Illness, Bodies and Contexts
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Making Sense Of
‘Health, Illness and Disease’
Illness, Bodies and Contexts
Interdisciplinary Perspectives

Edited by

Isabelle Lange & Zoë Norridge

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Introduction

Isabelle Lange and Zoë Norridge

Over four days in July 2005, historians, health economists, medical doctors and nurses, anthropologists, writers, sociologists and many more travelled to Oxford, England for the fourth annual ‘Making Sense of Health, Illness and Disease’ conference organised by Inter-Disciplinary.Net. The atmosphere at Mansfield College was charged as the fifty-five presenters gathered to share findings from their research and continued to discuss and debate long after the formal seminar periods ended and well beyond the coffee breaks, culminating in further collaborations in the form of joint-authored articles, conference projects and friendships. Delegates were driven by a shared desire to understand the challenges and complexities of inhabiting a social and physical body in cross-cultural and inter-personal setting where meanings are in a constant state of transformation.

This conference, concerned with health and ill-health, brought together participants with different nationalities, backgrounds, interests and approaches and the diversity of the event is reflected in this collection of essays. Disciplines represented include a wide range of social sciences (anthropology, sociology, psychology), arts (literature, visual arts, philosophy) and medicine (nursing, physiotherapy, palliative care). Such variation provided a valuable chance for interdisciplinary dialogue amongst delegates who were mostly working within traditionally defined academic disciplines, despite the increasingly multidisciplinary nature of health research in the UK and beyond. The danger of such cross-disciplinary conversation is that topics may be covered at a superficial level without a full understanding of the research context from which the ideas emerge. This is where clarifying questions and constructive criticism have proved so helpful: the philosophers remind us to refine our terms whilst the practitioners check that the more abstract thinkers are aware of the realities of patient experiences.

In the process of compiling this volume, we have strayed from the original conference presentation schedule to allow for emerging themes to be explored in appropriate sections. Creating subdivisions was not a straightforward matter, as it was apparent throughout the conference that participants’ interests overlapped in both theory and practice. We hope that reorganising the material presented offers new opportunities for comparison between chapters, juxtaposing diverging research approaches in a thought-provoking manner.

The collection opens with a section exploring personal experiences of illness and health, stressing the referent for illness narratives and grounding this selection of chapters in the human from the outset. Chapters in this section examine the tensions between subjective and objective interpretations of ill
health. Some of the writers speak from personal experience: Marlene Benjamin writes about her own experiences of living with cancer and Melinda Rosenberg offers a form of personal prescription for a productive doctor-patient relationship. Other essays are located within a more traditionally structured research framework. The solution offered by most of the writers is a renewed attempt at communication, be that through literature as suggested by Zoë Norridge, or talking therapy as proposed by Mary Didelot and Lisa Hollingsworth.

From this focus on personal experience, the compilation moves on to explore the ways in which physical states of health and illness are internalised and expressed in a section entitled ‘Bodies and Embodiment’. This section begins with Naomi Adelson reminding us that the notion of health is entrenched in cultural beliefs, which are embodied through constant enactment, thus becoming normalised. She uses the example of ‘fitness’ as an ideal and delves into what happens when a conflict between personal and cultural interpretations exists. Both Isabelle Meuret and Lisa Szcerba then discuss self-representations of bodily states and look at the themes that surface when writers going through similar experiences open themselves up to an audience. Meuret looks at the acts of self-starvation and self-representation as both being firmly grounded in the body and notes that writing and eating are inextricably linked to one another. Szcerba’s selections highlight the forms of expression that materialise when women write, paint and make films about their experience of childbirth. Charlotte Baker, on the other hand, looks at how writers represent the physical manifestation of an identity or a state of health - albinism in Africa - and characterise it in literature. Unlike the self-expression evident in Meuret and Szcerba’s studies, she finds that writers - outsiders - who observe and attempt to impose an identity onto others generally focus on the ‘flaws’ of the body instead of the actual condition. Themes of diverging perceptions of illness are then developed by Ian Brassington who adopts a philosophical stance on ‘ways of being’ in the world, looking at how medicine can be used to mediate our current and future selves. Gillian Bendelow’s chapter picks up on ideas of a divided self by exploring evolving concepts of mind-body dualism and health care systems’ responses over time.

The third section of this collection looks at the ‘Myths and Metaphors’ we use to make sense of illness and health. Chapters by writers from New Zealand, Sweden, Spain, Canada and the UK examine the recurrent images we draw on to represent our experiences of disease in both everyday spoken discourse and literature. These myths and metaphors are often used to help us interpret experiences of sickness and pain that seemingly defy medical explanation, as we see with Victoria Grace and Sara MacBride-Stewart’s accounts of pelvic pain and Katherine Byrne’s examination of Tuberculosis in Victorian Britain. Teresa Gilbert points out that in Atwood’s writing, metaphor is most frequently used to describe negative experiences of illness rather than
health. But for Katarina Bernhardson the issue is rather less clear-cut since from the point of view of the anorexic, an eating disorder is alternately friend and foe. All these contributors are interested in the potentially therapeutic applications of such representative strategies. For example, on a practical level, Jasna Schwind shows how metaphors were used as a tool for nurse/teachers in the classroom, helping them to come to terms with their personal experiences of illness. However, the situation remains complex since alongside their potentially healing properties, myths and metaphors are occasionally seen to impede medical intervention and foster misunderstandings of the body.

Medical perceptions of health and institutional interpretations of the body are addressed in the fourth section on ‘Meaning and Medicine’. The chapters in this section are concerned with how medicine is ‘consumed’ and how this consumption in turn shapes practices in the field. Inci Cinarli and Elgiz Yilmaz show how Turkish newspapers’ reporting on personal experiences of health fads and illness contribute to the active medical model, which in turn affects consumer choice. Linsey McGoey’s chapter directly examines how such public dialogue and discussion not only influences patients, but also medical practitioners who administer antidepressants. Both Christina Hahn and Ashley Morgan write about biomedicine and aesthetics, investigating not only how cosmetic surgery affects consumers but also how consumers in turn influence this branch of medicine. Hahn’s chapter looks at the media’s portrayal of Botox, setting the scene for her study examining the facial expressions and communication strategies of women treated with the drug. Morgan examines decision-making procedures of cosmetic surgery clients and determines that electing to undergo the surgery is a ‘practice of the self’. The subjectivity of different medical practices is then examined in Imre Bard’s chapter examining how diagnostic techniques are founded on theoretical understandings of medicine. Bard examines Traditional Chinese Medicine (TCM) alongside Western Medicine, stressing how a fundamental difference between the two is TCM’s recognition that humans are embedded in both the natural and social environment. This theme is explored in a different manner by Laura Kerr, who takes Canguilhem’s notion of health from the 1960s and examines how it fits into the present day and age.

The penultimate section of this collection looks at how we construct concepts of the ‘healthy’, desirable individual and what this means for those whose bodies and minds deviate from this norm. Much of the discussion here focuses on the interface between genetic, social and environmental determinants of ‘health’ and how we endeavour to control and interpret these factors. Elisabeth Gedge sets the scene for these debates in her opening chapter looking at prenatal genetic testing and the impact of selective termination on people living with disabilities. The issues of eugenics that Gedge introduces are then further explored in Stuart Oultram’s controversial
Introduction

critique of whether there is any moral difference between technological reproductive interventions and lifestyle advice for pregnant women. Themes of classification, standardisation and objectification are also present in Susan Rogers’ examination of how we construct criteria for what we consider to be healthy, desirable sperm. Here again, the socially determined aspects of health seem to be as crucial as the genetic markers privileged by biomedicine. Expanding on the emerging tensions between genetic determination and free will, Donavon Rocher’s chapter looks at our changing perspectives on alcoholism and their implications for treatment as seen in popular self-help books. The importance of the media’s representation of health is then developed in Joe Grixti’s Malta-based research on young people’s self perception and physical perfection. Finally, these themes of the biological, psychological and social are drawn together in Valerie Raoul’s chapter on how we use narrative to make sense of divergence from the standard of health.

The sixth and last section investigates the interface between health, medicine and human rights, questioning social norms whilst analysing the ethical and legal foundations of diverse cultures. As Michele Wates points out in her opening statement, legal frameworks have long existed to protect people from intentional or unintentional harm. She suggests that the current fight for the ‘right to die’ - a struggle that is based on a bias against physical illness compared to mental illness - will actually hurt more people who want to live, and undermine the value of human life. She proposes that these ‘rights’ may in reality be exercising discrimination in the process of determining the value of (a) human life. Building on themes of ethics and rights, Sebastian Bechman’s chapter looks at the recent healthcare reform debates in Germany, examining changing attitudes towards an employee’s right to health. Shared among the chapters in this section is the authors’ quest to look at the roots and social origins informing the judgment of those who mediate our experiences of healthcare. Lisa Schwartz and Alison Roberts Miculan propose a ‘social justice model’ to better aid ethical decision-making so that individuals’ rights are not violated in the process of creating effective healthcare provision. Delphine Arweiler on the other hand analyses frameworks for healthcare and the subsequent allocation of resources based on economists’ models, outlining how the conception of health is largely an ethical question, laden with subjective decision-making. This is also clearly demonstrated in Nina Preto’s chapter which illustrates the discrepancies in health care coverage by way of a case study of a young autistic boy whose therapy is not covered by the province in which he lives. Ethical issues surrounding the migration of medical professionals are addressed by Gloria Likupe, Laurie Lynn Kelly and Joyce Laboso-Abonyo’s study on the recruitment of nurses from the developing world to the developed world. Their study, among the others in this section, is a call for finding the best approaches to resolving conflicts between ethical considerations and economic interests in healthcare provision.
The current collection is part of an ongoing project: the diversity and complexity of issues debated in this e-book have the potential to open up avenues for further research and discussion both within the framework of Inter-Disciplinary.Net and beyond. Themes that have recurred throughout the volume and warrant further investigation include the construction, meaning and role of narrative; communication between patients and their physicians/carers; potentially reductive normalising ideas of health; and discussing death within the context of sickness and health. Understandably perhaps, most chapters in this collection are concerned with illness and disease as opposed to health. But even those chapters that focus on diseases with specific symptoms and illness trajectories define the nature of the experience in opposition to the healthy body and mind. Those writers who chose to look at disability point out how potentially harmful it may be for us to conceive of ‘perfect health’ as the norm for our societies. One key avenue for further research is therefore an exploration of how we can examine our lived experiences of the world without negatively pathologising difference. In doing this we must also bear in mind the plurality of medical belief systems and inequality of access to resources present in the world today. We hope that future conferences examining Health, Illness and Disease will take up these issues and develop them further.

Isabelle Lange and Zoë Norridge
Ghana and London, 2006
PART I

Personalising Illness Experience
Illness: The Redefinition of Self and Relationships

Mary J. Didelot and Lisa A. Hollingsworth

Abstract

Illness is a perceptual phenomenon: it is far more than a complex physiological element. As Lord John Habgood stated, 'life events are more important than our genetic inheritance […] we must take the whole of what we are into account.' There exists an objective and subjective duality to illness. The objective portion is the disease itself. The subjective nature is that of illness, or the experience of being ill. Recognising, as Nietzsche had, that 'we…are not free to divide body from soul,' a pivotal question is begged. How can the sick define themselves (discover meaning) in the experience of illness, which causes suffering? Accepting Wolf’s position that ‘a diagnosis is a statement about what we would like to be different about our existence,’ the disease can serve initially as an impetus for self-discovery through the suffering of illness. Enduring the journey from illness to health is uniquely dependent upon the meaning intentionally attached to the suffering. Viktor Frankl, a physician, was able to create meaning of senseless suffering. His philosophical stance incorporated in Logotherapy can give those who are ill the freedom to define themselves instead of allowing medical professionals and medical conditions the power of definition. More importantly, Frankl’s will to meaning can support those who are experiencing illness, bring dignity to their suffering and help them to endure their conditions through awareness and compassion for themselves and others. As Frankl wrote, ‘He who has a why to live can bear almost any how.’

Key Words: Self, illness, disease, subjectivity, duality, Frankl, Logotherapy

Illness is a perceptual phenomenon: it is far more than a complex physiological element. As Lord John Habgood stated, ‘life events are more important than our genetic inheritance and that we must take the whole of what we are into account.’ There exists an objective and subjective duality to illness. The objective portion is the disease itself. The subjective nature is that of illness, or the experience of being ill. The subjectivity includes the perceptual variables of each patient’s attitudes, life experiences, and creative strategies for approaching the challenges of illness. Miller and Thorenson stated that ‘health is better conceived of as a latent construct like personality, character, or happiness, as a complex multidimensional construct underlying a broad array of observable phenomenon.’ They add that health includes three broad dimensions: suffering, functional ability, and subjective inner
peace or coherence in life. These dimensions, then, encompass the cognitive, emotional, physical and spiritual facets of each unique person. If disease is treated in a mechanical, one-dimensional manner, just as an experience, and not as an experience with significant meaning, the treatment rendered is insufficient.

The duality of illness requires attention to perceptual variability of these attitudes, experiences, and creativity. To use Seligman’s operational definition of perception in regard to illness, there would exist for each individual recognition and interpretation of illness. The interpretation is completely subjective. Thus, the phenomenon of illness because of perceptual variables does not occur in a convenient linear manner from one person to another. It is interesting to further consider that some theorists even posited a far more complex perception of illness ‘that the relation of people to other people around them and to the society in which they live are important causes of disease.’

Given the workings of the perceptual variables, a conclusion may be drawn that the frequency and presentation of illness can change with the circumstances. However, many medical professionals are immersed in the assessment of disease by the event itself. They do not wish to contaminate patient evaluation with the perceptual variables. However, this linear model fails in its assessment of the individual experience. Research now indicates the importance of perceptual variables (the subjective nature) in protecting people from the onset of illness and aiding in effective treatment of illness. These are both health-enhancing behaviours. In illness, there needs to be a complete understanding of both the physiology and the psychology of disease. Illness not only redefines the parameters of physical abilities, but reaches further. The Self and all its components will also require redefinition. Prevention and treatment of illness that takes these factors into consideration will strengthen wellness. ‘Affective response significantly influences reactions to physiological consequences.’ In fact, researchers who conducted a large study on adults who experienced childhood trauma found an increase in heart disease. The subjective, perceptual nature of a medical event is an integral part of both illness and wellness.

The phenomenon of suffering from physical pain can further clarify this objective/subjective relationship. About 400 years ago, Rene Descartes challenged medical professionals with a concept of pain as solely a physical phenomenon with absolutely no psychological component. Suffering was objective. Treatment failed. Now, suffering can be the subjective experience of a physical pathology. Just within the United States, pain is the presenting condition in over 70 million physician visits each year. The assessment of pain presently requires an assessment of both the physical and perceptual aspects of the individual patient’s experience. A large part of that perceptual assessment is the patient’s attitude, experiences, and creativity.
Interestingly enough, Friedrich Nietzsche uses sickness and health as a metaphor for how an individual should live his/her life. During the Franco-Prussian War, he volunteered as a medical orderly. There he witnessed suffering first hand. He himself was painfully ill both physically and emotionally throughout his life. He believed that, ‘every sufferer instinctively seeks a cause for his suffering.’

Nietzsche’s Will to Power, *Wille zur Macht*, emphasises the expansion and venting of creative energy. He, in his own words, defined this term as, ‘Say yes! To life.’ It is a life affirming philosophy. This can be interpreted as the power of the Self, or the healthy expression of the Self. For Nietzsche, as his health deteriorated, his creative energies increased. It was during this period of illness that he wrote most of his works. Nietzsche has been recognized as a significant precursor of 20th Century existentialism.

Most importantly, for those in the 21st Century who work on a daily basis with individuals who are ill, Nietzsche’s core belief that, ‘we…are not free to divide body from soul’ should be a starting point for further thought.

Enduring the journey from illness to health is uniquely dependent upon the meaning intentionally attached to the suffering.

Viktor Frankl, a physician, found Nietzsche’s authenticity refreshing. As Nietzsche did, Frankl was able to create meaning out of suffering. Like Nietzsche, he endured and witnessed great suffering during wartime. Frankl was a prisoner of several Nazi concentration camps, including Dachau and Auschwitz, from 1942-1945. He suffered the losses of his parents, brother, pregnant wife, and numerous friends in the Holocaust. It was while he was a prisoner in the camps that he honed his existential theory that he had begun developing before being taken as a prisoner. His theory is based on his observations that humans are not determined by their environments, what happens to them, or their physical bodies. Frankl understood that humans have the unique ability to determine their own stance toward those situations that are unalterable, or in which they must endure something beyond their control. They are also unique in that they live in three dimensions: somatic, mental, and spiritual. It is the latter that makes humans different from other living creatures. Frankl’s approach to therapy, Logotherapy, was developed out of these convictions based on his life experiences.

Frankl’s existential theory is composed of three basic components: the freedom of will, the will to meaning, and the meaning in life. These are the foundational components of the Self and can be found in Logotherapy.
The freedom of will describes how all humans experience situations and limitations in life over which they have no power. Where they do have power, however, is to choose what stand they will take toward these situations. The will to meaning is defined as an innate desire for finding meaning and purpose in life and for actualising as many values as possible. The will to meaning is central in Frankl’s theory, because it is what drives human’s beliefs, attitudes, and actions. Without it, there would be no sense of fulfillment in life. When individuals are unaware of their will to meaning, or are struggling to find it, Frankl stated that they are experiencing ‘existential neurosis’. Because it is so necessary and powerful in people’s lives, it is important for individuals who are ill, or suffering in any way, to uncover their will to meaning. Illness and suffering cause many individuals to contemplate their meaning and purpose in life, which is at the core of their sense of Self. In finding it, they can better cope with pain, suffering and the losses that often accompany illness and disease. The third component of Frankl’s theory, meaning in life, recognizes that each human has unique life experiences. In order to assist individuals in finding their will to meaning, these life experiences must be explored and understood. Illness, for example, can only be truly understood if looked at in the context of an individual’s life, as can the meaning-making of experiencing the illness. The meaning of life is unique to each person and to each situation the person experiences.

The will to meaning can be achieved, according to Frankl, through actualising creative values, experiential values, and attitudinal values. Benson’s studies demonstrate that these values, and the discovery of meaning and purpose in illness, result in increased psychological and physical well being. Creative values assist people in finding the will to meaning by pursuing tasks such as work, artistic activities, and advocacy. Finding meaning through advocacy is a particularly powerful avenue to the will to meaning for people suffering from illness or trauma. The creative tasks of dance, music, sculpting, painting, or drawing can assist people in finding spiritual meaning. Meditation and dream analysis, and indigenous forms of healing are additional creative values that assist individuals in connecting with Self, others, and a Higher Power.

Experiential values also lead to a sense of connectedness and meaning in life. They are achieved by paying attention to, and appreciating, the good, the true and the beautiful, or by knowing an individual in all of his or her own uniqueness. Some examples of these experiential values include appreciating the everyday beauty in nature, enjoying art or literature, or being in loving relationships with others. It is not unusual for those diagnosed with an illness to begin to pay attention to, and appreciate, the beauty in everyday life. As Frankl stated, appreciating moments of the good, the true and the beautiful allow people to transcend suffering and even dehumanising experiences. Social support, derived from having healthy relationships with
others, is a crucial component of coping with illness and having better psychological and health outcomes. Frankl also considered a sense of humour to be integral to finding meaning in life, as it allows people to step back from the situation that they are suffering and see it from a different perspective. It assists in coping. Humour is a significant avenue to appreciate others and to feel one’s own presence in the world. Humour can also be an icebreaker when it is uncomfortable for others to interact socially or professionally with the person who is ill. Once communication is facilitated, the illness is not ‘the elephant in the room,’ and the person who is ill can interact authentically.

Although creative values and experiential values are effective paths to finding meaning, it is through attitudinal values that individuals find the most significant meaning. Humans cannot always control situations, such as illness, that cause suffering. Some suffering in life is unavoidable. However, people do have the ability to decide what attitude they will take toward inescapable circumstances. Frankl stated, ‘What is significant is the person’s attitude toward an unalterable fate.’ Attitudinal values are realised for individuals when they find themselves dealing with a challenge only they can confront, such as with illness or trauma. It is the dignity, courage, and outlook people take toward an unavoidable fate that brings them the most meaning and fulfilment in life. Consequently, life can be fulfilled in suffering. Frankl believed ‘suffering ceases to be suffering at the moment it finds meaning.’ The freedom to choose attitudes toward suffering serves as an opportunity to cope with difficult situations and to make necessary lifestyle changes with dignity. It also provides those dealing with illness an opportunity to feel a sense of control in what feels like a situation that is entirely out of control and overwhelming.

People who have not found their will to meaning through the achievement of values, or who have lost their meaning and purpose due to illness, have to redefine that meaning and their sense of Self. Illness also changes how people interact with each other, and it can cause individuals to re-evaluate their religious and spiritual beliefs. These transitions are significant, in that they increase depression and anxiety. They also reduce the ability to cope, which can exacerbate the depression and anxiety. Logotherapy is an effective approach to assist people with these existential crises.

The significance of attitudinal, experiential, and creative values can be readily extrapolated from a case study offered by Hollingsworth. The then 33-year-old mother of two had one kidney removed because of cancer, and had just received a diagnosis that indicated the cancer was spreading throughout her body. She would have to undergo immediate and aggressive chemotherapy and radiation treatments. At this point, the woman, Patrice (pseudonym), lost all hope for life. Patrice began the series of treatment. Her sister, in an attempt to ameliorate some of the suffering literally forced
Patrice to step away from all anguish and go on a short ‘vacation’ to the Western states to visit another sister.

While out West, the three sisters went to visit a Native American Reservation. They began a conversation with the tribal medicine woman. Upon learning of Patrice’s cancer, the medicine woman asked if she and the tribe could bless Patrice with a ritual healing ceremony. Patrice acquiesced and, at the ceremony, the entire tribe prayed for her, and created for her a medicine bag filled with blessed artefacts. Afterward, members of the tribe wrote to Patrice on a regular basis, sending their thoughts, prayers, and concerns for her. This relationship continues. Of this experience, Patrice said:

My spiritual beliefs are on several levels now. I know there’s a God who I totally believe in and give myself to fully. I also believe in spirituality. I have a medicine bag made for me by an Indian tribe. It’s blessed by the spiritualness [sic] of the tribe and can only be touched by me. There are stones in it that symbolize balance within myself, Mother Earth, the sky, and the flowers. We’re all connected. There’s a bloodstone that I rub on all my ill parts. As I heal, the green turns to white. It gives me energy. It’s a symbol to hold and see to help remind me of the spiritualness [sic] inside. To know someone cares this much to do this for you. I’ve never felt so much love from people, and I don’t even know each of them. It’s helped me open up spiritually for healing. I pray with it through God’s will. It helps me believe in me and that I will be healed. Spirituality comes from within our soul and everything else wraps around us like a blanket. It’s really gotten me into holistic healing. I believe in modern medicine, but I know I can do this myself. Its’ mind over matter. I wish others could get this feeling. Everyone has it in them.25

Patrice went into remission after the experience, and after the medical treatments. Her life has changed dramatically. She redefined herself and her relationships. After the ritual, she stopped identifying herself as a ‘cancer patient.’ She became mindful, particularly of the moments of beauty in her life. She now, for instance, will literally stop to smell the roses. She recalled how she was in a hurry one day to get her children to school. Along the way, she saw a beautiful bed of wildflowers off to the side of the road. She reflected that before her encounter with the medicine woman, her only focus would have been to get her children to school on time. However, post-ritual, she pulled the car to the side of the road, and Patrice and her children took in the beauty of the moment, and the peace of being one with the
universe. Patrice now has new attitudinal, experiential, and creative values. She is currently in remission, and finding meaning in life, moment by moment. Each of these moments has become a celebration of life.

This case exemplifies Frankl’s existential approach to therapy. Logotherapy can be broken into two words: logo is translated into the word ‘meaning’ and therapy means ‘healing.’ Thus, Logotherapy can be thought of as healing through meaning, or becoming whole through meaning. It is an approach that includes paying attention to the mind, body, and spiritual aspects of life. Frankl stated it is the most effective way to find meaning and to deal with the tragic triad: suffering, guilt and the transitoriness of everyday life. Individuals with illnesses suffer this tragic triad. As a result, they must often confront what Frankl called meanings of the moment. Every person has unique life challenges that only he or she can confront. It is within these moments that people have a unique opportunity to find meaning in these moment-to-moment changes. People dealing with illness endure a dynamic cycle of meanings of the moment. Meaning is found in the way that people experience the illness, as well as the kind of stance taken toward the numerous physical and psychological changes that may occur with illness. The meanings of the moment combine, then, to help people with illness to find meaning in life experiences and in the illness itself. They are also the conduits to the redefinition of Self and connecting with others.

The role of health care professionals, then, is to assist patients to redefine themselves as individuals with an illness, rather than defining themselves as their illnesses. This will help patients to facilitate a realisation of the significance of life that is meaning and purpose. In Logotherapy, this meaning and purpose is discovered through the exploration of creative values and of finding meaning in suffering. Thus, suffering becomes the springboard to finding meaning, as well as a need for finding it. Although Frankl viewed this as the responsibility of the patients, health care professionals can help to guide their patients’ journeys through the use of Logotherapy.

The framework of Logotherapy for individuals coping with illness utilises Frankl’s three major life responsibilities. The first is to help the patients identify possible meaning potentials in the future by thinking through their life experiences. The ramifications of these predicted meaning potentials should also be explored. The second life responsibility is to identify meaning potentials that present themselves as a part of coping with the experience of suffering symptoms of an illness and their ramifications for daily life. The final life responsibility to examine is the culmination thus far of meaning potentials from the past. It is important to celebrate and honour these meaning potentials, as well as assisting the patients in deciding which of them they would like to continue to explore to find the will to meaning. People who become overwhelmed by their illnesses and treatment regimens often lose track of the meaning and continuity of their lives before being...
diagnosed. Addressing what has been meaningful in the past can refuel a sense of purpose and a reason to take a stand toward this unalterable fate. It also provides a sense of temporal continuity between the past, present and future. This is not only comforting to patients, but it also provides a sense of constancy in life and a feeling of having some control.

There are four steps to assist patients in addressing the major responsibilities for those experiencing illness. The first step is to help the patients understand that they are more than their symptoms, illnesses, and diagnoses. These are certainly part of their realities, but are not who they are in totality. To accomplish this, the patients must be helped to step outside of their situation and avoid the victim role. The second step is to help the patients become aware of their attitudes toward having an illness, as well as the self-talk they use to define themselves and their lives. Once identified, these attitudes and self-talk may be reframed to be more empowering. Reframing the self-talk and taking a strong stand are crucial in redefining a holistic and healthy sense of Self. The third step is to assist patients in exploring their creative, experiential and attitudinal values to the fullest extent possible. The final step is to assist the patients in identifying new goals based on these values to find their will to meanings.

Health professionals can assist individuals suffering from illness to work through these four steps, as well as assisting them in finding coping mechanisms. Logotherapy incorporates numerous techniques, which adds to the flexibility it permits. Much of the work of Logotherapy is done with Socratic dialogue and problem-solving. However, narrative approaches to building a personal story, values clarification, humour, paradoxical intention, guided imagery, and dream analysis are also effective tools to incorporate.

When using Logotherapy, the topic of spirituality/religion is likely to surface. Frankl viewed this ability to function as spiritual human beings as a powerful advantage. Thus, exploring spiritual themes, if desired by the patients, can be empowering in exploring the values and will to meaning. People with high levels of spirituality have demonstrated less stress and symptom severity, as well as a better quality of life, despite how life threatening they perceive their illnesses to be. A strength of Logotherapy is that it can assist people in exploring spiritual themes, as well as find their meaning and purpose in life, whether they are religious or not.

Logotherapy is a flexible approach to working with patients dealing with illness, because it can be used alone or in combination with other therapeutic techniques. Another strength is its phenomenological approach. It is, after all, the patients’ interpretation and appraisal of events, based within their own historical contexts, that defines what is threatening and determines how stressful events will be. It is also what allows them to define what is personally meaningful in their lives. Thus, Logotherapy can be tailored to assist patients in finding their unique meanings in life and meanings in
suffering illness. The Logotherapy journey assists them in redefining themselves, their relationships with others, and any spiritual beliefs they may have. It often provides transcendence for patients, as they experience themselves as a part of something larger than themselves or their illnesses. Logotherapy is also an effective means for coping with the physical, emotional, and financial stressors of being ill. Most empowering, however, is the use of Logotherapy to help patients realise they are more than their symptoms, diagnoses, and treatment regimens.

Notes

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Cancer and the Idea of the Self: Philosophy, Memoir and Medical Trauma

Marlene Benjamin

Abstract
Recent work in mind theory utilises the distinction between objective and subjective viewpoints to gain insight into how the self operates in the world. This distinction is often criticized on the ground that it posits a metaphysical monster constructed along logically insupportable Cartesian lines. But the experience of cancer offers an illuminating philosophical tool for thinking about the relation between objective and subjective perspectives on the same thing. Experience used quite self-consciously as a philosophical tool, however, demands a dismantling and subsequent reassembly of the commonly received notions of just what constitutes analytic philosophy. In particular, and most obviously, the traditional formal structure of analytic philosophy impedes the very exploration it is striving for. Experience (here, specifically female, yet with implications reaching beyond gender) forces the abandonment of all traditional references to the literature. Instead, I combine some of the methodology of analytic philosophy with the descriptions of first-person narrative in an attempt to discover why the objective/subjective distinction makes sense, despite its Cartesian structural flaws. This chapter’s personal narrative form is itself an invitation to further explore what the failure of traditional philosophy to accommodate the experience of cancer may import for the inclusion of female experience (and feminist philosophy) into the mainstreams of analytic philosophy.

Key Words: Cancer, analytic philosophy, first-person narrative, personal philosophy.

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I have been trying for a long time to write a book on philosophy, trauma, and narrative. More precisely, I have been trying to write a book on philosophy and trauma from inside first-person narrative. In fact, I am embodied evidence of the compulsively philosophical turn of thought, obsessively interested in the relationship between philosophy, trauma, and first-person narrative, in a relationship whose ontology, whose metaphysical existence, came to me by way of an embodied autobiographical fact. Such facts are not everything. They do not ‘speak for themselves’. Embodied facts, like all facts, are empty on their own, and require meaning if we are to understand their import in our lives. But meaning is constructed, the result of the reflective powers of our minds. Here is where facts are put to use, where
they serve as objects of interpretation, but also, if viewed from the right perspective, as particularly rich means of interpretation.

My philosophical interests and voice changed in a most radical way in 1987. But not until 2003 did I find a companion voice in the works of Stanley Cavell. On the final day of the 2003 NEH Summer Institute on Emerson, Stanley Cavell - like a standup comic throwing away the best line of her act - said 'Philosophy is like a terrorist regime; it’s very costly.’ In wondering ‘if there are possibilities for writing philosophy now that are different from the alternatives currently available’, I heard in his speculations a confirmation that my own halting work was actually an answer to that question, that there are such ways, and that I had been muddling along in one of them for far too long on my own. After the Institute, I discovered A Pitch of Philosophy: Autobiographical Exercises, in which Cavell says, ‘there is an internal connection between philosophy and autobiography, that each is a dimension of the other… that there are events of a life that turn its dedication toward philosophy,’ and in which he speaks about some of those events in his own life.

Between 1987 and 1994, the year in which a A Pitch of Philosophy came out, I had read some philosophers who used what Cavell and Emerson famously call ‘the low’ and ‘the ordinary’ - the details of daily life - as a springboard for philosophical exploration. But I found no philosophers who used the ordinary details of their own daily lives toward such an end.

Unusually, Cavell does some of this in A Pitch of Philosophy. Having finally discovered, in 2003, a companion voice, I realised I needed to revisit the genesis of my own turn to philosophy. More accurately, I needed to revisit the first event in my life that re-dedicated my life towards philosophy, but towards a philosophy I had, in 1987, to make up out of whole cloth, because my prior education in its content and its ways was entirely bereft of what I now understood to be philosophy’s central features and crucially important methods. And so, from Cancer And The Idea Of The Self, this is how some of it went.

Samuel Johnson once observed, ‘The prospect of death wonderfully concentrates the mind.’ This is often quoted with the self-satisfied conviction of those who have found a pure and simple truth. The conviction is misplaced. The prospect does not always concentrate the mind; in fact, there are certain prerequisite conditions. To be fair, Dr. Johnson knew that two of these are more necessary than others. There must be some pressure of immediacy in the prospect, and there must be some clarity about the nature of the death whose prospect is faced. In the absence of these conditions, the prospect of death wonderfully concentrates the mind only when the mind that contemplates the prospect is made of heroic stuff; or, mundanely, somehow disposed to maintain a cool and analytic position toward the self that is engaged in contemplation.
My own experience has been a sort of ‘thickening’ of the brain, temporary but recurring, and unfailingly predictable: facing my doctors, half-undressed, I go stupid. To concentrate my mind, a piece of self-consciously willed effort is required, part of which entails mulling over why this fact is itself true. Of course, this is where, in my case, the prospect’s lack of clarity comes into play. Unlike some other women with breast cancer, in my case, my doctors say, the prospect of death is not high on the probability charts. This has to do with statistics. Women with early stage breast cancer and non-involved lymph nodes are in ‘the best possible statistical profile.’

Statistics persuade people. In certain moods, from certain vantage points, they persuade me. Or rather, some part of my self is persuaded. Call this the ‘objective’ self, who allies herself with her doctors and acknowledges empirical data as possessing some sort of predictive power. In this mood, with this angle of vision, it is enough to repeat to myself the litany of empiricism and scientific method I have learned from my doctors: ‘There is a very strong likelihood that the lumpectomy and the radiation were curative; but if these procedures have missed some free-floating sub-microscopic cells, the systemic hormone therapy will likely do the trick.’ This is as far as my doctors will go. The objective self is satisfied.

But there is another self in all of this, a self who takes no comfort from the data. This self resonates to a fact that the objective self is not much troubled by: according to current medical research, my doctors cannot say that I won’t confound the data; that I won’t number among the small percentage of women who, even while being in the best statistical profile, will nevertheless suffer a recurrence of the disease.

Call this the ‘subjective self’, who lives her life from the inside, for whom ‘the best possible statistical profile’ means nothing, an incomprehensible phrase in an impenetrable foreign language. In this mood, with this angle of vision, the litany of empiricism and scientific method fails not only to persuade; it fails completely to account for the larger metaphysical question that asks how to reconcile - for my self that is (somehow) not split, but whole - objective and subjective perspectives on the experience of cancer.

I wanted to shatter time and resurrect another, synergistic self. Waiting for the anaesthetic to take hold, astonished and still in a room full of green-cottoned doctors, reconciliation of perspectives wasn’t a problem. Fear and surprise wonderfully concentrated my mind. I want that clarity again. Without the fear or the surprise, I want to be that woman again.

Several things are going on here. I can sketch only small pieces of the metaphysical landscape. Also, the language I employ is itself problematic. Still, common sense definitions are sufficient and appropriate. ‘Objective’ means ‘seen from the outside’, an overview not limited to the viewpoint of any one person, but necessarily inclusive of many (perhaps all?)
individual viewpoints or experiences. ‘Subjective’ means ‘seen from the inside’, from the vantage point of one individual person, though not necessarily exclusive of objective perspectives, since these may be part of any given subjective point of view.

So much - or almost - for prologue. This too: I doubt if the experience of cancer is anyone’s philosophical tool-of-choice for thinking about the relation between objective and subjective perspectives on the same thing. It certainly wasn’t mine. But I hate to let anything go to waste.

Actually, the truth is different, or more. The truth is that I am compelled to avoid wastefulness, particularly when understanding is at stake, and even if at great psychological cost. There is a terrible tension here: the very thing I can’t let go to waste - the experience of cancer - is itself an impediment to its own preservation, both as the investigative tool of understanding, and as the experience to be understood.

This is the problem. Reconciliation between objective and subjective perspectives - says one philosopher whose writings often persuade me - is particularly difficult, perhaps impossible, when the subject is the self. Nevertheless, the push toward reconciliation, I find, is especially powerful precisely when the subject is the self, and even in the face of what may be irretrievably different conceptions of the same thing: the experience of cancer by a self capable of objective and subjective viewpoints.

Of course, this doubly capable self may be a metaphysical monster, constructed along insupportable Cartesian lines, and which, therefore, must logically be rejected. Rejecting what is logically insupportable appeals to me. I want things to be logical. Yet most days this doubly capable self makes (at least from the inside of this experience) an undeniable, exactly because it’s a schizophrenic, kind of sense.

This is a philosophical Catch-22. The only way out is to chart more carefully the intellectual terrain of the experience. Yet I am hindered in that exploration by an emotional paralysis of a sort I can’t often get very close to. The first problem, then, is how to get close enough to the affective side of the experience to allow exploration, close enough without suffering the sort of paralysis that undoes the very thing it strives for.

I wish for Daedelus, sculptor of enspirited statues and, behind Ariadne, architect of Theseus’ escape. Escape from this sort of labyrinth requires a philosophically unorthodox strategy, a different set of liberating methodologies. The usual philosophy article, full of technical language and buttressed by a footnote for every reference, must be avoided. I must do philosophy without the usual supports; must leave behind the highly codified structural requirements imposed by analytic philosophy.

Yet this sort of release is problematic, in part due to the insufficiency of a procedure that can hardly claim the title of ‘methodology’. More is needed.
Employing first-person narrative is the best way to go. Yet first-person narrative - precisely because it allows intimate emotional proximity to the experience - very quickly shuts down the exploration it originally encourages.

There is another danger. Without the powerful defences against affect supplied by the structural requirements of analytic philosophy, the project can degenerate into maudlin self-pity. Even worse, there can be a falseness about the whole enterprise: a use of the cancer explicitly claimed to aim at one thing, while actually (secretly?) aimed at another (such as getting people to think how good or brave or honest I am). A complex case of bad faith could be buried in all this.

I am too familiar with my own temptations not to be worried by maudlin self-pity and bad faith. The trouble is, I have no choice.

Think of my problem of the conflict between subjective and objective perspectives on the experience of cancer as a particularly intractable problem of cognitive dissonance. Its intractability centres in what may be the impossibility of harmonious reconciliation of the two perspectives when the subject is the self, combined with the unrelenting push toward reconciliation precisely because the subject is the self, and complicated by the fact that this is a subject capable of both perspectives.

Formulated like this, the problem looks hard because it looks like a choice between one perspective and the other, both of which make a compelling, though mutually exclusive, kind of sense. The problem of reconciliation is actually worse than that. In this case, the problem is so difficult of solution because the two perspectives stand at the farthest reaches of a continuum, with an infinity of more-or-less/es in between. I can’t articulate any of those in-between spaces when it comes to my own experience. I am left with the crude, extreme positions, with the rough boundaries of what feel like mutually exclusive truths about my own existence and how I experience it.

In centrally important ways, questions of perspectival reconciliation are probably similar in all cases of life-threatening diseases. But there are also crucial features of dissimilarity, and these deeply influence our sense of self. These features often involve the experience of the treatment appropriate to the disease: cancer is treated differently from kidney failure, and specific sorts of cancer are treated differently from one another. Still, certain kinds of treatment and examination are likely to raise certain questions in often predictable ways sooner (or later) than such questions may arise in other circumstances.

The question of sex and death is a good example. I know something about this. For nearly three months on a daily basis, my treatment required (and always will require, though less frequently) stripping naked and
submitting to examination a part of my body normally only viewed and touched in moments of sexual intimacy.

There is, and was from the start, something deeply odd about the vision of myself reflected back at me from the clinical perspective of my doctor’s gaze. Not just my continued existence is at stake in these examinations, but a sense of myself as viewed by others in this world I continue to inhabit. Breast cancer raises really messy questions about sex and death. To the extent that my sense of self is tied to a sense of my own sexuality, and to the extent that this is tied to a sense of myself as sexually desirable, the expressions on my doctors’ faces (all of whom are men), and the particular pressure of their hands on my skin, will contribute significantly to the way in which I conceive of myself.

With an exquisite attentiveness, some doctors intuit all this. They know that a high-wire sort of doctoring, addressed to body and soul at once, is needed to dissolve the tension here, to allow the patient’s recovery as a whole person; to allow a full, and perhaps even richer, re-inhabitation of the body.

Even so, this particular tension is expected to be dissolved according to widely accepted ‘civilized’ rules. Nowadays, these include forthright declarations, by both patient and doctor, about the absence of disfigurement. In my experience, these mutual declarations fail to reconcile the objective experience: no gross alteration or disfigurement, but only some continued swelling and several long scars - with the subjective experience: continued swelling and several long scars.

The emphasis is different, and this matters.

One philosopher I have in mind would probably point out that I am grappling with issues best answered by Reductionism. The Reductionist View claims that my continued existence just involves physical and psychological continuity and no further, deep fact that really matters. According to this view, ‘after a certain time, none of the experiences that will occur [after my death] will be related, in certain ways, to my present experiences’.

This, he would say, does not matter all that much. Thus, while I may have doubts at some deep level, at the intellectual or reflective level the Reductionist View would convince me. This would ameliorate what I call the problem of double vision, and this would liberate me from the self and console me. He admits that others may not respond this way, but these are the psychological effects he experiences when he thinks hard about the arguments for Reductionism, and he is therefore glad that the Reductionist View is true. He is glad because the arguments remove ‘the glass wall between [him] and others’.

I believe in philosophy as exorcism. Maybe this is wrong-headed, but it lets me carry on as if my puzzlement contains the possibility of
fruitfulness, which is itself a kind of consolation. Thus, I wonder if the easy slide from talk about these ‘two perspectives’ into talk about two ‘selves’ who hold different perspectives is just a piece of sloppy thinking, the culprit behind that logically insupportable, split-ego, Cartesian monster. I wonder why I think, and sometimes dream, that my existence is an all-or-nothing thing, even after working through some science fiction, but logically conclusive, examples of brain surgery and cell replacement and teleportation, all of which prove that my existence cannot possibly be an all-or-nothing thing.

And I wonder if this project is about to unravel because I am ever eager to fall back on the structural supports of analytic philosophy, which offer a comforting defence against the onslaught of my own emotions.

All this gives me a headache. The frustration is that in concentrating my mind in an attempt to keep from going stupid, I go stupid anyway.

I know what this is about. The fact that I have taken so long to get to the point is evidence of how hard it is to get close enough to the affective side of the experience of cancer to allow exploration. The point is just to reveal where this headache originally comes from by narrating its original genesis.

This is that genesis:

It is late January. Armed with my doctor’s lessons in statistics, I begin radiation. Statistics tell me that radiation combined with lumpectomy dramatically improves the long-term survival rate of women like me. Long-term survival is what I am after, and so for five days a week, over a period of six and a half weeks, I go down to the hospital’s basement where the linear accelerators are housed. Five days a week, for six and a half weeks, I undress from the waist up, put on a hospital gown, feel the low-level, continuous headache that began soon after surgery move up a few notches in intensity, and wait my turn on the machines.

Like all rooms down here, the room I wait in is garishly lit from above. I think this is meant to compensate for the absence of windows. But without natural light, everyone looks ill down here; doctors and technicians, as well as patients, carry a kind of malarial-yellow tinge across the face. (I have a Polaroid photo of me in an examining room down here, naked from the waist up, half my chest swollen and red and blistered, my face yellow and surprised.) Still, some look worse than others, and too many - some with bodies grossly deformed - are obviously close to death.

