic delusions in the light of what they call "experiential rationality." Traditional notions of rationality tend towards procedural rationality, where rationality is a matter of adhering to the rules. If a rule is to be universally applied, then the same premises will always bring about the same conclusion. Thus, one can be said to be irrational when one's actions are not governed by the relevant rule or reasoning process. The procedural account minimises the importance of the content of one's thoughts: they are not, generally speaking, relevant to the analysis of whether or not the thought is rational. The other standard account, content rationality, claims that some beliefs or desires can be irrational, but that if the irrational desire is combined with an irrational belief then the failing lies outside the normal notions of rationality. The irrational content of these beliefs or desires is irrational precisely because it is assigned in place of an alternative, better-fitting content. Gold and Hohwy's response is that cases of delusion fit neither the procedural nor the content approach to rationality, drawing on Frith's hypothesis that delusions in schizophrenia are caused by the "failure of the monitor to represent willed intentions."¹² Normal self-monitoring entails the awareness of one's intentions, one's actions and the awareness of the causal connection between the two. If I have the desire to ease my hunger, I form the intention to go to the kitchen and make a sandwich, and I

will then do so. The “monitor” represents the intention-action pair, the hunger and the sandwich making.¹³ This monitoring has the crucial effect of bringing the intention into the consciousness of the subject so that the subject is aware of the causal connection between intention and action. Gold and Hohwy rely on Frith’s notion here of the monitor as a “model of metarepresentation,”¹⁴ which represents the action-intention pair in the consciousness of the subject. The notion of a representationalist self-monitor is problematic, but even if we remove this layer of representation and suggest instead that direct perception of causal relations between intention and action is possible, then the end result remains the same. Monitoring these mental events directly, and creating a representation of them in the conscious mind, will bring us to the same conclusion, and so although there are potential problems of superfluity with this model, the mechanism remains largely the same and it is that which is interesting in this context.

Let us suppose now that this system of monitoring is defective, and so the intention is not available to the consciousness of the subject. I would find myself in my kitchen, making a sandwich, with no idea of the causal process that led me to be there. I would of course attempt to formulate an explanation for this strange occurrence: I did not (at least so far as I am aware) make the decision to do this, so why am I doing it? One possibility would be that some external force is responsible; this external force moved my body into the kitchen and surrounded it with cheese and bread for reasons of its own. This belief would of course be delusional. Assuming that I was able to be rational, I might conclude that perhaps I had forgotten that I wanted to make a sandwich, or that I would wandered into the kitchen and started making the sandwich without really paying attention to my actions, in the same way that I might not remember walking home because the route is so familiar that I did not have to be aware and so my thoughts were elsewhere. With my self-monitor being defective or absent, however, it is possible that such an explanation might not occur to me, or that I might reject it, thinking that there is no way that my own intentions could be opaque to me. What would happen then is that I would search for an answer that would explain the strangeness of finding myself in a place where I had not expected to be. This explanation would have to satisfy my criteria for sufficient explanation but would not necessarily have to fit any universal criteria for rationality, depending how rigorous my criteria for a satisfactory explanation were. Assuming I was unwilling to accept that I was suffering some sort of mental disorder, I could conceivably conclude that aliens had briefly abducted me and deposited me in my kitchen instead of on my sofa for reasons of their own. There is no evidence to the contrary, and all the evidence I have suggests that this actually happened: I started out on my sofa, and was then transported without my knowing to my kitchen. The only possible explanation that does not involve my serious mental (or possibly

physical, as in amnesia) illness is that something external to me moved me there. If I am unwilling to accept that I am ill, and it is by no means certain that I would accept this, since I presumably feel quite well, then I may well accept the alien abduction scenario and thus become convinced that I had been temporarily abducted.

Further to this temporal confusion, there is an alternative scenario that is more relevant to our purposes here: the hearing of voices. If I am forming the intention to go outside, it is logical to expect that I will then make the decision to perform all the steps in the process that will enable me to go outside successfully. If the first action in the process of getting ready to leave is to put on my shoes, I will, immediately after forming the intention to go outside, have the thought that I need to put on my shoes. If I have this thought without being aware of having had the intention to go outside and thus contextualising the putting on of shoes within an intention-action process, I might experience this thought as an ego-alien command, rather than as a step in the process of carrying out my intentional action.

Gold and Hohwy postulate that there is a procedural violation going on in these cases:¹⁵ for most people, there is a methodological principle involved in the processing and relating of intentions to actions that requires that one suspend explanation in those situations where there is no reasonable explanation available. If I return to my oft-mentioned kitchen to make a cup of tea, only to find that the milk carton is empty, I would search for an explanation, questioning the other person who uses the kitchen and making sure there was no leak in the carton. If, after my investigation, there is no apparent reason for its emptiness, I as a person with normal thought processes would suspend my explanation because I simply would not have one: the missing milk would be a mystery. It would be maximally rational for me not to infer the existence of a milk-drinking poltergeist, or believe that Schrödinger's cat had taken up residence in my refrigerator and was stealing accordingly. If I were schizophrenic, however, the option to abstain from making an explanation without full possession of the facts might be lacking. Rather than being puzzled by the absent milk but then moving on to something more important, the schizophrenic would consider it necessary to fill in this explanatory gap with *something*, no matter how unlikely, and if the schizophrenic were also paranoid, then this explanation could plausibly involve some sort of attack on the refrigerator by hostile agents with the aim of damaging the refrigerator's owner.

The aim of the therapist, then, is at least in part to overcome the problem of this explanatory gap. A further problem arising in this situation is that the patient may not believe there is a problem to be addressed. As in the case of the Hearing Voices Movement, the hallucinations may be seen as a normal process, and as such treatment is unnecessary. A hallucination arising from schizophrenia may be accompanied by paranoia, and an attempt to

bridge the explanatory gap may be seen as a sinister move to be treated with appropriate suspicion. It is theoretically possible to do so using a normative construction of illness, whereby the states we value are considered healthy states, and the ones we do not, disease states. Thus, a hallucination that offered advice or comfort would not be a disvalued state except insofar as it signified a possible lack of confidence in one's own conclusions or an absence of a close social circle.

The problem here is that there are states that we consider undesirable, but their designation as disease is controversial. The obvious example is addiction: it is an undesirable state to be an addict to, say, nicotine, but whether or not that addiction is a disease is not clear. Some may answer is that it is not, and the addict's behaviour is the problem, making the addiction a moral issue rather than one that comes within the scope of disease. It is not clear however whether addiction is caused by an underlying abnormality or poor behavioural choices, and so normativism cannot supply an acceptable designation of disease or otherwise to cover it.

A further problem with normativism is its inability to account for conditions that were considered diseases in the past but are no longer so designated. Homosexuality is an obvious example: the normativist would not be able to say that psychiatrists in the 1960s who considered homosexuality to be a disease were wrong, merely that their values were different. Englehardt explains that the reasons for determining a condition a disease or not is ideological rather than biological thus: "disease explanations are often favoured in order to classify a state of affairs a disease state for social or ideological reasons."¹⁶ While the normative claim that their position accurately depicts the common usage of terms like "health" and "disease" may be true, they thus fail to capture the intuition that there is more to the disease state and the process of defining it than prevailing social values.

In the case of mental illness, the normative position becomes complicated: in mental illness there are usually no physical symptoms that can be valued or disvalued by bystanders as well as sufferers because of their physical effects.¹⁷ The empathic aspect of the value judgement is not available; the onlooker knows that chicken pox is unpleasant because she knows what it is like to be itchy and feverish, but can usually only imagine what it is like to have a mental illness. There are larger problems than this, however: the stigmatisation of mental illness may lead to inappropriate disvaluation of symptoms that may not actually be damaging. Also, someone in the grip of some mental illness may not be rational enough to recognise that there is a problem, and so determination of the illness rests on people around the sufferer rather than the sufferer himself. This leads us into the problem of paternalism: at what stage of a mental illness, and under what circumstances ought a professional to intervene?

The naturalist position seeks to answer this question, and is closely related to the biomedical model of therapeutic treatment. According to Boorse, one of the more well-known naturalist theorists, a disease is an illness if and only if it is serious enough to be incapacitating, and therefore is

1. undesirable for its bearer;
2. a title to special treatment; and
3. a valid excuse for normally criticisable behaviour.¹⁸

Here Boorse contrasts disease and illness to show the distinction between the theoretical concept of health, which is value-free, and the value-laden state of freedom from illness.¹⁹ He later acknowledges this to be a mistake, since the terms “sick” and “ill” are synonymous, and yet “illness” is a term that in normal usage is applied only to humans, while buildings, animals and plants can be “sick.” His second reason for rejecting this construction is that disease and illness cannot be seen as the same essential thing, only in different degrees of severity. An illness is a systemic disorder, invading the whole organism, whereas a disease could be more specific, e.g., paraplegia or arthritis, affecting some of the organism’s limbs or its joints respectively but without permeating the entire organism in the way that, say, the flu does. Under this construction, “disease” is an objective fact about the state of the organism. “Illness” is also an objective fact, although it may become a value-laden one if there is some level of subjectivity involved in the level of incapacitation required in determining the severity of the set of abnormal conditions in question: at what point, for example, does a sniffle become a fully fledged illness? I may insist that I am at death’s door with the flu, while an unsympathetic observer may be equally convinced that I am malingering and should take an aspirin and stop complaining. The theoretical concept of illness in this account is value-free, but its practical application may require a degree of evaluation, which is necessarily subjective. A diagnostic tool such as the Glasgow Coma Scale or the DSM provides some measure of practical objectivity, but the interpretation of signals and symptoms remains largely subjective.²⁰

One alternative to the normative position is a hybrid theory combining elements of normativism and naturalism. Wakefield’s is the most well-known of these hybrid theories, and the statement he makes is that disease simply is “harmful dysfunction.” Thus the disease concept includes a value criterion related to any harm or loss of benefit caused by the condition, as determined by the person’s cultural values, and an explanatory criterion involving some loss of natural function. This approach narrows the field from the normative position, requiring that a disease be a condition that is disvalued *and* is a biological state with defined aetiology, thus removing counterexamples such as drapetomania from the class of disease. It is

possible to argue that this narrowing of the scope of the disease concept is too heavy-handed, in that it becomes overly restrictive and so it rules out disorders that do not fit the biological and value criteria, but which we would intuitively consider diseases.

What, then, would be an appropriate alternative? A hybrid theory seems indicated, given the problems with pure naturalism and pure normativism. What is suggested is an alternative hybrid theory that allows for both the objective, naturalistic facts and the normative judgements based on those facts to be examined in tandem, without conflating the two. Health and disease are value-laden terms that reflect the existence or non-existence of physical conditions that may be valued or disvalued. Their usage in the absence of further information about the state of the body or the mind is insufficient, because it can only tell us how the person feels about their state of body or mind. This is obviously useful information, particularly in the case of non-physical illnesses, because it allows insight into what we might call "how a person feels about how they feel." Further information is required in a medical setting, however, because an accurate judgement of whether or not a person is suffering some sort of disvalued condition requires a rational agent to make the judgement, and in the case of mental disorder this rationality is not guaranteed. The terms health and disease, therefore, comprise statements of fact about the value placed upon a condition. They do not inform us of anything inherent in the condition itself, and in a medical context they should not be treated as such. It is necessary that there is a concomitant description of how the body (or the mind) is: why is the discussion taking place?

In terms of hallucinations, then, a person who experiences them need only become a patient if there is an objective claim to be made that the hallucinations being experienced are negatively toned and therefore undesirable. While their presence in a person who does not consider them a problem and is rational might still be significant of some underlying problem - for example, the case of a person who is lonely and who hallucinates voices as company - this problem is not a medical one, and so the therapist-patient paradigm is inappropriate. What might be indicated is some sort of social program for the hallucinating agent, to enable development of social relationships to preclude the necessity for hallucinated social experiences.

There is a fine line to walk between the over- and under-medicalisation of mental health issues, and both extremes have their charms and their downfalls. Attention to both the medical and the social or subjective data available, without conflating the two, is a step in the direction of a treatment alternative that is ethically robust and avoids the traditional ethical pitfalls of paternalism and relativism.

Notes

- ¹ AY Tien, 'Distributions of Hallucinations in the Population', *Social Psychiatry and Psychiatric Epidemiology*, 1991, vol. 26, pp. 287-292.
- ² A Honig et al., 'Auditory Hallucinations: A Comparison between Patients and Nonpatients', *Journal of Nervous & Mental Disease*, vol. 186(10), 1998, pp. 646-651.
- ³ M Romme & S Escher, *Accepting Voices*, MIND, London, 1993, foreword.
- ⁴ Intervoice Online, *Are Voices a Symptom of Illness or a Variety of Human Experience?*, viewed on 26 June, 2008, <<http://www.intervoiceline.org/2006/11/27/are-voices-a-symptom-of-illness-or-a-variety-of-human-experience>>.
- ⁵ M Romme & S Escher, p.158.
- ⁶ *ibid.*, pp.160-161.
- ⁷ *ibid.*, p.160.
- ⁸ *ibid.*, p.161.
- ⁹ T Stone & AW Young, 'Delusions and Brain Injury: The Philosophy and Psychology of Belief', *Mind and Language*, vol. 12, 1997, pp. 327-364.
- ¹⁰ I Gold & J Hohwy, 'Rationality and Schizophrenic Delusion', *Mind and Language*, vol. 15(1), 2000, pp. 146-167.
- ¹¹ *ibid.*, p.147.
- ¹² CD Frith, *The Cognitive Neuropsychology of Schizophrenia*, Lawrence Erlbaum, Hove, 1992, cited in Gold and Hohwy, *ibid.*, p. 151.
- ¹³ CD Frith, *ibid.*, in Gold and Hohwy, *ibid.*
- ¹⁴ *ibid.*
- ¹⁵ I Gold & J Hohwy, p. 156.
- ¹⁶ T Englehardt, *The Foundations of Bioethics*, Oxford University Press, New York, 1986, p. 262.
- ¹⁷ There may be psychosomatic symptoms; however these are not prevalent in the majority of cases.
- ¹⁸ C Boorse, 'A Rebuttal on Health', in *What is Disease?*, J Hunter & R Almeder (eds), Humana Press, Totowa, New Jersey, 1997, p.11.
- ¹⁹ In practical discussions of health, we speak of blood tests coming back "clean," implying that if a disease were present the test would be "dirty." This is a clearly value-laden statement, which would be missing in a purely theoretical discussion.
- ²⁰ The increased diagnosis of specific disorders in which a doctor is interested was noted by Laing and has been supported in other research.

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PART III

The Patient in Literature

“To Write A Great Story:” Margiad Evans’ Illness Narratives

Sue Asbee

Abstract

Margiad Evans’s *Ray of Darkness* (1952) attempts to make sense of the onset of her epilepsy. Recognising her own compulsion to tell the story of her illness, she believes simultaneously that the condition separates her from the understanding of healthy people. I argue that in the text and the unpublished mss, tellingly called *The Nightingale Silenced* (1954), Evans’s concern is to establish and affirm and identity by writing, while at the same time believing that communication is impossible. In opposition to the impulse to “lie down [...] and sleep” is the “obstinate, instinctive expressive which wants to speak, to testify, to reason.” Evans continually questions whom she is writing for, at one point concluding that she may simply be talking to herself. *The Nightingale Silenced* was written when she was hospitalised. It charts a new acute phase of her disease: the frightening defamiliarisation of ordinary objects and “dream-like horror of the sufferer’s surroundings.” Household objects become the locus of fear, imbued with malevolent intent to destroy her mind. During some attacks, mind and body become divorced, while her own face in the looking glass appears as a “stain” provoking her “distaste and even fear.” With identity in such distressing crisis, her status as a writer trying to record such experiences is paramount for sanity and survival. Often presenting a tone of practical clinical detachment, she also subscribes to the notion of epilepsy as poetry, and a mystical sense of union with nature; I argue that these are ways of coping with fear of approaching complete loss of identity.

Key Words: Margiad Evans, pathography, epilepsy.

In 1954 Margiad Evans wrote an account of her experience of epilepsy which she had suffered from for some time, but which had moved into a new, acute phase. While she was a patient in Tunbridge Wells Hospital, she filled a series of six red notebooks with her reflections on her illness.¹ Her aim was not to describe treatment, which she considered the physician’s business, but her symptoms; her perspective was that of the patient: “my side of the illness.”² Her declared intended reader, however, was the physician, and her desire to “put into [his, and indeed her] hands a book of clues to the sensations of such an epileptic” as herself. Although it never

reached print, the account, which she called *The Nightingale Silenced*, was intended for publication. Her earlier *A Ray of Darkness* (1952) charted the onset of her condition in earlier middle age and it is here that she first described the "longing to write of one's symptoms" which appears "like an inspiration to write a great story."³ In 1954 she was 45 and had a two year old daughter.

The need to tell the story of one's illness is widely acknowledged. Arthur W. Frank's seminal work, *The Wounded Story Teller* (1995), as the title suggests takes pathography as its subject: "the stories that ill people tell come out of their bodies," he says. "The body, whether still diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told." A major illness forces the need to renegotiate our relationship with our bodies and the world. Things that we took for granted when we were well are inconceivably impossible once we are not. The need to tell and repeat is something Evans noticed among her companions on the ward: by this stage, she had experienced various hospitals, and felt that Tunbridge Wells's was "the easiest and most amusing" she had ever been in. There were no restrictions she says "on any comfortable vice such as smoking, which is my own or the bandying of symptoms, which is not."⁴ It is interesting that "the bandying of symptoms," which is another way of expressing the need to articulate what is happening to the body, was not generally encouraged by the medical profession at the time.

It is interesting too that Evans disassociates herself from this common form of illness narrative which habitually takes place, the endless describing and discussion of symptoms, instead seeing her own compulsion to write her story as a separate activity, belonging to a different sphere. There is, then, a need to assert her individuality and she draws on her identity as a writer in order to do this. At various crucial points throughout her account, she returns to it as an established fact as if to reassure herself that something of her former self survives.

Evans is highly conscious of her surroundings as she writes. She is on a women's ward and hers is one story among many. She is an individual, but her own story also comes to stand for those of others: she describes meeting a woman who has similar symptoms, though from different causes and concludes: "I am not quite talking to myself where my fellow patients talked aloud. Neither am I talking to her; but *for* her."⁵

The sufferers therefore I think of not only as sufferers but as texts and not only texts but as human beings each with his joys and reliefs as well as pains and pangs. These pains and pangs are very dreadful I know. So dreadful that the mark of them on another's face makes me weep; but also necessarily to be explored by young physicians, who, in

their turn, will have to hear them, for they are the pains of death.⁶

Bodies become texts to be read - the sum of the stories of their illnesses.

The compulsion to write worked in opposition to the physical impulse she had to “lie down and be warm and sleep,” a sensation which, she said, “is very like a longing to die.”⁷ In other words, to surrender her identity. But against this “there remains something obstinate, instinctive expressive which wants to speak, to testify, to reason, to raise up myself and others like me.” She has an inalienable desire to bear witness. It is, she says, Lazarus, and not Jesus who calls her.⁸ In this analogy, the act of story-telling and writing is equated with the act of life itself. Like characters in Beckett’s plays and fiction, as long as you have a voice and use it, death is postponed. Jesus, in this analogy then, stands for death. Evans, brought up to be a Christian, had little patience with formal religion but had strong spiritual beliefs which were important in making sense of and reconciling her to her illness.

“During certain types of minor attack,” she says, “the mind is emptied even to the extent of not knowing what to do with the body,” and she gives the following as an example:

It happened that a nurse brought me pills when I was in the middle of such a minor attack and practically fully conscious in the sense that consciousness usually seems to mean. I was walking up and down in my cubical. I looked at the pills which I had taken for four years and asked ‘what shall I do with them?’ She replied ‘swallow them my dear.’ And I instantly did so. This prising of mind and body is most horrible, terrifying and revolting.⁹

Reason is no help, though a sense of residual reason endures - sometimes even during episodes - and Evans tries to measure how far her illness has detached her from her earlier sense of reality. In her opinion, epilepsy is a mental illness, a claim which had been disputed by the 1950s, so she supplies her own defence in her narrative:

In speaking of epilepsy, perhaps of all mental illnesses one has to use vague and qualifying words. For instance, the disorder itself is both mental and not mental - it is nervous and intensely physical, but in some of its manifestations, particularly between bouts of attacks [...] it must be faced, that it affects the sufferer in a way that can only honestly be

called mental. I say this after four and a half years of suffering: nor would I have believed it in the beginning.¹⁰

This is her testimony, whether it agreed with received medical opinion at the time or not.

Most compelling is the way in which in her experience familiar inanimate objects become invested with intent to harm, sometime they are malevolent. Here Evans is describing what Freud might have termed the uncanny. She remembers looking at a tree,

an old cherry tree, in bloom which grows over our bungalow, and asking *why* it was so terrifyingly different. Inside the bungalow things were much worse. An appalling terror which nobody who has not experienced it could believe, a terror amounting to panic seemed to emanate from every piece of furniture, every book, every saucepan [...] the more real an object surrounded by this unreal horror became the worse it was. Had this been some hallucination, *something* unusual it might have been easier. But the objects I knew did not want my body; it was my mind they wanted to destroy.¹¹

This passage is followed by a sentence of remarkable clinical detachment: “Unfortunately I wrote no poetry while in this state, for it would have been interesting.” The very experience of recalling that particular dreadful mental state is so distressing that it demands a retreat into the safer (and known) identity of writer and in particular, perhaps, a writer of poetry where image and metaphor have heightened importance. Can prose do justice to the experience? Certainly the poetic device of repetition is used to interesting effect in this passage: the cherry tree is “terrifyingly different,” Evans feels “appalling terror” and says that the “terror [...] seemed to emanate from every” object. It is not just that she perceives objects as terrible, but that they themselves project terror. Repetition, then, binds perceiver and perceived into a whole, so that inner and outer worlds converge in a fearful, unknown, and threatening way. Inanimate objects are invested with a will of their own, and a desire to destroy her mind, the stuff of her consciousness and the seat of her identity.

The body, Frank says, “is often alienated, literally ‘made strange,’ as it is told in stories that are instigated by a need to make it familiar.”¹² Here the affliction of Evans’s body and mind makes the world around her strange. The laws of physics no longer hold good: lying in bed at home enduring the second day of a fearful episode, Evans felt herself to be attacked by “eerie

and impalpable sensations.” “I could” she says, “think of nothing but *doors*” [her emphasis], and she repeats:

As I lay in bed very uncomfortable and terribly uneasy I could think of nothing but doors. I wanted them shut and open at the same time. There seemed to be long periods when that was actually possible & that not only was the door of my bedroom both shut and open but that I was that door myself. In *A Ray of Darkness* it has been told how nearly every fit took place in a doorway: whether the old associations lay deep in my brain or whether there is anything to be learned from this delusion the readers who are competent must judge.¹³

The desire to have those doors shut and open at the same time speaks of a need to synthesise, to make a connection between the well person she was, and the sufferer she has become.

On that particular day, fearful that she was going out of her mind, that she was on the edge of a nervous breakdown, and that she might harm her small daughter, Evans had persuaded her husband to find child care for Cassandra, while a woman from the village remained at home with her. But visitors began to arrive, and she felt “wilder and wilder” exhausting her “tired and threatened brain” while apparently remaining externally calm. Then, paradoxically, her feeling was that the disease which caused her new and terrible relationship with reality also told her what to do to save herself: “fall down on the floor and frighten them.” She remarks that she “always found that there is profound sense in my illness.” This seems quite at odds with the “restless horror,” the “utterly evil, utterly causeless panic”¹⁴ which she describes elsewhere, but the fake “fit” does the trick and gets rid of the visitors.

The horror does not abate once she is alone again: “every object became impregnated with terror. I was still trying to reason & so in their fashion were *the*” - the objects -

I felt as if the hair on my head was whitening [...] and my body withering: I tried to read a simple women’s paper and the paper as I held it terrified me: I looked out of the window and saw a world made of trembling change.¹⁵

The narrative falters rather here, perhaps from the intensity of retrieving the memory:

Then I began to lock the doors from the *inside* to stop myself from getting *out*, and to throw my keys out of the window in case I should take an overdose: I did think of a particularly long vicious carving knife, but as I had often thought how easy it could be to kill before, this image was blunted and I was able to tell myself not to be a fool.¹⁶

Locking herself *in* would not in fact prevent her from taking an overdose, so there is an inconsistency in the account, but what I find extraordinary here is the shift from the impulse for self-preservation - faking a fit to relieve herself of the relentless good-natured but exhausting company of neighbours - and then almost immediately harbouring suicidal thoughts. There seems to be little “profound sense” in her illness at this point, but that is something that she herself fails to register. It is significant that the “long vicious carving knife” poses less of a threat because it is an “image” that she is familiar with.

Later Evans learned that while she appeared to be a quiet patient “suffering possibly from exhaustion but showing almost no other symptom,” she was in fact having convulsions that were “confined to mental sensations only.”¹⁷ In medical terms this presumably reconciles the contradictions of her faith in her illness to give her sound advice to save herself, and similarly to kill herself - unless we countenance the notion of death as a means of preservation, which is not a new idea in literature: Virginia Woolf’s shell-shocked character Septimus Smith throws himself from a high window onto rusty railings in order to preserve his identity. Evans refers to Virginia Woolf in this manuscript, though not to *Mrs Dalloway* (1925), the novel in which Septimus Smith appears.

The following day, taken by ambulance to the Bushey Neurological Institute, she had an impulse to “leap out of bed and tear open the ambulance doors.” Her whole attention “was focused on those doors;” she does not say whether this was a suicidal impulse or a return of the philosophical question of whether doors can be open and closed at the same time, or indeed if, as she suggested, that she could be the door itself. From a literary perspective the image of doors is a potent one, from Aldous Huxley’s account of the mind-altering drug mescaline in *Doors of Perception* (published in 1954, and roughly contemporaneous with Evans’s manuscript), to a more general sense of being between two separate spaces, poised on the brink of a new experience. “One of the peculiarities of my small attacks of confusion” she says, “was wanting to reach a doorway and dash through it.”¹⁸ There’s a sense of compulsion present in that statement, as well as a recognition that as the experience cannot be avoided, so she might as well get it over with.

Her own interpretation brings in a spiritual dimension, significantly once again endorsing a split between the physical and the spiritual:

As for the inevitable longing to escape, the sinister concentration upon doorways, it did seem always as if the spirit were seeking refuge and searching vainly, madly, rapidly for another firmer and more assailable home.¹⁹

Before convulsions she would often feel a mental sensation of “sudden light upon the body [...] I felt as if a ray of pure daylight concentrated upon my body,”²⁰ and again it is as if “some great being or light in another space had opened a shutter.”²¹ Her identification with Saint Teresa will come as no surprise then, given the religious connotations of the imagery of light here. The illness has different aspects, for what she calls the general “Cloud of Epilepsy” also produces besides confusion, “enlightenment, quickness of mind, a love of the Aesthetic and of God.” The cloud is not “utterly black,” but also a “golden cloud.”²²

This is one side of a popular perceived view of epilepsy, which has historically been considered a shameful affliction associated with insanity and moral degeneracy and on the other hand as having mystical and spiritual qualities, like Dostoevsky’s characterisation of Prince Myshkin in his novel *The Idiot* (1868). Evans also refers to Dostoevsky in her manuscript, claiming that “all [his] characters are epileptic,”²³ and in *A Ray of Darkness* she reminds us that epilepsy was once called “Possession.”²⁴

In 1893 Sutter wrote that epilepsy is “a disorder of the borderland between body and soul,”²⁵ his image relying on notions of separation between the two, while at the same time insisting on their connection. Evans’s own preoccupation with doorways suggests a similar idea of “borderland” - neither in one place nor another, but poised between two realms: one terrifying, the other spiritual.

I have mentioned Virginia Woolf as one of the writers Evans draws on; in fact she quotes from one of Woolf’s short stories, saying that although she is not suggesting that Woolf was a person with epilepsy, what follows reads like a description of a minor seizure:

And over them both came instantly that paralysing blankness of feeling when nothing burst from the mind, when it’s walls appear like slate, when vacancy almost hurts, and the eyes petrified and fixed see the same spot, a pattern, - a coal scuttle - with an exactness which is terrifying, since no idea, no impression of any kind, comes to change it, to modify it, to embellish it, since the

fountains of feeling seem sealed and as the mind turns rigid so does the body.²⁶

The use of the word “terrifying” there echoes a repetition of Evans’s own, while Woolf’s characteristic and driving concern to describe and record consciousness effectively defamiliarises ways in which we observe inanimate objects.

Evans believes that her kind of chronic illness is deeply connected with religion, metaphysics and poetry. She invokes Milton and Bunyan, both religious writers whom she credits with returning religion to a “first joyous life” which, she says, “creeds have destroyed.”²⁷ But she has a more vested interest in a claim she makes that “nearly all writers are ill,”²⁸ for by making it, she places herself in that their company, and finds a reason for both her altered states of consciousness and her identity as a writer. At one stage she considered her epilepsy an affliction visited upon her because she had not remained true to her calling as a writer. In this narrative, the last sustained piece that she wrote, she says that her task has been that of

giving an outside inside story. And it is my belief that if more people had attempted to do it, we should not now ask what mysterious madness killed the mind of the great Swift who was so marvellously equipped *to describe*, should not now be puzzled by the intellect of a Byron and could relieve a John Clare of the pain of genius while leaving him it’s joy.²⁹

This is one aim. Another unspoken, implicit need is to provide a rationale for her life-destroying illness - “nearly all writers are ill” - and in so doing, retrieve her identity as a writer to see herself through the vicissitudes of her illness. In this way she secures a place for herself in a context of celebrated writers, and continues to make use of her talent and ability while she still has the strength. As she wrote in *A Ray of Darkness*, “our health is a voyage: and every illness is an adventure story.”³⁰

Notes

¹ M Evans, *The Nightingale Silenced*, unpublished ms, The National Library of Wales, 1954, ms. 23368B.

² *ibid.*, p. 4.

³ M Evans, *Ray of Darkness*, John Calder, London, 1952, p.10.

⁴ Evans, *op. cit.*, *The Nightingale Silenced*, p.13.

⁵ *ibid.*, p. 5.

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- ⁶ *ibid.*, pp. 5-6.
⁷ *ibid.*, p. 2.
⁸ *ibid.*, p. 2.
⁹ *ibid.*, p.13.
¹⁰ *ibid.*, p. 27.
¹¹ *ibid.*, pp. 26-27.
¹² A Frank, *The Wounded Storyteller: Body, Illness, and Ethics*, University of Chicago Press, Chicago, 1995, p. 2.
¹³ Evans, *op. cit.*, *The Nightingale Silenced*, pp. 27-28.
¹⁴ *ibid.*, p. 31.
¹⁵ *ibid.*, p. 31.
¹⁶ *ibid.*, p. 32.
¹⁷ *ibid.*, p. 35.
¹⁸ *ibid.*, p. 125.
¹⁹ *ibid.*, p. 130.
²⁰ *ibid.*, p. 128.
²¹ *ibid.*, p. 134.
²² *ibid.*, p. 61.
²³ *ibid.*, p. 168.
²⁴ Evans, *Ray of Darkness*, p.11.
²⁵ S Lannon, 'Free Standing: Social Control and the Sane Epileptic', *History of Neurology*, vol. 59, June 2002, p. 1032.
²⁶ V Woolf, 'Together and Apart', in *The Complete Shorter Fiction of Virginia Woolf*, S Dick (ed), The Hogarth Press, London, 1985, pp. 187-188.
²⁷ Evans, *op. cit.*, *The Nightingale Silenced*, p. 140.
²⁸ *ibid.*, p. 70.
²⁹ *ibid.*, p. 4.
³⁰ *ibid.*, p. 11.

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**Patient, Doctor and Disease:
Margiad Evans and *The Wooden Doctor***

Karen Caesar

Abstract

Margiad Evans wrote four novels, two published works of autobiography, two volumes of poetry, and short stories as well as a great many unpublished letters, journals and drafts for further autobiographical texts. Her interest for this symposium is that she suffered from chronic cystitis as a young woman before developing epilepsy at the age of forty-two. The fits were the physical manifestation of the oligodendroglioma, a brain tumour which killed her on her 49th birthday, March 17th, 1958. Her illnesses, her responses to them and to the doctors who treated her are the core subjects of her writing. In her fictionalised autobiography, *The Wooden Doctor* (1933), the narrator, Arabella, describes the pain she experiences from what is eventually diagnosed by the eponymous doctor as cystitis. Patient, doctor and disease form a complex triangle in the novel, which this paper will analyse.

In *On Being Ill* Virginia Woolf remarks that there is no language to describe pain: it “runs dry.” Elaine Scarry, in *The Body in Pain*, agrees but shows how often in the face of this difficulty sufferers turn to the metaphor of a weapon to describe the experience: the pain is like treading on a nail or being hit by a hammer. Evans employs a more arresting metaphor, “It was like a fox in a bag scratching and rending to get out.” The implications and power of this powerful, extended metaphor will be discussed. However, the paradox at the heart of the novel is that the pain, which tears her apart, brings the attention of the doctor who, from the age of twelve, becomes her physician, Father-Confessor, the only person on earth that she loves. The iatrogenic nature of her relationship with the doctor who has the potential to both cause and cure her pain/suffering will be explored.

Key Words: Margiad Evans, cystitis, pathography, iatrogenics.

The subject of this paper is *The Wooden Doctor* a novel published in 1933 by the British writer Margiad Evans. Margiad Evans, real name Peggy Whistler, suffered various illnesses throughout her life which came to a premature end when aged 49 she died of a brain tumour. She was attended by a variety of doctors and specialists, some of whom were very eminent in their field; several of them were to play an important, even crucial role not only in treating her sickness but also in her creative and emotional life.

The Wooden Doctor is fictionalised autobiography. Although Evans presents her text as a novel insisting that the characters are “purely imaginary,” it is clear from her journals that Evans and her heroine, Arabella, share key feelings and experiences including the illness that brings the doctor’s attention, the passion he inspires and the realisation of an ambition to write. My suggestion in this paper is that these elements are inextricably entwined: the illness which may or may not be hysterical in origin brings the attention and ministrations of the doctor whose love she craves. The doctor fails to reciprocate her passion - hence the epithet wooden; he fails even to cure her sickness, but crucially he provides her with a subject for her writing.

At the beginning of the novel the new doctor, Flaherty, is called to examine Arabella when she is sent home from school suffering from a fever. She is at a very delicate, sensitive stage of early puberty. She has a deep awareness of, as well as a problematic relationship to her own body, a low opinion of her appearance and is disturbed by the evidence of her developing sexuality. This is the context in which the doctor first examines Arabella. Her account is highly charged with disturbing sexual overtones.

Dr Flaherty bending over her unbuttons her nightgown and pushes it open to listen to her chest,

As the stethoscope moved I suddenly knew terror, not of him not his machine - no, indeed - but of a dreadful, indescribable nightmare, a nightmare that came to us when we were wide-eyed, a nightmare that Esther shared with me and which we spoke about to each other and to nobody else. Everything glided smoothly, swiftly, flowing like the road beneath a car, then, oh, awful, oh, horror - chaos, weltering, tangled confusion.¹

The nature of this waking nightmare shared by her younger sister can only be guessed. However, the context in which it is brought on by the doctor pushing open her nightgown and the imagery and rhythm of the sentence about the swiftly flowing road culminating in chaos and confusion is suggestive of sexual abuse. This is reinforced by the next paragraph which describes the room spinning and her mother vanishing into a void. She then sees, “the doctor at the end of a long, long tunnel and sobbed at what was coming.” However the doctor smooths her hair away from her burning face. “His touch had cheated away the terror.”²

The doctor then assumes huge, almost talismanic/divine significance; he can cure by touch alone a terror against which her own mother could offer no protection.

Arabella’s body is central to the text which opens as it is about to undergo the crucial transformation of puberty. Puberty, as Elizabeth Grosz

has remarked, signals a girl's entry into her "reproductive reality:" it marks the boundary between infancy and adulthood, between nature and culture.³ The fact that Arabella seems to want to avoid making this transition, hating her body as it shows signs of the woman she will become gives further credence to the theory that hers is a body, which is suffering violation. According to Jeremy Holmes in his book *The Search for the Secure Base: Attachment Theory and Psychotherapy*, abuse by a family member leads to the sufferer pursuing one of two harmful attachment strategies, both of which involve the victim's own body. In the first the sufferer resorts to an aspect of the self, or her body as a "pathological secure base"⁴ which manifests in self harm or eating disorders. Here the body attacks itself but the experience of attack offers comfort: self-harmers often report a feeling of calm following the injury. The second strategy involves the sufferer using her body as a "surrogate secure base for self-soothing."⁵ In this model, according to Holmes, the "secondary gain of showing the wound to professional carers further mobilises attachment behaviours." In the case of Arabella, she develops a mysterious illness, which is finally diagnosed as cystitis. It is this illness which brings the attention of the doctor, the same doctor who "cheats the terror" of her waking nightmare with his touch and to whom she looks for the secure attachment which neither her mother nor her father cannot provide.

Some years later when Arabella is sixteen she returns from a period spent in Brittany as a teaching assistant suffering from severe pain. The wooden doctor diagnoses cystitis.⁶ Arabella conveys the pain vividly:

In the night the pain came back. It was like a fox in a bag scratching and rending to get out. My spirits trailed in the dust. The claws penetrated my sleep.⁷

I insisted upon getting up. I would not abase my existence before the fox that had entered into my body.⁸

She sees her pain as a creature, linked in folklore with wiliness and cunning. The fox is a predator lurking in the darkness ready to pounce on innocent, defenceless inhabitants of coop and field, rending and devouring them. Her pain is such a creature and it has actually entered her body. This metaphor is also directly linked with her home, which she describes early in the novel as "a cage of savagery"⁹ where family members sharpened their claws in each other's flesh. These striking linguistic clues seem to point to a link between the disease and its possible cause: abuse by her father - cystitis often being caused by sexual activity.

The doctor tries to cure her of the pain, but can do no more than cut the claws of the fox, giving her temporary relief before suddenly the creature attacks again, springing, "with flaming feet and famished jaws, rending, biting, tearing." The repetition of the word, "rending" is also suggestive of

violation: she feels torn apart by the searing pain. She goes back to the doctor and tells him she can stand no more. He examines her,

He stretched me on a couch and stuck all kinds of instruments up me. They hurt very much, and I should have hated anybody else to do it.¹⁰

Following the fox which entered her, Arabella's body again suffers violation, but the crucial difference is that this time the perpetrator is her beloved doctor.

Arabella goes on to submit her body to two further medical examinations, both of which involve admission to hospital, but the doctors conclude that there is nothing wrong, nothing to be done. Her reaction to this outcome is telling:

Shut up with the beast for the rest of my life. The image of the Wooden Doctor alone between me and despair, between me and the fox's mask.¹¹

The language echoes the first time the doctor stood between her and the terror of her waking nightmare.¹² This time the image of the doctor stands between her and the fox's mask - the mask itself providing a further sinister layer of disguise and concealment.

Arabella/Peggy's need for her Wooden Doctor can be explained in the context of her troubled relationships with both her mother and her father. It is my contention that in her novel Evans suggests that Arabella has been abused by her father. It is impossible to know whether this was a real or symbolic event in the author's own life, but given the many parallels it is tempting to accept that it was on some level also true for her. This would obviously have a profound effect on the ability of the young Arabella/Peggy to comfortably resolve the Oedipus crisis. It has been found that the experience of abuse often results in gender precariousness and a high degree of splitting and projection; a notable literary example of this is Virginia Woolf.¹³

It is a commonplace of Freudian theory that the task in adolescence is for the young girl to transfer from mother to father as primary love object in order to make a successful heterosexual resolution of the Oedipus crisis. For Peggy/Arabella her father is unavailable or inappropriate in this role which has two consequences: she seeks an alternative in the form of the wooden doctor and she demonstrates her profound uncertainty about heterosexuality by developing a sexual attachment to another woman. The latter is also affected by Arabella/Peggy's relationship to her mother. Alice Balint suggests that if the girl experiences a mother who is cold and who fails

to offer sufficient nurturing then because the child's love for her is unappeased, the necessary loosening of the bond between them does not take place.¹⁴ The consequence of this for the girl's adult relationships is that she will be forever seeking a mother substitute and often bring a child's immature wants and needs to a relationship.