This makes me sick. Like my first day on the job, years ago, in an Oxford geriatric hospital, the smell of disinfectant and disintegrating flesh makes me cringe. And this, in its turn, makes me doubly sick, morally sick, for I want to be better than this, more gracious towards those worse off.

Since December’s diagnosis, I have learned more about cancer than I ever wanted to know. I read about suffering as offering the ‘privilege of love and pain’. I dislike - and am wary of - this line of thinking, which
reminds me of Oedipus, cleansed of his moral failures through his suffering and pain, made ready for his assumption by the Gods. Perhaps this really worked for the Greeks, but I require more mundane comforts. Only when I get the pattern down; when I know which doctors to expect on which days; when I know all the technicians by sight - even those who don’t take my case - only then do I feel some small flicker of generosity toward my fellow patients.

But this is easily tried. There is something strange and awful about this place and these people. From my first day down here, I go into a kind of affective shock, hedging my heart round with whatever buffers I can invent. Much of this is automatic, but much is also willed: affective hibernation self-consciously chosen as a way to travel through time, my eyes fixed unblinkingly on a middle-distance future.

At the same time, I am matchlessly aware of this place, in whose main characters I am helplessly, morbidly, interested. I survey my fellow patients as if any one of them might be a terrorist with secret knowledge of the bomb that is going to blow us all sky high. Meticulously, I catalogue their deformities: a man without a nose, whose face - though half-covered by a hospital mask - shrivels demonstrably over the time I am treated; a woman whose head and neck loll heavily to the left, grotesquely weighed down by a bulging tumour gone completely wild. Once, while changing clothes, I hear something that sounds like R2D2. Stepping out from the changing stall into the waiting room, I see a man projecting strangulated noises by holding a small instrument against his throat.

Some days, the racket in my head is worse than others, and the low-level continuous buzz flares into a terrible, erratic pounding. But high or low, it’s always there. When it stops, about eight weeks after the end of radiation, I miss it for a bit, but am happy to have it gone. I think its going signals some psychic closure, some resolution of the problem of double vision.

I was wrong. Eighteen months after the end of radiation, the problem of double vision is back. So is my headache. Headaches like this are a post-cancer addition to my life. I have noticed a pattern in my responses. Because all tests are done to check for metastatic disease, talk of ‘less’ or ‘more fearful’ is imprecise. Yet the less specific in results, while biologically non-invasive and incomparable in their procedural sophistication, are somehow even more terrible, both in anticipation and in response.

Thus, the second Magnetic Resonance Imaging tests, done to track a process my haematology oncologist now says ‘doesn’t appear serious’, gave me a ringing headache before and after. The MRI doctor told my oncologist that he thought the test results showed cancer in my non-radiated breast. Reporting this to me, my doctor says, in support of his own assessment, that MRI tests are not used to diagnose breast cancer, and anyway we were
tracking the ‘hot-spot’ in my arm, which has diminished, and the one above
my liver, which hasn’t changed. These, he says, are good signs.

I know this is true, but it doesn’t do much for my headache.

The truth isn’t always liberating.

If I could believe the Reductionist View, I think that I, too, would
find it liberating and consoling. The problem is that I can’t understand the
arguments supporting Reductionism because I have a hard time breaking
through the literal headache I get when trying to think about the arguments as
applied to myself.

The emotional proximity given by narration of my headache’s
original genesis is a dubious gift. I’ve gone stupid again by trying not to.

A friend says that watching me made her think that having had
cancer is like living next door to a suspicious character: you lock your doors,
your security system works, there’s no current reason to worry, but... you just
never know.

This captures some of the uncertainty. But even the uncertainty
changes its shape, its content, and its feel. How can I explain the fact that
tests and examinations - even when they are physically non-invasive - hurt?

How can I reject what some part of me knows is a logically insupportable
Cartesian construction of the self, when some other part continues to feel as if
some metaphysical connective tissue has been bruised and traumatized?

The Reductionist View I want to believe says that what really
matters about our own future is just physical and psychological continuity.
There is no further, deep fact about our existence. Personal identity is
mistakenly believed to be the further, deep fact that says what is true and
important about our lives. But personal identity merely coincides with, and is
not itself, what matters. According to this version of the Reductionist View, it
is possible to care less about one’s own death because ‘after a certain time,
one of the experiences that will occur [after our death] will be related, in
certain ways, to [our] present experiences. Can this matter all that much?’

I want to say that this matters very little. I can’t. I think this is
because there is something absent in the Reductionist account of what
matters in our concern about our own future. It misses something important
about the way in which personal identity is in part a conception of the self in
relation to others. Not to other past or future selves, but to actual, different,
other people. These relations are not just another way to talk about personal
identity, which could then be claimed by Reductionists to merely coincide
with what matters. Only if what matters in personal identity is radically
independent of other people can such claims of coincidence be true and thus
(possibly) dismissed.

What matters? If there is some deep fact about our own existence, it
is buried in our relationships, in the first instance with other people, but also,
though perhaps less immediately, in all our relationships. What matters is the
complex set of ways in which our sense of self is formed by what is mirrored back at us.

The Reductionist View will leave unanswered doubts that arise on levels not reached by the logical powers of reflective and intellectual inquiry because important aspects of our relations are unaccountably beyond such powers.

I cannot account for this, but the logical powers of reflective and intellectual inquiry cannot reach the roots of, and therefore cannot calm, my anxiety. (Perhaps someone else can account for this, but that misses the point). For part of my anxiety when I think about the possible results of some test or check up has to do with how those close to me will respond.

I imagine the worst: metastatic cancer, chemotherapy, death. I envision my funeral. I see a large crowd. Starting with those I love most, and who love me most, the scene is awash in tears.

It is not enough to explain this as a piece of neurotic wish-fulfilment: finally, people admit how much they love me. Of course, there is some of that, but there is more. The point is that my personal identity, though not fully dependent on, is yet complexly bound to the lives and sense of self of other people.

This is not merely coincidental with what matters. The Reductionist account of what matters cannot explain why the absence, in my experience, of continued physical and psychological continuity - why future experiences not related to my current experiences in any meaningful way - should liberate me from the self and console me when the self is bound so closely with others.

I will not be here, and the sadness I feel in anticipating the failure of my continued existence will not be connected to any future experience I will have. But the sadness I know now in anticipating and empathizing with the sadness and loss of the sense of self that others will feel later at the failure of my continued existence, at the absence in their experience of their sense of self which is, in part, connected to the reflection they see mirrored back at them from my eyes, is - even factoring in neurotic wish-fulfilling explanations - anything but consoling.

Perhaps this says nothing at all about the Reductionist View, and everything about my own double-visioned confusion, about my own philosophical shortcomings.

Even so, philosophy as exorcism has its (own) limits. But that is how it should be, for if I had a spade today it would be turned, struck hard against the bedrock limits of language (and our use of it), and we would need tomorrow to begin again.
Notes


2 Several years after I wrote Cancer and The Idea of The Self, a friend sent me a copy of an article by Martha Nussbaum, whose work I have come to admire and in which I find numerous resonances for my own philosophical explorations, despite some very significant differences. The article, called Love and The Individual, was based on a paper she had delivered at a conference and was later published in her book Love’s Knowledge: Essays on Philosophy and Literature. In this essay, Nussbaum relies on a literary conceit to ‘integrate’ (if that was her intent) personal experience and first person narrative with analytic philosophy. But the conceit – which claims that Nussbaum (the author of the essay we are reading) has discovered papers and articles written by another woman strikingly like herself -whose experiences and first person narration of them provoke the philosophical reflections and first person narrations of the author (Nussbaum). It is a wonderful essay, but does not do what I am here attempting, for the very conceit relied upon - of a character similar to the author – and juxtaposed to the analysis of philosophical investigation, keeps the author separate from the experiences being documented, maintains a barrier between Nussbaum and the experiences she reports. Perhaps this is the same conundrum in which I found myself writing Cancer and The Idea of The Self, but there is no self-conscious recognition that such is the case, and that is, as far as my own work goes, central to the philosophical. Nussbaum does more straightforward personal narration in a later book on the intelligence of the emotions, yet even here there feels as if a barrier remains between the person engaged in doing the philosophy and the experiences narrated by that person, despite explicit claims about the role played by such experiences and the emotions they evoke in our self-reflective lives. This is particularly true for me (though perhaps not for others) in her discussion of her mother’s death. In 1995, I had written an essay about my own mother’s dying and death in 1993 (part of a book in progress), and used some of Nussbaum’s insights in her 1994 book The Therapy of Desire: Theory and Practice in Hellenistic Ethics but later found the chapter on her mother in Upheavals of Thought: The Intelligence of Emotions somehow at odds with the claims about experience and emotions made there. But personal experience is often untranslatable, and this is not so much a criticism as an observation about the problems inherent in attempting to bridge the gap between analytical philosophy and literary narration.

3 It is interesting that even here there is less mention of his own body than might have been philosophically informative. There is the obvious, and wonderfully lyrical, metaphorical connections between his ear problems and
his turn away from music and towards philosophy. Yet about the ear and its often unconsciously selective listening capacities, more could have been made, and made less euphemistically than Cavell does, particularly about the sexually self-reflective role that such capacity can, and apparently did, play in his life. But this is, as above with Nussbaum, more a remark about the problems inherent in attempting to bridge the gap between analytical philosophy and literary narration. But it is also another point that may be worthy of deeper exploration, for it is part of the caricature that men (here, male philosophers) are less likely to actually locate (as much) meaning in their lived bodies than women, who are far more quick to embark upon that road. This is a caricature, or a tendency, however, that warrants close attention. Cavell goes far in breaking this mold, yet does not fully reshape it to reflect a real movement into a usefully different interpretation. But such is the delight in reading him, a delight that gives all the more reason for feminists, especially, to study him with care. An excellent reading of Cavell’s relation to feminist philosophy is in Susan Field, *Emerson, Cavell, and Feminism* (forthcoming).

4 The general issues in which I have been interested were raised in Thomas Nagel’s *The View from Nowhere*, 1986, and in Derek Parfit’s *Reasons and Persons*, 1984, past personal readings.

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Perceptions of Pain in Contemporary Zimbabwean Literature: Personal and Public Narratives in Yvonne Vera’s *The Stone Virgins*

Zoë Norridge

Abstract
Human suffering has long been a dominant representative theme of African literature. Consequently, bearing witness to the disabling violence of the colonial project and giving voices to the powerless in pain is a key feature of both nationalist and feminist literary theoretical approaches. Rather than focusing solely on witnessing the infliction of bodily pain, contemporary writers are also exploring the possibilities of living with unforgettable pain. Zimbabwean novelist Yvonne Vera is one such writer. Vera’s acclaimed 2002 novel, *The Stone Virgins*, tells the story of two sisters who are attacked by a dissident in the early years of Zimbabwe’s independence. The attacker beheads one of the sisters and cuts the lips off the other. The narrative surrounding this incident is an exploration of the social currency of the body and strategies for survival in a physically uncertain world. This chapter investigates how such extreme experiences are described through innovative use of both language and temporal structures. Bodies, in health and in sickness, are figured throughout the text, and the recurring motif of exposed bones works to dissolve the barriers between the internal organs and social surface of the body. These bodies also interact with the historical contexts of colonialism, guerrilla war and continued violence post-independence. Yet Vera’s text remains morally ambiguous towards this politicisation of the personal. As a Zimbabwean woman from Bulawayo, Vera the writer is located within a similar geographical and temporal framework to her heroine. So finally I will ask how the writer of such pain is also implicated in her project. Are the traumatic elements of the text a deliberate narrative strategy or is the storyteller also sick? And if the writer of pain is indeed also in pain, then what are the implications for the work’s readership and literary theory? Understanding these questions will help us begin to make sense of pain narratives in contemporary African fiction.

Key Words: Pain, Zimbabwe, literature, Yvonne Vera.

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African literature is no stranger to pain narratives. From depictions of the horrors of colonial occupation to accounts of ongoing poverty and health inequalities, both mental and physical suffering remain constant...
themes. They are not however the only theme, and monolithic representations of Africa as a place of disease and death, still common in the European media today, sustain a deeply uncomfortable stereotype for many African intellectuals.

However, I believe that celebrating Africa’s diversity and creativity does not necessarily mean avoiding researching the more painful aspects of Africa’s literary output. Rejecting any study of pain or violence in Africa is becoming a cliche in itself, particularly when so many of the currently fashionable themes in African literary studies, such as nationalism and gender, are founded on an understanding of mental and physical health in a specifically African context. The main challenge for anyone researching representations of pain in African literature is finding theoretical approaches that take into account both the African context of the texts available and existing research by pain theorists.

The area of pain studies is diverse, innovative and spans several disciplines. Nonetheless it has concentrated predominantly on Western subjects. Biomedical research has a tendency to categorise and pathologise, looking for diagnostic criteria to facilitate practical interventions in the context of national healthcare systems, founded on specific expectations and beliefs. More culturally focussed anthropological studies of pain by researchers such as Arthur Kleinman and his North American colleagues provide richer frameworks for literary analysis, but are still mostly focussed on the West. In Africa, the ethnographic work of medical anthropologists rarely seems to engage with African writers themselves. My research aims to begin to bridge this gap, bringing African literary theory together with pain theory to generate new understandings about how African literature makes sense of health, illness and disease.

One way to bring these disciplines together is through combining divergent theoretical approaches in the detailed study of specific literary texts. This chapter examines particularly striking pain narratives in Zimbabwean Yvonne Vera’s most recent novel, The Stone Virgins. I will argue that Vera’s work offers us unique insights into Zimbabwe’s turbulent past whilst at the same time enriching our understanding of fictional pain narratives, both in general and in a specifically African context.

Vera’s complex, poetic texts carry within them an insidious sense of sadness, a feeling for the tragedy of people frustrated by surroundings and circumstance. Her five novels and short stories are located in the Zimbabwean past, treating taboo subjects such as incest and abortion through descriptions of the personal lives of women. The text for discussion here, The Stone Virgins, is Vera’s first novel to treat post-independence Zimbabwe. Set in Matabeleland in the 1980s, it describes the devastating civilian impact of dissident guerrilla attacks and violent government oppressions. The pain she depicts is a pain of violent causation - harm infliction through mutilation,
rape and burning alive. Nonceba, the main female protagonist, is attacked by a dissident guerrilla soldier in her home. The terrified woman watches her sister being beheaded, before the attacker rapes her and cuts off her lips. The rest of the narrative forms an attempt to make sense of this violence, and describes Nonceba learning to live with her broken body and mind.

_The Stone Virgins_ depicts a historical period of time from a strongly literary perspective: not seeking to uncover new facts and evidence but instead moving towards an understanding of events through an imaginative probing of the perceptions of individual people in pain. The 1980s Matabeleland violence she describes forms a highly contested period of Zimbabwe’s history. Largely unreported in the press at the time, events began to come into the public eye in 1997 with the publication of the Catholic Commission for Justice and Peace report, *Breaking the Silence*. Terrence Ranger, one of the few historians researching the period, has claimed that the current government has deliberately tried to simplify and suppress what Mugabe himself refers to as ‘ugly history’. Evidence reports also frequently cite civilian fear of speaking out about these events of the past. The complex narrative of _The Stone Virgins_ is therefore both a brave political move and a means to resist the simplification of history. By fictionalising brutalities that more factual accounts argue did take place, the novel explores a realm of past possibilities and uncertainties for their aesthetic and ethical ambiguities. Creating personal stories about multifaceted individuals in pain deepens our human understanding of what the facts and figures of this violent period really mean.

Vera’s literary account also offers a different angle to the very functional first person narratives in existing evidence reports. More than a straight description of what happened, or a set of medical case notes, Vera’s fictional representations communicate emotional perspectives on pain that are so personal they are not easily shared by the real victims of the tragedy. She opens up new possibilities for human intuition, engaging the reader in the attempt at understanding and empathy. This process is inherently discursive. Vera’s complex poetic style and the inconsistencies and gaps in the narration challenge the reader to make sense of the experiences described, reflecting the real pain patient’s quest to make sense of his or her own narrative confusions. As Indian sociologist Veena Das explains:

In repeatedly trying to write the meaning(s) of violence against women in Indian society, I find that the languages of pain through which the social sciences could gaze at, touch or become textual bodies on which this pain is written often elude me. […] Some realities need to be fictionalised before they can be apprehended.
Not only does Vera’s fiction provide a privileged space for the exploration of pain, the construction of The Stone Virgins, whether consciously or unconsciously, also mirrors characteristics of narratives of real people in pain. Vera’s treatment of time and space, the structures she employs and the language and narrative voices she uses, all have some resonance with the pain experience as described by pain patients themselves.

Firstly let us examine Vera’s novel’s structure and chronology. The central narrative of The Stone Virgins is the story of two sisters who suffer a brutal attack resulting in the death of one and the rape and mutilation of the other. From the very beginning of the novel, which is set years before this central incident, we have the sense of an impending tragedy, a feeling that the description is leading towards a revelation. Although the story unfolds in the present tense, it also seems to be told in retrospect. At times this impression is generated by the narrator, for example when Vera writes: ‘She has no idea now, or ever, that some of the harm she has to forget is in the future, not in the past…’ At other moments the characters themselves seem to have prior knowledge of what is to come. This focus around a central defining incident bears strong resemblances to narratives of real pain patients who define their lives in terms of the onset of their condition. This is at times, as Byron Good suggests, because the telling and retelling of a story helps to make sense of how and why the patient’s pain began. In The Stone Virgins this is explicitly seen in the way Vera repeatedly revisits the attack with differing levels of detail. It also links into Arthur Frank’s theory that the pain experience forms the filter for subsequent narratives, because it is the patient’s illness that provides the motivation for remembering the past.

Another manner in which Vera’s novel resembles patient pain narratives is in the renegotiation of space; both the internal spaces of the body and the external places where the pain experience is lived out. This is beautifully captured in a passage that describes Nonceba waking in hospital for the first time, faced with a new physical reality:

She can feel the cloth pressing down, the smell of medicated ointment. Her mouth is slightly open under the cloth. Her tongue is moving in her mouth. She is thirsty; her throat is burning. She moves her tongue over and over, searching for saliva. She wants to reach the bandage with her tongue. To loosen it. To breathe through her mouth not her nose. […] Everything is changing. She has a desperate feeling that everything has already changed, gone, not to be recovered. Nothing can be the same. Her own arms have changed, her body. Kezi, her place of birth, is no longer her own.
This sense that the world has irrevocably changed and that what was once accepted can no longer be taken for granted is echoed in the words of people who are physically and mentally wounded describing how even every day activities are transformed into challenges to be overcome. In Vera’s text physical belonging is fundamentally linked into the person in pain’s renegotiation of identity. We see violence taking place within the domestic space, resulting in removal of the patient first to a medical institution, and then to another refuge for recovery. Everything that is known and safe has become foreign. As the quote above illustrated, these two alienations, of body and place, are fundamentally intertwined.

Vera captures this sense of a world made strange in her language. She challenges the normal sequencing of words, the linguistic categorisation of experience, by pulling together divergent concepts and metaphors to reveal a fractured world view. Ato Quayson, a Ghanaian literary theorist working in Cambridge, uses an analysis of the proliferation of these strange metaphorical categories to suggest that ‘the literary text somehow refracts the consciousness of trauma that percolates in the African postcolony to different degrees’.

He argues that painful narratives form a key part of the fabric of life for any African writer. Vera’s texts are rendered disjointed through her almost inevitable representations of traumatic acts. Quayson proposes that The Stone Virgins shows an ‘ex-centric symbolisation compulsion’, driven by an ‘epistemological enigma’, which is itself shaped by trauma. That is to say, the way trauma creates disjointed memories and uncertainties in real life is reflected in the structure and language used by Vera in her novels because in some sense the writer is also sick. Pathologising an entire continent of novelists is obviously not unproblematic, but the concept is compelling, particularly when we look at authorial identification with wounded literary protagonists.

The Stone Virgins, in common with many other African novels dealing with complex pain narratives, includes a bewildering array of different narratorial voices. This is potentially symptomatic of the disturbing creative writing process during which the writer attempts to imaginatively inhabit other bodies. The novelist’s fractured sense of identity also resembles the discordant perception of reality that afflicts the new patient of pain. The first person narrator surfaces at moments of extreme pain, and the ‘I’ pronoun is used for the first time by Nonceba in the initial description of the attack. Vera writes:

*I* am waiting. *I* am alive, now, a companion to his every thought. *I* am breathing. *My* temples, beating. *She* closes *her* eyes and *her* body listens as his movements pursue each of *her* thoughts. *She* breathes. Harm
The narrative voice is both first and third person, both personal and removed, drawing the reader into an immediate engagement whilst also maintaining an observant perspective. As Quayson suggests, Vera herself is arguably implicated in the pain narrative here. But does this mean that all the pain narratives Vera creates are fundamentally centred on her own experiences, determined by her own sense of trauma? Or does Vera’s fiction somehow open up spaces for the description of differing experiences of pain? The next section examines how Vera manages to create links between different pain experiences whilst preserving their diversity.

We have seen that fiction offers a privileged space for the exploration of pain and that Vera’s work in many ways mirrors real pain narratives. However, having drawn these links between different pain experiences it is also important to ask how different pains diverge. *The Stone Virgins* contains many descriptions of hurt, often concerned with the central traumatic incident but also depicting different yet related events, other civilian experiences of pain stemming from the 1980s Matabeleland violence. These different representations of wounded bodies form a pictogram of pain in constant transformation. Each transformation is coherent within its own context, yet if you tried to separate out the pain accounts and assign them to discreet categories of experience with definite meanings the text would collapse. That is to say, the word ‘pain’ does not always signal the existence of the same sort of pain. The pain of a woman forced to kill her husband with an axe is related to Noncbe’s painful witnessing of her sister’s beheading, but different since the wife feels the agony of guilt whilst Noncbe is also suffering severe physical pain from facial mutilation. Noncbe’s physical pain is related to Vera’s descriptions of a local store keeper who is burned to death by government forces, but is also separate since the store keeper and the young woman have different personalities, experiences of the world and positions within the novel’s narrative. How can these pain experiences written by the same novelist and often described with very similar language also produce divergent and individual meanings?

A promising analytical approach to this question can be found by borrowing anthropologist Rodney Needham’s term, the ‘polythetic’. Needham uses this term to introduce a certain fluidity into his research, by destabilising our assumptions about categories of experience, in our context categories denoted by words such as pain, hurt and suffering. He observes that ‘the conventional definition of a conceptual class is that its members must possess certain properties in common’. However, Needham is not satisfied with this definition, and uses the work of Vygotsky and Wittgenstein to argue that classes are composed in the form of a ‘chain complex’. This means that ‘the definitive attribute [of a class] keeps changing from one link to the next’ since there is no consistent relationship between the elements and instead ‘the variable meaning is carried over’ from item to item with no
overarching features in common. Needham cites Wittgenstein’s powerful rope analogy to illustrate the concept: ‘The rope consists of fibres, but it does not get its strength from any one fibre that runs through it from one end to another, but from the fact that there is a vast number of fibres overlapping’. This can helpfully be applied to *The Stone Virgins*. In a linear narrative fashion (which is notably not chronological) the experiences described in *The Stone Virgins* are all related, can all be lined up like small threads of the textual rope. But if these pain elements, or threads, are separated out then it becomes more difficult to analyse them in terms of a common category.

To illustrate this concept of the polythetic, let us compare the descriptions of the Matabeleland women as a collective group with the description of Nonceba as an individual in pain. Women’s lives in all Vera’s texts are characterised by resilience and hardship. The women of Kezi are no different. Towards the end of the first section of the novel, when independence seems to be upon them, the women celebrate their existence:

> They sing earth songs that leave the morning pulsating. [...] Their minds a sweet immersion of joy, they float, jubilant. Their senses almost divine, uplifted; their pain inarticulate. Voices rise to the surface, beyond the dust shadows that break and glow, and lengthen. They will not drown from a dance in the searing dust, from the memories of anger and pain. They will not die from the accumulation of bitter histories, the dreams of misfortune, the evenings of wonder and dismay, which should have already killed them.\(^{18}\)

The collective and bearable pain expressed here may initially seem to be unrelated to the pain experienced by Nonceba when her lips are cut. That pain is more immediate and intense, even ‘surprising’.\(^{19}\) When the dissident guerrilla hurts her ‘a piercing pain expands, and my body turns numb, motionless, with a searing pain’.\(^{20}\) However, as the novel continues the two experiences appear increasingly related. As she recovers, Nonceba remembers the ‘haze of days succeeding days, anger and pain, and an insistent absolute silence’.\(^{21}\) All these women are angered by their suffering and the silence that in Nonceba’s case is a result of her bandaged mouth seems strangely linked to the celebrating women whose pain remains ‘inarticulate’. Memory is also key to both of the accounts, the past seen as something threatening, something to be consciously lived with and resisted. Pain here is a polythetic category tangentially linking experiences yet recognising their differences.

It could be argued that a polythetic analysis of pains in *The Stone Virgins* reveals how different incidents are deliberately thematically linked
for narrative coherence. This might initially seem like a rather artificial aestheticisation of experience, a departure from real pain narratives. But the lines between fiction and non-fiction are not as clear cut as this might suggest. Strangely in fact, this argued aestheticisation actually links us back to real life. Pain narratives told by pain patients only include details of other people’s pains that have some bearing on their own experiences. But does this mean that we are only ever telling our own pain story, or is there some way of preserving the alterity of other experiences within a polythetic context?

Sociologist Arthur Frank identifies a type of illness narrative that engages with the depths of extreme experience by failing to fully articulate their essential points of difference. He writes that:

The paradox of the chaotic voice is that it would seem to be incapable of storytelling. Here the losses, the pain, the incoherence of suffering become so overpowering that language cannot resocialise what has happened. In this heart of darkness, ‘the horror’ cannot be told; any telling can only point toward what happened in the vaguest terms […] what is tellable about chaos is no longer the chaos itself.22

This citation has multiple implications for our discussion. Firstly, if we accept Frank’s argument that some extreme areas of pain are unrepresentable and can only be pointed towards by peripheral descriptions then we open up the possibility that Vera’s text may contain similar yet divergent descriptions of pain indicating unique and unrepresentable areas of experience. It is then the reader’s role to attempt to intuit some understanding of these diverging holes of meaning. However, the danger inherent in Frank’s suggestion is linked to his explicit reference to Conrad’s Heart of Darkness when he writes that: ‘the horror’ cannot be told; any telling can only point toward what happened in the vaguest terms. The colonies were built on the shared agreement not to represent the painful reality of those human beings who paid for the foundation of empires with their cultures and lives. So continuing to unquestioningly accept this trope of the unrepresentable is deeply problematic for postcolonial literary theory. This also ties into questions of imaging Africa raised in the introduction to this chapter and requires further investigation elsewhere. This takes us in a full circle back to where we began discussing the implications of research into pain representation in Africa and provides another convincing argument for the importance of this academic enquiry.

Here we have seen that fiction provides a privileged space for the representation and understanding of pain narratives that is nonetheless
intricately linked to the experiences and stories of real people in pain. Exploring the similarities and structures of pain narratives has repeatedly thrown up the need for an understanding of the interlocutors’ underlying ideologies and individual subject positions. Vera’s novel is a public gesture that nonetheless explores very private and personal experiences of pain. And the aesthetics of her literary art have been seen not to proclude, but to maintain her stories’ individuality and humanity. Let us finish with a quote from the linguist MAK Halliday who expresses the nuances of this topic so simply when he suggests that: ‘[pain is] a uniquely complex area of human experience: one that is unlike anything else - precisely because it is like almost everything else, at least in some respect’.23 Our challenge is to find the frameworks to make sense of pain’s interactions with this ‘everything else’.

Notes

1 M Good et al., 1994.
5 Cf. the fearful avoidance of the topic in Staunton, 1990.
7 Cushman, 2004.
8 Vera, 2003, 36.
10 Frank, 1994, 4.
11 Vera, 2003, 90.
12 This quote is from an e-mail Ato Quayson sent me on 28/05/05 in response to my request for clarification on issues in his new work Calibrations, 2003.
13 Quayson, 2003, 87.
14 Vera, 2003, 68 (my italics).
15 Needham, 1975, 349.
16 Ibid., 350.
17 Ibid., 350.
18 Vera, 2003, 52.
19 Ibid., 69.
20 Ibid., 109.
21 Ibid., 149.
22 Frank, 1994, 7.
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Empathic Witnessing in Patient Pathographies

Melinda Rosenberg

Abstract
The purpose of my chapter is to discuss ‘empathic witnessing’ in patient narratives of illness, or pathographies. I will call upon the work of Arthur Kleinman to facilitate this discussion. Arthur Kleinman has written extensively about illness narratives. Kleinman, a medical doctor, has lamented the traditional approach to the clinical encounter that most physicians adopt. There is more to the patient than simply taking down her medical history and asking where it hurts. Kleinman has christened his approach the ‘Alternative Therapeutic Approach’.

Key Words: Empathy, narrative, illness, disease, body, patient, physician

The doctor said that so-and-so indicated that there was a so-and-so inside the patient, but if the investigation of so-and-so did not confirm this, then he must assume that and that... [T]he real question was to decide between a floating kidney, chronic catarrh, or appendicitis. It was not a question of Ivan Ilych’s life or death, but between a floating kidney and appendicitis.

Ivan Ilych is a very average middle-aged man when he suddenly becomes infected with an illness that never seems to be correctly diagnosed. His enigmatic illness is put into one diagnostic category by one physician and into another by the next. As the physicians meditate on what disease the symptoms signify, Ivan Ilych’s life is thrown out of equilibrium. Whether or not the disease is acute, chronic, or terminal does not matter to him. Any disease is a disruption of a life in progress, be it an ordinary or extraordinary life. A disease can leave any body agitated and troubled, even if the person is of sound mind. Disease reminds such sufferers as Ivan Ilych just how frail and mortal they truly are. What is remarkable about this short story is that Ilych’s reflections on how his numerous physicians minister to his needs are so often demonstrative of the grievances many actual patients have when they visit their physicians. Very often, the patient is treated as a carrier of a disease and not someone suffering from an illness. Illness is the patient’s experience of a disease. Yet the pathophysiology of a disease, which is fastidiously ordered and classified, is the objective data that physicians use to make clinical judgments about a particular patient.
According to Edmund Pellegrino, disease is an ‘ontological assault’ on the body, disrupting a very familiar pattern of life the sufferer lived previously. A person’s daily routine may be breached with the onset of a disease. Double vision or shortness of breath may appear out of nowhere and do not go unnoticed by the sufferer. These are symptoms that may point to a far more serious problem. Pellegrino elaborates further:

When a person becomes ‘ill’, he is therefore in an exceptionally vulnerable state, one which severely compromises his customary human freedoms to use his body for transbodily purposes, to make his own decisions, to act for himself, and to accept or reject the services of others. The state of being ill is therefore a state of ‘wounded humanity’, of a person compromised in his fundamental capacity to deal with his vulnerability.

Illness is a subjective experience of a body fallen into disrepair. Sufferers solicit the help of a physician to reinterpret these symptoms into a disease. H. Tristram Engelhardt observes that a diagnosis is a social label, signifying that the patient has fallen short of a norm of health. Heart disease, cancer, stroke, and pneumonia are only a few constituents of the colossus of maladies identifiable by medical authorities. The patient sees a physician hoping that she can be healed in some way. Assigning a name to the illness is a clinical judgment that orients the patient in the direction of a curative process, a process commencing under the tutelage of a physician.

It often seems that in a clinical encounter, the physician is in pursuit of a cure for a disease, omitting any consideration of the patient’s concerns or fears. Eric Cassell observes that the notion of ‘anecdotal medicine’ or, the patient engaged in a conversation about her experience of an illness is rendered a subjective tampering of science. Stories of illness are discounted because of their subjectivity and fallibility. As Elaine Scarry points out, pain cannot be confirmed by the one who is listening, nor can it be denied by the sufferer who speaks of it. The experience of having a cancerous lung, to the sufferer, has a multiplicity of interpretations. To the physician, it always looks like a cloudy mass in the chest x-ray.

How can the clinical encounter between a patient and physician be successful if the medical parlance of the latter is not translated into terms the former can understand? Can something be done about the fissure between the medico-scientific knowledge the physician possesses by virtue of his craft, and the phenomenological experiences of aches, pains, and anguish the patient endures by virtue of being sick? The physician is epistemically privileged in the profession of medicine, but should the patient be disadvantaged as a result? Can clinical judgments be the culmination of a
bilateral agreement between patient and physician when the former is, in many ways, uneducated in medicine? I maintain that one aspect of healing is a mutual understanding between the patient and the physician. In helping patients recover, the physician should not apply the same curative formula to every patient, even if all the patients suffer from the same disease. If an essential element of healing is this understanding, the physician should hone his interpersonal skills by getting to know each patient by their name, and not by her respective disease. I do grant that some patients prefer their physicians to simply be technicians. A patient may not want to discuss her conception of the ‘meaning of life’ with her physician. There are patients who do not want their physicians to be conversational companions through the healing process. I argue that the clinical encounter I am delineating is for patients who do wish to have a meaningful dialogue with their physicians.

I also concede that the patient-physician dyad may be an outdated model. I must take into consideration that the clinical encounter may have more than a patient and physician as its *dramatis personae*. This dyad is modeled after primary care physicians and general practitioners who are the first physicians an ill person visits. In the era of for-profit health care and medical specialization, a patient-physician dyad may seem quaint and perhaps no longer useful. However, I believe that the model is still instructive. Even though there are specialists who examine only one part of the body and nurse practitioners who have increasingly replaced physicians for basic medical examinations, there is still a physician on one side of the desk, and a patient on the other. This is the relationship I wish to explore.

Illness magnifies the patient’s experience of loss of control. Acts such as breathing or getting out of bed in the morning can become toilsome tasks. An illness compromises the patient’s sense of self, her being-in-the-world. How a patient agonises over her illness is exacerbated if her relationship with her physician has soured or was never agreeable from the beginning. I am not suggesting that the patient and the physician have to be enduring friends. But, a physician who exhibits only ‘detached concern’ for his patients neglects the enormity of the patient’s illness experience. On the other hand, a physician cannot be so empathically attuned to the patient’s experience that he is emotionally incapacitated and unable to continue care.

Arthur Kleinman has written extensively about illness narratives. Kleinman, a medical doctor, has lamented the traditional approach to the clinical encounter that most physicians adopt. There is more to the patient than simply taking down her medical history and asking where it hurts. Kleinman has christened his approach the ‘Alternative Therapeutic Approach’. Kleinman recommends this approach because of two goals he has in mind for a successful healing relationship:
1) the empathic witnessing of the existential experience of suffering
2) the practical coping with a major psychosocial crisis that constitutes the menacing chronicity of that experience.

There is nothing facile about ‘empathic witnessing’. Many assume that a person can be empathic only if she has been through a similar experience of illness. With this interpretation, a physician could perhaps have a vicarious experience of an illness through the patient’s narrative, but he could never be an empathic witness. I believe this interpretation is mistaken. I believe Kleinman to be arguing along with myself that empathy is an imaginative identification with another person’s subjective state. This is not to behoove the physician to become the patient as an actor becomes Hamlet or Othello. Rather, being an empathic witness enjoins the physician to be able to identify with the sudden fragmentation of a person’s being-in-the-world after an illness strikes. The physician witnesses the patient describe the loss of normalcy that comes with her illness. As the physician witnesses the patient search for meaning that has been stripped away by illness, he can participate in the patient’s feelings and ideas of which she speaks. This witnessing transcends medical terminology, microscopy and magnetic resonance imagery. Empathic witnessing also permits the patient to cope with her situation because she can trust that her physician is listening and not merely showing ‘detached concern’ for her. The physician can keep some aesthetic distance from his patient to preclude becoming too emotionally invested and committed to his patient. However, he must never chart too vast a clinical distance between himself and his patient lest empathic witnessing become nothing more than an empty philosophical concept.

The alternative approach is important to Kleinman for he claims that the role of the physician is to assist the chronically ill and those around them to come to terms with the personal significance that is concomitant with any illness. This approach, according to Kleinman, will allow a patient to accept, master, and change the calamities that have befallen her. Kleinman believes that this approach can empower the patient. The patient-physician relationship is an inveterately asymmetrical relationship. It is a relationship based on trust - the patient visits the physician when she falls ill, hoping that the physician can heal her since she cannot heal herself. The patient will always be at an epistemic disadvantage the same way that a parent is in a privileged position next to her son, and a lawyer privileged next to her client. This does not mean that a patient is prevented from being a dialogical equal. Medical knowledge may entitle the physician to have the balance of power in this fiduciary relationship, but this epistemic power should not be abused for the sake of ‘therapeutic privilege’ or any other form of paternalism. The purpose of this alternative approach is to not only enlarge respect for patient
self-determination, but also to allow the patient a more active role in her own care instead of being the passive receptacle of medicinal therapy. According to Kleinman, this approach affords the patient an opportunity to reconsider her illness as no longer a ‘wild natural experience’, but instead as a ‘controlled cultural experience’.

Edmund Pellegrino has also written about the patient-physician dyad. The patient’s initial goal is to be healed by the physician, and if that is not possible, the physician can at least offer palliative care. The end of medicine, according to Pellegrino, is a ‘technically right and good healing action’. It is an action that must be taken in the interests of a particular patient, and not an abstracted ‘reasonable patient’. A technically right action still entails a physician ordering an MRI or a biopsy of the lung. The physician then applies this medical data while taking the gender, race, socioeconomic, and cultural particularities of each patient into account. Medicine has appropriated its own scientific and objective data. This is the ‘technically right’ part of the action. According to Pellegrino, what makes it a good healing action is contextualizing the technical application to each individual patient. As Richard Zaner observes, a physician must ‘never lose sight of the person being diagnosed and treated, nor the patient’s narrative expressing the experience and its meaning’.

For a physician to determine what is right and good for this patient, he will have to bridge the gap between the objective scientific knowledge in which he is trained, and the subjectivity of each patient with whom he is confronted. Stephen Toulmin points out that obtaining a medical history demands more than just the age and race of the patient. A genuine medical history is ‘the chronicle of an individual human life considered and digested with selective attention to the episodes significant for current treatment’. The objective knowledge of the physician is generalised and compartmentalised into tidy medical categories, which attain significance when applied to patients. More is needed. Tidy medical categories have no opening for an understanding of how a particular patient ought to live her life or how she ought to be treated. A patient will most likely have her own ideas about what constitutes a good life. One patient’s conception may entail a long life at any cost. Another patient’s conception may entail a peaceful death. While the patient is the beneficiary of the physician’s care, his care must respond to the way she wishes to live her life. A physician should not delegate all medical decision-making to himself even though he is epistemically privileged in the relationship. In my view, it is incumbent on the patient to be honest and open about herself to the physician, so they can pursue the best course of treatment together. Noncompliant patients may have their reasons for being noncompliant, but dishonest and disingenuous patients seemingly have no veritable interest in their own healing. Patients guilty of ‘doctor shopping’ for unlimited prescription drugs may sadly fall
into this category. Patients who expect all physicians to pursue homeopathic or natural therapies cannot expect a good healing relationship either.

It is not only physicians who shoulder the burden of the healing relationship, nor should it be. Patients have concealed their smoking from their cardiologists. Patients with diabetes have concealed their sugar addictions from their endocrinologists. Patients often forget to take their medicine. Sometimes they simply refuse to take their medicine. The veracity of patient narratives can often fall under suspicion. As critical as illness narratives are to the clinical encounter, self-deception and dishonesty may prevail at times. Kleinman anticipates this possibility when he points out that:

\[\text{R}\text{etrospective narratization can readily be shown to distort the actual happenings (the history) of the illness experience, since its \textit{raison d\text{'}etre} is not fidelity to the historical circumstances but rather significance and validity to the creation of a life story.}\]

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In order to make a coherent and orderly narrative, the patient may not be true to her story. The process of ‘emplotment’, making the story a comprehensible sequence of events leading up to her clinical visit, may require some embellishment. A patient seeks to find meaning in her illness, but perhaps only finds meaning if she strays from the actual sequence of events that comprise her untold narrative. This is a stern warning to a narrative approach to clinical encounters. A patient may choose style over substance to allow for her illness experience to be significant instead of trifling. She may erroneously order her past for the sake of coherence the same way she may lie to her physician about the number of alcoholic drinks she consumes for the sake of expediency. This does not mean that patient narratives are superfluous testimonies. However, this does mean that for the healing relationship to occur, it is incumbent upon the patient to be honest with her physician and herself. But this onus on the patient is not as great as the one that falls on the physician.

The physician does need to be attentive to the values of his patient, even if those values are a counterpoise to his own. Edmund Pellegrino and David Thomasma claim that any clinical judgments should be dictated by the ‘therapeutic necessity’ of the clinical encounter.14 This means that every person who sits before a physician does so because she can no longer manage the discomfort brought about by disease. People seek medical counsel for similar reasons, but the subsequent therapy and treatment are not uniform among all patients. The scientific privilege of medicine compels many physicians to believe the same treatment will yield the same results. Medical knowledge and its domain prescribe what ought to be done with all patients who are placed in the same diagnostic category. The values and life projects
of each patient are not outside the parameters of the clinical encounter. Therapy, according to Pellegrino and Thomasma, depends on the ‘biography of the lived self,’ which requires a dialogue between the patient and the physician to negotiate corresponding interests.\textsuperscript{15}

Margaret Urban Walker has observed in a slightly different context that a moral conversation that pays close attention to the history or narrative of each patient can culminate in a ‘passage’ in the clinical dialogue.\textsuperscript{16} Achieving a passage in a clinical encounter means that both patient and physician have reached an understanding of each other: who they are and where they are coming from. The patient and the physician have reached a passage (or understanding) because they have duly communicated their respective values to each other. I am not implying that every patient and physician should know each other’s entire life story. However, knowing where the patient and the physician stand on relevant moral issues is essential for a working relationship. Attaining an understanding in the dialogue is in effect a transition from the point when the dialogue began between two strangers. An understanding can be the product of, in James Lindemann Nelson’s words, ‘shared cooperative activity’, which is an activity between the patient and physician that is mutually responsive and supportive.\textsuperscript{17} Both the patient and physician stand to gain immensely from cooperation.

Responsibility is not one-sided in the clinical encounter. While the physician is responsible for the care of his patient, the latter, if she is considered to be a moral agent, has responsibilities too. The patient cannot place herself in a ‘sick role’ and excuse herself from the responsibilities she has to her physician. If a patient wishes to act for herself, she is not morally immune. Her actions may affect others. All information about herself that is relevant should be shared with her physician, even if it is embarrassing. A patient can just as easily expose a physician to risks. If the patient and physician do not have a thriving relationship between them, it might be prudent to mutually terminate the relationship. A physician should not be required to work alongside a patient who makes impracticable demands on him. A patient should not be required to stay with a physician who is heedless and undemonstrative of the care and compassion she needs.

The project of sketching a healing relationship reminds us of a familiar problem - the problem of a patient trying to take an active role in her pursuit of health. This is a bid to determine whether the patient-physician relationship can be refined at all. A real clinical encounter does not necessarily involve just the patient and the physician. Other parties are included in this encounter such as family, friends, nurses, and even insurance companies. However, the patient-physician relationship is an essential model of healing since it is the most immediate of all clinical relationships. It is a relationship between a patient who is sick and a physician who professes to heal. It is not the only clinical relationship, yet it is a fundamental one.
Is this clinical encounter that I have sketched just a philosophical figment or a bit of intellectual sleight-of-hand that has no basis in the real world? The quest for a good healing relationship may come up empty-handed at times. This is no reason to maintain the status quo. I do not want to relinquish the quest for an understanding between patient and physician. It is certainly a quest that may not be accomplished in every encounter, but it is still a goal for which both sides ought to aim. The recommendations that philosophy can offer are intended to improve, not perfect, clinical encounters. The principal advisory is that communication must be bridged between the patient and physician, not silence. Many clinical encounters resemble a Tower of Babel where the patient and physician are speaking languages that neither can understand. No relationship can succeed in this fashion. There will always be some impassable barriers that both patient and physician erect between themselves. All the advice in the world cannot encourage every person to both speak and listen. Nonetheless, it is a suggestion, and a very good one. It is advice that patients and physicians can choose to disregard. However, unless they wish to remain strangers in the same room, they should heed the advice.

Notes

1 Tolstoy, 1972, 145-5.
2 Pellegrino, 1977, 44.
3 Ibid., 45.
6 Scarry, 1979, 4.
7 Kleinman, 1988, 10.
8 Ibid., 43.
9 Ibid., 49.
10 Pellegrino, 1978, 164.
12 Toulmin, 1977, 40.
13 Kleinman, 1988, 51.
14 Pellegrino and Thomasma, 1982, 113.
15 Ibid., 113.
16 Walker, 1993, 35.
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PART II

Bodies and Embodiment
The Fit of Health: Embodied Health Ideals and Its Implications

Naomi Adelson

Abstract
Health is never simply the expression of the condition of one’s body. Rather it is a fundamental expression of how we define ourselves as social, cultural and political beings. Why, for example, is health so often equated with a particular sense of individual fitness, control and youth in urban, industrialized societies and how is that linked to a particular rationalization of the human body? I explore these valuations of health and contrast them with an alternative model of well-being. In the Aboriginal Canadian context health is centred less on an individual’s level of fitness or wellness and more on the relationship between the individual and his/her social, cultural and environmental networks. Without idealizing either health ideal, I address how notions of ‘health’ reflect larger cultural metaphors and how those metaphors are embodied and hence naturalized and normalized. Moving from the study of health as regulative towards a critical analysis of health as the embodiment of cultural norms, I draw from these two ideal types in order to highlight the ways in which health is constituted as normal and natural. These idealised, embodied expressions of health however can also impede communication of health knowledge(s) across cultural, social and political divides.

Key Words: Medical anthropology, health, health metaphors, First Nations, Cree (Canada).

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1. Introduction
From: Leeat
Sent: Monday, March 7, 2005 2:36 pm
Subject: My Epiphany for Today

I just joined the [downtown health club] as my new gym and the people there keep insisting - I mean insisting - that I take the ‘fitness test’. It doesn’t cost anything (well, it doesn’t cost any money anyway), it’s not about making more money on my membership, but there is this pressure to take the test (because they have the technology, you see) so that they could see how ‘fit’ I am and what percentage of body fat I have and what the density of my bones and muscles are and on and on and on. And I really don’t want
them to do this. I really, really, really don’t want to do this and I keep telling them that I’m happy with my body (which they don’t believe), that I know that I am healthy and fit and don’t need to measure anything to prove it.

And, as I was being harassed about this, it occurred to me that this one teeny example is a reflection of the larger culture which insists on women objectifying their bodies in the name of ‘health’ and of ‘science’. I mean literally demanding that women take an objectifying view of their own bodies by commodifying it in these numerical measurements so that they could presumably become more ‘healthy’. It’s just so crazy that their definition of health is obsession and neurosis over disciplining and controlling one’s body.

In medical anthropology, as in so many of the social sciences, we explore the ways in which ‘normal’, ‘natural’ entities - like our bodies or our ideas about health and illness - are drawn from and reflect our relationship to our social, cultural and political worlds. We critically examine the taken-for-grantedness of our ‘western’ assumptions about the dominance of biomedicine and its Cartesian and reductionist mode of analysis (i.e. the primacy of the biological body reduced to the microscopic, and now genomic, level in the quest for disease and cure). As Byron Good writes,

It is difficult to avoid a strong conviction that our own system of knowledge reflects the natural order, that it is a progressive system that has emerged through the cumulative results of experimental efforts, and that our own biological categories are natural and ‘descriptive’ rather than essentially cultural and ‘classificatory’.1

Thus while a highly successful model in many ways, the biomedical model emerged and grows with its own particular history, hagiography, political manoeuvrings, and cultural embedded-ness. That model similarly informs, and has been informed by, the notion of the body as object, as separate not only from mind but from the rest of society, and as an interchangeable conglomeration of bits and pieces.

The email communication which opens this chapter comes from one of my graduate students who wrote to me these reflections on and frustrations with her new gym. In the process of describing her experience of being objectified and commodified, she is able to express in vivid terms the ways in which health translates as a body that is both in control and yet also
controlled and disciplined in the urban, western context. These reflections bring to mind the works of Deborah Lupton, Robert Crawford, and the influence of Foucault’s post-structuralism on their studies of the embodiment of health ideals. A few years ago, Simon Williams expanded upon the relationship between bodies, health and control by introducing the importance of moral performance to the mix. The pursuit of health, wrote Williams, ‘is an embodied practice and moral performance in which bodies, literally and metaphorically, become ‘viable’ - i.e. socially and culturally legitimated, materially shaped and practically ‘enmattered’…. Health, he continues ‘…is not simply something one has, or is. Rather, it comprises a reiterative set of practices and ritualized performances by which one literally and metaphorically, materially and culturally, socially and morally, become ‘viable’ at all.’ In other words, health is the accumulative expression of how we ‘matter’ in our social worlds.

2. The ‘Fit’ of Health? A Cross-Cultural Comparison

Focussing his work on the push and pull between corporeal desire and social/moral order, Williams raises the question of holism and holistic health as increasingly more (seemingly) transgressive health practices spread though the middle class of urban centres in a sometimes uncertain balance between desire and order. The ‘fit’ of health, for Williams, is a negotiated balance between cultural ideals of transgression and control (and sometimes both at the same time).

Excluded from Williams’ discussion, however, is any explicit acknowledgement of how some reiterative practices and ritualized performances ‘matter’ more than others. A particular power dynamic, for example, explains why my student felt obliged to ‘take control’ of her body/health through disciplinary acts of measurement and regulated acts of ‘fitness’ at the gym (or, more specifically, how she railed against the system that demanded that she do so). That fit - the predominantly western-oriented and biomedically influenced model of a healthy ‘body’ - reflected in the initial excerpt I read, is linked to a model of health that is based upon western ideals of the individual, of efficiency, of success, all filtered through the authority of the biomedical paradigm (which is also referenced at one’s local gym by the technologically sophisticated measurement paraphernalia).

Taking a critical cross-cultural perspective, I see not only the cultural specificity of the ‘western’ biomedically informed model of health but also a power imbalance when that model is used as a gauge for health on differently ‘encultured’ bodies. As much as my student was (rightly) offended by the degree of persistence exhibited by the gym workers, she is still reacting from within an individualistic sensibility regarding ownership (a new way to define ‘corporate’ management?) and her degree of ‘fit’ with the prevailing conceptualization of body health. What happens, though, if we
shift the discussion from the embodied health metaphors of control and release to other body metaphors of health?

Much of my own research has been done with the Cree of northern Quebec and, in particular, with a small community of about 600 who lives at the mouth of the Great Whale River as it pours into the Hudson Bay. My initial work with this community allowed me to explore their ideas and ideals of health. Let me begin with a brief review of Cree health ideas and ideals.

For this particular community, and more generally, for the Cree of northern Quebec, health is intimately tied as much to their social and cultural worlds as it is to their physical locale and their political ability. I am not presuming any sort of idyllic scenario here nor do I want to falsely reduce this argument to one between the individual body in the ‘Western’, biomedically-mediated body in health versus the socially-mediated body in health for the Cree. Having said that though, it’s also fair to say that the Cree people do talk about their own health and health ideals as something that links them to their hunting traditions and to their integrated sense of self and community. For example, for this hunting and trapping population (caribou, beaver, goose), hunting and all bush-related activities including camp preparations, protection from the cold, a keen awareness of the environment (both topography and the food or medicinal value of the plants and animals), and the physical exertion of bush living are all part and parcel of health for the Cree. Further, the proper hunting, handling and eating of bush foods are all intimately associated with this expanded notion of ‘health’ for this hunting people. For example, if one’s gun or traps are not in proper working order, if the camp is improperly maintained, if the animal is not skinned or butchered with respect, or if the food is not distributed appropriately according to age and gender, then the animal’s spirit will not allow the success of future hunts. Similarly, if the land is not properly maintained in order for the animals to live well, a Cree person cannot be healthy. Health is thus associated with a range of good and proper beliefs and practices that are the culmination of inter-personal (social, kin), spiritual (animistic as well as Christianity), cultural and political relations. There is no distinction made between individual bodies, the social body, spirit, or land in the valuation of what constitutes the ideally healthy person. A man or woman cannot, by definition, be healthy outside of this larger network. It should come as no surprise then, that there is no word that translates back into English as ‘health’ in the Cree language. *Miyupimaatisiun* (‘being alive well’) is the closest equivalent but the word evokes this larger web of relations necessary to Cree ‘health’. In fact, at the time that I was originally working on this project, the Quebec Cree nation was fighting against the construction of a massive hydro-electric project. Health for any individual Cree was inextricably bound to the health of the land. As one Cree elder explained to me:
If the hydro project cannot be stopped, considering the damage and the loss that will be done to the land, this will also speed up the loss of the Iyiyuu/Cree way of life, therefore, the Iyiyuu will not be *miyupimaatisiiu*, in essence, the factors that enabled the Iyiyuu to be *miyupimaatisiiu* will be destroyed and lost for them.  

3. **Discussion - Encountering Differences and the Lack of ‘Fit’**

Returning for a moment to Williams’ examination of the relationship between holism and health, I can’t help but contemplate a hypothetical encounter between a Cree patient and a non-Native health worker as I struggle with Williams’ ultimately unsatisfactory (to me) assessment of contemporary urban, western health ideals. Williams is right in his analysis regarding the ways in which so-called ‘transgressive’ health practices are being used today. My frustration is with the potential implications of the naïve assumptions made by the ‘transgressors’ as they may integrate bits and pieces of alternative health therapies.

Imagine this scenario: a well-meaning health care worker at a remote northern or urban First Nations clinic is delighted by her new-found knowledge of traditional healing, sweat lodges, and herbal therapeutics and sees these practices as wholly connected to health maintenance. A First Nations individual comes for help. With no particular knowledge of community dynamics, of available resources or the individual’s particular beliefs, the non-Native health care worker casually suggests that the First Nations person go to seek help from one of the community healers before embarking on the biomedical route. In this instance, I am not referring to a clinic that has already integrated various forms of therapeutics into their treatment programs (this is growing in First Nations Canada, United States, New Zealand) but rather a medical clinic that is the only local source of biomedical assistance in the community. Also, I am imagining the health care worker as one of Williams’ ‘new more sensual, emotionally informed seekers of ‘the authentic’ and ‘the sacred’’. An assumption made by the health care worker is that the individual coming to their door is not fully realizing their own cultural potential. Why would one not go, after all, to the shaman, if one is available? This is, to be sure, a hypothetical exchange but does point to many commonly held assumptions about the way in which Native people are viewed as somehow more ‘natural’ and hence more ‘authentic’. There is also a power differential that permeates the encounter as it takes place within the sphere of the clinic. Biomedicine as a profoundly powerful set of beliefs and practices - and with its attendant models of health ideals - paradoxically informs the way in which the health care worker can make presumptions about how this Native person should ‘think’. What could be more ‘normal’ or ‘natural’, after all, than a Native person attending to their health through
Indigenous practice? My point here is not about how First Nations individuals attend to their health but rather the way in which their health practices are idealized as more ‘natural’ or more ‘authentic’ and how the clinic encounter highlights the authority that the health care worker can assert in making these sorts of (primitivist) judgments. Indeed, what if the Native person came to get a prescription filled so that s/he could head off to the family’s bush camp for the next 2 months (realizing that ‘health’ has more to do with checking trap lines and bush living and less to do with any particular bodily ailment, although s/he knows that the prescribed high blood pressure medication needs to be taken daily, even in the bush)?

Let’s continue with this hypothetical encounter. Now, the First Nations person informs the health care worker that s/he is at the clinic to have their blood sugar level tested. The health care worker notes that the person is considerably overweight. The health care worker begins to ask questions about what the person is eating, how much exercise they are getting and, would the person want to have their weight checked (recall now my student’s encounter at the urban, downtown gym). The First Nations individual becomes uneasy and feeling put upon as the blood test normally takes only a few minutes and s/he has had no food since last night and needs to stop for a quick breakfast before work. The health care worker persists. Regardless of all of the successes and gains made in First Nations/non-Native relations in Canada, there remain remnants of the protracted history of colonialism in spaces such as the clinic. Add to this the usual weight of biomedical authority within the clinic space. The First Nations person acquiesces - quietly annoyed by the invasive quality of the encounter - yet feeling powerless under these doubly burdened conditions.

When the health care worker further suggests that the individual think about what they are eating and how often, the First Nations person, in turn, thinks about the exorbitant cost of fruits and vegetables in the north, about the different diet that would be required compared to the rest of the family, about how that diet doesn’t make sense with respect to his/her work schedule and, ultimately, to how s/he may be teased for ‘looking white’ if s/he slimmed down too much. Studies done amongst Cree, as well as with another First Nations population in Quebec, show that there is a very different sense of what ‘healthy’ looks like for adult men and women. In the not so distant past a larger, more heavy-set person exemplified ‘health’ as the best indication of an abundant food source and respectful and proper hunting practices by both men and women (and the most highly prized food was - and remains - animal fat). That larger build now signifies more than prosperity, it is a statement of belonging. In one Quebec study of a group of young Innu men and women at risk for or already diagnosed with diabetes, to be seen eating foods that differ from one’s peers (and especially, an abundance of fruits and vegetables - foods that are not typically part of either the traditional...
or modern diet) and, more specifically, to become considerably slimmer than one’s peers meant being singled out for teasing or social ostracism.  

Health is neither neutral nor universal. Powerful metaphors of the ‘fit/ness’ of the citizen in his or her cultural and social worlds are expressed simply as ‘health’ but differ profoundly across cultural realms. Further, there are historical and particular imbalances in the valuation of cultural ideals, as we certainly know. Cultural clashes, borrowings and domination, after all, are hardly new. What is new though is the increase in options available to Indigenous people as they attempt to bring a variety of perspectives and practices into their worlds. Health for the Cree is an embodied statement of political, social, cultural and individual wellness. How that wellness is expressed however is dependent on a range of older and newer valuations of what it means to be a healthy Cree person. My worry is that we risk re-colonizing by attempting to make health perfectly ‘fit’.

Notes

1 Good, 1994, 3.
5 Quoted in Adelson, 2000, 96.
7 Lavalée, 1987; Roy, 2002.
8 Roy, 2002.

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Some Thoughts on Physicians and Metaphysicians

Iain Brassington

Abstract

Medicine, in its commonsense form, implies a metaphysical separation between the person and the body. This allows for the idea that, by altering a person’s body, it is possible to ‘save’ him from circumstance. Yet the tenability of such a standpoint is questionable: for such thinkers as Heidegger, the ‘self’ is fundamentally worldly, existentially predicated on and inseparable from apparently contingent facts and circumstances. But, if the separation of self and body is less radical than we may presume, a question is raised concerning what - if anything - this means for medicine. I shall suggest that medicine cannot liberate us from disability or illness, but that its function can be thought of as mediating the relationship between ourselves, our future selves (with which we are only be provisionally identifiable), the world, and our projects. The line I shall pursue is ethical, because it deals with our place in, and relationship with, the world: our ethos or ‘accustomed place’: the relationship between ethics and existential analysis is much closer and more dynamic than may appear to be the case at first sight. Despite this ethical dimension, I shall avoid making normative claims - with a small and tentative exception.

Key Words: Self, body, Heidegger, project, therapy, Nietzsche.

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1. Self and Body

I want to look at what is going on when we try to make sense of health, illness, disease, or anything else. I want to say that x informs our understanding of ourselves and that this self-understanding cannot help but feed back on our understanding of that x, which feeds back on self-understanding… and so on.

Deborah Lupton suggests that ‘contemporary western culture is based upon… the philosopher assumption that the mind is separate from the body’ and that ‘[t]hese tenets pervade biomedicine’.1 I am not sure that this is entirely true of all medicine: the wide acceptance and use of brain-based treatments for at least some psychiatric conditions surely militates against the claim. But if one interprets her separation of the mind from the body as a way of talking about a different separation - a broadly Cartesian separation of the self from the body - she seems to have a point. Intuitively, such a separation means that an attempt to make sense of health, illness and disease is - or can
be - logically distinct from an attempt to make sense of ourselves. But this intuition is one that I hope to disrupt in this chapter.

But perhaps I am getting ahead of myself. I want to begin with Descartes’ account of his relationship with the world around him - I shall take this to include the body, since, for him, the body is just as ontologically alien as is the rest of the world. Sitting by his fire, Descartes can doubt the world and the body, but not himself, and concludes that he knows about each differently. But if his knowledge of each is radically different, the two cannot be fundamentally the same thing. Hence he is not reducible to his body; he draws what is sometimes called an epistemologically real distinction between the two. This is an account that feels natural to us. Introspection seems to suggest that I am separate from my body and my circumstances. I have a body, but, at the same time, I cannot help but to feel that the person that I am is essentially different from the body; even the grammar that we use when we say that a person has a body is that of possession, not identity. I do not have to provide a positive account of what a word like ‘I’ indicates - if it indicates anything; it is enough that I seem to know what it does not indicate.

2. Medical Dualism

This dualism informs a number of claims that we might make about medical practice and the objects of its concern. Morally, a plausible line of thought would seem to hold that medicine in its broadest sense need not be thought of as being all that concerned by the body per se. This is not to deny the obvious point that medicine is clearly concerned with the body: it spends time and money on the repair of broken or malfunctioning bodies, on the minimisation of suffering when repair is not possible, on the prevention of damage, and on research. All the same, the body is only the object of proximate concern, and we treat it (and treat it well) because we care about the person, not because we care about the body in its own right; and if the body is something that we may alter, it is something that we may alter (or, in the case of children, it is perhaps something that we ought to alter) for the sake of the person. Medicine’s concern with the body is instrumental. Correlatively, the permissibility of bodily manipulation is limited by considerations that pertain not to the body but to the person (and here we may think of Kant’s insistence that it is impermissible to allow oneself to be treated as a punch bag in return for beer and his suggestion that selling one’s own hair ‘is not altogether free of blame’; his concern is not with the body, but with the person therein).

As far as the translation of these lines of thought into medical practice is concerned, the prevailing wisdom is that, while the fact that the body is in poor plight does provide a reason for medical intervention, this reason is neither sufficient nor necessary. The insufficiency of the reason means that a competently-made refusal of even life-saving treatment ought to
be respected. The lack of necessity means that a procedure such as cosmetic surgery or, more controversially, the amputation of a limb from a person with some sort of body dysmorphia, neither of which is biologically indicated, might be seriously considered permissible and worthwhile. (We might think that cosmetic surgery is psychologically indicated - for example, a person may genuinely be suffering because of unhappiness about his or her appearance - but this point merely plays into the point that I have made that, *ceteris paribus*, the body, *qua* body, is generally seen as malleable and of secondary importance at most.)

Metaphysically, the claim is that there is a sense in which I am essentially different from and therefore insulated from the body and other aspects of the world around me. It is possible for there to be all manner of changes happening in the world, instigated by us, germs, the pernicious effects of gravity, or whatever, but none of them has to be thought of as implying any deep alteration of *me*. As everyday Cartesians, it comes naturally to us to think that, though we are close to our bodies, and only slightly less close to the rest of the world around us, we are still sufficiently far from them to mean that when I break my leg, I do not thereby break *myself*. More generically, we tend to think that the circumstances in which a person finds himself are just that - things that surround him without permeating him.

Yet, allowing that we do draw a serious moral and metaphysical distinction between the self and the body, and that something like this distinction can be detected throughout biomedicine, what if that way of thinking is *false*? What would such a conclusion mean for the way that we ought to think about ourselves - and thereby, what we need to bring to the table when we are trying to make sense of health, illness or disease? And what would it mean for practice?

Recent contributions to the understanding of the body and the embodied self, to a greater or lesser extent, owe a debt to Martin Heidegger, and it is his thought, especially as expressed in his earlier work, on which I shall concentrate as I attempt to sketch a response to these problems.

**3. Existence, Ek-sistence and Medicine**

Heidegger’s response to Cartesianism changes throughout his career, but is never anything other than a rejection. In *Being and Time*, Heidegger replaces the *cogito* with Dasein; Dasein is ‘an entity which in each case I myself am’ and is distinguished from other entities ‘by the fact that, in its very Being, that Being is an issue for it’. (Note, though, that Dasein is not to be equated with the self; Dasein is what the self is, rather as a feline is not a tiger, but it is what a tiger is.) Though ‘Dasein’ is not a Heideggerian neologism, what is done with the idea is new. Henceforward, the word is to be taken at face value. ‘Da-Sein’ means ‘Being-there’; as far as Heidegger is
concerned, Dasein is not a being in its own right, separate from the world around it.

The manner in which Heidegger distances himself from Descartes is made clear around half way through *Being and Time*, at which point he asserts that it is the ‘I am’ rather than the ‘I think’ in the Cartesian *cogito, ergo sum* that has priority:

If the ‘*cogito sum*’ is to serve as the point of departure for the existential analytic of Dasein, then it needs to be turned around, and furthermore its analytic content needs new ontologico-phenomenal confirmation. The ‘*sum*’ is then asserted first, and indeed in the sense that ‘I am in a world’…

The phrase ‘I am’, extrapolated to ‘I am in a world’ is of vital importance, indicating as it does that the very possibility of my being depends on the world. By the time of the *Letter on ‘Humanism’*, and prefigured in such essays as *On the Essence of Ground*, the position has moved further away from Descartes; here, ‘existence’ has taken the sense of ‘ek-sistence’. The explanation of this shift, which is of more than lexicographical interest, is that ‘existence’, understood conventionally, implies that Dasein could be taken from the world in the same sense that the rabbit can be taken from the hat - that is, just because it was never in the hat in the first place, so much as surrounded by hat-stuff. By contrast, ‘existence’ understood as ‘ek-sistence’ rams home the point that Dasein’s being is mediated by the world around it. Dasein is ‘ahead-of-itself-in-already-being-in-a-world’, and is in-the-world in the most fundamental sense: the rabbit is woven into the hat, and, as such, it stays put. There is no self without circumstances - no self, that is, without ‘facticity’; henceforward, I shall use the term ‘ek-sistence’ rather than ‘existence’ to keep this point clear.

In this flurry of activity, we should not forget the claim that Dasein is an entity for which its own Being is an issue. Put less floridly, this simply means that Dasein is that entity which asks questions about itself and the mode of being of which is at least partially constituted by its understanding of itself. However, inasmuch as Dasein ek-sists, this means that its self-understanding has to be contextualised by its understanding of the world in which it is. Thus ‘Dasein itself - and this means also its being-in-the-world - gets its ontological understanding of itself in the first instance from those entities which it itself is not but which it encounters ‘within’ its world, and from the Being which they possess.’

It is on this basis that we can begin to move back towards an attempt to make sense of health, illness and disease.
Each of us has the most intimate of relationships with the world around us; we owe ourselves to the world in which we find ourselves. Note, though, that the world in which Dasein ek-sists is one that is formed from things like hammers or music (rather than undetached hammer parts or sound waves) - and from illness, which is no less something that we encounter than is anything else, and is 'ontologically prior' to disease. With this sort of consideration in mind, I want to suggest that illness contributes significantly more to Dasein’s being and self-understanding than does health, and does so simply because being healthy is experientially null - after all, as Schopenhauer noted, just as we never notice shoes except for when they pinch, we never notice having a head except for when we have a migraine (or a hangover). Similarly, we only notice the hammer when it is absent in the context of some project that we have; when it is there, we can reach for it without noticing it. But we need (a) a project, and (b) absence really to get to grips with hammers. What I am proposing, then, is an account of health in which health obtrudes into our world and is an object of thought or scrutiny only when we want it and have want of it. And this intrusive absence, which gets called 'illness' or something of the like, is what we notice. Illness features in the world in which we ek-sist in a way that wellness simply does not.

How, then, ought we to think of medicine and its aims? If Heidegger’s thought - or something at least tolerably similar to it - is correct about our relationship with the world around us (and even that choice of words is not without its problems), it would seem that we are forced to concede two points. The first is that, inasmuch as something like illness constitutes a part of the world from which the Dasein that I am draws itself, it is de facto constitutive of the self that I am at any given moment. Illness is not something that happens to me: it is something that is formative of me at this moment. A change in the world, though, means a change in the Dasein that I am. A disease, illness, or injury does not interrupt the biographical trajectory along which I might be tempted to see myself as travelling: it alters the trajectory, right enough, but it therefore also alters me, qua being with those possibilities, because the trajectory that ‘I’ follow is essential to the Dasein that I am.

The second point that we have to concede capitalises on this line of thought, and is that, when we say that something like an illness or a medical intervention does not change a person essentially, we are correct, but for the wrong reasons: if a change in a person’s circumstance does not change that person essentially, this is only because there is nothing (or no thing) there to change. A person’s present self is determined by the world in which he presently ek-sists; his future self is, at any given moment, simply a matter of possibilities determined by the world’s possible future. By the same token,
any alteration in the world will have a corresponding influence on the person that I will be.

In respect of what this means for medical practice, we end up having to rethink what it is we are doing when we intervene. In the commonsense account, in curing someone of a condition we are thereby ‘liberating’ them from that condition or a future in which they have that condition - John Harris, for one, has claimed that medical research offers a chance to ‘liberate’ ourselves from illness.16 But such an account is false, and the idea that we might intervene medically for the sake of a person with a determinate future ‘proper’ to him is unsustainable: medical intervention - or other forms of intervention such as social work, for that matter - means, at most, intervention on behalf of a particular possible future. In intervening, we express a preference for a particular kind of future person, rather than for a kind of future with this person in it. Therefore the very idea of soteriological medicine is a non-starter. Even if people believe that they are freeing their future selves from this or that, or that this is what medicine is for, their belief is false. Yet we might well ask whether, if medicine is not about freeing a person from a condition (or freeing him from the constraints of a condition, or something along those lines), it is possible to give a more substantial account of what it is for.

4. Preference and Therapy

Health is notable by its absence, but to the extent that its absence obtrudes only when we have want of health, its absence is made clear to us through the focus of a project that I might have. Thus, if my project is, say, mountaineering, those factors that prevent me from mountaineering will become particularly apparent to me; without the project, they would not have done so. It goes without saying that some - or many - of these factors will not merit the term ‘illness’ or its cognates (it might be sloth that stops me nimbly hopping up the slopes of Kilimanjaro); some, though, will. Other projects can be fairly trivial, but many illnesses interfere with even the most trivial projects - those that we don’t really count as projects - and this is precisely why they intrude on our lives with such persistence. We can decide to give up mountaineering, and when we have done so, the leg injury recedes into the background except on those occasions when we are put in mind of mountaineering; but it is much trickier to decide to give up a more modest project such as independent living. Even being alive in the future is a project, in the sense of pro-ject, even though itis not one that we tend to choose so much as accept (and there is no reason why projects should have to be consciously chosen); still it is this project that makes the possibility of death reveal itself fully to us.

Medicine, I think, can be thought of as clearing the way for the fulfilment of a certain project - but might also be to reconcile the patient to
the loss of some possibilities and projects. The difference is that between cure and therapy. My lead comes from Aristotle, who claims that

'[i]t is not the function of medicine to produce health but to bring the patient to the degree of well-being that is possible; for those that cannot attain health can nevertheless be well looked after.'

In respect of medicine’s role as looking after those who cannot attain health, Aristotle uses the word *therapeusai* - which implies simple attendance as much as it does cure. Sometimes, this will mean that the role of the health care professional is medically curative in the everyday sense; sometimes, though, the professional’s role will be aimed more at reconciling a person to the possibilities that they do have, rather than those that they would like to have. Faced with a health problem, cure seeks to solve it; therapy seeks to *dissolve* it.

5. An Ethic and a Norm for Postmetaphysical Medicine

The word ‘ethics’ comes - obviously enough - from the Greek *ethos*. Spelt with an é psilon, this word means ‘custom’ or ‘habit’; in an older form, spelt with an eta, it has the sense of ‘accustomed place’; Heidegger defines ethics as being that which ‘ponders the abode of human being’. But since Dasein ek-sists and self-understanding is crucial to its being, it *has to* ponder its accustomed place in order to be Dasein; it is, in this sense, ethical (although ‘ethics’ here carries no connotation of right or wrong). The relationship between ethics and existential analysis is much more dynamic than we might at first think. Moreover - and I make no bones about the fact that this claim calls for much more work if it is to be made strong - it seems to me that we could mount an argument that an understanding of medicine that is hopeful (that is, which emphasises the ability of medicine to ‘liberate’ us from outrageous fortune) is unethical because it obscures the ethos - the ‘abode’ from which Dasein springs. Ethics demands Nietzschean *amor fati*, and, at risk of glibness, means that an eighty-year-old’s proper understanding of himself will recognise and reconcile him to the proximity of death and the likely impossibility of trampolining; such a reconciliation is what I would be tempted to call therapeutic.

This ethic does not translate easily into a matter of normativity. The overarching point that I am trying to make is nothing more than that the belief in medicine as a kind of salvation is false. But, false as the belief may be, it is also coherent, and it is apparently harmless; as such, we have little *prima facie* reason to abandon it or the faith in medicine that it feeds, or the hope to which we may feel entitled thereby. I want tentatively to go further,
though, and claim that one ought not to invest too much faith in medicine’s liberating abilities, because it is harmful after all. Hope’s concentration on medicine as a liberator encourages a quixotic attempt to get from medicine something that it cannot give, and denies us the space to get from it the therapeutic benefits that it can offer. Emphasis on medicine as offering hope for a cure preserves the concept of illness or mortality as something to be overcome. But when the illness or the death cannot be overcome, it remains as a problem - a problem compounded by the mere fact of its tenacity. Hope need not be a virtue: Nietzsche’s interpretation of the story of Pandora’s box is that ‘the Greeks considered hope the evil of evils, the actual malignant evil: it remained behind in the box of evil’.\(^{20}\) Therapy, which seeks to bring reconciliation rather than hope, avoids this evil; liberating, curative medicine perpetuates it.

And there must be something to say morally in favour of anything that avoids evils.

**Notes**

1 Lupton, 2003, 92.
2 Kant, 1979, 119.
3 Kant, 1998, Ak VI, 423. Where possible, I shall give pagination according to the Prussian Academy edition of Kant’s work; this is standard practice and allows for easier cross-referencing across editions.
5 There is, of course, an interesting set of questions to be asked about the number of cells in my body that I would have to lose, change or gain in order to stop being me. If I was to have a heart transplant, and if, *per impossibile*, my new heart came from Britney Spears, I would not become her. But, if I had enough of my own organs replaced with hers, there would seem to come a point at which it was unclear what my identity was. In a version of the sorites problem, we might ask what the point is - surely there is one - at which Iain-with-some-of-Britney’s-cells becomes Britney-with-some-of-Iain’s-cells. The example is far-fetched, but it does suggest that there might be limits to the distinction that we draw between a person and his body.
6 Heidegger, 1999, H 53. Henceforward, as with Kant, I shall try to give Heideggerian pagination according to ‘H’ numbers to ease cross-referencing across anthologies, editions and translations.
7 Ibid., H 12 (emphasis Heidegger’s).
8 Ibid., H 211.
9 ‘On the Essence of Ground’ in Heidegger, 1999b, H 37.
10 Being and Time, H 192.
11 Ibid., loc cit.
12 Ibid., H 69.
13 Ibid., H 71.
14 Ibid., H 73 ff.
15 Boorse, 1975, 56n.
16 Harris, 2005, passim.

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Beyond Biomedicalisation: Mind/Body Models of Health and Illness

Gillian Bendelow and David Menkes

Abstract
The past twenty years has seen an explosion of interest in embodiment in social science, but criticism has been levelled at the abstract nature of the conceptualisation of the body. More recently, embodiment has been linked to empirical research and to medical sociology, but the ‘emotionally expressive’ body within health and illness still remains relatively underexplored. Central to this understanding is the critique of Cartesian dualism in scientific medicine in the separation of mind and body and the creation of ‘body machines’. Social sciences and humanities associated with medicine, particularly medical sociology, philosophy/bioethics and health psychology, have shaped modern ideas about health and illness and over the course of the twentieth century formed a major challenge to the narrow philosophical grounding of biomedicine. Furthermore, illnesses of ‘late modernity’ feature multifactorial aetiologies and complex mind-body relationships which require traditional categories, formulations and management strategies to be re-evaluated; hence the turn to more holistic models of health and illness, which are now permeating medical education and practice.

Key Words: Mind/body, models of health and illness, embodiment, biomedicine, holistic health.

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1. Introduction
In the early twenty first century health and illness are multi-faceted concepts, which span a range of disciplines and have varied meanings in different societies. Since the nineteenth century we have witnessed dramatic advances in the understanding and cure of disease with, at least in ‘western’ countries, an unprecedented extension of both quality and length of life. Yet even as medical science has progressed, there has been a decline of faith in biomedicine and its dominance challenged by litigation, scandal, government regulation, lay expertise and social activism. Social sciences associated with medicine, particularly medical sociology, philosophy/bioethics and health psychology, have shaped modern ideas about health and illness and over the course of the twentieth century formed a major challenge to the narrow philosophical grounding of biomedicine. The critique of biomedicine’s emphasis on high-technology, cure and ‘body
machines’, has developed alongside the infectious diseases as ‘big killers’. Infectious diseases have largely been replaced (in the West) by degenerative illnesses such as cancer, diabetes and vascular disease, diseases associated with old age such as Alzheimer’s and Parkinson’s, and morbidity associated with lifestyle factors such as obesity. Both biomedicine and the social sciences have been challenged by these sometimes-controversial illnesses with multifactorial aetiologies and complex mind-body relationships. This has resulted in the re-evaluation of traditional categories, formulations and management strategies.

The combined impact of these factors has prompted critical developments in medical education and practice, reflected in the UK in the rise of the ‘new’ medical schools and in radical changes in the medical curriculum including an unprecedented emphasis on the social sciences and ethics. Within medicine itself there are competing models of health, with general practice and new sub-disciplines such as liaison psychiatry and behavioural medicine gaining visibility. Moreover, the raised professional and academic status of allied professions including nursing, social work and occupational therapy, together with established social science disciplines such as medical sociology and health psychology, have contributed to make health and illness studies one of the most vibrant and important theoretical and empirical arenas in modern life. The contribution of the arts and medical humanities widens the agenda further. Health awareness has become a facet of everyday living, even a ‘national obsession’ and lay perceptions and understandings (including collective enterprises such as politics and the media) play a vital role in defining concepts. Table 1 charts the paradigm shift in models of health which renders the labels of physical and mental illnesses as outdated and redundant.

<table>
<thead>
<tr>
<th>Biomedical Model</th>
<th>Integrative</th>
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<tbody>
<tr>
<td>Mechanistic</td>
<td>Holistic</td>
</tr>
<tr>
<td>Body-mind dualism/reductionism</td>
<td>Interaction between body/mind</td>
</tr>
<tr>
<td>Single fundamental cause of illness</td>
<td>Multicausality</td>
</tr>
<tr>
<td>Isolated individual</td>
<td>Socially connected individual</td>
</tr>
<tr>
<td>Curative - ‘magic bullet’</td>
<td>Preventive health maintenance</td>
</tr>
</tbody>
</table>

Integrative models may be particularly useful for examining the phenomena of Medically Unexplained Symptoms (MUD), in other words illnesses or syndromes which are not definable in terms of ‘abnormal’ organic pathology and are often perceived to be low in ‘illness hierarchy’. MUDs are also known as ‘contested conditions’ (e.g. ME, CFS, RSI, chronic lower back pain) in which the patient experiences distressing
physical symptoms such as problems with mobility and coordination, intermittent paralysis, fitting, pain, fatigue and vision problems but there is usually an absence of clinical explanation or medical diagnosis. This ‘diagnostic limbo’, which widens the gap between ‘clinical reductions and lost metaphysics’ may be irresolvable for biomedicine, but can be accessed by integrative, more holistic approaches, as seen in the following example of chronic pain.

2. The Example of Chronic Pain

Treating or alleviating pain is often perceived as a primary role of medicine. But what actually constitutes pain can be defined in many ways.

Theories of pain have traditionally been dominated by biomedicine and concentrate upon its neurophysiological aspects, both in diagnosis and treatment. Hence, scientific medicine reduces the experience of pain to an elaborate broadcasting system of signals, rather than seeing it as moulded and shaped both by the individual and their particular socio-cultural context. A major impediment to a more adequate conceptualisation of pain is the manner in which it has been ‘medicalised’, resulting in the inevitable Cartesian split between body and mind. Consequently, the dominant conceptualisation of pain has focused upon sensation, with the subsequent inference that it can be rationally and objectively measured. Medical practice has concentrated on the nociceptive or sensory aspects of pain, employing the acute/chronic differentiation which does not necessarily take emotional aspects of pain into account. It is universally acknowledged that one of the most complex and difficult types of pain to treat is idiopathic pain - that is, pain for which there is no established physical pathology - often termed chronic pain syndrome.

Yet as well as being a medical ‘problem’, pain is an everyday experience, and not the sole creation of our anatomy and physiology. Rather, as Morris suggests, it emerges only at ‘the intersection of bodies, minds and cultures’. Moreover, defining pain is a semantic problem; in any language there may be wide variations in interpretation and meanings. For example, according to the Oxford Reference Dictionary, pain refers to any or all of the following:

PAIN [from the Latin poena, meaning penalty or punishment]
1. An unpleasant feeling caused by injury or disease of the body.
2. Mental suffering.
3. [old use] punishment e.g. on pain of death.

In Greek, the word used most often for physical pain is algos, which derives from roots indicating neglect of love. Another Greek word is akos,
meaning ‘psychic pain’ from which we derive the English ‘ache’. Implicit in these meanings is a broader definition of pain than the narrowly defined Cartesian proposition that inevitably acts to divorce mental from physical states and tends to attribute single symptoms to single causes.

Indeed, the notion of pain having a substantial emotional component, literally the obverse of pleasure is much older than that of pain being a physiological sensation and can be traced back to Plato’s (429-347 BC) deliberations of extremes and opposites in the World of Forms. He declares pleasure and pain to be the twin passions of the soul, the result of interactions between earth, air, fire and water. Aristotle (384-322 BC) developed the pain/pleasure principles further, describing them as basic moral drives guiding human action and believed the pain experience to be negative passion that had to conquered by reason. He believed that pain was conveyed by the blood to the heart, yet excluded it from his classification of the five senses, instead preferring to describe it as an emotional quality of the soul, the epitome of unpleasantness. Literature, theology and philosophy abound with considerations of the nature and purpose of pain and the pleasure/pain dichotomy is constantly evoked and reinforced.

The critique of the limitations of biomedicine has been developed from within medicine itself by those working in the area of pain, most notably Melzack and Wall, and Bonica. Developments such as the widespread acceptance of Melzack and Wall’s Gate-control theory of pain and the influence of the hospice movement have shifted the pain paradigm, increasing the emphasis upon cultural and psychological components and the need for a multi-disciplinary approach. Social science, in particular the sociological literature on chronic illness, offers a framework for understanding the experience of chronic pain by focusing on the person rather than the pain. Here, concepts such as biographical disruption, narrative reconstruction and illness adjustment have been particularly valuable. In relation to adjustment to chronic pain, Kotarba charted the process of becoming a ‘pain-afflicted’ person, in order to trace the continuity of personal identity. Using pain biographies, he identified three stages in this process. First, there is the ‘onset’ stage, which is perceived to be transitory, and can be dealt with by diagnosis and treatment. Here, pain is diagnosed as ‘real’ by physicians, having a physiological basis. The second stage concerns what Kotarba terms the ‘emergence of doubt’. At this stage, treatment may not work, there is an increase in specialist consultations but patients still feel in control, seeking the best care available. Finally, the third stage concerns what Kotarba terms the ‘chronic pain experience’. Following the shortcomings of treatment, the patient, at this stage, may return to the lay frame of reference and seek help within the ‘chronic pain subculture’.

Using a focus on the person, rather than measuring so-called objective symptoms, allows us to encompass more easily the notion of total...
pain, which includes psychological, spiritual, interpersonal and even financial aspects of chronic pain, as well as its physical aspects, as was advocated by Dame Cicely Saunders, one of the founders of the hospice movement. Additionally, beliefs about pain have been shown to have an important effect on compliance with physical therapy interventions. However, whilst at a theoretical level, medicine may acknowledge the holistic, multi-faceted nature of pain, the attempt to transcend the mind/body dualism in treatments or therapy may be subject to geographical and cultural variation. Moreover, a recent study by Glenton maintains that the acknowledgement of pain as ‘real’ by a physician is still the most important aspect in treating chronic pain.

Pain clinics or pain centres are institutions, which have been developed specifically for the treatment of chronic pain conditions (pain with no demonstrable cause was rarely treated before the 1970s). The concept of having special institutions for treating pain originated with John Bonica, an anaesthetist in the United States, who recommended that the treatment and understanding of pain would be best achieved through the co-operation of different disciplines in *The Management of Pain*. The first pain clinic was set up in the United States in 1961 with specialists from thirteen different disciplines, aiming to collaborate in a non-hierarchical manner. The subsequent developments of pain centres throughout North America and Europe vary in provision and resources, but are characterised by diversity in the organisation of work, medical specialities, working principles and therapies. They can be private organizations, or affiliated to medical schools, university departments or hospitals, and may incorporate a variety of treatment methods, or adopt one approach. A cross-sectional survey of 25 pain centres in a single urban community in the United States found that there were wide variations in the treatment modalities offered, the types of pain conditions treated, the populations served, the patient selection criteria and the diagnostic and aetiological frames of reference. The research also examined pain centres and clinics across the whole of the United States and identified three different types. First, they found multidisciplinary, comprehensive pain centres, which are dedicated to all kinds of pain problems and offer a wide range of treatment modalities. Secondly, there were syndrome-orientated centres, which only treat one kind of pain problem (e.g. headache or back pain). Finally, there were modality-orientated treatment centres, which offered only one type of treatment modality (e.g. analgesic nerve blocks).

The increasing emphasis on interdisciplinarity in understanding pain has influenced the development of pain clinics. Vrancken reviewed the theory and practice of pain in eight academic pain centres in the Netherlands, and identified five broad approaches to both theoretical and practical aspects of pain, as follows:
Table 2 Therapeutic approaches to chronic pain.