Arabella's search for a mother-substitute is clearly described in an unpublished draft of the novel. Here Arabella, while teaching in Brittany is attracted to the mother of one of her pupils, Renée Maréchal. In an exchange where Renée remarks to Arabella that she is old enough to be her mother, the name Peggy has been crossed out and Arabella substituted, indicating the close identification of writer and subject. During this episode Arabella displays an intense awareness of her own physicality and that of Renée; one seems mirrored in the other. She watches her own reflection as she dresses, "raising and lowering my arms with dollish stiffness, marking the taughtening and relaxing of my breasts,"¹⁵ before watching Renée,

She bathed her face and shoulders and arms. The vertebrae [sic] protruded, the pale fine skin shone on each little knob with the soft lustre of a pearl.¹⁶

These details together with the fact that they constantly "touch and kiss each other;"¹⁷ lend the story an undeniable eroticism. The climax of their relationship comes with a "confession" Renée makes to Arabella. She speaks of,

Man and her experience of him: whether she spoke in English or French I cannot recall only that her wild fierce resentful confession was most truly, most terribly, most agonisingly clear.¹⁸

However, Arabella's account of this confession is far from clear. We learn that whatever happened to Renée deprives Arabella of any hope in the possibility "of tenderness, or kindness in living;" it terrifies her and leaves her feeling in desperate need of comfort. They part at dawn and at dawn Arabella writes to the wooden doctor, the one who can "potently protect" her from such terror. The link between the two relationships is made explicit later in the draft when at another time of emotional turmoil she writes, "A year ago I should have written to Renée Maréchal, two months ago to the wooden doctor."¹⁹

In the published novel, the wooden doctor becomes a surrogate parent for Arabella, most obviously a father substitute but he clearly also provides some of the nurturing and protection she might have expected from her mother. When she is in Brittany, the *directrice* of the school writes to

Arabella's mother complaining of her behaviour: she has formed a friendship with a young Englishman. Arabella's mother writes back to both the *directrice* and Arabella, siding with the former and apologising for her daughter's bad behaviour. Arabella describes her mother's letter as "bitter and biting."²⁰ She imagines by contrast how she thinks the doctor would have reacted,

The Irishman would not have judged so harshly, nor so cruelly condemned... Never shocked he drew truth from me as nobody else could; to him I told my faults as studiously as I laboured to conceal them from others. He has called himself my Father-Confessor: he was more. Against vice, brutality, stupidity and evil, I weighed this one man whose puissant image was the strongest influence in my life, and he more than balanced all.²¹

The suggestion here is that he is more than either father or mother. He is her Father Confessor an almost God-like figure whose image can ward off vice, brutality and evil - in other words, the "terror"²² of her "savage"²³ home, and the fox's mask.²⁴ Evans's original title for the novel, *The Divine Image* reinforces this aspect of the doctor's significance for Arabella. In her hour of danger, Arabella says, she longs not for her mother, but only for her wooden doctor.²⁵

Finally Arabella feels compelled to confess her feelings to the doctor,

I was no longer a child and I realised that I loved him with all the affection and passion that stored in my heart could find no other outlet.

Significantly she starts her confession with, "Papa-doctor, I am going away." This is the first of several times she addresses him as papa - she dreams that she is knocking on his door crying, "Let me in Papa, this is my home."²⁶

While her words powerfully convey the extent to which the doctor represents father and home for her, she persists in her conviction that they could be lovers and her revelation of these feelings to the doctor prompts a letter from him which leaves her anguished.

Dr Flaherty tells her that he can be no more than her Father Confessor. She realises that he has always thought of her as a child and treated her as if he were her "tender and indulgent father."²⁷ She cannot accept the letter, but feels compelled to face him. He reminds her of the age difference, "I am old enough to be your father."²⁸ Arabella writes, "It was

death. He did not love me.”²⁹ That father and lover are inextricably linked in Arabella’s perception is emphasized at the end of the interview when the doctor kisses her on the lips for the first and only time in response to her request, “Kiss me, Papa.”³⁰

In a letter written to her husband, Michael Williams, on January 24th 1946, thirteen years after the publication of the fictionalised account of her infatuation with the doctor, she tells him of a conversation she has just had with a friend, following seeing Dr Dunlop in the street. The friend assured her that she was better off with Mike than the doctor who was too old for her.

I said I knew it... But there are times when I feel sad that I can’t *spea*k to Dr Dunlop first to tell him that my feelings *in a way* have never changed. You see I don’t think I ever wanted him particularly to marry me. I asked him to *adopt* me! And that I think would have worked.³¹

In Arabella, Evans is presenting a version of her own experience: both Arabella and her creator, longing for a substitute father, turn to the doctor who offers a cure for the intimate pain which strikes at the core of her sexual self, like a frenzied fox rending the “fleshy cage”³² which confines it and from which it is desperate to escape. The fox represents not just the disease but the sufferer’s sexuality which she yearns to express but which is confined and repressed due to the confused emotions called up by “Papa-doctor.”

In Freud’s *Introductory Lectures on Psychoanalysis* (1917) he deals with the issue of transference. He describes how a woman in an unhappy marriage may be “seized with a serious passion for a doctor who is still unattached.” She may be prepared to seek a divorce or even enter into a secret liaison with him:

Such things come about even outside psychoanalysis. But in these circumstances we are astonished to hear declarations by married women and girls which bear witness to a quite particular attitude to the therapeutic problem: they had always known, they say, that they could only be cured by love.³³

For Evans, and her heroine, her love for her doctor was the transference of the compromised love she felt for her father.

Arabella’s pain brings the attention of the doctor. Freud famously suggested that one of the ways that the unconscious can struggle to the surface is through psychosomatic symptoms and illness. Unconscious desires seek expression; the ego forces them to be blocked and repressed. The

internal conflict leads to neurosis and results in symptoms which simultaneously protect and covertly express unconscious desire.

After Arabella has endured the full battery of tests and investigations, the specialist, Mr Maitland concludes that there is nothing to be done. On hearing this Arabella's mother observes, "It just bears out what I have thought all the time... that it's nothing but nerves."³⁴

Even Dr Flaherty tells Arabella to fight it herself. "Nerves," hysteria was, according to Freud, the illness most directly associated with repressed Oedipal desire. In her book, *Critical Desire: Psychoanalysis and the Literary Subject*, Linda Ruth Williams describes "conversion hysteria." This occurs when a patient "converts" unresolved mental phenomena into bodily symptoms.

With conversion hysteria [...] the body of the hysteric literally 'speaks' with a body language which expresses symbolically something which cannot otherwise be spoken.³⁵

Elaine Showalter in her book, *Hystories* makes the same point,

Throughout history, hysteria has served as a form of expression, a body language for people who otherwise might not be able to speak or even admit what they feel.³⁶

According to Arthur Kleinman in *The Illness Narratives*, where there is illness, there is "unresolved conflict" in the life between what one desires and what is expected, between what one desires and what is available, or perhaps between two conflicting desires.³⁷

The significance of Arabella's cystitis is illuminated by these theories. Whether hysterical or physiological in origin, whether the result of abuse or not, Arabella's body speaks and can be read like a text by both doctors and readers. Arabella's body in its pain calls for the attention of the doctor with whom she is obsessed; his medical instruments enact the sexual encounter she unconsciously desires. Her body speaks the words she cannot articulate.

Paradoxically, however, the "fox" - her metaphor for her pain - can only be defeated by words. At the end of the novel she records how she finished writing her book in a four-hour session "at furious speed." Just as she finishes and tries to stand up, "The fox ripped my stomach." She murmurs to herself, "Oh, you ugly beast, oh, what a brute you are to torture me... this pain is unendurable."³⁸ But in the following lines she says, "But really, in spite of the fact that I could no longer stand upright, I cared very little for the animal; it did not darken my mood."³⁹ The power of the pain, the

creature which has been gnawing her insides, has been negated by her intellectual achievement, has been put to flight by language.

The doctor has offered a cure, but not in the form of medicine or a pill; he has through the passion he awakened and her subsequent pain and humiliation offered her a subject. Her love for him, although unrequited and unconsummated was fertile: her text was its issue. Evan's own *Journal* records her recognition of this:

I was unhappy - what of that? I have conveyed my misery - what of that? Ah a great deal. I have wrought bones, muscles, a beating heart. My book's alive and it was worth it.⁴⁰

Notes

¹ M Evans, *The Wooden Doctor*, Honno, Wales, 2005, p. 9.

² *ibid.*

³ E Grosz, *Volatile Bodies: Toward A Corporal Feminism*, Indiana University Press, Bloomington and Indianapolis, 1994, p. 205.

⁴ J Holmes, *The Search for the Secure Base: Attachment Theory and Psychotherapy*, Routledge, London and New York, 2001, p. 97.

⁵ *ibid.*, p. 100.

⁶ Evans, *The Wooden Doctor*, p. 71.

⁷ *ibid.*

⁸ *ibid.*, p. 72.

⁹ *ibid.*, p. 12.

¹⁰ *ibid.*, p. 74.

¹¹ *ibid.*, p. 80.

¹² *ibid.*, p. 90.

¹³ R Minsky, *Psychoanalysis and Culture: Contemporary States of Mind*, Polity Press, Cambridge, 1998, p. 91.

¹⁴ N Chodorow, *The Reproduction of Mothering: Psychoanalysis and the Sociology of Gender*, University of California Press, Berkeley, Los Angeles and London, 1999, p. 135.

¹⁵ Evans, *The Wooden Doctor*, National Library of Wales, ms 23357B, p. 134.

¹⁶ *ibid.*, p. 136.

¹⁷ *ibid.*, p. 132.

¹⁸ *ibid.*, p. 139.

¹⁹ *ibid.*, p. 181.

²⁰ Evans, *The Wooden Doctor*, 2005, p. 54.

²¹ *ibid.*, pp. 54-55.

- ²² *ibid.*, p. 9.
²³ *ibid.*, p. 12.
²⁴ *ibid.*, p. 80.
²⁵ *ibid.*, p. 92.
²⁶ *ibid.*, p. 108.
²⁷ *ibid.*, p. 114.
²⁸ *ibid.*, p. 118.
²⁹ *ibid.*, p. 118.
³⁰ *ibid.*, p. 120.
³¹ M Evans, *Letters*, National Library of Wales, ms 811, January 24th 1946.
³² Evans, *The Wooden Doctor*, 2005, p. 81.
³³ S Freud, *The Standard Edition of the Complete Psychological Works of Sigmund Freud, Vol. XVI: Introductory Lectures on Psychoanalysis*, Hogarth, London, 1961, p. 441.
³⁴ Evans, *The Wooden Doctor*, 2005, p. 102.
³⁵ LR Williams, *Critical Desire: Psychoanalysis and the Literary Subject*, Edward Arnold, London and New York, 1995, p. 5.
³⁶ E Showalter, *Hystories: Hysterical Epidemics and Modern Culture*, Picador, London and Basingstoke, 1977, p. 7.
³⁷ A Kleinman, *The Illness Narratives: Suffering, Healing and the Human Condition*, Basic Books Inc, USA, 1988, pp. 97-99.
³⁸ Evans, *The Wooden Doctor*, 2005, p. 175.
³⁹ *ibid.*
⁴⁰ M Evans, *Journal*, National Library of Wales, ms 23366D, 1933-4, p. 141.

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Frances Burney and the Empowering Patient Perspective

Maria Vaccarella

Abstract

Frances Burney's account of her 1811 mastectomy in one of her most famous letters is generally regarded as one of the first and finest pathographies. Scholars have extensively investigated her extraordinary ability to control male agency (her husband's and her surgeon's) over her own body and operation through the act of narrating her traumatic experience. Only on few occasions, however, has it been suggested that Burney's novels display a similar empowering practice. This study examines to what extent the patient Frances Burney builds upon her novelistic experiments in female self-expression to produce an accurate pathography. On the one hand, the representation of her breast surgery was meant to reassure her relatives and friends of her health status; on the other hand, it sanctioned her challenge to a male-dominated medical culture. In this analysis, *Cecilia, or the Memoirs of an Heiress* (1782) - one of her novels written before 1811 - constitutes a pivotal moment in Burney's career. In this text, she originally explores the social significance of a woman's illness, particularly her twofold deprivation of self-expression as woman patient. Yet, the heroine is given the possibility of reconfiguring her mental illness as a moment of self-knowledge and of gradually achieving the firm control of her discourse, which is effectively conveyed through Burney's original integration of dramatic and novelistic forms. In my opinion, Burney's narrative technique yields insight into a particularly socio-historical marginalized patient condition. More significantly, she sets an example of a convincing, innovative representation of women's relationship to their body.

Key Words: Frances Burney, mastectomy, history of medicine, patient empowerment, doctor-patient relationship, *Cecilia*.

1. Introduction

Best known as a novelist experimenting in the field of modern realism, Frances Burney was also a formidable letter and journal writer, reporter of her own life and of the social life of late eighteenth-century England.¹ In all of her writings, she constantly focuses on physicality, and particularly on the suffering body, not only *per se*, but also as a projection of mental distress. In her journals and letters, she describes the wounded bodies of soldiers at Waterloo and later her husband's dying body. She reports on King George's ravings, too, which she witnessed first hand as the Second

Keeper of the Queen's Robes at Court, a shocking experience that brought her on the verge of a nervous breakdown. A smallpox epidemic opens her third novel *Camilla* (1796), while in the plots of *Cecilia* (1782) and *The Wanderer* (1814), madness, both suffered and enacted, is a pivotal moment communicating loss and remorse, inner fragility and social oppression. As these few examples make clear, Burney's approach to illness is not one dimensional, but rather manifold.

Her extraordinary ability to investigate such a complex topic is best displayed in her 1812 letter on her own mastectomy, generally regarded as one of the first and finest pathographies. My study asks to what extent the patient Frances Burney builds upon her novelistic experiments in female self-expression to produce this document. Apparently a confidential letter to her sister, it is much more than a challenge to a male-dominated medical culture. It is a convincing, innovative representation of women's perception of their bodies, conveyed through an original narrative technique, and it yields insight into a particular moment of the social history of the doctor-patient relationship.

2. Performing a Mastectomy: the Patient as Director

Frances Burney underwent a mastectomy of her right breast in 1811 in Paris, because of a supposedly malignant carcinoma.² Not only did such abnormal growth invade the visible realm of her femininity, it also caused her an unbearable pain in her right arm, which prevented her from writing even a letter.³ She was thus deprived of one of her greatest pleasures, and ultimately of her identity as a writer. Although at first she challenged the doctors' authority to the point of refusing to be examined, it is unquestionable that the fear of a permanent inability to communicate in writing greatly contributed to Burney's compliance with the "repugnant" mastectomy.⁴ It is worth remembering here that no anaesthetic was in use at the time, ether and chloroform being introduced only decades later.

In order to prevent the spreading of inaccurate accounts and rumours across the Channel, she wrote a thorough description of her operation over the following months, in the form of a letter to her eldest sister Esther, who was entitled to unfold its contents at her discretion. Burney's mastectomy letter is thus a multifaceted narrative - partly private correspondence, partly public address - in which medico-surgical data and intimate feelings conflate.⁵ Moreover, the letter contains two annexes: her husband's own brief account of her operation and a medical report in French, regarding her surgery and postoperative condition, with dietary recommendations and medical prescriptions. Such complex structure testifies the originality and significance of this early pathography.

Consistent with her aim of assuring her family of her perfect recovery, Burney devised a heartfelt, yet medically precise narration. Literary

critic Julia Epstein maintains that, in the very act of relating her surgical experience, Burney “presents herself as both physician and patient.”⁶ Yet, I argue that this explanation does not take into due account Burney’s intention to direct all the “performance” of her mastectomy.⁷ During all the phases of her operation, she refuses to be a passive witness and reclaims an active role in the management of her own body.

Being a woman patient at the beginning of the nineteenth century puts educated Burney in a particularly uneasy position, whose powerlessness she perceives with horror. For example, she is utterly distressed after one of her first medical examinations, when Dr Dubois tells her nothing about the diagnosis and just tries to calm her down, preferring to discuss the situation with her husband in private.⁸ Burney is by no means an “ignorant patient,”⁹ yet her doctors - and to a lesser extent, her husband as well - deliberately disregard her intellectual involvement and simply objectify her diseased body.

It is noteworthy that she uses the terminology of criminal sentencing to describe her feelings towards the impending operation: she feels “condemned,”¹⁰ the operation is “doom,”¹¹ a “coming blow,”¹² a “sentence”¹³ or an “execution.”¹⁴ Such semantic field helps her convey her role of passive victim in the hands of doctor-executioners. In Epstein’s words, it is “a play of professional authority against female autonomy [...]”¹⁵ Burney cannot rewrite the gendered plot on which this play lies, yet she tries to participate actively in its staging. During her operation, she struggles to reclaim and assert an empowered patient perspective.

An original blend of realism and sentimentality had previously characterized her fictional production, in which physical and mental pain originates from social strictures.¹⁶ Apart from this thematic similarity, Burney’s mastectomy letter and her previous fictional works share a dominant dramatic rhythm and tone, a tangible trace of the author’s frustrated dream of becoming a dramatist. From a stylistic point of view, Burney’s mastectomy letter may be profitably divided into two sections: a first narrative, or memoir, of the times preceding her operation, followed by a more dramatic description of the same, of which Burney herself is the director.¹⁷

Being given only a two hours’ notice of her mastectomy and intending to spare her husband General d’Arblay any concern, she writes:

I affected to be long reading the Note, to gain time for forming some plan, & such was my terror of involving M. d’A. in the unavailing wretchedness of witnessing what I must go through, that it conquered every other, & gave me the force to act as if I were *directing* some third person.¹⁸
[italics mine]

With the aid of her son and one of General d'Arblay's superiors, she enacts a mock urgent business to keep her husband out of the "operating theatre,"¹⁹ whose arrangement she supervises, as well. At last, to her astonishment, Burney is confronted with a pool of seven doctors - among them, hated Dr Dubois and compassionate Dr Larrey - and asked to follow a humiliating procedure: lying on a bed instead of sitting in an armchair, sending her maid and nurses out of the room and disrobing.²⁰ Even here, Burney regains some control over the situation, by imposing the presence of a nurse and by challenging paternalistic Dr Dubois with the words: "Can *You* [...] feel, for an operation that, to *You*, must seem so trivial?"²¹ Then, once she is on the bed, with a very theatrical gesture, Dr Dubois spreads a handkerchief on her face, a curtain coming down to hide from her sight the upcoming event, an obscene ("off-scene") matter. Burney reports that through the handkerchief she could see the "glitter of polished Steel"²² and the doctors communicating by signs that her whole breast was infected and had to be amputated - "the fatal finger describing the Cross -& the circle."²³

Here we find her bravest attempt at participating actively in her own operation. After Dr Larrey's melancholic question "Qui me tiendra ce sein?" ["Who will hold this breast for me?"; translation mine] remains unanswered, Burney awakens from a "passively submissive state"²⁴ - as she defines it - and shows courage and determination:

Excited by this idea [the amputation of the whole breast], I started up, threw off my veil, &, in answer to the demand 'Qui me tiendra ce sein,?' cried 'C'est moi, Monsieur!' ["I will, Sir!"; translation mine] & I held My hand under it, & explained the nature of my sufferings, which all sprang from one point, though they darted into every part. I was heard attentively, but, in utter silence, & M. Dubois then replaced me as before, &, as before, spread my veil over my face. How vain, alas, my representation!²⁵

She hints at an alternative plot for her operation. Nonetheless, her doctors pursue their own performance and proceed to remove her whole breast tissue down to the breastbone. From this moment on, Burney is denied any directing possibility, and pain - the unbearable pain of someone who feels the knife scraping her breastbone²⁶ - is her only means of expression and representation.

This, however, must not be perceived as the end of her interaction with the doctors. Pain itself is reconfigured as a shared experience between patient and doctors, as she recollects:

However, I bore it with all the courage I could exert, & never moved, nor stopt them, nor resisted, nor remonstrated, nor spoke - except once or twice, during the dressings, to say 'Ah Messieurs! Que je vous plains! -' ["Oh Sirs! How I sympathize with you!"; translation mine] for indeed I was sensible to the feeling concern with which they all saw what I endured, though my speech was principally - very principally meant for Dr. Larry [sic].²⁷

At the end of her mastectomy letter, Dr Larrey is explicitly described as a model of "humane physician," just like Dr Lyster in her novel *Cecilia*. Though he is the principal surgeon in the operation, inflicting her the most excruciating pain with his own hands, Burney keeps a tender memory of a doctor, whose gaze, far from being exclusively pathologizing, shows sincere concern: "[...] & then I saw my good Dr Larry [sic], pale nearly as myself, his face streaked with blood, & its expression depicting grief, apprehension, & almost horror."²⁸

4. The Voice of the Patient: Performing Female Self-Expression

Among her novels written before 1811 - the year of her operation - *Cecilia*, or *Memoirs of an Heiress* contains fundamental reflections on the condition of the woman patient and the doctor-patient relationship at the end of the eighteenth century. Particularly in this novel, Burney refines that "melting pot of dramatic and novelistic rhetoric,"²⁹ which served so effectively the purpose of her mastectomy letter.

Burney wrote *Cecilia* right after *The Witlings*, a comedy, whose staging had been strongly censured in her family circle. Musicologist Dr Burney, her father, thought a career as a novelist was more appropriate for a woman and her fatherly literary mentor Samuel Crisp thought she lacked the talents of an authentic dramatist. Frances Burney's biographer Margaret Ann Doody claims that:

Cecilia [incorporates] at a very deep level the author's reaction not only to the suppression of *The Witlings* but to what that suppression means. It is a much more daring novel than *Evelina* [...]. *Cecilia* has no artless ingénue narrator [...]. Female insight is raised to an authorial universal principle, not deprecatingly put into the words of a charming teenager.³⁰

Thus, *Cecilia* must not be understood as an undemanding rewriting. The discreet editor of *Evelina*'s letters becomes here a convincing omniscient narrator. Her dramatic experiment helps Burney achieve a satisfying balance

between fictional diegesis and dramatic mimesis: the narrator's interventions are significantly reduced in crucial scenes, when characters are allowed a full theatrical expression through dialogue.³¹ If Burney's first novel *Evelina* reminds of a comedy, *Cecilia* is better understood as the novel of the "widespread spectacularity."³²

This novel portrays a developing consumerist society, in which every action conforms to an all-pervading social theatricality, including death, which takes the form of a spectacular suicide in Vauxhall Gardens. The pressure of such a constraining society is well represented in the book, where many of the main characters - and particularly the two protagonists Cecilia and Mortimer - suffer from mental distress at some point. Cecilia's agency is further restrained by her uncle's will, which puts her in the care of three male guardians until she comes of age and inherits her estate - which she will nonetheless lose, if her husband does not agree to take her surname.³³

Her madness exemplifies her ultimate rebellion towards a patriarchal society, which prevents her from managing her wealth and from marrying her beloved Mortimer Delvile, who cannot dispose of his aristocratic surname. As Julia Epstein remarks: "[...] there is no sane response to the circumstances she finds herself in. [...] Cecilia's madness is distilled from the frustration of unbearable powerlessness, the frustration of always having to enlist to another's authority."³⁴ She finds in a pathological condition the possibility of reclaiming the self-expression she had been hitherto denied:

And thus, though naturally and commonly of a silent and quiet disposition, she was now not a moment still, for the irregular starts of a terrified and disordered imagination, were changed into the constant ravings of morbid delirium.³⁵

Her verbal delirium allows her to come to terms with her repressed feelings. Burney explores the social significance of a woman's illness, and Cecilia is given the possibility of reconfiguring her disease as a moment of self-knowledge and of gradually achieving the firm control of her discourse. Consequently, her serious illness does not precede a tragic death; on the contrary, it fosters a readjustment of the novel's tensions towards a negotiated happy ending.³⁶

A central figure in these final developments of the novel's plot is Dr Lyster, "a petty Doctor out of the country,"³⁷ as he defines himself. Nonetheless, unlike his London colleagues, he has an enlightened understanding of the indissoluble connection between human mind and body. He explains: "[...] in the course of my long practice, I have found it impossible to study the human frame, without a little studying the human

mind [...].”³⁸ Dr Lyster recognizes Mortimer’s bad cold as a psychosomatic symptom of his depression, just like he realizes that Cecilia’s health will never be completely restored, if the Delviles do not accept her as Mortimer’s lawful wife. At the end of the novel, Dr Lyster - “[t]hat humane physician, not more alarmed at the danger of Cecilia, than grieved at the situation of Delvile”³⁹ - becomes a sort of *deus ex machina* from a classical Greek comedy, and personally negotiates the reconciliation between Mortimer and his father. Moreover, he is charged with the task of drawing a moral out of Cecilia’s story: he identifies her “unfortunate business”⁴⁰ as “the result of PRIDE and PREJUDICE”⁴¹ - a felicitous phrase that will become the title of Jane Austen’s famous novel some years later.

5. Final Remarks

In dismissing *The Wiltings*, Samuel Crisp had compared it to Molière’s *Femmes Savantes* (1672), in order to underline Frances Burney’s “immense inferiority.”⁴² Significantly, in *Cecilia*, Burney carries on Molière’s criticism of dogmatic and repressive doctors, with no less talent than the celebrated French playwright’s.⁴³ Her criticism is definitely constructive, since she undertakes to create a model of the “humane physician” and ventures to explore the possibilities that a less paternalistic medical practice opens up for a woman patient.

While drawing a comparison between Burney’s mastectomy letter and her novels, Epstein comments:

The way Burney presents the embattled female body in this familiar letter maps the iconography as well of her embattled fictional heroines. That mapping itself - the careful inscription of a trapped female (body) in the world - empowers the female voice in all Burney’s writings.⁴⁴

This empowered female voice, which expresses the repressed, and even pathologized, female body, has a distinctive dramatic tone. In *The Wanderer* (1814), the novel Burney wrote after her mastectomy, the presence of drama is even more pervasive, since the protagonist Juliet struggles to be a “public performer.” After having being herself at the centre of the disquieting “operating theatre,” Burney is even more convinced that the ostentatious physicality, typical of drama, may be reconfigured as a moment of self-awareness and self-expression for a woman.⁴⁵

Notes

Rosy Colombo first encouraged me to read and work on Frances Burney's mastectomy letter. Throughout my research, she offered me continuous and generous support and made valuable suggestions about my drafts. To her I owe my thanks.

¹ Burney's biographer Margaret Ann Doody writes: "The publication of her Diary and Letters begun in 1843 (only three years after her death) was intended by the editor, her niece Charlotte Barrett, as an admiring tribute." (MA Doody, *Frances Burney. The Life in the Works*, Cambridge University Press, Cambridge, 1988, p. 1)

² "It is impossible to speculate at this remove, but modern physicians have questioned the validity of the diagnosis made of Burney's illness. Her twenty-nine year post-operative survival – she lived to the age of 87 – suggests that the amputated breast had probably not contained a malignant tumor in the first place." (J Epstein, 'Writing the Unspeakable: Fanny Burney's Mastectomy and the Fictive Body', *Representations*, vol. 16, Autumn 1986, p. 142. On this point, see also J Hemlow et al. (eds), *The Journals and Letters of Fanny Burney (Madame D'Arblay)*, Clarendon Press, Oxford, 1972-1984, 12 vols., vol. VI, p. 607n (hereafter *JL*).

³ *ibid.*, pp. 607-609.

⁴ *ibid.*, p. 600. Epstein maintains that "[h]olding and using a pen remained painful and difficult for her until at least 1815." (Epstein, *op. cit.*, p. 55).

⁵ On this point, Epstein writes: "She is also always conscious of audience, aware that as she writes her experience moves from a private to a public sphere. She spent years editing, revising, and collating both her father's and her own manuscripts, mindful of publication possibilities and dangers." (J Epstein, *The Iron Pen. Frances Burney and the Politics of Women's Writing*, Bristol Classical Press, Bristol, 1989, p. 51)

⁶ Epstein, *Writing the Unspeakable*, *cit.*, p. 141.

⁷ This is a possible interpretation Epstein herself only slightly hints at when she writes: "[...] it is a text that articulates medical reality by overlaying it with the imaginative and dramatic possibilities intrinsic to the aptly named operating theater, as it is a text that carves a writer's self-representation out of the body's encounter with the knife" (*ibid.*, p. 162). John Wiltshire, too, often uses theatrical terms to analyse Burney's letter (e.g. "the drama of the sick-room," J Wiltshire, 'Early Nineteenth-Century Pathography: the Case of Frances Burney', *Literature and History*, Autumn 1993, p. 13), without studying any implication in depth.

⁸ Antoine Dubois (1756-1837) was a leading surgeon and obstetrician, in service of the Empress herself.

⁹ Epstein, *Writing the Unspeakable*, *cit.*, p. 142.

¹⁰ *JL*, p. 603.

¹¹ *ibid.*, p. 604.

¹² *ibid.*, p. 605.

¹³ *ibid.*, p. 606.

¹⁴ *ibid.*

¹⁵ Epstein, *Writing the Unspeakable*, cit., p. 146.

¹⁶ *ibid.*, p. 131.

¹⁷ Epstein thus describes the text structure: “As soon as the alternative of surgery has become a certainty, a curious apparent shift occurs in the narrative. From repugnance, concern for herself, and anxiety about the prognosis, Burney turns all her energy to her family in order to remove and defuse her own fears and to establish her autonomy in an ordeal that she knew ultimately she must endure alone [...]” (*ibid.*, p. 144).

¹⁸ *JL*, p. 608.

¹⁹ *ibid.*

²⁰ Dominique-Jean Larrey (1766-1842) was a pioneering army surgeon, operating on the main battlefields during Napoleon’s wars.

²¹ *ibid.*, p. 611.

²² *ibid.*

²³ *ibid.*, p. 612.

²⁴ *ibid.*, p. 611.

²⁵ *ibid.*, pp. 611-612.

²⁶ *ibid.*, p. 612.

²⁷ *ibid.*, p. 613.

²⁸ *ibid.*, p. 614.

²⁹ RM Colombo, ‘Intorno a Shakespeare: Frances Burney, Lear e il conio della modernità’, *Memoria di Shakespeare*, 1, 2000, p. 173 [translation: MV].

³⁰ Doody, op. cit., p. 101.

³¹ F Saggini, *La messinscena dell’identità: teatro e teatralità nel romanzo inglese del Settecento*, Sette Città, Viterbo, 2003, p. 185 [translation: MV].

³² *ibid.*, p. 164 [translation: MV].

³³ Doody, op. cit., p. 119.

³⁴ Epstein, *The Iron Pen*, cit., pp. 167-168.

³⁵ F Burney, *Cecilia*, Oxford University Press, Oxford, 1988, p. 901.

³⁶ In the end, Cecilia is admitted to the Delvile family, but she has to take her husband’s surname and consequently to renounce her inheritance. On Burney’s heroines’ social abidance, Juliet McMaster writes: “[Burney] won’t make her heroines feminists, or overtly be one herself. Instead she creates heroines who suffer under the social sanctions that maintain women’s subordination, and are conscious of them as disabilities; but like their author they abide by them” (J McMaster, ‘The Silent Angel: Impediments to Female

Expression in Frances Burney's Novels', *Studies in the Novel*, vol. 21(3), Fall 1989, p. 237).

³⁷ *ibid.*, p. 910.

³⁸ *ibid.*, p. 932.

³⁹ *ibid.*, p. 911.

⁴⁰ *ibid.*, p. 930.

⁴¹ *ibid.*

⁴² LE Troide (ed), *The Early Journals and Letters of Fanny Burney*, Clarendon Press, Oxford, 1990-1994, vol. III, p. 349.

⁴³ D Gambelli, 'Introduzione', in Molière, *Don Giovanni*, transl. D Gambelli and D Fo, Marsilio, Venezia, 1997, p. 30.

⁴⁴ Epstein, *The Iron Pen*, cit., p. 55.

⁴⁵ Colombo, op. cit., p. 173.

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PART IV

Treatments: Mind/Body Dualisms

Moravagine:
The Materialization of the Body in Literary Works

Marina Guiomar

Abstract

The work focuses on Blaise Cendrars' *Moravagine* (1925). *Moravagine* is the Austrian patient of the Waldensee Sanatorium, whose escape from the mental institution is made possible with the intervention of the character's psychoanalyst, Dr. Raymond La Science.

The *rapport* patient/doctor takes place in 1900, the year of the publication of Freud's *Traumdeutung*. This is not a fortuitous occurrence in the narrative, but a rhetorical device that, by means of metonymy, allows for an immersion in the sphere of psychoanalysis. I defend the thesis that *Moravagine*'s compulsion to objectify and materialize people, feelings, moral conducts, and everyday deeds is an attempt by the author Blaise Cendrars to bring together in a literary work both the body and the psyche. Materiality proper, or the veritable presence of the body in literary works, rather than meaning, is thought to have no translation in the written text. Or has it? My claim is that, by means of a precise depiction of the physicality of the patient, *Moravagine*, and of the patient's machine-like, palpable, as it were, intellect, the crevice between the body, *stricto sensu*, and the mind is lessened, in the text by Cendrars, an intention which is not so different from Freud's, in 1900.

Key Words: Literature, psychoanalysis, presence, body, meaning.

Moravagine is Blaise Cendrars' second novel, published in 1926, one year after the successful publishing of *Gold* (*Gold* is the fictionalized biography of John Sutter, the misfortunate land owner whose estate in the Sacramento Bay area in northern California was piled and destroyed as a consequence of the 1850s' gold rush). *Moravagine*, who lends his name to the title of the book, is patient number 1731 at Waldensee Sanatorium, a mental institution near Berne, Switzerland. He had been institutionalized for over sixteen years, after the brutal killing of the woman he was in love with, Rita, when Dr. Raymond La Science, the stereotype of the young, brilliant, newly-graduated psychologist, becomes his analyst, in 1900. A strong relationship is built up from the regular visits of La Science to *Moravagine*'s cell, and the reader soon realizes that the roles in this patient/doctor relationship are somewhat inverted, for it is *Moravagine* who exerts a veiled authority over Raymond La Science. After a few months' treatment, the

psychoanalyst, captivated by the patient's biography and also by the patient's machine-like drive towards action, movement, and death, arranges for Moravagine's escape and follows him, leaving thus behind a promising career in psychoanalysis and engaging in a journey of murder and ceaseless revolution across Berlin, St. Petersburg, America, Mars, which will last for almost twenty years.

The encounter between the patient Moravagine and the doctor takes place in 1900, the year of the publishing of Freud's *The Interpretation of Dreams*. This is not a fortuitous occurrence in the narrative, but rather a rhetorical device which reasserts the dominion of psychoanalysis in the diegesis, both at the level of the construction of the characters and the plot, and at the deeper level of speech. It is in fact in the plane of discourse that I wish to explore the presence of such important references to psychoanalysis like the one just cited. The relevance of the Freudian theories concerning dreams, memory, and the unconscious is undeniable for many reasons, one of them being the fact that it was one of the first attempts to coalesce the body and the mind, matter and the transient, from a scientific standpoint. This was accomplished by mapping on the brain the location of the elements that compose the psychic apparatus, a task to which Freud resists more than often, but mostly by endorsing the idea that mental pathologies, such as neuroses, assume visibility in the human body, in the shape of symptoms, for example.

The intertwining of intangibility and materiality, as it were, can also be read in the analogies that Freud brings forth between the mental apparatus and the mechanics of other energetic models existing in the empirical "reality," from optical devices such as the microscope or the photographic camera,¹ to writing devices, such as the "mystic writing-pad."² Regardless of the machine chosen in the establishment of the analogy, what matters is that its functioning depends on the inscription of a material (light, ink, chalk) onto a surface (celluloid, paper or wax). Psychoanalytic theory makes therefore frequent use of the metaphor of the photographic negative and of the indexical properties of the celluloid. In "Notes on the concept of the unconscious in psychoanalysis," Freud compares the *rapport* conscious/unconscious to the photographic process as follows:

The first stage of the photograph is the 'negative;' every photographic picture has to pass through the 'negative process,' and some of these negatives which have held good in examination are admitted to the 'positive process' ending in the picture.³

One learns from the reading of *Moravagine*, but also from the reading of both his journals and fictional works of the 1920s, that Blaise Cendrars was extremely interested in the mechanics of the mental apparatus,

as depicted by Freud, and in applying them to literature and film. The recurring references to the energetic model of the psychic apparatus in works such as *A night in the forest*⁴ or *Dan Yack*⁵ account for an understanding of psychoanalysis that goes beyond literality and rather signifies the will to approach the matter from the perspective of someone who construes the machinic assemblage of elements that compose the human psyche as a metaphor for writing or for cinema making.

Cendrars is known for his literary work but one does not always realize how important the cinema was for the author. In 1917, Cendrars worked together with Abel Gance in the making of *J'Accuse*, in which the writer played a small cameo part, that of a WWI victim (Cendrars had himself lost the right arm in the War, in 1915, where he served as a lieutenant for the Foreign Legion). Later on, he was assistant producer for Gance's *La Roue* and he tried to direct, in the early 1920s, his own feature film, entitled *The Dark Venus*, a project for the Roman production company Rinascimento which would never see the light of day. He wrote screenplays and dialogues for directors as crucial to the history of the medium as Fernand Léger, Man Ray or Marcel Duchamp. Apart from these factual approaches to film production, the cinema is also present in Cendrars' writings through constantly referring to major directors such as Chaplin and Griffith; through the actual intertwining of the literary prose with formal mechanisms known for being specific to the realm of the cinema proper, such as montage, superimposition, simultaneity;⁶ and, finally, through the detailing of film paraphernalia (reels, cameras, projectors, screens, sound apparatuses). When reading Cendrars, then, one is invited to experience an immersion into what can be called "written cinema,"⁷ for the allusions to film are so many and so various, that it becomes almost impossible to discern the written page from a movie screen.

On the white tiles of the wards the bathtubs, ergometers and immense percolators appeared as if on a screen, with the same terrible and savage grandeur that objects have in films: a grandeur of intensity, which is also the scale on which we measure Indian masks and primitive fetishes, expressions of latent activity - the egg! - the frightening sum of permanent energy contained in every inanimate object.⁸

Or to discern the written page from a movie theatre.

The employees of the place were styled to match. The chemist pulled on his gloves with reverence; in his gutta-percha cabin the electrician started up his motor; the

urinalysis proceeded like a ritual; thermometers were shaken, the mercury dropped to zero. Simultaneously throughout the establishment the day shift moved in to replace the night shift. [...] The door of the poison cupboard received its key. A chair appeared. A rocking-chair. And even some sort of musical instrument unfolded slowly out of nowhere. Everything happened silently, according to a pre-established and deliberate rhythm, a strict and ruthless discipline, a Prussian exactitude which ruled everything down to the most minute details, leaving nothing whatever to chance.⁹

But why, then, does Cendrars seem so concerned with inscribing the cinema in the pages he writes? In so doing, Cendrars is clearly paying homage to the medium that so much fascinated him while, at the same time, he is following the modernist aesthetics of the period, which championed, as we all know, velocity, synthesis, technical precision, movement, and rhythm. But I believe there might be yet another motivation for doing this.

The reason for registering upon the screen-like white page numerous cinematic references and cinematic techniques might have to do, I understand, with an urgency in bringing together under the same text both the body and the intellect. In his literary works, especially *Moravagine*, Blaise Cendrars seems to be constantly aiming at doing without the mediation that emerges as soon as bodies are verbalized. In other words, Cendrars wishes to lessen the crevice between the empirical world and speech, utterance as it were, by means of an attempt at crystallizing the materiality of the body on the white page. One way this is made possible is by bringing the analogy between the cinema and the mental apparatus to the fore. If we take into consideration the fact that both filmmaking and the energetic model of the mind work the same way, that is, through an indexical process, then we succeed in understanding to what extent the two machinic practices contribute for the materialization of the bodily phenomena on the written page.

One could claim that the existing breach between the external world and the textual resides in the process of writing. But the interval between thing and discourse is not accentuated by the interference of the word itself. Quite the contrary, a word is a graphic sign and this specificity translates in the fact that it is matter as any given object or body. When they are engraved onto a text, words demand for space in it; the traces they leave on the sheet of paper assume a material localization, a specific geography; they are mapped out; they become road signs. But they also become hieroglyphs and need thus decoding. It is rather in the decoding of the hieroglyph, in the constant process of meaning-attribution, that words lose their materiality to become

fleeting, as fleeting as the *Mem.-elements* retained in the *Per.-system*, “which has no capacity to retain changes.”¹⁰ The transience I am referring to is obviously related to principles of arbitrariness and commutation that preside in the process of meaning-attribution.¹¹

Let us now see how Blaise Cendrars proposes to capture onto his pages the transience that typifies the word after meaning-attribution. In the first pages of the novel, *Moravagine* is described as follows.

He stands planted there, his legs apart, swaying a little back and forth as if he were slightly dizzy. He is a dark little man, skinny, knotted and desiccated as a vine-stock, seemingly burned by the flame that flickers in the depths of his great eyes. His forehead is low. His eye-sockets deep. The circles beneath his eyes almost touch the creases about his mouth. His right leg, the knee afflicted with ankylosis, forms a right angle, and he limps terribly. His hands dangle at the ends of arms as long as a monkey's.¹²

The narrator, Dr. La Science, “at once felt an irresistible liking for this tragic and singular little effigy who dragged himself along within his iridescent voice like a caterpillar in its own skin.”¹³ Raymond La Science compares *Moravagine* to an effigy, and he must indeed look like a statue to the eyes of the narrator, for he is immobile, “sitting in a corner,” his grandeur confined to the four walls of his cell.

I consider statues to be paradigmatic of the paradox which traverses literary creation. Statues are, on the one hand, empirically tangible objects, bodies as it were, but they also are, on the other hand, the representation of something that no longer exists, of something transitory. Statues hint, therefore, at the impossibility of apprehending both touch and the transient. This seems to be the case in literature, for, after signification and meaning-attribution hardly can the page and the written word hold the corporality of the empirical reality within its boundaries.

The presence of the effigy, or the statue, if you like, in *Moravagine* allows for a reflection upon the possibility of lessening the creases between the transitory and the concrete. *Moravagine*, patient 1731, with his petrified knee, and his petrified psyche, set for killing alone, represents the synthesis between body, text, and mind. In presenting us *Moravagine* as a bigger-than-life creature (another reading of *statuesque*), Blaise Cendrars suggests that the body needs to be quiescent, still, as if a statue or a photographed image imprinted on the negative, if it is to be materialized at a textual level.

Materialization demands a loss of meaning. Signification deters, as said before, the body-mind-text synthesis and its annulment might be the

solution for this query. As we all know, this is an impossible task, though. Meaning and signification are so important in our culture that its end is not believed to be within reach, even though the question has been frequently posed by many influent thinkers of the last decades.¹⁴

In *Moravagine*, the case is not that meaning is absent from the text, and from the words that compose it; rather, signification has been withdrawn from the bodies themselves, a process prior to speech.