<table>
<thead>
<tr>
<th>Approach</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Somatico-Technical</td>
<td>Pain = organic, time is the only distinction made between acute and chronic.</td>
</tr>
<tr>
<td></td>
<td>Treatment = surgical procedures to eradicate, block or ease pain, long-term use of narcotics.</td>
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<tr>
<td></td>
<td>Cured = disappearance of symptoms.</td>
</tr>
<tr>
<td></td>
<td>Treatment = supposedly no distinction between body and mind, focus on nociceptive (i.e. the purely sensory).</td>
</tr>
<tr>
<td></td>
<td>Cure = pain is gone.</td>
</tr>
<tr>
<td></td>
<td>Treatment = behaviour management.</td>
</tr>
<tr>
<td></td>
<td>Cure = pain behaviour replaced by effective 'well behaviour'.</td>
</tr>
<tr>
<td>4. Phenomenological</td>
<td>Pain = complex of reactions and behaviours, result of an interrupted healing process, pain sufferer is unable to find a place in the world.</td>
</tr>
<tr>
<td></td>
<td>Therapy = to return the person to human life by (re)awakening through human encounters.</td>
</tr>
<tr>
<td></td>
<td>Recovery = being-in-the-world.</td>
</tr>
<tr>
<td>5. Consciousness</td>
<td>Pain = incorporated into the meaning of being 'human'.</td>
</tr>
<tr>
<td></td>
<td>Therapy = unspecific, may be any form of treatment but preferably not invasive surgery.</td>
</tr>
<tr>
<td></td>
<td>Recovery = by pain disappearing or by gaining enough insight to accept and manage it.</td>
</tr>
</tbody>
</table>

Thus, integrative approaches using illness narratives and phenomenological accounts have become intrinsic components of pain treatment in many pain clinics and can be seen to provide a challenge to the biomedical model.
Notes

6 Williams, 1984.
11 Williams, 1984.
12 Kotarba, 1983.
13 Kotarba, 1983.
15 Williams & Thorn, 1989.
17 Bonica, 1953.
20 Vrancken, 1989.

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Writing Size Zero: Figuring Anorexia in Contemporary World Literatures

Isabelle Meuret

Abstract
Anorexia, defined as a mental illness by both William Gull and Charles Lasègue in 1873, will be explored in this chapter on the basis of experiential texts written at the end of the 20th century. Although self-starvation has always existed, it took epidemic proportions at the turn of the millennium. As a result, the anorexic body has been dissected *ad nauseam*, and the fascination for this enigmatic disease has been growing without any satisfying treatment being found. Self-starvation is a very complex endeavour, whose objective is to approach one’s limit as a living being, but without dying. By focusing on experiential texts, this chapter aims to bring to light new epistemologies and to debunk the myth of anorexia - *anorexia nervosa* - as it is represented in contemporary medical and cultural discourses. Anorexia is not a disease of young female white Westerners, as it is often claimed. Indeed, testimonies from America and Europe abound, but texts from Algeria, Zimbabwe, and Mauritius also refer to the phenomenon. In these texts, anorexia is figured as a pathology of language, an act of terrorism, a cultural disease, or a search for the sacred, to name just a few examples. It is also surprising that a number of prominent authors suffered from anorexia, such as Byron, Gide, Woolf and Blixen. This chapter will therefore also highlight some intriguing features about the relation between writing and starving. In all instances, anorexia appears as a writing disorder. While anorexia is a debilitating experience, its writing, or *Writing Size Zero* - as I venture to call it - is an ethical process. By appending a message to their mysterious pathology, the authors convey meaning to anorexia and are thereby sentenced to life. *Writing Size Zero* is a gift of life.

Key Words: Anorexia, eating disorders, language of expression, writing, narrative.

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The question underlying this research is how to reconcile the medical discourse which mostly defines anorexia as a ‘mental’ disease and what anorexics actually say about their experience of self-starvation. In other words, is it possible to make sense of this hunger strike, which is often misunderstood and whose sufferers consequently receive inappropriate treatment?
The once enigmatic term anorexia, which was hardly known before the 1980s, has today become common parlance and is no longer restricted to the medical jargon. It seems that anorexia has reached epidemic proportions at the turn of the millennium, although figures often remain vague. Nevertheless, like hysteria in the nineteenth century, anorexia nervosa, as it is qualified today, has become a fin de siècle disease and sparked off massive interest from doctors and researchers from other disciplines. This compelling pathology has copiously fed the medical, but also sociological, cultural, feminist, literary and psychoanalytical literature, to wit the number of books on the topic and the publication of magazines which specialise in food pathologies. Reviews like the American Journal of Eating Disorders dissect the body ad nauseam, with articles ranging from the origins of anorexia in the brain, to the prevalence of anorexia in the Jewish population, to male anorexia.

True, the pathology is fascinating. Starving in a world of plenty is a daring challenge, and it is worth mentioning that this ‘mental’ disease has the highest death rate in the West. Such facts confirm, if need be, that anorexia is more than the passing fad of some fashion-conscious teenagers. It is, as Maud Ellmann argues, ‘a strange adventure in seduction’ since you cannot really starve without obliging the other to intervene. The objective of this chapter is twofold. First, on the basis of experiential texts written by women who suffer(ed) from self-starvation or witness(ed) the ailing condition of a relative, it describes a writing process – writing size zero, which provides information about the pathology and its related creativity. Second, it dismantles some myths regarding anorexia. Although self-starvation is a killer, it cannot be reduced to a debilitating disease. Indeed, there are many preconceptions and reductive interpretations of anorexia, for instance that it is the malady of young, white, female, upper-class westerners. In this perspective, the multicultural aspect of the study is of special interest.

In the manner of Susan Sontag, we posit that anorexia is not a metaphor. Anorexics are literally starving. Based on its Greek etymology αν and ορεγομαι, anorexia means absence of desire. It is the sublimation of an insatiable appetite, the yearning for something that has yet to be expressed. As Lacan said, it is ‘eating nothing,’ and this nothing represents a void that has to be named. We define anorexia as a pathology, rather than a disease, i.e. as the expression of pathos and as an effort of the organism to regain its balance and retrieve its harmony, whatever it takes.

As it has often been repeated, the term was first coined simultaneously in England and in France in 1873, as anorexia nervosa by William Gull and as anorexie hystérique by Charles Lasègue, respectively. The former emphasised the physical or biological factors in the aetiology of anorexia, whereas the latter was convinced that the pathology was a consequence of a deficient psychological mechanism and flawed emotional
bonds. Yet, a case of ‘nervous consumption’ was described earlier, namely by Richard Morton in 1689 and then 1694 in his *Phthisologia; or, a Treatise on Consumptions*, and a phase of insanity called ‘sitomania,’ or fear of food, was identified by William Stout Chipley in 1859.⁵

For Rudolph Bell, the current *anorexia nervosa* entails a link with the holy anorexia of medieval saints like Catherine of Sienna. Although one should not obliterate the religious rationale behind the fasting of those women and their lack of concern with thinness, there remains a common attitude of abnegation and desperate need to control their bodies. While it is impossible to conflate medieval and modern fasting because of the totally different cultural contexts in which they occur, Bell insists that both involve ‘the need to establish a sense of self, a contest of wills, a quest for autonomy.’ Moreover, the so-called *vitae* on which Bell bases his assumptions were very effective means to publicise self-starvation.⁶ Showalter also believes that the countless self-help books and autobiographies that come out today have the same effect as the hagiographies of the Middle Ages.

Carolyn Walker Bynum, for her part, identifies various forms of fasting depending on the motivation behind self-starvation in her impressive study on the significance of food to medieval saints.⁷ The key issue for Bynum is to understand why food has always been central as a language of protest for women. There is indeed much to say about the female body, which is itself food when it bears life, but also about the constricted and stifling domestic roles played by women across time and space. The numerous occurrences of anorexia in the Victorian period testify to this phenomenon as well. Anna Krugovoy Silver, for instance, highlights the continuity between the nineteenth century woman, whose control of the body was a ‘fundamental component of Victorian female gender ideology,’ and the current frenzy to conform to beauty ideals. For Silver, anorexia is thus a cultural paradigm.⁸

The work of Joan Jacobs Brumberg is instrumental in understanding the switch ‘from sainthood to patienthood.’⁹ Fasting women commanded admiration; their behaviour was inspirational. But the fascination lasted until the sixteenth century, when the clergy decided that these women were insane and not saints. The general craze for self-starving women then faltered and finally disappeared. Some anorexics obviously emphasise the sacred dimension of their endeavour, but most of them are bound to defend such a line of thinking given that their family is religious in the first place. The ascetic determination that pervades the testimonies collected by Caroline Giles Banks is undeniable, and the overrepresentation of anorexia in the Jewish population is a fact, as Doctor Thomas Silber has shown, but the pathology is in these cases always determined by the particular background of the sufferers.¹⁰ Obviously, the ritual of the dieting process provides a
structure for subjects who may lack substance and need a sense of direction. A pathology can therefore be a coping mechanism to avoid depression, for instance. In this perspective, Brumberg is right to emphasise that sadly enough, the pursuit of thinness is one of the few coherent philosophies offered to young women today. Religious or not, the objective is, as Maud Ellmann argues, to experience a miraculous transfiguration, be it ‘in the body of a movie star’ or ‘the body of an angel’.

So much has been written about anorexia, that it is difficult to separate the wheat from the chaff. The very term anorexia nervosa is a modern construction, which reductively poses limits as to the signification of self-starvation today. Like Jacques Maitre, I prefer to cut the term to the bone and to relieve it from any oversimplification or improper interpretation. According to Maitre, there is an ‘anorexic way of being in the world,’ which might have even been thought of as an anorexic ideology. And it is true that ‘morbidity is still a way of life,’ as Georges Canguilhem argues.

As the overabundance of studies on anorexia proves, the pathology is saturated with meanings, so much so that some authors now refer to its inevitable ‘coding problem’. Abigail Bray conceives of anorexia as a ‘reading disorder,’ given that ‘the territory of the anorexic body has been colonized by a motley group of discourses contesting the truth of the anorexic lack’. Starting from a taxonomy of different interpretations, from which countless neologisms have sprung up, she denounces the imprisonment of anorexics in ‘the sentence of the medical discourse’. Bray regrets that anorexics have to fit into a prewritten text which is very restrictive and alienating.

There is indeed an ‘epidemic of signification,’ both within the field of medicine, but also within all other disciplines taken together. The latest version of the American psychiatric manual, DSM IV, has an increased number of entries regarding eating disorders, and anorexia is now referred to as a code number - DSM IV-307.1 - which raises questions as to the dehumanisation of the pathology. Some doctors, though, believe that tinkering with the criteria and creating subcategories has not helped our understanding of anorexia at all. The ‘epidemic of signification,’ as Bray calls it, characterises the mythologizing of anorexia. Roland Barthes explains that ‘terminology’ and consequently neologisms, are necessary to ‘decipher myths.’

Nevertheless, although Bray makes a point in denouncing the fact that right-thinking doctors and therapists may have induced more stress or despair in some patients, it would be an outright aberration to reject the medical breakthroughs in the field of eating disorders. The current research carried out on both sides of the Atlantic, for instance by Dr. Walter Kaye in the United States, and the team of Drs. David Collier and Janet Treasure in England, focuses on the genetic and biological predispositions of people with
eating disorders. By identifying the genes that could possibly be responsible for anorexia - a process which implies a careful observation of the levels of serotonin in the patients’ brains - these scientists are contributing to a better understanding and, most importantly, an effective treatment of anorexia.

As Deleuze and Guattari said about Kafka’s work, writing is fasting because food and words compete with each other. It seems that some fall prey to the disease following a language problem, and can paradoxically get back into life through writing itself, which is their saving grace. Also, it is particularly intriguing to note that some of the most prominent writers confessed that they had eating disorders. Interestingly enough, Leslie Heywood has thrown into relief an ‘anorexic logic’ that undermines modernist literature. As for Maud Ellmann, her work on starving and writing is a milestone in the field. While the former emphasises the literal body becoming text, the latter believes in the inverse process of writing to starve.

As this chapter illustrates, anorexia and writing are two faces of the same coin. Both signifying practices are - solidly or flimsily - grounded in the body. Contrary to Heywood, we would rather postulate that Writing Size Zero is the textual body becoming flesh. Writing, i.e. the production of a ‘linguistic flesh,’ is the body of the weaning author. In other words, the writing process of anorexics is beyond representation, and is more on the side of figuration. Abigail Bray and Claire Colebrook denounce the harmful effects that excessive representations can have on anorexics:

> In terms of eating disorders, this ambivalence surrounding representation might be cashed out as follows: the anorexic is the victim of representation, trapped in embodiment through stereotypical and alienating images - but at the same time only representation can cure this malaise; only a realistic, nonrepressive and less regulative form of representation will allow women to see themselves as autonomous subjects.

Bray and Colebrook’s perception of the anorexic body as ‘productive rather than representational’ is illuminated by insights into the Deleuzean theoretical interpretation of anorexia as a complex mechanism. Although it is impossible to reconcile Lacan with Deleuze, it is nevertheless essential to delve into the latter’s perceptive reading of anorexia as a question of ‘fluxes,’ and not just ‘food fluxes’ but also ‘a clothes flux, a flux of language, a flux of sexuality’. Therein lies the truth of the anorexic, i.e. in their dealing with a prismatic life experience and concurrent short-circuit.
Most of the writers turn to a fragmented kind of writing, resort to their own sensations, to translate self-starvation. Prisoners of language and food obsessions, often entangled in an enmeshed relationship with their mothers, anorexics regress to a pre-subjective stage. Unable to define their body outline, they desperately lack autonomy and have no access to the other and desire. Their figurative writing, which is a semiotic assemblage of flesh and words, intends to reflect these sensations as much as it keeps them in a certain motion. As already mentioned, anorexic writing is a question of figuration and not representation, the latter being an ‘embarrassed figuration,’ i.e. ‘when nothing emerges, when nothing leaps out of the frame’. Writing Size Zero is the dynamic binding of multifarious vanishing lines that shake the anorexics out of their lethargy and help them reconcile their parallel worlds or modified states of consciousness.

By écriture faminine, I refer to the abundance of experiential texts that constitute a noticeable literary movement. Beside the plethora of self-help books and autobiographies that has appeared both in the United States and in Europe, texts have also emerged from more surprising places regarding the alleged overrepresentation of the pathology in the West. Examples are the diary of Algerian author Sabrina Kherbiche and the novel of Zimbabwean writer Tsitsi Dangarembga. In both cases, anorexia epitomises a problem of hybridity and conflicting identities. The former, Sabrina Kherbiche, has an Algerian father and a French mother, and she is completely torn apart between two cultures, all the more so since she loses her virginity before marriage, which means that she is lost, in the Algerian context. The consequence of this is that she has her virginity reconstructed - a new hymen is sewn inside her body, hence the title of her diary, La Suture. On her wedding night, the fraud is discovered and she is rejected by her husband and forced to flee to France to avoid shame in her country. Following this terrible trauma, she becomes severely anorexic. In Tsitsi Dangarembga’s Nervous Conditions, a young Zimbabwean girl, Nyasha has to leave her country with her family to study in England. Being separated from her grandmother, from her African roots, she is also desperate because she ends up being a stranger everywhere. She is not British, but she is no longer African. She is desperately looking for authenticity and anorexia is the response to her internal fragmentation. In their writings, both authors manage to reconcile both identities. Kherbiche writes a diary (a western kind of genre) with a lot of Arab motifs (i.e. light and music), while Dangarembga produces a text that appropriately fits in her grandmother’s tradition of story telling, i.e. allegorical at some point, and peppered with Shona words (her mother tongue).

Mauritian author Lindsey Collen brings forward the testimony of a young anorexic woman whose pathology derives both from family and cultural problems, such as the Americanisation of her society. Countless
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examples exist across the world, some of them figuring anorexia as a hunger strike, a sociocultural syndrome, or a search for the sacred. Notwithstanding the difficulties of dealing with texts originating from a variety of cultural backgrounds, there nevertheless exists a common ground to analyse them. This joint fabric is writing itself, made of textual and corporeal ‘regimes of signs’ that are intertwining to form a body of evidence. All texts testify to the coalescence of fluxes which make up the anorexic logic, or philosophy.

Three subcategories can be delineated on the basis of the multicultural corpus. A first, limited, category of texts, renunciation/disincarnation, is produced by women still in the throes of anorexia. Their writing is opaque, schizophrenic, fragmented (use of different pronouns, impersonal sentences), and extremely confusing. A second group of texts, enunciation/incarnation, deals with testimonies by women who are in the process of recovering from anorexia. They are writing using the pronoun ‘I’ and manage to express their fears and anger. The last category, denunciation/reincarnation, is more critical of medical misinterpretations and sometimes offers alternative treatments. Here, more distance is taken from anorexia, the author resorting to the ‘she’ pronoun, as if to keep the pathology at bay.

From this group of texts, Australian author Fiona Place’s Cardboard stands as a good example of the first subcategory. Her text is about the reminiscences of an anorexic young girl named Lucy, who confesses how ‘frightened and withdrawn’ she felt while in the midst of events she could not control. Her text offers several clues as to the enigma of anorexia. First, there may exist a biological predisposition to develop the condition; second, anorexia shares similarities with schizophrenia and should be understood as a pathology of language. In a few straightforward words, the narrator Lucy announces her decision to starve:

It was then that I decided to stop eating altogether.

to ward off
Panic

Fiona Place is very critical of the medical jargon that is a ‘linguistic straightjacket,’ which tends to standardise or universalise the pathology. She is, in fact, the only author to point out that physiological reasons play a part in the onset of anorexia. While on a trip from Australia to England, a trip that was like a maturity test which involved leaving her family behind her, she had an ulcer, lost blood, and ended up in intensive care. As a doctor told her later, she then deceived herself into thinking that separating from her mother meant dying. Both events - ulcer and bleeding - were in fact symptoms of a panic attack, which triggered her self-starvation. Indeed, anorexia is for Lucy the inevitable response to ‘fear [that] ate at [her]
constantly'. According to Julia Kristeva, those who suffer from maladies of the soul are unable to structure themselves. Therefore they represent through their bodies. Creating a process that mingles flesh and words helps figure rather than represent the anorexic experience. Through the voice of Lucy, Fiona Place identifies her pathology as a language problem. At some point, she develops a fear of words and letters, which I like to call 'physiograms,' i.e. units in which flesh and words coagulate and reveal the essence of her condition. These ‘physiograms’ constitute the yardstick with which to read the grammatology of anorexia. By way of illustration, Place writes that:

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she got to
the stage
where she was
scared of
the letter e

E for employment
E for existence
E for ego

little e’s
were jumping
up and down
before her eyes
every minute of
the day
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At this stage, Lucy’s ego is broken and fragmented. Consequently, she topples over into a world where her perception of reality is altered and her apprehension of language is irrational. Lucy is thus both afraid of food and language - ‘[t]he e was nearly choking [her] to death’. Eating disorders and language problems are also symptoms of schizophrenia, and in Place’s text, the narrator clearly suffers from a depersonalisation which leads to a schizoid fragmentation. Lucy’s food and word phobias are also concurrent with her hearing voices, bouts of madness and delusions:
The food wouldn’t stop screaming. The neat little nuclear family of edibles stared white into white. The vegetables linked forces with the fish, the apple pie serenaded the ice cream and the yoghurt nestled healthily next to the overripe banana.

The rest of the food glared beadily up at me, but I refused to be sucked in. 36

Janusz Wróbel describes schizophrenic language as ‘a separate linguistic system,’ which is opaque and difficult to understand. 37 This particular idiom is mired in neologisms, metaphors, and chains of associations. The hallucinations show that ego, food and language confluence in a very tight knot, and Lucy resorts to new words of her own making to share her experience of living in the obsessive anorexic world:

She parch onion lipped one tired evening that she was no longer my mother.

She gave me a cool fisheye look and opened the fridge door to get out her own dinner. 38

As Wróbel notes, neologisms and also peculiar punctuation characterise schizophrenic language, and Fiona Place’s reshaping and reformatting of English is a strategy to match it with her anorexic experience. Indeed, Wróbel shows that, at least in the case of schizophrenia, there is an adaptation of language to experience, and not the opposite. By infusing the language with new and ‘sensory-pictorial’ words, Place makes her pathology palatable for the reader and indicates that her being-in-the-world has been modified. 39 Other means are used to convey the idea of fragmentation. For instance, she writes either in prose or poetry, or she uses italics and bold types to show her awareness that language is made of different subtexts, some of which she cannot grasp. And finally, she changes perspectives, using first and third person pronouns, as well as odd and eccentric punctuation, as if to torture language as she does with her body.

Fiona Place’s claim that anorexia is ‘first and foremost a language problem,’ emphasises the fact that her condition is constitutive of the speaking subject in a particular social and cultural context. Second, she also suggests that the clinical discourse is reductive because it is homogenising. In other words, she denounces the patients’ dependence on physicians and experts, who may ignore or play down the variety of anorexic experiences. As Abigail Bray explains, ‘Place argues that the clinical definition of anorexia nervosa creates the identity of the subject who practises self-
starvation by excluding everyday language: any other understanding of the anorexic’s identity is marginalized. Or, to put it differently, Place’s reminiscences provide not only a guiding framework to capture anorexia from within, but they are also an attempt to explain the relevance of experiential writing and take issue with some therapeutic practises.

Anorexia, although predominantly female, is not limited to women. Intriguing is the fact that a number of prominent writers, both male and female, were openly anorexic. Some of them spontaneously linked their self-starvation to their writing. André Gide confessed in his journal that he suffered from anorexia, and that writing helped him get his appetite back. Byron is often cited as the perfect model of the romantic self-starving artist. He spent his life trying to dominate his appetites and tame his body. Kafka confessed in his own diary that he had to abstain from food to be able to write. Neither was Karen Blixen productive when she ate, and she preferred to starve herself for art’s sake. Emily Brontë had her own issues with food, just like Virginia Woolf, or the American poet Emily Dickinson before her. And these are just a few examples. This puzzling observation originates from the dual relation between food and words, but again, all these authors were led to fast and even starve for various reasons. Further research should be conducted on the compulsive writing and obsessive note-taking that anorexics often develop.

Surely there are various forms of anorexia, all of which engage with a diverse range of issues. While some anorexics deliberately embark on a hunger strike against any kind of authority, others respond to an unnameable trauma, have psychosomatic reactions to panic attacks, suffer from the consequences of physical injury, do penance because of religious ideals, or go on a starvation diet amid contradictory messages from the consumer society. All these facets need to be observed, and all of them touch up the portrait of the anorexic. As Helen Malson notes, there is ‘fictioning’ of various ‘anorexias’ - and the plural is intentional - which is attributable to the interdisciplinarity of a thought-provoking subject matter. The many interpretations that have emerged are of crucial significance to understand the phenomenon and, most importantly, to try and cure people who claim they are not patients and that anorexia is their way of living.

Although anorexia is a debilitating experience and a lethal pathology, Writing Size Zero is an ethical process. By appending a message to their pathology, the authors convey meaning to anorexia. Indeed, by exposing the agony they are going through, and by offering their personal testimonies, they contribute to the creation of new epistemologies. The abundant research that has been carried out in the field has paradoxically complicated our perception of anorexia, and treatment has remained highly unsatisfactory. As some writers stipulate, we are led to believe that writing autobiographically or simply writing, i.e. laying out letters on chapter,
building up words and sentences, and possibly constructing a plot, obviously helps some anorexics to pull themselves together. Therefore, Writing Size Zero is also a way to recover. The paradox is that some may fall prey to anorexia following a language problem. Conversely, some anorexics manage to repair the disjunction they experienced at some point in their lives, and keep on track by substituting words for food, and then food for words. In this perspective, we should encourage creative and curative cultures. Writing Size Zero is a gift of life.

Notes

3 This paper is part of a wider project, published in Meuret, Writing Size Zero: Figuring Anorexia in Contemporary World Literatures, forthcoming.
4 Canguilhem, 1999, 85, 12.
6 Bell, 1985, 8, 150.
7 Bynum, 1988, 197.
8 Silver, 2004, 11.
9 Brumberg, 2000, 43-61.
14 Bray, 1996.
15 Beumont et al., 1994.
16 Barthes, 1993, 120-121.
17 For latest research on anorexia, and more precisely in the field of genetic factors contributing to the development of eating disorders, see the work of Walter Kaye, Janet Treasure, and David Collier. For instance, Bergen et al., 2003 and Collier and Treasure, 2004.
18 In their critical work on Kafka, Deleuze and Guattari write that ‘writing transform[s] words into things capable of competing with food … To speak, and above all to write, is to fast.’ See Deleuze and Guattari, 1986, 20.
19 Heywood, 1996.
20 Chawaf, 1980, 177-178.
22 Ibid., 57.
23 Deleuze and Parnet, 2002, 109, 111.
27 Deleuze and Parnet, 2002, 111.
28 Place, 1989, 24. Author’s emphasis.
29 Ibid., 153.
30 Ibid., 162.
31 Ibid., 39.
32 Devlin et al., 2002, 689-696.
33 Kristeva, 1995.
34 Place, 1989, 16.
35 Ibid., 71.
36 Ibid., 41, 45.
38 Place, 1989, 3. My emphasis.
40 Bray, 1996, 424.
41 Malson, 1995, 97.

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Writing Over the Illness: The Symbolic Representation of Albinism

Charlotte Baker

Abstract
The manifestation of albinism in the whiteness of albino skin makes it a condition that is loaded with symbolism and meaning in terms of racial difference. The lack of pigment that marks the albino apart in Black Africa is also frequently portrayed as symbolic of his or her links to the spirit world, or functions purely as a marker of difference and deviance. Underlying all such representations of albinism is a failure to see albinism for what it is; a medical condition. The albino experience portrayed in the work of Williams Sassine, Patrick Grainville and Didier Destremau is firmly located in an African context, a context that aggravates an already difficult predicament. The African albino suffers overt discrimination that results from a fundamental and recurrent misunderstanding of the condition. Apart from the real disability caused by albinism, the albino body is often attributed other inadequacies that are imagined or assumed, such as deafness and muteness. Furthermore, albino skin is frequently perceived as a sign of physical weakness that is often interpreted as indicative of mental inadequacy. The small amount of critical attention to the albino body that exists has focussed simply on its whiteness, indicative of a general inability to see beyond it to the person beneath. As a result, there has been a distinct failure to address the other differences or supposed deficiencies that mark the albino apart; differences that explain why the albino body is invariably depicted in representation as damaged, lacking, or flawed. This chapter will attempt to redress this tendency and will expose the ways in which albinism and those with the condition are consistently (mis)represented.

Key Words: African literature, illness representation, albinism.

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Albinism, oculocutaneous: an hereditary disorder characterised by deficiency of the pigment melanin in the eyes, skin and hair. The lack of eye pigment causes photophobia (sensitivity to light), nystagmus, and decreased visual acuity.1

This is the short description of albinism found in the Webster’s New World Medical Dictionary. Certainly, the description fulfils the aim of such dictionaries, that is, to give a succinct summary of the condition. Yet it falls
Writing Over the Illness

far short of explaining the physical, psychological and social consequences of living with the condition, failing to express the ways in which albinism is often misinterpreted and the fact that its etiology is often ignored. What is best known about the disorder, as the citation from Webster’s confirms, is that oculocutaneous albinism manifests itself in the whiteness of albino skin, making it a condition that is loaded with symbolism and meaning in terms of racial difference. Indeed, the small amount of critical attention to the albino body that exists has focused simply on its whiteness. This is not surprising, for the enigmatic location of white skin on ‘Black’ features problematises racial categorisation according to the connotations of skin colour. In such terms the albino body emerges as subversive, particularly in a postcolonial African context, as much of my research to date has revealed. However, in this chapter I wish to move beyond the whiteness of the albino body in order to explore the tendency to view it as purely symbolic and the consequent failure to see albinism for what it is: a medical condition.

The striking appearance of the Black albino has for centuries been a source of fascination, and even today, a plethora of misconceptions about albinism persists. The condition is often wrongly assumed to occur only among those of African descent, for it is clearly more visible within Black communities. This assumption is typical of the misunderstandings surrounding the albino that manifest themselves in myth and stereotype, and which pervade representations of albinism. The entertainment industry is brimming with grotesque or fantastic characters that are labelled ‘albinos’ such as the demonic albino in Peter Hayan’s horror film, *End of the Days* (1999). Likewise, the character Jeremy Reed in Victor Salva’s film *Powder* (1995), born to a mother struck by lightning while she was pregnant, is apparently able to conduct electricity all over his body and La Lunatica, a ‘mutant’ from the *X-Men 2099* series, is depicted with the stereotypical physical traits used to characterise people with albinism. Typically, the qualities of albinism are exaggerated to identify such characters as deviant or strange and they become villains with pale skin, white hair and blood-red eyes. The Arts, film, fiction and the medium of comics are replete with albino figures that possess supernatural powers and other qualities that serve to emphasise their abnormality; a trend that contributes to the difficulties faced by people with albinism, for it compounds the tendency of others to regard them as freaks of nature, or objects of morbid curiosity.

The novels of Williams Sassine, Patrick Grainville and Didier Destremau are, in many ways, characteristic of such representations of albinism in their insistently negative portrayal of the albino body and in both their conscious and unconscious tendencies to impose meaning onto it. The complex nature of the albino body and the taboos and prejudice that it evokes make it an inspiring subject for writers. However, there is no middle ground in the portrayal of the albino. That is to say, albino characters are defined by
extremes, marked apart by physical difference that is reproduced in various forms of social deviance. Sassine’s representation of his sociopathic protagonist Milo Kan demonstrates this tendency, but at the same time attempts to explain the cause of such deviance, for Milo’s madness manifests itself in a two-way process. His albino body is portrayed as being at the root of his madness, but in turn his madness becomes an expression of his difference. Portrayed as the result of a lifetime of suffering, Milo’s madness raises questions about the institutions and discourses that marginalise individuals and the assumptions upon which they are built.

Although the three novelists whose work I explore here write from very different perspectives - Sassine is Guinean, Grainville and Destremau are French - their portrayal of the albino is startlingly consistent and in all four novels the focus is very much on the albino body, on its importance and adequacy (or otherwise), for the construction of identity. The human body is generally perceived to offer boundaries to the Self, presenting both the uniqueness of the individual and a site for the marking of difference. It is deemed a key site for identity construction; important because it shapes identities and structures both an individual’s interventions in, and classifications of, the world. However, the pervasive negativity of the references to the albino body in the works of Sassine, Grainville and Destremau problematises the possibility of viewing the albino body in this way. Sassine’s fiction in particular is populated by sick, damaged or dying bodies, and all four novels examined here depict the albino body as vulnerable, inadequate or failing; an insistent negativity that signals a failure to affirm albinism for its own sake as a legitimate identity.

It is the non-pigmented skin of the albino that marks him apart and therefore albino skin is most often seized upon for its symbolic value in fictional representation. Skin is generally supposed, at the very least, to protect. However, the skin of the albino is open to assault from the sun and easily becomes damaged or diseased. The skin that would generally be considered a boundary or a seam is broken down and becomes inefficient as a membrane of separation, as a divide between the individual and the world. Notions of the skin as ‘final boundary’ and the sense of the ‘closed person’ are challenged in the albino body, and with this breaking down of boundaries comes a characteristic disruption of categories. The failure of albino skin to ‘contain’ or to delimit is emphasised in the novels of Sassine, Grainville and Destremau in descriptions of its transparency, with the skin failing to provide a division between the internal and the external. A common analogy is drawn in these novels between the transparency of skin and the associated sensitivity or transparency of emotions. Whereas dark skin is often interpreted as impenetrable and ‘concealing’, light skin is portrayed as revealing and open to interpretation. So, just as albino skin is open to damage from the sun, it becomes vulnerable to the gaze of others and therefore the
albino individual is rendered open to their judgement and to the imposition of identity from the outside. The perceived ‘transparency’ of albino skin is carried still further in representation, to the point of absence. Since albino skin fails to protect, to ‘contain’, or to carry out the functions of ‘normal’ skin, it is often perceived and portrayed as inexistent. In Grainville’s words, albinos are, ‘[i]ncomplete, unfinished, without a definitive skin’, ‘more naked than a worm’. The ‘skinless’ albino is stripped naked and his body exposed as defective.

A web of misconceptions surrounds the albino body, permitted precisely by such perceptions that the albino body is in some way ‘lacking’ or ‘inadequate’. Apart from the real disability caused by albinism, the fictional albino body is often attributed other defects that are imagined or assumed. Albino skin, already perceived as a sign of physical weakness, is often further interpreted as indicative of mental inadequacy. The albino is often portrayed as being feeble minded, as in Sassine’s representation of the albino Condélo who struggles to comprehend the world in which he finds himself. Moreover, since people with albinism generally have poor eyesight, the specious conclusion is drawn that they must also be deaf and mute. The disgust that is so often portrayed as being inspired by the albino body is often rooted in another common misconception about albinism: that it is contagious. There are many references in the secondary literature on albinism to the fact that if an albino has touched food, it will not be eaten by anyone else. In Destremau’s Nègre Blanc, the association of albinism with leprosy reinforces the notion of the contagious nature of the condition. Because of the web of beliefs surrounding albinism, albinos, like lepers and the other disabled, were traditionally segregated in African society. Today this continues in some parts of Africa in more subtle ways, as people cross the road to avoid albinos in the street and albino children are prevented from mixing with their peers for fear that their ‘disease’ will spread.

Such responses to albinism appear ridiculous when its genetic provenance is recalled. However, the rooting of such misconceptions in traditional and religious belief means that even when the genetic cause of albinism is fully explained, an undercurrent of superstition remains. Grainville illustrates perfectly the reluctance to accept the genetic explanation for albinism as his protagonist Houphouët-Boigny expresses his horror at the revelation that the albino Alpha is his son,

I’ll accept a superior progeniture. But an albino! My genes exclude this defect, this larva-like lineage. There has never been an albino in my family. Never! Nowhere! […] My mother descends from a tribe of Akoué chiefs. Our genealogy proves it. My father, a Samori soldier, hero, rebel, conqueror.
A similar reaction is found in Destremau’s Nègre Blanc as Samate’s father decides that, ‘... the albino couldn’t be his son, he could not possibly figure in his lineage’. The implication is that albinism is a stain on the reputation of the family, a sign of failure or weakness. Destremau later describes the albino as being, ‘beyond tolerable norms’, articulating the limits of acceptance that are particularly significant in terms of rural African society where children are still killed at birth if they are found to be disabled. Indeed, the killing of disabled children is central to Destremau’s novel for it is in fear for her son’s life that Mbuya, the mother of an albino child, leaves the village to live in isolation with her son Samate in the forest. We learn that, ‘if albinos, just like others disabled at birth, are not found in the village, it is because they are eliminated, but by a process that is more discrete, less sacrificial by nature’.

It becomes evident then that the fictional works of these writers serve to perpetuate the misunderstanding of albinism, sustaining the myths surrounding the condition. Yet, there is also significant misrepresentation in their writing through the refusal or failure of the writers to address certain issues, for example, the poor sight of the albino. Characteristic of much writing about disability, the sexuality of a body deemed ‘disabled’ is also ignored, or alternately is portrayed at the other extreme as a perverse sexuality that is equally deviant. There are repeated instances where events are glossed over, aspects of albinism that are not ‘appropriate’ to the writer’s particular portrayal of the albino are side-stepped and, of course, there is the natural tendency of representation towards stereotyping and the expression of prejudice. Even Destremau’s attempt in his foreword to explain his reasons for writing about albinism appears sentimentalising:

This book is neither an ode to albinism, nor a treaty on this congenital illness that strikes many Africans. But, having so often encountered those poor children squinting in the sunshine, or those courageous adults, deprived of pigmentation and suffering terribly from their eyes, I wanted, in my own way, to restore the humanity of ‘those who see in the dark’, which is how, until quite recently, they were described...

The tendency of representation to distort and misinterpret, to amplify and to misrepresent is evident in these narratives. Yet, as Edward Jayne reminds us, misrepresentation is a natural constituent of fiction, for unless the truth is distorted or reorganised, fiction cannot, by definition, be fiction. The misrepresentation of the albino in these novels may simply result from this, since the albino body, in its perceived ‘emptiness’ and ‘lack’, invites interpretation and inspires elaboration. The tendency in
literature towards misrepresentation and the failure to portray a positive image of the albino may also be due to the fact that without any albino writers there is no acceptable model of representation. Albino writers have struggled to find a voice and as a result of the lack of writing by albinos, there has been a consequent failure to deconstruct the recurrent misrepresentation of the albino in literature. Equally, when knowledge is absent, representation becomes a substitution of the unknown and even critics and writers who on the surface appear to have researched the condition are frequently revealed as being misinformed or as tending to generalise. However, it is the extreme negativity with which the albino is portrayed that is of interest here, for albinism is constantly distorted to become something else, to signify. It is significant that such negativity persists across all writing about albinos, as well as in other forms of representation.

Misrepresentation of the albino occurs on many levels. Certainly, the myths and stereotypes surrounding albinism in Africa evoked in the work of Sassine, Grainville and Destremau play a central role in this, built in to common belief systems as they are. However, these myths and stereotypes in themselves are typical of a more general tendency. That is to say, the need to emphasise the real or assumed deficiencies that mark the albino apart, reinforcing his difference and ultimately serving to confirm the normality of those who designate his body as defective. The need to categorise, to define and to ‘know’ the Other is continually frustrated by the albino body and it has become evident that this is particularly problematic for the writer attempting to represent the albino. There seems to be a recurrent need in fictional writing about albinism to account for that which is perceived to be lacking, a desire to complete the albino body by imposing meaning onto it. Therefore, despite the wealth of research and documentation on the genetic nature of albinism, the tendency has been to focus purely on the symbolic potential of albinism and to write over the reality of living with the condition.

Notes

2 Although I use the term ‘albino’ throughout this paper, the term, ‘person with albinism’ is now considered to be most acceptable, for it puts the person before the condition. See the website of the National Organisation for Albinism and Hypopigmentation (NOAH). 11 June 2005. (08.06.05) http://www.albinism.org.
3 This chapter will focus on the Black albino of African descent as the protagonists of Grainville, Sassine and Destremau’s novels are all Black male
albinos, although many of the issues discussed are experienced by albinos of other races too.

4 Skin cancer is common among African albinos who have not been educated about the damaging effect of the sun on their skin or who do not have access to healthcare and skin products.

5 For further discussion of these terms see Benthien, 2002.


7 Ibid., 124.

8 My translations throughout. The phrase, ‘plus nu qu’un ver’ does not translate well into English. In French it is a commonplace simile.

9 See, for example, Masha, 2005.


11 There are repeated references to people crossing the road to avoid walking near an albino and to the segregation of albino children in not allowing them to attend school in the publications of ZIMAS (Zimbabwe Albino Association) and NOAH (National Organisation for Albinism and Hypopigmentation).


13 Destremeau, 2002, 47.

14 Ibid., 237.

15 The reality is that in much of Africa, disabled people often remain excluded from education and employment, incapacitated by inadequate transportation systems and substandard living conditions. Poverty and a lack of healthcare and social security systems further aggravate the situation, putting the burden of care onto the family.


17 Sex is very much associated with youth and physical attractiveness, and when it is not it is often considered less acceptable. See Garland Thompson, 2002, 231-269.

18 Destremeau, 2002, 1.


20 For example, Charles Martin’s sweeping statement that ‘the skin conditions of albinism and vitiligo cause little or no physical debilitation’ is typical of the many misunderstandings about albinism. See Martin, 2002, 186. Although Martin fails to acknowledge the practical problems caused by non-pigmented skin, he does note the stigma attached to albinism.

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The Aesthetics of Self-Representation in Pregnancy and Childbirth

Lisa Szczerba

Abstract
Through this chapter I will explore women’s artistic self-representations of pregnancy and childbirth, highlighting common representational strategies, themes and motifs. My perspective has been informed by the literature from a wide range of disciplines, much of it bridging work from psychoanalysis, women’s studies, cultural studies, nursing scholarship and aesthetic criticism. By acknowledging works of ‘everyday creativity’ as well as analysing those of established, artistic practice, it is my hope that the audience will gain insight into some of the ways in which women creatively represent their experiences of this phenomenon. The study includes an aesthetic analysis of Carol Maso’s (2000) journal, The Room Lit by Roses, Rian Brown’s (1999) short autobiographical film, Presence of Water, and Anne Harris’ (1996-97) painting, Second Portrait with Max.

Key Words: Self-representation, subjectivity, pregnancy and childbirth, self-portraiture, autobiography.

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Theorists from a variety of fields assert that women’s bodies are often the site where much of their significant life experience transpires, and thus these bodies serve as the backdrop for much thinking about the female self. Moreover, many have argued that the bodily experience of pregnancy / childbirth is a potential plot point around which a woman’s story pivots. The vital connection between female experience and embodiment has its roots in women’s privileged reproductive status as potential child bearers. It is therefore not surprising that so many women - both those who identify themselves as artists and those who don’t - follow the impulse to express this bodily phenomenon through creative means.

This chapter will explore women’s artistic self-representations of pregnancy and childbirth, highlighting common representational strategies, themes and motifs. By acknowledging works of ‘everyday creativity’ as well as analysing those of established, artistic practice, it is my hope that the audience will gain insight into some of the ways in which women creatively represent these experiences. This analytical model may be useful for practitioners to employ when working with aesthetic representations of such bodily phenomena and those people that create them. By initially looking at the creative work, what emerged was a pattern of narrative strands leading to
a network of relationships: to the artists’ family members, her culture, her work, her own body, and her issues around privacy. The results suggest both common strategies as well as portrayals that are unique to each woman.

What can we learn from these works? What insights can they give us about the deeper and more eternal meanings of pregnancy / childbirth, and how might this knowledge inform practice? How might it shape the ways in which pregnancy / childbirth are understood by clinicians, as they gain deeper insights into the experiences of their patients and clients? And lastly, how might this understanding encourage both creators and those with whom they work to look at the experience of pregnancy / childbirth as pro-creative and normative, rather than as a variant of illness? Pregnancy has been culturally constructed as a variant of illness, when in fact it may be more useful to understand it as liminal: simultaneously normative and non-normative. Being pregnant in contemporary western culture is to be thrust into a paradoxical situation: one plays out an eternal, mythic and privileged role, while having one’s body inscrutably attended to, if one is fortunate, by a team of medical experts who employ the latest technology in rationalising the experience. I hope to draw attention to the implicit constraints of this thinking about the pregnant woman as situated in either health or in illness, encouraging us to consider the phenomenon from a more elaborated perspective than this duality allows.

After studying a variety of works representing the theme, I chose to perform a close aesthetic analysis of three works: Carol Maso’s journal, *The Room Lit by Roses*, Rian Brown’s short autobiographical film, *Presence of Water*, and Anne Harris’ painting, *Second Portrait with Max*, from the painting series *With Max*. Delimitations were closely drawn in order to acknowledge the potential impact that cross-cultural, racial, and historical factors undoubtedly play in the experience.

In *The Room Lit by Roses: A Journal of Pregnancy and Birth*, author Carole Maso writes using a variety of means: poetry, traditional prose, and freewriting, thus defying traditional generic boundaries. These unconventional strategies aptly reflect Maso’s attitudes toward similarly unconventional choices that she has made with respect to writing, partnering and mothering. Her choice of alternative strategies suggests the variety of themes that she associates with her own experiences of conception, pregnancy and childbirth; her own physical, psychological and hormonal transformations, and the unexpected ways that they play out in her daily life; her ongoing resistance to conforming to societal pressure in her personal and professional lives; and her connection to and belief in the timeless spirit of her child - even prior to its conception. Breaking and re-creating stylistic rules and conventions mirror the author’s experience of her pregnancy and childbirth. Thus, her unconventional narrative form provides an ideal vehicle through which to portray and examine her unconventional pregnancy.
Rian Brown’s short film, *Presence of Water*, is noteworthy for its teasing of boundaries between experimental and narrative storytelling. The film is remarkable for its evocative, lyrical quality, layering realistic and abstract imagery with sound. In addition to its stylistic complexity, *Presence of Water* highlights significant themes that arise in the first-person narratives of many women on the brink of motherhood: childbirth as a liminal stage in one’s adult identity, and the conscious decision-making in passing on of one’s maternal lineage versus the desire to forge new practices.

Consistent with the avant-garde aesthetic, this film does not follow traditional narrative film conventions; instead it relies on extended montage sequences, grainy, documentary-like footage, abstracted visuals, and non-synchronous sound in order to evoke what the filmmaker refers to as the ‘oestrogen-induced dreaminess’ that permeates the work. In this way, Brown creates a film whose representational strategies are consistent with the often amorphous qualities of pregnancy: the ever-changing shape of the physical body, the inexplicable nature of psychic osmosis in the sharing of essential fluids between mother and foetus, and the evolving identity of the mother and child dyad as they, in the months following childbirth, cleave into distinctly separate individuals.

Rhetorically, the film moves back and forth between abstractions of water (e.g. the warbling of a sonogram) and journalistic reminiscing. There is no synchronized (sound and visual) live-action during the film. Instead, it is characterised by pensive voice-overs (usually the artist’s, sometimes her husband’s) together with ambient sound, and slow-motion visuals, intercut with sounds and visuals of water. The central portion of the film is composed of sequences shifting against one another, sometimes overlaid as transparencies, creating a montage effect similar to that of human memory.

*Second Portrait with Max* is a highly realistic, nude self-portrait, painted by Anne Harris during her third trimester of pregnancy. It explores the artist’s fascination with manipulating likeness and the plasticity of the human body. While she identifies the paintings in her *With Max* series as self-portraits, she uses the genre as a starting point from which she then departs, distorting her pregnant body to extremes both beautiful and horrific. Moreover, she highlights the skin’s function as a membrane that simultaneously contains and protects both mother and child. Harris renders the skin as a translucent material, thus drawing attention to the very visceral qualities of the body. *Second Portrait with Max* depicts two levels of morphic distortion: the inevitable distortion of the pregnant body during the third trimester, as well as the distortion which Harris renders through artistic license, specifically her emphasis on the engorged, lactating breast and the linea nigra.

In this painting, Harris creates an ethereal representation of the self despite the stark directness of the figure’s pose. Moreover, the painting
portrays numerous themes related to pregnancy and the physical transformation of the female body: the body as an envelope of mutable identity, the skin as a translucent container of contents and barrier to the external environment, self-conscious reference to historical iconography, and pregnancy / childbirth as an ideal opportunity to explore notions of mutability and identity.

The painter renders the figure with minimal use of line, often blending - or at least not marking distinctions - between separate volumes. For example, the boundary between the abdomen and the arms is fused at their tangential point. The artist uses the same technique in blurring the boundary between the forearms and the backdrop, thus manipulating both colour and line to give the viewer an overall sense of seeing the subject as if through a filmy, gauze scrim. This obscurity is visually interrupted though, by the excruciating detail with which the artist renders her facial features. This technique emphasizes the merging of figure with ground - both within the frame, and for the artist and her external world. Thus, she simultaneously creates both a sense of unity (between figure and ground) as well as a lack of differentiation for the figure within its setting, thus subtly anticipating the artist’s concerns regarding the no longer distinct and crystallised quality of her evolving self-image.

This self-portrait radically opposes traditional self-portraiture strategies of childbirth / pregnancy that emphasise the more nurturing aspects of this phenomenon, and especially of the mother. Her employment of a hyper-realistic painting style in rendering a ghostly image opposes the viewer’s natural tendency to view the body of the Mother as one that invites either identification or sentimentality. Through the strategic use of colour and detail, the artist depicts the body as corpse-like and with the detached gaze of a surgeon, thus inviting a similarly clinical relationship between viewer and painting. Ultimately, this detachment is freighted with the rich history of maternal iconography and archetypes. In the historical and cultural context of American popular imagery in the twentieth century, images of the Maternal body are frequently rendered as nurturing and sentimental; conversely, much of this painting’s power resides in its invocation of the Maternal as grotesque and powerful.

I utilized a two-part model focusing on representational strategies and themes / motifs. Representational strategies refer to the ways in which the unique capabilities of each art form enables or affords distinct modes of communication, and with it distinct story content. Literary work affords the writer the opportunity to manipulate linguistic strategies, especially with respect to literary devices, subjectivity, point of view, and reflexivity. The visual arts afford the artist the opportunity to manipulate sensory, formal, technical and expressive properties of a surface. Lastly, film makes use of
both linguistic and visual strategies, yet contains additional unique capabilities.

According to personality theorist Dan McAdams, two fundamental themes found in much personal storytelling are Agency and Communion\(^7\). I began exploring the variants of themes and motifs in the selected works, by looking for evidence of either of these independent factors. McAdams describes agency and its story motifs as comprised of 1) Strength / Impact; 2) Status / Recognition; 3) Autonomy / Independence; and 4) Competence / Accomplishment. Communion and its story motifs are comprised of 1) Love / Friendship; 2) Dialogue / Sharing; 3) Care / Support; and 4) Unity / Togetherness\(^8\). This matrix proved a successful starting point for drawing out further motifs and relationships in the work.

Representational strategies employed by the artists reflected their deliberate manipulation of language and visual means. Themes and motifs that emerged grew out of the representational strategies. By intercutting text from childbirth education literature, author Carole Maso contrasts it with her own, implying textual irony. Since as focaliser, her tone is the normative one, the authorial voice of the literature suggests something at once awkward and cold, perhaps even the patriarchal world against which Maso positions herself. The disembodied voice of the educational material is chosen in order to act as a foil for Maso’s experiential point of view, in effect highlighting the distance between ideological perspectives, and the epistemological distinction between knowledge derived from the authority of the establishment and that gained from one’s own bodily experience\(^9\).

Both Maso and Brown employ traditional techniques for advancing a narrative, as well as lyrical passages (e.g. montage, poetry, freewriting) that serve to interrupt this narrative progression at portentous plot points, elaborate on them, and ultimately return back to the narrative arc. Both Maso and Brown rely heavily on the journal form, a reiteration of the official childbirth literature women are given to read during their pregnancy. This literature functions as a discursive constraint, shaping the way in which women story their pregnant existence. It attends to the developing embryo in minute detail, rationalising the experience in physically developmental terms. Illustrating the way the experience of pregnancy is shaped by chronology, Maso writes, ‘And so it is possible to say, when asked what you have been doing - I made two human feet today.’\(^10\) The journal is a form uniquely suited to self-representation for the pregnancy / childbirth experience. Maso’s choice of a journal, with entries partitioned by date, chronicles the physical development of the embryo as a twin narrative strand: the narrative of the pregnant mother intertwined with the narrative of the developing embryo, forming a double-helix. Filmmaker Rian Brown structures her work in journal form, highlighting entries by date, stressing chronological time and foetal development. Lastly, painter Anne Harris
employs a similar chronological strategy in *Second Portrait with Max*. But in Harris’ work, the sequencing is only evident when looking over the range of her *With Max* series: *First Portrait with Max*, *Second Portrait with Max*, and *Third Portrait with Max*. Each of Harris’ paintings portrays a different developmental period in the artist’s changing body, affording her the opportunity to represent chronology in a manner that cannot be communicated within a single, static image.

Motifs emerged in the following clusters: references to the child’s father, metaphors of the wild (animals and the natural world), malleable bodies, intergenerational linkage, personally relevant gestational periods, and contextualised relationships.

One of the significant connections between Maso’s *The Room Lit by Roses* and Brown’s *Presence of Water* are the artists’ strategy of simultaneously emphasising their babies’ fathers while leaving them unnamed. Both artists draw attention to this effaced quality: Maso by referring to ‘the mysterious e’tranger’ and Brown by the conspicuous use of ‘he.’ Both artists assign the father a position of some prominence, but by leaving him unnamed, open up an interpretive gap that indicates a large degree of ambiguity for the beholder. The strategy draws attention to the father’s existence, but raises the question of the father’s role in the mother’s understanding of her own story. Such a deliberate exclusion of the father serves to highlight the centrality of the mother as well as designate a hierarchical structure within the phenomena of pregnancy / childbirth.

Significantly, both Maso and Brown chose to metaphorically represent themselves during pregnancy as wild animals. Brown says, ‘I have come here like a wolf. I have found a safe place to bear my cubs[,]’ while Maso writes, ‘My mane grows wild and I stare. Into space forever. Lion haired. My nails grow strong and sharp. The eye searching the horizon line.’ Both Erich Neumann in *The Great Mother: Analysis of an Archetype* and Birkhauser-Oeri in *The Mother: Archetypal Image in Fairy Tales*, seminal works in archetypal representation, discuss the representation of the mother as an animal. Birkhauser-Oeri writes that animals, ‘live out their drives and instincts without the restraints of conscious, rational considerations which inhibit human beings[,]’ and therefore, such representations of Mother as Animal inhabit and emphasize those same characteristics and drives.

In addition to looking to animal metaphors, Maso and Brown each rely on an aspect of the natural environment as a leitmotif: for Maso it is Air and for Brown it is Water. Maso’s use of language and story content refers to angels floating, her conception in an airplane, and descriptions of effervescence and looking through the atmosphere at her (imagined) child waving from a distance. Brown’s film title references water, and the sound of gurgling and frothing hyper-blue water, abstracted images of a brook (that
evoke a more general sense of the human body as water-filled), and the indirect reference of water with one’s emotional life carry her film.

There is a significant emphasis on plasticity or malleability of the body during pregnancy. Maso describes pregnancy as ‘Fragile, evolving, and in motion. Continuous and discontinuous’. Scholars have characterised the pregnant woman as an essentially empty vessel that exists solely to serve the foetus, thus ignoring this unique developmental stage for the pregnant woman. This motif of the pregnant woman as empty vessel resonates in the selected literary autobiography and autobiographical film. The artist’s awareness of herself as a body containing a body - a doppelganger - refers to the physical body, but has far-reaching psychological consequences for personal identity and understanding of the self at this time. For nine months, the pregnant woman is no longer one person, but two. She shares her body and her nutritional resources; she sacrifices her shape and breathing for the other. Painter Anne Harris also emphasises the malleability of the pregnant woman’s body, but her work embodies this malleability; she doesn’t just write about it. While Maso and Brown use language to describe what it feels like to inhabit a woman’s evolving body, Harris demonstrates this malleability, by exploiting the plastic potential of paint and the painting surface in manipulating her self-image into often grotesque permutations.

Both Brown and Maso chose overt representational strategies for communicating intergenerational transmission, or linkage between mothers and daughters. Brown’s film contains such an embedded biography. In fact, the filmmaker posits two vastly different mother models: one (her own mother) who offers sage advice for coping with the future’s indeterminable challenges and responsibilities, thus relying on a mother archetype characterized by wisdom and experience. The second mother-model (Brown’s mother-in-law) is presented by way of the film’s dialogue on housekeeping and cooking traditions, and relies on a more retrogressive mother archetype - one associated with the maintenance of cultural traditions. Nancy Chodorow contends, ‘among women, motherhood in part regains a sense of being mothered’. And author Jo Malin advances the thesis that contemporary women’s autobiographical texts commonly contain embedded biographies of their authors’ mothers. The aesthetic findings from Maso’s and Brown’s work corroborates this perspective, in both containing embedded narratives of the artist / mother’s mother, as well as serving as an opportunity for reflection on how one was mothered. This was handled in various ways: both in reminiscing of past experiences, as well as commenting on contemporary experiences and conversations that the artist had with their mothers.

Gestation periods are another forum for creative manipulation by the artists. Maso shapes the very definition of pregnancy and its gestation period to suit her own experience. While the allopathic medical community and
western worldview conceptualise pregnancy as a carefully-boundaried medical phenomenon, Maso stretches the boundaries of her relevant experience to include the period prior to conception and beyond birth, yet triangulates off of the clinical and popular literature, language, and framework. She refers to her daughter as a being that existed prior to conception - as an imagined and ethereal being, becoming, all potential waiting to be realized. In this way, the author figuratively stretches the gestation period beyond the forty weeks traditionally defined by the medical community, into one that contains longing and desire as vital and necessary preconditions for Maso’s conception. She writes of longing as a precondition.

Both Brown and Harris address gestational periods within the very structures of their work: both articulate their projects based on discrete stages of pregnancy. Brown divides her film into three major parts (trimesters). She begins her story with a discussion of geographically re-locating for her pregnancy, and ends it with her return back home to the United States, after her child is now a roving toddler. Thus, her gestational period is not boundaried by the in-utero experience, but by travel: by leaving and returning home.

Harris painted her *With Max* series as an expression of the evolving nature of the body with each successive shift in her pregnant profile. Thus, the overall series encompasses her entire experience, including paintings that reveal close-ups of her baby’s face and clenched fists. Thus, the existence of the child is included as a central figure for each of the artists.

The contextualising of the pregnancy and childbirth experience within the broader context of one’s life is a central strategy for both Carole Maso and Rian Brown, as they incorporate their experiences of pregnancy with other significant relationships. This challenges the allopathic medical model of pregnancy as a solely clinical, bodily phenomenon - thus rendering it obsolete, since it ignores it as a social and politicised construct, heavily inflected by cultural complexities. Brown layers her experience of pregnancy with cross-cultural concerns, her abrupt confrontation with old-world European peasant values and traditions, and Maso positions hers against the complexities of the academic world and social conventions. In doing so, both women position themselves against a self-other backdrop in order to heighten dramatic tension. This strategy serves to distinguish the protagonist - the artist - from her environment, as a figure-ground strategy.

Ultimately, the self-portrayal of pregnancy and childbirth through the representational strategies discussed, reveal lived experiences that are far more complex, personal and inchoate than could ever be adequately represented. Embedded in the works themselves, is the message that these lived experiences are ultimately reified through representation - they cannot be portrayed authentically, except as the inevitably insufficient attempts that they are. The nature of representation is revealed as noble, but as generally
inadequate to sufficiently capture dynamic, lived experience: impossible to be contained by expression. Although the works themselves are descriptive in nature, the artists’ larger objective is clearly generative: to provide a supplementary, aesthetic experience that ultimately enriches the portrayal of the experience and directly or indirectly challenges the dominant definition of this phenomenon.

Only when pregnancy is expressed through narratives that emphasise lived experience can it transcend its status as a solely clinical event - neatly framed by separate trimesters - that is articulated by the medical community through sonograms, blood and urine analyses, and amniocentesis results. Thus, the subject’s portrayal of pregnancy and childbirth reveals the experience to be dynamic and multi-layered, influenced by the dynamics of her social and personal life. Therefore, the over-arching meaning of this conclusion is not about the individual meaning of any given self-representation or aesthetic strategy, but about the uniqueness of each, which counters the model narrative of pregnancy / childbirth as it exists in the popular educational literature and formal/informal teaching passed on to women.

Notes

1 Maso, 2000.
3 Harris, 1997.
5 Neumann, 1983. The author provides an exhausting encyclopaedia of images giving precedent for visualizing the image of Mother in a variety of complex ways, representing both the ‘terrible’ and the ‘good’. Neumann’s work is valuable for many reasons, but for this analysis, it provides the necessary conceptualisation of the maternal image as one that has not always been associated with gentle and nurturing qualities.
6 Silverman, 2003. Based on aesthetic and educational theorist Harry Broudy’s *Enlightened Cherishing: An Essay on Aesthetic Education* Silverman developed a comprehensive methodology for the aesthetic analysis of works of art, that calls for the explication of a work through the analysis of four distinct properties: sensory, formal, technical and expressive.
7 McAdams, 1993.
8 Ibid, 297-299.
9 Belenky, et al., 1997. The distinctions between these epistemological positions are richly developed in *Women’s Ways of Knowing*. Belenky et al. distinguish between possible ways of knowing: received knowledge, subjective knowledge, procedural knowledge, and constructed knowledge.
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PART III

Myths and Metaphors
Finding Meaning through Metaphors: Following a Narrative Thread from Experience to Research to Classroom

Jasna Krmpotić Schwind

Abstract
Life is made up of experiences, which are shaped through the stories we tell about them. It is through these narratives that we ‘articulate and understand ourselves’ and the world around us. In my doctoral work I explored, through the process of narrative inquiry, three nurse-teachers’ personal experiences of serious illness. The multidimensional nature of narrative inquiry helps us, through its reflective process, to reconstruct these past experiences, glean new meaning from them in the present moment, and by so doing affect our future ways of being in the world. Through personal stories, metaphors, letters, poems, and drawings my co-participants and I were able to explore our individual relationships with our respective illnesses. For example, Ruth’s liver wrote her a ‘forgiveness letter’ in form of a poem, Elizabeth was able to express her life with lupus through a series of drawings depicting herself as a flower, I in turn wrote myself a letter from my ‘messenger tumour’. All three of us revisited our illness events through the buffer of metaphor, which allowed each of us to ‘broach a painful situation and turn it on its head in order to examine it more closely and make sense of it’. Metaphors thus may serve as useful tools that help us ‘make connections between a concept that is difficult to grasp, such as a serious illness, and a similar one that we are already comfortable and more familiar with’. In summary, I believe that the reflective process of narrative inquiry brings to the fore the learning that can arise from purposeful self-exploration that results in change and growth, not only in ourselves, but in the healing of those in our care.

Key Words: Narrative, metaphor, serious illness, self-exploration, healing.

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Journal entry on my initial encounter with a serious illness:

It is a regular late February day in south-western Ontario…cold and windy with frozen snow on the ground. I am going in for an annual physical exam. This year’s exam is a little different in that my husband and I are preparing to start our family. I am giddy with excitement. Dr. Jones, an expert diagnostician, begins his routine head-to-toe exam. During these exams we usually chat about our
common professional interests, that of emergency care. This time however, I am asking questions about the relationship of Toxoplasmosis to pregnancy. Suddenly he interrupts me and asks me to swallow. I do as he requests and continue with my questions. Dr. Jones stops me again repeating his request. I swallow as his fingers gently press around my trachea. I know that he is assessing my thyroid … but he does so every year. I am mildly annoyed that he keeps on interrupting my excitement. When Dr. Jones interrupts me for the third time I inquire if there is a problem. He says that he can feel a little nodule on the right side of my thyroid gland. The word ‘nodule’ alarms me, and my stream of questioning changes immediately to the newly presented findings about my thyroid. What does he think it is, I ask. He responds cautiously that he is not too sure, but that it needs to be investigated. We both become silent. In his own way of trying to break the tension he tells me not to go home and traverse all the medical books looking for what could possibly be wrong, adding that we nurses are notorious for jumping to conclusions too quickly. The rest of the exam is a blur for me. My mood is subdued as I leave the office. In my head I am scanning all the possibilities.

It seemed to me that my life changed forever that day in the doctor’s office. Not the way I had anticipated, of having a family, but in the most opposite way, of eventually being diagnosed with a malignant tumour of the thyroid gland. I encountered this illness on two major levels: personal and professional. Jasna the person was scared of that illness whose name starts with the letter ‘c’. She had heard stories of curtailed dreams and shortened lives by such sicknesses. Jasna the professional knew the chances of having a malignant thyroid tumour and the options available to deal with it.

It is not until several years later that I was well enough to consider my own illness experience as a basis for research. In the sphere of my doctoral studies, I questioned: ‘What impact may a serious illness have on the personal and the professional life of a nurse-teacher, like myself?’ and ‘How would the shift from the role of a caregiver to that of a carereceiver play out in nurse-teacher’s interaction with her students and patients?’ To deepen the scope of my research I invited two nurse-teacher colleagues, Elizabeth and Ruth, who themselves experienced illness, to join me on this exploratory journey.

Elizabeth was in her twenties when she first experienced exhaustion and fever that were attributed to the flu and end-of-semester fatigue. In the
past three decades that she has been living with lupus, Elizabeth has experienced numerous side effects of the illness itself as well as from the treatments for the illness. She commented, ‘The thing with lupus is that there is no ‘ten years’. It’s with you. It’s forever.’

Ruth was at work when her colleague commented that her eyes were jaundiced and advised her to seek immediate medical attention. Ruth’s liver, in response to an arthritis medication, was in severe toxic shock, nearly requiring a liver transplant. Her road to recovery was challenging and painfully slow. Today, Ruth still lives in the shadow of fear: not knowing how her liver would respond should she ever require any pharmaceutical treatment again.

Through the process of narrative self-expression such as storytelling, metaphor, drawing and creative writing, Ruth, Elizabeth and I explored our respective illnesses and their impact upon our lives. We began by sharing our individual illness accounts. This process brought up for us some painful feelings and dreaded memories. Realizing that we need to delve deeper beyond the surface layer of words, no matter how thick this layer may be, I suggested that we each choose a metaphor for our respective illnesses. I believe that metaphors help us create a link between a new idea that may be too complex to comprehend or a feeling too painful to behold, and another, already known concept that we are comfortable with. In this way metaphors are an arc between the current understanding and the new enlightenment, be it in terms of cognitive comprehension or psychological meaning-making. In relation to the illness experience, I propose that metaphors could be safe zones where individuals may dwell for a longer time in order to chip away at the iceberg-like shape of their traumatic event, and thus make sense of it.

Through her metaphor, illness as a pathway that leads her to a fork in the road, Ruth began to recognize the role her illness had played in her decision to enter early retirement and to take a job she cherishes. Exploring her metaphor further Ruth became aware of the fullness of her private as well as her professional life. She realized that these demands challenged her desire to live more holistically. This notion was further supported by Ruth’s two drawings, where only one was requested. She created separate images, denoting her personal and professional life respectively, under the title *Myself in Relation to my Illness.*

Drawing is one of the modes of narrative self-articulation that allowed my co-participants and I to access the ‘depths of our being unreachable by words’. Through this process the images emerged that prompted further questions while uncovering possible answers.

Writing creatively consisted of receiving a letter, or a poem, from our respective illnesses. By doing this we gave them a voice, and thus found that illnesses do not always have to be the ‘wicked assailants’, but may, in
Finding Meaning through Metaphors

some way, just be there to ‘do their job’, like my thyroid ‘Messenger Tumour’. Both the letters and the drawings provided images that helped us, through metaphoric reflection, to more fully articulate our illness experiences and our relationships with them. By stretching our thinking and expanding our understanding in this way, we were able to make connections between the illness and its place in our personal and professional contexts.

Through my role as a researcher I was able scholastically to examine the narrative plotlines that became apparent through the reflective process that Elizabeth, Ruth and I undertook: diminished patient’s voice within the caregiver - care receiver relationship, objectification of the patient, disconnectedness of the mind and the body of the caregivers, and the illusive identity of both, the caregivers and the care receivers. I thus learned that the weakest link in the caregiver-care receiver relationship is, in fact, its humanness. Based on this revelation, in form of a letter to my professional colleagues, I suggested that nurse-teachers focus, in addition to the science and the skill of nursing, on its art. When I returned to my nurse-teacher role I decided to take my own council and so, as part of my teaching-learning methodologies, I applied the same narrative self-expression process: storytelling, metaphor, drawing, creative writing, as I did with Elizabeth, Ruth and I, with my fourth year nursing students. I thus learned that the weakest link in the caregiver-care receiver relationship is, in fact, its humanness. Based on this revelation, in form of a letter to my professional colleagues, I suggested that nurse-teachers focus, in addition to the science and the skill of nursing, on its art. When I returned to my nurse-teacher role I decided to take my own council and so, as part of my teaching-learning methodologies, I applied the same narrative self-expression process: storytelling, metaphor, drawing, creative writing, as I did with Elizabeth, Ruth and I, with my fourth year nursing students.

I shared with my students the notion that each life experience contributes to who we are personally and professionally, and that by revisiting our past experiences we may learn and thereby increase our understanding of who we are in the present moment. In other words, through personal narratives we reflect on our life experiences in order to make sense of them, and in this way, to construct new, more positive ways of being in the world.

As an initial step of the process, in the fall term, I invited the students to think back on their life and to note what memories came up for them. They were to write a story for each of these remembered events. I urged them to pay attention to how their emotions and feelings played out in their bodies in response to each of these reminiscences. I then recommended that, at a later time, they review their writing to learn if there was a common thread that ran through these events. I further invited them to explore how the string of these stories contributed to where they were at that moment, personally as an individual, and professionally, as a nurse.

Later in our seminar class I suggested that students share a story of their choosing with two of their classmates. By hearing about others’ lives we learn about our own. Conle suggests that by telling and retelling our stories and ‘with the resonance provided by an audience, some tacit elements become more explicit’ thus allowing a possibility for insight and growth. This process of recounting our various life events leads to deepened awareness and becomes a vehicle through which experience gains meaning.
In this way, not only is the author altered in the process, but so are the receivers of the told stories as these become part of their own life narratives.

I also cautioned my students that some of their stories may be intensely personal and emotionally charged, while others may simply be events that stood out in their minds, and that for this reason to choose wisely what part of themselves they felt safe to expose. After hearing one another’s stories the students wrote each speaker of their small group a response letter on how their narratives might intersect; that is, how their classmates’ accounts may have shed light on their own life experiences, and how hearing one another’s narratives might impact their future personal and professional paths.

Another homework assignment for the students consisted of finding a metaphor for their life and responding to some guiding questions designed to assist their reflective process. For example: ‘What metaphor would you choose to represent your life? What does that metaphor mean to you? How does it help you understand yourself and your professional practice?’

Once the students had their life metaphor in place I asked them to draw it. Finally, I suggested that they have their metaphor write them a letter to see what it would tell them. Bonnie’s life metaphor, the ring, concluded its letter to her with encouragement and advice:

Do not forget, the good does not come without the bad. As you look at me (a ring) you see everything that encompasses your life. You have a few minor scratches for those events that were not very pleasing. … And then there are those invisible scratches, the good in your life. All in all, both the scratches and the smooth surfaces of the ring are what hold the ring together; it makes up one ring, which cannot be destroyed. It makes up you!

Your Ring.

In the winter term, I moved the reflective process more overtly from the personal to the professional. I asked the students to reflect on, and then respond to, a number of questions on the notion of caring in relationship to nursing. They were invited once again to choose and draw a metaphor, only this time it was to represent themselves as caregivers. As they described the qualities of their chosen metaphor, I encouraged them to ask themselves how they were like that metaphor. Glenda’s metaphor for herself as a caregiver was a willow tree. She described the characteristics of the tree and reflected on how her caregiving qualities are the same. She wrote:
Dynamic: I am continually moving, learning, improving. I am able to care for others who are sometimes unable to move for themselves.

Protective: Like the branches of a willow tree I can care for people by protecting them. I advocate for people who, because of their circumstances can’t care for themselves.

Strong, Solid: It is the trunk of the tree that gives it strength. My caring trunk is my life experiences and the knowledge that I have learned.

Subsequently, I invited the students to consider the two images they had created over the two terms: life metaphor and caring metaphor. They reflected upon such questions as, ‘How are these two images connected to one another? and What aspects of my images do I recognize in me?’ By exploring the chosen metaphors the students learned how they interact with life and what qualities of their own caregiving are embedded in that interaction. For example, for her life metaphor in the fall, Louise chose, what she termed, a ‘sky-walker’. She saw herself walking on a tight rope, way up high, while maintaining her balance by strict, rigid focus and a long stick in each of her hands. In her letter from her metaphor Louise spoke of how the sky-walker ‘entertain[ed] the audience’ by doing and saying whatever they wanted her to do, ‘just to make other people happy.’ When it came to finding a metaphor for herself as a caregiver, the following semester, Louise chose an owl to represent her. She felt that the owl, as a symbol of wisdom and knowledge, corresponded to her own ever-expanding nursing knowledge. Louise likened the owl’s ability to keep an eye on the surrounding areas by rotating its head 180 degrees, to her own conscientious watchfulness over her patients. The owl’s nocturnal activity reminded Louise of herself working night shift, being alert and caring for her patients when the rest of the world slept.

When I asked Louise if she could see any connections between her life metaphor and her caregiver metaphor she hesitated at first, but when I suggested that she look at both images and describe their characteristics, the common threads began to emerge for her. Louise’s insecurity and the tension of walking the tight rope, and the fear of falling down, the way she saw her life at the start of her school year, evolved for her in the winter term to an owl, a bird that is strong and confident, that negotiates the sky with ease and grace. As a result, Louise was able to reflect on how she developed as a nursing student over the academic year. She became more confident in her knowledge, nursing skill and compassion.

At the end of the school year, in my last e-mail letter to this group of students, I urged them to revisit their metaphors from time to time, especially when they might need to refocus their life or to ground themselves. Although
our life metaphors may change according to circumstance and developmental life-stages we find ourselves in, I believe that the core values and beliefs inherent in the chosen metaphors remain constant. Consequently, metaphors, which may be accessed through creative narrative expression, may be used, not only as guiding posts along life’s path, but also as venues into the depths of ourselves, where humanness lives. By reaching our own humanness we become available to connect with the same in others. In healthcare this means that it is only when we are in touch with our own human-self that we may relate on that same level with our patients. Why is that important? Because the experience of illness permeates both, our physical body and our ethereal soul. Illness shakes us to the core and often forces us to examine the life path that we have been on. I agree with Kleinman, that ‘nothing so concentrates and clarifies the central conditions of living as serious illness’. With this in mind, I suggest that the human dimension of being cannot be taught as an extrinsic object. It is a lived dimension of who we are, and in order to teach it we need to live it. Therefore, when we teach caring we need to acknowledge our students’ personal knowing as a possible core curriculum thread and so need to guide them through a reflective process that brings this part of themselves to the fore.

By exploring life experiences through narrative, a doorway opens to the possibility of examining the relationships between our past experiences and our current ways of being, and in so doing creates new learning possibilities for the future. The stories, which may take shape of words, drawings and metaphors, are told, constructed, reflected upon, deconstructed, and then retold, reconstructed, with the intent of gleaning deeper meaning from the experience in our personal and consequently our professional lives.

Together, my students and I explored the role of metaphor as a possible tool for gaining understanding of how their personal life events may contribute to who they are as persons and graduating nurses. The paradox of human beings is that we are each unique and individual and yet, at some level, we are the same. It is at this level that our individual narratives are generalisable. By participating in the narrative reflective process the students were able to learn more about who they are, and how that awareness may impact their caregiver-carereceiver relationships. Narratives of our life experiences, when shared with others, contribute to the development of caring in relationship. Narrative research facilitates teachers and students to tell their stories of experience. In this way, transparency in the narrative plotlines helps them enact new stories of relationships with their patients. This newly constructed knowing then allows them to make conscious choices in how to enter into future caregiver-carereceiver encounters more holistically. My own narrative thread of illness has thus moved from personal experience, through research, education, and hopefully back into the
field of praxis, where knowledge and experience interface in my students’ interaction with their patients.

Therefore, to restore the humanness and caring into the care receiver’s lived experience of illness, we as caregivers need to value our own life narratives, especially the ones of illness, as well as those of our students and patients. In this way we encompass not only the human, caring aspect of healthcare but also the theoretical and technical aspects as well: we provide holistic care. Through that process the illness experience of a fellow human being is given voice and is thus honoured.

*I would like to acknowledge and thank my students who kindly agreed to share with me their personal writings based on the class and homework assignments.

Notes

3 Clandinin & Connelly, 2000.
4 Schwind, 2003, 28.
6 Toxoplasmosis: ‘A disease due to infection with the protozoa Toxoplasma gondii. The organism is found in many mammals and birds.’ From: Thomas, 1989, 1885.
7 Schwind, 2004, 6-7.
12 Schwind, 2004, 56.
14 All student names have been altered to protect their privacy.
15 Conle, 1999, 12.
16 Kleinman, 1988, xiii.
17 Young et al., 2004.
18 Clandinin, 200.

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Metaphors of Health, Illness and Disease in Margaret Atwood’s Fiction

Teresa Gibert

Abstract
This chapter explores the functional significance of the metaphorical language used by Margaret Atwood in her novels and collections of short stories in order to ascertain how one of our most influential contemporary writers perceives health, illness, and disease. A close analysis of the metaphors in Atwood’s fiction reveals her various ways of approaching these multifaceted phenomena, which have always attracted her attention and which she has treated from different perspectives. Many of Atwood’s metaphorical expressions involve illness and disease either in the source domain or in the target domain, health being less frequently evoked than its two counterparts. Plants and fruit constitute the most commonly used source domains of Atwood’s metaphors that place both healthy people and ill people in their target domains. Rather than resorting to conventional metaphorical expressions, Atwood prefers to articulate the concept of illness by means of innovative similes. Atwood often places disease in the target domain when she associates it metaphorically with many different concepts, which include honesty (compared with psoriasis and haemorrhoids in Bodily Harm),¹ the use of swearwords (described as ‘a minor contagious disease, like chicken pox’ in Bluebeard’s Egg),² and even people who ‘spread themselves like a virus’³ or who ‘may be catching’.⁴

Key Words: Margaret Atwood, metaphor, disease, literature.

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Like many other postmodernist authors, Margaret Atwood regards metaphor essentially as an instrument to shape and convey thought, rather than a mere rhetorical strategy to embellish her writings. Throughout her works, we find numerous examples that prove how her metaphorical representations - both the ones she is promoting and the ones she is fighting against - are anything but neutral. She uses metaphor effectively in order to communicate perceptions of reality, ideas and values to an increasing number of readers. Therefore, if we consider that Atwood is one of our most successful contemporary writers, we will easily understand why exploring the functional significance of her metaphorical language is important for two reasons: 1. because her works reflect current attitudes, which we often take for granted, but seldom examine as critically as they deserve, and 2. because, apart from depicting prevalent views, Atwood is also exerting a great deal of influence
by means of her own metaphors, which function as persuasive devices and produce strong emotive effects upon her audience. By focusing on the metaphors which appear in Atwood’s novels and short stories - not only the ones she has drawn from everyday language, but particularly those she herself has constructed - we can fruitfully analyse any of the main themes and topics that attract so many people to her fiction. As the approach to metaphor propounded by cognitive linguistics provides extremely helpful explanatory tools to survey any field of human experience, we will apply such theoretical tenets in order to ascertain how Margaret Atwood conceptualises health, illness, and disease.

Many of Atwood’s metaphorical expressions involve illness and disease, either in the source domain or in the target domain, health being less frequently evoked than its two counterparts. Plants and fruit constitute the most commonly used source domains of Atwood’s metaphors that place both healthy people and people who are ill in their target domains. For instance, in Bluebeard’s Egg, Yvonne is described as ‘a plant - not a sickly one, everybody comments on how healthy she always is - but a rare one, which can flourish and even live only under certain conditions’. Likewise, in Life Before Man, Auntie Muriel is conceptualised as ‘their roots, their root, their twisted diseased old root’. Similarly, a woman suffering from breast cancer in Bodily Harm has bad dreams in which ‘the scar on her breast splits open like a diseased fruit’.

Rather than resorting to conventional metaphorical expressions, Atwood prefers to articulate the concept of illness through innovative similes. Thus, in The Robber Bride, the author refers to how Karen ‘could see the illness spreading on her mother’s skin, like the hairs on arms, gone out of control; like filaments of lighting, only very small and slow’. Karen’s mother is one of the numerous maternal figures who are presented as being afflicted with either real or imaginary illness, such as the unnamed protagonist’s mother of Surfacing, whose children ‘ceased to take her illnesses seriously, they were only natural phases, like cocoons’. In Oryx and Crake, Atwood’s latest novel, the metaphors used to describe how Crake’s mother fell ill and died contribute to the depiction of illness and death in the most grotesque manner: ‘In any case she’d picked up a hot bioform that had chewed through her like a solar mower’. In the same novel, the illness and sudden death of Uncle Pete is also represented with absolute disrespect, as an amusing matter to make jokes about: ‘Crake’s next news was that Uncle Pete had died suddenly. Some virus. Whatever it was had gone through him like shit through a goose. It was like watching pink sorbet on a barbecue - instant meltdown’. No reverence or pity is to be found in the treatment of sickness throughout this novel, which many readers may consider disturbing or offensive for various other reasons as well.

The main purpose of some metaphors is to amuse, for laughter often arises from improbable combinations. Such metaphors are central to any
analysis of Atwood’s humour. Her playfulness and her clever sense of the absurd account for a number of grotesque metaphors, which reinforce many other elements of grotesquerie that she herself has acknowledged when commenting on her fiction. And, when it comes to making fun of serious or unpleasant topics, Atwood seems to have no limit. It may be argued that illness and death are common sources of humour in most cultures if we bear in mind the number of jokes that deal with the disturbance or even the interruption of vital functions, perhaps as an attempt to cope with the most tragic events in human life. Some characters in Atwood’s fiction probably resort to this strategy in order to evade suffering and to fight despair in the midst of their painful existence. For example, the protagonist of Bodily Harm, Rennie, is absolutely devastated after a breast-cancer operation, but she is still strong enough to joke about it in a conversation with her surgeon. She asks him, ‘How much of me did you cut off?’ And when he gently replies, ‘About a quarter,’ she says, ‘You make it sound like a pie’. The metaphorical association of a diseased body undergoing surgery with a pie which is cut into pieces is intended to brighten up the bleak atmosphere of this passage. In the same page of the novel, Rennie makes another comic metaphorical link when a nurse tells her how lucky she is because there are no other malignant tumours in her body, unlike other patients who are ‘full of it, they cut it out and it just pops up somewhere else’. The nurse avoids the word cancer, and her euphemistic reference to it vividly reminds Rennie of bread popping up from toasters. The same humorous procedure is used later on in the novel, when Rennie ponders the words remission and terminal, the latter being associated in her imagination with ‘bus stations: the end of the line’. Whenever Rennie is able consciously to control her own train of thought, she actively seeks a positive perception of cancer by means of jokes. However, when she is asleep she cannot avoid the most gruesome aspects of her disease, for she dreams not only about a sort of centipede that crawls out of the scar on her breast, but also that she is full of white maggots eating away at her from the inside. Haunted by so many frightening images, there comes a point when Rennie imagines that she is infested and does not feel human any more. Still, she works hard at verbalizing her irrational fears by resorting to humour once again. She has not been swimming after the operation because ‘her real fear, irrational but a fear, is that the scar will come undone in the water, split open like a faulty zipper, and she will turn inside out’. Apart from her own thoughts and feelings, Rennie is aware of her mother’s perception of the disease: ‘Cancer was a front-parlour subject, but it wasn’t in the same class as a broken leg or a heart attack or even a death. It was apart, obscene almost, like a scandal; it was something you brought upon yourself’.
counter such widespread notions about cancer by patiently explaining to her that ‘it isn’t a symbol, it’s a disease’.  

In spite of Dr. Luoma’s wish to deprive cancer of its symbolic connotations, it nevertheless works as the central metaphor of Bodily Harm. Indeed, this novel is both about the cancer that destroys the human body of the protagonist and the malignancy that corrupts the body politics of the Caribbean country she travels to when life at home becomes unbearable to her. At the very beginning of the novel, the author uses a foreshadowing device to evoke disease, a concept that soon becomes the most prominent aspect of this narrative. On her way to the island of St. Antoine, during a stopover in Barbados airport, Rennie notices that ‘in the washroom there’s a blow-dryer for your hands, which claims to be protection against disease,’ and the third-person narrator observes about the protagonist: ‘She is all in favour of protection against disease’.  

Health is also mentioned early in the novel, in connection with Jake, Rennie’s former lover. The narrator’s comment about Jake, ‘He was healthy and healthy people are embarrassed by sickness’ also works as an effective foreshadowing device to anticipate that he will not remain with Rennie for long. Almost inevitably, Rennie falls in love with her surgeon, in spite of her efforts to avoid a situation she deems both inappropriate and ridiculous: ‘One did not look at doctors; doctors were functionaries, they were what your mother once hoped you would marry, they were fifties, they were passé. […] Falling in love with your doctor was something middle-aged married women did, women in the soaps, women in nurse novels and in sex-and-scalpel epics with titles like Surgery and nurses with big tits and doctors who looked like Dr. Kildare on the covers’.  

Apart from her relationship with Dr. Daniel Luoma, when Rennie speaks about the medical profession she also draws some inspiration from her own family background. Her maternal grandfather ‘had once been the doctor. Not a doctor, the doctor: they had territories then, like tomcats’. In the stories told by Rennie’s grandmother, he always came out as a hero to the extent that, when Rennie was little, she wanted to be like him. However, after a few years at school, she forgot about those plans because she had reached the conclusion that ‘Men were doctors, women were nurses; men were heroes, and what were women? Women rolled the bandages…’  

Once Rennie is diagnosed, she becomes so obsessed with her disease that she renders her sexual experiences exclusively in medical terms. Thus, even before the operation, while she was in bed waiting for Jake to come out of the shower, she felt that ‘she was only waiting for a certain amount of time to be over, as if she were in a dentist’s office, waiting for something to be done to her. A procedure.’ And when they finally made love, ‘her body was nerveless, slack, as if she was already under the anaesthetic’ so that Jake had to work hard at ‘trying to break through that barrier of deadened flesh’. After the operation, the sexual relationships between Rennie and Jake
became more and more unsatisfactory until they ceased altogether because, according to Rennie, ‘He was afraid of her, she had the kiss of death on her, you could see the marks. Mortality infested her, she was a carrier, it was catching’.28 But, rather than give way to her frustration in an absolutely bitter manner, Rennie resorts to humour again as she recalls ‘something she had seen written in a men’s washroom once when she was doing a piece on graffiti. Life is just another sexually transmitted social disease’.