At the age of eighteen, a few months before making his first victim, Rita, Moravagine develops “a violent passion for objects, for inanimate things.” This is how he describes his newly-found interest to his psychoanalyst:

By objects I don't mean all those useful articles, the rich furnishings and *objets-d'art* with which the palace was crammed and which, by some erethism of mind or sentiment, evoke, suggest or recall an ancient civilization, an age long past, a faded family or historic scene, charming and intriguing one with their shapes, their baroque lines, their anachronistic refinement, with all the things that situate them, date them, giving them their names and revealing in a curious way the signature of the fashion that imagined them; no, I fell in love with ugly objects almost without workmanship, and very often with raw matter, primary matter itself. I surrounded myself with the most heteroclitic articles. A biscuit-tin, an ostrich-egg, a sewing machine, a piece of quartz, a lead ingot, a stovepipe. I spent my days turning them this way and that, touching them, smelling them. I rearranged them a thousand times a day.¹⁵

The objects which enclose any trace of meaning (“the rich furnishings,” “les objets-d'art”) are rejected by Moravagine who prefers the rawness, the grain, the irregularity of primary matter. Things and bodies are thus emptied of any signification in the novel. They become as hollow as the female bodies killed by Moravagine, and as stationary as the character's grandiose figure. To a greater extent, existence itself is also seen as being “idiotic, imbecile and vain, without ultimate purpose. And life is futile.”¹⁶ The novel can be perceived, ultimately, as a depiction of a world upside down. The inversion occurs at the level of speech (in the annulment of meaning in the realm of experience itself), and at a moral level (in which existence, death, love become emptied categories); but a first inversion suggested itself earlier in the narrative. I mean the reversal of roles in the relationship doctor/patient and the suspicion that

health is, after all, [...] only the sad mimic of some illness which has grown unfashionable, ridiculous and static. [...] A commonplace, a physiological cliché, a dead thing. And it may be that health is death itself.¹⁷

Notes

¹ S Freud, *The Interpretation of Dreams*, in *The Complete Psychological Works of Sigmund Freud*, James Strachey (ed.), Hogarth Press, Toronto, 1973, vol. V, p. 536.

² S Freud, 'A Note upon the "Mystic Writing-pad"', in *The Complete Psychological Works of Sigmund Freud*, James Strachey (ed.), Hogarth Press, Toronto, 1973, vol. XIX, pp. 225-232.

³ S Freud, 'Notes on the Concept of the Unconscious in Psychoanalysis', in *The Complete Psychological Works of Sigmund Freud*, James Strachey (ed.), Hogarth Press, Toronto, 1973, vol. XII, p. 264.

⁴ "There's no reason today why we cannot unravel the complex skeins of a human character on the screen, in the way slow motion shows us the germination, burgeoning, budding, blooming, and death of plants. [...] why not capture the life of the mind in action, the chemical reactions of the brain, the silver bath of associated images, the over- or underexposure to an idée-force, and the marvellous surfacing of that developing agent, the unconscious." B Cendrars, *A Night in the Forest*, University of Missouri Press, Columbia, 1985, p. 35.

⁵ "He was the victim of a psychic phenomenon to which the most cultivated as well as the crudest of creatures [...] quite commonly succumbs during the long polar night. [...] Suddenly [...] you are distracted by an image of some kind which rises in your consciousness and imposes itself on you with an intensity, an appearance of reality and a minuteness of detail which are almost painful. [...] This kind of double vision lasts only a few seconds and you soon regain contact with the reality around you. But it can easily cast a shadow over a mind inclined to melancholy." B Cendrars, *Dan Yack*, Peter Owen, London, 2002, p. 45.

⁶ For examples of accelerated montage, simultaneity and juxtaposition cf. *Napoléon* (Abel Gance, 1927), in which the French director explores the potentialities of the film apparatus, namely the frame and the filmstrip, by means of what the author himself calls "simultaneous horizontal montage." By means of cinematic techniques such as superimposition, polyvision, and triple screen, Gance conveys the idea of movement which is inherent to the aesthetic principles of modernism, along with repetition, simultaneism, and fragmentation. The movement here implied is not only the movement of the camera, which Gance released from the tripod, hence from rigidity, and from

the technician who carries it, thus from a strictly human POV, but is mainly the movement and simultaneity that derives from superimposing up to sixteen times the same frame, from dividing the screen up into nine frames, and from collating three contiguous frames, thus broadening, in the frame, the scope of a landscape or of a battlefield. The cinema of Abel Gance, and for that matter, the cinema of the French Impressionist school, is utterly interested in the “quantity of movement” and in the film’s “metrical relations” both within the shot and within the continuum of the film. It is a cinema concerned with “algebra,” as Gance puts it, with calculating and measuring rhythm, interstices, angles, tonalities of light, and all the variants that make up a film text. It is a cinema-machine and, in that sense, a cinema which emulates the machinic model of the human psyche.

⁷ For a definition of “written cinema” cf. P Levi’s ‘Doctor Hypnison and the Case of Written Cinema’, *October*, vol. 116, Spring 2006, pp. 101-118. According to Levi, “written cinema” is “a film scenario never intended to be made into an actual film.” It occupies a space “somewhere between literature and cinema: [it is] a generic hybrid,” “neither a ‘rounded,’ self-enclosed literary work, nor a film scenario proper (in the sense of representing a discrete stage in the process of filmmaking),” p. 101.

⁸ B Cendrars, *Moravagine*, New York Review Books, New York, 2004, pp. 25 and 26.

⁹ *ibid.*, p. 26.

¹⁰ Freud, *The Interpretation of Dreams*, p. 539.

¹¹ “The general concept meant by the word is enriched by any given perception of a thing, so that what emerges is a new, more specific word formation which does more justice to the particularity of that act of perception. However certainly speaking implies using pre-established words with general meanings, at the same time, a constant process of concept formation is going on, by means of which the life of a language develops.” HG Gadamer, *Truth and Method*, Continuum, London, 2006, pp. 427, 428.

¹² Cendrars, *Moravagine*, p. 27.

¹³ *ibid.*, p. 27.

¹⁴ For a thorough account of the numerous reflections that have been taking place both in the American and in the European academia, cf. HU Gumbrecht’s *The Production of Presence: What Meaning Cannot Convey*, Stanford University Press, Palo Alto, 2004.

¹⁵ Cendrars, *Moravagine*, p. 41.

¹⁶ *ibid.*, p. 69.

¹⁷ *ibid.*, p. 17.

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The “Other” Pain: Wittgenstein Visiting the Patient

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Abstract

In this paper the patient is treated as the “Other,” both in terms of his/her alienation from the healthy majority and of being regarded as the second pole in the binary pair of: doctor /healer - patient /sufferer.

This otherness, the extent to which it constitutes a distinctive element of one’s identity and how this identity is being constructed through narration and narratives (according to Paul Ricoeur and Clifford Geertz) along with the role of the body in self-perception are issues critical in a philosophical approach of the patient.

Pain is a crucial criterion in the identification and consequent categorization of the patient as such. Ludwig Wittgenstein’s late philosophy, as developed in *The Blue and Brown Books* and in the *Philosophical Investigations*, deals with the philosophical aspects of pain in Self and Other, its perception and its immediate connection with language and the social context.

Other aspects of Wittgenstein’s late philosophy such as the notions of language games, rule-formation, forms of life and theory of meaning, can prove valuable tools in examining the state of the patient, her/his feelings, fears, pre-occupations while experiencing the instability of the “between,” and the danger, hovering, like an acrobat, over boundaries and numerous binary oppositions (life/death, health/illness, dependency/independence, decency/indecency, hope/fear, happiness/unhappiness etc.)

Apart from second Wittgenstein and the possibility to achieve or not a level of empathy with the patient and her/his perspective, the ethical dimensions involved in the condition of the patient are also explored with the aid of social anthropology studies - these of Veena Das’ for instance - acting as a rich resource of pain account and of the state of the patient globally.

Key Words: Wittgenstein, pain, patient, otherness, life forms, empathy, synaesthesia, ethics, philosophy, anthropology.

Maurice O’C. Drury tells us about Wittgenstein’s repeated visits to a mental patient at St Patrick’s Hospital in Dublin in the year of 1938. At a certain visit, with Drury present, the patient and Wittgenstein were entertaining a conversation on philosophy. Drury writes:

I was fascinated to see how gently and helpfully Wittgenstein was able to discuss with the patient. When at one point I tried to join in the discussion, Wittgenstein at once told me to *shut up*. Afterwards, when we were walking home, he told me: “When you are playing ping-pong you mustn’t use a tennis racket.”¹

Wittgenstein has been visiting the patient ever since. Treating him/her with care and attentiveness. Attempting to resolve the knots in the ropes that tie sick Prometheus upon a rock, the patient on her/his bed. After all, as Wittgenstein saw it, philosophy had a therapeutic aim, to aid the suffering from misconceptions and injuries from walking on the slippery ground of language. As a Doctor of Philosophy, in *Culture and Value* he says: “A philosopher is someone who first needs to cure many of his own intellectual illnesses before he reaches the notions of the healthy human intellect.”²

1. The Patient’s Identity/Otherness

Defining a patient is as complicated as defining her/his humanity or personhood. Undoubtedly, it is someone with impaired health, someone in need of care, with a righteous claim to health, someone with lawful expectations from others - be it individuals or an organized social system. In this view, there exist a considerable number of beings, that are *not entitled* to claim the “doomed” state of the Patient. Really, who deserves to be called a patient?

Ludwig Wittgenstein, particularly in his late philosophy, declared an aversion for generalizations, definitions, scientific explanations. He considered them dangerous tools when approaching a topic philosophically. Instead, he opted for individual case treatment and description, based on expressed indications and behaviour.

To go along this line, the patient as we know her/him, appears to have feelings of uneasiness, pre-occupations or hope, impatience, wonder, injustice, anger, fear, loneliness, grief, despair, futility, existential anguishes, while experiencing the fragility, vulnerability, the danger and the instability of the *between*; hovering, like an acrobat, over boundaries and numerous binary oppositions such as life/death, health/illness, dependency/independence, decency/indecency, happiness /unhappiness etc.

Being situated on the *marked*, in semiotic jargon, sides of these bipolar relations, the patient is treated as the *Other*, both in terms of his/her alienation from the healthy majority and of being considered the second pole in binary pairs as are those of: doctor-patient or healer-sufferer.

This otherness and the extent to which it constitutes a distinctive element of a person’s identity are critical issues in the philosophical approach

to the patient. According to Paul Ricoeur, identity is being constructed through narration and narratives. Otherness is seen as part of the Self, both as defining it by contrast as well as existing inside the Self.³ The doctor is the current or future patient of another doctor for instance; the dividing line is constantly being crossed. After all, anyone is a potential patient.

2. The Concept of Pain

A crucial criterion in the identification and consequent categorization of the patient as such, is pain. Ludwig Wittgenstein's late philosophy, as developed after 1929 until his death in 1951, in *The Blue and the Brown Books* and in the *Philosophical Investigations*, among other issues deals with the philosophical aspects of pain in Self and Other, its perception and its immediate connection with language and the social context.

In one of his conversations with his friend Bouwsma in Oxford, in September 1950, Wittgenstein refers to pain as being a *sensation* (*Empfindung*), that he categorizes "together with pleasure, which is not a sensation. The reason is, that both pain and pleasure are depicted on our face, our eyes, our body posture. *Is a man in pain? Look at him! Does he feel well? Look at him!*"⁴

As C.A. van Peursen tells us for the Viennese philosopher, the internal in external behaviour is not a surplus value of words; it is not "*hidden* behind man's action and speech - it is *precisely* what is expressed by them. *Will* and *idea* [...] are no longer kept in watertight compartments!"⁵ For Ludwig Wittgenstein, the mind-body dualism is fundamentally illogical.

Even neuroscientists, committed materialists who adamantly insist on this aspect of their anti-Cartesianism, have, Bennett and Hacker (2003) argue, merely jettisoned the *dual substance* doctrine of Cartesianism, but retained its faulty structure with respect to the relation of mind and behaviour. The current generation of neuroscientists repudiated Cartesian dualism, replacing the mind with the brain as the explanatory locus of human psychological and emotional capacities. That leaves intact the misguided Cartesian conception, replacing the ethereal by grey glutinous matter. Merely replacing the mind with the brain falls short of a repudiation of the structure of the Cartesian explanatory system.⁶

Unreasonable inflation of the conception of the *brain*, through assigning to it powers and activities that are normally reserved for sentient beings and the *degree* to which these assertions depart from the norms of linguistic practice, send up a red flag. It is one thing to suggest on empirical grounds correlations between a subjective, complex whole (say, the activity of deciding and some particular physical part of that capacity, say, neural firings), but there is considerable objection to concluding that the part *just*, is the whole.

Wittgenstein remarked that it is only of a human being that it makes sense to say “it has sensations, it is conscious or unconscious.”⁷ The question whether brains *think* is a philosophical question, not a scientific one. To attribute such capacities to brains is to commit what Bennett and Hacker identify as *the mereological fallacy*, that is, the fallacy of attributing to parts of an animal, attributes that are properties of the whole being.⁸ Neuroscientific research that proceeds from conceptually flawed premises is likely to yield incoherent empirical questions and answers that escape illumination of any kind. In this regard, Bennett and Hacker make the case that, done well, philosophy matters deeply for the proper conduct of neuroscience.⁹

Philosophers of mind are themselves prone to similar conceptual errors. Consider what John Searle tells us on pain and the role of the brain:

Common sense tells us that our pains are located in physical space within our bodies, that for example, a pain in the foot is literally inside the area of the foot. But we now know *that* is false. The brain forms a body image and pains, like all bodily sensations, are part of the body image. The pain-in-the-foot is literally in the physical space of the brain.¹⁰

Bennett and Hacker object on grounds of logical grammar: one does not have pains *in the brain*. Pains (other than headaches) are not *in the head*. If there is a locus of pain, it is a distributed feature of the whole experience, the brain being only one physical part of it. For the experiencing subject, of course, “[h]is pain is located where he sincerely suggests it is” (phantom pains being in need of special explanation). This is not to deny that in the absence of a proper functioning brain, one would feel no pains. But that does not license the claim that pains “are felt either in or by the brain. What hurts when one breaks one’s leg is typically one’s leg, not one’s head.”¹¹

Bennett and Hacker agree that Cartesian dualism, behaviourism, eliminative materialism and functionalism are all rejected, and rightly so. Searle advocates *biological naturalism*; the view “that consciousness is a biological phenomenon, a proper subject of the biological sciences.”¹² The authors raise no objection here. It is Searle’s claim that “mental phenomena are caused by neurophysiological processes in the brain and are *themselves* features of the brain” that Bennett and Hacker strongly disapprove of.¹³ Searle’s claim commits the mereological fallacy discussed earlier. Brains are no more conscious,

than they are capable of taking a walk or holding a conversation. True, no animal could do either of these

things without a properly functioning brain. But it is the person, not the brain, that engages in these activities.¹⁴

3. Actual Pain

Ontological structures are projections of primarily given language structures.¹⁵ “You acquired the notion of pain acquiring your mother tongue” says Wittgenstein.¹⁶

Social anthropology studies - those by Veena Das’s for instance - act as a rich resource of pain account. According to Veena Das, the Wittgensteinian concept of language that acquires substance and meaning only within the context of existing *life forms*¹⁷ - a central term in the philosopher’s later thought - helps explain the inability of expression and verbalization of certain incidents recorded in ethnography.

Incidents of unbelievable cruelty and violence, that have caused indescribable pain, cannot even be uttered as there is a deep moral energy in the refusal to represent some violations of the human body, for these violations are seen as being against nature, as defining the limits of life itself being almost beyond recognizable life forms:

Some forms of life are seen as not belonging to life proper. Was it a *man* or a machine that plunged a knife into the private parts of a woman after raping her? Were those *men* or animals who went around killing and collecting penises as signs of their prowess?¹⁸

Apparently, the exact span and range of human life forms cannot possibly be known in advance, just like the meaning of a word is not known in advance.¹⁹ To quote Wittgenstein “Imagining a language means to imagine a form of life.”²⁰

The Austrian philosopher “emphatically denies the possibility of a private language that refers to what is internal or private to creatures”²¹. Though nobody can have *my* thoughts in their mind or *my* pain in their body, as Wittgenstein states, Das says nonetheless that it would be a mistake to think of pain as essentially *incommunicable*:

To say ‘I am in pain’ is to ask for acknowledgement from the other, just as denial of another’s pain is not an intellectual failure but a spiritual failure, one that puts our future at stake.²²

Wittgenstein in his analysis of how we ascribe pain to others, clearly shows that ascriptions of consciousness and pain to others have, as a

precondition, that we have an attitude to these others; that they are of a “type” which *may be conscious* and *be in pain*.

For instance, in order to attempt answering the question: “Does a patient at a Permanent Vegetative State feel pain while not demonstrating physical signs of pain?” our disposition is of critical importance. This attitude (being a *value judgement*) is not amenable to a scientific determination; it is dependent on the existence of empathy between the observer and the observed.

Our preconditions for recognising and evaluating pain are also directly related to other aspects of Wittgenstein’s late philosophy such as the notions of language games, rule-formation, theory of meaning and the primacy of context; all of which can prove valuable tools in examining the state of the patient.

Clifford Geertz, a leading figure in postmodern interpretive cultural anthropology, recognizing Wittgenstein as his mentor, advocates the primacy of language and context. Human beings, through their cultural narratives weave their own web of meaning, Geertz says.²³

Stressing the importance of context, Wittgenstein himself writes in 1948: “I believe that modern education tends to decrease people’s endurance in pain [...] Supposedly, pain should no longer exist; it is not in fashion any more.”²⁴

For example, only within the last ten years, has it become *fashionable* that newborn infants may feel pain; in *recent* times it has become generally accepted that animals have the ability to feel pain; Descartes argued that they had no such ability. The issue of whether a foetus can experience pain is currently still a subject of controversy.

4. Ethics and the Patient

The ethical dimensions involved in the condition of the patient are indeed worth exploring. When Wittgenstein talks about *forms of life*, above the level of purely pragmatic analysis and behaviouristic description, there is still something of a recognition of values.²⁵ When it comes to the patient, what form of life is worth saving? Are the criteria philosophical, physical or socio-economic ones? Does the life of a child in Somalia or Sudan matter or weigh the same as the life of a child in Italy or Canada? Is an injured soldier from Afghanistan treated with the same care as an injured American soldier? Will a raped 5 year old girl in Rwanda receive the care that a Swiss little girl will receive? The majority of life forms on the planet are dispensable, and that stands for the majority of human lives as well. Tragically or ironically enough, the state of a patient is a privileged one if regarded from a perspective. It denotes recognition of her/his humane quality, it attributes a certain value to her/his existence. Millions of people may cease to exist, and they do, every day, but if *our* people, our child, our parent, our spouse or

friend perish, our life seems pointless, loses in meaning according to the significance of the dead person in our life. The closer the bond, the higher the value of the Other's life. The less central the role this person plays in the social sphere, the less pain her/his suffering or her/his loss will inflict upon others. So, what patient? Can a patient be regarded on equal terms globally? What constitutes a life form worth of respect? Is a foetus such a life form? Is a deformed neonate such a life form? A PVS patient?

What form of life is life? Is a sick plant a patient? For some people the cure of their sick pet dog values more than the cure of a child unknown to them. Pharmaceutical companies experiment ruthlessly on patients of the developing world, putting their lives in danger and shattering their hopes in order to provide treatment for the first class citizens of the developed world.

The semantic load of the patient varies tremendously if explored spatially. It does so, possibly even more, when explored temporally. In the past, poor living conditions, meagre medical means and a short life expectancy did not render a pregnant woman in labour a patient. In ancient Sparta, rules of economy dictated throwing deformed or weak newborns off a cliff.

Even an indicative exploration of the etymology and the actual meaning of the word *patient* in different languages would give us interesting highlights of the conceptual variations that inevitably interfere with actual life. In English, it is somebody who needs to show patience, in Greek it is *ασθενής* (*asthenis*) meaning weak, without strength, in French *malade*, deriving from *mal* which means bad, evil. A complete definition of the patient would involve its meaning in all languages, like a complete definition of life would include all life forms. Not only the existent but all prospective life forms.

Advances in technology produce artificial limbs or organs for the patient. Just for the sake of the argument, let us assume that the majority of a man's limbs and organs, including the brain, get substituted by artificial spare parts. How human would then that person be?

Far-fetched though such possibility may be, it is in the process of realization. A brief tour on the Internet can prove shockingly revealing. Humanoids and robots, acting, speaking, moving, looking like humans are in the speedy process of perfection. In, say, fifty years from now, one might prefer to live with or marry a spouse that possesses all the qualities and features of the humans, without fragile health or annoying free will. Who wouldn't want a pet that wouldn't soil, bite or die? Or a baby, born with no pain and no possibility to inflict pain, that would stay healthy and young for as long as we desired?

Diminishing pain will gradually equal to diminishing life and humanity as we know it. It is a controversial issue: humans in pain or painless artificial life?

5. Conclusion

Applying Wittgenstein’s philosophy in the patient’s otherness and pain means in fact to consider her/him holistically - not as a brain or as a body, but as a *person* in pain. A person situated in a social and linguistic context, never in a vacuum, never isolated or extracted from her/his surroundings. The latter plays a critical role, even in defining the patient as such.

When the patient is the Other, aiming at *empathy*, that is, sharing one’s suffering, being *inside* the Other’s *pathos* (πάθος, as the Greek etymology implies) appears a noble aspiration, yet, epistemologically speaking, rather unattainable. And, in a way, not essential: identifying pain does not necessarily presuppose exploration of inner worlds, entering of any unknown caves. Just being alert, aware, with *syn-aisthesis* (συναίσθηση), a Greek word meaning *to feel with* the Other, together, not *her/his* feelings but her/his account of them, verbal or physical account; that would do.

Being himself a patient, Wittgenstein writes: “No pain can be greater than the one you can find in a single human being; feeling lost, this is the greatest pain of all.”²⁶

Man is part of nature. And death, as Nietzsche said, is like the storm.²⁷ When it strikes you, you don’t ask how it came or why. You just try to find your way about. When illness strikes, don’t let the Other feel lost. Precondition for any of these is one’s disposition: to be there, aware, with your eyes and ears open to see the heavy clouds, hear the thunders, feel the drops of rain on your skin. Nature is in pain. You can’t ignore the signs.

Wittgenstein wrote: “There exists tragedy only where the tree breaks instead of bending.”²⁸ When you find yourself in the storm, just *act*: don’t let the tree br-ache.

Notes

¹ M O’C Drury, ‘Conversations with Wittgenstein’, in *Recollections of Wittgenstein*, R Rhees (ed.), Oxford University Press, Oxford, 1984, p. 140.

² L Wittgenstein, *Culture and Value*, G.E.M. Anscombe, Blackwell, Oxford, 1958, p. 73.

³ P Ricoeur, *Moi-meme comme un Autre*, Editions de Seuil, Paris, 1990, pp. 14-61.

⁴ L Wittgenstein, *On Ethics*, Editions Kardamitsas, Athens, 2000, p. 122.

⁵ CAP Peursen, *Ludwig Wittgenstein, An Introduction to His Philosophy*, Faber and Faber, London, 1969, p. 107.

⁶ MR Bennett & PMS Hacker, *Philosophical Foundations of Neuroscience*, Blackwell Publishing, London, 2003, p. 26. Descartes reconceived the soul “not as the principle of life, but as the principle of thought or consciousness,”

a thesis which led to the idea that the mind was separate from the body in all respects. This formulation inevitably casts a long shadow over neuroscientific reflection (A Dinopoulos, *Neuroethics. Νευροηθική*, Παρισιάνου, Athens, 2008). Descartes further complicated his position by insisting that while distinct, mind and body are united. The central problematic for both Cartesianism and its inheritors is how to explain the connection between mind and body. The only thesis of Descartes that withstood critical objection was his claim that “explanation at the neurophysiological level will be in terms of efficient causation” (p. 27). In this respect, Bennett and Hacker remind us that “Descartes contributed substantially to advances in neurophysiology and visual theory” (p. 27).

⁷ L Wittgenstein, *Philosophical Investigations*, § 281.

⁸ J.Z. Young speaks of knowledge and information encoded in the brain “just as knowledge can be recorded in books or computers” (JZ Young, *Programs of the Brain*, Oxford University Press, Oxford, 1978, p. 192). Milner, Squire and Kandel all speak of *declarative memory* which, they maintain, is “stored in the brain” (B Milner, LR Squire & ER Kandel, ‘Cognitive Neuroscience and the Study of Memory’, *Neuron*, vol. 20, 1998, p. 450).

⁹ Bennet and Hacker, p. 71.

¹⁰ J Searle, *The Rediscovery of the Mind*, MIT Press, Boston, 1992, p. 63.

¹¹ Bennet and Hacker, pp. 122-123.

¹² Searle in D Patterson, *Philosophy Reviews*, Notre Dame University, Paris, 2003, p. 444.

¹³ Searle, *Rediscovery*, p. 1.

¹⁴ Bennett and Hacker, p. 73.

¹⁵ N Avgelis, *Philosophy of Language*, Editions Avgelis, Thessaloniki, 2001, p. 40.

¹⁶ Wittgenstein, *Phil.Inv.*, §384, p. 153.

¹⁷ A term possibly borrowed from the German philosophical usage (in 1914 W. Spranger in his *Lebensformen* analysed various personality structures with reference to the various forms of value experience) or the symbolic logician in Muenster, H. Scholz, who in his *Religionphilosophie* (1921) described the “forms of life” as differentiations of the religious consciousness (in Peursen, pp. 108-109).

¹⁸ V Das, ‘Wittgenstein and Anthropology’, *Annual Review of Anthropology*, vol. 27, 1998, pp. 171-195; p. 182.

¹⁹ F Tsobanopoulou, *Late Wittgenstein and His Influence on Postmodern Anthropology*, M.A. dissertation in Philosophy, Aristotle University of Thessaloniki, 2007, p. 54.

²⁰ Wittgenstein, *Phil. Inv.*, §19, p. 32.

²¹ Das, op. cit.

²² Cavell, p. 94.

²³ C Geertz, *Available Light, Anthropological Reflections on Philosophical Topics*, Princeton University Press, Princeton, 2000.

²⁴ Wittgenstein, *Culture and Value*, p. 109.

²⁵ Peursen, p. 109.

²⁶ Wittgenstein, *Culture and Value*, p. 76; p. 18.

²⁷ F Nietzsche, *Gay Science*, Nisides Editions, Thessaloniki, 2004, p. 190.

²⁸ Wittgenstein, *Culture and Value*, p.18.

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PART V

Health Care: Depersonalising Systems, Alienating Spaces

***Ars Moriendi and Being-toward-death: Marlene van
Niekerk's Memorandum: A Story with Paintings.***

Jean Rossmann

Abstract

Memorandum presents a visual-verbal dialectic between South African Afrikaans writer Marlene van Niekerk's narrative of a cancer patient and Adriaan van Zyl's stark hospital still lives which intensify the reader/viewer's sense of the alienating experience of hospitalisation. *Memorandum* is the story of J.F. Wiid, a lonely civil servant diagnosed with liver cancer, who on the night before a potentially life-prolonging surgery starts to write a memorandum about a strange conversation he overheard between two fellow hospital patients during a previous hospital stay. Indeed, a substitute title for this memorandum could be *ars moriendi*, the medieval texts which prescribe the "art of dying," and to which Wiid directly refers. I argue that *Memorandum* is a contemporary evocation of *ars moriendi* and the Heideggerian notion of being-toward-death, an authentic mode of human existence which involves an angst-ridden grasp of one's finitude. I explore Van Niekerk's representation of the alienating experience of the hospital and its technologies as an inauthentic mode of being that separates one from one's own humanness and from others.

Key Words: South African fiction, *ars moriendi*, being-toward-death, Heidegger.

The South African Afrikaans writer Marlene van Niekerk is perhaps better known for her first novel, *Triomf* (1994 [1999]), and more recently *Agaat* (2004 [2006]) or *The Way of the Women* as it has been renamed by the UK publisher, Little Brown. Her most recent text, *Memorandum: A Story with Paintings* (2006),¹ marks a thematic transition from a critique of the demise of Afrikaner nationalism to an exploration of individual mortality through a cancer patient's rejection of clinical care. Whether telling stories of the demise of certain cultures or of individuals, in South Africa death is, arguably, the national narrative. It is significant that the euphoria of the first democratic elections in 1994 announcing a "new" South Africa with all its associations of social regeneration and renewal has not pervaded South African literature with a more light-hearted subject matter. Instead, after the transition from strife-torn apartheid to a multicultural democracy, HIV/AIDS has superseded freedom struggles as the urgent matter of the day.²

Memorandum is not an AIDS narrative; however, it arguably reflects a broader social concern with death as a structuring force in our ways of being. In this paper I argue that *Memorandum* is a contemporary evocation of the *ars moriendi*, the fifteenth century treatises on the “art of dying well,” and the Heideggerian notion of being-toward-death, an authentic mode of existence that involves an anticipation and contemplation of one’s own death. Van Niekerk’s narrative presents the alienating experience of the hospital and its technologies as an inauthentic mode of being and through her protagonist presents the ultimate form of defiance against hospitalisation: a self-affirming, informed advance toward death.

This fictional autobiography that centres on a dying man’s chance eavesdropping of a bizarre “nocturnal symposium”³ between his two ward-fellows presents a polemic on hospitalisation grounded in references to Ivan Illich and his upbraiding of the medicalisation of care and death, as well as the writings of Foucault and Nietzsche, amongst others. The protagonist, Johannes Frederikus Wiid, a thorough and meticulous Director of Parks & Playgrounds, Sanitation and Maintenance for a Cape municipality, a teetotaller, and hermit-like bachelor has been diagnosed with metastasised liver cancer and during a hospital stay is made privy to a fragmentary and oblique conversation between the two patients that lie on either side of him in the ward. These two characters, who Wiid names Mr X and Mr Y, sagacious and somewhat ethereal, disappear without a trace the following morning and leave Wiid wondering if they were merely a figment of his imagination:

Could I have imagined it all? X, the fanatical poet without feet, who chattered about birds and birds’ nests, Y, the blind mocker, who delivered one speech after another on antique building methods, the foundation of cities and on hospitals when he wasn’t singing? [...] A secret language filled with nonsensical references which they bandied to and fro?⁴

Wiid’s feelings about being subject to this unusual disclosure are initially ambivalent: he is either “a chance dumping site for a kind of over-production” or “a beloved person to whom precious mysteries had been entrusted.”⁵ However, it is the latter sentiment that presides, for an increasing “disquiet” evoked by these unexplained “mysteries” causes Wiid to begin extensive research into all the references made by X and Y and finally on the night before a potentially life-extending operation to write a memorandum on his findings.

The reference to X and Y’s discourse as “precious mysteries,” the didactic effect of their exchange and Wiid’s “overture” to the beginning of his tale, “Therefore, so help me God, I take a leap in the dark,”⁶ all resonate

with the notion of the *ars moriendi*. According to Philippe Ariés, in *Western Attitudes Towards Death*, the fifteenth century texts and iconography of the *ars moriendi* reveal a shift from the early modern view of death as a “collective fate” and an expected and normal part of the life cycle to new anxiety about personal mortality prompted by the Renaissance exaltation of the individual.⁷ The *ars moriendi* was meant to unveil the mysteries of the moment of death and advise an appropriate attitude toward one’s own death which involved the practice of the *contemplatio mortis*, a formal meditation on one’s death.⁸ These visual and verbal texts presented a dramatisation of the dying man’s trials and temptations and emphasised his active role in freely deciding his destiny, for the final moments of his life will “determine the meaning of his whole life.”⁹ In contemporary bio-medical discourse an active anticipation of, and advance toward death, as Y observes “*is seen by the modern doctor as a form of consumer resistance.*”¹⁰ Y, regretting his surgery, suggest to X that “*we would have been better off if someone had taught us the age-old ars moriendi instead of allegedly being delivered here of redundant parts.*”¹¹ Implicitly it is X and Y, who dramatise and thus teach Wiid this art. In Wiid’s self-composed glossary, listing all the strange words and references made by X and Y, he includes this definition:

‘arse moo-randy’? - Artes bene moriendi. (Lat.) Literary texts 1415-1450 with prescriptions and drawings for a good death. Humility, detachment, patience etc. Application of these dying virtues at the right moment is called an “art.” Mmm. Joop says the ending of a work of art is never doomed because of an uncertain start.¹²

The anecdotal asides and thoughtful pause in his description imply his self-conscious adoption of this tradition. Indeed, *ars moriendi* could be a substitute title for the novel.

In *Memorandum*, Wiid’s determined excavation of the meaning in X and Y’s musings triggers a reassessment of his attitude toward life, his illness and death, and becomes in effect a metaphysical quest. Various quest motifs are invoked in the narrative, not least Wiid’s Marlovian “leap in the dark.” Like most quest heroes, Wiid cannot rely on his ingenuity alone. His visits to the town library find him an unlikely ally in the chief librarian, Joop Buytendagh whose administrative style and appearance cause Wiid much alarm. In a letter of complaint he describes him as, “barefoot and clad in a faded T-shirt and low-slung jeans, with a ragged beard, unwashed hair in a ponytail, three shark’s teeth on a thong around his neck, a match between his teeth, a collection of silver rings around his ankles, and not overly fresh as regards personal hygiene.”¹³

Joop becomes Wiid's guide in his labyrinthine quest towards death and his *amicus mortis* (literally, friend of death), a word Wiid overhears X use in describing his relationship with Y.

To whom do you entrust the most beautiful dream of your life? X exclaimed at one stage, when he was slightly buoyed up by some or other stimulant that they'd added to his drip, *see I should never have told you so much about myself in that wretched waiting room when I met you for the first time, but now we are hazarded to each other – you are willy-nilly my -* and then the strange word followed.

I feel flattered, Y said. *I trust that it is reciprocal: army-kiss-mortice. That's really,* he added, *how a physician is to understand his role, like the Muslim doctors in the maristans [Islamic hospitals] of Constantinople.*¹⁴

Wiid's glossary explanation of *amicus mortis* presents a tangential link between the *ars moriendi* and Heidegger's concern with the fact that death has become an enigma. Wiid quotes from Ivan Illich's essay, "Death Undefeated" where he states:

The ordinary man suffers from an 'inability to die.' Are there still people who are 'capable of the act of dying'? For that a wise man must make and cherish 'a friend unto death, someone who will tell you the straightest truth & stay with you to the bitter end.'¹⁵

According to Heidegger the ultimate possibility of being is death. In *Being and Time* he writes, "death, as the end of *Dasein* [being-there], is *Dasein*'s ownmost possibility [...]. Death is, as *Dasein*'s end, in the *Being of this entity* towards its end."¹⁶ In addition, as Jonathan Strauss explains, "[d]eath, by separating me off as finite, makes me capable of being a whole to myself, and I actually *do* become whole to myself through my attitude toward that death."¹⁷ Although we die alone, we can never know our own death and this wholeness can only be *imagined* in and through the death of others.¹⁸ Thus it is through X and Y, and guided by the librarian that Wiid comes to face his own death and it is, by extension, death that gives meaning and fullness to Wiid's life. Returning home after listening to X and Y's imparted "mysteries," Wiid surveys his "living arrangement of thirty years" and realises what a cheerless place it is.¹⁹ He has managed to avoid his neighbours entirely and he receives no visitors in hospital only an apology from his boss for not being able to visit. It is also significant that Wiid lost his

twin brother when they were 8 months old due to jaundice. Wiid asks: “Have I always been my brother’s still life?”²⁰ Still life or *nature morte*, in the more apt French term, highlights the constant presence of death in the midst of life. Arguably, the duality in the nameless X and Y can be seen as a manifestation of Wiid’s lost “whole.” However, in forming new connections, initially through the intertextual overflow of X and Y, and later in forging a bond with the librarian, Wiid comes to experience Heidegger’s phenomenology of being, as not only being-toward-death, but also being-with-others, not in the sense of losing a unique sense of self in mass society (our fallenness), but in terms of the unifying concept of care.

Being *in* the world implies being among other beings and “‘being-with’ other beings occurs in the matter of being *concerned* with other beings.”²¹ Heidegger’s term, *Sorge*, care or concern, signifies a state of existence “(1) which is confronted with its being as a task to be fulfilled, whose own being is a being which ‘can be,’ (2) which finds itself as already thrown into existence, and (3) which exists in the midst of other beings, taking care of and care for them.”²² Wiid does not encounter care in the hospital. In fact the paradox of modern medicine is that, as Y states, “*They care for you in the finest details but don’t care in the least about your cares.*”²³ X and Y present the interior design of hospital spaces as a metaphor for the lack of intimacy or meaningful connection between people in hospitals:

[...] Mr Y sang, *a cage with four walls provided with a door and a window and a ceiling with headroom adequate ABOVE the floor and ON the floor a sohelpmegod WARDROBE and Iaskyou a BED and NEXT TO the bed a BEDSIDE CABINET and ABOVE the pillow a bedside light complete with little SLUMBERLAMP [...].*

*Here we have all the prepositions, Y said, that connect things to one another, ABOVE one another, ON TOP OF one another, while the human being’s own measure and status is denied, and people in wards like this feel NEXT TO one another instead of WITH one another.*²⁴

Patients are not only disconnected from each other in their shared suffering, but, as Wiid begins to realise, the mobility of things in the hospital, contribute to a psychic dismantling of identity and agency. Wiid observes, “That what is fixed in a house can be wheeled away in a hospital? And that all the bed and trolleys on their provisional stops in ward and passages and lifts made one feel like a loose hub instead of a person with volition?”²⁵ Wiid, decoding one of X and Y’s references to Ivan Illich provides an exposition on

the hospitals strategies in usurping the patients independence, as well as the sovereignty over his/her body and pain.

In order to prepare man for maximally efficient medical service, it is necessary according to Illich that your wholeness and independence, your whole world, should be 'unmade,' that you enter 'fully' into your pain and no longer tolerate yourself. Only then are we sufficiently stripped by 'the powers seeking our subjugation,' available from head to toe to the 'body burglary' of medical care, the industry that has 'mastered and possessed' us unto our very flesh, as one Descartes apparently recommended.²⁶

The Cartesian mind/body dichotomy is central to this critique of the bio-medical discourse that reduces illness and death to pure physiology managed by technology.

Wiid's assessment of how he, as a patient, was treated in hospital reveals how technology objectifies the body under the medicalising gaze, reduces one to a number and detaches one from one's subjectivity.

The entrance marks you as nought. In the centre you register as a blip on a screen. At the exit you're even more null and you have to convince yourself all over that you have a name like Wiid. When I got home after being in that place for the first time, I came to sit here in a bemused state and looked at my finger in the ear of the cup, my elbow on the table, and even though my flat was bare and cold, it was a miracle of homecoming.²⁷

Returning home, Wiid has to reaffirm his existence as a visceral human being, marvelling at the body parts that were reduced to "null." It is the technologies of medicine that turn flesh and blood into a "blip."

The hospital has displaced the central symbolic position the sick-bed and death-bed have held as a place of love and rest, and it is no longer the nurturing environment of the home that is the refuge of the dying. The hospital bed has become the place of death: secular, alienating and clinical. As Phillip Ariés notes, "Death is no longer the occasion of a ritual ceremony, over which the dying person presides amidst his assembled relatives and friends. Death is a technical phenomenon obtained by a cessation of care."²⁸

However, Wiid forsakes the medical prescription of "nil per mouth" and symbolically takes Joops advice of "*in vino veritas*"²⁹ in a final communion with his reader and his *amicus mortis* to whom this *Memorandum* (or *ars moriendi*) is entrusted. Via the interventions of X and

Y, Wiid departs from his initial faith in the anonymous medicalised care offered by the hospital and his view of himself as a “privileged [client] in a mega-teaching hospital” to embrace the personal care he receives from his *amicus mortis*.³⁰ From X and Y, Wiid learns that the origin of the term “hospital” lies in is the word “hospitality.” In “ancient times,” notes Wiid:

ordinary people were hosts and every householder invited in and supported for free a stranger, or a lost traveller or a sick person. Later this hospitality went out of fashion and Christian outside agencies started to care for the sick in catchment houses, later yet the state took over this function in hospitals that in addition became dependent on taxes.³¹

The result of this is the anonymous “health care” industry we know today.³² In the spirit of *Sorge* Wiid returns the hospitality offered him by Joop, with his gifts of sweet wines, sultanas, and the constant support offered in his quest, by finally forsaking a potentially life-extending operation and deciding to invite Joop for dinner. What would otherwise seem a moment of loss is in *Memorandum* presented as a moment of triumph and hope. Gone is the desolation he feels at the beginning of his narrative when he was still in mind to leave for hospital the following morning. As a postscript Wiid presents Joop (and the reader) with his dream of an afterlife of his own creation. Death has become, in Heidegger’s terminology, his “ownmost possibility,” a final home, where Wiid stands as host, declaring:

Stranger, be welcome to this place! Death has here been restored! And if I should by chance see a lonely tramp, before the last circuit, who like me has need of comfort, I shall be his friend and hospice and take him to Mimosa, to my nest already prepared for him as bequest, and to the end with him abide.³³

Notes

¹ The paintings are by a South African artist, Adriaan Van Zyl.

² B Carton, ‘The Forgotten Compass of Death: Apocalypse Then and Now in the Social History of South Africa’, *Journal of Social History*, vol. 37(1), 2003, p. 199.