The rendering of sexual experiences in medical terms is not restricted specifically to Bodily Harm, a novel published in 1981. This connection is also prominent in Atwood’s first novel (written in 1965 and published in 1969), The Edible Woman, where sex relationships are far from being pleasurable activities. The protagonist of The Edible Woman, Marian, recalls her fiancé’s caressing her in bed in terms of a clinical check-up on a doctor’s examination table:

Then he would run his hand gently over her skin, without passion, almost clinically, as if he could learn by touch whatever it was that had escaped the probing of his eyes. [...] It was when she would begin feeling that she was on a doctor’s examination table that she would take hold of his hand to make him stop.30

Some metaphors and similes used by Atwood throughout her fiction contribute to her depiction of sexual relations in the most grotesque manner. Generally there is no passion, no enjoyment, no sense of communion, of sharing, nor even giving and receiving pleasure. Sensuality is completely absent, and sexual intercourse tends to be presented as unsatisfactory, wearisome, threatening, or disgusting. Among the many illustrative examples of Atwood’s humorously eccentric articulations of matters concerning sex, we find a number of metaphors in which the sexual relationship between a man and a woman is depicted as a medical interaction between a doctor and his patient. In the case of The Edible Woman, Marian sees herself as a patient not only when she relates to Peter, her fiancé, but also when she goes to have her hair done, because she perceives her hairdresser as if he were a doctor operating on her. In The Edible Woman, the narrator’s observation that at the hairdresser’s ‘they treated your head like a cake: something to be carefully iced and ornamented’31 is the first explicit instance of Marian’s identification of one part of her body with a cake. But her visit to the hairdresser’s is not exactly like a visit to a kitchen, a bakery or a confectioner’s workshop. Instead, it is described in terms of a visit to a hospital to undergo surgery. What follows is an extended metaphor:
She had felt as passive as though she was being admitted to a hospital to have an operation. She had checked her appointment with a mauve-haired young woman who [...] was disturbingly nurse-like efficient; then she had been delivered over to the waiting staff. Marian had closed her eyes, leaning back against the operating-table [...]. She thought it would be a good idea if they would give anaesthetics to the patients, just put them to sleep while all these necessary physical details were taken care of; she didn’t enjoy feeling like a slab of flesh, an object. Then they had strapped her into the chair [...] a surgical cloth around her neck - and the doctor had set to work. [...] by the rack of gleaming instruments and bottled medicines on the counter in front of her.\footnote{32}

After one of the nurses had pronounced her dry she was returned to the doctor’s chair to have the stitches taken out; she found it rather incongruous that they weren’t wheeling her back on a table.\footnote{33}

The final interpretation of this extended metaphor possesses aesthetic coherence because the mapping structure is evocative of a broad theme. The hairdresser’s is likened to a hospital, Marian to a patient, the hairdresser to a doctor, and the waiting staff to nurses. Having one’s hair done is an operation, the chair is an operating table, the towel is a surgical cloth, the flasks of hair lotion are bottled medicines, and the rollers that are taken out are stitches. The extended metaphor can be summarized in the following table:

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<thead>
<tr>
<th>SOURCE</th>
<th>TARGET</th>
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<tr>
<td>PATIENT</td>
<td>MARIAN</td>
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<tr>
<td>HOSPITAL</td>
<td>HAIRDRESSER’S</td>
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<td>DOCTOR</td>
<td>HAIRDRESSER</td>
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<td>NURSES</td>
<td>WAITING STAFF</td>
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<td>HAVE AN OPERATION</td>
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<td>OPERATING-TABLE</td>
<td>CHAIR</td>
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Near the end of the novel, when Marian is baking the cake which is a replica of herself, the third-person narrator again uses the language of ornamentation and operation employed in the scene at the hairdresser’s. In her own kitchen Marian begins ‘to operate’ on the cake-woman just as she was operated on at the hairdresser’s, and re-enacts what was done to her when her hair was decorated like a cake. This technical device provides a connection not only between Marian and the patient, but also between the cake and the patient. The interaction between Marian, the patient and the cake may be represented by the following diagram:

Both food and medical metaphors point to the victimisation of women and are linked to other clusters that reinforce this theme. Marian also identifies with animals which are threatened by being trapped, caged, hunted and ultimately served as food. Furthermore, Marian is described as a series of objects, such as a car and a camera newly owned by her fiancé, and she recurrently sees herself as a doll. Therefore, if we consider the whole novel by focusing on the metaphors that place Marian in the target domain, we have to include at least five source domains, because she is conceptualised as a cake, a patient, an animal, an object and a doll.
Apart from Marian in *The Edible Woman*, other female characters in Atwood’s fiction see themselves as patients in a variety of situations which are actually unrelated to medicine. For instance, while the protagonist of *Cat’s Eye*, the visual artist Elaine Risley is being interviewed by a journalist about the current exhibition of her paintings, she is very uneasy and finds no better way to convey her feelings than to resort to a medical simile. Thus, she explains: ‘I feel as if I’m at the dentist, mouth gracelessly open while some stranger with a light and mirror gazes down my throat at something I can’t see’. Later on in the novel, Elaine turns again to the same sort of comparison when she remarks: ‘I’m suspended, as in airports or dentists’ waiting-rooms, expecting yet another interlude that will be textureless and without desire, like painkiller or the interior of planes’. If men who are in fact unrelated to the medical profession are depicted as doctors in their interactions with women (who are seen as patients), there are also women (equally unrelated to the medical profession) who are depicted as if they were nurses when they perform a nurturing role towards the men they care for.

Apart from placing doctors and nurses both in the source and in the target domains of many of her metaphors, Atwood often situates disease in the source domain when she associates it metaphorically with many different concepts, which include honesty (compared with psoriasis and hemorrhoids in *Bodily Harm*), the use of swearwords (described as ‘a minor contagious disease, like chicken pox’ in *Bluebeard’s Egg*), and people who ‘spread themselves like a virus’ (*Surfacing*), or who may be called ‘a social disease’ (*The Handmaid’s Tale*). The metaphors that are applied to Zenia all through *The Robber Bride* consistently stress how she plays the part of the villain: strong, deceitful, utterly evil. After her death, she becomes ‘an invisible cloud of viruses’. The last metaphor affixed to her at the very end of the novel is conclusive: ‘Zenia was a tumour’.

The negative attitude that Atwood’s female characters generally express towards pregnancy, even when it is normally developed as a natural process, leads them to mentally connect it with the concept of disease.
instance, in *The Edible Woman* Marian speculates on the mysterious contents of her friend Clara’s belly in the following words: ‘Maybe it isn’t a baby at all but a kind of parasitic growth, like galls on trees, or elephantiasis of the navel, or a huge bunion...’. 47 These fantasies should not be perceived with surprise by readers who have already discovered how, at the beginning of this novel, marriage had been presented as a disease, since the proliferation of weddings was referred to as an ‘epidemic’ and a ‘national disaster’ rather than a ‘minor mishap’. 48

We may conclude this brief survey of Atwood’s metaphors related to health, illness, and disease by pointing out that health plays a very small role in her fiction, whereas its two counterparts pervade her narratives. Many of her characters are either doctors or people afflicted with various physical and mental disorders. 49 Depending on the features the author wishes to illuminate, she conceptualises such characters and the diseases they exemplify by using metaphors with positive or with negative connotations, all of which convey vivid images to her readers. Furthermore, when Atwood wants to emphasise the pathological condition of many aspects of human life, she generally resorts to metaphors that place illness and disease in the source domain, and often does so with a comic intent. Rather than treat these matters in an earnest fashion, she prefers to adopt a grotesque manner that is appealing to some readers and perhaps disgusting to others, but rarely leaves us indifferent to her writings.

**Notes**

1. Atwood, 1986, 64.
3. Atwood, 1979, 123.
6. Atwood, 1982b, 121.
11. Ibid., 253.
12. The following simile, extracted from Joan’s *Lady Oracle* (a novel purportedly authored by the protagonist of Atwood’s novel of the same title), can only be interpreted as a surrealist joke: ‘her figure that spread like crabgrass, her hair that spread like fire, her mind that spread like cancer or pubic lice’ 1982a, 319. It should be noted, however, that Atwood seldom goes this far with buffoonery and that here she is presenting a parody of a
literary genre in order to ridicule the Gothic romance which her protagonist is writing.

13 Atwood, 1986, 34.
14 Ibid., 34.
15 Ibid., 59.
16 Ibid., 60 and 83.
17 Ibid., 83.
18 Ibid., 80.
19 Ibid., 82.
20 Ibid., 83.
21 Ibid., 16.
22 Ibid., 35.
23 Ibid., 33.
24 In *Lady Oracle* Atwood humorously refers to nurse novels in disparaging terms: ‘They were standard fare, each ending with nurse and doctor wrapped in each other’s arms as firmly and antiseptically as elastic bandages’ 1982a, 153.

25 Atwood, 1986, 55.
26 Ibid., 53.
27 Ibid., 21.
28 Ibid., 21.
29 Ibid., 201.
30 Atwood, 1989a, 149.
31 Ibid., 208.
32 Ibid., 209.
33 Ibid., 210.
34 Ibid., 269.
35 Ibid., 208.
36 Atwood, 1989c, 89.
37 Ibid., 385.
38 Atwood, 1982b, 167, 272.
39 Atwood, 1986, 64.
40 Atwood, 1989b, 20.
41 Atwood, 1979, 123.
43 Ibid., 181.
44 Atwood, 1993, 535.
45 Ibid., 543

46 There are some rare exceptions in narratives where pregnancy is perceived with a positive attitude (Cf. the novel *Cat’s Eye*, 1989c, 340-41, and the short story entitled ‘Giving Birth’ included in the collection *Dancing Girls*).
Apart from Dr. Daniel Luoma in *Bodily Harm* and Dr. Simon Jordan in *Alias Grace*, there are unnamed doctors in *The Handmaid’s Tale*. In *Bodily Harm*, Rennie’s grandfather is a doctor, like the grandfather of the protagonist of ‘Significant Moments in the Life of My Mother,’ a short story included in the collection *Bluebeard’s Egg*, 1989b, 11-12. If cancer plays a central role in *Bodily Harm*, anorexia is equally important in *The Edible Woman*, bulimia in *Lady Oracle* and psychiatric disorders in *The Robber Bride*, *Alias Grace* and *The Blind Assassin*.

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Abstract
The present chapter explores the metaphors of illness found in eleven Swedish narratives on eating disorders, published between 1987 and 2005. The authors use the metaphors of powerful beings such as the serpent and the devil to name their illness, and these metaphors can be analysed as being part of the master metaphors of battle, territory and intruders. This chapter discusses the metaphors used to envision the flesh and the body as well as three important ‘intruders’: the eating disorder itself, food and hunger.

Key Words: Narratives, metaphors of illness, eating disorders, literature, anorexia, bulimia, self-mutilation.

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1. Introduction
Metaphoric thinking is fundamental for the human mind, and when faced with a crisis such as being struck by illness, thinking in metaphors can become an important way of handling the situation. Metaphors are used both as a way of handling the illness, assigning meaning to it, and explaining the illness experience to others. Thorough metaphors or myths are commonly found in pathographies, as Anne Hunsaker Hawkins has shown in her study Reconstructing Illness. In this chapter I will discuss the metaphors used to handle and communicate the experience of eating disorders. I group these metaphors under the master metaphors of battle and the body as a territory, and the concept of intruders, as will be seen through my examples.

First a few words about my material. I will examine a group of books where the dominant theme is the protagonist (always a girl) falling ill with an eating disorder. This corpus of books has appeared in Sweden during the last two decades; the first full-length novel, Evelyn Spöke [Evelyn Ghost], was published in 1987, and the latest, Ludenben [Hairylegs], just some months ago. In between them slightly less than twenty books have been published on the topic, and this literature has been acknowledged by critics to be a new subgenre.¹ In this chapter I am studying eleven of these books. They are predominantly written by girls in their twenties, often as their début or even their only book. Most are pathographies, some are novels, but regardless of genre they all have a stated autobiographical background.² They are all written from the ill girl’s own perspective, and this means that I
will here only discuss metaphors used by the girls themselves, a perspective that may seem distorted or alien for the readers.

Discussing literary works as an expression of actual experiences does present some problems. With regard to these books, all of the authors say that their aim is to make the reader understand the illness described. I thus presuppose that the authors’ intention to describe the mental world of the illness means that they use metaphors they have found functional and suitable to communicate the experience to the reading audience. In this chapter I will thus explore these metaphors as actually used for understanding the illness. When I use a girl’s name or ‘she’ I refer to the character, who is also in most cases the narrator, and not to the author.  

The types of eating disorders depicted in these books range from anorexia and bulimia to binge eating. Most common is a combination of anorexic and bulimic behaviour. There is also a high rate of self-mutilation and cutting in the books. All these disorders blend together in self-disgust and a search for self-annihilation which here has a thoroughly female voicing.

The all-embracing metaphor I have found structuring the narratives of eating disorders is derived from what Hawkins calls ‘the battle myth.’ As Hawkins shows, this is one of the most common myths used in illness narratives, and the use of metaphors like intruders, attacks, allies, sides, enemies, war and threats alludes to this myth. I want to argue that in the case of eating disorder narratives this battle myth is partially transformed, in contrast to its use in somatic illnesses. In a cancer narrative, for example, the illness is clearly seen as an enemy, and the doctor and the patient become allies in the battle against it. Here metaphors such as enemy, attack and defence (or immune defence) are comparatively unambiguous. When it comes to eating disorders, the relationship is different. In the narrative on eating disorders, the battle has, just as in the somatic case, two fronts (represented by the doctor and the illness) but the patient has problems deciding which side she is on. She changes sides all the time, fighting alternately for both parties. Another way to describe this relationship is to say that she becomes a passive participant; not just her body but also her self becomes the place where and over which the battle takes place. She becomes a territory instead of an agent, the agent part of her being suppressed. This can be seen for example in the metaphors the girl uses to describe her self: she pictures her inner self as a faint whisper, as a very small girl, a ghost, air, a small white rat, an inhabitant in a dictatorship, a slave or a puppet...

Myths and metaphors may serve as enabling structures, and make the ill person come to terms with his or her illness. But as Susan Sontag famously pointed out, metaphors may as well function as disabling structures. For the Battle Myth to be enabling for an eating-disordered girl, it is crucial for her to envision the illness as something separated from herself. As long as
she views the anorexic behaviour as a part of herself -maybe even as her true inner self - the battle myth is counterproductive and makes her experience every attack on the illness as an attack on herself.

Thus, the creation of some kind of creature or being as a metaphor for the illness behaviour can help to make the battle myth an enabling structure. In these books the metaphors allude to strikingly powerful entities of evil, like devils and serpents, and the metaphors are considerably grander in the pathographies than in the fiction. Presumably the vividness of the metaphors helps the girl to dissociate herself from her illness.

My claim is thus that the all-embracing metaphor in these books on eating disorders is the concept of territory and, closely linked to this, the concept of the intruder: The body as a territory threatened by intruders and invaders, enemies both from within and from outside.\(^5\) The girl’s sense of her self and of her boundaries are to begin with blurred and imprecise, which seems to turn into the extreme consciousness of boundaries which is typical of the anorexic thinking. By controlling and defining her body she hopes to achieve a stable sense of her self.

The territory becomes a battle field, where the fight stands between powers in the dichotomies good-evil, life-death, angels-devils. Katarina, the protagonist in Hairylegs explicitly states that she starves herself, binge eats, gets drunk and eats pills ‘exactly to not let the real world take up space in me’.\(^6\) She chooses one kind of intruder, the self-inflicted and artificial, over another, the outer world, which is seen as too painful.

I will here briefly discuss the metaphors used to envision the flesh and the body as well as three important ‘intruders’: the eating disorder itself, food and hunger.

A. The Eating Disorder

In her 2003 study Reading Eating Disorders: Writings on Bulimia and Anorexia as Confessions of American Culture, Greta Olson notes that the American eating disordered girl often projects her urge to eat onto an outside force, often dangerous and supernatural.\(^7\) This is true of my material too, but the most prominent supernatural forces are here not representing the urge to eat, but the compulsion not to eat.

In the books I study, anorexia is metaphorically seen as a creature, alternating between being one part of a divided self, and being a creature in its own right. This being may be another girl (‘a mad girl’ in the head, according to one of the narrators), \(^8\) it may be a harsh and punishing voice without a bodily appearance, or it may be a revolting creature. The most common metaphor is the serpent. This metaphor obviously permeates the book Ormen och jag (The Serpent and I), but it plays an important role in several of the other books as well. The serpent wriggles inside the stomach as a protest against the attempts to force food into the girl. It fills the stomach
and it sinks its poisonous teeth into her. The metaphor incorporates the wriggling sensation in the hungry stomach as well as carries powerful associations of sin and evil, stemming all the way from the temptation of Eve. The serpent in the narratives has a particular ability to pervert the girl’s perceptions, deluding her to interpret things in the wrong way.

The most prominent part of all these metaphors is the illness’ power to coerce the girl into doing things. It is the serpent, or one of his other incarnations, that is depicted as active: forcing the girl, ruling over her, lying to the surrounding people. Other names for him are the less powerful ‘Tangle’,9 or some kind of devilish or demonic name. In Zebraflckan [The Zebra Girl] he is called Lucifer, dictator and monster. The smaller the girl becomes, the larger the serpent or Lucifer grows, and he is depicted as feeding on her and her self-starvation. Following the metaphor of territory, the creature within is alternately pictured as an ally (her only friend) or as an intruder. Evelyn in Evelyn Ghost describes the two sides of intruders fighting over her - the one forcing her to starve, the other to eat - and says that ‘Whatever I do, I disappear’.10 She cannot see an outcome where she can preserve her own self.

Sofia in The Zebra Girl is not only depicting herself as having a monster or Lucifer inside, she expands this metaphor to bear on her friends and the rest of the outer world as well. She is conscious of the prevalent tendency to diet and envisions everybody carrying a monster on their shoulder, monsters with sharp claws and of different sizes, who make each other grow larger.

For Anna-Lena in Nej tack, jag åt nyss! [No Thanks, I’ve Just Eaten!] the binge eating is a development of an anorexic ideal, since she is constantly trying not to eat, living on something like half an apple, until she devours large amounts of food instead. She envisions her anorexic thinking as a transparent thin ballet dancer, a metaphor of the neat female ideal. The ballet dancer proves to be hard and skeletal and tries to strangle her in her bed.

B. Food

The invader who causes most disgust is no doubt food, which is seen as something dirty and repulsive. The narrators show a constant inversion of values, where destructive metaphors are used for things we normally see as constructive. Elisabeth in I himlen får jag äta [I may Eat in Heaven] has completely inverted the values of food. She sees the calories as bacteria, which clearly associates them with invasion and destruction. Food, which is actually building up the body, instead becomes destructive. Or even the very construction turns into destruction; she writes: ‘Soon the calories would reach the intestines and become parasites who make me swell up’.11
The picture of calories as parasites is totally counter-intuitive; in the same way the girls see their self-annihilating lifestyle as a sign of them having built up their own life.

The moral quality of food is acute for the narrators, who treat food in terms of sinfulness. Accordingly, the urge to eat is viewed as a fall, just as the biblical fall from grace - a metaphor that Greta Olson also finds prevalent in American accounts of eating disorders. The dirtiness of food gives the urge for purification whenever having touched it. Anna-Lena feels the compulsion to rub herself with a pumice every time she has put something in her mouth. Several of the girls finally do not dare even to eat an aspirin out of fear for the invading calories possibly hidden within it.

Seeing food as an evil intruder is linked to the girls’ belief that they, as pure selves, actually can live without food. As Greta Olson points out this is a kind of magical thinking, and this magical thinking is often seen regarding food. The girls view themselves as getting fat after only one bite; Klara in Vårfröst [Spring Frost] even goes outside to carefully exhale the smell of cooking, out of fear that the smell otherwise will ‘cling to her, become a film of fat under her skin’.

C. Hunger

For the eating-disordered girls, hunger is, in addition, something they choose to dissociate from themselves. When they ‘fall’ and eat this is commonly described as if the food, or someone outside themselves, is being the active participant. This tendency is stressed by a tendency to shift the narration into a third person voice.

Hunger is depicted as a wild beast, tearing and clawing and ‘going berserk’ in the stomach. The metaphor of the wild beast captures both the physical pains of hunger, associated with the claws and teeth of a beast, and the picture of a predator savagely tearing its prey into parts. The violence is thus associated with both hunger and eating, as well as with imprisonment, since wild beasts tend to rage when in a cage.

When Karoline in Vissa föddes perfekta och andra som jag [Some Were Born Perfect, Others Like Me] desperately binges at one point (again described as a fall from grace) it is not she who stuffs food into her mouth, rather, it is the wild beast who is ‘frantically chewing swallowing’. Evelyn identifies strongly with the starving she-wolf she pictures having inside of her and at times she becomes the wolf, howling, running around in the moonlight and cutting her arms as if it is the she-wolf’s claws that hurt her. Something similar is happening with Katarina - her inner hunger takes shape as ‘Ludenben’, which means ‘Hairylegs’. This metaphor captures the physical appearance of the anorectic, since one characteristic is that she develops more hair on her body. But it also alludes to a character in a
Swedish children’s story, the troll Hairylegs, always hungry as a wolf, who devours four goats and in the end of the story bursts open so the goats are set free.16 This becomes her definition both as an anorectic: always being hungry, and as a bulimic: actually outliving the hunger. This is a more negative symbol than the she-wolf, although they have many similar features.

Binge eating is charged with sexual violence. For Andrea in Pappa Pralin [Daddy Chocolate], the bulimic eating and the humiliating casual sexual intercourses seem to hold the same meaning as invasions of her body that she cannot hold back. Two girls, Anna-Lena and Karoline, use the metaphor of rape for the binge eating and the fingers put into the throat to provoke vomiting. In Kräklek [Vomiting Game] the violent intrusion through the throat happens by ‘crumming stick after stick into the mouth rummage in the throat with toothbrushes and hairpins scratching cuts in the throat’.17 This is a hurtful way for the territory to have its boundaries trespassed, and neither the violence nor the sexual imagery is prevalent in anorexic literature, only in the bulimic or binge eating - not surprisingly, of course.

2. The Flesh and the Body

The most repulsive word for the girls seems to be the word ‘swollen’. The thought of themselves swelling up, becoming rounded and big, bursting like a bud, their fat overflowing, is their greatest fear. The word ‘swell’ is heavily associated with concepts of ripening, fertility, pregnancy, femininity and life, all things that the anorectic tries to escape, choosing a barren landscape above a lush one, teeming with life. Greta Olson calls it a ‘nearly universal’ theme in literary accounts of eating disorders, ‘the profound disgust for female flesh’.18 The books dwell on the fear of becoming a woman, and the swelling is also linked to food by the image of rising dough. The fat body is likened to that of a cow or a pig.

The eating disordered girls have clearly integrated the Cartesian split between body and soul into their world view. They see the body as a prison for the soul. They also put this split into the body itself, viewing the perceived body fat as a prison for a truer body form within, that they may shape like a sculptor through starvation.

When a doctor examines the emaciated body of Lina in När mörkret kom [When Darkness Came] she cannot identify with it. She writes: ‘The thing on the bunk is a lump of fat’.19 Karoline too speaks of her body as ‘inescapably mine, never me but mine’.20 Several of the girls do not have any sense of their own self: without other people’s judgments and attention they do not know who or what they are. Katarina writes: ‘Without their gazes over my body I had nothing I could call me. I was air rather than a ghost’.21

Sofia is the girl with the most extreme self-mutilation tendencies.

She cuts herself, pours acid into her mouth which partially makes her tongue
dissolve, and once she manages to hang herself in her room although a nurse is present. The metaphor Sofia uses to describe herself is the black and white zebra. The zebra is an image of her mix of light and darkness, her normal self and her destructive self. It also captures her striped arms, striped from her cutting herself.

3. **Conclusion**

In this chapter I have shown that the narratives on eating disorders, in the Swedish corpus I am examining, are incorporating strikingly fierce metaphors of wild beasts, trolls, devils and serpents, as well as the fall from grace. I have argued that these narratives are structured by what Anne Hunsaker Hawkins calls ‘the battle myth’, and linked to this the metaphors of territory and intruders. This does not mean a territory in the sense where the female body is seen as a ‘dark continent’ to explore, but rather ‘a territory of her own’: a land to keep controlled, clean and free from invaders - in the end, a place to keep barren and dead.

**Notes**

1 The publishers range from the leading publishing houses in Sweden to small publishers and author cooperatives.

2 This is shown either in the books themselves and their paratexts, or in the presentations in book catalogues and in interviews.

3 Since several of the protagonists have the same names as the authors, this needs to be stressed.

4 Greta Olson (Olson, 2003, 8-9) writes in her 2003 study that in an American context there has not yet emerged full length depictions of either bulimia or self-mutilation. In Sweden the case is different. Half of the books in my material contain bulimic behaviour, and a majority include self-mutilation.

5 This common structure, that I argue functions as an organiser of the Swedish narratives of eating disorders, has also been observed by the Norwegian anthropologist Jorun Solheim in her *Den åpne kroppen. Om kjønnsymbolikk i moderne kultur*, 1998.


7 See for example Olson, 2003, 82.


In the same way as all the values are inverted, so is the Fall. The actual fall (or direction downwards) rather happens as the girl is pressed down from her depression, or when she literally falls, in forms of fainting or not being able to stand or sit up because of her fragile state.

'klibba fast, blir en hinna av fett under huden'. Ehn, 1995, 147.


'stoppa pinne efter pinne i munnen gräva i halsen med tandborstar och hårnålar […] river sår i halsen'. Ericsdotter, 2002, 91. ‘Kräklek’ is a word play. Literally it means ‘vomiting game’ or ‘vomiting play’; ‘lek’ meaning both game and play. It is a neologism and alludes to the Swedish word for love, ‘kärlek’. ‘Kräk’ can also be interpreted as ‘wretch’ and ‘beast’.

Olson, 2003, 49.


‘ofränkligt min, aldrig jag men min’. Johansson, 164.


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Constructing a Consumptive Myth: Medical Discourse and the Representation of Tuberculosis

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Abstract
This chapter focuses on the ways the Victorian medical profession attempted to 'make sense' of the then mysterious and incurable illness tuberculosis by exploring, utilising and developing the cultural myths and metaphors that traditionally accompanied it. Given the absence of medical knowledge about the cause of consumption until Koch identified the bacillus in the 1880s, superstition and stereotype were important, if highly unscientific, sources of information for physicians struggling to identify, explain and treat this disease. For example, one of the most pervasive traditional assumptions about tuberculosis was that it only afflicted the young and beautiful, a belief commonly expressed in the Victorian novel, but by no means confined to fiction. Medical discourse 're-wrote' the consumptive stereotype as a consumptive diathesis, and this notion of a clearly identifiable pathological type became a popular diagnostic tool for many physicians. Similarly, the idea that consumptives were sexually deviant was explored and perpetuated by medical writing that sought in this behaviour both a cause of the disease, and its potential cure. In this chapter I explore the medical perpetuation of these and other consumptive myths, and examine why they were appealing to physicians, even though they possibly hindered the progression of knowledge about the disease and had damaging implications for the social perception of the tubercular patient - implications which still have resonance today.

Key Words: Tuberculosis, Victorian era, literature, myth, metaphors of illness, medical writing.

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This chapter sets out to identify the myths and metaphors which surrounded tuberculosis in the nineteenth century, to reveal the ways in which these were perpetuated and even utilised by the medical profession, and to explore the implications they had for those people who were afflicted with the disease. Tuberculosis, or consumption as it was more commonly called, has formed a perpetual accompaniment to human history through the ages: tubercular lesions have been found in mummified skeletons dated at 3000BC,¹ and despite the antibiotic revolution in the twentieth century this disease remains a threat to one third of the world’s population today.² However, I focus here on the Victorian period, as this was the age in which
the occurrence of the disease was at its peak in Europe and the point at which it exerted the most powerful influence over the contemporary political and literary imagination. Consumption killed more people in this era than cholera and smallpox put together, and it was the biggest single cause of death of people under 35. Yet despite being such a common disease, tuberculosis always seems to maintain its status as what Susan Sontag describes as a ‘disease of individuals’, in that it seems to be set apart from other illness like cholera or typhoid. These fevers infect the whole community in epidemic proportions and then die away until the next outbreak. Tuberculosis, in contrast, remains an endemic, constant social threat, but afflicts only certain individuals within the population. Fevers or plague would grip a whole street or even a whole city: tuberculosis did not. Disease becomes invested with a particular significance when it is not the common affliction of a whole community. The consumptive individual was commonly thought to be special in some way, singled out from his or her neighbours: as their disease was different, so they must be in some way different too.

The cause of consumption remained mysterious for most of the century. It was not until 1882 that Robert Koch identified the tuberculosis bacillus and confirmed that the disease was infectious, and even this did not explain the seemingly random selection of victims. One member of a family could become consumptive but the others who were in contact with that person every day might remain well, or might become ill but only years after their parent or sibling had already died of the disease. The disease was probably present in the air every day, but not everyone who breathed it in became sick. Hence, infection alone could not be responsible for the spread of consumption, for individual susceptibility seemed dictated by an unknown ‘X-factor’, which could be interpreted as the workings of fate or providence, or which could, more sinisterly, be the result of the victim’s own actions or lifestyle. This meant that being afflicted with this disease did not simply mean you were unfortunate: it said something about you as a person, and this question about what consumption was perceived to be ‘saying’ about its victims forms the central focus of this chapter.

Many of the metaphors and stereotypes that surrounded the figure of the consumptive can be found in the popular fiction of the Victorian period. This was an appropriate medium, considering tuberculosis’ traditional reputation as a ‘literary’ disease. This representation came about partly because so many important writers and poets were afflicted by the illness: from the Brontës to Robert Louis Stevenson, there is a long list of famous literary consumptives throughout the disease’s history. Such a representation was also, however, born out of consumption’s mysterious quality and its identity as a ‘disease of individuals’, which lent it a useful capacity to act as a cultural signifier, a means of indicating certain traits in a character or signalling certain social concerns. Hence it was used as a recurrent motif in
much of the popular fiction of the period, which utilised some existing myths around consumption and developed and even created others. Many of the resulting consumptive stereotypes associated with literature still have resonance with us today: the tormented, love-sick poet who is an unrecognised genius (like Keats) the pure and innocent child (Dickens’s little Nell, or Dick in *Oliver Twist*), or the beautiful, desirable young woman whose wasting, self-sacrificial body acts as penance for previous sexual sins (Mimi in *La Bohème*, or George Du Maurier’s *Trilby*).

These fictional images differ according to their context, but emerging from them is a picture of consumption as a disease that seems only to afflict those who are young, beautiful, spiritual and pure, in other words, those physically and emotionally superior beings who are ‘too good to live’ or ‘too good for this world’. There was some element of truth in this identification, for as I have mentioned, consumption did seem to carry off the younger sections of the population, with most of its victims dying before they reached middle age. So it was in a sense a disease of the young, with the glamour that encompasses, but the idea that it sought out the best of that youth was simply a product of fictional romance. However, this belief that there was a specific tubercular ‘type’ did not remain in the pages of best selling novels. In fact, it formed one of the most pervasive views about the disease and penetrated Victorian society even to the extent of affecting medical thinking about the disease. A physician writing about tuberculosis in the 1850s, Dr. John Balbirne, stated that, ‘amiability is a usual characteristic of the consumptive’, and adds that their ‘intellectual facilities indeed seem prematurely developed - they are remarked as apt, wise and knowing beyond their years...’

This ideal is reminiscent of consumptive literary heroes and heroines, like little Paul Dombey, in Dickens’s *Dombey and Son*, and the religious mystic in Brontë’s *Jane Eyre*, Helen Burns. Later in the century Dr. R. Allinson stated that it affects ‘the talented, gifted and beautiful more often than coarser humanity’. And similarly, Dr. Alabone suggested in 1880 that:

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\text{The taint of consumption can in many cases be easily recognised by physical signs ... the eyes possess a most remarkable brilliancy ... the nervous system is especially developed, hence it is a frequent thing for consumptive patients to be of a most refined nature ... being remarkable for gentleness, amiability, and great purity... (my italics)}
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This may not seem like a negative outcome for real-life consumptives. If one must be ill it is no bad thing to be afflicted with a disease associated with purity and physical beauty rather than with disfigurement or shame, like syphilis. But the pervasiveness of these kinds of
perceptions about the disease did have problematic consequences for patients. This was largely because they made things difficult for the nineteenth century physicians who were trying to come to a greater understanding of the illness and the best ways to treat it. As Alabone observed: ‘Superstition and prejudice have agreed in their creation ... in the supposed causes of consumption, and it is a task of great difficulty in the present day to separate the real from the unreal’.7

Alfred Hillier, a personal friend and colleague of Robert Koch, acknowledges the importance of the artistic influence on social and medical thinking about the illness, but he is aware that this influence may be a dangerous one. He is particularly concerned about the role certain common literary myths have played in the medical identification of a tubercular diathesis, or the consumptive ‘type’:

Tennyson’s ‘May Queen’, than whom there was none so fair ‘in all the land, they say’, with her bright eye, brilliant gaiety, and pathetic death, is sometimes taken to be a typical description of the tuberculous constitution. But on the other hand, how frequently do we see patients suffering from pulmonary tuberculosis obviously not fashioned with that ethereal delicacy which tradition - begot, perchance, of the bereavement of parents - has associated with the so called ‘consumptive tendency’. 8

Hillier sets out here to destabilise the assumptions which literature and ‘tradition’ have together forged about the consumptive, revealing that the reality of the disease may be much more prosaic. ‘Tuberculosis reflects the large in build, the coarse in feature, the dull and sluggish, as freely as the fairest and brightest in the land’,9 he concludes. Hillier is aware that reliance on the stereotypical view of the consumptive type was a common means of diagnosis throughout the period, and one that might lead the physician astray. Tuberculosis’ association with the pious, the angelic and the refined in literature was frequently replicated in medical texts and used there as facts about patients, facts which form diagnostic tools with which to identify consumption.

Moreover, the myths and metaphors which surrounded tuberculosis were not always positive. Alongside its identification as the most spiritual of diseases was its seemingly paradoxical reputation as an illness brought about by socially deviant behaviour. This conception was born out of the awareness that if consumption is not simply a matter of infection, something about the sufferer or their lifestyle has made them susceptible to it - even invited it - and that they are in a sense responsible for their own illness. This is, of course, frequently a means of viewing the patient afflicted with a sexually
transmitted disease, and was a common way of thinking about syphilis in the Victorian era as it still is about HIV today. It is even more controversial, however, in relation to tuberculosis, whose means of transmission were unknown. Yet it was still a common way for physicians to think about the cause of the disease, particularly in female patients. One Victorian doctor, John Hughes Bennet, suggested that consumption was ‘almost invariably the consequence of circumstances which induce impoverished nutrition’. This was a reasonable assertion, and one which with hindsight we know to be correct, but he goes on to point out that whilst among the poor malnutrition was an unavoidable condition, members of the more affluent classes had only themselves to blame for their unhealthy diet. Consumption was ‘...ushered in with bad and capricious appetites, [and] anorexia...’.

Such individuals [consumptives] have a most capricious appetite, loathe all kinds of animal food, and it will be found that even when they say that their appetite is good, and that they live well, their diet is actually either deficient in quantity, or in quality.

It is significant here that the consumptive is defined not only as a faddy eater, but also as secretive and deceptive about their eating habits. The picture drawn here is reminiscent of the behaviour exhibited by patients with anorexia nervosa and is a veiled condemnation of women who diet in order to achieve or maintain the wasp-waisted figure that was fashionable at the time. Bennett does not limit personal responsibility for illness to diet, however. He also discusses the disastrous effects of what he terms other ‘intemperate habits’, which include alcoholic drink and ‘the attractions of fashion’. In other words, late-night parties and other social gatherings which ‘the young can seldom resist... they return to their homes late at night, exposed to the chill air, the injurious effect of which is augmented by the previous heat and foul air of crowded assemblies’ (the possibility of sexual misdemeanours are also implicit here, I think). Of these ‘intemperate habits’, alcohol use is perhaps the most commonly suggested cause of consumption, and again this is an assumption born out of cultural rather than medical reasons, a response to evangelicalism and the temperance movement rather than to any medical evidence.

Physician Edwin Alabone cites female vanity as a major cause of consumption in women, and explains that their desire to display themselves through ‘extravagancies in dress’ leads them to ignore his advice, with fatal results. Alabone is particularly disapproving of the bare flesh exposed by fashionable gowns, and of corsetry, which was thought to be linked to consumption. Even one’s mental or emotional state may be intrinsically
pathological. Alabone is only one of a number of physicians who believes that ‘depressing passions and violent emotions of the mind pre-dispose greatly to this disease’. This idea that consumption afflicts those who are racked with grief or unrequited love certainly has its roots in fiction, for such a concept enables the literary trope of ‘dying of a broken heart’ to take on a tangible physical meaning. This useful plot device is put to work in novels like Emily Brontë’s *Wuthering Heights*, where the disease of (inevitably female) consumptives functions as an outward expression of their inward suffering. And this is, of course, another form of the responsibility theory: the consumptive becomes ill because their psychological instability and over-indulgence in grief makes them vulnerable to the disease.

According to the medical literature of the period, the archetypal consumptive was an idealised figure: young, physically attractive, highly intelligent and spiritually pure - in other words, ‘too good to live’. Yet to become consumptive in the first place, that person must also be a flighty, self-indulgent being who puts their pursuit of pleasure - by drinking alcohol or frequenting late night parties, or of fashion - by starving themselves or wearing flimsy dresses and restrictive corsets, ahead of their health. Even those who become ill because of emotional suffering can be regarded as lacking in self-restraint. These stereotypes are useful in the Victorian novel, where consumption frequently acts as a means of punishing inappropriate or morally questionable behaviour, and where the purifying power of the disease can bring about redemption. But of course they are problematic in the real world.

There seems to be an essential ambivalence in the way both the disease and the type of person commonly afflicted by it were viewed by physicians. The medical profession’s observations and guidelines were paradoxical, contradictory and reliant on cultural myths - myths either created or perpetuated by the literature of the period - rather than on scientific fact. But, of course, fiction must be especially hard to dismiss when facts themselves are in short supply. Due to the absence of accurate information about the disease, for most of the century medical thinking about consumption was a rather unscientific mix of speculation and hypothesis.

There was little new knowledge with which to update or alter the enduring, culturally persuasive literary portrait of phthisis. And, of course, the necessity of searching for a cure, without really understanding the nature of the disease, meant that many of these medical writings were a kind of fiction in themselves. A large number of these texts were written to make claims about their author’s knowledge and skill as a physician, and frequently put forward new ideas about or possible treatments for consumption, which demanded the faith of readers and patients alike, yet were usually unsupported by any kind of real evidence and had little hope of success. The
whole canon of Victorian medical writing on consumption reveals the struggles of a frustrated profession with a deadly and mysterious disease, a search toward truth hampered by lack of certainties and facts, and confused by a proliferation of myths and assumptions. The absence of this truth meant that out of necessity was born a reluctant open-mindedness towards other possible sources of information about the disease. This is summed up by the words of a Dr. Elliotson, who wrote in the *Lancet*: ‘I cannot cure phthisis; I shall therefore put to the test any-thing that I hear of from a respectable source, or which appears in itself plausible, which may be able to help...’

Notes

1 Cave, 1939, 142.
2 http://www.who.int/tb.
3 Sontag, 1977, 30.
4 Balbirne, 1856, 9.
5 Allinson, 1854, 1.
6 Alabone, 1880, 24.
7 Ibid, 34.
8 Hillier, 1900, 80.
9 Ibid, 80.
10 Bennet, 1859, 64.
11 Ibid, 17.
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Metaphors of Injury: Women Make Sense of Pelvic Pain

Victoria M. Grace and Sara MacBride-Stewart

Abstract
Women experiencing chronic pelvic pain find generating an understanding of their condition extremely important. Chronic pelvic pain frequently frustrates the attempts of biomedicine to provide satisfactory explanations, or diagnoses. In this chapter we ask how do women generate understandings of their pain? What discursive patterns feature in their narratives specifically in relation to making sense of the interior of the pelvis? Why is an ‘understanding’ important, and what does this mean? How is gender ‘read’ into meanings of the pelvis-in-pain? Participants are forty New Zealand women of European descent who have or have had chronic pelvic pain unrelated to menstruation or sexual activity. Many also have pain with periods, and/or pain with penetrative sexual activity. Open-ended interviews generated narratives conveying the meanings of pain through a conversational exploratory method. This chapter explores how women make sense of their pain both within and against biomedical binaries; how visualisation of the ‘workings’ of the pelvic interior are crucial for many women as a sort of boundary-marking that possibly confines the pain; and how metaphors of injury create an intelligibility of painful processes that helps to anchor women-in-pain within a meaningful world of others.

Key Words: Chronic pelvic pain, narrative, meanings, women, gender, femininity.

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Our research is on the question of meanings that women generate when talking about their experience of chronic pelvic pain. It grew out of a concern with understanding how the role of meaning in the very experience of pain might be explored through a critical, social, interpretive study of language, or narrative in the broadest sense. For many women, their chronic pelvic pain remains medically unexplained and untreatable, and therefore often persistent and enduring over long periods of their lives.1

It is increasingly recognised that a biomedical approach to chronic pain through a binary conceptualisation of organic function and socio-cultural meaning, or biology/culture, object/subject, so critical to traditional biomedical science, fails to provide a basis for generating an understanding of chronic pain processes. Rather, the physicality of the experience of human pain is understood as embed with meaning, and cannot be approached from
within a paradigm that splits the objective body from the subjective experiencer of that body.\textsuperscript{2,3,4}

Gender has a special significance with respect to pain.\textsuperscript{5} Chronic pain is without doubt a ‘women’s health issue’. We are interested in the cultural meanings women generate in the narration of their experience of pelvic pain. The pelvic area in women is strongly associated with femininity as the site of sexuality, ovulation, menstruation, conception, contraception, gestation, birth, and species reproduction. It is also the site of the last stages of the digestive tract, of urination and defecation. The female pelvis variously symbolises the gendered cultural imaginary of life, jouissance, blood, sacrifice, pain and suffering.

This chapter explores how women talk about their pelvis-in-pain, and interrogates the implications of key metaphors, giving particular consideration to gender.

1. The Somatic Imaginary

We locate our research within current theoretical debates around how embodiment might be theorised; how can we understand socio-cultural dynamics and contingencies of individual histories as embodied in the biology of human beings, and reciprocally how might we understand our biological being as irreducibly embedded in our social institutions, language, and cultural discourse?\textsuperscript{6}

Philosopher Moira Gatens, writing in 1996, proposes the notion of the ‘imaginary body’, as the lived body, an approach that foregrounds the significance of ‘image’, or ‘imagery’. The imaginary body is not a ‘natural body’,\textsuperscript{7} or we could equally say the ‘natural body’ is an imaginary body. Psychoanalytic understandings in particular invariably problematise the notion of ‘biology’ as somehow split off from the psycho-social lived and experiencing body.\textsuperscript{8}

To interpret the meanings that transpire through women’s narration of their experience of pelvic pain, to make sense of the narration of the disease of persistent pain in the viscera of the pelvis, we will focus on analysing the discourse on the bodily interior as an imaginary constitution. Taking a ‘biocultural’ theoretical approach of this sort, we are sceptical of the dualisms of subject/object, mind/body, culture/biology, and reject both biological and cultural reductionism.\textsuperscript{9} We adopt a critical ontology that enables us to explore how symbolic cultural meanings and biological processes are, or might be, reciprocally infused. The methodological approach we take to this analysis might broadly be called ‘semiotic’, distinguishing discursive, narrative and thematic levels of analysis.\textsuperscript{9} Turning now to the question: how do women talk about the physicality of their bodies, of the pelvis-in-pain? And most importantly, what can we learn about the experience of pain through the study of this talk?
This analysis is based on open-ended interviews conducted with 40 women of European descent in New Zealand during 2002. Women recruited to the study had participated in a nation-wide prevalence study. The prevalence study was based on a random sample of New Zealand women between the ages of 18 and 50, and participants were asked if they would be willing to be contacted for further in-depth qualitative research in the future. Participants in the current qualitative study were women who had at the time, or in the past, chronic pelvic pain (pain in the area below the navel, and of longer than six months duration) which includes pain with menstruation, with penetrative sexual activity, and pain that is not associated with either of these.

The interviews took the form of guided conversations, whereby the interviewer began with an open-ended question asking participants to ‘tell me about your pain’, avoided asking leading questions and prompted further conversation through deliberate employment of the interviewees’ own language.

For the analysis presented in this chapter, we identified all sections of the interviews where women had spoken about their bodies in any way, or made statements about their perceptions and understandings of the bodily processes involved in their pain. The questions guiding this analysis were:

- What discursive patterns feature in the narratives on the question of making sense of what is happening to, for, by the body to create this pain?
- Why is an ‘understanding’ important? And what role does this play?
- How is gender read into meanings of the pelvis-in-pain?
- How do women make sense of the pain both within and against the subject/object binary (experiential and objective)?

2. Metaphors of Injury: A Body with Organs

We identified the central figurative discursive modalities women used through focussing on key words and phrases used when talking about the somatic phenomenon of the pelvis-in-pain, and there is no doubt that the imaginary body is, in this case, a ‘body with organs’; a body with parts, an anatomical body.