³ M van Niekerk & A van Zyl, *Memorandum: A Story with Paintings*, Human & Rousseau, Cape Town, 2006, p. 23.

⁴ *ibid.*, p. 23.

⁵ *ibid.*, p. 25.

⁶ *ibid.*, p. 10.

⁷ P Ariés, *Western Attitudes toward Death: From the Middle Ages to the Present*, trans. PM Ranum, The John Hopkins University Press, Baltimore, 1975, pp. 105-107.

⁸ *ibid.*, p. 107.

⁹ *ibid.*, p. 109.

¹⁰ van Niekerk, p. 60.

¹¹ *ibid.*, p. 61.

¹² *ibid.*, p. 134.

¹³ *ibid.*, p. 139.

¹⁴ *ibid.*, p. 132.

¹⁵ *ibid.*, p. 135.

¹⁶ M Heidegger, *Being and Time*, trans. J Macquarrie & E Robinson, Harper and Row, New York, 1962, p. 303.

¹⁷ J Strauss, 'After Death', *Diacritics*, vol. 30(3), 2000, pp. 97-8.

¹⁸ *ibid.*, p. 102.

¹⁹ van Niekerk, p. 47.

²⁰ *ibid.*, p. 67.

²¹ JM Demske, *Being & Death: A Key to Heidegger*, University Press of Kentucky, Lexington, 1970, p. 19.

²² *ibid.*, p. 22.

²³ van Niekerk, p. 44.

²⁴ *ibid.*, p. 43.

²⁵ *ibid.*, p. 44.

²⁶ *ibid.*, p. 60.

²⁷ *ibid.*, p. 79.

²⁸ Ariés, p. 88.

²⁹ van Niekerk, p. 8.

³⁰ *ibid.*, p. 35.

³¹ *ibid.*, p. 58.

³² *ibid.*, p. 59.

³³ *ibid.*, p. 124.

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**Screened Medicine: Hospital Environment, Familial
Support-System and Patient Well-Being in Denys Arcand's
*Les Invasions Barbares***

Amir Cohen-Shalev and Esther-Lee Marcus

Abstract

The title of Denys Arcand's 2003 film, *Les Invasions Barbares* (The Barbarian Invasions), carries both an immediate connotation and a metaphorical one. The former is historical and political, referring to the terrorist attack on the Twin Towers in New York, which is part of the film's diegesis, a backdrop against which the characters act. The latter, however, is purely medical, referring symbolically to the invasion of terminal disease into the body of the protagonist, a history professor hospitalized for incurable cancer in a Montreal public hospital. The setting provides a fertile ground for an ultra-realistic treatment of various key topics pertaining to the condition of being a patient in a state-controlled medical system. These include overcrowding, an obtuse bureaucracy, professional (as well as unprofessional) attitudes on the part of the medical staff, the role of modern communication systems in patient-family relationships, family support system and conflict-ridden pressures among family relatives and care-givers, the patient and his/her family's rights and options vis-à-vis the system, private care within the system's constraints (including, in the extreme, bribery, favoritism and corruption), issues of life review and intergenerational relationships, use of illegal drugs in euthanasia, etc. This presentation is intended to review these issues and concentrate on the utilization of cinema for training of medical staff.

Key Words: Film studies, health-care system, Denys Arcand, patient-family relationship, euthanasia, intergenerational relationships.

The title of Denys Arcand's 2003 film, *Les Invasions Barbares* (The Barbarian Invasions), carries both an immediate connotation and a metaphorical one. The former is historical and political, referring to the terrorist attack on the Twin Towers in New York, which is part of the film's diegesis, a backdrop against which the characters act. The latter, however, is purely medical, referring symbolically to the invasion of terminal disease into the body of the protagonist, a history professor hospitalized for incurable cancer in a Montreal public hospital. The setting provides a fertile ground for an ultra-realistic treatment of various key topics pertaining to the condition of

being a patient in a state-controlled medical system. These include overcrowding, an obtuse bureaucracy, professional (as well as unprofessional) attitudes on the part of the medical staff,¹ the role of modern communication systems in patient-family relationships, family support system and conflict-ridden pressures among family relatives and care-givers, the patient and his/her family's rights and options vis-à-vis the system, private care within the system's constraints (including, in the extreme, bribery, favouritism and corruption), issues of life review and intergenerational relationships, use of illegal drugs in euthanasia, etc.²⁻⁴ This presentation is intended to discuss some of these issues and concentrate on the utilization of cinema for training of medical staff.^{5,6}

A memorable scene, one of many, in Carol Reed's 1949 classic *The Third Man*, depicts police inspector Callaway taking American writer Holly Martins to a children's hospital in war-stricken Vienna, where the victims of Harry Lime's diluted penicillin lie. The scene is shot from a low-angle position, with the camera focusing on the two men's expressions as they would be seen by the patients, but the viewer is saved from the horror of gazing at the poor victims. This omission is significant: *The Third Man*, although a powerful depiction of human brutality and moral nihilism, a thought-provoking cinematic commentary on the human condition, is first and foremost a piece of entertainment. Excellent as it may be as a piece of filmmaking, it purposely avoids going too far in the exposition of horrors that may interfere with commercial success.

There obviously is a lot of killing and death in the world of motion pictures, yet the great majority of deaths are embedded in depersonalized, genre-related conventions, such as the Western, *film noir*, crime, war film, etc. As such, death and dying can be experienced with safety, as it were. There is little market for the grim side of life on the silver screen, for aging, sickness or dying. For these to receive some kind of filmic treatment by the mainstream motion-picture industry, these issues have to be seriously modified. A recent illustration of this can be found in Rob Reiner's *The Bucket List*, where Jack Nicholson and Morgan Freeman portray two aging cancer patients who set out to make the most of the time left for them, a mission that soon deteriorates into an adventure comedy with a rather sentimental, self-serving moral to boot, in short, a typically Hollywood exercise in the denial of mortality and illness.⁷

An intriguing exception to the above, exceptional in that it operates within the limits of commercial cinema, but yet transcends them in meaningful ways, is Denys Arcand's *Les Invasions Barbares* (*The Barbarian Invasions*, 2003).^{8,9} Denys Arcand, a native Quebecois, first made a mark on the Canadian and, later, the international filmmaking industry with *The Decline of the American Empire* (1986), an ironically pretentious title to a spicy, quick-witted comedy of mostly verbal manner, dealing with the sexual

and intellectual tensions within a highly erudite and equally highly libidinous group of Canadian history professors, during a weekend get-together in a lakeside chalet. Seventeen years later, Arcand reunites the very same group of friends, each having gone his or her own personal and professional way since, this time gathering around the bedside of one of the members, Remy, who is dying of cancer in a Montreal hospital. The reunion however, turns out to be only one aspect of the situation, in fact not even a central one, but it does provide a context and a perspective against which the director unfolds and explores several issues of considerable magnitude. The film's style, a cross between fiction and docudrama, lends reliability to its treatment of patient-related issues. Artistic attributes lend added credence and depth to the contemplation of these issues at the time of watching, and, no less important, the processing of the viewing experience that must follow.

The main justification for using a film to highlight and instruct on issues of relevance to a professional or paraprofessional audience concerns the unique characteristic of the given artistic medium. Television, for instance, often deals with patient-related issues, mainly through hospital series, but the visual and narrative features of television series stand in the way of a solid, profound treatment of the issues involved. Hospital series often glimpse through issues such as the treatment of the terminally ill, family support system, euthanasia, etc. But these issues bow before the medium's inevitable concern with superficially dramatized conflict and stock characterization, as well as stereotyping of patients, caregivers and staff alike. This is a limitation that cinema, provided it is made with talent and professional acumen, can transcend. To a far greater extent than television, a film can create a universe of interconnected meanings and a complex metaphorical exemplification system that can alert viewer's attention, feeling, and critical faculties to the multi-layered and multifaceted nature of the issues it explores via the art of filmmaking. We would like to substantiate cinema's claim to critical relevance, with respect to patient-related issues, by discussing selected scenes of the *The Barbarian Invasions*. In this short presentation we focus on the metaphorical multiplicity embedded in and projected through the film's suggestive title, namely the barbarian invasions (note, in the *plural*). This multiplicity is established early on, with the exposition scene, lasting barely three minutes, creating not just mood, but, visually, an environment replete with potential interpretations. This interpretative plurality that Arcand lays out before the viewer encourages suspension of judgment and increases the likelihood of empathy, both attitudes essential to the experience of the film, conducive to the consideration of moral ambiguity embedded in the sensitive and always difficult issues it raises.

The first image to appear is a close-range shot of two hands placing wafers in a small gold-coated box, against baroque music playing on the

soundtrack, angelic in its purity and bright lucidity. The first audio/visual mix suggests religiosity of sorts, a soft, idealized and abstract image, unattached to any specific time and locale. This proto-religious tranquillity cracks down in the following shot, which, in absolute opposition to the static first one is all incessant, energetic movement, sinuous, invasive, literally gut probing. Contrary to the first images, the suggestion is disquieting, and the locale becoming more and more specific, and rather ominous. The second shot relates to the first narratively: the hand that patiently arranged the discs belongs to a Catholic hospital nun preparing for her daily tour among a Montreal hospital's inmates, and what we observe in the second, long, travelling shot, is her walk along the hospital corridors. The scene is shot as if through her eyes, its pace seems accelerated, engulfing the viewer into a visceral, first-hand experience of the place. The quickened travelling shot throws the unprepared viewer directly into the infernal magma of a public hospital: underground maze of narrow corridors, overcrowded with occupied beds until there is hardly any room for passing through. There are no windows, no external source of light, and the artificial light colour is a yellowish hue, suggesting sickness, calling attention to the stifling environment of a public hospital.

The title "Barbarian Invasions" is a multiple metaphor spotlighting various contrasting aspects of the patient's world. The very act of hospitalization is an invasion upon one's privacy, blissful sense of daily, normal routines, and, going even deeper, one's sense of identity, falling abruptly from the grace of perceived independence to helpless passivity.

The very process of the disease is an invasion of the body by foreign destructive elements. Given the hospital context, this long, travelling shot conjures an invasive, endoscopic medical procedure examination, where the cinematic camera parallels the progression, as well as the function, of a lens at the end of the optical fiber used in endoscopy. A correspondence is thus established early on between the invasion of the body through high-tech procedures and a high-resolution cinematic exploration of patient-related realities. It is as though the filmmaker's camera performs an operation of its own, exposing and dissecting the arteriosclerosis of a nationalized medical system.

The analogy between medical procedure and cinematic exposure of the ills of the medical system goes a long way into the hidden corners of indifferent bureaucracy (an entire floor of the hospital is vacant due to administrative inadequacy) and the "invasion" of corruption (Sebastian, Remy's son, bribes both the administrator in charge and a workers' union head into moving his father to a private suite).

The answer to the implied titular question "who are the barbarians?" becomes complicated and highly ambiguous as the film unfolds, creating a universe abundant with associations and doubts. The metaphorical

repleteness of the barbarian invasions echoes throughout the film and constantly undermines social and political certainties, even as the certainty of life itself is undermined for the principle character, cancer-stricken Remy.

As the understandings of the film's title are almost inexhaustible, we'd like to offer, by way of conclusion, a division into exogenous (explicit, literal) and endogenous (implicit, metaphorical) ones. The endogenous ones have already been mentioned (cancerous cells attacking the body, offensive medical procedures, bureaucratic invasion of privacy and patient dignity, the indifference of the socialized medicine establishment, the assault on the patient's sense of identity, as well as on bodily intactness). To these we can add a second category of invasions, the exogenous barbarians:

1. Islamic terrorism: the most explicit reference to barbarianism takes its cue from the actual terrorist attack of September 11, 2001, appearing on the television screen within the action of the movie.¹⁰ Yet Arcand is obviously ambivalent towards this issue. In a marked juxtaposition to the protagonist's deconstructed family, we are witness to a harmonious dinner of an Islamic family, toppling stereotypical definition.
2. High-tech communications: Remy calling his son Sebastian "the prince of the barbarians," and it seems high-tech invades the whole fabric of life, replacing and making concrete communication superfluous.^{11,12} Although Sebastian never read a book, as Remy complains, he is an expert at computer games, making them his leisure preference (in fact, the introductory scene can be seen as a "Game Boy" run through a computerized maze). The computer has thus invaded leisure activity, to the dismay of the verbal old guard, and has made their world obsolete. This invasion is more subtle: while the wires of medical apparatus are all out in the hospital corridors, high-tech communication is wireless: unseen but pervasively felt.
3. The heroine invasion: Sebastian hires the service of a drug addict, once a childhood mate to help sweeten his father's last days, as well as ease his way out. Drugs intake is again a moot moral point: detrimental to individuals and society, but also a welcome relief to terminal patients.

The rich complexity of meanings Arcand achieves through cinematic elaboration of the title, within the viewing experience, can be profitably harnessed for medical staff's training, as it transforms either-or solutions into a more complex fabric surrounding the patient-related dilemmas and situations confronted by caregivers to the terminally ill.

Notes

- ¹ C Maccabe, 'Cannes 2003'. *Critical Quarterly*, vol. 45(3), October 2003, pp. 111-114.
- ² R Imboden, 'The Barbarian Invasions (Les Invasions Barbares)', *Film Quarterly*, vol. 58(3), Spring 2005, pp. 48-52.
- ³ N Carrey, 'The Ties that Bind', *Canadian Medical Association Journal*, vol. 171(10), 2004, pp.1224-1225.
- ⁴ F Ollivier, 'Convenient Arrangements with Death', in *Layers of Dying and Death. Papers Presented at the Fourth Global Conference: Making Sense of Dying and Death. July 2006*, K Woodthrope (ed.), Inter-Disciplinary Press. Oxford, United Kingdom, 2006, pp. 193-202.
- ⁵ WA Alarcon & CA Aguirre, 'The Cinema in the Teaching of Medicine: Palliative Care and Bioethics', in *Journal of Medicine and Movies*, vol. 3(1), January 2007, pp. 32-41, viewed on 11 October 2008, http://www.usal.es/~revistamedicinacine/Vol_3/3.1/ing.3.1.pdf/c_paliat_ing.pdf.
- ⁶ J Shapiro, 'Movies and Medicine: an Elective Using Film to Reflect on the Patient, Family, and Illness', *Family Medicine*, vol. 39(3), 2007, pp. 317-319.
- ⁷ R Ebert, 'The Bucket List. O Death, where is Thy Sting-a Ling- a-Ling?' January 10, 2008, viewed on 11 October 2008, <http://rogerebert.suntimes.com/apps/pbcs.dll/article?AID=/20080110/REVIEW/801100301&template=printart>.
- ⁸ IM Albaina, 'The End. Deaths in the Cinema', in *Journal of Medicine and Movies*, vol. 4(3), September 2008, pp.122-130, viewed on 11 October 2008, http://www.usal.es/~revistamedicinacine/Vol_4/4.3/ing.pdf/muertesdecine_ing.pdf.
- ⁹ R Aldarondo, 'Cinema as Relief and Final Goal', in *Journal of Medicine and Movies*, vol. 4(3), September 2008, pp.108-112, viewed on 11 October 2008, http://www.usal.es/~revistamedicinacine/Vol_4/4.3/ing.pdf/alivio_ing.pdf.
- ¹⁰ AS Dundjerovic, 'Contradictions and Paradoxes in Denys Arcand's *The Barbarian Invasions*', in *London Journal of Canadian Studies*, vol. 21, 2005/2006, pp. 3-18, viewed on 11 October 2008, http://www.canadian-studies.info/lccs/LJCS/Vol_21/Dundjerovic.pdf.
- ¹¹ *ibid.*
- ¹² M Yacowar, 'Corporate Invasions, Barbarian Invasions', *Queens's Quarterly*, vol. 111(1), Spring 2004, pp. 87-95.

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Transforming a Teacher and a Terrorist: Hospitalization in *Wit* and *The Cyclist*

Judith Musser

Abstract

The relationship between a character and the health care system becomes particularly evocative when the patient's personality, background, motivations, development, and education all factor into the healing process. The reader discovers that one of the most difficult challenges for Dr. Bering, in Margaret Edson's play *Wit*, is her professional displacement as an independent, tough, unsympathetic scholar to a dependent, childlike, and needy patient. The transfer is complicated by the fact that one of the residents is a former student and that her only visitor is a former professor. In the end, because of the medical environment, the patient, the doctor, and the visitor all experience a transformation.

The unnamed fictional narrator in Berberian's *The Cyclist* provides a different model to demonstrate the importance of a patient's identity in relation to his healing. The narrator is a terrorist; specifically, he was on a mission of destruction when he had a life-threatening bicycle accident. In this novel, as in the play *Wit*, there is transformation of a character; however, the cyclist arrives at the hospital already feeling alienated and violated by a system. Early in the novel, we know that the narrator is violent, highly sexualized, and a gourmand. We know this partially because his description of his healing process is expressed through imagery inducing these three aspects of his personality: the surgery performed by the doctors is compared to butchery, the intimate care of the nurses is sexualized, and the patient's recovery is motivated by his desire to taste food.

Despite these polar differences in their personalities, circumstances, and outcomes, both characters reveal a universal experience of transformation shared by their relationship to the health care system.

Key Words: Edson, Berberian, professor, terrorist, transformation, patient, cancer, *Wit*, *The Cyclist*.

1. Introduction

As I sit here at this table, I can tell you that, at the present time, I am not a patient. And as I look out into this audience, I believe I am correct in assuming that, at this moment, no one in this room is a patient. Before you

raise your hands in legitimate objection, I need to clarify my definition of the patient.

Visual stereotypes might be one way to begin. We are not in a hospital or medical facility; we are in an open space. We are not confined to a bed; we have mobility. We are not wearing a hospital gown; we are wearing our professional attire. We are not attached to machines with wires, tubes, monitoring devices. Someone did not measure our weight, our output, or our vitals two hours ago. We were free to choose our breakfast this morning, our wake-up time was determined by us, and the day's schedule, albeit connected to the conference, was ultimately self-determined. In other words, regardless of the health of our bodies and minds, we are not patients because we have control.

The discussion I will present examines this premise in the context of American literature. I will look at two characters, Vivian Bearing, a professor of English from Margaret Edson's Pulitzer Prize winning play *Wit* and an unnamed narrator/character whom I will call "the terrorist" from a novel by Viken Berberian called *The Cyclist*. Vivian Bearing has been diagnosed with ovarian cancer and the terrorist is in critical condition caused by a bicycle accident. Both the teacher and the terrorist confront the challenges of being a patient in a hospital. This new identity causes them to re-evaluate the importance that control has in their lives.

2. *Wit*

Dr. Vivian Bearing is a professor of English specializing in the 17th century metaphysical poetry of John Donne. Her role as a professor exudes control. Throughout the play, flashbacks take us to her classroom where she berates a student for his inability to answer her questions. In addition, we also see her callously refusing to grant an extension on a paper to a young woman whose grandmother has died. Vivian responds, "Do what you will, but the paper is due when it is due."¹ These examples demonstrate her command in the classroom as well as her control over her students.

Vivian's identity as a scholar of the English language also adds to her ability to manage her life. She controls her emotional objectivity because she is a scholar, an occupation that literary critic Bregman believes embodies that "cold intellectuality that precludes empathy."² Her studies of Donne's texts, even to the point of analyzing the significance of the placement of a comma, allow her to maintain control over her analysis of that text. Words are the tools of her trade and thus, before she first faces her cancer treatment, she, as any good researcher will do, assembles a medical bibliography and acquires new vocabulary. As Dr. Kelekian explains her diagnosis, Vivian internalizes his words and places them in categories that she recognizes, that she controls. When Dr. Kelekian uses the word "insidious" in his diagnosis,

Vivian questions his usage, redefines the word, catalogues the new definition of the word in her mind, and then gives him permission to move on.

While in the hospital, Vivian also attempts to control her identity. In one scene, a medical technician is recording Vivian's medical history and asks, "Doctor?" Vivian replies, "Yes, I have a PhD." The technician clarifies the question. "*Your* doctor." Vivian names Dr. Kelekian, but she reasserts her identity with, "I am a doctor of philosophy ... a scholar of seventeenth-century poetry."³

But as Vivian steps into the role of patient, her control diminishes. As a professor, she had control over her students; but as a patient, she must relinquish her control to her doctors, one of which, ironically, is her former student, a clinical researcher named Jason. As a scholar, she performed analysis on the text; as a patient, she is now the text that is read. As a master of the English language, she revelled in the power of words; but as a patient, her mastery of expression is reduced. For example, after an especially difficult treatment cycle resulting in violent vomiting, Vivian says to the audience, "O God. What's left? I haven't eaten in two days. What's left to puke? You may remark that my vocabulary has taken a turn for the Anglo-Saxon. God. I'm going to barf my brains out."⁴

Vivian's loss of control is demonstrated through her gradual regression into a childlike need for control and dependency. As death approaches, Vivian gives up her authority and her independence in exchange for a kind of childlike trust. In one scene, "like a frightened child who summons a parent for a late-night drink of water,"⁵ Vivian pinches her IV tube so that an alarm will bring Susie, the nurse, to her room. "I wanted her to come and see me," Vivian explains to the audience. "So I had to create a little emergency. Nothing dramatic."⁶ Susie quickly recognizes that Vivian is afraid of dying, and Vivian, who has now lost her self-control, is weeping. Susie asks, "Vivian, would you like a popsicle?"⁷ Edson's stage note indicates that Vivian, "like a child" says "Yes, please." Later in this scene, Susie returns and continues her mothering care to a nearly comatose Vivian by rubbing baby oil on Vivian's hands.

Vivian is not only childlike with the nursing staff, but also with her one and only visitor. She is visited by E. M. Ashford, an 80-year woman who was Vivian's professor in graduate school. During this visit, Professor Ashford reads to Vivian from a children's book, *The Runaway Bunny*, while cradling Vivian on the bed.

The final scene of the play demonstrates the culmination of Vivian's loss of control. In an earlier conversation with Susie, Vivian had made a choice concerning her end-of-life experience. Vivian decided that if her heart stops, she does not want to be resuscitated. However, when the moment comes that Vivian's heart does stop beating, her choice is not followed. Jason, the clinical fellow, ignores the DNR code⁸ and frantically administers

CPR⁹ and calling for a code blue. Susie tries to tell him that Vivian is DNR, but he screams back “She’s Research!”¹⁰ More screaming ensues as the Code Team comes rushing into the room. The stage directions read,

They throw Vivian’s body up at the waist and stick a board underneath for CPR. In a whirlwind of sterile packaging and barked commands, one team member attaches a respirator, one begins CPR, and one prepares the defibrillator. Susie and Jason try to stop them but are pushed away. (...) As they administer electric shock, Vivian’s body arches and bounces back down.¹¹

Even after her death, Vivian’s body is not under her control.

3. *The Cyclist*

Viken Berberian’s book presents a patient quite different from Vivian. We discover, from his internal monologue, that the unnamed narrator is part of a terrorist organization, referred to as “The Academy,” which is plotting to set off a bomb in a hotel building in an unnamed Middle Eastern country. The narrator’s part in this plot was to be the carrier of the bomb while under the guise of a competitor in a bicycle race that ends at the hotel. However, before the terrorist/narrator reaches the end of the race, he has an accident. He describes the accident as follows:

And then out of the middle of nowhere, like a useless gate that stands by itself in the middle of the desert, a parked car sends me into the cement. I’m not sure of the model or make, but I feel as though I’m in a public stadium, completely naked. The bystanders watch as if witnessing an execution. My bicycle trembles and the crowd roars in anticipation. I have difficulty recalling the moment of impact, except that the force sent me tumbling to the ground. In an instant, the world turns prune black, shriveled at the edges. I slowly lose my appetite. My senses start to fade. My blood, sweeter than a pomegranate, drains from within me. My limbs taken from me so that others can eat.¹²

Stylistically, you will note that this narrator relies on food-related metaphors (prune black, losing his appetite, blood sweeter than a pomegranate, an allusion to his body feeding others.) A second thing to notice is that in this description, the narrator presents himself as a victim, the one who is acted upon, the one being controlled. Twice he is the passive

receiver of something that is “sent”: he says that a “parked car sends [him] into the cement” (not that he collided with the stationary car) and that the force “sent [him] tumbling to the ground.” He also is the object being acted upon when he describes that he felt like he was in “a public forum” with witnesses objectifying his naked body as at “an execution.” To finalize his lack of control, his description does not acknowledge his own body’s reaction; instead, it is his bicycle that “trembles.” Keeping these two conditions in mind (his obsession with food and his lack of control at the time of the accident), I would like to look at the three passages in which this terrorist describes his adjustment to being a patient.

Remembering Edson’s play, Vivian Bearing entered the hospital from a position of control. As a professor of English, she maintained autonomy in her job, her classroom, her research, and her identity. This narrator’s story is about someone who enters the hospital from a life in which he had no control. The Academy, the terrorist organization he trains with, completely dominated his education, his movements, his community, his romantic relationships, and his destiny. His participation in the bike race was not his decision. His accident demonstrates even more clearly that his body was not under his command. And Berberian creates a terrorist who has a fetish for food. He is a self-proclaimed gourmand and is obsessed with all things culinary. We learn that this obsession has taken over his life from childhood to the present. It controls his physical capabilities, his pastimes, and, as we have seen already, his language. So, what happens when this terrorist faces a hospital setting?

When Vivian entered the hospital, she proclaimed her profession, her academic credentials, and employed her research skills to control her language. Our terrorist patient cannot proclaim who he is; he can only complain about his loss of identity. He tells the reader,

I’ll spare you the grisly details of my surgery, except to say that the butcher who sent me into the torpid sleep sliced a section of my gray matter like a knife-wielding chef about to serve a cold-cut platter. I now spend my days in a bed. My head is shaved. My ribs are sore and my face, which in normal times has a chocolate hue, is bludgeoned blue. My mouth smells like fermented lentil stew. My portly build has turned pita thin.¹³

We recognize him because of his familiar use of images related to food. And we recognize the victimization implied in his description; the surgeon is not a skilled doctor with a scalpel who is performing lifesaving brain surgery, but a butcher who has now caused his state of unconsciousness.

Even though we recognize him, the patient does not recognize himself because his body has changed. He says that his face was the colour of chocolate, but now it is blue; his once portly body is now as thin as pita bread. He reiterates his alteration when he remembers that he used to enjoy the freedom of motion and the power of being physically conditioned. "Look at me now," he says,

strapped to a hospital bed, more useless than a loaf of stale bread. All around me blood oozes through plastic tubes: a sanitized highway of body fluids and liquid nutrients race through me. I'm a drugged giant on an IV, an emaciated zucchini. The doctors have turned my body into a basin full of polysyllabic chemicals: an unsavory stew of pain killers. Seeing me like this you would never guess that I'm a well-seasoned cyclist, that I've covered continents, raced along the Loire under the luminous summer sky. My body was fighting fit. I benched 103 kilos, no sweat.¹⁴

We remember that Vivian Bearing came into the hospital from a position of self-determination and asserted her identity. The terrorist comes into the hospital from a position of victim-hood; he was a pawn of "the Academy," the victim of a parked car, the prey of an uncontrollable appetite, the casualty of a masochistic surgeon, and the sufferer of endless hospital tubes. Vivian's experience as a patient caused her to lose control, but the terrorist, who began his hospitalization in a state of complete dependency, actually uses his condition of being a patient to gain control.

Because of his cycling accident, the terrorist had brain surgery resulting in an induced coma and temporary paralysis. One of the bodily functions that he has no control over is his urination, thus he has a catheter. However, as he begins to regain consciousness, in his first attempt to gain control and, simultaneously, to enact revenge against the hospital nurses, his body, somehow, rejects the insertion of the catheter. This causes the nursing staff to create a system of using cotton padding which they must dispose of every morning. The terrorist comments, "I cannot help relish the disgust etched in her face. Just when she's finished pampering my penis, I squirt an extra ounce of warm piss with measured grace."¹⁵ Another example of his attempt to "leave her with a trail of [his] reaffirmed existence"¹⁶ is to control the timing of a "fantastic fart."¹⁷ His next act of defiance comes when he is able to move a finger for the first time. Although it is just a pinky, he directs it at the nurse as a "substitute for the middle finger."¹⁸ Finally, he is able to make his "two hands rise from the bed ... a miracle no less epic than the parting of the Red Sea," and he relishes in his ability to make the "nurse look at [him] with incredulous eyes."¹⁹

This slow progression of power and control is most significantly noted when the patient/terrorist begins to move his body. He describes this progress as follows: "I start to crawl to the four corners of my room. Eager to engage the outside world, I begin to reconstruct my words. Like a tiny fetus, I enter a period of rapid growth. I turn circles in my bed from breech position."²⁰ This patient is gaining control and his progress is described in the context of a growing fetus and a crawling baby. His active verb construction indicates a change in his ability to control his world. In contrast, Vivian Bearing was retreating into a state of childhood that was dependent, reclining, unengaged, and immobile. For the terrorist, the allusions to childhood reflect his gaining power and he progresses from infancy to the wheelchair and eventually to return to the world.

So what do we learn from these depictions of two characters? I think it would be too simplistic to use these literary texts as symbols of an artistic vision of punishment and reward or cause and effect. Margaret Edson is not proposing that empowered professors of literature have to face a deadly disease and a painful death to understand what losing control is all about. And Viken Berberian is not proposing that pawn-like recruitments for terrorism can be made whole through six months of lying in a hospital bed pissing on nurses. What I do find significant is that these two writers chose the hospital as the setting to depict their creative expression of dramatic insight.

I began this discussion with a premise that all of us in this room are not enacting the role of a patient because we have some control over our lives. These two pieces of literature support this premise. We are not patients because, unlike Vivian, our professional identities are intact - just look at your name tags; we can express ourselves in specialized, yet translatable language; we behave and are treated according to our ages; and we can expect our wished and desires to be carried out. We are not patients because like the terrorist, we can control our bodily functions; we can use language and gesture to express our sentiments; and we can take our ideas, now expanded from this conference, back to our other worlds.

Notes

¹ M Edson, *Wit*, Faber and Faber, New York, 1999, p. 63.

² B Bregman, 'Blame the Scholar, Not the Discipline', *Lancet*, 6 March, 1999, p. 851.

³ Edson, pp. 16-17.

⁴ *ibid.*, p. 32.

⁵ M Eads, 'Unwitting Redemption in Margaret Edson's *Wit*', *Christianity and Literature*, vol. 51, 2002, p. 247.

⁶ Edson, p 64.

⁷ *ibid.*, p. 65.

⁸ Do Not Resuscitate.

⁹ Cardio Pulmonary Resuscitation.

¹⁰ Edson, *Wit*, p. 82.

¹¹ *ibid.*, p. 83.

¹² V Berberian, *The Cyclist*, Simon & Schuster, New York, 2002, p. 187.

¹³ *ibid.*, p. 14.

¹⁴ *ibid.*, p. 38.

¹⁵ *ibid.*, p. 57.

¹⁶ *ibid.*, p. 60.

¹⁷ *ibid.*, p. 76.

¹⁸ *Ibid.*, p. 60.

¹⁹ *ibid.*, p. 76.

²⁰ *ibid.*, p. 77.

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PART VI

How Patients Talk with Doctors

The Patient and Communication: *Logos, Pathos, and Ethos*

Carie S. Lambert

Abstract

Historically, patients have considered physicians as public servants who shared their knowledge and skill to save lives and treat disease. Patients would present with symptoms, and the physician would examine the patient and diagnose and treat the illness. However, today, patients participate more in the treatment process by providing family and personal medical histories, discussing possibilities, and sometimes having a say in the treatment that physicians prescribe. Patients read provided information, learn about illness, and give informed consent for treatment.

The relationship between a patient and a physician is just that - a relationship - and a healthy relationship requires that both parties actively participate. Therefore, as patients wish to acquire quality care, they must communicate with their physicians and be responsible to learn about diseases and the physicians' diagnoses, ask questions, comply with the physicians' instructions, and pay for services. In communicating with their physicians, patients should apply Aristotelian elements of rhetoric:

- *Logos* (reason) - to accurately explain symptoms and concerns and participate in decision-making,
- *Pathos* (emotion) - to communicate with physicians despite emotions such as fear or concern and without threatening the physician, and
- *Ethos* (integrity) - to build trusting relationships with their physicians.

Patients must apply these elements to their communication but without manipulating their physicians, rather to express what the patients know and are experiencing. While using these Aristotelian elements to communicate, patients cannot adopt Aristotle's theory that each situation has an absolute truth. Physicians will diagnose and treat illnesses according to their own education and experiences; therefore, different physicians may choose different options to treat their patients.

Once patients understand that their physicians are human (and not perfect) and they honestly work with physicians as service providers, their medical care will be more personalized and will better meet the patients' - and the physicians' - needs.

Key Words: Patient, responsibility, communication, Aristotle, *logos, pathos, ethos*, technical communication.

1. Introduction

Historically (as Woods states), physicians have been considered to be public servants who work to provide care for anyone in need.¹ Physicians train in the medical field - completing medical school, residency, and sometimes fellowship - and then use their knowledge and skill to care for patients. Patients present with symptoms, and the physicians talk with and examine patients, diagnose their diseases, and then inform patients of treatment options, recommending the best options. Physicians cannot, however, accurately diagnose illnesses without the patients' information, and patients must present information and do so to persuade their physicians to diagnose and to treat patients.

To persuade physicians to act, patients must apply persuasive speech. Persuasive speech, according to Aristotle, leads to action. Aristotle states, "The use of persuasive speech is to lead to decisions. (When we know a thing, and have decided about it, there is no further use in speaking about it.)"² This persuasive speech must occur to ensure a relationship exists between the physician and the patient.

This relationship between a patient and physician is just that - a relationship - and a healthy relationship requires that both parties actively participate. A healthy relationship, according to Crowe, has four characteristics: a shared vision for the future, boundaries that allow both parties to benefit, a "shared work ethic," and "communication about communication."³ A healthy relationship between a patient and a physician requires that they share a vision for the patient's health; they share boundaries such as fair billing and prompt payment, so both benefit; they share a "shared work ethic" in which both parties work to maintain the relationship; and they communicate. Communication is the focus of this paper.

Ellingson and Buzzanell write that effective communication between the physician and the patient

can(a) elicit patient concerns, particularly on sensitive issues that patients find uncomfortable or difficult to discuss; (b) maximize patient satisfaction; (c) improve preventative medicine; (d) produce more accurate diagnoses; (3) increase patient compliance; (f) decrease malpractice suits; (g) enlist political support from patients in shaping federal medical policy decisions; and (h) create more professionally rewarding medical practices.⁴

The American Medical Association (AMA) and the American Association of Retired Persons (AARP) published a document on "The

Patient-Physician Relationship.” This document addresses patient and physician responsibilities: for partnership, communication and shared decision making. The design of the document reflects the importance of communication in this relationship, in that communication is the second section in the document. The document presents responsibilities for both the physician and the patient to communicate.⁵

Physicians and patients can more effectively communicate if they apply Aristotle’s classic elements of rhetoric: logos, pathos, and ethos. In the past, physicians have been held responsible for the communication in the patient-physician relationship; however, more researchers, medical organizations, and physicians are now expressing that patients must also take responsibility for communication with their physicians. Patients can best communicate with their physicians using classical elements of rhetoric to overcome communication barriers and communicate effectively and ethically.

This paper simply outlines and simplifies Aristotle’s elements of rhetoric so educators can share this information with patients and thus empower patients to better communicate their needs and thus improve their experiences with their physicians.

2. The Responsibility of Communication

According to Ellen J. Belzer,⁶ Mary R. Talen, Kate Grampp, Angela Tucker, and Janet Schultz,⁷ and Deborah McGee and Donald Cegala,⁸ most literature addresses physician-patient communication primarily as a responsibility of the physician. The physician is responsible to diagnose the disease, share medically related information with the patient, and instruct the patient, who must follow the physician’s instructions. However, recently, hospitals, physicians, medical organizations, and researchers have addressed that patients are also responsible for communication in the patient-physician relationship, according to Iltis and Rasmussen.⁹ By definition of a relationship, a patient must participate and communicate, and (according to Benjamin) the patient has a moral obligation to participate in the relationship with the physician.¹⁰

Common sense supports this, as a physician cannot know a patient’s history, symptoms, or needs unless the patient - or someone on the patient’s behalf - shares personal information. Research by Charles, Gafni, and Whelan;¹¹ Ellingson and Buzzanell;¹² and Siminoff, Ravdin, Colabianchi, and Saunders Sturm¹³ also shows that when patients communicate, they experience more satisfaction with their physicians and medical care and they experience improved health outcomes.¹⁴ The patient can communicate during face-to-face meetings at the hospital or physician’s office or, as Stensland and Malterud stated, through illness diaries in which patients document what they experience between their appointments.¹⁵

To communicate with the physician, the patient must prepare and present information in an ethical and rational manner. Physicians take notes, but, as *Consumer Reports on Health* states, patients should also note what they want to discuss with their physicians.¹⁶ The patient must include information about family and medical histories, financial difficulties, concerns, and expectations of the physician. Otherwise, the patient cannot expect the physician to provide the highest quality of care.

3. Aristotle's Elements of Communication

Aristotle determined that rhetoric was a skill that any speaker would use to persuade someone to act. Rhetoric is "the means of persuasion on almost any subject presented to us; [...] in its technical character, it is not concerned with any special or definite class of subjects."¹⁷ Bizzell and Herzberg paraphrase Aristotle; in other words, through rhetoric, the speaker presents information to persuade but not always about a topic on which the speaker is an expert.¹⁸ Further, Aristotle determined that a speaker's presentation "[...] should appeal to reason (*logos*), emotion about the subject under discussion (*pathos*), and trust in the speaker's character (*ethos*)."¹⁹ In other words, effective communication combines *logos*, *pathos*, and *ethos* - classical elements of rhetoric - to present truth.

Physicians need to apply Aristotle's elements of rhetoric. Patients also need to apply these elements when they communicate with their physicians; however, few researchers have addressed how patients should communicate with their physicians. This researcher searched the words "patient logos pathos ethos" through the electronic library system at The University of Texas at Dallas, using 16 Internet databases:

- HealthWatch
- CINAHL
- General Science Abstracts
- Health Source - Consumer Edition
- Health Source: Nursing/Academic Edition
- MEDLINE
- Pre-CINAHL
- PsycARTICLES
- PsycINFO
- Essay & General Literature Index
- Humanities Abstracts
- Humanities International Index
- Religion and Philosophy Collection
- America: History & Life
- Historical Abstracts

- Philosopher's Index

(These databases are part of two "Academic Search Complete" commands: one for medicine and one for the humanities, literature, and philosophy.)

This search resulted in zero (0) matches; no articles address or instruct patients on how to communicate with their physicians using classical elements of rhetoric. The results of this search indicate that researchers are not using classical terms - specifically these Aristotelian terms - to evaluate or teach patient communication. However, *logos*, *pathos*, and *ethos* are, according to Polansky, "timeless principles of persuasion,"²⁰ and patients should apply these elements of rhetoric: to fully express their requests and persuade the physician to act on the patient's behalf, establishing a relationship and providing treatment for the patient's disease.

a. *Logos*

The first classical element of rhetoric is *logos*. Aristotle defines *logos* as the process of proving something with logic and reason using examples and logical thought processes. In *Rhetoric*, Aristotle writes, "Every one who effects persuasion through proof does in fact use either enthymemes or examples: there is no other way."²¹ He then writes, "'Examples' are most suitable to deliberative speeches; for we judge of future events by divination from past events. Enthymemes are most suitable to forensic speeches; it is our doubts about past events that most admit of arguments showing why a thing must have happened or proving that it did happen."²² Aristotle explained that a speaker will establish *logos* through experience or through enthymemes, which are argument statements that begin with a fact, state a supporting statement, and then allow the audience to make the conclusion.

Logos applies to the intellect, and a patient can best provide information that supports his physical need for care through *logos*. By applying *logos* to communications with the physician and then applying *logos* to interpret what the physician says, the patient will rationally approach medical care.

The patient must apply *logos* as the element of reason: to accurately explain symptoms, frequency of symptoms, medical histories, and other facts. The AMA/AARP statement of patient and physician responsibilities lists four communication responsibilities, one of which requires patients logically share information with the physician. The statement says, "I will talk to my physician about personal choices and future decisions, including end-of-life care and organ donation."²³ The patient must address the situation with logic to address what family members or the physician *might* need to know.

In addition to applying *logos* to what he says or believes, the patient must apply *logos* to ask questions. As McGee and Cegala report,

Research consistently shows that patients typically do not ask doctors many, if any, questions, even though virtually all patients claim they want as much information as possible about their medical condition.²⁴

Patients must ask questions and apply logic to understand the physician's answer and to provide what information the physician needs.

b. *Pathos*

The second element of rhetoric is *pathos*. Aristotle states, "The Emotions are all those feelings that so change men as to affect their judgements, and that are also attended by pain or pleasure. Such are anger, pity, fear and the like, with their opposites."²⁵ Patients cannot deny their emotions, or the emotions of their physicians, when they pursue medical care. In fact, according to Greenley, Young, and Schoenherr, patients who admit their feelings - specifically anxiety and fear - are more likely to be satisfied in their medical care than those who deny their feelings.²⁶ Patients who apply *pathos* when they communicate with their physicians will acknowledge their concerns, allow the physician to see their vulnerabilities, and potentially increase their satisfaction with their medical care.

One researcher (Benjamin) states that patients have a moral obligation to report about their medical status to their physicians,²⁷ and another researcher (Brody) states that patients have a moral obligation to also report their thoughts and feelings to their physicians.²⁸ To apply *pathos* to communication, the patient must admit his feelings and thoughts so the physician can address those emotions as part of the treatment.