There were persistent references to location of pain (there, here, to the side, left side, right side, down low, to the back, front, internal, inside, deep inside); and location was also specified by reference to organs (in the ovaries, right/left ovary, uterus, vagina, cervix, tubes, stomach, tummy, bladder, bowel, kidneys, digestive system) and body parts (leg, hips, back, ribs, muscles). And there was something of a continuum here, from specific
to vague; for example, from *the right ovary* to *in the pelvic area*; from *I have bowel pain* to *in my lower tummy, or what feels like you presume is your tummy*.

There was also an important temporal dimension; time cycles and reproductive events constituted a framework for making sense of change and varying patterns of predictability and unpredictability. Time-related terms were used to relate pain to a cyclical event such as menstruation or ovulation, or an event such as pregnancy, childbirth, menopause, or intercourse. Extremes of predictability and unpredictability created a sense of different experiences of distress in relation to pain that was relentless and debilitating in its predictability on the one hand, or pain that would be equally debilitating but would come *out of the blue* on the other hand.

There was a sense of a pelvis in which there is a considerable amount of movement; the pelvis as a highly active site where pain is implicated in bodily processes of constant change. Words of activity and movement brought the experience of pain into this scene of internal workings: *twisting, grabbing, squeezing, pushed out, build up, released, cramping, radiating, passing*. And as these processes worked away - pain, we argue, was implicated in a discourse of damage through almost violent processes involving friction, forces, hydraulics, and abrasions as movements occurred around and between organs and viscera. This damage would happen when something *was not working*.

Metaphors of externally observable processes of injury - of being bruised, cut, ripped, torn, broken - were evident in the talk about the workings of the interior, creating pain that was *deep inside*. This was the case for talk about menstruation, ovulation, and *hormonal* influences working within the body, whereby *hormonal* influences tended to be recuperated into the same mechanical figuration. It was the case for medical procedures (*they burnt the lining off my uterus; tubes tied; he went in looking for polyps; if I have everything ripped out; they’d [ovaries] be gone like a shot, cut out*). It was also the case for injurious processes associated with gestation and childbirth (*everything gets beaten up; gets a bit of a battering; squashed; inflammation everywhere; strain on the body; stretched out of place; stretched through the whole area; cut through the muscles; huge amount of scar tissue; bladder stopped working; tears and splits*). The most generic statement of the body imagined as an articulated assemblage was: *it just seemed to be after having, after finishing the family... and um which was when I was about 32 then it all fell to bits, my body* (22.56:36).11

Here we see the process of injury being associated with gendered life events such as menstruation, ovulation and birthing. There was a desire and expectation that the ‘injury’ or pain would cease with the menopause. Pain with penetrative sex was also expressed in terms of mechanical forces, often with already *tender* parts being *pushed, touched, wacked*. 
Women talked frequently about having a mental picture of their bodily workings: I suppose uterine contractions are my mental image (27,19:50), I sort of imagine like on the diagrams you see, [...] it was just like one specific ovary and it was just, at times [...] I could just feel I could reach in there and just rip it out (22,12:36). Accordingly, where the construction of a mental image is not able to be imagined, there is often a desire for an image: if they could explain some of those sort of things to you, with the diagram [...] It'd be nice just to say well look, hey this is what, you know point out, say this is where your problem is and this is what happens (2,79:43); it'd be nice to have a little trap door, have a look (28,69:40); sometimes you wish you had a camera - you could look inside, I do (33,119:29).

This visualisation of what is articulated as the workings of the inside of the pelvis, or this desire for a visual image of the interior allows for a kind of boundary-marking that appears to play a role in confining the pain through constructing a visual basis for knowing the dynamics responsible for it, for example: I've had so many scans and [...] I can see, I know exactly where the cyst is and you know, where all the other bits and pieces are and what's going on, mmm, so it sort of helps in a way (26,61:34).

3. Narrative Dynamics of Isolation and Connection

One of the core oppositions within the narratives of the women interviewed is that of isolation and connection. Pain isolates, narrative connects. Living with bodily pain, particularly when there is no diagnosis, is invariably socially isolating. Failure to communicate, an inadequacy of expression, a sense of hopelessness resulting from the inability of others to enter into the experience of pain effectively shuts those suffering pain out of social existence. Being-in-pain can be an experience of social exile, disconnected from empathy and understanding through the inability to communicate the meaning and sensory reality of pain. As one woman said people can accept that physical illness, because someone's got a broken leg but a mental illness, you know, it's not seen or, and I guess, in some ways I probably liken it to that because I can't see what's wrong, it's inside... (15,73:33).

A discourse of the anatomical body is culturally viable; it is a means to establish connectedness with others. Knowing through visualising the imaginary anatomical body and articulating what's going on through metaphoric reference to injurious processes creates a culturally credible intelligibility. It invokes processes that can be understood to produce pain. For another woman: I know exactly where all the other bits and pieces are and what's going on, mmm, so it helps in a way, I think it's worse if you don't know what's going on and you almost think like no one will believe you, yeah, which is awful (26,61:34).
But this imaginary constitution of the anatomical pelvic interior, although it enables connectedness and cultural intelligibility, it disallows a construct of the body less as a ‘thing’ and more as a dynamic process of ‘becoming’ that is fundamentally semiotic and interconnected with that which is not confined to the pelvis, or even to the body. If we assume the semiotic body as a point of departure, then the body as a living embodiment of its biocultural history is disallowed and has no ‘voice’, no social being, no desire. The pathologies of the organism are silent, are inherently meaningless. This invisibility arguably has a particular salience in terms of gender.

4. The Pelvis and Femininity
What is important here is how gender is read into the imaginary anatomical pelvis-in-pain - being a woman, having these complicated, cyclical bodily processes marked by life-course events, having pain deep inside that is associated with these processes, and that is somehow mysteriously non-conforming to the dominant sociocultural perception of medical discourse, is to have a body that refuses to signify. In a sense it refuses to be an organism, refuses to be a body with organs that renders a pathology to the objective clinical gaze.

In connection with this paradox, there is another, more muted or subdued way in which being a woman with pelvic pain was expressed by those interviewed, one that transpired through the very hesitancy, or at times even flippancy, in articulating the perception of a body with organs: *Because it’s in your pelvic region, I mean it takes in a few wee bits and pieces there, and you know, and there’s your tummy and your pelvic area, and the top of your legs and you know, it’s that little area there, well I mean, it’s not your legs and it’s not your tummy, it’s just there, yes, and it’s at the front, it’s not at the back in which case it would be your bottom, sort of thing, you know and it’s not your back, coz it’s not your back it’s at your front […] but that’s the thing, it’s there.* (1,268:45)

This very approximate way of talking conveys a narrative about a complex set of experiences, a nexus of experience, for which there is a socially constructed requirement for an embodied place and for which there is *no-place*; an absence of location within a discourse entirely anchored in a primacy of location. This absence reflects a cultural absence; a place that is unnameable, unrepresentable.

5. Concluding Reflections
The body with organs is a body captured by the requirement for an objective construct of bodies, rendering the body potentially ‘abject’ in Kristeva’s sense, if it fails to signify. The ‘abject’ marks the not-yet subject who falters at the boundary of the symbolic order, being-at-a-loss
when confronting the demand for signification. This failure to produce the requisite signification is in tension with the desire for connectedness with others through the mutuality of a dynamic process of meaning-making through social encounter.

The anatomical body with organs, is one territorialized by what in some ways might for sure be an outdated medical discourse (this is not a neurological, biochemical body involving complex processes of distributed signalling and feedback). But our point is that this dualist framing women employ possibly to render their experience intelligible, of an objective body of biology fundamentally disallows the possibility of meaningful semiotic, ontogenetic, biological processes that are integrally social, in which histories of experience, meaning and interpretation are sedimented in the organic integrity of the organism. Such a ‘biocultural’ rendition might enable much greater understanding of how experience of gendering is integral to the experience of pelvic pain for women.

Notes

1 Grace, 1995.
2 Carr et al, 2005.
4 Bendelow and Williams, 1994.
5 Bendelow, 2000.
6 Gatens, 1996, 82
7 Wilson, 2004.
11 This reference is to interview number, paragraph number, then age of interviewee.
12 Kristeva, 1982.
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PART IV

Meaning and Medicine
Methods of Diagnosis: The Path towards Dialogue

Imre Bárd

Abstract
This text presents the eastern methods of medical diagnosis, stressing the point of fundamental interconnectedness in Chinese medicine as opposed to the isolating rationalism more typical of the West. Through this comparison, we find ourselves confronted with the ancient philosophical problem of truth and its value. Because biomedicine understands itself as being based on natural sciences, it leaves almost no room for the subjective experiences of illness and other non-measurable, but rather significant, descriptions of health and disease. The resulting alienation in the patient-doctor relationship and the increasing rate of medicalisation urge us to engage in open-minded dialogue with medical systems other than our own. I shall not consider Chinese medicine to be a set of complementary treatments, but regard it as an equal partner in an intercultural and interdisciplinary dialogue, which could help us to reflect upon and revise the assumptions we have always taken for granted. In my chapter I briefly sketch some of the philosophical principles in Europe and China that have led to the birth of two completely different but well-functioning medical models. Taking their methods of diagnosis as starting point, I pay special attention to the area where dialogue is most crucial, the patient-doctor relationship.

Key Words: Traditional Chinese Medicine, biomedicine, diagnosis.

In the abstract of my chapter, I promise to present the ‘eastern methods of medical diagnosis’. This is clearly an overstatement, not only because such an undertaking would by far exceed my competency, but also because ‘eastern methods of diagnosis’ as such does not exist. We would find completely different medical systems in India, China or Japan. Therefore, I will only compare our own school medicine with Traditional Chinese Medicine - or TCM for short. Since I am an expert in neither of them, my presentation could mainly be understood as a philosophical look at some of the principles underlying these two systems. Philosophical, though in a non-classical sense. Instead of setting out to analyse certain ideas or notions, I would like to employ philosophy in order to reveal the assumptions, which medical practice and western natural science in general take for granted. Referring to biomedicine, I mean ‘the predominant medical system in Europe and North America’, which ‘understands itself as a medicine based on the principles of natural science’.1
Speaking of TCM, apart from its institutionalised form I mean all classical elements as well, which are almost impossible to hand down within the frameworks of university education, but which are known to us from numerous texts. It might be important to state at the very beginning that I consider TCM to be a coequal medical system beside biomedicine. The question, therefore, is not whether methods of TCM should be considered scientific in our sense, and thus become parts of our practice, but rather if there is anything within the mentality of Chinese medicine which could contribute to solving the problems arising from the shortcomings of our own methods.

I shall argue that our ways of diagnosis and treatment, which are considered to be scientific and objective are in fact determined by certain cultural factors and that the striving for objectivity itself is an occidental characteristic. Due to the vastness of the subject, I must confine myself to dealing with only a few of the manifold possible questions. I will attempt to show the theoretical difference between TCM and biomedicine by taking their methods of diagnosis as a starting point.

We are all pretty familiar with the methods of western diagnosis such as blood pressure tests, ultrasound, X-rays, ECG, and so on. Looking carefully at such proceedings, we can identify at least four essential characteristics of biomedicine. Firstly, that every examination is a quest for the single underlying cause of a disease; seeking the malformation almost as if it was an independently existing thing within the body, thus objectifying the sickness. Secondly, that different diseases require different methods of diagnosis, hence the description of them stems from different viewpoints. Thirdly, that diagnostic results are always compared to set norms, whereby normality seems to be the correspondence with statistical averages, and finally, that the examined patient is expected to remain passive throughout the entire process.

The ideal of modern medicine is to gain ever more knowledge about ever smaller parts of the body, which results in diagnosis occurring mainly at molecular or sub-molecular levels, with the patient as a whole being left in the waiting room. Biomedicine lacks the theory to present an overall diagnosis of the body and considers diseases to be pathological entities, which, with well definable qualities are occurring within our body. This body, in turn, seems to be the aggregation of more or less independent parts. Hence the task of medicine is to locate and extinguish diseases with utter accuracy.

The pursuit for a better understanding of the processes of the physical body and the advancement of technology have led medical diagnosis to shift its attention from the subjective experience of illness to a biological description of diseases. According to Cassell, we could say that an illness is what the patient feels when he goes to the doctor, whereas a disease is what
he has on the way home from the doctor’s office. An illness we feel, a disease we have. With the ongoing medicalisation, the disease model gains exclusive validity over social or subjective narratives.

Our medical practice of treating the human organism as a whole consisting of tiny parts, and the perception of diseases as definite entities, reflects traditional philosophical presuppositions of the West. The tendency of European medicine to objecify diseases is usually traced back to its time of rebirth as a positivistic medicine in the nineteenth century, though the seeds of this ontological attitude have already been present in our thinking at much earlier times.

At the dawn of philosophy in Greece, we find an ontological question, which seeks to discover the fundamental categories of being. For most of us, this seems to be the natural task of philosophy, but it is exactly this acquaintance, which hinders our ability to see the included presuppositions. Namely the unquestioned premises stating that the structure of the world and the structure of the mind concur and that the workings of the world are to be unravelled by rational means, not by other methods. The firm belief in the primarily logical consistency of the world, and hence the search for governing laws are some of the main attributes of European thought that have remained uncontroversial for most of its history.

Philosophers and linguists of the twentieth century have shown that many of our fundamental philosophical convictions result from the grammatical conventions of the Indo-European languages. Numerous philosophical problems have arisen from false objectifications of linguistic structures. The law of contradiction, for example, states that the same thing cannot at the same time be and not be. This law served as a fundamental principle of western sciences until the birth of quantum mechanics. Until then, this linguistic rule was thought to be a law of existence.

Accordingly, languages do not represent the world as it is given, but partially construct the overall way we look at the world. Grammatical convention decides how we discern objects and events from each other. The world is only given as a culturally and linguistically filtered experience whereby no method of classification or linguistic description - not even the one called scientific - can be true in an absolute sense.

Furthermore the scientific quest for truth seems to be the ideological heritage of the Platonic theory of eternal Forms and of the Christian idea of the Absolute. Both of these theories present the essentials of the world to be of a conceptual, abstract and pure nature as opposed to the flux and ambiguity of everyday life. A result of this dichotomy is mind/body dualism. How can the non-material mind affect the material body, and vice versa? This problem seemed to be an insoluble dilemma, though it simply arises from the sharp separation between the mental and the material.
Because the mental ruled over the material and the abstract was thought to be more important than the concrete, the task of philosophy - and later of the sciences - was to bring bright theoretical order into the obscurity of life. To unlock the secret mechanisms that make the world go round and to make it more suitable for human needs is a long desired goal.

An unfortunate corollary of these endeavours was that they involved absolute value judgments. Thus, life became Good while sickness, disability and death were seen to be Evil; the mental, the spiritual and the eternal seemed to be true and came to be valued while the bodily and the ephemeral turned worthless. Biomedicine’s desperate battle against diseases and ultimately against death itself seems to be the onerous legacy of this dichotomy.

The biomedical methods of translating human conditions into measurable quantities and the reduction of patients to mere spectators of their own curing have unfortunately engendered a significant rate of alienation between patient and doctor. Because scientific enquiry demands that non-measurable factors are left out of observation, emotional, cultural, and social elements as possible causes of sickness necessarily remain intact. Medicine is only concerned with the restoration or maintenance of the human organism at a statistically derived equilibrium. This often has unwanted side effects. Fatal adverse drug reactions rank from the fourth to the sixth leading cause of death in the United States after heart disease, cancer, and stroke. Costs associated with adverse drug reactions were estimated at up to $4 billion a year.

The increasing rate of medicalisation poses severe questions about how society and medicine should define normality and treat variation. We have seen that our medical thinking, though amazingly effective in, for example, surgery and urgent care, has raised some serious problems.

The Chinese mentality is of course not better than ours, and naturally no wonder therapy, but because of its otherness, it can be of great value to us. Keeping in mind that no medical model is ‘true’ in an absolute sense, one should try to accept the possibility that radically different, but well functioning models of health and illness are conceivable. Avoiding extremes in the evaluation, without mystification or uncritical depreciation, we should simply take TCM for what it is, a coherent and independent system of thought and practice that has been developed over two millennia. Based on ancient texts, it is the result of a continuous process of critical thinking, as well as extensive clinical observation and testing.

Unlike the western approach, Chinese thinking lays almost no emphasis on the formulation of universal truths. It does not search for an ultimate reality, a final cause or a creator because a moral or social-political question, rather than an ontological one motivates it. The question could
simply sound something like this: How can people live together harmoniously?

Chinese philosophy is not concerned with the fundamental categories of being, because it never seeks to leave the realm of human activity. Ethics, medicine, science and philosophy are all concerned with the practical horizon of human life. Harmony is the key concept, which is described as the circular, dynamic balance of two polar complements, Yin and Yang. These polarities are not to be understood as forces or material entities, rather as ‘convenient labels used to describe how things function in relation to each other and to the universe.’

To name just a few qualities associated with them: cold, rest, passivity, responsiveness, darkness and decrease are Yin; while heat, stimulation, movement, activity, light and increase are Yang. Obviously, something can only be Yin inasmuch as it is opposed to something Yang. Hence, they are not entities, rather modes of description.

According to TCM such qualities are in constant motion within the universe and thus within our bodies as well. The relative excess or deficiency of one of them results in illness. Such disharmonies occur due to the ‘environment, emotional responsiveness, way of life, and heredity’. This already reveals that the human being is regarded as existing inseparably embedded within both his natural and social environment.

Because of the concept of dynamic harmony, Chinese thinking has always been at peace with the sombre side of life. Health and Illness, Birth and Death, Rise and Fall, Growth and Decline naturally and necessarily belong together and create the constant unfolding of the world. Not the beginning, not the cause nor the end concern Chinese contemplation, rather the ever-moving dynamics of phenomena. What things essentially are is a lot less interesting than their relations to each other and their ability to change.

It’s complicated for us to understand these thoughts of polar unity and circularity, because our ideal is to achieve eternal growth and expansion with the banishment of decline and caducity, to penetrate to the core of existence and create a flawless world. One of the latest examples of this is the Human Genome Project, which seeks to excavate the primordial element of life in order to be rid of diseases forever. Instead of looking for the primary building blocks of the world - much like the LEGO game - Chinese thought is searching for the relations between the elements and the whole. Nevertheless, these relations are not causal links, for the mentality is not mechanistic. Instead of thinking in the linearity of cause and effect, Chinese thought is circular, and tries to discern patterns by organizing phenomena side by side, rather than one after the other.

The goal of Chinese medicine is to understand how things function in connection to each other. It focuses on the interrelations within the human organism, between people, and ultimately between people and the universe.
Because of its essentially holistic attitude, TCM has not developed a surgery, and is not concerned with the exact physical location of organs or diseases. It maintains that cutting the organism would destroy its original entirety.

Since relations are of crucial importance, TCM does not see diseases as separate entities somewhere within the body, rather as states of disharmony, affecting the whole person. Because of this attitude, TCM knows no psychosomatic disorders, for the psyche and the soma have not been philosophically separated from each other. According to this mentality, TCM doesn’t hunt for the physical causes of diseases, rather tries to weave as many characteristics as possible - the physical, emotional and social relations - of the person into a chiselled image or pattern of disharmony. Ted Kaptchuk has described this method of diagnosis with the metaphor of painting the landscape of the person; a landscape in which the stones, mountains, mist, and pebbles represent the different information a physician collects from his patient. However, none of this data would have meaning if it did not in the end build a discrete image. In fact, this final image, the context of the parts determines their meaning. Quoting Kaptchuk: ‘No component of the pattern can be isolated; no piece has an ontological significance independent of the entire environment.’

This idea of meaning being ultimately dependent upon the context pervades Chinese thought in general and manifests itself in such different areas as the structure of the language, the principles of ethics, philosophical concepts and as we have seen, in the practice of medicine as well. Because no symptom, complaint or sign has significance per se, the true strength of TCM lies within its ability to diagnose people, rather than sum up medical facts.

The lack of anatomical knowledge led Chinese doctors to very carefully observe the qualities of the pulse, the colour of the skin and the tongue, the manner of speech, the tone of voice, a persons pace, gait and gesticulation and the relationship of these to the environment, emotions and way of life. There is a telling difference between the Chinese and the western idea of taking the pulse. For biomedicine, the pulse reveals an attribute of the heart, namely how many times it pumps in a minute. Purely quantitative. Chinese medicine distinguishes between many, rather poetically described, qualities of the pulse, such as: rapid, wiry, thin, empty, slow, floating, deep, sinking, full, slippery, choppy, tight, short, long, moderate, minute, frail, and so on…

We can sense that there is something almost artistic in the methods of Chinese diagnosis requiring the doctor to be extremely skilful at observing subtle details and in discovering the whole in any part. Diagnosis is always a deeply personal collaboration between the physician and the patient, which assumes that they share an atmosphere of trust and that illnesses are not seen as embarrassing conditions better kept in secrecy. Therefore it is not just the medical view in China, which differs from our own, but the attitude
of the general population as well. Illness is not considered to be one’s private concern. The whole family might accompany a person when they visit the doctor to find the solution together. It should be noted that TCM is originally a preventive medicine, aiming at keeping the person healthy rather than curing him of serious diseases, which suggests that the success of the occasional application of the methods of TCM is strongly questionable.

I have deliberately not gone into the practice of TCM in detail as my main intention was to present the possibility of an alternate model of health and illness. To borrow methods from this system in order to cure diseases, or to attempt to verify its principles with ‘scientific’ methods is a complete misunderstanding both of science and of interdisciplinarity. We cannot judge an independent system of thought according to our own criteria. That would prove nothing merely confirm our own preconceptions.

The title of my presentation was: The Path Towards Dialogue. I should have added a question mark at the end. Surely, diagnosis should be a form of dialogue in every medicine. Whether TCM and biomedicine are able to communicate with each other is another matter. The incompatibility of their fundamental principles might prevent that they ever merge, but that is certainly not the aim.

Biomedicine needs to solve its current problems within its own theoretical frameworks, upon its own grounds, and steps are already being made. However, the acceptance of other systems of thought could help us to review our own assumptions, realise barriers and broaden horizons. A vast field for future interdisciplinary work is at hand.

Notes

2 Cassel, 1976, 47-83.
3 Such thinkers as Franz Rosenzweig, Ludwig Wittgenstein, Alan Watts, Paul Feyerabend, Edward Sapir and Benjamin Whorf.
5 Drugintel Statistics on Adverse Drug Reactions.
6 Kaptchuk, 2000, 2.
7 Ibid., 8.
8 Ibid., 144.
9 Ibid., 284.

Bibliography


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Disease in the Information Age

Laura K. Kerr

Abstract
In the 1960s, Georges Canguilhem wrote an addendum to The Normal and the Pathological in which he addressed the impact of conceiving life according to the concepts of information theory. He described a new social order in which the concepts used to articulate disease are as significant for determining health as the diseases themselves. According to Canguilhem, health is no longer ‘life lived in the silence of the organs,’ as the French surgeon René Leriche stated in the nineteenth century. Instead, it is now plagued by the necessity of the continual search for information about disease. No longer are we truly healthy, since we can never abandon our anxiety about being diseased; we now know health only in relation to the possibility of falling ill. The person in this conceptual environment, Canguilhem argued, suffers from chronic health in which ‘the menace of disease is one of the components of health.’ This chapter presentation outlines Canguilhem’s conception of chronic health and discusses its occurrence forty years after his original depiction. While his characterisation of chronic health remains accurate, the situation is nevertheless changed by the sheer amount of information now available, the accessibility of this information to consumers via mass media and the World Wide Web, as well as rapid changes in conceptions of health and disease that require an almost hyper-awareness of medical advances. Living with uncertainty about health and disease has become an unquestioned norm as people reflexively ask themselves ‘Am I that disease?’ in their encounters with medical information. Unforeseen by Canguilhem, medicine has come to rely on consumers’ reflexive responses for its own production of knowledge. As a result, medicine has become reflexive like the people it treats, a point that is explored in this depiction of chronic health in the new millennium.

Key Words: Canguilhem, health uncertainty, disease, information age.

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Originally, I titled my chapter ‘Disease in the Information Age’ while I was in America, where I live less than three miles from one of the world’s premier medical centres and in the heart of Silicon Valley, a well-known catalyst for the creation of the Internet and the information age. I am in Oxford following time I spent in South Africa at a women’s health clinic in the notorious Khayelitsha Township that borders Cape Town proper. I feel I should rename my chapter, as it is difficult to make sense of health and
disease in the context of these contrasting venues given the globalising undertones that the title ‘Disease in the Information Age’ suggests.

Nevertheless, I believe there are commonalities between these radically different experiences of health and disease that can be understood through the dialectical tension existing between representations of the modern and the traditional. Let me begin by dismissing a simplistic glossing of this relationship in which the modern and the traditional exist on a continuum with development tracing the progress from traditional healing to the high-tech conglomerate and capitalist venture that modern medicine has become in some places. In the centre of such a developmental progression we might imagine the medicine practiced in the townships surrounding Cape Town, South Africa, where traditional healing as well as westernized medicine influences its inhabitants. In the women’s health clinic I visited in Khayelitsha, the Swedish doctor was just one source for treating the estimated one-third of a million people in this township infected with HIV. Despite the presence of this Western clinic, anti-retroviral therapy only recently became ‘widely’ available. An anxious and sometimes frenetic search for information about how to treat AIDS-related diseases continues to exist in which medical advice competes with traditional healing and daily gossip as the wellspring for cures to AIDS. Besides anti-retroviral therapy, cures for AIDS have been associated with purification and protection rituals; the ground bones of giraffes; various herbal remedies; and most horrifying, sexual intercourse with a virgin. This last notion has led to numerous rapes of infants and young children.

This may sound more like the ‘misinformation age,’ perhaps reflective of the early development of Western medicine. We might wonder if it is no different than the reliance on ideas such as the miasma of free-floating disease that existed in the West before disease became localized in the body and Rudolf Virchow’s subsequent discovery of cellular pathology. The continuum model of the relationship between the modern and the traditional assumes the displacement of one, tradition, by the other, modernity. Or at least this is how the story of the development of modern medicine is sometimes told.

This chapter will examine a different dialectic between the modern and the traditional, in which tradition represents an inversion of what constitutes normal and acceptable modern medical science and practice, while being necessary for the production of modern medicine as well. As the philosopher and historian of science, Georges Canguilhem stressed, ‘Every preference for a possible order is accompanied, most often implicitly, by the aversion for the opposite possible order.’ Like some of our African sisters and brothers, many of us in the West also respond to disease with anxiety, although we often do so without the impending siege of death. It is in the anxious pursuit of medical information that tradition exists side-by-side with
modern medicine while also being denied by it. In what follows, I will demonstrate that it is not the absence of tradition that distinguishes modern medicine from developing world medicine, but the sublimation of tradition into the anxious pursuit of information about health and disease even in the absence of illness or injury.

To make this point, I begin with the observation that the Enlightenment Project and the creation of modern societies are largely based on a cognitive revolution in which tradition has been sublimated into our emotional worlds. A rigorous division between the rational and the emotional cleaves our experience of individuation in modern societies. This does not mean that modern society lacks emotional character, but rather that its emotional character is developed in response to the aversion and sublimation of tradition.²

Tradition, according to the sociologist Anthony Giddens, is an organizing medium of collective memory whose ‘integrity’ is derived from the commitment to repetition of shared practices and beliefs rather than their sheer ‘persistence over time.’³ Giddens argues that it is this commitment to repetition that leads to the continual creation of tradition. When tradition is sublimated into emotions, the collective practices may be lost, yet the need for repetition continues. Giddens observes this to be the compulsive character of both modern society and our experience of individuation. He states:

The past lives on, but rather than being actively reconstructed in the mode of tradition it tends to dominate action almost in a quasi-causal fashion. Compulsiveness, when socially generalized, is in effect tradition without traditionalism....

Constant compulsion leads to anxiety. Sigmund Freud made this observation in his book, *Civilisation and Its Discontents.*⁵ Here, he theorized that heightened anxiety is the outcome of a civilisation that relies on its members’ instinctual repression for advancement and development. Today, anxiety seems to have reached epidemic proportions. In America, the diagnostic category psychiatrists most often assign their patients is anxiety disorder, which I interpret as a prevailing social condition rather than as evidence of the presence of individual pathology.⁶ Indeed, many modern societies, if not all, are going through a transformation, and this is reflected in the increased expression of anxiety. The sociologist Ulrich Beck identifies this new era as the second wave of modernisation, and others have referred to it as the post-modern.⁷ This new era continues the sublimation of tradition, although in a context of heightened individuation, choice, and uncertainty.

Beck labels this second phase of modernisation as ‘risk society,’ in which the defining attribute is that modern society has become problematic.
The phrase *risk society* distinguishes the point at which the threats associated with the development of industrial societies determine the future progression of modernity. Environmental degradation, global pandemics such as AIDS and tuberculosis, econocides, diasporas, and even genocides can be linked to the industrialisation of societies. These problems have become so encompassing that they have changed the path of modernisation. Modern societies are now required to progress reflexively rather than expansively. Rather than conquering nature and creating alternative, assumedly controllable environments, what constitutes development, particularly in the sciences, has changed to become more dependent on social norms for the production of acceptable environments and technologies.

Rationality in many contexts has become questionable as a foundation for decision-making. Persuasion through politics, witnessed in the proliferation of special interest groups, now holds as much sway as scientific argumentation, although the former often rely on the latter to support their positions. More often, we witness experts contradicting experts in the search for culturally acceptable solutions to the problems modernisation has incurred. With the emerging uncertainty for how to proceed, the inversion between the modern and the traditional begins to destabilise. As confidence in rationality decreases, it is worth examining how we are making choices in the face of uncertainty and asking whether the emotional character associated with our decision-making processes determines the choices we make.

The reflexive search for solutions extends to the process of individuation. The disintegration of certainty about the future progression of societies aggravates our compulsion to find, and more frequently, create, certainty in our individual lives as well. In few circumstances is the search for certainty witnessed with as much clarity as in the search for certainty around health and disease. Before expanding this point, a brief comment about the relationship between the development of risk society and the dissemination and application of information theory is required, for the two are inseparable.

Of profound influence is how Claude Shannon originally developed information theory. Shannon defined *information* internally, basing it on relational differences between bits of messages without regard for the context that gives meaning to the information sent. As technologies and scientific theory became more dependent on information theory for their development, the cultural context was similarly altered. Without a consensus on meaning, and because of the emerging possibility of manipulating and reconstituting informational texts at will, a new understanding of environment as *context* has emerged in which the arbitrary quality of situations and events is the operative condition of the worlds we inhabit.

In the 1960s, Canguilhem observed the impact of information theory on both the development of molecular biology and the Western experiences for itself. The phrase *risk society* distinguishes the point at which the threats associated with the development of industrial societies determine the future progression of modernity. Environmental degradation, global pandemics such as AIDS and tuberculosis, econocides, diasporas, and even genocides can be linked to the industrialisation of societies. These problems have become so encompassing that they have changed the path of modernisation. Modern societies are now required to progress reflexively rather than expansively. Rather than conquering nature and creating alternative, assumedly controllable environments, what constitutes development, particularly in the sciences, has changed to become more dependent on social norms for the production of acceptable environments and technologies.

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In the 1960s, Canguilhem observed the impact of information theory on both the development of molecular biology and the Western experiences
of health and disease. In an addendum to his book, *The Normal and the Pathological*, Canguilhem pointed out that before molecular biology, distinctions between the normal and the pathological were made by examining a person’s interactions with her or his environment, and most often, it was the social environment that was most influential in determining what constituted normal behaviour.12 In this cultural milieu, what Beck might identify as the first wave of modernisation, tradition continued to influence through the expectation that social norms were the final arbiters of individual ascriptions of the normal and the pathological.

Molecular biology, however, heralded a shift in focus away from the environment to the physiology of the organism, initiating the identification of norms in the *structure* of the living being. Canguilhem identified this change as primarily a conceptual shift that occurred with the introduction of the term *hereditary biochemical error*. With the term ‘error,’ Canguilhem stated, ‘a new nomenclature of disease is thus established, referring disease not to the individual considered in its totality but to its morphological and functional constituents.’13 As a result, the psychosocial environment is subordinated to the supposedly neutral information theoretic conception of error.

For Canguilhem, information theory implied that sufferers of disease were no longer responsible for their illness, but rather were victims of chance. He stated:

> Disease is no longer related to individual responsibility; no more imprudence, no more excess to incriminate, not even collective responsibility as in the case of epidemics. As living beings, we are the effect of the very laws of the multiplication of life, as sick men we are the effect of universal mixing, love and chance.14

For Canguilhem, this lessened our reliance on traditional methods for organizing our behaviour according to social and cultural norms. It initiated a shift from a predefined environment to a more fluid conceptual context of the individual’s making. Canguilhem observed:

> …the environments in which the living beings find themselves are carved out by them, centre on them. In this sense the organism is not thrown into an environment to which he must submit, but he structures his environment at the same time that he develops his capacities as an organism.15

The shift to a context of our own making also increases our dependency on information about health and disease. Once again, tradition is
not lost, and its impact is arguably redoubled in the information age in which anxiety about health and disease is linked to the seemingly exponential proliferation of information through the media and the Internet.

Canguilhem associated health and disease in the information age with the ceaseless search for information. Both health and disease, he observed, require moving around a conceptual space, finding the necessary information for maintaining life, while continually searching for more information. Disease, in part, is related to receiving incorrect information. According to Canguilhem, 'Man makes mistakes because he does not know where to settle. He makes mistakes when he chooses the wrong spot for receiving the kind of information he is after.' Health, in contrast, is equated with the greatest amount of information with the most variety, motivated by the anxiety to keep searching.

Because of the commitment to the constant search for disease, the healthy person is not healthy in the sense of health as defined by the French surgeon René Leriche in the nineteenth century in which health is ‘life lived in the silence of the organs.’ The individual inhabiting risk society can never abandon anxiety about being diseased. Health is known only in relation to the possibility, often statistical, of falling into disease. Canguilhem said about this driving anxiety that it creates a new sense of disease as the lack of biological confidence in oneself. It sends the otherwise healthy person on a quest for the most information possible to assure that she or he is shielded from disease. Health then becomes the experience of “…an anxious quest for the greatest possible quantity and variety of information.” The person in this conceptual context could be said to suffer from chronic health in which according to Canguilhem, ‘the menace of disease is one of the components of health.’

Michel Foucault has pointed out that to live in our world of conceptual uncertainty is not a diversion from life but rather affirms our commitment to living. In the introduction to Canguilhem’s The Normal and the Pathological, he stated:

That man lives in a conceptually architectured environment does not prove that he has been diverted from life by some oversight or that a historical drama has separated him from it; but only that he lives in a certain way, that he has a relationship with his environment such that he does not have a fixed point of view of it, that he can move on an undefined territory, that he must move about to receive information, that he must move things in relation to one another in order to make them useful. Forming concepts is one way of living, not of killing life; it is one way of living in complete mobility and not immobilizing life….
The problem may not be for the individual who must make a life in a context of uncertainty and choice. Rather, the threat may well lie with the institutions that must rely on individuals’ creative use of information to guide their institutional development. As Beck argues, in risk society, more often institutions appear unreal, and even anachronistic, in their programs and foundations. Not surprisingly, the tactical approach to information use and ‘meaning making’ witnessed with individuals often determines institutional strategies for survival.

With regards to this point, I will conclude by sharing a bit more with you about my neighbourhood. Asian approaches to healing are present where I live in America. In fact, next to my neighbourhood cleaners stands not one, but two acupuncture clinics. In response to overwhelming patient demands, the HMO that insures me recently began subsidising acupuncture treatments at such clinics as well as massage therapy and chiropractic treatments at other local facilities. In this bricolage of health care, we might ask, What is modern medicine?, What is traditional healing?, and sadly wonder if, in the information age, access to choice of health care is the decisive difference between medicine in parts of the West and many developing countries.

Notes

1 Canguilhem, 1991, 240.
2 Giddens, 1994, 66.
3 Ibid, 64.
4 Ibid, 70.
5 Freud, 1989.
6 For a discussion of anxiety as a social strategy, see Gottschalk, 2000, 18-48.
7 Beck, 1994, 2.
8 Ibid., 5.
9 Ibid., 9-11.
13 Canguilhem, 1988, 140.
15 Ibid., 284.
16 Canguilhem, 1994, 319.
18 Ibid., 286.
19 Canguilhem, 1994, 319.


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The Media Manufacturing the Sense of Health, Illness and Disease: Health Coverage in Turkish Newspapers

İnci Çınarlı and Elgiz Yılmaz

Abstract
Health information in the mass media is rich in quantity but poor in quality. Turkish newspapers, one of the most widespread forms of print media and one of the major sources of public health information in Turkey, are particularly inadequate at shaping our perceptions of health, illness and disease. The health messages of the news media are frequently paradoxical and conflicting and far from being informative or in the public’s best interest. This is perhaps because of the use of unreliable sources of information, the non-specialisation of health reporters, the translation of health news from developed countries’ information sources and the expectations created by the news about new health technologies. This chapter presents how newspapers contribute to the medical model of health and explores the individualised, sensationalised and mostly commercialised health meanings produced, such as ‘lifestyle’ discourses, ‘miraculous cures’, ‘health rituals’ and so on. To achieve this, a qualitative and quantitative content analysis of health coverage in eight Turkish newspapers was conducted during the first three months of 2005. This examined the significance of health, illness and disease as manufactured by the media.

Key Words: Health information, mass media, health coverage, health messages.

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‘...the press may not be successful much of the time in telling people what to think, but it is stunningly successful much of the time in telling people what to think about.’

Bernard Cohen, The Press and Foreign Policy, 1963

1. Introduction
The ‘lifestyle discourses’ of our era such as anti-ageing, detox, botox, diets, unnecessary plastic surgeries, liposuction and depression drugs have been spread and imposed through globalization. These ‘health industry rituals’ are supported and manipulated through the news media, in particular newspapers, which contribute to the medical model of health.¹

The medical model of health is the most powerful and influential discourse about health that focuses mainly on individual patients, treatment
and cure of disease. In this model, disease and sickness are explained within a biological framework. According to Zola, this concept of medicalisation involves an expansion of the medical institution, perceiving human life and its deviances from a medical perspective.

As a result of this medicalisation, ordinary and crucial aspects of human development (e.g. menopause, fertility) have become subject to the expertise of physicians and other health professionals. In such a medical context, if 'health is the mirror image of disease', the mass media is the mirror.

Health information received from the media is rich in quantity but obviously poor in quality. Furthermore, information is mostly paradoxical, conflicting, commercialised, individualised and sensationalised. Consequently, it is far from being informative, or in the public interest. This is perhaps because of the use of unreliable sources of information, the non-specialisation of health reporters, the translation of health news from developed countries’ information sources and the expectations created by news about new health technologies. Besides which, this dependency on foreign news sources creates an impression that the meaning of health and disease must come from elsewhere.

The purpose of this research is to determine how newspapers manufacture the significance of health, illness and disease so inadequately. To that end, a qualitative and quantitative content analysis of health coverage in eight national newspapers in the authors’ home country Turkey was conducted over the first three months of 2005.

2. Methodology

Based on the arguments outlined above we can formulate the following interconnected hypotheses (H):

H1: Newspapers contribute to the ‘medical model’ of health.
H2: Newspapers manufacture our perceptions of health, illness and disease.
H3: Newspapers reflect mostly paradoxical, conflicting health information, conveying individualised, sensationalised and commercialised health messages.
H4: Dependency on foreign news sources creates an impression that the meaning of health and disease must come from outside of the country.

To address these hypotheses, a content analysis system particularly suitable for the descriptive and comparative study of print media (newspapers) was chosen. Since content analysis is a quantitative method, to
examine the ineffectual nature of how the media manufactures health, illness and disease meanings, a qualitative method was also required.

In order to conduct a quantitative content analysis, eight national newspapers (Zaman, Hürriyet, Sabah, Vatan, Takvim, Yeni Şafak, Cumhuriyet and Radikal) have been chosen. The total circulation of the 34 Turkish national newspapers’ is reported to be 4,804,102 and four of our selected newspapers (Zaman, Hürriyet, Sabah and Takvim) rank in the top five for circulation (Zaman 553,601, Hürriyet 498,539, Sabah 425,332, Takvim 278,447, Vatan 271,098, Yeni Şafak 108,909, Cumhuriyet 58,485, Radikal 40,500; in total: 2,234,911 copies). Posta, the highest-selling newspaper, does not offer a website and for this reason has been excluded from our research.

Each of these newspapers, each with their own website archive, was selected to be studied over the first three months of 2005. The papers were chosen because they are influential nationwide, known to be agenda-setting and, most importantly, offer a representative picture of the national newspapers’ political tendencies. As such they were selected from two political extremes: Cumhuriyet and Radikal are left wing, Zaman and Yeni Şafak are right wing. Hürriyet, Sabah, Vatan and Takvim could be placed between these two extremes.

The unit of the analysis was health related articles in the selected newspapers. Our first analytical categories were health subjects in these units, in order to describe the significance of health, illness and disease manufactured by the media. To this end, every single reference on health, illness and disease has been coded. Finally, collected data for each analytical category has been entered into an Excel table to help draw conclusions. Our second analytical categories were source citations in health related articles. Consistent with the objectives of this research, each newspaper categorised into ten news topics. Then a supplement containing health information was used to find out the credibility and dependency of the news for the public.

The categories of news topics are as follows: actuality, politics, world news, economy, health, columnists, serial, lifestyle, culture, science and supplement. Since every newspaper categorises articles under different names, we regrouped them under identical names. Subsequently, health related articles were coded according to news (information) sources; sources citing national/international news and no-source citing national/international news. Collected data has been also entered into a more basic tabular calculator to make conclusions.
3. Findings and Discussion Part 1

**Table 1:** Frequency of health subjects in selected newspapers between the 1st of January 2005 and 31st of March 2005

<table>
<thead>
<tr>
<th>HEALTH SUBJECTS</th>
<th>ZAMAN</th>
<th>HURRİVET</th>
<th>SABAH</th>
<th>TAKVİM</th>
<th>VİYAN</th>
<th>VİNSFİB</th>
<th>GÜMÜŞ GÜMÜŞ</th>
<th>RADÍKAL</th>
<th>TOTAL</th>
<th>%</th>
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</thead>
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<td>21</td>
<td>30</td>
<td>29</td>
<td>21</td>
<td>13</td>
<td>25</td>
<td>13</td>
<td>169</td>
<td>6</td>
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<tr>
<td>Women’s health</td>
<td>15</td>
<td>22</td>
<td>19</td>
<td>33</td>
<td>24</td>
<td>14</td>
<td>9</td>
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<td>Paediatrics</td>
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</table>
Table 1 indicates the frequency of health subjects in selected newspapers between 1st of January, 2005 and 31st of March, 2005. In order to analyse the significance of health, illness and disease in newspapers, 40 categories of health related subjects (diseases, epidemics, lifestyle discourses, health care providers news, malpractice and health scandals, medical innovations, religious health advices, health campaigns, environmental health conditions, health organisation adverts, celebrity health news, pharmaceutical news, popular health knowledge and miscellaneous) were coded within the articles and the resulting sample consisted of 2,749 health related subjects. Hence, a variety of health related subjects were covered from a good range of newspapers.