The AMA/AARP statement of patient and physician responsibility instructs patients to be responsible to "[...] share my health concerns with my physician" and to "[...] talk openly about my health with my physician."²⁹ The patient is responsible to put aside feelings and logically discuss his health and his concerns with the physician; however, even if a patient sets emotions aside, he must acknowledge that those emotions exist and share those with the physician.

c. *Ethos*

The third element of rhetoric is *ethos*, through which patients can establish their integrity and reputation as a patient. Aristotle addresses *ethos* in *Rhetoric*; he says "[...] persuasion is effected through the speech itself when we have proved a truth or an apparent truth [...]."³⁰ He also states, "There are three things which inspire confidence in the orator's own character - the three, namely, that induce us to believe a thing apart from any proof of it: good sense, good moral character, and goodwill [...]. anyone who is thought to have all three of these good qualities will inspire trust in his

audience.”³¹ To establish trust, the patient must communicate information as well as trustworthiness.

The physician must present as an ethical, trustworthy individual; however, the patient must take the same responsibility. A physician does not want to treat an untrustworthy patient; the risk of treatment failure, complications due to noncompliance, malpractice, and other negative outcomes are too dangerous and could cost the physician’s medical practice. Many patients pursue a relationship with a physician for selfish, unethical, or illegal gain: to obtain prescription medications, to seek attention, or to gain financially. Patients need to approach physicians with pure motives - to obtain medical care and thus reinstate health - and to ethically present to their physicians. As Gauthier says,

Patients have a responsibility to be truthful with their physicians whose time and expertise, as a health care resource, are being invested in making treatment recommendations based on the information provided to them.³²

Patients must also apply *ethos* when they follow-up with physicians, accurately reporting about their compliance with the physician’s instructions or about any developments that have occurred since the patient’s last visit. For example, according to Benjamin, if the patient has not taken medication that the physician ordered, the patient should be responsible to accurately report this to the physician so the physician can trust the patient, know if the patient has complied, and apply that knowledge to future treatment.³³ The American Hospital Association’s document “A Patient’s Bill of Rights” states

Patients are responsible for providing information about past illnesses, hospitalizations, medications, and other matters related to health status. To participate effectively in decision making, patients must be encouraged to take responsibility for requesting additional information or clarification about their health status or treatment when they do not fully understand information and instructions. Patients are also responsible for ensuring that the health care institution has a copy of their written advance directive if they have one. Patients are responsible for informing their physicians and other caregivers if they anticipate problems in following prescribed treatment.³⁴

The AMA/AARP statement on “The Patient-Physician Relationship” also states that the patient is responsible to be honest and to openly talk about health and concerns.³⁵ Patients who honestly discuss their histories, their compliance, their feelings, and their expectations establish themselves as trustworthy participants in the patient-physician relationship.

4. Aristotle’s Theory of Absolute Truth

Aristotle believed (according to Bizzell and Herzberg) in an absolute truth, which one could discover, not through debate between experts but through scientific presentation.³⁶ Aristotle’s idea of an absolute truth cannot apply to medicine, because physicians apply their own education, philosophies, and experiences and must determine the best treatment option, not through an absolute but by considering each individual patient and that patient’s history, symptoms, current health situation, and needs. The physician must apply discernment driven by medical standards and personal knowledge of the patient.

Unfortunately, some patients expect medicine to be driven by absolutes. Patients come to their physicians expecting answers and predicted outcomes from their treatment, and sometimes physicians cannot offer absolute answers or predict outcomes. Patients expect physicians, with their education and experience, to fix all ailments; but patients and physicians are only humans and both must have realistic expectations and allow for inherent flaws. Physicians try to communicate that each case differs - through pre-operative and follow-up appointments, secondary information sources, and informed consent; however, patients are sometimes surprised by what they consider unexpected outcomes.

Patients must realize that each case is individual, and each outcome is unique. They must trust their physician to make the wisest choices and provide the best care, but patients must also realize that outcomes differ from patient to patient.

5. Barriers to Effective Communication

When they communicate with their patients, physicians must overcome barriers to communication. Patients must also recognize and seek to overcome those barriers, which include educational, emotional, and perceived barriers. If patients apply classic elements of rhetoric, they can more easily overcome these barriers to better understand and communicate with their physicians.

a. Educational Barriers

Patients are rarely as educated in medical issues as are their physicians (otherwise, those patients would not need the physicians). Physicians are working to tear down these educational barriers by providing

websites, printed information sheets, and additional resources and encourage patients to research diagnoses and learn about illnesses and treatments. Patients also need to overcome education barriers: by

- choosing physicians who speak their languages
- asking questions if they do not understand
- reading about diseases so they better understand their diagnoses and treatment.

Patients can first address educational barriers by applying *logos* and recognizing that physicians are subject-matter experts and therefore do have more education and information about medicine. Patients can then apply *pathos* and express their confusion or concern if they do not understand what their physicians say. Patients should also apply *ethos* to overcome educational barriers by asking questions and being honest with their physicians, understanding that, while they have extensive education, physicians have studied to establish their skill and thus credibility as medical practitioners.

b. Emotional Barriers

Anytime patients undergo medical treatment, they must address emotions such as hope, fear, anxiety, joy, and relief. Therefore, patients must

- recognize their emotions
- communicate those emotions to their physicians
- ensure that emotions do not affect their communication or their decision making

Patients can apply *logos* to their communication and understand that all patients undergoing treatment sense similar emotions. Patients will most likely apply *pathos* without effort; however, they must acknowledge that their emotions can create barriers but can also help them comply with their physicians' instructions. Patients should also apply *ethos* and acknowledge their feelings so their physicians do not have to guess about what the patients are experiencing.

c. Perceived Barriers

While patients may not realize it, they must deal with perceived barriers that result from information that they gather from sources outside of their physicians' offices. These sources can include the patients' families, friends, society, and media: that is, newspapers, books, movies, and television.

The media has created real barriers to communication through unrealistic portrayals of physicians. One physician (Dr. D. Lambert) recently stated, "Television programming has created unrealistic expectations of doctors. Because of television, patients think that everything will work out in the end: that the physician will know the patient's diagnosis when he walks into a room, and that patients won't experience complications. That perception just isn't true."³⁷ Patients may believe they know more about the education, the experiences, and the careers of physicians because the media presents entertaining stories about physicians. Belzer states that coverage about new procedures and equipment have influenced patients to expect physicians to be able to recognize and treat anything.³⁸

Patients need to apply *logos* to these superficial barriers and realize that the media does not always present its audience with reality. Patients also need to apply *pathos* to empathize that physicians are normal humans who experience joy, anger, pain, and the other emotions that any human feels. Patients also need to apply *ethos* to put aside the perceived barriers and trust that physicians want to see their patients healthy and thriving.

6. The Issue of Informed Consent

Physicians are legally required to inform patients about treatments, potential complications, and potential outcomes; this is called informed consent. Informed consent protects the patient and ensures that the physician gives patients information about treatment. During an interview, Dr. D. Lambert described informed consent: "In ethical terms, I am responsible for informing my patient of the diagnosis, explaining the treatment and potential complications, answering questions, and discussing other treatment options."³⁹

Informed consent may not, however, protect the physician if the patient does not take responsibility to ask questions or communicate with the physician. "In legal terms, legal consent does not exist," said Dr. Lambert. "Even if I inform the patient and he signs a consent form, he can sue me if something does not go the way he wants or expects."⁴⁰ Patients need to participate in communication and help protect their physicians, just as their physicians seek to care for patients.

7. Conclusion

Communication is today recognized as a responsibility of both physicians *and* patients if they are to have an effective relationship. Patients must participate in their relationship with their physicians, and they can communicate more effectively and more ethically if they apply classical elements of rhetoric - *logos*, *pathos*, and *ethos* - to communicate and to overcome barriers to communication with their physicians. When patients communicate more effectively, they enable physicians to know more about

the patients and therefore provide more accurate treatment. However, many principles of communication are too complex for patients; therefore, patient educators and technical communicators can apply these simplified definitions to better prepare patients to communicate with their physicians.

In addition, by applying *logos*, *pathos*, and *ethos* to their communication with physicians, patients understand that their physicians are human (and not perfect) and they enable their physicians to provide more personalized and more effective health care. The idea opens doors for future research and the establishment of communication education for patients.

Notes

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- ¹⁸ P Bizzell & B Herzberg, 'Introduction', *The Rhetorical Tradition: Readings from Classical Times to the Present*, Bedford Books, Boston, 1990, p. 29.
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- ²⁰ B Polansky, 'Ethos, Pathos, and Logos', *Dental Economics*, 2007, viewed on 11 October 2008, <www.rdhmag.com/display_article/338293/54/none/none/Colum/Ethos.-pathos.-and-logos?host=www.dentaleconomics.com>.
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- ²² *ibid.*, p. 36.
- ²³ American Medical Association, op. cit., p. 1.
- ²⁴ McGee & Cegala, op. cit., p. 413.
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Ethical Spaces: Ethical Dilemmas in the Clinical Encounter between Patients and Their Biomedical and Complementary Medicine Practitioners

Ondine Spitzer

Abstract

In Australia complementary medicine practitioners are not required to have medical training. In fact most complementary medicine practices are not even registered. Thus the range of disciplines and levels of training of complementary medicine practitioners vary enormously across the country. At the same time public use of complementary medicines and techniques is extremely common. For a variety of reasons patients are not telling their doctors about their utilization of complementary medicines and practices.

This scenario creates the potential for complex interactions between doctors, complementary medicine practitioners, and their patients. And these interactions involve a number of ethical concerns: safety, beneficence, autonomy. This paper explores the dynamic triangular interface of the clinical encounter between patients and their chosen health providers. It focuses in particular on the ethical dilemmas and complexities that may, and often do, arise at this interface.

As a health researcher in the medical faculty of a prestigious university I will present the findings of a number of studies about complementary medicine use in Australia. As a complementary health practitioner with 13 year clinical experience, including 9 years working alongside medical practitioners, I will also bring personal accounts of this complex ethical space into discussion.

Key Words: Complementary medicine, bioethics, medical ethics, clinical issues, clinical relationship.

1. Introducing the Issue...

There are three key elements in this issue. Firstly, unlike in many other countries, Australian complementary medicine practitioners are not required to have medical training. In fact most complementary medicine practices are not even registered. The range of disciplines and levels of education and training of complementary medicine practitioners thus varies enormously across the country. Second, rates of complementary medicine use in Australia are extremely high. And third, for a variety of reasons patients are not telling their doctors about their utilization of complementary medicines and practices.

This scenario creates the potential for complex interactions between doctors, complementary medicine practitioners, and their patients. And these interactions involve a number of ethical concerns: safety, beneficence, autonomy. This paper explores the dynamic triangular interface of the clinical encounter between patients and their chosen health carers. It focuses in particular on the ethical dilemmas and complexities that may, and often do, arise at this interface.

2. ...And Me

I am a middle-class, middle-aged, Westernised woman, influenced primarily by mainstream Australian values, including the hegemony of modern mainstream medicine, which I will call biomedicine. I am also a complementary medicine practitioner, a naturopath. My training in naturopathy was a Bachelor degree incorporating a thorough grounding in the medical sciences as well as in those areas particular to the practice of naturopathy, namely herbal medicine, nutrition, and homoeopathy. I am also a medical anthropologist, with a Masters degree in the study of health beliefs and practices in different cultures. Primarily the culture I have studied is the culture of naturopathy. I am also a health researcher working on a number of projects in Australian universities. So professionally I am both a health practitioner and a critic of health practice. I am, as we all are, profoundly influenced by the dominant paradigm of biomedicine, but I am also intimately familiar with other modes of health belief and practice. I am mainstream in that I have health science qualifications from a prestigious university but I am placed on the fringes as a complementary medicine practitioner. I am both an insider and an outsider, influenced by both conventional cultural values and “alternative” ones.

3. The Story

I begin by describing the setting for the practice of complementary medicine in Australia, then go on to discuss the meaning of this for the different characters in this story: the patient, the doctor, and the naturopath. What will become clear then, I hope, is the potential for conflict for and between each of these characters. I will then outline the ethical dilemmas in this complex setting and finish off with some comments about where to from here.

Case Study. What kinds of ethical concerns does this situation raise?

A patient presents to the doctor and while describing the current state of his arthritis mentions that on the advice of his naturopath he is taking fish oil supplements to decrease levels of inflammation in his body and this seems to be working. The doctor casts doubt on whether fish oils can be useful preventatively and suggests to the patient that this is a waste of money.

4. The Setting

a. What Is Complementary Medicine?

Let me begin by explaining what complementary medicine is and how it is practised in Australia. Actually the term in vogue in medical discourse is CAM, “Complementary and Alternative Medicine.” The medicines themselves are derived from natural products - herbs, mineral, foods, etc. - and are thus often called natural medicines. What practices CAM encompasses varies according to the author, their cultural and historical context, their profession, and their relationship to conventional medicine. CAM is a cultural construct and the nuances the term carries now are culturally specific, historically entrenched and syncretic. Furthermore the parameters of CAM are dynamic: what was once alternative may now be mainstream and vice versa.

For convenience let us take the definition developed and adopted in 1995 by the Office of Alternative Medicine in the USA:

Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting well-being.¹

In other words, any health practice outside biomedicine could be considered CAM. There are a number of problems with this. Firstly, this definition does not make clear whether we are discussing an approach that is in addition to or a substitute for biomedicine. Second, to define CAM only in relation to biomedicine is to devalue it as being the “other” which is always and necessarily in a lesser position in relation to the dominant paradigm. Third, using this definition of CAM we are lumping together various practices under one heading, one label, which makes it difficult to untangle and clarify any discussion of non-biomedical practices, especially in relation to published research. Fourth, boundaries within CAM and between the CAM

domain and the domain of the dominant system are porous; they are not always sharp or fixed.

b. Prevalence of CAM

CAM is extremely popular in Australia with over two-thirds of the population using CAM therapies and over 40% visiting CAM therapists. Overall Australian patients visit CAM practitioners as frequently as they consult with medical practitioners.² There are many reasons for CAM's popularity, but one of the most common is dissatisfaction with "the orthodox medical encounter [...] [including] a sense of not being valued sufficiently as a person within the medical system."³

c. Naturopathy

For the purposes of this discussion I would like to focus on the CAM practice that I am most familiar with and which is in common use in Australia, and that is naturopathy. In contemporary Australia, naturopaths utilise one or all of a number of healing modalities that incorporate use of natural medicines and techniques. These include herbal medicine, homoeopathy, and nutritional medicine, and sometimes also physical therapies such as massage, osteopathy or kinesiology. The underpinning paradigm of naturopathy is the action of a vital force that enables the individual to heal, given the right conditions. This paradigm is based on empirical evidence and retains some of the pre-scientific features of its origins. Naturopaths assess where and why obstacles to this self-healing ability have developed, and provide individualised treatment using natural medicines and techniques.

In Australia there is no formal registration of naturopaths. There are, however, incentives for formalized training and the gaining of recognised educational qualifications focused around qualifying for health insurance rebates and professional indemnity insurance. The curriculum content and standard of education in naturopathy in Australia varies enormously. As a rule, students are taught ethical concepts and practitioners belong to professional associations which have professional codes of conduct, including standards for ethical behaviour.

There is a growing body of (scientific) evidence of clinical efficacy and safety of natural medicines but much clinical information about them is still largely empirical rather than "evidence based." There are many in the biomedical field concerned about issues of safety and efficacy of CAM in the face of few clinical trials. Naturopaths, generally, are comfortable and confident about empirical based evidence. Certainly there are contested understandings about CAM in the broader community.

So CAM is complementary and alternative to biomedicine. Where biomedicine is mainstream, regulated, scientific and reductionist, CAM in

Australia is various, generally unregulated, and based on empirical evidence. It is also very popular. Naturopathy is one CAM and utilises natural medicines and techniques within a paradigm of individualised assessment of vitality.

5. The Characters

The characters in this presentation are patients, their doctors, and their complementary medicine providers.

Firstly, the patient. It has been established in the literature that to get relief from their symptoms patients ultimately make pragmatic decisions congruent with their worldview when they choose which kinds of health practitioners and practices they utilise.⁴ However, most people do not expect naturopathy alone to cure them and use natural therapies as adjuncts to more mainstream medical treatments. Alarming in Australia while almost 50% of CAM users concurrently take pharmaceutical drugs with their natural medicines, less than half of these report their use of CAMs to their doctor.⁵ This is of concern largely because of the potential for drug interactions (either positive or negative) between conventional and CAM medicines.

The other characters are the health practitioners. Many doctors are antagonistic towards CAM therapies and practitioners. Often the feeling is mutual. CAM practitioners commonly deride doctors for their dangerous treatments and impersonalised approach. When advice and treatment for a health complaint is sought from more than one healthcare provider, especially when each practitioner utilises different paradigms, medicines and techniques to understand and treat health problems, we have complex interactions and the potential for conflict. I would like to focus in on these complexities by looking at some of the ethical dilemmas that can arise in this triangular interface between patients and their chosen health practitioners. We will look specifically at the clinical encounter between doctors, naturopaths, and their patients.

6. The Plot

The fact that naturopaths are unregistered and, like many other CAM practices in Australia, naturopathy is to an extent unregulated, means that neither doctors nor patients can confidently know what training, qualifications, or clinical experience a naturopath may have. Doctors and patients tend to make assumptions about CAM practitioners and medicines based on their knowledge of the field and on their own cultural values.⁶ So we have a variety of characters with contested understandings about medicine and healthcare, and a range of opinions about each other.

a. Ethical Considerations

While (bio)ethical issues are broadly similar across all health disciplines, the dynamic in the triangulated clinical encounter between patients and their biomedical and complementary medicine practitioners is where ethical dilemmas can and do arise. These dilemmas are found in the realms of the basic ethical concepts of beneficence (doing good), non-maleficence (“first do no harm”) and respect for autonomy. To describe each of these ethical precepts in detail is not the aim of this paper. Rather I wish to briefly point to areas of conflict or ethical concern that commonly arise in the clinical interface.

b. Ethical Dilemma 1 - Safety and Efficacy

One ethical concern is around safety and efficacy of natural medicines. Whilst there is an increasing amount of research into CAM medicines and techniques, and this evidence based information is keenly sought by all healthcare givers, including naturopaths, the basis for usage of many natural medicines is empirical, traditional and historical. It is assumed in the naturopathic (and lay) community that generally following traditional usage (including the form and dosage in which medicines are taken) is at least a guide to safety and efficacy of those medicines. Governments tend to follow this guide also, and judge natural medicines as low risk. For biomedical practitioners, on the other hand, traditional empirical evidence, even if that evidence is promising, is not deemed to be a sound enough basis for prescription. They seem to feel that the “research base for making evidence based decisions about treating conditions with CAM”⁷ is insufficient or that there is too much uncertainty and therefore too much risk involved.

This raises concerns about inappropriate use of natural medicines, which may indeed be unsafe (although this is not common), and also concerns about the potential for drug interactions. Ethical naturopaths not only ensure they know what drugs their patients are taking and have some knowledge about the potential for drug interaction, but also encourage their patients to keep their doctor/s informed about all the treatments they are utilising. Unethical naturopathic practice would include discouraging patients from following their doctor’s advice or from taking prescribed medicines without further discussion with their doctor. Doctors also need to keep abreast of latest research about natural medicines and potential interactions or, more realistically, have reputable resources to glean this information from. The more common scenario is that doctors are ignorant of the research that is available and so tell their patients to stop using the natural medicines whose effects are “unknown.” Is it that there really is no evidence based research about particular medicines or is it that the doctor simply does not know about it, let alone have an understanding of any pre-existing empirical

grounds for their use? Advice from a health practitioner which is based on inadequate or incorrect information impinges on the patients' right to choose the health treatments that best express their own values and preferences.

To use the previous case study: fish oils are commonly used by naturopaths to decrease inflammatory responses in arthritis, and there is an increasing body of evidence identifying their pharmacological mechanisms. This doctor is not well informed about the latest research on fish oils and is concerned that there is no evidence of efficacy. Rather than investigating this further by doing their own research or consulting with the naturopath, the doctor assumes there actually is no evidence and advises the patient to stop wasting their money.

The doctor may, of course, be concerned that not only is the efficacy of the therapy questionable, but she may also query its safety. According to the principle of non-maleficence, "do no harm," the naturopath is under the same obligations as all health practitioners. But there are a variety of views as to the safety of natural medicines generally. Some have a scientific evidence base and others not. And there is also the potential to do harm by not appropriately treating the problem. Where the naturopath may believe she is providing safer alternatives to pharmaceutical medicines renowned for their side-effects, or surgery with its inherent risks, doctors may take a different view.

Let us remember in this context that biomedicine is not without risks. The paradox here is that even where drugs have been subjected to carefully controlled clinical trials there are many instances of pharmaceutical drugs causing harm, even when used for the specified conditions and in the recommended doses. This is justified in medical circles when drugs are assessed as causing more benefit than harm. In these same circles natural medicines are given no such leeway - any harm is automatically considered to outweigh any benefit, often because biomedical practitioners may believe there is no demonstrable benefit that is no randomised controlled trials to demonstrate efficacy.

c. Ethical Dilemma 2 - Preventative Approach

To do good and to do no harm, that is to enable healing, should be the principal goal of all healthcare providers. How this is enacted may however be contentious. For a complementary medicine practitioner beneficence may not represent only the curing of a condition; other therapeutic priorities may take precedence. For instance, one of their roles may be "to promote harmony by encouraging their patient's own restorative forces to establish wellness and vitality not simply a lack of symptoms."⁸ There are many health practitioners of all persuasions who recognise and value this approach as preventative, however if doctors take this approach they may be accused of over-servicing. Thus doctors tend to be pejorative

and suspicious of this aspect of the naturopathic approach to primary care and accord it little value.

Again to cite the case study, prescribing fish oil supplements to decrease inflammation is deemed by many doctors as using a medicine that is not well proven and trying to treat in a way that is not well established (i.e. preventatively). For a naturopath this is good treatment as the prevention of further inflammation is highly valued, sometimes even prioritised, over the treatment of acute pain as it addresses the underlying cause of the pain.

This kind of philosophical or paradigmatic difference is also the locus of an ethical dilemma for each of the characters we are discussing. For the doctor there is the belief that the patient is relying upon unproven therapies and may indeed be wasting their money. For the naturopath there is a covert attack on their professional credibility. And for the patient there is confusion and conflict about which of their health practitioners to trust and believe. Ultimately this dialogue impinges on patients' rights to act in accordance with their own values and beliefs.

d. Ethical Dilemma 3 - Medical Pluralism

Contested understandings about the safety and efficacy of natural medicines become more ethically complex when doctors denounce patients' use of them, undermining their confidence in the medicines and the prescribing practitioner, their naturopath. This is both an unethical attack on the naturopath's professionalism and an infringement of the patient's right to make autonomous decisions about their healthcare.

In our case study the doctor's uncertainty about safety and efficacy of fish oil supplements is translated into a negative and pejorative assumption that is then conveyed to the patient in a way that demeans both their choice to utilise a naturopathic approach to the management of their arthritis and the naturopathic approach *per se*.

As previously mentioned, patients ultimately make pragmatic decisions congruent with their worldview when they choose which kinds of health practitioners and practices they utilise.⁹ In accordance with the principle of autonomy, which "requires that a person act in a manner that respects the rights of others to freely determine their own choices and destiny," patients have the right to make their own decisions about how they approach their healthcare, including their choice of healing modalities and practitioners.¹⁰ To make these autonomous decisions the patient needs to be sufficiently informed about their options and should not be misinformed. Wherever possible, safety and efficacy of treatments must be clearly enunciated by the health practitioner, whether it is a doctor prescribing drugs or a naturopath prescribing natural medicines. In addition, uninformed views should not be presented with the weight of professional authority behind them.

e. Ethical Dilemma 4 - Medical Paternalism

This dilemma highlights a further ethical concern: that of medical paternalism. Many would agree that in modern medicine paternalism is no longer justifiable, and yet doctors could too often be accused of deciding for their patients that CAM is not appropriate or safe. It has been argued that “it is wrong for conventional medicine to define a complementary practice as harmful merely because it is a complementary practice.”¹¹ As we have seen, this leads to a conflict between autonomy and beneficence as ethical precepts guiding the doctor’s behaviour.

To our case study again: the doctor expresses doubt about the use of fish oil supplements to prevent and treat inflammation and suggests the patient is wasting money. This is a paternalistic approach to “care” that is not only unwarranted but could also be considered unethical.

If there is to be true complementarity amongst health professions, with recognition and admission of the limitations of one’s own healing modality and mutual regard for other modalities, then all health professionals should offer their patients comprehensive information on the best (combination of) treatment options for them. Some in the field suggest that “in the absence of firm data that a treatment is harmful [...] the conventional physician should give the complementary practitioner the benefit of the doubt as long as the delivery of good medical care is not compromised.”¹² Unfortunately this is seldom what happens. In fact too often naturopaths are warning patients away from “dangerous” medical practices, and doctors are warning patients away from “dangerous” naturopathic practices. There is often ignorance, misinformation, scare-mongering, competitiveness, and derision between these two types of health professionals, and rarely a co-ordinated effort to find the best combination of therapies for each patient.

For the patient this situation infringes on their right to choose the combination of healthcare practices that best suit their needs, values and beliefs. Good lines of communication between CAM and biomedical professionals, and with their patients, are necessary but rare.

7. The Sequel

I would like to finish with some discussion about the future of pluralistic healthcare, a topic only indirectly related to the ethical concerns raised, but one that situates and contextualises these.

The practice of healthcare is an inexact art that is culturally mediated. What it is and what it means to those that practice or receive it varies between people, time and place. Biomedicine does not hold all the answers. It is neither always effective nor always safe. It is not itself always evidence based. It is flawed. Patients know this and are voting with their feet. They are making clear their desire for alternatives that better suit their own values. It is neither honest nor helpful for biomedical practitioners to dismiss

CAM as quackery until proven otherwise. So what are they to do? How do they manage this without compromising the important ethical considerations raised here?

a. Integrative Medicine

Thus far I have focused in on the antagonism between biomedical and complementary medicine practice. The paradox is that concurrently in Australia, and elsewhere, biomedicine is hopping aboard the CAM train by adopting those CAM tools or techniques that have been “proven” safe and effective and calling it “integrative medicine.” This is one way of countering the public’s loss of confidence in biomedicine and interest in CAM: by incorporating the pharmacopoeia of natural remedies and techniques into mainstream biomedical practice (“if you can’t beat ‘em, join ‘em”). At the same time CAM practitioners want legitimisation and there is increasing emphasis on medical content in degree courses in CAM modalities like naturopathy. So there is a “mainstreaming” of CAM also alongside “a progressive “CAMing” of mainstream medicine.”¹³ There are, however, problems with integration.

Case Study. In what ways is this an alternative or an integrated approach?

The doctor diagnoses his patient with depression. He has read the research which demonstrates that the herb Hypericum (St John’s wort) is as effective as SSRI medications for the treatment of depression but has fewer side-effects so he prescribes the recommended dose of a standardised tablet of Hypericum.

b. Plurality

This model of integration does not allow for the plurality of approaches to healthcare it is clear that patients want. Patients are looking for something different from the biomedical approach to healthcare. As it is currently practiced, integration is the co-option into the dominant health paradigm of other healing tools and techniques once they have been sufficiently proven, in their own eyes, to be useful. This is a kind of phagocytosis, to use a medical metaphor, with alternative modalities subsumed into mainstream practice where they become acceptable to that domain through cultural shifts. In our case study, Hypericum is used instead of an SSRI; the doctor is choosing one “drug” over another. There is nothing “alternative” - or even “natural” - about this approach to the treatment of depression.

The naturopath would approach this quite differently. Firstly the diagnosis would not focus on a “disease” state but something broader like

“nervous depletion.” Then the treatment protocol would be individualised according to the unique set of circumstances ascertained to have led to this state of depletion. And finally the treatments themselves would be individually prescribed and may, or may not, include the use of the herbal nerve tonic, Hypericum.

c. Contextualization

It is important to recognise that the appropriation of CAM therapies into a biomedical paradigm is taking them out of their own therapeutic, social, cultural and professional contexts, removed from their traditional paradigm of use. The differences between CAM and biomedicine are greater than the medicines and techniques - they each have very different epistemologies. Simply utilising new practices or medicines within a biomedical paradigm ignores the limitations of that paradigm that lead patients to seek alternatives and limits patients' choices. To go back to our case study, in naturopathy the cause and expression of the depression would determine what treatments the patient would be given. Treatments are tailored to individuals. A diagnosis of nervous debility is one possibility and, if so, herbal nerve tonics, perhaps including Hypericum, may be prescribed.

d. Complexity

CAM therapies are complex and multiple and naturopaths uphold that this is integral to their therapeutic action. Herbal medicines, for instance, have a number of active constituents that work in complex and synergistic ways to effect change in the body. That herbs have very few side effects is believed to be largely due to this. When used in their whole form they are not the same as pharmaceutical drugs which are reduced down to one particular chemical constituent and potentised to give powerful physiological responses. As the case study shows, you can do this with herbs too, herbs can be used like drugs. But I believe we will find them causing as many adverse events as do drugs if we go down this path.

And not only are natural medicines themselves complex. In its philosophy and practice naturopathy offers complex approaches to complex processes. It does not focus, as biomedicine does, on disease of one organ of the body; rather it looks at dysfunction as the net result of a number of complex and interacting processes within the whole person over time. And treatments are as unique, complex and multifaceted as the causes. The appropriation of CAM methods or medicines into a medical framework does not allow for nor acknowledge that different approaches are more about the paradigm than the methods or the medicines used.

e. Healing

It is important to remember that control of healing lies primarily with the patient. The healing ritual, the healer, the methods or medicines utilised, are ultimately facilitators of the patient's own healing process. A good healer will look for the meaning the illness has for the patient and work with that. A good healer will tap into the magic, the mystery, of the healing process in a way that is affirming and empowering of the patient. This takes time, empathy and communication. Quick consultations, symptomatic relief, and generic treatments will not facilitate this kind of healing.

f. Communication, Respect, Humility and Cooperation

The trajectory towards the integration of biomedicine and CAM obscures some of the important ethical issues, such as professional respect, medical pluralism, and consumer choice. Integration will not make ethical issues go away. It is only through open and respectful communication between doctors, CAM practitioners, and their patients that ethical concerns can be alleviated.

Discussions between doctors, CAM therapists and patients often cast the CAM professional as the bad guy. From the other side of the fence, as a CAM professional, the situation often looks very different. I have great respect for the practice of biomedicine, and I would not want to live in a world without the benefit of modern drugs or surgery. But I also believe CAM practices such as naturopathy have something valuable and different to offer. What is required by us all is the humility to admit that no one approach has all the answers, openness to other possibilities, belief in the opportunities pluralistic approaches to healthcare offer, and a commitment to ongoing, innovative research to help to understand and test different approaches to healthcare. I do not believe that integration of CAM with biomedicine is necessarily the way forward. But I do passionately believe in the necessity for mutual regard, collaboration and communication between health practitioners and with patients. By recognising the uniqueness of each patient we enhance the agency of each patient. If we all work co-operatively we can together explore and better understand the complex process of healing.

8. Conclusion

In this paper I have taken the clinical encounter between patients, their doctor, and their complementary medicine practitioner and described some of the ethical dilemmas that this dynamic triangulated space potentiates. I have highlighted some of the areas of complexity and conflict, and raised thorny issues of safety and efficacy of medicines, preventative medicine, medical pluralism and medical paternalism. I have critiqued the trajectory of integrative medicine. And, finally, I have offered some ideas on the way

forward to enable sophisticated approaches to healthcare that respect and empower patients.

Notes

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⁴ *ibid.*

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¹¹ *ibid.*, p. 49.

¹² *ibid.*, pp. 50-51.

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Patients' Reactions to the Content of Their Health Records

Torunn Wibe and Laura Slaughter

Abstract

In many countries, an increasing number of patients now make use of their legal right to access their health record. In this paper, we shed light on how patients perceive the dominant biomedical perspective of the record. Do patients think that other perspectives should be more present? We report preliminary results from an interview study in which eight patients who have asked for a copy of their electronic health record following a hospital stay have been interviewed. Our results show that the patients are not surprised by the dominant biomedical perspective of the record and they generally do not react negatively to it. Some patients, however, point out situations where this perspective has showed to be too limited and ask for a more holistic view on their situation. At the same time, health personnel's attempt to relate bodily symptoms to psychosocial issues is sometimes experienced as stigmatizing by patients and is not always welcomed. We conclude that for the documentation of psychosocial issues in the health record to be of value, health personnel should be more aware of their own potential prejudices and ask patients about their view before concluding on these issues in the record.

Key Words: EPR, record access, psychosocial issues, prejudice, biomedical perspective, medicalisation.

1. Introduction

Recent legislation in many countries has given patients the right to access their own health records.¹ However, little is known so far about patients' reactions to reading them.² We report on a project to describe patients' feelings, perceptions, and interest in reading their own record. Although the health record contains multiple stories within the documented tests, images, and health personnel notes, the content is dominated by the biomedical perspective.³ Do patients think that the content of the health record matches their own perceptions of their health situation and of important events during their hospital stay? Do they believe important matters are left out in the documentation? In this paper, we will focus especially on how patients have experienced the documentation - or lack of documentation of psychosocial issues in their record.

According to Foucault, medicine of our time is characterized by the focus on pathological anatomy where disease is located in the body of the patient. There is no disease without presence in bodily organs. The patient is

looked upon with *the clinical gaze* in order to find out where the organs deviate from normal functioning and subsequently healing the disease by bringing the organ back to normal functioning.⁴ This understanding of disease results in health personnel tending to treat psychosocial issues as non-medically relevant. The focus on organ dysfunction is claimed to contribute to a fragmented view of disease, and a lack of holistic thinking.

The patient-provider encounter is known to be dominated by *the voice of medicine*, and perhaps even more so the documentation in the health record.⁵ The documentation of psychosocial issues could possibly bring more of what Mishler refers to as *the voice of the lifeworld* into the record, with respect to seeing the patients' bodily symptoms or diseases more in connection with their total life situation.⁶ But do patients necessarily feel that *the voice of the lifeworld* should be more present in the record or do they accept the dominant place of *the voice of medicine*?

2. Objectives

In this study, our main objective is to gather data concerning how patients perceive the dominating biomedical perspective of the record.

Research questions related to this objective are:

- How comfortable do patients feel with descriptions in the record that show how health personnel have looked upon them with *the clinical gaze*?
- What other perspectives, e.g. psychosocial, do patients think should be more present in the record?
- Are there situations where patients react negatively to documentation of psychosocial issues?

3. Materials and Methods

To answer the research questions stated above, we are conducting in-depth interviews with patients who have asked for and received a copy of their health record following a hospital stay. In total, we hope to have approximately twenty interviews finished and analyzed by March 2009. We are now reporting from the findings in the eight first interviews.

a. Participants

Eight patients - seven women and one man - between the ages of 33 and 67 have been interviewed. They have had different diagnoses (e.g. cancer and childbirth) and different lengths of hospital stay.

b. Inclusion Criteria

Potentially eligible patients are men and women over 18 years old, who have asked for a copy of their health record at the hospital, speak/read fluent Norwegian, and have no known cognitive impairment.

c. Procedures

The participants are recruited through the central record archives at two of the university hospitals in Oslo. An invitation to take part in the interview study is sent directly from the archives when patients request a copy of their record. The interviews are conducted a few weeks after the patients have received the copy of their record in the mail, in order to give them time to read them. The interviews have taken place either in the researcher's office or in the patient's home or work place, depending on the patient's preferences. We use a qualitative, semi-structured interview technique that lists a predetermined set of "loosely ordered" questions or issues to be explored. An interview guide serves as a check list during the interview. The interviews are tape recorded and then transcribed in a slightly modified verbatim mode.⁷ The abstracts from transcripts presented in this paper have been translated from Norwegian to English by the first author.

d. Analysis

Content analysis of the interviews has been conducted in four steps: 1) getting an impression of the whole material and identifying main topics by reading through each interview thoroughly 2) identifying text elements in each interview related to the main topics 3) abstraction of the content of the text elements and 4) summarizing meaning. These steps are described more in detail by Malterud.⁸ As the focus of this analysis has partly been patients' emotions, re-listening to the tone of the patient's voice on the tape when they are talking about this issue, has also been helpful to understand what emotions they are expressing.

4. Results**a. How Comfortable Do Patients Feel With Descriptions That Show How Health Personnel Have Looked Upon Them With *the Clinical Gaze*?**

The patients interviewed show some common reactions to the information contained in the records. They generally express tolerance towards the dominant medical voice of the records, even though the language is difficult to understand. Many of them have spent a great deal of time to learn what the medical terms mean in order to match the documentation to their own lay version of the experiences. This common tolerance towards the biomedical perspective can be illustrated by what one patient said about her reaction to reading the surgeon's description of the surgery she had undergone.

It was kind of exciting, actually and a little strange. It becomes... at least a description of a surgery and that kind of things... it's very direct. You kind of imagine yourself on the operating table with two arms far inside your body, kind of. So it's kind of strong in a way. But I'm very pragmatic actually, so I related to it very much as concrete information, kind of, yes... I pick out what I need and that's it, kind of... But I can see that for some people this would be very tough to read, if you are a more vulnerable person and don't read with a filter, in a way. So I would perhaps think that it could be a bit heavy for sensitive souls to read about how, in a way, somebody has rummaged inside your body.

b. Do Patients Miss More Psychosocial Descriptions in the Record?

Most of the patients we have interviewed so far do not see the need for more descriptions of psychosocial issues in their record. One patient answered when asked in the interview if she found it natural that so many of the notes were pure physical descriptions, that she had in fact found a few descriptions like "women of that and that age with two children of that and that age" and "the patient has recovered relative quickly" (after a cancer operation). But this patient did not immediately quite see the need for more than this. Thinking more about it, she later said: "[...] perhaps with these kind of serious diagnoses, cancer diagnoses and such, there could perhaps be written some more around this... Yes, the psychosomatic then, how one copes with the situation." Later in the interview she commented on the record note where it was documented that she was informed about her cancer diagnosis: "It was very concrete and very... kind of clear. I was a little excited actually, to see what they had noted there... kind of, but it was very... it was very... only clean facts... there was nothing such as..." And she continued: "The biggest crisis in my life, just commented down to three sentences, and very kind of...that's the way it is... kind of... But this is the way it is, then. And there is something about facing the realities, kind of... There is no use..."

This patient showed no strong emotions when talking about this. Her calm and sober-minded way to talk about this was surprising and the interviewer really got the impression that she did not expect more expressions of sympathy or embellishments of her life situation in the record notes.

We find this expectation towards the record content to be rather typical for the persons we have interviewed so far. The patients seem to be well prepared to meet what for the most are pure physical descriptions in the record. Most of them do not express anything that could indicate that they

miss any more description of their psychological status or their life situation as such.

There is, however, one of the interviewed who contrasted this more common expectation and told us about a situation where she found this mere physical perspective to be far too limited. Her story was one of her newborn son being moved to the intensive care unit just after the birth, because he had a low blood sugar. She found the whole situation with him being put in the intensive care unit as very alarming, and thinking about it later she saw that she was in a state of shock because of this. What also happened was that she herself came in a life-threatening situation because of severe internal bleeding after the birth. She was operated on to stop the bleeding, but had lost a great deal of blood and was according to her own expression in a “pretty shaky condition.” This increased because her son was in the intensive care unit. At the unit where she was treated, the personnel documented that the mother seemed well and rather unaffected after the operation. Commenting on this, she said:

How wrong can one be! ‘She hasn’t had much pain’. That’s OK. That’s quite correct. But seeming quite unaffected! I was totally... I was... I was gone! That is, I was in a state of shock! ...So I’m very surprised to read this.

Later in the interview she said:

I feel it’s all about a more holistic assessment... not the pure clinical...The psychological picture... the holistic picture... that was the matter here. It was probably very much about the psychological... because it all came down to that the reason for my son’s low blood sugar was me not having enough breast milk for him.

The patient was disappointed that it took two weeks before the health personnel managed to see this connection between her own and her son’s condition. To date, she is not even sure that they understood how both her psychological and physical state probably contributed to her not having enough breast milk, but at least they finally concluded that her son did not receive sufficient nutrition only by breast milk.

c. Are There Situations Where Patients React Negatively to Documentation of Psychosocial Issues?

We have found some indications in the interviews that patients sometimes are irritated at health personnel’s attempt to relate bodily symptoms to lifestyle issues. What characterizes these situations seems to be

that the patients think that health personnel are in fact revealing their own prejudices when commenting on these issues and this makes the patients feel undeservedly stigmatized. Once documented in the record it seems difficult to get rid of the stigma, and the patients are confronted with it again and again.

As an example, one patient found it very unnecessary and totally out of place that one hospital had sent information about the sterilization that she had undergone many years ago, to another hospital where she was now being examined for a fall injury to her shoulder. The doctor in this hospital had asked her questions about the situation surrounding her sterilization, and this she found completely out of place and humiliating. Two other patients brought up obesity and fatty liver, respectively, as examples of how they feel they are undeservedly stigmatized in the record. The obesity was automatically talked of as a lifestyle problem every time the patient met a new doctor, while the patient claimed that if they studied her record thoroughly, they would find that there was a dysfunction in the hypophysis that caused her obesity problems. The patient that had been diagnosed with a fatty liver felt that it was taken for granted that this was caused by alcohol, although she had never been drinking. It bothered her very much that this prejudice about the reason for her fatty liver was documented in her record and she felt powerless as the health personnel did not believe her when she said she had never been abusing alcohol. The repeated stigmatization that patients feel, related to the description of psychosocial issues in the record, is very likely, when one knows how record notes from a consultation at the outpatient clinic or from a hospital stay, builds not only on the assessments and observations of the health personnel that is documenting there and then, but also on earlier notes from other health personnel in the record.⁹

5. Discussion

Should one be surprised of patients' general acceptance of the dominance of biomedical perspective in their health records? Through these interviews we perceive that the patients are generally well prepared to meet this perspective, and that their acceptance may be coloured by their expectations. The patients expect the record to be written mainly by health personnel for other health personnel. The findings in this respect indicate that the patients find it more natural that they themselves make an effort to understand the record, rather than health personnel changing their way of documenting. Lupton points out that the move towards *demedicalisation* when lay people are becoming more informed about medical matters and thereby reducing doctors' power based on medical expertise, may paradoxically be interpreted as a growing penetration of *the clinical gaze* into the everyday lives of citizens.¹⁰ Lay understanding of illness is increasingly influenced by a biomedical understanding. We accordingly interpret these

patients' acceptance of the dominant *voice of medicine* in the record as an expression of their interest in getting more knowledge about the medical aspects of their health problems. They are already accustomed to the biomedical understanding of disease from health information they have found on the Internet or other sources of information. This influences their expectations of what kind of information they will find when they read their health record.

The patients interviewed do not seem to expect more expressions of empathy or embellishments of their life situation in the record. This might contrast the findings from studies investigating what patients find important in encounters with health personnel, where, as Mishler formulates it, recognition of patients' health problems within the context of their lifeworlds of meaning are seen as criteria for human care.¹¹ Halloway also found in an interview study on patients' encounters with health personnel that dissatisfaction with the encounter arose from health personnel's failure to treat them as persons or failure to take their concerns seriously.¹² That patients get irritated when psychosocial issues are brought into the records, may however have to do with a feeling of not having been taken seriously or been seen as a person in the direct contact with health personnel. Health personnel's conclusions on the reason for obesity, fatty liver or the patient's coping with dramatic events, in this material seem to be based on their own observations, results from tests, prior record notes etc. without really asking the patient any further. Thus one might say that health personnel tend to treat psychosocial issues as objective facts in the documentation, when in fact the patients' own view on these issues could contribute to better assessments and conclusions. This is not only irritating for the patients to read, it is hurting to find that they, according to their own view, have been incorrectly categorized and even stigmatized.

6. Limitations

First of all, these are preliminary results from a relatively small number of interviews and our analysis is so far on a rather descriptive level. A limitation of our work is that the sample is self-selecting. Patients who have a story to tell about bad experiences with health personnel or the hospital as an organization might be more likely to agree to be interviewed for the study than patients who do not have these kinds of experiences. One should therefore be careful to generalize these findings as typical for patients' experiences on this area.

Other studies have found that women are much more likely than men to be interested to read their records.¹³ Even if the low number of men recruited to the study may reflect the number of men asking for a copy of their health record in Oslo, the unequal participation of genders is of course a limitation of the study.

7. Conclusions

We conclude that for the documentation of psychosocial issues in the health record to be of value - both for health personnel and patients, these issues must be discussed with the patient. These are issues that *the clinical gaze* alone is unfit to perceive. When we as health personnel try to conclude on these issues only based on our own observations and prior record notes from colleagues, we risk that our conclusions are severely "contaminated" by our own and our colleagues' prejudices. What patients then perceive as a wrong conclusion or worse as an unjust stigmatization when reading their record, might make them feel that they are not respected as persons and thus possibly harm the patient-provider relationship.

Notes

¹ SE Ross & CT Lin, 'The Effects of Promoting Patient Access to Medical Records: a Review', *J Am Med Inform Assoc*, March 2003, vol. 10(2), pp. 129-138.

² LB Fagerli, 'Å få det svart på hvitt': om innsyn i pasientjournalen, Report from Høgskolen i Østfold, 2007.

³ G Bowker & M Berg, 'The Multiple Bodies of the Medical Record: Towards a Sociology of an Artifact', *The Sociological Quarterly*, vol. 38(3), 1997, pp. 513-537.

⁴ M Foucault, *The Birth of the Clinic: an Archaeology of Medical Perception*, Routledge, London, 2003.

⁵ E Mishler, *The Discourse of Medicine: Dialectics of Medical Interviews*, Ablex Publishing, Norwood, N.J., 1984.

⁶ *ibid.*

⁷ K Malterud, *Kvalitative metoder i medisinsk forskning: en innføring*, Universitetsforlaget, Oslo, 2003.

⁸ *ibid.*

⁹ Bowker & Berg, *op cit.*

¹⁰ D Lupton, 'Foucault and the Medicalisation Critique', in *Foucault, Health and Medicine*, A Peterson & R Bunton (eds). Routledge, London, 1997.

¹¹ Mishler, *op.cit.*

¹² N Halloway, 'Encounters with Medical Professionals: a Crisis of Trust or Matter of Respect?', *Med Health Care and Philos*, vol. 11(4), 2008.

¹³ J Fowles et al., 'Patients' Interest in Reading Their Medical Record', *Arch Intern Med*, vol. 164, 2004, pp. 793-800.

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PART VII

Pedagogies

Teaching Empathy for the Patient

Mary Buchinger Bodwell

Abstract

Efforts to teach empathy to health care professionals often take the form of bringing the humanities into the curriculum, such as having students read and discuss medically related literature and poetry. However, for many students, these efforts seem “tacked on” to the curriculum. Humanistic interventions are not easily integrated into the dominant scientific culture and although increasing emphasis has been placed on medical humanities, there is little evidence of success. Joanne Shapiro (Department of Family Medicine, University of California, Irvine) suggests this failure is due to a lack of understanding the root of the challenges to teaching empathy. Shapiro writes about how the demarcation of illness from health leads to increased isolation and “othering” of the ill, accentuating the impulse of care providers toward self-preservation. The central narrative of modern medicine involves diagnosis, treatment, and solution or restitution. This narrative reduces the patient to a problem to be solved and also makes it less likely that a patient with a chronic condition will be treated empathically. This paper discusses the implications of these challenges to teaching empathy in the context of an upper-level interpersonal communication course for health care professionals.

Key Words: Health care pedagogy, empathy, medical humanities.

Empathy is a beleaguered value in health care; it is not immediately efficient nor obviously practical.¹ Humanizing the patient is not a topic included in medical science curricula. In fact, as Jerome Groopman, a physician who writes about his profession, reports, doctors increasingly are trained to diagnose using flowcharts and algorithms - and insurance companies approve. As Groopman points out, this approach is largely effective as long as the diagnosis is “run of the mill;” if not, however, it can be dangerously limiting as he demonstrates in his book *How Doctors Think*.² Not including the patient in the diagnosis is problematic for many well-documented reasons. Yet, regardless of the medical errors and misdiagnoses resulting from breakdowns in communication with patients and the perennial calls for better instruction in communicative strategies for medical personnel, a certain indifference toward training in “bedside manner” pervades the medical profession.

I teach interpersonal communication to pharmacy, pre-med, health psychology, and nursing students at a small pharmacy and health sciences

college in Boston, Massachusetts. My students often self-identify as “math and science” people, as if it were an exclusive category. They assume the logical conclusion is that being math and science people, they should have no interest in the arts and humanities. In a small college that is specifically dedicated to the health professions - where no other academic majors exist, no history or political science or economics or literature majors, no theatre or studio arts, etc., the perceived chasm between the sciences and the humanities remains largely unchallenged. Of course, not all students fall into this trap and efforts are made to bridge the two; but within the culture of the college, these efforts draw attention to themselves as efforts. Like the humanities and other liberal arts courses at the college, the interpersonal communication course is considered by students to be secondary to the science courses they are concurrently taking, such as virology, pharmacokinetics, pathophysiology, etc.

In *Zen and Art of Motorcycle Maintenance*, philosopher and novelist, Robert Pirsig, discusses what he calls the “classic/romantic barrier.” He writes,

[...] the classic mode proceeds by reason and laws [...] [it] is straightforward, unadorned, unemotional, economical and carefully proportioned. Its purpose is not to inspire emotionally, but to bring order out of chaos and make the unknown known [...] [whereas] the romantic mode is primarily inspirational, imaginative, creative, intuitive. Feelings rather than facts predominate. “Art” when it is opposed to “Science” is often romantic. It does not proceed by reason or by laws. It proceeds by feeling, intuition, and aesthetic conscience.³

Pirsig argues that this dichotomy ultimately lacks meaning; nonetheless, each mode dominates in different fields of study and imposes consequential limitations. Medical training is identified more closely with the classic mode and Jerome Groopman believes this is a problem. In *How Doctors Think* he writes: “The effects of a doctor’s feelings on his thinking gets short shrift in medical training and in research on decision-making.”⁴ He quotes Croskerry, an emergency room doctor who studies physician cognition: “Most people assume that medical decision-making is an objective and rational process, free from the intrusion of emotions.”⁵ Yet, Groopman continues:

[...] the opposite is true. The physician’s internal state, his state of tension, enters into and strongly influences his clinical judgments and actions [...] technical errors account for only a small fraction of our incorrect diagnoses and

treatments. Most errors are mistakes in thinking. And part of what causes these cognitive errors is our inner feelings, feelings we do not readily admit to and often don't even recognize.⁶

Clinical empathy has been defined as having four dimensions:

(1) emotive, the ability to imagine patients' emotions and perspectives; (2) moral, the physician's internal motivation to empathize; (3) cognitive, the intellectual ability to identify and understand patients' emotions and perspectives; and (4) behavioural, the ability to convey understanding of those emotions and perspectives back to the patient.⁷

In light of the research reported in Groopman, the definition of clinical empathy should perhaps include a fifth dimension, one on which all the others might be said to depend, that is self-knowledge and awareness of one's emotional state. Efforts to encourage empathy in health care professionals often focus on bringing the humanities into the curriculum, such as having students read and discuss medically related literature and poetry. Fictive modes are used to evoke the patient and to invoke empathetic responses in the caregiver. For many students, these efforts seem "tacked on" to the curriculum. Humanistic interventions are not easily integrated into the dominant scientific culture; despite the greater emphasis on empathy in the training of medical professionals, there is little evidence of success.

Stanley Fish, perhaps the most well-known literary critic in the United States, would argue there is no reason to expect the study of the humanities to make students more humane. He cites his experiences in humanities departments as rife with backbiting and infighting. The humanities, he says, cannot save us; literary criticism changes nothing, has no impact on the world; "the humanities are their own good."⁸ In his book *Why Read?* Mark Edmundson, professor of English, and literary and cultural critic, agrees that studying literature does not make one more humane or empathetic, unless, that is, it includes deliberate and thoughtful identification with the characters. Too often, he says, students in literature courses are pushed to engage in abstract analysis without being allowed to insert themselves into the narrative.⁹ Within a medical curriculum, literary analysis, like diagnosis, quite easily can be engaged in without personal involvement with the material.

Keeping this in mind, I use literature in two ways in the interpersonal communication class; firstly, I ask students to read reflective narratives written by health care providers, which tend to be found on the

back pages of professional journals. Many practitioners write to find meaning in their work and in their relationships with patients; the writing helps practitioners better understand themselves and, according to Atul Gawande, a surgeon and essayist, “makes the machine feel less like a machine.”¹⁰ These practitioner narratives, so different in purpose and tone from the scientific studies that generally precede them in the journal, provide students with insight into the practice of medicine and the place of empathy in relationships with patients. One example of this type of literature is Robyn Churchill’s story *Blue Hours*; Churchill, a midwife, relates her emotionally harrowing experiences caring for a severely mentally ill woman and helping to deliver her infant who, immediately after birth, is permanently removed from the care of the mother.¹¹ Narratives like this, which explore and strive to understand relationships with patients and the impact of these relationships on the health care professional, generally do not find their way into the medical curriculum. However, these are just the kind of stories that specifically invite health care providers in to find themselves - as Edmundson urges all readers to do - to figure out who they are and how *they* might act and feel in the world of caring for patients.

Secondly, I engage students in drama and role-playing; specifically, reading aloud plays on clinician-patient interactions. Medical Readers Theater, developed by Todd Savitt, a medical ethicist and historian at East Carolina University, uses dramatic adaptations of literary short stories, such as William Carlos Williams’ *Use of Force* as a teaching tool.¹² Students take the parts of characters - patients, doctors, family members - and read through the drama in front of the class. Alyce Getler, a clinical professor at Harvard Medical School recently evaluated Medical Readers Theater and, in a preliminary study, found that participants reported it “enhanced empathy [and] broadened perspective by allowing identification with the dilemmas of characters.”¹³ Role-playing allows students to enter safely into the emotional and psychological experience of the patient and the practitioner and, through the dramatic dialogues, gain greater sensitivity toward the co-construction of the patient’s sense of health, illness, and agency.

In writing about why medical schools are failing in their efforts to teach empathy, Joanne Shapiro, who teaches in the Department of Family Medicine at University of California, Irvine, points to the basic assumptions of modern medicine wherein, she says, lies the root of the challenges. Shapiro writes about the Cartesian dichotomy between illness and health and how this contrasts with Eastern philosophical traditions, which have a more unified view of death as a part of life. She notes that the demarcation of illness from health leads to increased isolation and “othering” of the ill, and accentuates the impulse of care providers toward self-preservation. The dominant narrative of modern medicine involves diagnosis, treatment, and solution or restitution. This narrative reduces the patient to a problem to be solved. As

Shapiro points out, the “reductionism and objective positivism that underpin medicine are not morally neutral”¹⁴ and, in effect, reduce empathy. While she acknowledges that countless medical breakthroughs have been and continue to be achieved on the basis of these tenets, Shapiro notes that patients who do not fit into this narrative, such as those with a chronic condition, are problematic for health care providers and at most risk for not being treated with empathy. The challenge, as Shapiro frames it, is to complement the biomedical narrative with a narrative that specifically engenders empathy and revolves around interpersonal relationships.

In his moving essays about his experience as a patient, Anatole Broyard, a literary critic, writes of his yearning for a doctor who “*enjoyed*” him (emphasis in original).¹⁵ Illness, routine for the health care provider, is never routine for the patient. Broyard insists he is not asking his doctor to love him or to suffer with him, rather to simply keep from depersonalizing him or his illness. That is, in his words, “to go beyond the science and into the person.”¹⁶ Groopman discusses the importance of compatibility between a patient and doctor. He cites research by Hall and Roter that demonstrates patients are able to tell, with a high degree of reliability, whether or not their doctors like them; they have also established that a doctor’s negativity toward a patient can affect treatment and ultimately be detrimental to the patient’s well-being.¹⁷ As Shapiro also suggests, good medical care is dependent on good interpersonal relationships and relationships are developed through communication.¹⁸ Judith Hall, professor of social psychology at Northeastern University, who studies medical communication, writes:

[T]he communication piece is not separable from doing quality medicine. You need information to get at the diagnosis, and the best way to get that information is by establishing rapport with the patient. Competency is not separable from communication skills. It’s not a trade-off.¹⁹

In my interpersonal communication course, students are asked to collect data on their interactions outside of class. I find that without data, the skills and strategies we discuss remain unpopulated, disembodied, and separate from “real life;” whereas with data, students become attentive and aware and often are surprised by what they discover about themselves and about communication. So, for example, after reading about the methods of reflective listening, which include paraphrasing and reflecting back both feelings and meaning, students deliberately “try out” the strategy and write about their experience. One student who works as an assistant nurse at a hospital tried reflective listening with a patient. The patient was severely diabetic, yet repeatedly and vociferously refused to have the sugar level in her blood checked. The nurses had labelled her “crazy,” although there was

no history of mental illness, and they strongly discouraged the student from trying to check the patient's blood. However, my student insisted on talking with the patient and, through reflective listening, discovered that the patient was afraid she would have no blood left after all the different procedures that had been performed on her. Learning that this was the patient's fear, my student was able to reassure her that her body continually makes new blood and she will not run out. In this case, listening to the patient possibly saved that patient's life. Listening does not come naturally in the action-oriented milieu of health care and is not reinforced in a narrative that presupposes a problem and a problem-solver.

Another way to challenge the traditional narrative is to place the patient in the role of teacher. I do this by inviting into the classroom an acquaintance, Marjorie Scott, who is wheelchair-bound and has an oxygen tank. Rather than telling the students about herself, Ms. Scott asks them, "What would you like to know about me? Ask me anything you'd like." The first dozen or so questions focus on a diagnosis: "Do you have Multiple Sclerosis?" "Do you have Lupus?" etc. Only after she prompts them to think outside the medical box, do they begin to ask questions like: "Where are you from?" "Do you have children?" "Did you go to college?" and begin to learn about who she is as opposed to what diseases she suffers from. Afterwards, students reflected on making this shift and on their surprise at discovering their initial focus was exclusively on her illness. This focus clearly had the effect of "othering" Ms. Scott, which was neither intentional nor conscious on their part. After getting to know more about her - her advanced degrees, publications, community work, etc. - they were astounded at the extent to which they had eclipsed her personhood in pursuit of a diagnosis.²⁰

Two pieces of advice for doctors that Gawande gives in his recent book, *Better: A Surgeon's Notes on Performance*, include: "Ask the unscripted question" and "Write something."²¹ In my class, I ask students to spend at least an hour interviewing a patient. Before the interview, they read the chapter on clinical narratives from S. Kay Toombs' book *The Meaning of Illness*. In this book, Toombs provides a phenomenological account of her experiences with Multiple Sclerosis and writes about the profound gap between medical descriptions and the personal experience of illness, which she calls "illness-as-lived."²² She references accounts written by doctors who themselves became ill, noting how they do not dwell on "objective signs and clinical data but rather on loss of certainty [...] [on] fear and anxiety."²³ In talking with patients about their experiences, students are gathering data - data which may cast their assumptions into relief and make them visible. In addition, like Gawande, they learn to appreciate the person of the patient. Getting to know the patient as an individual whose life has been profoundly affected by illness helps the care provider to think beyond the diagnosis and outside of the traditional medical narrative.

In sum, my approach to teaching empathy for the patient is two-pronged: through engagement with literature and collecting data on interpersonal interactions, students gain greater self-awareness, and greater appreciation for the person of the patient. Ultimately, only so much can be done to nurture empathy in the context of an interpersonal communication course. If the medical community is committed to a central, foundational role for empathy, then the entire curriculum for health care providers should reflect this commitment. Humanities and communication courses are not the sole repository for instruction in empathy - responsibility must be distributed across the curriculum. Empathy is complex and multiply manifest, but its hallmarks are unmistakable and its significance in health care indisputable.

Notes

¹ However, recent research suggests that expressing empathy does not necessarily lead to longer office visits and, in fact, may be more efficient; cf. DS Morse, EA Edwardsen & HS Gordon, 'Missed Opportunities for Interval Empathy in Lung Cancer Communication', *Arch Intern Med*, vol. 168(17), 2008, pp. 1853-1858.

² J Groopman, *How Doctors Think*, Houghton Mifflin, New York, 2007.

³ R Pirsig, *Zen and the Art of Motorcycle Maintenance*, HarperCollins, New York, 1974, p. 61.

⁴ Groopman, p. 36.

⁵ Croskerry as quoted in *ibid*.

⁶ Groopman, pp. 36, 40.

⁷ K Stepien & A Baernstein, 'Educating for Empathy: A Review', *Journal of General Internal Medicine*, vol. 21(5), May 2006, p. 524.

⁸ S Fish, 'Will the Humanities Save Us?', *The New York Times*, January 6, 2008.

⁹ M Edmundson, *Why Read?*, Bloomsbury Publishing, New York, 2004.

¹⁰ A Gawande, *Better: A Surgeon's Notes on Performance*, Picador, New York, 2007, p. 252.

¹¹ R Churchill, 'Blue Hours', *Journal of Midwifery and Women's Health*, vol. 51(5), Sept-Oct 2006, pp. 376-377.

¹² TL Savitt (ed), *Medical Readers' Theater: A Guide and Scripts*, University of Iowa Press, Iowa City, 2002.

¹³ A Getler, 'Medical Readers Theater: Promoting Empathy, Broadening Perspective, and Building Community', Presentation, Massachusetts College of Pharmacy and Health Sciences, October, 2008.

¹⁴ J Shapiro, 'Walking a Mile in Their Patients' Shoes: Empathy and Othering in Medical Students' Education', *Philosophy, Ethics, and Humanities in Medicine*, vol. 3(10), 2008, viewed on 29 January 2009,

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2278157>.

¹⁵ A Broyard, *Intoxicated By My Illness*, Ballantine Books, New York, 1992.

¹⁶ *ibid.*, p. 49.

¹⁷ Groopman, pp. 17-25.

¹⁸ Shapiro, *op. cit.*

¹⁹ J Hall, quoted in Groopman, p. 20.

²⁰ This is an example of the “tyranny of diagnosis” described in C Rosenberg, *Our Present Complaint: American Medicine, Then and Now*, Johns Hopkins University Press, Baltimore, MD, 2007.

²¹ A Gawande, *Better: A Surgeon’s Notes on Performance*, Picador, New York, 2007, p. 252.

²² SK Toombs, *The Meaning of Illness*, Kluwer Academic Publishers, Dordrecht, 1992, p. 108.

²³ *ibid.*

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Israeli Views of Empathic Physician-Patient Communication

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Abstract

We measured the importance attributed to empathy by Israeli physicians and medical students. Participants viewed one of two videotaped consultations in which one actor simulated an empathic or a non-empathic physician and a second actor simulated a patient and completed a two-part questionnaire. Part A assessed ten characteristics of the physician in the consultation, plus a single global performance assessment. Part B assessed the importance attributed to those same ten characteristics for medical consultations in general. Six of ten characteristics related to empathy and were derived from an abridged, Hebrew-language version of the Consultation and Relational Empathy (CARE) questionnaire, and four related to clinical competence and knowledge.

Both physicians and students attributed high importance to empathy, and consistently rated the empathy component of the empathic physician's behaviour as higher than that of the non-empathic physician. They also gave the empathic physician a significantly higher score for overall performance, which is consistent with their declared attitudes. Non-empathy-related competencies were rated slightly more important than empathy.

The abridged, Hebrew version of the CARE questionnaire appears to be a valid tool for examining empathy in Israel. Future research in Israel may use this questionnaire to study the impact of empathy on a broad range of clinical and other outcomes.

Key Words: Communication, empathy, Israel, patient, physician.

1. Background

For much of the twentieth century, physician-patient communication was equated with the rigidly structured interview that was considered essential to reach a diagnosis in hospital-based medicine. "Bedside manner" was the rather dismissive term used to describe adjustments to this core process that were intended to make the patient feel comfortable so as to gain his or her cooperation.

This orientation was driven by the 1910 report from Abraham Flexner on medical education in the United States and Canada.¹ Flexner criticized 199 of the 200 medical schools then in existence, praising only

Johns Hopkins, where students were taught a science-based curriculum by experts in their respective fields. Within ten years, a third of schools either closed or attached themselves to universities, and the science-based curriculum was universally adopted. Instructors were generally hospital-based and research-oriented. In the wake of Flexner's report, the medical profession at large adopted the ideal of the physician-scientist over the physician as a practitioner of the healing arts.

This paradigm shift led to a flight from general practice to the burgeoning new medical specialties,² an explosion of research, and great medical advances. This progress, however, had a price. The demise of the general practitioner led the public to complain not only of a shortage of first line physicians, but also of the eclipse of personal medical care by a less humane and more scientific style of medical practice.

By mid twentieth century, several physicians began to offer solutions to the perceived deficiencies of the scientific approach in the current medical culture. Michael Balint wrote on the therapeutic aspects of the physician-patient relation,³ and Enid Balint stimulated the movement to patient-centred care.⁴ McWhinney wrote convincingly on generalism as a worthy scientific discipline,⁵ and Engel expanded the clinical horizons of hospital-trained physicians with his biopsychosocial model.⁶

Common to all of these authors was the belief that the patient could be understood only in the context of his/her unique psychological, social, and cultural reality. This belief led naturally to a growing interest in the special communication skills needed by physicians in their expanded psychosocial role. Today most medical schools teach communication skills beyond those needed for gathering patient data, and most state licensing agencies and specialty boards demand communication competencies. Finally, physician-patient communication has become a growing field for research. A study, showing that a patient-oriented physician style could lower the risk of litigation, only further boosted interest in the topic.⁷

Roter led efforts to create a classification of communication on which other research could be based.⁸ Her validated system, which involved classifying and counting every utterance in the dialogue, enabled studies to prove the influence of communication style on a wide range of clinical and other outcomes.⁹

Empathy, defined as the physician's ability to recognize, elicit, and respond appropriately to the emotional aspects of the patient's condition, is considered the most powerful of communication techniques, and is perhaps the most frequently studied aspect of physician-patient communication. Researchers have developed two approaches to measuring the degree of empathy in communication – the use of Roter's system or similar counting techniques specifically designed to assess empathy,¹⁰ or, alternatively, the use of validated questionnaires for self-reporting or for rating observed

empathy.¹¹ More recently, interest in “mirror neurons” has led to the search for the neurobiological basis of empathy.¹²

It would appear that empathic behaviour, as defined above, is culturally bound. Cultures differ in the way empathy is expressed and in the value that is attributed to caring. Israelis, for example, are thought to cherish a tough exterior, and to eschew public display of neediness, sentiment, or emotion. For example, while giving a lecture on empathy to Israeli medical students as a visiting professor from the USA, one of the authors of this study (DSM) showed a clip of a simulated physician-patient interview, which was meant to illustrate ideal empathic communication. To our surprise, on seeing this American clip, our students burst out laughing, explaining later that they felt the physician’s empathic reactions were so exaggerated as to be ludicrous. We concluded from this experience that research on empathy in Israel requires tools appropriate for the local culture.

The intent of the study was to compare the degree of importance attributed to empathy by medical students, various groups of physicians, and laymen in Israel. To date we have collected data only from medical students and hospital-based physicians; we plan to expand the study in these two groups and to collect additional data from laymen and community-based physicians.

2. Methods

The study was approved by Hadassah’s Institutional Review Board (Helsinki Committee); the requirement for informed consent was waived.

Medical students were recruited from the Hebrew University Hadassah Medical School, which has a six-year program of studies. E-mail messages were sent to all second (preclinical) and fifth year (clinical) medical students with an invitation to participate in research to study the attitudes and perceptions of various groups in Israel toward physician-patient interaction.

Attending physicians and residents were recruited by e-mail in a similar manner as the medical students. Eligible physicians included all fulltime physicians working in clinical positions at the Hadassah Medical Center’s two hospitals in Jerusalem, at Ein Kerem and Mount Scopus.

Two videotaped simulations of a physician interviewing a patient newly diagnosed with diabetes were prepared, using the same pair of actors. In one simulation, the physician demonstrated a high degree empathy (high-empathy physician), and in the other, a low degree of empathy (low-empathy physician). The degree of empathy in the two interviews was confirmed by eight physicians recognized by their peers as expert communicators.

A two-part questionnaire using a 9-point scale (9 - highest) was developed for the study. Part A of the questionnaire was used to rate 11 characteristics of the physician and her interview, while Part B was used to

rate the importance the participants attributed to the same characteristics in real-life interviews.

The questionnaire was based on a Hebrew translation of the Consultation and Relational Empathy (CARE) questionnaire, a previously validated English language empathy questionnaire.¹³ From the original ten questions in this questionnaire, we selected six questions relating to the emotional component of empathy, and eliminated four that dealt with components that we felt were related more to patient-centredness than to empathy per se. We also added four questions of our own, for the purpose of this study (1, 3, 6, and 9), which were related to the perceived knowledge and clinical competence of the physician and were unrelated to empathy. In an eleventh question in part A, participants were requested to rate the overall performance of the physician in the interview. The questionnaire also included demographic questions that were appropriate to each of the participant groups.

The second and fifth year medical students, residents, and attending physicians who volunteered to participate were divided randomly into two subgroups according to which version of the interview they would see. The participants were not told that there were two versions of the interview. A copy of the questionnaire was emailed to all participants, together with the address of an Internet site where the designated videotape could be viewed.

A study coordinator tracked participant responses and sent e-mail reminders to individuals who were slow to respond. When the questionnaires were returned, the coordinator removed all names and personal identification from the response, and assigned a code number. The blinded responses were then forwarded to a data manager for further evaluation. Incomplete questionnaires were excluded from the analysis.

The Student's t-test for continuous variables was used to compare the two groups' responses to the different films. Multiple regression analysis was used to control for confounders. Any background characteristics (confounders) that were significant or that influenced the main dependent variable are reported. All tests were two-tailed with $p=0.05$ considered significant. We used SPSS for Windows, version 15.0.

3. Results

The study population comprised 67 participants, including 29 medical students at the end of their second year in medical school, 14 students at the end of their fifth year, 11 residents, and 13 attending physician specialists. The mean ages for the groups were 25, 27 for second and fifth year students respectively, and 40 for the physician-resident group. The ratios of female/male respondents in the groups were 13/16, 7/7, and 8/16 respectively. The percentages of native Israelis (born in Israel) in the groups were 93%, 64%, and 79% respectively (Table 1). No demographic

differences between the groups influenced the responses to other parts of the questionnaire in our study population.

A mean empathy score was calculated for each participant by taking the average of responses to the six questions relating to empathy in Part A of the questionnaire. A mean clinical competence score was calculated by taking the average of the four questions relating to clinical competence.

Participants rated the high-empathy physician above the low-empathy physician on all of the six empathy-related questions. The high-empathy physician received an overall mean empathy score of 7.2 ± 1.6 , as compared to a mean empathy score of 3.3 ± 1.6 for the low-empathy physician ($p < 0.001$, Table 2). Participants viewing the high-empathy physician also rated her mean clinical competence more highly, with a score of 7.6 ± 1.1 , compared a mean clinical competence score of 6.2 ± 1.2 from participants viewing the low-empathy physician. The difference between the groups for the mean clinical competence score was smaller than that for the mean empathy scores, but still achieved statistical significance ($p < 0.001$, Table 2).

Participants' overall performance scores (Part A, item 11) were also influenced by which video version was viewed. The overall performance scores for the high-empathy physician (7.5 ± 1.3) were significantly higher than those for the low-empathy physician (4.8 ± 1.8 , $p < 0.001$).

Responses to Part B of the questionnaire, which evaluated the importance the participants attributed to the same ten physician characteristics in real-life interviews, revealed no differences between participants who viewed the high-empathy and low-empathy simulations (Table 3).

Multiple regression analysis was used to assess the degree to which assessments of overall performance were influenced by such potential confounders as gender and other demographic details, video version viewed, and attitudes about the desired characteristics of the physician in physician-patient interviews, as reflected in Part B. The video version viewed had the strongest contribution to overall performance scores, and even after controlling for the above variables, participants rated the more empathic physician's overall performance 3.65 points higher on average ($p < 0.001$). The score for overall performance was also directly influenced by the participant's attitudes as expressed in part B. For each additional point participants attributed to the importance of empathy, participants reduced the overall performance score by 0.5 points ($p = 0.02$), but for each additional point they attributed to the importance of clinical competence in section B, they increased the overall evaluation by 0.8 points ($p = 0.02$). Demographic variables did not influence the overall performance score.

Multiple regression analysis was also applied to assess the factors influencing the mean empathy score. The only factor found to influence this score was the version of the video viewed: the high-empathy physician

received a mean empathy score 4.0 points above the score for the low-empathy physician, controlling for confounding variables ($p < 0.001$).

We also used multiple regression analysis to examine influences on the mean clinical competence score. The level of empathy in the interview had only a borderline influence, with the high-empathy physician receiving 1.2 points more than the low-empathy physician on this score ($p = 0.07$).

Examination of the answers to the questions in Part B of the questionnaire, shows that Israelis attributed high importance to both clinical competence (8.4 ± 0.6) and empathy (7.8 ± 1.2). There was a high degree of correlation between importance attributed to these two groups of questions ($r = 0.68$; $p < 0.001$); participants who attributed high importance to empathic communication also considered clinical competence as important. Nevertheless, the 0.6 point difference between them was highly significant ($p < 0.001$) according to the paired t-test.

5. Discussion

Our results indicate that all the Israeli physicians and medical students in our sample were able to identify the presence or absence of empathic communication in the high- and low-empathy consultations respectively. Moreover, both subgroups placed a high value on empathy. This is reflected in the high ratings for all empathy-related items in the attitude portion of the questionnaire (Part B). Additionally, it is reflected in the influence of the mean empathy score on assessments of the physician's overall performance in Part A. In other words, not only did participants declare that empathy was important, but, when seeing the physician in action, the higher they rated her empathy, the higher they rated her overall performance in the interview.

There were no significant differences noted between the responses of the two subgroups of medical students or between medical students and practicing physicians. Overall, all participants attributed slightly more importance to clinical competence than to empathy. The difference between these attributions was statistically significant, and the two scores were strongly correlated ($r = 0.68$).

The more importance individual participants attributed to empathy in Part B, the lower they tended to rate the overall performance of the physician in Part A. In contrast, the more importance participants attributed to clinical competence, the higher they rated the physician's overall performance. Our preliminary interpretation of this finding is that participants who attribute greater importance to empathy tend to be more critical of the physician's overall performance in comparison with those who place greater value on clinical competence.

The ability of all participants to distinguish between the degree of empathy evinced during the high- and low-empathy physician-patient

interviews suggests that the two simulations succeeded in demonstrating empathic and non-empathic communication. It is interesting to contemplate whether a set of interviews with more subtle differences in this area may have resulted in differences between physicians and medical students or differences related to demographic characteristics of participants.

Fifth-year students did not attribute less importance to empathy than the second-year, preclinical, students. Although this finding appears to contrast with the results of studies elsewhere, which showed a decline in students' empathy over their years in medical school,¹⁴ what we actually measured was the value placed on empathy, and not actual conveying of empathy. It is also possible that the relatively small number of students in our sample simply did not allow for differences between the groups to be expressed. This issue will be more fully addressed as we expand our study population. As part of our ongoing research it will be necessary to compare the characteristics of our volunteer participants with those of students and physicians who declined to participate, in order to rule out selection bias.

Our study was intended to measure the importance that Israeli medical students, physicians, and laypeople attribute to empathy in physician-patient communications. In our preliminary assessment, we found that empathy is indeed valued by medical students and physicians, which suggests that efforts should be focused on identifying and removing the institutional and educational barriers to empathic communication and on improving physicians' skills in this area.

Barriers to adopting empathic communication style were hinted at in an earlier study of empathy in Israeli physicians.¹⁵ Participants in the study ranked empathy as the most important quality of a good physician, but the least important quality needed for professional advancement in their hospitals.

Empathy has also been studied in Israel in the context of undergraduate medical education. One study, based on focus groups and students learning empathic communication, noted that students perceived a conflict between empathic care and efficient, scientific care. In response, empathic communication skills were reframed in the curriculum as clinical competencies.¹⁶

Another study in Israel using Hogan's empathy scale¹⁷ found no differences in empathy between Israeli social work students and medical students.¹⁸ There was a relatively low score on empathy for Israeli students (mean 38.46 ± 6.5), relative to the data presented by Hogan (mean 42.4 ± 5.3) for medical students he had studied. The authors of this study attributed this finding to a possible sense of self-centredness of the Israeli students.

A third study compared the degree of empathy among 153 Israeli medical students to that of other university students, and evaluated the impact of the psychiatric clerkship during medical school on their degree of

empathy.¹⁹ This study found that the medical students were more empathic than students in other domains, with the exception of the psychosocial sciences, such as psychology and social work. It further noted that group experiences in the psychiatric clerkship could increase the medical students' empathy significantly.

Both the value placed on empathy and caring, and the specific ways empathy is expressed, vary between cultures and are subject to cultural influences. We thus felt it important to develop a validated Hebrew-language tool for measuring empathic communication that is culturally appropriate for Israel. Our choice of the CARE questionnaire was based on its simplicity as well as the way the questions were framed in both professional and laymen's language. However, we felt that four of the original ten questions on the questionnaire reflected patient-centredness and not empathy, because they lacked an emotional component, an essential part of empathy. The high consistency in responses to the high- and low-empathy simulated interviews in our study supports the validity of the modified and translated questionnaire. It would be interesting to compare a similarly modified version translated back into English with other existing, validated tools in English.

The use of a centralized, distant, website for viewing two contrasting versions of a simulated interview is, to the best of our knowledge, a novel way of researching physician-patient communication. It was easy and inexpensive to organize, allowed the participants to view the interviews from their homes and at their convenience, and allowed us to reach relatively large numbers of potential participants in a short period of time.

6. Summary

Our study measured the importance attributed to empathy in physician-patient communications by Israeli physicians and medical students. Not only did both groups attribute much importance to empathy, they also gave significantly higher global ratings to the physician evincing more empathy.

It appears that the modified, Hebrew version of the CARE questionnaire is a valid tool for examining empathy in Israel. Future research in Israel may use this questionnaire to study the impact of empathy on a broad range of clinical and other outcomes.

We have established the high value placed on empathy by a group of 67 Israeli medical students, residents, and attending physicians. We intend to enlarge the numbers in the existing groups and to add groups of Israeli laymen and community-based physicians.

Notes

¹ A Flexner, *Medical Education in the United States and Canada*, The Carnegie Foundation for the Advancement of Teaching, Bulletin No. 4, 1910.

² RJ Haggerty, 'Etiology of Decline in General Practice', *J Am Med Assoc JAMA*, vol. 185, Jul 20, 1963, pp. 179-182. AS Kraus, EH Botterell, DW Einarson & MG Thompson, 'Initial Career Plans and Subsequent Family Practice', *J Med Educ*, vol. 46(10), Oct 1971, pp. 826-830.

³ M Balint, *The Doctor, his Patient, and the Illness*, Pitman Medical (Reprinted 1986, Edinburgh, Churchill Livingstone), London, 1957.

⁴ E Balint, 'The Possibilities of Patient-Centered Medicine', *J R Coll Gen Pract*, vol. 17(82), May 1969, pp. 269-276.

⁵ IR McWhinney, 'General Practice as an Academic Discipline - Reflections After a Visit to the United States', *Lancet*, vol. 1(7434), Feb 19, 1966, pp. 419-423.

⁶ GL Engel, 'The Need for a New Medical Model: a Challenge for Biomedicine', *Science*, vol. 196(4286), Apr 8, 1977, pp. 129-136.

⁷ W Levinson, DL Roter, JP Mullooly, VT Dull & RM Frankel, 'Physician-Patient Communication - the Relationship with Malpractice Claims among Primary Care Physicians and Surgeons', *J Am Med Assoc JAMA*, vol. 277(7), Feb 19, 1997, pp. 553-559.

⁸ D Roter & S Larson, 'The Roter Interaction Analysis System (RIAS): Utility and Flexibility for Analysis of Medical interactions', *Patient Educ Couns*, vol. 46(4), Apr 2002, pp. 243-251.

⁹ G Makoul & RH Curry, 'The Value of Assessing and Addressing Communication Skills', *J Am Med Assoc JAMA*, vol. 298(9), Sep 5, 2007, pp. 1057-1059. DL Roter & JA Hall, *Doctors Talking with Patients / Patients Talking with Doctors: Improving Communication in Medical Visits*, Auburn House, Westport CN, 1992. MA Stewart, 'Effective Physician-Patient Communication and Health Outcomes: a Review', *Can Med Assoc J CMAJ*, vol. 152(9), May 1, 1995, pp. 1423-1433.

¹⁰ L Del Piccolo, N Mead, L Gask, MA Mazzi, C Goss, M Rimondini & C Zimmermann, 'The English Version of the Verona Medical Interview Classification System (VR-MICS)- an Assessment of Its Reliability and a Comparative Cross-Cultural Test of Its Validity', *Patient Educ Couns*, vol. 58(3), Sep 2005, pp. 252-264.

¹¹ SW Mercer, M Maxwell, D Heaney & GC Watt, 'The Consultation and Relational Empathy (CARE) Measure: Development and Preliminary Validation and Reliability of an Empathy-Based Consultation Process Measure', *Fam Pract*, vol. 21(6), Dec 2004, pp. 699-705.

¹² T Singer, 'The Neuronal Basis of Empathy and Fairness', *Novartis Found Symp*, vol. 278, 2007, pp. 20-30; discussion pp. 30-40, 89-96, 216-221.

¹³ BW Newton, L Barber, J Clardy, E Cleveland & P O'Sullivan, 'Is There Hardening of the Heart During Medical School?', *Acad Med*, vol. 83(3), Mar 2008, pp. 244-249.

¹⁴ S Carmel & SM Glick, 'Compassionate-Empathic Physicians: Personality Traits and Social-Organizational Factors That Enhance or Inhibit This Behavior Pattern', *Soc Sci Med*, vol. 43(8), Oct 1996, pp. 1253-1261.

¹⁵ AE Raz & J Fadlon, 'We Came to Talk with the People Behind the Disease: Communication and Control in Medical Education', *Cult Med Psychiatry*, vol. 30(1), Mar 2006, pp. 55-75.

¹⁶ R Hogan, 'Development of an Empathy Scale', *J Consult Clin Psychol*, vol. 33(3), Jun 1969, pp. 307-316.

¹⁷ J Lachter & A Mosek, 'Similarities and Differences Between Social Work and Medical Students in Empathy, Conflict Resolution, and Professional Image', *Soc Sci Med*, vol. 1(2), 1995, pp. 107-116.

¹⁸ A Elizur & E Rosenheim, 'Empathy and Attitudes among Medical Students: the Effects of Group Experience', *J Med Educ*, vol. 57(9), Sep 1982, pp. 675-683.

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Appendices

Table 1: Characteristics of the study population

	MDs	5 th Year Students	2 nd Year Students
Number	24	14	29
Median Age Range	40 29-65	27 23-30	25 21-31
Gender (F / M)	8 / 15	7 / 7	13 / 16
Native Israelis	79%	64%	93%

Table 2: Participant responses to Part A of the questionnaire

Question	Physician Characteristics	High-Empathy Physician (mean \pm SD)	Low-Empathy Physician (mean \pm SD)	P value
1 – Co	knowledgeable	8.0 \pm 1.3	7.6 \pm 1.0	NS
2 – Em	gives patient space	5.6 \pm 2.1	3.0 \pm 1.6	<0.001
3 – Co	efficiency	7.3 \pm 1.5	6.0 \pm 1.9	0.002
4 – Em	compassionate	7.4 \pm 1.8	3.4 \pm 2.2	<0.001
5 – Em	good listener	7.7 \pm 1.6	3.8 \pm 1.9	<0.001
6 – Co	explains clearly	7.6 \pm 1.6	4.2 \pm 2.2	<0.001
7 – Em	shows interest	7.4 \pm 1.7	3.2 \pm 1.6	<0.001
8 – Em	reassuring	7.2 \pm 1.9	2.5 \pm 1.8	<0.001

9 – Co	medical decisions	7.7 ± 1.4	7.1 ± 1.9	NS
10 – Em	understanding	7.9 ± 1.8	3.5 ± 2.5	<0.001
General evaluation		7.5 ± 1.3	4.8 ± 1.8	<0.001
Mean empathy*		7.2 ± 1.6	3.3 ± 1.6	<0.001
Mean competence**		7.6 ± 1.1	6.2 ± 1.2	<0.001
Overall performance		7.5 ± 1.3	4.8 ± 1.8	<0.001

Abbreviations

Em = the question concerns empathy

Co = the question concerns competence

1 = the lowest score, 9 = the highest score

NS = nonsignificant.

* mean empathy score – average of responses to questions 2, 4, 5, 7, 8, 10

** mean competence score – average of responses to questions 1, 3, 6, 9

Table 3: Participant responses to Part B of the questionnaire

Question	Physician Characteristics	High-Empathy Physician (mean ± SD)	Low-Empathy Physician (mean ± SD)	P value
1 – Co	knowledgeable	8.7 ± 0.6	8.5 ± 0.6	NS
2 – Em	gives patient space	7.2 ± 1.6	7.2 ± 1.2	NS
3 – Co	efficiency	7.9 ± 1.3	7.9 ± 1.1	NS
4 – Em	compassionate	8.0 ± 1.3	7.9 ± 1.8	NS
5 – Em	good listener	8.1 ± 1.3	7.9 ± 1.1	NS
6 – Co	explains clearly	8.3 ± 1.4	8.5 ± 0.8	NS
7 – Em	shows interest	7.8 ± 1.4	7.7 ± 1.4	NS
8 – Em	reassuring	7.8 ± 1.4	8.0 ± 1.5	NS
9 – Co	medical decisions	8.7 ± 0.8	8.8 ± 0.4	NS
10 – Em	understanding	7.9 ± 1.2	8.0 ± 1.2	NS
Mean empathy*		7.8 ± 1.2	7.8 ± 1.2	NS
Mean competence**		8.4 ± 0.9	8.4 ± 0.4	NS

Abbreviations

Em = the question concerns empathy

Co = the question concerns competence

l = the lowest score, *9* = the highest score

NS = nonsignificant.

* mean empathy score – average of responses to questions 2, 4, 5, 7, 8, 10

** mean competence score – average of responses to questions 1, 3, 6, 9

Questionnaire

Part A relates to the interview you have just watched. On a scale of 1 to 9 (1-lowest, 9-highest) please circle the number best describing the statements' applicability to the physician in the interview. Following each statement there is a short explanation.

If you are unable to answer a question, please mark the "x" at the end of the line.

1	<i>She is knowledgeable</i> (It appears she has vast theoretical and practical medical knowledge)	1 2 3 4 5 6 7 8 9	X
2	<i>She lets the patient tell her story</i> (She gives the patient enough time to say what he has to say, in his own words, without interrupting or distracting her.)	1 2 3 4 5 6 7 8 9	X
3	<i>She interviews the patient effectively</i> (She conducts the interview efficiently, and uses the time allotted for the interview well.)	1 2 3 4 5 6 7 8 9	X
4	<i>She is caring and compassionate</i> (It appears she really cares, connects with the patient as a human being, is <i>not</i> indifferent or distant.)	1 2 3 4 5 6 7 8 9	X
5	<i>She really listens</i> (She follows the patient attentively, and does not look at her notes or the computer when the patient is talking.)	1 2 3 4 5 6 7 8 9	X
6	<i>She explains things clearly</i> (She explains her thoughts regarding the diagnosis and what is further required patiently and clearly.)	1 2 3 4 5 6 7 8 9	X
7	<i>She is interested in the patient as a whole person</i> (She knows and asks relevant questions about the patient's life and condition, and does <i>not</i> treat her as "just another case.")	1 2 3 4 5 6 7 8 9	X
8	<i>She makes the patient feel at ease</i> (She is being friendly and warm, <i>not</i> cold or abrupt, and treats the patient with respect.)	1 2 3 4 5 6 7 8 9	X
9	<i>She makes correct medical decisions</i> (It appears she bases her decisions regarding the patient's diagnosis and treatment on sound facts.)	1 2 3 4 5 6 7 8 9	X

10	<i>She fully understands the patient's concerns</i> (She communicates that she has accurately understood the patient's concerns, and <i>does not</i> overlook or dismiss anything.)	1 2 3 4 5 6 7 8 9	X
11	How would you rate the overall performance of the physician in the interview?	1 2 3 4 5 6 7 8 9	X

Part B relates to the importance you attribute to the following physician characteristics in general. On a scale of 1 to 9 (1-lowest, 9-highest), please circle the number best describing the importance you attribute to the statement describing physicians' characteristics in general. Following each statement there is a short explanation.

If you are unable to answer a question, please mark the "x" at the end of the line.

1	<i>The physician is knowledgeable</i> (It appears she/he has vast theoretical and practical medical knowledge.)	1 2 3 4 5 6 7 8 9	X
2	<i>The physician lets the patient tell his/her story.</i> (Gives the patient enough time to say what he has to say, in his own words, without interrupting or distracting him.)	1 2 3 4 5 6 7 8 9	X
3	<i>The physician interviews the patient effectively</i> (Conducts the interview efficiently, uses the time allotted for the interview well.)	1 2 3 4 5 6 7 8 9	X
4	<i>The physician is caring and compassionate</i> (It appears she/he really cares, connects with the patient as a human being, is <i>not</i> indifferent or distant.)	1 2 3 4 5 6 7 8 9	X
5	<i>The physician really listens</i> (Follows the patient attentively, does not look at her/his notes or the computer when the patient is talking.)	1 2 3 4 5 6 7 8 9	X
6	<i>She/he explains things clearly</i> (Explains her thoughts regarding the diagnosis and further requirements or issues patiently and clearly.)	1 2 3 4 5 6 7 8 9	X
7	<i>The physician is interested in the patient as a whole person</i> (Knows and asks relevant questions about his life and condition, does <i>not</i> treat him as just another case.)	1 2 3 4 5 6 7 8 9	X
8	<i>The physician makes the patient feel at ease</i> (She/he is friendly and warm, treats him with respect, is <i>not</i> cold or abrupt.)	1 2 3 4 5 6 7 8 9	X

9	<i>The physician makes correct medical decisions</i> (It appears she/he bases her decisions regarding the patient's diagnosis and treatment on sound facts.)	1 2 3 4 5 6 7 8 9	X
10	<i>The physician fully understands the patient's concerns</i> (She communicates that she accurately understood his concerns, and <i>does not</i> overlook or dismiss anything.)	1 2 3 4 5 6 7 8 9	X

PART VIII

Culture and Communication

“I’m not sick, I just have pain:” Silence and (Under) Communication of Illness in a Nicaraguan Village

Aleksandra Bartoszko

Abstract

The Masaya volcano in Nicaragua is currently the world’s strongest sources of sulphur dioxide and also emits large amounts of carbon and halogen gases to the atmosphere. According to health reports, this volcanic air pollution is the most prevalent cause of mortality in the region. Alongside this it is responsible for lung and skin diseases, arthritis and dental problems. People living in the area do not, though, acknowledge being sick and especially men present themselves as healthy ones and are silent about their medical problems. However, they do acknowledge having pains, but not in front of the medical staff from the nearest town. The object of this article is to analyze this situation. I suggest that the local conception of the healthy body and different ideas about the relation between pain and illness constitute the main barrier in communication and mutual understanding between patients and the medical staff. Drawing on theories about normality as a social construct I explore how “the normal body” can be defined. Normalisation of pain is a central issue I discuss in relation to the image of “the rural body” and health practices. The traditional, for this village, power relationships are the main reason of men’s absence from health centres. The local gender relations are based on *machismo* ideals and the conception of the passive and subordinate women and the active and dominant man is challenged by female medical practitioners.

Goffman’s symbolic interactionism, Barth’s generative models of behaviour and constructionist understanding of health and illness constitute the theoretical foundation for this article.

Key Words: Nicaragua, environmental health, pain management, health understanding, normality, gender, machismo, doctor-patient communication.

1. Introduction

This article is based on six months fieldwork I conducted in 2007 in a Nicaraguan village, which I will refer to here as Santiago. The village is situated in the mountains near an active volcano. The Masaya volcano is currently the world’s largest source of sulphur dioxide (SO₂) and also emits large amounts of carbon and halogen gases to the atmosphere. The volcano is currently undergoing an episode of strong gas emissions with emission rates

well over the acceptable levels.¹ According to health reports, the volcanic air pollution is the most prevalent cause of mortality in the region. It also causes lung and skin diseases, arthritis and dental problems.² However, my informants did not acknowledge being sick and especially men presented themselves as healthy and were silent about their medical problems. They did, though, acknowledge having pains, but not in front of the medical staff from the nearest town. The purpose of this article is to explore the reasons for this state of affairs. I think that one of the obstacles to mutual understanding concerns different ideas about the relationship between pain and illness. Drawing on theories about normality as a social construct I will explore how “the normal body” is defined in Santiago. Normalising of pain is a central issue I want to discuss in relation to the image of “the rural body” and health practices. The third factor involves local gender relations based on *machismo* ideals, where women are seen as passive and subordinate, and men as active and dominant. This conception is challenged by female medical practitioners.

2. Diarrhoea and the Normal Body

I would like to start with a case from one of the doctor’s visits in Santiago. A woman in her forties came to see the doctor with her grandchild. While the child was vaccinated one of the nurses asked the woman standard questions such as whether the child had fever, diarrhoea, rash, and if she ate enough. The dialogue was as follows:

Nurse: The child looks a little bit weak.

Grandmother: Yes, she has eaten very little recently.

Nurse: Does she have diarrhoea?

Grandmother: No, just the normal one.

Nurse (a bit irritated): Does she have diarrhoea or not?!

Grandmother: Actually yes, she has it a bit.

Nurse (more irritated): How long has she had the loose stool? A week? Two? Three?

Grandmother: Yes, perhaps two weeks, but she has it very often.

This situation made me aware of how my informants understood and interpreted what happened to their bodies. This short excerpt highlights local views on health and illness, which stands in contrast to that of medical staff. WHO formulates a definition of diarrhoea as “[a] passage of 3 or more loose or liquid stools per day, or more frequently than is *normal* for the individual (my emphasis).”³ This definition has a relational meaning since diarrhoea is defined by what each individual considers as normal. We know from Dupre,⁴ Garfinkel⁵ and Goffman⁶ that normality is socially constructed and that *the normal* is classified and defined by comparison with the rest - with the

majority. I would add that it is also, if not mostly, defined by our personal experiences, especially when it comes to bodily functions. For the grandmother, the child's diarrhoea was normal not only because everyone in the village had had it, but also because she had experienced it herself. It was a part of her everyday life and as such remained within accepted limits. These limits were contextual, without any universal regulations within which WHO operates. Various conceptions of and attitudes towards the body⁷ result in different opinions on how the body should function, what is acceptable and what *the normal body* is. "It [diarrhoea] is annoying now and then, yes, but that is just how we live here," expressed one woman: abnormality or pathology becomes a possibility of normal functioning.⁸ "It will pass," said the grandmother laughing. Then she explained: "The child poos a little, but is it diarrhoea? I don't know. Sometimes they say it is, other times they say that it's normal. It depends on who comes here, you know." So misunderstanding applies not only to the experience of having loose stool, but also to the names and categories which the medical professionals use. Physiological functions were categorised by the experts and, like many others in the village, the grandmother did not entirely understand those terms. She also believed that the health personnel do not always agree with each other. The relativity of health categories applies therefore not only to differences between lay people and experts, but also to the internal disagreements within specialised circles. This creates confusion among the health service receivers: "One day they say we are healthy, another day they say something else." In this way the personnel undermines its own, as well as the medical science's authority that they are intended to impart.

However, it should be pointed out that Santiago residents have an ambivalent attitude towards diarrhoea and how normal it is. I talked to Alma about this issue. She was 26 years old and had two children. Since I had been a little bit sick, I had not visited her for a couple of days. When I arrived, she was at home making dinner and asked why I had not come earlier. I told her that I had had a fever and diarrhoea. She listened to me and said casually: "I also have diarrhoea today." I was surprised by how unpreoccupied she was, so I asked her if she did not think that it was dangerous. She smiled and replied:

Yes, you in the city believe it is dangerous, they [doctors] are saying it is dangerous. I think that it may be [dangerous] for children, but we all have it [diarrhoea on a regular basis]. That is how we live here in the village. We do not have any medicines and we are drinking contaminated water. What can we do? We have to live with that.

Alma’s statement is evidence for that it is not right that “they do not understand that diarrhoea is a disease,” as the nurse said to me. Rather, we can observe a *relational understanding* of symptoms and diseases. People in Santiago are aware that what happens to them is not entirely as it should be yet they accept it as part of their life. They had to do so, meant Alma. Poor access to health services and medicines, and their socioeconomic situation causes them to live in a state of *situational normality*.⁹ Therefore, I believe that in societies like Santiago medical expressions are declassified, redefined and, in fact, meaningless while facing the village’s reality. My informants’ illness definition and their experience were not alike the one described in the WHO’s reports and which are communicated by the local health personnel. Categories as well/sick, normal/abnormal and dangerous/safe do not have the same content in these two worlds. The reference point for both groups is different and brings about communication problems.

3. Pain, Symptom and Disease

In studies of illness understanding, social scientists focus on social interpretation of *symptoms*.¹⁰ This involves problems like the one with the grandmother and the diarrhoea. Most of my informants did not understand diarrhoea or pains as a symptom of disease. That is why I mean that the research focus should fall not only on the *interpretation* of symptoms, but also on their *acknowledgment* and on the *recognition* of a disease.

When I tried to collect narratives about the volcano in Santiago I rarely heard that it had influence on people’s health. When I asked my informants if they were ill because of the gases the standard response was: “No, it does not make us ill.” What opened my eyes was when Carlos said:

No, we are not sick from the volcano. It is just that, when you are working a lot and you are tired, then you get such a pain in your lungs. It really hurts. It is the smoke [gases from the volcano] that causes it.

Then I realised that there was a nuance that differentiated pain and illness for my informants. Another day Emilio said: “It [gases from the volcano] causes such a headache, but only in the winter. We get along here. We don’t give in to this bastard [the volcano]. We keep ourselves healthy.” These statements show that my informants did not see any relationship between illness and pain as the experts do. Health reports mention a high occurrence of lungs diseases in the region, and the existence of arthritis, pneumonia and waterborne diseases is considerably higher than in other regions.¹¹ Still, experience of these diseases is much lower among my informants. “Here we are all in good health,” said Igor one day. The definition of oneself as a healthy person in spite of painful experiences is a result of the relational

understanding of symptoms. What is defined as a symptom depends not only on an individual's knowledge, but is also determined by the context the individual finds himself in. Diarrhoea or chest pain is more common among the rural people so they do not regard them as symptoms, but rather as *a bother* which they get used to living with. Humans define their health condition by comparing it with other people, but also in relation to their own everyday life.

4. Pain Normalisation and the Rural Body

In Santiago pain was not always interpreted as deviation, but was rather perceived as something typical of the village, fitted in their "form of life"¹² and therefore normalised. By normalising I mean physiological, psychological and social adaptation. People of Santiago had their own explanation for this. One day Manuela took me to the valley to pick some yucca. When we were digging up the roots I saw her hand bleeding, but she continued working. She had hurt herself in the fields the day before. When I asked, she admitted it did hurt a bit, but it did not matter because she had *a rural body (cuerpo del campo)* and therefore was used to pain. The other day I was amazed to see local children working with the pitahaya shrubs that have huge thorns. Their father said: "If you have *a peasant body (cuerpo del campesino)* nothing hurts." These examples show that both men and women presented their own body as *a rural body* which is imprinted with pain and they explain themselves, and their situation through rural way of life, which constructs a body type: it is vulnerable, but at the same time strong and immune to pain.

5. The Active Body

People in Santiago value physical activity and effort, which is also perceived as a fundamental element of their lives. "If you are born in the countryside, you have to work like a horse," said Eloisa when we were walking for miles with a bucket of rain water we fetched at the reservoir. The activity was also crucial for perceiving oneself as sick or not. What determined my informants' view on what it means to be healthy pertained to their functionality, that is, their body's functionality. The active body is synonymous with a healthy body. Such understanding was confirmed time and again, when I observed people with pains working in the fields, but who still claimed they were healthy. Jensen defines health as "[being] able to carry out normal actions and activities in relation to one's everyday life or role"¹³ and the people of Santiago define it the same way. The body should fulfil its function. It is a tool in work and in daily life. "*Mi cuerpo es mi alimento*" - My body is my food - concluded Mario and then went on to say:

I cannot lie in bed just because I have a bit of pain. When you are lying in bed, you are not getting better [...] Yes, when you are really sick, so that you are not able to go, then you have no choice, but it almost never happens here. I mean that when [...] you go to bed, you start thinking about the food you cannot bring, the money you are unable to get for your family, and all of this; that you are not useful [...] That is our body we work with and earn a living with. Not with the head as you do [he smiled].

Mario’s statement contains three key values: physical functionality, male pride and responsibility for the family. I will now elaborate on the relationship between the idea of masculinity and disease, and show how it influences the communication with the medical staff. My informants’ interpretation of their own gender identity is a key point here and constitutes an obstacle for illness communication. Role conflicts are of central importance in this case.

6. Gender of Illness

One day I was sitting with some women in front of the house where the doctor was seeing patients. Suddenly we saw a man coming in our direction and some women burst out laughing. When he came closer they started shouting at him: “Hey, Pedro, do you need an ointment?” “Do you have arthritis?” and “Should Maria [his wife] clean the pitahaya?”¹⁴ And they were laughing. He turned a little red and snapped something to the women. He asked how long the queue to the doctor was and then he walked away. The women continued mocking him: “Go and make dinner!” and everybody laughed again. I asked why they did that and I was told that it was unusual for a young man to go to the doctor. They thought it was funny to see him there. One said: “Only we are coming here with children. Our men are in the fields,” and she pointed to a clear division in use of the public arenas. This place was meant for women. “Our men are healthy,” said Carla. A few days later she explained to me that she did not mean that the men could not be sick every now and then. “Pain is normal in the countryside,” she said, “but they do not complain, so they can work.” De Swaan¹⁵ points out that “[in] a medical perspective, what matters is the loss of bodily functions; in [a] sociological perspective what counts is the loss of social functions, contracting and condensing of the network of dependency.” In the same way, I am interested in the loss of social functions that occurs in connection with illness situations. “They are men after all,” said Carla, and confirmed that it is work that defines masculinity. Physical activity is necessary in order to carry out work in the village, and a reduction in his activity would therefore mean that the man cannot fulfil his duties. “That he is not a man,” as Carla could

have concluded. It is expected that men are the strong and active ones in the household. Illness belongs to women and children, and becomes therefore a gendered phenomenon. The illness in Santiago has a gender, and it is feminine.

7. Machismo and the Patient Role

A traditional notion of masculinity in Latin America is affected by the concept of machismo.¹⁶ In short, the concept includes a cult of men, paternalism, male strength and virility. In relation to the opposite sex it is expressed through aggression, systematic oppression, sexualising of the female and an idealisation of their reproductive abilities. Machismo culture requires activity and dominance. Women's culture does not allow this. Every action, gesticulation or walking manner is interpreted as feminine or masculine. Conduct that is not consistent with the gender-established expectations is "a matter out of place" and may lead to social sanctions. The previous example of the male patient and the laughing women illustrates this very well.

The relationship between professionals and clients is a power relation and always involves a form of domination.¹⁷ In the classic situation where the idea of user involvement is not implemented, it is the professionals who have the power to change and influence the patient's situation. To be a patient, therefore, is synonymous with being *subordinate*, something that crashes with my informants' concept of masculinity. Belief in the passive woman does not fit in when it is women who make the diagnoses and give instructions to the male patients. Specific power relationships in Santiago are turned on their head when male patients come for advice to a female doctor. "We prefer to let it [pain] go by itself [rather than to visit the health centre]," said 27-year-old César. Men in Santiago say that they are healthy when they are asked and you almost never meet them in the health centre that then becomes a gendered space.

8. The Body's Communicative Aspect

The body is important for people of Santiago because of its practical value. I want to go a step further and look at the body's relationship with others: the body's communicative aspect. What do people in Santiago communicate with their bodies? What do their healthy bodies say? In Augé we read that "to think about one's illness is already to make reference to others."¹⁸ In various conversations Santiago residents often refer to the distinction between "us" (the village) and "them" (the town). Ernesto said:

They [in the town] say that we up here are poor and stupid. Tell them that we at least are strong and able to work with our hands [...] It is very hard, but we are proud of it [...] but

they say only bad things about us. It is not our fault that we are poor. That is how it is here in Nicaragua. It is not easy.

His wife said: “They come here when they want, and only repeat that we are sick [...] they only see our diseases and nothing else.” “No, they do not see how good we are,” added Ernesto. This affects their attitude and willingness to speak openly about their ailments. They are tired of being looked on as poor, sick and inept people. They do not want to be stigmatised, so they choose to be silent and let their bodies express: “We live in the countryside, and we manage ourselves well. We are strong and healthy and can look after our families.” They want to show strength because they know that they are weaker than others. Their silence becomes “a weapon of the weak.”¹⁹ According to Barth²⁰ every group’s own values get stronger in meeting with “the other.” Community feeling actualises especially when the group’s values are threatened. Through meetings with medical staff, the collective identity in Santiago is being reinforced. My rural informants undercommunicate their health problems, while physical strength and activity becomes the group’s mark. Through the choices people in Santiago make, the relationship they have with the medical staff is maintained and the boundaries between them are strengthened.

9. Silence, Maintaining a Façade and the Social Order

Physical activity and the responsibility to feed their family is an inseparable part of male identity in Santiago. Men believe that if the body fails, they fail as well. A desire to maintain the status of the strongest, the richest and most virile does not apply only in relation to other members of the household, but also in relation to the other men. To admit illness would mean confessing weakness. One day two women were running down Elena’s husband who stayed at home several days because of the arthritis. One woman said: “She [Elena] says he has such a pain that he cannot go!” The other replied: “Honestly! You know, he’s just irresponsible! He says that he is sick just to avoid working! We are lucky that our men do not talk such nonsense!” I stood in the kitchen with one of the women later the same day and she retold her husband the story. He smiled and said: “Oh, maybe I’ll get sick, too?” Then he started joking: “Ooh, I have such a back pain. And knees ache. Ooh, I cannot work. Delia, you need go down to clean the pitahaya.” The family burst out laughing and I realised the value of the active body. Why did they mock the sick man? His behaviour was interpreted as irresponsible. One does not avoid working just because one has pains.

Freund and McGuire write: “Under some situations, persons suffer excruciating pain, yet must quickly learn to manage their expression in order not to threaten a group’s morale or its ability to function.”²¹ Men in Santiago were silent not only in order to save face, but also to maintain harmony in

their society. “This is how we do it here, Aleksandra. They are out in the fields, we are here around the house and with children,” said Claudia. The gender-fixed balance works well for both men and women. Both sides will preserve this order. Maintaining the social approved façade was important in Santiago. Unlike the individually chosen façade Goffman elaborates on,²² the *macho* façade is created, selected, supported and reproduced collectively in the village. I believe that this idealised masculine front stands between patients and health personnel, and silence is a tool to maintain this relationship. Men’s absence at health centres or their silent “self-command”²³ can be interpreted as an avoidance strategy. They avoid situations such as the one Maria’s husband experienced when he came to the doctor’s office and where their “projected self” is not compatible with the “presented self.”²⁴

10. Concluding Remarks

I have shown the social context of health and illness and presented the way people in Santiago relate to the body and its functions, how they interpret the various symptoms and what “the normal” means to them. I argued thus that “health can never be defined in a purely unbiased manner and free of value.”²⁵ I have also shown how pain normalising occurs as a result of the individual’s living conditions. It is also important to remember what Freund and McGuire²⁶ point out when they write that “normalizing a disturbance [...] does not necessarily make it unimportant or less real.” My informants’ high tolerance to pain and small need to talk about it does not mean that they are indifferent to their own health, or to the opportunities to improve it. I interpret the normalising and silence practice as a *survival strategy*. To categorise something as “normal” is a way to deal with the situation.

Façade theory sheds a new light on this. I have shown how important it is not to present the villagers as weak people. The presentation of self as less vulnerable can be seen as *an empowerment process*. According to Crocker and Quinn²⁷ self-esteem is situationally constructed. People who feel stigmatised in any way overcommunicate positive aspects of their own *persona* in social situations to regain the self-respect that was weakened by the stigmatising person. By presenting themselves as healthy, Santiago residents contribute to the diminishing of the differences between “us” and “them.” They try to achieve equality that they cannot achieve in other ways or in other arenas.

Established power relations between genders in Santiago were challenged by female professionals. By using Barth’s process-oriented model of action it is possible to say how this difficult relationship is maintained. According to him, society is “an aggregator of people who are making choices while they are under the influence of certain limits and incentives”²⁸ and according to their own interests and values. All social interaction is thus

a negotiation that “involves a very clear feature of over and undercommunication.”²⁹ A dialogue with the medical staff becomes then a *selective communication*. The player’s action starts with calculation of the potential gains and losses. I have shown how this strategic *silence play* takes place in Santiago. Male pride is in danger when it is confronted with disease and the medical staff. The losing of the face is considered to be a huge loss and the value of what is achieved through silence practice is assumed to be bigger than that provided. I have explained why the health centre becomes empty in spite of the fact that people in Santiago value the modern medicine. They are often aware of the consequences of their choices, but the social factors still play a central role in their decisions. This has nothing to do with rationality or lack of intellectual capabilities. A risk- and cost-benefit analysis³⁰ of the situation can be helpful to understand it. There are both individuals’ material benefits and values that are at stake. Their rational choice is guided by what is important in their world view, that is, the concept of the ideal man or woman.

Notes

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¹⁰ e.g. A Kleinman, *Writing at the Margin: Discourse between Anthropology and Medicine*, University of California Press, Berkley, Calif., 1995.

¹¹ SILAIS Masaya, *Infecciones Respiratorias Agudas 2000-2007*, SILAIS Masaya, Masaya, 2007.

¹² L Wittgenstein, *Philosophical Investigations*, Blackwell, Oxford, 1967.

¹³ UJ Jensen, 'Sundhed, liv og filosofi', in *Sundhedsbegreber - filosofi of praksis*, UJ Jensen & PA Fuur (eds), PHILOSOPHIA og forfatterne, Århus, 1995, p. 15.

¹⁴ Pitahaya cleaning in the winter is male work. Women pick up the fruit in the summer.

¹⁵ A De Swaan, *The Management of Normality. Critical Essays in Health and Welfare*, Routledge, London, 1990, p. 22.

¹⁶ RN Lancaster, *Life is Hard. Machismo, Danger, and the Intimacy of Power in Nicaragua*, University of California Press, Berkley, 1992. M Melhuus & KA Stølen (eds), *Machos, Mistresses, Madonnas. Contesting the Power of Latin American Gender Imagery*, Verso, London, 1996.

¹⁷ N Ainsworth-Vaughn, *Claiming Power in Doctor-Patient Talk*, Oxford University Press, New York, 1998. E Freidson, *Professional Dominance: The Social Structure of Medical Care*, Atherton Press, Inc., New York, 1970. T Parsons, *The Social System*, Routledge, London, 1991, chapter X. De Swaan, 1990, p. 25.

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²⁸ Barth, 1994, p. 33. [translation A.B.]

²⁹ *ibid.*, p. 41. [translation A.B.]

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**“His body was a map of disease:” Remapping the Body of the
Person with AIDS in Robert Ferro’s *Second Son* (1988)**

Gian Pietro Leonardi

Abstract

Robert Ferro’s semiautobiographical novel *Second Son* (1988) is arguably one of the first books dealing with Aids and its complex cultural and medical history. It recounts the story of Mark Valerian, whose Aids diagnosis condemns him to a certain death in the 1980s. His terminal illness - shamefully imputed to his homosexuality - puts into question his own position within his conservative Italian American family and pre-antiretroviral medical culture. This study examines the depiction of the person with Aids in *Second Son*, in the attempt to capture a particular moment in the history of this illness, when it was still considered a mere gay plague, and the position of the patient within a medical framework, in which her/his condition is subdued to therapeutic choices, possibly depriving her/him of the will to choose what is good for them.

As a person with Aids, Valerian is presented with a number of cultural collisions. First of all, his diagnosis collides with his father’s religiosity, according to which only prayer and hard work could represent an alternative to medical inefficiency while coping with the disease. At the same time, Valerian is not happy with the doctors’ attitude towards his condition, which reduces him to an anonymous donor of urine and semen specimens. In the end, his disease forces him to face the multifaceted issues related to the assessment of gay “quality of life,” in terms of expectations and priorities. To this respect, meeting Bill - who has Aids himself - envisages a new possibility of well-being beyond the medical world, thanks to a profitable sharing of patients’ experiences and unbiased affection. I argue that, far from being only a valuable historical document, *Second Son* casts a new light on the issues of well-being within illness, assessing the crucial importance of the patient’s personal concerns in the therapeutic approach.

Key Words: Robert Ferro, AIDS, metaphor, Susan Sontag, stigma, gay, plague, patient, map, disease.

Despite Luc Montagnier and Françoise Barré-Sinoussi were awarded with the 2008 Nobel Prize for Physiology or Medicine for their groundbreaking research on HIV, no vaccine or cure has been found for AIDS yet.¹ A recent CDC report² on HIV/AIDS, moreover, estimates that the

number of people living with the virus worldwide has increased to 33 millions, while 25 millions have died of AIDS since the first reported cases in 1981. The population living with HIV is growing as more people become infected and as effective treatments delay AIDS-related deaths. Gay and bisexual men still represent a significantly greater proportion of estimated new infections in 2006 than any other risk group.³ In the wake of these figures, gay activists are demanding a re-gaying of prevention, in contrast with the approach taken by much of the AIDS community in the last 15 years. Reclaiming back the disease would set prevention targets and prioritize resources and interventions.

Since the outburst of the infection, in fact, gay writers have tried to respond to the intrusiveness and fatality of the virus by speaking the unspeakableness of AIDS, by exposing their readers to the dangers of the disease, by calling attention to its emergency, and ultimately by showing the suffering and solitude of the affected ones. Immersive AIDS literature is, after all, a social literature: apparently moralistic in tone and dramatic in performance. Like other forms of witness writing, it emerged in reaction to the general denial and unfamiliarity with its subject, but from the start it was clear that it called the readers to declare their accountability in silence and to share the burden of testifying and commemorating those who perished. Robert Ferro's *Second Son* is arguably one of the first novels to deal with AIDS in such terms. Though other books had been previously published but had gone unnoticed, due to the prominent role in the developing of a gay literature of its author, *Second Son* was the first one to receive public attention and to be widely read and reviewed. In this paper I will examine the depiction of the person with AIDS in the novel, in the attempt to capture a particular moment in the history of this illness, when it was still considered a mere gay plague, and the position of the patients within a medical framework, in which their condition is subdued to therapeutic choices, possibly depriving them of the will to choose what is good for them. I will then compare it to Susan Sontag's *AIDS and its Metaphors* (1989), particularly to her fierce resistance to metaphorical patterns when dealing with and explaining AIDS. Robert Ferro's novel, contrastively, draws much of its inspiration and critique from the apocalyptic discourses surrounding the AIDS pandemic which arose and informed the late 80's, but then the author discharges them in order to create new metaphors, new ways of representing and speaking the disease through the voice of those who suffered from it and from the general stigmatisation. The end is impending for everyone, not just for those who have contracted HIV, and Chernobyl is a sad reminder for all of us. In the end I will locate in the literary space or, more accurately, in the fictional space of the novel, a productive area where the biomedical and cultural discourses collide, where one can cope with the affliction unashamedly and can guess new meanings for its irrationality, and ultimately

envisage an “outer space” unaffected by the virus, or at least where it can be stopped or made inoffensive.

From the very beginning, *Second Son* seems to resist the apothegm that every story about AIDS has a set structure, that death is its natural and inevitable consequence.⁴ The house which Mark Valerian, the main character of the novel, objects to sell in order to get liquidity for the family factory, is inhabited by the spirits of those who have died in it. These spirits speak to “whomever might be listening,”⁵ but only Mark seems to be able to hear them. Being represented as the bridge between the world of the living and the world of the dead, Mark does not belong thoroughly to either. As a matter of fact he is “ill, dying perhaps,”⁶ but not dead yet.

Death itself, apparently, had retreated, again becoming the abstract notion it was to most people—not real, not imminent; dying perhaps, but not death.⁷

“The stupendous news of his illness”⁸ ends the lifelong quarrel with his father over the acceptance of his homosexuality, but it starts a more challenging one, against social stigma. Though Mark told his father, his siblings and three close friends about his condition, he’s not prone to be open and frank about it. This omission is underlined by Robert Ferro’s choice never to mention AIDS by its name throughout the novel and only referring to it as “the plague” or, more generically, as “It.” Accordingly, Mark chooses to embody the “secretly ill” persona, thus perpetuating the metaphorical cliché of the homosexual as a victim:

Nothing, I see, has much changed: it is still a question of coming out of the closet with something vile about yourself. [...] The secretly ill, no just because of the evil associations everyone makes, the fear harboured or suppressed; but because being ill is itself in such bad taste.⁹

The tastelessness of the disease, “offensive on other than medical grounds,”¹⁰ threatens Mark’s artistry: if once homosexuality elevated him from the middleclass milieu in which he was raised, now AIDS throws him back to the hollow world of common people. Thus AIDS can be conceived here as a revenge of the values of the Italian-American family and a menace to the economic system based on them. And it is not by chance that the news of Mark’s infection is shortly followed by the sudden financial breakdown of the family factory. Now, just like then, HIV targets mainly young adults in productive ages, thus posing a serious threat to the very fabric of society. Being an outcast, Mark Valerian bears the signs of exclusion, the stigma/ta of the dangerously ill.¹¹ His disease speaks through his body:

For him it was all in the skin, with weals and lumps of five or six varieties—raised tumors filled with blood, dark flat smudges just below the skin, small red welts, paired purple spots like spilled ink, deeper, palpable pea-shapes, hard and movable, too deep in the flesh to see; a raised mole had come up one night suddenly, like a mushroom, beneath the hair on the back of his head, a hard beaded little shape just outside the skull. Much of the bottom of his right foot was purple. The disk in the fascia below his sternum was larger. A small mark like a purple lentil had appeared one day on the point of his cheekbone, but over the next few days had then faded away, like a warning. He could still look in the mirror and pretend he was unaffected; but naked, with all these spots lighted up by the hot water and steam of his bath, his body was a map of disease.¹²

Arthur W. Frank remarks that: “serious illness is a loss of the ‘destination map’ that had previously guided the ill person’s life: ill people have to learn ‘to think differently.’”¹³ To this I would add that one must learn to think through the disease, not to let it speak in his or her stead. The vegetable imagery used in the novel to show the symptoms of Kaposi’s sarcoma strongly clashes with the medical realism of much of AIDS literature. The oxymoronic device tends to tame the aggressiveness of the infection and to make it more familiar. David Bergman notes how Robert Ferro repeatedly relies on metaphors to cast a “projection of meaning onto the meaninglessness of disease,”¹⁴ thus contradicting Susan Sontag’s advice to avoid rhetorical patterns when explaining AIDS. In her witty and frantic essay, she strongly rejects labelling AIDS as a plague, due to the many implications that the word implies. Furthermore, she argues that:

disease is seen as an invasion of alien organisms, to which the body responds by its own military operations, such as the mobilizing of immunological “defences,” and medicine is “aggressive” as in the language of most chemotherapies.¹⁵

But, nevertheless, the body of the person with AIDS is depicted in *Second Son* on one side as the object of the assault of the disease and, on the other, as the field of counterattack by physicians and scientists. His body is a map on which offensive and defensive strategies are drawn.

Mark needed their research and discoveries, but must be wary of which of them he chose, for afterwards he could

not reclaim virginity and choose again. And they wanted and needed him, because, more than a year after diagnosis, he was still comparatively unaffected.¹⁶

At the same time, Mark Valerian is not happy with the doctors' and paramedics' attitude towards his condition, which reduces him to an anonymous donor of blood, urine and semen specimens. Significantly, he is sceptic about the ongoing researches on the virus: "it's not a cure they're looking for, it's a vaccine. Protect the healthy, let the sick die off;"¹⁷ hence he turns down a proposal to be enrolled in a therapeutic protocol, because the doctor, who shows no sign of compassion towards his patient, refuses to give him any explanation about it. But then again, Robert Ferro chooses to represent the world of hospitals and cabinets at its fullest, thus introducing Dr Thompson, whose advice and medical care keep pace with the course of Mark's illness and who becomes a more familiar Theo later in the novel, and the competent and fearless nurse, who wears no mask nor gloves.

To this regard, it is worth mentioning that Mark believes that only love will save him from solitude and ultimately from AIDS: "since love made me ill, it should be that it cure me."¹⁸ And when love finally comes in the person of William Mackey, who has Aids himself, it entails a new possibility of well-being beyond the medical world, thanks to a profitable sharing of their personal experiences and unbiased affection.

They were sick in similar ways [...]. The physical side seemed balanced, in their case, by the absence of what might have made it worse: loneliness, the fear of doing this alone, whatever it was or would be – a gradual decline, in imperceptible stages. They were not afraid simultaneously; it seemed one's fear stimulated the other to protectiveness. Fear was the dream they woke each other from.¹⁹

Their passion is seen as a thrilling rebellion set at the heart of the family codes. Assuming at the same time the roles of the patient and of the caregiver, thus believing to know what is good for each other and confronting the disease together, the gay couple can finally pronounce their vows of eternal loyalty, till death do them apart.

"I am here now," [Bill] said, holding Mark in his arms.
 "Will you stay with me always?"
 "Always and always," Bill murmured in his ears.
 "It's no good unless we both live." Mark sat up and looked at him. "I mean it."
 "I know. Don't you think I know that?"

"Well, will you?" Mark asked again, now that the question was qualified.

"I will never leave you," Bill whispered.

"-Whatever happens," Mark went on. "No matter what."

"No matter what," Bill repeated.²⁰

When one is ill, his or her life tends to be subsumed by their illness. Affections, family and work tend to be relegated in the background of their existence, to the night-side of life. Being a gay writer, Robert Ferro feels compelled to deal with a subject that "continues to change and affect our lives,"²¹ but he does not want to reduce gay life to the spectre of AIDS:

I did not set out to write a novel about AIDS. *SECOND SON* is not *about* anything. It's a story, a love story actually, in which a life-threatening disease, never specified or even named, is a complicating factor.²²

Ferro insists on considering AIDS as a mere plot device, and his approach to the disease is ambivalent in many ways. He knows that its denial "has been and continues to be the major motivating dynamic of the epidemic,"²³ but nonetheless he wishes to run away from it. In the novel, correspondingly, Mark and Bill are presented with a similar choice. Matthew, the friend who played matchmaker between them, a novelist whose campy letters interweave with the narration, offers them the chance to join him in an interplanetary trip to Splendor, a gay planet, where the plague can be cured. A more terrestrial and substantial option is offered them by Dr Thompson: a new treatment for AIDS which requires the processed leukocytes of siblings. Consistently, the novel ends with the couple deciding for the medical treatment, but leaving the door open to the realm of possibility. A world where AIDS can be cured.

They sat together atop the tower in the afternoons, and often late at night before bed paced the deck over the porch, waiting for the ship to Splendor. For it seemed that what they would do together - what would be done to them in hospital - was a kind of trip, a voyage home. As with Matthew the ship had become their metaphor, something to look for by day over the horizon, by night among the stars.²⁴

In accordance, *Second Son* itself can be thought of as a sort of vessel, in which the disease can be coped through the fictional space, both physically and emotionally charged.

Notes

¹ For a comprehensive history of AIDS see LO Kallings, 'The First Postmodern Pandemic: 25 Years of HIV/AIDS', *Journal of Internal Medicine*, vol. 263 (3), March 2008, pp. 218-243.

² The full report can be downloaded here:

<<http://www.cdc.gov/nchhstp/Newsroom/docs/Fact-Sheet-on-HIV-Estimates.pdf>>.

³ MSM, men having sex with men, accounted for 53 percent of estimated new HIV infections in 2006.

⁴ See for example the incipit of Adam Mars Jones' *Monopolies of Loss*: "How do you tell a fresh story when the structure is set?", Random House, London, 1993, p. 1.

⁵ R Ferro, *Second Son*, Arena, London, 1988, p. 3.

⁶ *ibid.*, p. 4.

⁷ *ibid.*, p. 131.

⁸ *ibid.*, p. 19.

⁹ *ibid.*, p. 105.

¹⁰ *ibid.*, p. 54.

¹¹ Sight is a major issue in AIDS related complications, as about two-thirds of people with HIV or AIDS develop eye problems. Many people with Aids believe that their condition can be disclosed through their eyes and therefore fear stigmatization. Robert Ferro epitomises this attitude: "Death. Sometimes I see it in people's eyes. They look at me and it's death looking down" (*ibid.*, p. 167). And further in the novel, "He saw and noticed these people, not until you looked closely, until you saw a telltale mark or lump or color, or lack of color; o noticed the sad, tired eyes, which all sick people had and which, beyond a certain point, could not be smiled again. He wondered if, should he be cured suddenly, this look would leave him: all pleasure gone, nothing about to happen" (*ibid.*, p. 54). Cfr. "On vit la maladie dans le regards d'autrui," Guy Hocquenghem, *Eve*, p. 54.

¹² Ferro, p. 156.

¹³ AW Frank, *The Wounded Storyteller. Body, Illness, and Ethics*, The University of Chicago Press, Chicago and London, 1995, p. 1.

¹⁴ D Bergman, *The Violet Hour. The Violet Quill and the Making of Gay Culture*, Columbia University Press, New York, 2004, p. 232.

¹⁵ S Sontag, *AIDS and Its Metaphors*, Penguin, London, 1989, p. 9.

¹⁶ Ferro, p. 60.

¹⁷ *ibid.*, p. 28.

¹⁸ *ibid.*, p. 70.

¹⁹ *ibid.*, p. 137.

²⁰ *ibid.*, p. 214.

²¹ Bergman, p. 230.

²² *ibid.*, p. 229.

²³ *ibid.*, p. 230.

²⁴ Ferro, pp. 214-215.

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PART IX

Patient Identities

The Dying Professor Is Killing Me: How Media Help Make Illness a Moral Issue

Lisa Roney

Abstract:

In 2007 and 2008, Carnegie Mellon University professor Randy Pausch created a whirlwind of public commentary and emotional outpouring in response to his “last lecture” in which he announced his imminent death from pancreatic cancer and which was then widely distributed via YouTube. Pausch was widely featured on TV and received a multi-million-dollar book contract. This paper examines the media framing of Pausch and two other “public patients” and asks who and what are served by the relentless, even hegemonic, adulation of this kind of cheerful bravado. It argues that the media intensify the negative moral judgments that cultural historians have noted attach to many ill people. Even though the ill themselves, like Pausch, are sometimes committed to this outsize cheerfulness and “bravery,” perhaps exhibiting something like the double consciousness described in late nineteenth-century African Americans by W.E.B. Du Bois, it is my argument that many ill people are punished by this discourse of heroism and that the patients the media chooses to focus attention on are not only characterised by cheerfulness, but also tend to be white, well off, and physically attractive. Ironically, they usually appear to be the picture of health and provide a false sense of the actual personal strength that may indeed accompany serious illness.

Key Words: Randy Pausch, Kris Carr, Kristin Elliott, Dying Professor, media representation, double consciousness, attitudes toward illness, illness and morality, patients.

1. Introduction: The Public Patient

You may be surprised when you see on television some of the representatives of the ill and dying in the U.S. today. They do not look it, do they?¹

I want to examine a phenomenon I have dubbed the “Public Patient,” and how that image is created and used in today’s mass media, particularly television news and news magazines. This train of thought was inspired by three such Public Patients, examples of one subset of representations that continue to influence widely social attitudes toward illness and disability.

The first of these three Public Patients is Randy Pausch, who came to be known as “the Dying Professor” in September 2007 after he gave a so-called last lecture at Carnegie Mellon University, where he was on the faculty in computer science and engineering. CMU has a long tradition of asking faculty members to record what might be their final words of wisdom, but it just so happened that when Pausch was asked to do this, he had recently found out that he was, indeed, dying of pancreatic cancer. The lecture, filled with bravado, cheer, and admonitions to “have fun,” was placed on YouTube and began its influential sweep.² Pausch appeared on *The Oprah Winfrey Show*, an ABC news special, and before Congress to testify about the need for research dollars, and he co-authored a best-selling book based on his talk.³

The two others that inspired me - though perhaps not in the way they meant to - were Kris Carr, who also appeared on Oprah’s show, and Kristin Elliott, a teenager who used her Make-a-Wish Foundation funds to help build an orphanage school in Zambia and consequently became an *ABC World News* Person of the Week.

One thing that I want to make clear is that I am not a heartless, grim, grumpy type who means disrespect to these individuals. The Public Patient is an image and is distinct from any human being. I myself was moved by the stories of these people, just as I was supposed to be. I feel great sympathy toward them as individuals. But I think that the twenty-first-century Public Patient can be as damaging an image as the obviously unflattering ones that we have seen throughout history and that have been commented on by Susan Sontag, Sander Gilman, and others. Many of these past studies have focused on how the ill and disabled have been depicted as pathetic, perhaps even in today’s terms as inevitably losers, even sometimes as a stand-in for evil.⁴ However, today’s representations - gorgeous, secure, upbeat, and uplifting - can also make it difficult to be a real patient.

2. Norman Cousins and the Positive Patient

It is widely acknowledged that the patient-doctor relationship began to change in the past few decades as medicine became more and more technologised and expensive, and as various kinds of health care systems have standardised what happens between physicians and their patients. This trend, usually seen negatively, has been balanced by a positively conceived of shift in authority, wherein individuals insisted on more say in their own care.

One important moment in this trend toward patient control was the publication of first the article in the *New England Journal of Medicine* in 1976 and then the book called *An Anatomy of An Illness* in 1979. Norman Cousins recounted how he had taken his care into his own hands and cured himself of ankylosing spondylitis, a debilitating inflammatory ailment. His methods: high doses of Vitamin C and the laughter caused by him watching

hours of funny movies. Cousins, formerly a magazine editor, based a new career as a medical humanities expert and faculty member at the UCLA School of Medicine on this work. Although he had used an “alternative” healing therapy he had done so in cooperation with his physicians.⁵

But it also happened that Cousins was a watershed in the movement to prove a connection between positive attitudes and positive health outcomes. There have been in the years since a constant stream of studies making this link: if you are happier, you are healthier. If you are sick, but are happy, you have a better chance of getting better. Sometimes, if you are dying and remain positive, you will have a miraculous cure. This set of beliefs has become sacrosanct in American culture, even though the scientific evidence is mixed and muddled at best. And even if medical personnel know better, in the media, the fact that correlation does not equal causation is ignored altogether. And there is a moral aspect to this assertion, which I’ll come back to more later. Norman Cousins was one of the first Public Patients in the tradition I want to discuss today. At the time of his publications, however, there was a fair amount of counter-argument and controversy, which has largely disappeared today.⁶

3. Biases in Media Coverage of the Ill

Recent studies have demonstrated that in terms of both medical care and media coverage, there is racial bias.⁷ Predominantly white illnesses receive more attention, over and above associations with severity and morbidity. One of these recent studies also mentions that younger people get a disproportionate amount of coverage.⁸ For instance, even though breast cancer occurs mostly in older women, almost all the women featured in news stories about breast cancer are young.⁹ The American Cancer Society estimates that in 2008, there will be about 126,000 new cases of cancer in those under age 45, but more than 752,000 in those over age 65.¹⁰ Yet we seldom if ever see a news story about an older person’s cancer. The authors of the study rationalise that we consider these cases more tragic, as youthful death is more of a shock than that of an older person. Certainly, we are also used to thinking that the young do not deserve to die.

Somewhat to my surprise I can find no acknowledgment that these younger patients also tend to be more attractive. As with any tendency, it is not universal, but easily noticed. Pausch, Carr, and Elliott are all not only white and young, but physically beautiful.

Kris Carr, the one who appeared on *Oprah* along with Randy Pausch, is in fact a former model and aspiring actress, and is not only pretty, but fashionable, with clear skin and full hair, with perfect make-up, clothing, and a beautifully decorated Manhattan apartment. Kristin Elliott, although she was photographed in Africa, was never without her make-up. Randy Pausch himself was tall, tanned, athletic, with a shock of hair that never fell

out during his treatment, and large, soulful eyes. He continued to show off his virility by doing push-ups on stage at his Last Lecture in the Fall of 2007 and carrying his wife off the stage when he was invited back to Carnegie Mellon for a graduation speech in the Spring of 2008.¹¹ Pausch reported from time to time that he might cry in the shower sometimes and that public appearances were physically difficult, but he kept such strains off-camera, basically unseen. The strain might peep through, but only as Pausch and his wife clearly struggled to contain it. His smile remained dazzling and he handsome. Good looks are a requirement for celebrity today, even when that celebrity stems from illness.

Another slant to the Public Patient is that he or she tends to be well off. One anecdote used to prove what a great guy Pausch was came from an email sent to him by an acquaintance in Pittsburgh, who driving home one evening observed a guy in another car, what she took to be a man enjoying his own drive home, with the top down on his convertible on a beautiful spring evening, drumming his hands on the steering wheel, and smiling. Lo and behold, the emailer realized, it was Pausch in the other car enjoying himself in spite of his diagnosis.¹² However, note that the fancy convertible is a requirement of this pleasure, a pleasure that is deemed morally superior.

Pausch was also photographed with his oldest son, Dylan, then age five, swimming with the dolphins at Sea World. Pausch used these to recommend that if anyone else out there is terminally ill, they should “create memories” with their children.¹³ Unfortunately, many people who get serious illnesses end up unable to afford this kind of recreation; in the U.S. the number one cause of personal bankruptcy is a serious health problem in the family. While I am glad that Pausch will have left his son with these pleasant memories, I am not glad that Pausch is considered superior for having done so. These moments that he shared with his son are as much a matter of luck and wealth as they are a matter of heroism.

Likewise with Kris Carr, about whom there was no concern with her current work life or the fact that she had time and money to shop daily for organic vegetables and prepare elaborate and expensive meals for herself and pursue every alternative treatment known to humankind. Nowhere in any of this is there ever any mention of how much anything costs or how it was paid for - perhaps a larger issue in the U.S. than elsewhere, but an issue that should hardly be ignored.

Kristin Elliott, the young *ABC World News* Person of the Week - a high school athlete suffering from Ewing’s sarcoma, who was given Make-a-Wish Foundation money - looked into what charitable things she could do with the amount of cash provided and decided to go to Africa to participate in building a school instead of taking a trip to Disney World. All very good, but when she was interviewed, what she said about Disney was “been there.” She added, “I couldn’t think of anything else I would need.” It was clear that

Africa was a bigger adventure, and it was clear that her family and financial support were already excellent. Again, on a personal level, perhaps it is significant that to this young girl the creation of meaning in her life comes from something that will help others, but this was based on an unremarked position of lofty privilege, even *noblesse oblige*, not to mention a Christian missionary intention.

Perhaps a single mother with cancer who must continue to work a low-paying job as long as possible, but with few smiles, in order to put basic food on the table is more heroic, or an elderly man who lies alone with untreated pressure sores in a Medicare nursing home bed the last months of his life, but we do not see them in the news.

4. Phases of Patient Awareness

Part of all of this is that we also do not see in the news are the later stages of illness. Public Patients appear healthy in spite of their diagnoses - Pausch referred to himself as “the healthiest dying man in America.”¹⁴ The knowledge they have, I would suggest, is not yet a knowledge come home to roost.

My friend S-, several years ago, was diagnosed with breast cancer. Her mother had it and eventually died from it, her sister had it, and S- got it as well. Like many a Public Patient, S-'s family was well off and she got the best treatment possible. S-, an artist, quit her teaching job and focused on her own painting. She took up a daily yoga practice, and she and her husband adopted a macrobiotic diet. Her work, intricate collaged paintings of mythological beasts on background patterns woven with words like “gratitude” and “beautiful,” were exhibited at area cancer centres and other public locations, and they sold like her work never had before. S- was interviewed in area newspapers and on television about her can-do approach to cancer. At the five-year mark she was declared cured, and S-'s success was celebrated in the local media. The story was that her behavioural changes had paid off.

But two years after that, the cancer recurred, and this time the testing showed that S- has “the gene” for breast cancer. I have to admit that I was not surprised. With her family history, it seemed odd to me that she had not been tested for the gene before. She, on the other hand, was surprised by the diagnosis and also by her own anger. She had done everything she could do, and it had not mattered. A whole different, more realistic phase began for her, and this one was not covered by the media. This time, although she continued all the same forms of self-care, she recognized that neither the illness nor the cure was entirely in her hands, and she faced the complex liminal space that is serious illness, a life lived partly in life and partly in death.

On the other hand, Randy Pausch noted that he was “not interested” in talking about death, that his talk was to be about life, and this, I believe, is related to the fact that we met him when he was still feeling healthy in spite of his prognosis.¹⁵ He had not fully entered a place of new knowing, and in fact consciously resisted it. Pausch noted repeatedly that he was leaving his lecture and his book for his children, and clearly they were so young that though he could think of them after his impending death, he could not really think of them beyond childhood. This leads to my only point of critique that could be conceived to be about him, and that is the unfortunate banality of most of what he said.

Pausch gives us commonplaces along the lines of: you cannot control the cards that are dealt you but only how you play them, “brick walls are there not to keep us out but to show us how badly we really want something,” live every day as a gift, “love will win out,” look for the best in others, do not complain (just work harder), and so on.¹⁶ At one point, Pausch takes the wind out of any potential dissatisfaction with this approach by saying, “I love clichés. [...] As I see it, the reason clichés are repeated so often is because they’re so often right on the money.”¹⁷

Many of these clichés may indeed be useful in life, but one of his bromides from “The Last Lecture” that stuck in my chronically ill throat was that “Each of us must decide: Am I a fun-loving Tigger or a sad-sack Eeyore?” This is a statement I am not sure how we can let stand, as it oversimplifies and degrades our humanity. We are not cartoon characters, and we have much more complicated and nuanced decisions about our behaviour than this, especially as we face pain, illness, and death. The media presentation of Pausch and other Public Patients elides the truly liminal space that surrounds death, the times of suffering and of knowledge. There are many who have given us deep insight into those spaces - Harold Brodkey, Anatole Broyard, Barbara Ehrenreich, Ann Fadiman, Nancy Mairs, Paul Monette, Alice Wexler, and Thom Gunn, Marilyn Hacker, Jane Kenyon, Sharon Olds, and Alicia Ostriker, to name a few memoirists and poets - and these writers are often well known.¹⁸ But nonetheless they are not the ones who become phenomena, the ones widely embraced by the media.¹⁹ This seems to me a wasted opportunity since many of the dying and those close to them do actually know things that we have not been told before. I think, however, that our culture likes to hear repeated what it already thinks it knows; in the voice of a Public Patient, it is justified, supposedly rendered more deeply true. In this mode, death makes the Public Patient an expert, not on death, but on life. Later stages of awareness are erased.

5. Double Consciousness and the Cheerful Patient

In the Public Patient’s denial of what he really knows and the substitution for it of what we all already think we know, I find a similarity to

the phenomenon of “double consciousness,” described by W.E.B. Du Bois, in which nineteenth-century African Americans took on the values and judgments of their oppressors and believed that all things “black” were inferior.²⁰ Sometimes I even jokingly refer to it as a form of Stockholm syndrome in which the kidnapped come to support their abductors. The healthy, after all, dominate all discourse in our culture, and their values hold sway, perhaps usually but not always for good reason. Unlike the “black is beautiful” movement, arguments for the “beauty” of illness do not get very far. The ill do not want to be ill, but even those who claim to have learned great things from their perspective often deny, even while they claim to be accepting, anything new in their consciousness.

For that is the other thing that the Public Patient must do, and that both Randy Pausch and Kris Carr on *Oprah* did: they first insist even if faced by the inevitable terminal prognosis, that they will fight it to the utmost, and they will fight it with simple bravado. Cheerfulness in this mind-set is the last hold-out for a miracle. God may intervene - and one study showed that 57% of the general public and nearly 20% of physicians believe that God can intervene in a terminal situation to save a patient.²¹ God will no doubt be more likely to help those “who help themselves.” And so many Public Patients and their audiences take the studies that show that attitude affects health and turn that into a central tenet of their health care plan.²² It is for this that they are praised. “I like the fact that she didn’t just trust modern medicine,” said Dr. Oz, Oprah’s resident physician of optimism of Kris Carr. “I love the fact that she was empowered, and she was going to go out and find solutions. She wasn’t going to take no for an answer.”²³

Carr’s film called *Crazy Sexy Cancer* and her two related books present her as someone given a fatal diagnosis, told that her late-stage cancer is untreatable, and who made herself heroic by curing herself with alternative treatments and a positive attitude.²⁴ Her cancer is now in remission. But it is never mentioned anywhere that her particular cancer, epithelioid hemangioendothelioma, has a notoriously variable progression and not infrequently goes into spontaneous hold, based on no apparent medical reasons, for up to twenty years.²⁵ Of course, I do not know the details of her particular case, as medical information is hard to come by in her accounts, and I do not mean to dismiss her prognosis, but her self-presentation seems to me perhaps even disingenuous in addition to naïve. The actual reality of her situation does not seem to have mattered to Oprah’s vetters, however, perhaps because Carr allows Oprah to promulgate the idea that your health is in your own hands, a comforting message for those distancing themselves from the ill and a popular one in times when access to health care is shrinking, when undeniable evidence of environmental and commercial causes of cancer is rising, and when political messages of self-responsibility surround us.

In April 2008, when he reappeared on TV in an hour-long special on ABC, it was noted quite pointedly that Pausch had already outlived his original prognosis of six months. Clearly, this was supposed to be tied to his optimism and better moral fibre than to the fact that he is well off and has probably sought out the highest quality medical care available, that he could afford to quit his job and pay full attention to his health, and to the sheer fact that predicting how soon death will arrive for cancer patients is something of a crap shoot. Though it was clear by this time that Pausch would die and soon, he could still be presented as triumphant due to his slightly extended life. If a miracle cure is not forthcoming, then a few extra weeks is one's evidence of moral superiority.

And this goes beyond Pausch and other media darlings. A recent study in the U.K. showed that more than 50% of obituaries printed in newspapers describe patients who have lived beyond an original prognosis, and their survival beyond the original prognosis is often listed among their lives' important accomplishments.²⁶ One might wonder if those who die early are less decent folks.²⁷

6. Triumphalist Death

Mostly, I think of the dying professor - in the incarnation in which we all first met him - as a newbie in the land of illness, too new to really know what he was talking about yet and baldly exploited by a media machine that found him - or a simulacrum of him - useful for the kind of message of triumph of which they are so fond. The dying professor had received a horrible diagnosis of pancreatic cancer that was scheduled to kill him within a few months. That is enough to elicit sympathy all by itself. But he was still young, handsome, strong, well off, happy, and "one of us" in his simple understanding. In other words, all those qualities we have come to value in our culture. He did not cause trouble or try to tell us anything different from what would comfort us. Once you have said, "I am Tigger," on national TV it is hard to show any other side, even though you might admit that you have had bad moments *in private*, as Pausch did.

Privacy protects ill people, and too often we have to give it up to all kinds of uncomfortable scrutiny - needles in arms and feet, our body's blood siphoned off, our pale and flabby behinds exposed and poked, our histories plumbed for things we did wrong - but privacy is what we are given for our emotional difficulties. But privacy protects others as well as us, protects them from our sorrow, our smells, our inabilities. Many ill people protect not only strangers, but family members, friends and health care workers by grieving only in private. Some of this might be understandable.

However, when one dying man "inspires millions" by being held up, with his blithe cheerfulness, as an example of what all ill and dying people should be, how we all should live every moment, then ill people everywhere -

including him - are punished for our failures. Illness itself is one kind of failure, but even when we have worked hard to erase stigma toward an illness itself, morality attaches to how the ill person behaves, how she reacts to the bad diagnosis, how he submits to doctor's orders, how she goes beyond Western medical care to seek "whatever will help," whether or not he complains or marshals on, the extent to which she makes her family and neighbours suffer by asking that they suffer with her. If one is ill and not cheerful, one becomes a worse person in the eyes of this society. No matter that such cheerfulness may be delusional (based on hope of a miracle cure) or simply a lie (based on a desire to please and to prevent abandonment), we value it beyond the truth of difficult experience. Perhaps these depictions of the Public Patient are not as damaging as those that show the ill as inevitably bitter or demonic, but they can harm the ill nonetheless by promoting unreal expectations for us all. Like the black man who wants to be white or the anorexic girl who wants to be thinner, there is a real problem when the dominant image of the dying man is the picture of health.

Notes

¹ Photographs of the three examples discussed here can be found readily on the internet. See: 'Dr. Oz: A Special Report on Death', *The Oprah Winfrey Show*, 22 October 2007, viewed on 23 January 2009

<http://www.oprah.com/dated/oprahshow/oprahshow_20071022>

and 'Fighting Cancer, Teen Reaches Out to African Orphans', *ABC World News with Charles Gibson*, 7 May 2008, viewed on 23 January 2009

<<http://abcnews.go.com/WN/PersonOfWeek/story?id=4776877&page=1>>.

Basic information about these individuals comes from these sites.

² R Pausch, 'Last Lecture: Achieving Your Childhood Dreams', presented at Carnegie Mellon University, 18 September 2007, posted to *YouTube* 20 December 2007, viewed on 23 January 2009

<http://www.youtube.com/watch?v=ji5_MqicxSo>.

³ 'Dr. Oz: A Special Report'; 'Dying Professor's Lecture of a Lifetime', *ABC News*, 21 March 2008, viewed on 23 January 2009

<<http://abcnews.go.com/GMA/story?id=3633945>>. M Roth, 'Congress Hears

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R Pausch and J Zaslow, *The Last Lecture*, Hyperion, New York, 2008.

⁴ S Sontag, *Illness as Metaphor* and *AIDS and Its Metaphors*, combined ed., New York, Farrar, Straus and Giroux, 1978 and 1989. S Gilman, *Difference and Pathology: Stereotypes of Sexuality, Race, and Madness*, Cornell University Press, Ithaca, NY, 1985, and *Disease and Representation: Images of Illness from Madness to AIDS*, Cornell University Press, Ithaca, NY, 1988.

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⁵ N Cousins, *Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration*, Norton, New York, 1979.

⁶ See, for instance, F Ruderman, 'A Placebo for the Doctor', *Commentary*, May 1980, pp. 54-60. 'The Cousins Case' (letters to the editor), *Commentary*, August 1980, pp. 12-15. and C Holden, 'Cousins' Account of Self-Cure Rapped', *Science*, vol. 214(20), 1981, p. 892. No such critiques have been forthcoming about Pausch, perhaps because he died, although there are a few bloggers who hold it against him that he did not emphasize religious belief more. These admittedly extreme voices are summarily drummed out by the approving ones.

⁷ See E Armstrong, DP Carpenter & M Hojnacki, 'Whose Deaths Matter? Mortality, Advocacy, and Attention to Disease in the Mass Media', *Journal of Health Politics, Policy and Law*, vol. 31(4), August 2006, pp. 729-772. CJ Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*, University of Chicago Press, Chicago, 1999. Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, B Smedley, A Smith & AR Nelson (eds), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, National Academies Press, Washington, 2002. JDH Downing & C Hubbard, *Representing Race: Racisms, Ethnicity and the Media*, Thousand Oaks, CA, SAGE, 2005. K Kline, 'A Decade of Research on Health Content in the Media: The Focus on Health Challenges and Sociocultural Context and Attendant Informational and Ideological Problems', *Journal of Health Communication*, vol. 11(1), January 2006, pp. 43-59.

⁸ Armstrong et al., p. 738.

⁹ PM Lantz & KM Booth, 'The Social Construction of the Breast Cancer Epidemic', *Social Science and Medicine*, vol. 46, 1998, pp. 907-918, cited in Armstrong et al., p. 739.

¹⁰ American Cancer Society, 'Estimated New Cancer Cases by Sex and Age, 2008', no date, viewed on 23 January 2009

<http://www.cancer.org/docroot/PRO/content/PRO_1_1_2008_Cases_and_Deaths_by_age.asp>.

¹¹ Pausch, 'Last Lecture,' and R. Pausch, 'Pausch Inspires Graduates', graduation speech presented at Carnegie Mellon University, 18 May 2008, posted to *YouTube* 19 May 2008, viewed on 23 January 2009

<<http://www.youtube.com/watch?v=RcYv5x6gZTA>>.

¹² Pausch & Zaslow, pp. 64-65. also in Randy Pausch, personal blog, entry for 17 April 2007, viewed 23 January 2009

<<http://download.srv.cs.cmu.edu/~pausch/news/index.html>>.

¹³ Pausch & Zaslow, p. 192. Pausch, personal blog, entry for 4 September 2007.

¹⁴ Pausch, personal blog, entry for 1 December 2007.

¹⁵ Pausch & Zaslow, pp. 9, 17-18. Pausch himself acknowledges that he looks healthy and that others might have a hard time believing in his prognosis, though he denies he is in "denial." See also the widely quoted statement, "The lecture wasn't about dying, it's about living. The book is the same way. I had no interest in writing about dying;" 'Dying Professor's Book Offers Life Lessons', *CBS News*, 7 April 2008, viewed 23 January 2009

<http://www.cbsnews.com/stories/2008/04/08/national/main4001449.shtml?source=related_story>.

¹⁶ 'Dying Professor's Lecture of a Lifetime', op. cit.; Pausch & Zaslow, pp. 73, 101, 79, 145, 138-139.

¹⁷ Pausch and Zaslow, p. 146.

¹⁸ H Brodkey, *This Wild Darkness: The Story of My Death*, Henry Holt, New York, 1996. A Broyard, *Intoxicated by My Illness and Other Writings on Illness and Dying*, Clarkson Potter, New York, 1992, rpt. Ballantine, New York, 1993. B Ehrenreich, 'Welcome to Cancerland', *Harper's Magazine*, November 2001, pp. 43-53. A Fadiman, *The Spirit Catches You and You Fall Down: A Hmong Girl, Her American Doctors, and the Collision of Two Cultures*, Farrar, Straus & Giroux, New York, 1998. N Mairs, *Plaintext*, University of Arizona Press, Tucson, 1986. N Mairs, *Carnal Acts*, HarperCollins, New York, 1990. N Mairs, *Waist-High in the World: A Life Among the Nondisabled*, Beacon Press, Boston, 1994. N Mairs, *A Troubled Guest: Life and Death Stories*, Beacon Press, Boston, 2001. P Monette, *Borrowed Time: An AIDS Memoir*, Harcourt, Brace, Jovanovich, San Diego, 1988. P Monette, *Becoming a Man: Half a Life Story*, Harcourt, Brace, Jovanovich, New York, 1992. A Wexler, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*, Random House, New York, 1995. T Gunn, *The Man With Night Sweats*, Farrar, Straus & Giroux, New York, 1992. M Hacker, *Winter Numbers*, Norton, New York, 1995. S Olds, *The Father*, Knopf, New York, 1992. A Ostriker, *The Crack in Everything*, University of Pittsburgh Press, Pittsburgh, PA, 1996.

¹⁹ For a well-argued overview of the factors involved in this limited kind of approach, see D Bloom, 'Reading Breast Cancer: Reflections on a Dangerous Intersection', *Health*, vol. 5(2), 2001, pp. 249-268.

²⁰ WEB Du Bois, *The Souls of Black Folks*, AC McClurg & Co., Chicago, and University Press John Wilson and Son, Cambridge, MA, 1903, p. 3.

²¹ LM Jacobs, K Burns & B Bennett Jacobs, 'Trauma Death: Views of the Public and Professionals on Death and Dying from Injuries', *Archives of Surgery*, vol. 143(8), August 2008, pp. 730-735.

²² "Positive psychology" is such a widespread movement in both academic and popular spheres that it is hard to cite one particular source, but the man usually credited with its promulgation is MEP Seligman, author of *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfilment*, Simon and Schuster, New York, 2002, and *Learned Optimism*, 2nd ed., Simon and Schuster, New York, 1998 (originally published 1990). Claims that positive psychology also positively impacts physical health have been less clear, but for a summary see PJ Hershberger, 'Prescribing Happiness: Positive Psychology and Family Medicine', *Family Medicine*, vol. 37(9), October 2005, pp. 630-634, which makes much out of a handful of small studies. In the academic world, one of the main opponents to positive psychology is B Held, author of *Stop Smiling, Start Kvetching: A 5-Step Guide to Creative Complaining*, St. Martin's, New York, 2001, and *Back to Reality: A Critique of Post-Modern Theory in Psychotherapy*, Norton, New York, 1995. See also B Held, 'The "Virtues" of Positive Psychology', *Journal of Theoretical and Philosophical Psychology*, vol. 25, 2005, pp. 1-34.

²³ 'Dr. Oz: A Special Report on Death'.

²⁴ *Crazy Sexy Cancer*, dir K Carr, perf K Carr & R Yee, Good Times Studios, 2007. K Carr, *Crazy Sexy Cancer Tips*, skirt!, Guilford, CT, 2007. K Carr, *Crazy Sexy Cancer Survivor*, skirt!, Guilford, CT, 2008.

²⁵ HEARD [Hemangioendothelioma (HE), Epithelioid Hemangioendothelioma (EHE), and Related Vascular Disorders] Support Group website, no date, viewed on 23 January 2009

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²⁶ B Bytheway & J Johnson, 'Valuing Lives? Obituaries and the Life Course', *Mortality* vol. 1(2), 1996, pp. 219-234.

²⁷ Ehrenreich has noted this phenomenon more specifically in the upbeat survivor-oriented talk of the breast cancer support world ('Welcome to Cancerland', p. 53) and more generally in 'Pathologies of Hope', *Harper's Magazine*, February 2007, pp. 9-11.

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The Patience of the Patient: A Meditation

Harold Schweizer

In this presentation, I offer some meditations on the temporality of patienthood. My argument is that the experience of time is one of the definitive distinctions of being a patient. How does the patient wait? What are the temporalities in which she waits? How are we to understand this denomination “patient” that shares its etymological root - “to suffer” - with “patience,” a mode of being in time - hence the title of my paper. How, then, does the patient suffer time? How is she patient? As I propose my thoughts about these questions, I assume that the patient before us is one who faces a severe, perhaps an ultimate, situation. She has been well all these years, but now her body has failed her and she might not get well again.

“It is we who are passing when we say time passes,” as the French philosopher Henri Bergson writes.¹ We are the time that passes, though we don’t know it. There is, for Bergson, no time other than the time that we are. This identity of time with being seems most literally exemplified in the patient, whose denomination “patient” insists on this identity between time and being. The patient, in short, is consummately one who has become the time that passes.

Let us say that the doctors are puzzled by her symptoms. There is no diagnosis as yet that would objectify her waiting, and that would prescribe a certain course of action, so that she would be delivered from this drifting in a suddenly unstructured, unmarked, open-ended time. Who is this who waits in the intimacy of a time that has become wholly hers? Lying in her bed, this patient has suddenly nowhere to go, no appointments to keep, nothing to do. Superficially, one might be waiting for the evening news; a spouse’s, a partner’s, a friend’s visit; the medical rounds, the next injection of pain medication. But in a deeper sense, the patient does not wait for something outside of herself, rather she waits deep within herself - for herself. What she is waiting for is happening inside of her. She is a patient. She is forced to endure the most fundamental aspect of human existence: that we are, that we are time. We surround ourselves with things - furniture, jewelry, cars, Shakespeare’s *Complete Works* - so as to be distracted from our endurance of time, so as to be relieved, for a time, from the fact that we too are time embodied. Such embodiment of time seems to me implied in the temporal implications of the term “patient.”

Professional and personal caregivers, even casual visitors too, can do worse than share with a patient this fundamental temporal ontology. Those who attend to the patient must be patient. To give a patient time is to go

where she is, to be where she is, in her time. In the time that is her body. Physical closeness to the body of a patient - holding her hand, stroking her hair - is the physical analogue of this temporal proximity. We are present.

The French philosopher and activist Simone Weil has written about this going into the time of another as the giving of one's presence. "The capacity to give one's attention to a sufferer," Weil writes, "is a very rare and difficult thing; it is almost a miracle; it *is* a miracle."² Weil considers the kind of waiting that we perform in the presence of the one who suffers as a subservience to nothing but waiting. Such waiting, for Weil, is not activity but substance - not an activity of the self but the substance of the self. It is the same substance, she writes, that is submitted by one who waits faithfully for God and whose identity is nothing but her waiting. It is this kind of waiting that one offers to a sufferer whose need is not only that something gets done but that someone is there. A primary need of the patient is the proximity of the other. But with the patient one waits not in the time of clocks but in Bergson's deeper time that he calls duration. This deeper time, as Emmanuel Levinas notes, is "interpreted as a relationship with the other and with God," and which Levinas explains as "a proximity that cannot be reduced to spatial categories or to modes of objectification and thematization."³

If the patient waits in this inward realm of pure duration - time stripped of its illusory objectifications in numbers and things - then the waiting of the person who attends to the patient also eludes measure or description. To wait with a patient is not a matter of length or efficacy but of proximity and sympathy; in short, of presence. If bedpans have to be emptied, sheets changed, and drugs administered, such activities derive their quality entirely from the proximity and the sympathy of the person who performs them. What matters is that one gives one's presence to the patient not as an activity but as the substance of waiting. "It is," Weil insists, "only watching, waiting, attention."⁴ We learn much about the patient's patience, in other words, if we become patient too. The presence required of one who attends to the patient helps us intuit the temporality of the patient, what time she endures, how she endures time. There are many poignant examples of such gifts of presence. In her book *Narrative Medicine*, Rita Charon evokes such situations repeatedly. "We sit in one another's presence, silenced by the other's mystery, its plentitude, its alterity, in suspense, waiting."⁵

But we who attend to the sufferer can come and go - we have appointments and obligations - while the patient must stay. We can give our presence and must withdraw it after a time. Our presence, unlike the patient's endurance, has measure and description. But such giving and withdrawing of presence is also practiced by the patient when she seeks distraction from her duration by watching television, reading magazines, greeting visitors, receiving gifts, entering into occupations. Her distractions are numerous, and each is eagerly awaited, and yet - as much as our coming and going - they

occur in a superficial time, the time of clocks. The clock cannot deliver the patient from the time that has taken possession of her. For us who are not patient (pun intended) time runs external - we catch up with it, we use it, we spend it, we waste it; mostly our time is transparent, a medium not a substance; mostly it runs its course unconsciously within us. But for the patient, time is not an invisible medium, nor can it be externalized or objectified in activities or things. The patient's time is internal. The patient's time is her body. She must wait for her body. She must wait for herself. A patient, then, is someone whose object to be waited for is not external but internal. In her inability to objectify what she is waiting for, the patient endures time. Her visitors and occupations are to distract her from her endurance of herself. But the patient endures herself in a time that is difficult to share because her time seems almost unsharably deep within herself. "We have no interest in listening to the uninterrupted humming of life's depths," Bergson writes, and yet, he goes on, "that is where real duration is."⁶

Who is this patient who is listening to her body? It is one whose body has refused to be useful, whose body has become opaque, a hindrance rather than an instrument. Like the body whose use makes it invisible, time used is invisible. But now time has become the body. The patient may well seek to be separate from her body, like that desperate patient in Charon's book who would like to flee from it, and who retreats mentally to a far corner of her room. "Who *I* am," she exclaims, "could not endure the torture of that room."⁷ Who *she* is cannot endure. And yet, her body is a room and she is in it. It has to be endured. An endurance has taken room in her body. We who sat with her can come and go and reenter the world where the body is transparent like time. But the patient is confined to her room, to her bed, to her body, and deep within that body, to its endurance. Her body is her room. She is in it.

A patient begins her waiting in clock time. She does not yet endure her identity. She has not yet internalized her time. Time is still outside of her and she - impatiently - wants to rejoin the realm of synchronized, communal, economic time. Her impatience implies that she has not yet agreed to become (a) patient. "Who *I* am," she cries, "could not endure the torture of that room" - but she will and must, unbearably, endure it. Endurance is already within her. We are the time that passes. Although the impatient patient negates, denies, refuses, rejects her temporal identity, although she is an impatient, although she does not want to be the time that hums within her, she is already a patient - her impatience is already part of her patience.

The diagnosis reveals that her illness does not have an immediate cure, and that it will likely require long-term treatment. At the beginning of her illness, she had merely looked in from outside, so to speak. She had looked in to see herself as a patient in a hospital room. She had seen herself lying in a bed, wasting her time. Then she couldn't wait to get well. She had

already spent enough time, but her body would not agree to an economics of time. Now her body has become truly profligate, wasteful. It lies in bed, it spends time without getting anything in return for it. This patient gets nothing for the time her body wants to spend.

In a world of appointments, tasks, and occupations time ought to be transparent like a hall to be traversed, like a waiting room to be passed through, like a window. Who would have thought that she would not be able to pass through this space? Now time is long, slow, opaque, thick. The patient is out of sync with the synchronized time of clocks that runs its course in the public domain outside her room. She is different. She has fallen out of the official parameters of clock time and has entered duration. Time felt is duration. Time felt is time endured.

In duration, the patient waits in her own, intimate, un-synchronized, unsharable time. It is a time that cannot be exchanged; it is worthless time, or it is a time whose worth is gratuitous like the blooming of flowers. Her hospital room has become an extension of her body and not, as she had hoped at the beginning, a room that she would simply pass through. She waits in her body. Her body can no longer simply be passed through. Formerly it could be used, now it must be endured; formerly it could serve a purpose, now it has become its own purpose.

If she agrees with the time that her body has become, she waits patiently. If impatience is a refusal of one's temporal identity, patience is acceptance. The patient who waits with her body, at one with her body, in her body, waits patiently. Patience is the agreement to endure the body, the body that is time, the body that endures. Patience is willing endurance, the agreement to experience time, the agreement finally to let time enter us. Just as we "disregard our bodies until they cause us trouble,"⁸ so we disregard time until it causes us trouble. The greatest trouble time can cause us is, of course, the time of sickness and death, and yet to agree to that trouble is the patience of the patient.

But how is such agreement achieved? How does one become patient? Part of the answer is already implied in the way I am asking. For if I ask, how does one become a patient? The answer is easy: one becomes *a* patient through *a* gratuitousness, *an* accident, marked by the indefinite article "a." A patient is *a* patient, one of them. It could be you, me, anybody. To be *a* patient is to be subject to the accidental nature of what happens. Patience opposes the accidental, anonymous nature of time. Patience makes time one's own. To say that the patient waits patiently is thus perhaps to say that the patient has turned the accident of her body into her will. To be patient, thus, is a quality of being present in this accident that sickness is, though it is a quality that has to be achieved through impatience, despair, and resignation. One attains patience, in other words, through impatience.

When Maurice Blanchot writes that “true patience does not exclude impatience. It is intimacy with impatience - impatience suffered and endured endlessly,”⁹ the intimacy with impatience seems to me precisely the endless effort that patience is. The patience of the patient is an effort by which she embraces and accepts her impatience. If she suffers and endures her impatience endlessly, the endlessness of this endurance must tell us that patience is not something one does, not something that can be done or that can be accomplished, but something one endures. If the time of patience is not the time of clocks in which things get done, to endure patience means to descend into what Bergson calls the “profound time” of duration, a time that is by definition existential and immeasurable. Patience is immeasurable. As soon as it measures time, as soon as it asks “how long?” the impatience that is part of patience announces itself. To practice patience is thus - Simone Weil is right - a miracle. It is a miracle because it demands that we move into a temporality without spatial categories or modes of objectification, to borrow Levinas’ words once more. Patience has to be endured in a room without walls, a body without end, a time without limit.

The miracle of patience is an agreement that one endures. It is the substance of a person. And like the substance of a person, patience is an intrinsic quality. One is not patient *for* something. Patience is its own reason and reward. That is why patience is not an activity, but a substance. Patience shares the ontology of the patient’s body whose purpose has become nothing but its endurance, like a blooming flower. In patience, the patient is in closest proximity to her body, indeed in patience, if its miracle can be achieved, time is shared. The patient shares her body with herself, gives her presence to her body, just as the person at her bed gives her presence to the patient. It is a miracle, of sorts.

Notes

¹ H Bergson, *Duration and Simultaneity* in *Henri Bergson: Key Writings*, KA Pearson & J Mullarkey (eds.), Continuum, London, 2002, p. 216.

² S Weil, *Waiting for God*, trans. E Craufurd, Perennial Classics, New York, 2001, p. 64.

³ E Levinas, *Entre Nous: Thinking-of-the-Other*, trans. MB Smith & B Harshav, Columbia University Press, New York, 1998, p. 224.

⁴ S Weil, *Waiting for God*, trans. E Craufurd, Perennial Classics, New York, 2001, p. 64.

⁵ R Charon, *Narrative Medicine: Honoring the Stories of Illness*, Oxford University Press, New York and Oxford, 2006, p. xii.

⁶ H Bergson, *The Creative Mind: An Introduction to Metaphysics*, trans. ML Andison, Dover Publications, Mineola, N.Y., 2007, p. 125.

⁷ Charon, p. 91.

⁸ *ibid.*, p. 88.

⁹ M Blanchot, *The Infinite Conversation*, trans. S Hanson, University of Minnesota Press, Minneapolis, 1993, p. 121.

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