The frequency of the health coverage for each newspaper was as follows: Takvim 509 (19%), Sabah 372 (14%), Hürriyet 370 (13%), Zaman 360 (13%), Radikal 344 (13%), Vatan 338 (12%), Cumhuriyet 251 (9%) and Yeni Şafak 205 (7%).

Overall, the majority of health related subjects written about in the selected newspapers focused on internal diseases (8%), substance abuse (7%), healthy living (6%), cancer (6%), women’s health (5%), malnutrition, overweight and obesity (5%), paediatrics (5%) and infections (5%). Cardiovascular disease, mental health, medical innovations, health organisations adverts and miscellaneous (superstition) were 4%. Pharmaceutical news, herbal remedies-alternative medicine and celebrity health news were each 3%. Articles referring to eyes and vision, immune system, brain and nervous system, rare cases, malpractice and health scandals occupied 2% for each. And the minority of articles referring to mouth and teeth, the disabled, epidemics, ear-nose and throat, plastic surgery, sexuality, genetics, organ transplantation, euthanasia, health care providers’ news, religious health advices, environmental conditions, health campaigns and popular health knowledge were 1% for each. From the results we see that diseases, illnesses and their treatments are the main health subjects found in
newspapers. Indeed, the dominance of ‘medicalisation’ of health or the medical model of health is obvious. The social model consisting of political, economic, social, psychological, cultural and environmental factors of health has not been mentioned in the articles with the exception of 1% coverage for environmental conditions.

4. **Findings and Discussion Part 2**

The next eight consequent tables (Table 2 to Table 9) indicate the frequency of health related articles in selected newspapers, categorized into ten news topics/categories (actuality, politics, world news, economy, health, columnists, serial, lifestyle, culture, and science) plus supplement. Among these newspapers, *Vatan* and *Yeni Şafak* have a health section, *Hürriyet* has a specialised health reporter and two MDs as columnists and *Radikal* also has a specialised health reporter. Hence, specialisation in health news is not common in Turkey.

*Table 2*: Frequency of health related articles in *Zaman* evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

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<th>National No-Source Cited</th>
<th>International Source Cited</th>
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</table>
Table 2 indicates health related news in Zaman frequency of 54% in actuality, 38% in lifestyle, 3% in columnists, 2% in economy, 2% in supplement and 1% in politics. 83% of health related news was national source cited, 1% was national no-source cited, 12% is international source cited and 4% is anonymous.

**Table 3**: Frequency of health related articles in Hürriyet evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

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<th>Source</th>
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<th>National No-Source Cited</th>
<th>International Source Cited</th>
<th>International No-Source Cited</th>
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<td>Lifestyle</td>
<td>102</td>
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<td>9</td>
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<td>1</td>
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</tr>
<tr>
<td>Supplement</td>
<td>27</td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>27</td>
<td></td>
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<tr>
<td>TOTAL</td>
<td>182</td>
<td>4</td>
<td>125</td>
<td>11</td>
<td>30</td>
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</tr>
</tbody>
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Table 3 indicates, health related news in Hürriyet frequency of 55% in lifestyle, 18% in supplement, 7% in actuality, 7% in columnists, 5% in world news, 4% in economy and 4% in science. 52% of health related news is national source-cited, 1% is national no-source cited and 36% is international source cited, 3% is international no-source cited and 9% is anonymous.
Table 4: Frequency of health related articles in Sabah evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

<table>
<thead>
<tr>
<th>Source</th>
<th>National Source Cited</th>
<th>National No-Source Cited</th>
<th>International Source Cited</th>
<th>International No-Source Cited</th>
<th>Anonymous</th>
<th>TOTAL per news topics</th>
</tr>
</thead>
<tbody>
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<td>Actuality</td>
<td>93</td>
<td>25</td>
<td>38</td>
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<td>1</td>
<td>163</td>
</tr>
<tr>
<td>Politics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>World news</td>
<td>1</td>
<td></td>
<td>68</td>
<td>21</td>
<td></td>
<td>90</td>
</tr>
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<td>Economy</td>
<td>6</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>Health</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Columnists</td>
<td>14</td>
<td>19</td>
<td>1</td>
<td></td>
<td>1</td>
<td>34</td>
</tr>
<tr>
<td>Serial</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle</td>
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<td></td>
</tr>
<tr>
<td>Culture</td>
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<tr>
<td>Science</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supplement</td>
<td>54</td>
<td>10</td>
<td>15</td>
<td>4</td>
<td>9</td>
<td>92</td>
</tr>
<tr>
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<td>168</td>
<td>54</td>
<td>124</td>
<td>31</td>
<td>11</td>
<td>388</td>
</tr>
</tbody>
</table>

Table 4 indicates health related news in Sabah frequency of 42% in actuality, 24% in supplement, 23% in world news, 9% in columnists and 2% in economy. 43% of health related news is national source cited, 14% is national no-source cited, 32% is international source cited, 8% is international no-source cited and 3% is anonymous.
Table 5: Frequency of health related articles in *Takvim* evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

<table>
<thead>
<tr>
<th>News Topics</th>
<th>Source</th>
<th>National Source Cited</th>
<th>National No-Source Cited</th>
<th>International Source Cited</th>
<th>International No-Source Cited</th>
<th>Anonymous</th>
<th>TOTAL per news topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actuality</td>
<td></td>
<td>52</td>
<td>14</td>
<td>7</td>
<td>15</td>
<td>17</td>
<td>105</td>
</tr>
<tr>
<td>Politics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>World news</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Columnists</td>
<td></td>
<td>5</td>
<td>3</td>
<td>1</td>
<td></td>
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<tr>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle</td>
<td></td>
<td>13</td>
<td>9</td>
<td>18</td>
<td>32</td>
<td>25</td>
<td>97</td>
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<tr>
<td>Culture</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Science</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supplement</td>
<td></td>
<td>72</td>
<td>21</td>
<td>12</td>
<td>213</td>
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<td>318</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>142</td>
<td>26</td>
<td>47</td>
<td>59</td>
<td>255</td>
<td>529</td>
</tr>
</tbody>
</table>

Table 5 indicates health related news in *Takvim* frequency of 60% in supplement, 20% in actuality, 18% in lifestyle and 2% in columnists. 27% of health related news is national source cited, 5% national no-source cited, 9% international source cited, 11% international no-source cited and 48% anonymous.
Table 6: Frequency of health related articles in Vatan evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
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<td>Actuality</td>
<td>36</td>
<td>18</td>
<td>2</td>
<td></td>
<td>56</td>
</tr>
<tr>
<td>Politics</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>World news</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economy</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>Health</td>
<td>10</td>
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<td>3</td>
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<td>Columnists</td>
<td>12</td>
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<td>Serial</td>
<td>3</td>
<td>2</td>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>62</td>
<td>75</td>
<td>5</td>
<td>2</td>
<td>144</td>
</tr>
<tr>
<td>Culture</td>
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<td>Science</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Supplement</td>
<td>32</td>
<td>31</td>
<td>7</td>
<td>10</td>
<td>80</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>162</strong></td>
<td><strong>129</strong></td>
<td><strong>17</strong></td>
<td><strong>13</strong></td>
<td><strong>321</strong></td>
</tr>
</tbody>
</table>

Table 6 indicates health related news in Vatan frequency of 45% in lifestyle, 25% in supplement, 17% in actuality, 5% in health, 4% in columnists, 2% in serial and 2% in economy. 50% of health related news is national source cited, 40% is international source cited, 5% is international no-source cited and 4% is anonymous.
Table 7: Frequency of health related articles in Yeni Şafak evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

<table>
<thead>
<tr>
<th>News Topics</th>
<th>Source</th>
<th>Total per news topics</th>
</tr>
</thead>
<tbody>
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<td>Actuality</td>
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<td>7</td>
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<td>Politics</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>World news</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Economy</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Health</td>
<td>74</td>
<td>2</td>
</tr>
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<td>Columnists</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Serial</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Lifestyle</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Culture</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Science</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Supplement</td>
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<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>156</td>
<td>18</td>
</tr>
</tbody>
</table>

Table 7 indicates health related news in Yeni Şafak frequency of 30% in actuality, 4% in economy, 4% in lifestyle, 2% in world news and 1% in politics. 76% of health related news is national source cited, 8% is national no-source cited, 10% is international source cited, 1% is international no-source cited and 5% is anonymous.
Table 8: Frequency of health related articles in Cumhuriyet evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

<table>
<thead>
<tr>
<th>News Topics</th>
<th>Source</th>
<th>National Source Cited</th>
<th>National No-Source Cited</th>
<th>International Source Cited</th>
<th>International No-Source Cited</th>
<th>Anonymous</th>
<th>TOTAL per news topics</th>
</tr>
</thead>
<tbody>
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<td></td>
<td>108</td>
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<tr>
<td>Politics</td>
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<tr>
<td>World news</td>
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<td></td>
<td>52</td>
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<tr>
<td>Economy</td>
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</tr>
<tr>
<td>Health</td>
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</tr>
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<td>Lifestyle</td>
<td></td>
<td>2</td>
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<td></td>
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<tr>
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<td></td>
</tr>
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<td>1</td>
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<td>53</td>
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<td>4</td>
<td>112</td>
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<td>1</td>
<td>232</td>
</tr>
</tbody>
</table>

Table 8 indicates health related news in Cumhuriyet frequency of 47% in actuality, 23% in supplement, 22% in world news, 7% in columnists and 1% in lifestyle. 50% of health related news is national source cited, 2% is national no-source cited and 50% is international source cited.
Table 9: Frequency of health related articles in Radikal evaluated according to news topics and sorted to source citation between the 1st of January, 2005 and 31st of March, 2005

<table>
<thead>
<tr>
<th>News Topics</th>
<th>National Source Cited</th>
<th>National No-Source Cited</th>
<th>International Source Cited</th>
<th>International No-Source Cited</th>
<th>Anonymous</th>
<th>TOTAL per news topics</th>
</tr>
</thead>
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<td>Actuality</td>
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</tr>
<tr>
<td>Politics</td>
<td>7</td>
<td>1</td>
<td></td>
<td>8</td>
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<td>32</td>
<td></td>
<td></td>
<td>32</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economy</td>
<td>12</td>
<td>3</td>
<td></td>
<td>15</td>
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</tr>
<tr>
<td>Health</td>
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<td></td>
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<tr>
<td>Columnists</td>
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<td>1</td>
<td>5</td>
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<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supplement</td>
<td>1</td>
<td>2</td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>151</td>
<td>5</td>
<td>204</td>
<td>3</td>
<td>363</td>
<td></td>
</tr>
</tbody>
</table>

Table 9 indicates health related news in Radikal frequency of 58% in lifestyle, 25% in actuality, 9% in world news, 4% in economy, 2% in politics, 1% in columnists and 1% in supplement. 42% of health related news is national source cited, 1% is national no-source cited, 56% is international source cited and 1% is anonymous.

Overall, 2,730 health related articles have been scanned (in the first part of our research, the overall health related citations in eight newspapers were 2,749, which can be explained as more than one health related citation could be coded within the same article). 1,466 of these articles (54%) are national news, 917 (34%) are foreign news and 338 articles (12%) are anonymous. Thus, foreign news in the national newspapers occupies quite an important percentage overall, alongside a significant amount of 'anonymous' news which is translated into Turkish from global news agencies’ news, no doubt. This indicates the high level of dependency on foreign news sources, reproducing the significance of health as determined from the outside of Turkey. For example, although substance abuse is not a major health issue in Turkey, it was the second major category of health subject with 7% as indicated in Table 1. Furthermore, most of the substance abuse stories are
among crime related articles and mostly individualised. Economic, social and environmental reasons for substance abuse were still not been mentioned.

Another finding indicates, 92% (1,356) of national news is source-cited, 8% (110) have no source cited whilst 83% (803) of international news is source cited, with 12% (114) having no source-cited. In total, 20% of overall news has no-source cited, which indicates low accuracy and credibility level. Anonymous news with 12% contributes to this low accuracy and credibility level, making a total of 32%.

Overall, 29% (791) of health related articles is in actuality news, 29% (785) is in lifestyle, 23% (616) is in supplements, 7% (185) is in world news, 5% (124) is in columnist opinion pieces, 4% (111) is in health, 2% (61) is in economy, 1% (16) is in serials and 1% (14) is in politics. As a result, the majority of health related articles is in actuality or in lifestyle categories. These two categories contain health coverage on healthy living, miscellaneous or superstition, plastic surgery, diets, new technologies and innovations in medicine etc. This tendency indicates the commercialised significance of health, reflecting mostly health industries’ rituals, contributing the medical model of health.

In addition to the quantitative content analysis on the above, a qualitative content analysis has been conducted in order to critically analyse the sensational, commercial and individual significance of health, illness and disease. To that end, below titles of health related articles have been randomly selected and contents have been analysed semantically.

Examples of sensationalised and commercialised significance of health are as follows: ‘To live 3000 years is no longer a dream’ (Sabah’s supplement, 27.03.2005), ‘Do anti-depression drugs cause suicide?’ (Sabah, 06.01.2005), ‘Heart attack is over’ (Cumhuriyet, 10.01.2005), ‘This pill makes you younger’ (Sabah, 13.02.2005), ‘Marriage is a men’s health risk’ (Takvim, 26.02.2005), ‘Bust-up with chewing gum’ (Sabah, 20.03.2005), ‘In-vitro fertilization by credit card installment payment’ (Yeni Şafak, 02.01.2005), ‘Celebrities apply haemorrhoid ointment to their faces’ (Sabah, 22.03.2005). These articles were mostly no-source cited and moreover, many examples of articles on new technologies and innovations in medicine, especially on ophthalmology, were cited by the name of the health organization or the ophthalmologist which is unethical and also violates regulations. These examples have been categorised within health organisation adverts in our research.

Some examples of paradoxical titles with conflicting health messages are as follows: ‘Coffee prevents cancer’ (Takvim, 22.01.2005), ‘9 diets in 10 in USA reported useless’ (Sabah’s supplement, 05.01.2005) and in 10 days another title in the same newspaper appeared: ‘A new body with 10 days diet’ (Sabah’s supplement, 14.01.2005) or ‘Chocolate is not harmful to

And finally, individualisation in reporting diseases, illness or epidemics such as HIV/AIDS, cancer, hepatitis, food or drug poisoning etc. is very common in Turkey and are not covered as public health issues.

5. Conclusion

The media contributes to the medical model of health through sensationalised, commercialised and individualised health coverage. Newspapers reflect the health industry’s rituals, and offer paradoxical and conflicting health information with more or less the same frequency according to their political tendencies. This manufacturing process, resulting from the globalisation, is far from being informative or in the public’s interest.

Nowadays, information can no longer be controlled through prohibition and is instead determined by inadequate sources and the role of the global media. Health coverage in Turkish newspapers must be evaluated within this global news context. Specialisation in health reporting, source citation for accuracy and credibility, covering ‘real world indicators’ on health issues and more importantly the use of salutogenic approach or social model of health in newspaper coverage is essential. Furthermore, increased media literacy would be a vital tool in the fight against the negative effects of the media. As such, the media-literate individual would be a healthier individual.

Notes

1 Çınarlı and Yılmaz, 2005, 1.
2 Jones, 2000, 29-30.
3 Zola, 1972.
4 Geist-Martin et al., 2002, 11.

Bibliography


**Newspapers Analysed**


**Author Affiliation**

İnci Çınarlı and Elgiz Yılmaz, Galatasaray University, Faculty of Communication. Their paper is supported by the Galatasaray University Scientific Research Projects Commission.
Debates over the SSRI Antidepressants: Prozac, Seroxat and the Paradoxes of Evidence-based Medicine

Linsey McGoey

Abstract
Throughout the past two years, debates over the safety of SSRI (selective serotonin reuptake inhibitors) antidepressants have become headline news; almost daily the British and North American media report another aspect of the growing controversy. Debates over SSRIs are focused on three main areas: Questions about the safety and efficacy of SSRIs, questions about how and when psychiatrists and GPs should prescribe such drugs, and questions about the regulation and licensing of pharmaceuticals in Britain. The second area of contention noted above 'the debates over how SSRIs should be prescribed, and the clinical uncertainty created by such debates' is forming the basis of my ongoing doctoral research into the influence of the SSRI controversy on the perceptions and beliefs of British psychiatrists. The chapter presented at the Making Sense of Health, Illness and Disease conference draws on this research in an initial exploration of how the debates over antidepressants are affecting psychiatrists' perceptions of clinical practice, their perceptions of the design, process and publication of randomised controlled trials, and their perceptions of the regulation of pharmaceutical drugs in Britain. The chapter focuses on two theoretical approaches. Firstly, it discusses the role of credibility and personal reputation in the acceptance or the rejection of medical discoveries, drawing on Rabinow’s Making PCR and Shapin’s A Social History of Truth. Secondly, drawing on Bourdieu’s analysis of the Barthes-Picard Affair in France, the chapter would discuss Bourdieu’s concept of illusio in relation to how practitioners perceive, internalise and seek to manage controversy.

Key Words: SSRI, mental illness, depression.

I will be focusing on some of the themes in my current PhD research, which is centred on the recent debates over the safety and efficacy of selective serotonin reuptake inhibitors, or SSRIs - drugs such as Prozac, which is made by Eli Lilly, and Seroxat, which is made by GlaxoSmithKline and sold in the United States under the brand name of Paxil.

Over the last two years, questions about the risks of these drugs - and particularly the question of whether they cause suicidality in some users - have become headline news in the UK and North America, with a combination of patient advocacy and practitioner reports of adverse affects
leading to two recent large scale government reviews, in the UK and US, into the safety of the drugs.

The focus of my research is a study of the UK government regulators and practitioners - from psychiatrists to epidemiologists and psychopharmacologists, who have been central to the recent controversy over SSRIs. I am about halfway through my field research, having completed a number of interviews with practitioners, from expert witnesses at the recent UK government inquiry into the drugs, to psychiatrists who have insisted for over a decade that SSRIs cause suicidal ideation.

In this chapter, I will briefly sketch a background to the controversy over the drugs, and then I will discuss some of the theoretical implications to what I am finding. To give a brief recap on SSRIs, they are a class of antidepressants first marketed in the States and Britain in the late 1980s. Medically, the effects of the drug are uncertain. Though it has been proven SSRIs somehow act on the serotonin transporter in the membrane of nerve terminals in the brain, their exact therapeutic action is still unknown.¹

One of the less ambiguous aspects of SSRIs is the reality of their profitability. In 2004, more than 3.5 million people in Britain received 20 million prescriptions for SSRIs. Britain’s GlaxoSmithKline generated $1.8 billion from sales of Seroxat in 2003.² The all-time bestselling SSRI is Eli Lilly’s Prozac, which saw its patent expire in 2001. In the years leading up to 2001, Prozac generated about $2.6 billion for Eli Lilly annually, a full quarter of the company’s total revenues.

Though questions about the safety of SSRIs have been aired for at least a decade, asserted by lone practitioners such as David Healy in Wales and health activists such as Charles Medawar of Social Audit in London, media debates over the drugs did not become widespread until 2003, when the UK’s Medicines and Healthcare products Regulatory Agency (MHRA), the body responsible for all drugs regulation in Britain, established a working group to review the safety of the drugs. The move to establish this working group was motivated in part by a series of three documentaries on the BBC’s Panorama programme, aired between 2002 and 2003, that suggested tens of thousands of people had suffered adverse reactions to Glaxo’s Seroxat. From the beginning of its establishment, the MHRA’s SSRI working group was plagued with difficulties.

In March, 2003, after a flurry of news articles reported that most members of the working group directed to assess the safety of SSRIs had heavy financial links to the pharmaceutical companies that manufactured the drugs, the MHRA moved to dissolve its first working group entirely and set up a new one composed of practitioners who had fewer ties to industry.³

Such moves, though, did little to mitigate the media outcry later on in 2003 when the MHRA’s second SSRI working group was handed a dossier from GlaxoSmithKline which contained surprising evidence: Two of the
company’s own clinical trials indicated Seroxat caused suicidal thoughts in children and adolescents. When the group received the dossier from Glaxo, they alerted the MHRA of the finding, spurring the regulator to issue an immediate ban on the use of Seroxat in children.

In December, 2003, the MHRA expanded the ban to include all SSRIs except Prozac. A year later, in December, 2004, the regulator advised the National Institute of Clinical Excellence (NICE) to revise its practitioner guidelines for the use of antidepressants in the treatment of depression across all age groups. The actions taken by British regulators led to government hearings in the United States, where the FDA recently undertook a lengthy investigation into the safety of SSRIs.

I will mention two last background points. Firstly, in February, 2005, the BMJ published a series of three meta-analyses reviewing the safety and efficacy of the drugs. These articles are pointed to by both detractors and advocates of the suicidality hypothesis as conclusively proving their very separate positions. I will come back to this scope for competing interpretations of individual meta-analyses in the second half of this chapter.

To point to a final political ramification of the controversy, the UK’s House of Commons Health Select Committee recently completed an in-depth inquiry into the influence of the pharmaceutical industry on health policy. The report, released in April, was particularly critical of the regulatory capacity of the MHRA, which, since 1989, has been 100 percent funded by pharmaceutical companies.

To sum up, the controversy over SSRIs is still ongoing, with patients and practitioners asking questions such as:

1) Is the MHRA, given its funding structure, a sufficiently impartial body to licence all drugs in Britain?
2) What should be the legal ramifications faced by pharmaceutical companies if it is proved, as a number of leaked memos show, that they deliberately suppressed clinical trials indicating a link of suicide?
3) Finally, do the drugs or do they not cause suicide?

Which takes me to the point of departure for my own study. The first question is that usual question of, so what? Controversies over the safety of psychotropic drugs are almost most striking for their mundane nature, and the regularity of their appearance. In a number of ways, the SSRI controversy is very similar to the controversy over Thalidomide, over the neuroleptic drugs, over the safety of the benzodiazepine c. The drugs may change, but the chorus of media clips - quipping cries of corporate malfeasance, government corruption and the spectre of overly drugged citizens - sound eerily the same.
What phenomena - if any - are unique to the current controversy over SSRIs? And what do practitioners themselves think of the cyclical nature of drug crises? An argument of my research is that the SSRI controversy differs from earlier crises in two key ways: Firstly, the widespread use of the Internet made it possible for patient groups to counter weaknesses in the UK’s ‘yellow card reporting system’ for adverse drug effects (ADR) by fostering the patient-directed circulation of adverse drug reactions to other lay users via online sources. It is possible that one of the most novel aspects of the debates over SSRIs is simply the relatively shorter detection time of adverse effects thanks to the grassroots efforts of patient groups.

Secondly, the controversy over SSRIs is one of the first large-scale controversies over psychotropic drugs to arise after the paradigm of evidence-based medicine began reconfiguring clinical practice in mental health and in medicine generally. As such it provides, I think, a good empirical entry-point for an analysis of the paradoxes of the EBM model in general.

Given the status of EBM as perhaps the current buzz phrase in clinical medicine, I hope giving a brief sketch of its emergence will not be too redundant for people here. The term itself was coined less than fifteen years ago by a group of clinical epidemiologists working out of McMaster University in Hamilton, Canada who criticised clinical decision-making based on individual experience as an out of date paradigm and who sought to develop a system of assessing the risk and benefits of drugs which would apply statistical probability theory to clinical decision-making practices.

A central tenet and expectation of EBM theory is that the application of probabilistic studies and the use of evidence from large-scale randomised controlled trials (RCTs) will help to minimize clinical variance and result in higher standards of health care. Since the early 1990s, EBM has created a storm of regulatory reconfigurations across western governments, and is now routinely taught throughout medical schools in North America, the UK and parts of Western Europe.5

Contrary to the expectation that EBM will help to reduce clinical ambiguity, however, the SSRI controversy has emerged despite the development and the widespread availability of clinical trials - through collaborations such as the Cochrane - assessing the risk-benefit profile of SSRIs. Its emergence therefore raises questions about 1) problems with the design and interpretation of RCTs and 2) difficulties in applying epidemiological studies among clinical populations. Rather than minimizing differences of opinions among clinicians, the very availability of trials on SSRIs has helped to foster dissenting opinions among practitioners.

The focus of my research, then, is pointing to an analysis of the ethical and epistemological conflicts felt by practitioners as they struggle to
interpret and apply the evidence from randomised controlled trials. One of the intentions of this focus is an examination of one of the key controversial ramifications of the EBM paradigm: namely, the establishment of a hierarchy of evidence which critics argues debases the status of practitioner observation and experience.

Discussions of such a hierarchy of evidence are not new, but what - I think - is possibly more novel, is the relatively recent attempt in the social sciences to specifically scrutinise the design, the interpretation and the application of what is, inarguably it seems, the reigning methodological technique in EBM - the randomised controlled trial.

My own decision to focus analytically on RCTs stems from a series of three anecdotes from my initial field interviews, all of which took place after the publication in February of the three seminal BMJ meta-analyses on SSRIs.

The first interview was with a psychiatrist known for being a long-standing proponent of the idea that SSRIs cause suicide in some users. During the interview, he pulled out his laptop and pointed happily to the cover of the February 19th issue of the BMJ, which featured a chart above the question ‘Do SSRIs cause suicide?’

A brief glance at the chart suggested without doubt: yes, they do. Three weeks later I met with a colleague of this first psychiatrist, a man equally well known among those following the debate for being in opposition to the idea that the drugs cause suicidal ideation. He was equally happy with the BMJ articles, as he stressed in the interview, saying, to quote: ‘Anyway, the BMJ articles clearly show these drugs do not cause suicide. That’s a fact. They may cause a bit of agitation - suicidal thoughts in some people - but that’s, you know, a small price to pay for getting better.’

Finally, I spoke with the principal author of one of the three BMJ meta-analyses, an individual who had been a member of the 18-month MHRA review into the safety of SSRIs. This particular meta-analysis had the distinction of having analysed not simply published studies, but also unpublished data submitted to the MHRA by pharmaceutical companies.

It was this article in particular, of the three February BMJ pieces, that I had found to be most mobilised by those in opposition to the suicidality hypothesis. The author seemed slightly horrified, though, when I said this to him, saying, ‘No, no, that’s not what we were saying at all.’ I looked at him expectantly. Finally, there I was with the author of the study most often cited by the practitioners I had been speaking to as proving their positions. Regardless of what their positions were. Finally, answers from the person who had authored what was essentially the end result of the MHRA’s 18-month review. He held up his hands. ‘We concluded that more studies need to be done.’
The competing interpretations of the BMJ articles reminded me of Bruno Latour’s description of inscription devices in the essay ‘Visualization and Cognition: Thinking with Eyes and Hands.’ Latour uses the concept of inscription devices to characterise the phenomena - from written words, to laboratory devices, to engineering drawings - which are most used to mobilize allies to a given argument in a polemical situation. He argues that the idea of inscriptions can help to explain the emergence of new innovations in science and medicine, arguing that it is more the simple craftsmanship of recording findings into forms of writing and imagery which carry a physical trace of a discovery (and can therefore be propagated to others), that help account for the emergence of current techniques and achievements in bioscience and biomedicine, instead of ideas of universal laws of nature or grand shifts in human consciousness. Latour stressed that, ‘The essential characteristic of inscriptions cannot be defined in terms of visualization, print and writing. In other words, it is not perception that is at stake…[but] that of mobilization.’

A number of sociologists have applied Latour’s argument of the rhetorical function of inscription devices to the realm of numbers. Nikolas Rose, for example, has stressed that numbers, like other inscription devices, often constitute and create the domains they appear to represent by rendering phenomena amenable to calculation and deliberation. Rose was focusing more on aspects of biopolitical governance such as the opinion poll and the government census, but I think his point has a lot of potential relevance for RCTs - perhaps fast becoming one of the ultimate inscription devices - in the sense of mobilizing authority to a particular political or personal vantage point - in medicine. In psychiatry in particular, the rhetorical authority of numbers is perhaps particularly acute, given that treatment effects are measured on scales which are themselves constructed, such as the Hamilton Rating Scale for Depression.

I am going to conclude with a sketch of theoretical avenues I am pursuing with this focus on the SSRI controversy as an entry point for a discussion of the paradoxes of the EBM model. The first key theme is the reluctance among proponents of EBM to perhaps fully allow for the restrictions on, firstly, the creation of evidence within RCTs, and secondly, political or economic barriers on the implementation of that evidence. There are at least five overarching obstacles hindering the access and interpretation of RCTs:

1. Biases in the participant inclusion criteria for the studies themselves. For example, ethical obstacles toward including patients at the most severe end of a disorder. Or, the ethical objections to placebo use in trials.
2. Pharmaceutical companies are not mandated to supply all evidence from trials to regulatory bodies, so that much of
the evidence that finds itself at collaborations such as the Cochrane has been pre-selected by individual drug manufacturers.

3. There is the difficulty in accessing disaggregated individual patient data from trials, a complaint voiced often by the practitioners I have spoken with.

4. There is the reality of time constraints on practitioners in accessing databases such as the Cochrane given clinical and other duties.

5. As the competing interpretations of SSRI studies show, there is much room within even a particular study for either the accidental or the willful misinterpretation of results among practitioners.

Despite these obstacles, RCTs are still held as the gold standard for determining therapeutic efficacy. Although, particularly in times of crisis over the safety of drugs, the findings and structure of individual trials are often critiqued, RCTs as a methodology retain their authority. In times of drug failure, more RCTs are called for, not less; faith in the methodology is in fact strengthened.

This invulnerability of method can be compared with what Michael Power, a social theorist of auditing and accountancy, calls an ‘opacity of process.’ Power stresses that a curiosity of the audit is that in times of financial failure, belief in the audit as a policing mechanism becomes even more entrenched. Calls are heard for more audits, and very rarely for an analysis of how the detection process was flawed in the first place. It seems RCTs, with audits, share such a methodological inviolability.

None except for one of the twelve practitioners I have spoken with so far has questioned the validity of RCTs as a process. And yet all noted a sense of real frustration with access to SSRIs trials, with the publication of trials, with the withholding of studies by companies, and with what they viewed as the MHRA’s general incompetence at assessing the evidence from trials. This gulf - between the acceptance of individual studies as flawed, and a reluctance to question the integrity of a process - is something I am hoping to explore more as I go on with the project. Thanks for listening.

Notes

Debates over the SSRI Antidepressants

7 Ibid., 7.
8 Rose, 1999.

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Botulinum Toxin Facial Treatment: Are there Specific Influences on Women’s Communication Processes?

Christina Hahn and Daniel Leising

Abstract
During the past decade, it has become popular to use botulinum toxin (‘Botox’) as a so called ‘anti-aging treatment’. The toxin works in a rather simple way: it weakens or paralyzes the muscles, thus diminishing or erasing wrinkles caused by activated muscles. The effect is smoother looking skin. At the same time, these muscles are the ones that enable facial expressions. As facial expressions play an important role in our everyday social interactions, e.g. by revealing our feelings, displaying friendliness, empathy and attention, the Botox treatment may result not only in aesthetic improvements, but also affect (and possibly impair) communication. On the one hand, the media portray the rejuvenation treatment as an effective anti-aging procedure with side effects: ‘Botox has worked its numbing magic on the face of America. [...] In certain social enclaves it is rare to see a woman over the age of 35 with the ability to look angry.’ (Kuczynski 2002). Plastic surgeons observe their patients losing expressivity, e.g. scepticism or astonishment. On the other hand, patients hear their facial regions being labelled as ‘crow’s feet’, ‘frown lines’, ‘turkey-neck’ or ‘plaster chin’ (cp. Sommer, Sattler 2001). The US FDA appears to pathologise frown lines by its approval of botulinum toxin use on the glabella. The leading manufacturer of botulinum toxin uses the slogan ‘It’s not magic, it’s Botox cosmetics’ to promote the use of the drug. This chapter presents work in progress of an interdisciplinary project joining communication studies and psychology, as well as cosmetic dermatology. Recognizing the public discourse on expressivity, aging, attractiveness, and aesthetic medicine, the project aims to investigate the effects of Botox treatment on dyadic communicative processes. To this aim, the facial expressivity of women treated with botulinum toxin will be assessed within a standardized interaction task, and compared with the expressivity of untreated women.

Key Words: Cosmetic surgery, aging, aesthetic medicine, non-verbal communication, Botox.

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1. Introduction
During the past decade, it has become popular primarily among women to use botulinum toxin (widely known under one of its trademark: Botox®) as a so called ‘anti-aging treatment’. The anti-aging treatment with
Botulinum Toxin Facial Treatment

Botulinum toxin is used against facial lines which are considered signs of aging. As a method of aesthetic improvement, the increasing success of the treatment with botulinum toxin was promoted mostly by word of mouth. Women introduced this specific form of treatment to their circle of friends. At the same time, the knowledge and technique of this wrinkle treatment was spread among aesthetic surgeons as well as other physicians through workshops and other professional channels.

The treatment itself as well as its growing popularity entered public discourse around the turn of the century - we could trace German articles as early as 2000 - and reached its maximum of public attention in 2002 which coincides with the FDA approval of using botulinum toxin against frown lines between the brows in April 2002. This chapter addresses several aspects related to botulinum toxin facial treatment. First of all, it explains how botulinum toxin works its way to the face. Secondly, it sketches relevant aspects of the public discourse on botulinum toxin. Thirdly, it lays out some social and cultural aspects of women’s faces as well as their facial expressions. Both aspects are discussed in relation to the communication process. Lastly, it introduces the guiding research question of the work in progress.

2. Botulinum Toxin Facial Treatment

Botulinum toxin works in a rather simple way: it weakens or paralyses the muscles, thus diminishing or erasing wrinkles caused by activated muscles. By doing so, it differs from other injection treatments which are augmented into the skin like collagen or rejuvenation techniques that peel the skin with laser or acids. Botulinum toxin affects the deeper level of underlying muscles, which are relaxed by blocking the neurotransmitter acetylcholine.

The procedure involves identifying the facial regions to be treated - such as the areas between the brows, around the eyes or the forehead. The next step involves assessing the bone and muscle structure of the individual patient and her specific pattern of wrinkling. Therefore, patients are asked to grimace to activate the muscles. Individual injection sites are marked and highly diluted botulinum toxin is injected through very fine needles. Depending on the concentration, the drug usually affects an area of one or two centimeters around the injection site. Full response to the treatment takes up to two weeks and then the effect gradually decays within the next four to six months. In order to keep up the results, it is necessary to repeat the treatment up to three times per year. The effect is smoother looking skin as far as mimetic lines are concerned. The treatment cannot affect wrinkles caused by heavy smoking or sunbathing or other severe cell aging.

The wrinkle-causing muscles are those that enable our vivid facial expressions. As facial expressions play an important role in our everyday
social interactions, e.g. by revealing our feelings, displaying friendliness, empathy, and attention, the botulinum toxin treatment may result not only in aesthetic improvements, but also affect interpersonal communication.

3. **Portrait of Botulinum Toxin Treatment and its Effect**

Two indicators illustrate the relevance of the cosmetic use of botulinum toxin: one is the public discourse, the other is the increasing number of different cosmetic procedures including botulinum toxin treatment. In 2002, 6.6 million aesthetic procedures were performed in the US. 1.1 million were botulinum toxin treatments. About 88% of the botulinum toxin patients were women. The number of aesthetic procedures has increased over 170% between 1997 and 2000. Botulinum toxin injections have increased by 1600% during the same time.

This increase is remarkable also because it is only since April 2002 that advertisement for this type of wrinkle-treatment is approved. Up to then, botulinum toxin was promoted by word of mouth, which is quite interesting in our diverse media-based society. Botulinum toxin is a drug that receives a substantial amount of public attention. The portrait painted in the media of botulinum toxin is based on four main themes: it being ‘magic’ or like a biological weapon, botulinum toxin parties, and the treatment’s effect on facial expression. The following are examples of the botulinum toxin discourse (translated from German) in order to illustrate these concepts:

1. [Botulinum toxin] makes an old dream of mankind come true: wrinkles are gone. Without surgery, without pain. […] It is not magic. It is modern medicine.

2. A biological weapon against wrinkles. The little brother of anthrax and the plague is injected into the skin of more than a million US citizens.

3. The first party that smooths wrinkles.

4. It’s a strange experience to be in a conversation with a person who has Botoxed herself. (It’s still mostly women who do this, but that is changing.) She may talk about how ‘thrilled’ she was to be promoted to executive vice president, or how ‘adorable’ she thought the recent school play was, in which her daughter starred as Tinkerbell, or even how ‘moved’ she was by the New York Times series on the victims of September 11, but you’d never know it by her face.

The leading manufacturer of botulinum toxin feeds on the idea of magic and uses the slogan ‘It’s not magic, it’s Botox® Cosmetic’ to promote the use of the drug. These themes would provide quite interesting fodder
for a discourse analysis. Regarding this research project, the last example shows the common sense view regarding facial expression and botulinum toxin facial treatment. The media portray the rejuvenation treatment as an effective anti-aging procedure with communicative side effects: 'Botox has worked its numbing magic on the face of America. [...] In certain social enclaves it is rare to see a woman over the age of 35 with the ability to look angry.' After recognizing this portrayal and reviewing theories on facial expression and interpersonal communication we began to develop our research project.

The discourse within the field of aesthetic medicine in particular brings another twist to the general dialogue surrounding facial expression. First of all, by its approval of botulinum toxin use on the glabella, the US FDA appears to pathologise frown lines. Here we are facing the problem that any cosmetic treatment that penetrates the skin’s surface is defined as invasive and therefore seen as drug, and not as simply a cosmetic product. Again, this forces physicians who administer this treatment to declare wrinkles as some kind of illness. They are doing so by stating that patients experience psychological distress because of the way their face appears:

The frown gesture is created by drawing the brows together, which connotes the expression of anger or distress. Most people view these as unpleasant expressions and are happy to ‘hide’ that feeling.

The dermatologists Heckmann and Rzany who recommend botulinum toxin facial treatment noticed the discourse on facial expression and wrinkles. They report that frown lines or horizontal forehead lines result from corrugator muscle activity correlated with feelings of depression, anger, unpleasant experiences, or fatigue. Lines caused by such activity are involuntarily interpreted as negative expression by others. Persons with pronounced wrinkles would experience this as unpleasant misinterpretations and report that people form impressions of anger or repellence that do not resemble the actual feelings of the individual. Dermatologists have reported many cases in which patients do not even realize their permanent frowning. Some causes for frowning are not even emotional in nature, but merely caused by, for example, concentrating on an exhausting task, suboptimal computer workspaces, or shortsightedness. These could be reasons why people appear fatigued, weary, or unable to cope with existing requirements. This would result in stigmatisation. In addition to this, the dermatologists quote some use of facial expression in the history of arts where wrinkles display unpleasant situations of depicted personalities. This would cause unpleasant associations for patients with wrinkles from which they would like to be freed. Similarly, crow’s feet are identified to be ‘primarily a con-
sequence of hyperkinetic activity of the orbicularis oculi muscle that en-
circles the eye. Their appearance is considered to be an early sign of
aging, which is considered negative:

The aged face has multiple stigmata, all unhandsome, namely excrescences, blotches, sags, bags, wrinkles, yellowy leatheriness, roughness, and dryness. This visage not only repels, it frightens. The wrinkle, anatomically insignificant, is psychologically threatening and it destabilises composure and assurance. Billions are spent to combat wrinkles, even tiny ones, because they are harbingers of decline, signalling that one is ‘over the hill,’ sliding downward toward decay and death.

The strategy of pathologising aging and wrinkles therefore includes the use of psychological distress, the dissociation between experience and bodily expression, the constant conflict by misinterpretations of other people, stigmatization of patients, as well as defining muscle activity as hyperfunctional.

4. Some Social Aspects of a Woman’s Face and its Expression

The framing of the face in public discourse and in aesthetic medicine calls for a more detailed review of the literature on the face, facial expression, emotional expressivity, attractiveness, aging, and the dyadic communication process.

The face plays a pervasive role in everyday life. It is a person’s face that we perceive first and that we remember longer than any other characteristic. In western cultures, the face is also called the mirror of the soul or window to the soul. For instance, facial expression helps us to express our astonishment or reveals our anger. It plays a fundamental role in social interaction by displaying friendliness, openness, or attention. It is due to his or her face and facial expressions that we assign certain qualities to a person. An immediate unconscious impression builds upon the emotional facial expressions of the other.

According to common-sense experience, facial expression and emotions are closely connected as we read people’s minds from their faces and speak of happy faces, sad faces, angry faces, or the like. This idea is reflected in one prominent research tradition of the psychology of emotion. Since the 1970s, the research on emotion and on facial expression has converged. This tradition follows some ideas of Charles Darwin. Paul Ekman, Wallace Friesen and Carroll Izard are three of the key representatives. According to their theory, there are universal patterns of facial
expressions for discrete emotions such as fear, anger, sadness, happiness, surprise, disgust, and contempt. These emotions are considered as basic to all other feelings and are governed by culture-specific display rules.\textsuperscript{16}

During the last ten years, more diverse approaches that regard facial expression or facial display as modes of action readiness, social communicative behavior, conversational signal, signaling behavior, and as dependent on context or situation have emerged within the research field of facial expression.\textsuperscript{17} Such a wide range of approaches to facial expression reflects the pervasive role of the face and facial expression in human interactions.

As one mode of nonverbal behavior it is also considered to have para-syntactic, para-semantic and para-pragmatic functions in conversations.\textsuperscript{18}

Among the different facial actions, eyebrow movements and smiles received significant attention. For example, eyebrow-raising is considered as emphasising or underlaying a verbal utterance. Frowning is perceived as anger or disapproval.\textsuperscript{19} Another facial action very prominent in literature is smiling that occurs in a variety of contexts. Both brows and smiles are of special interest to this study as both can be affected by the botulinum toxin facial treatment, which is very often administered to the upper part of the face.

Generally, smiles are seen as reflecting positive feelings. Yet, ‘[people] smile when they are embarrassed, uncomfortable, miserable, and socially apprehensive.’\textsuperscript{20} Smiling, therefore is considered one of the most deliberate facial expressions and different types of smiling have been identified, all of which occur during conversation.\textsuperscript{21}

As far back as 1862, Duchenne noted that smiles of enjoyment involved not only the mouth muscle (zygomatic major) but also the muscles that circle the eyes (orbicularis ocularis). […] Subsequent research has confirmed that smiles with Duchenne’s marker (crowfeet wrinkles at the edge of the eyes) show the strongest link to actually experienced positive affect. The originally designated ‘false smile,’ now renamed the non-Duchenne smile, is actually any smile that does not involve contraction of the orbicularis ocularis muscle. In fact, it is less a particular smile type than a class of smiles that appear to be more social in character and not necessarily reflective of positive feelings.\textsuperscript{22}

LaFrance and Hecht investigated how display rules based on gender and on power affect facial expression. They consider cheerfulness to be mandatory in many cultures. They report:

Thus a flight attendant is trained to ‘really work on her smiles’ and is expected to ‘manage her heart’ in such a way as to create a smile that will both seem and be ‘spontaneous and sincere’.\textsuperscript{23}
This description of smiling during interactive situations illustrates how dynamic and very subtle aspects of the face affect impressions we create during interaction. These impressions are linked to attractiveness and attraction. Most research on facial attractiveness is conducted by using still photos and uses anthropological, ethnological or cultural approaches. Often, research carried out focuses on physiognomy and appearance. The main characteristics that appear to affect facial attractiveness are smoothness, youthfulness, symmetry and most fundamental averageness.24

But research on attractiveness and attraction has offered another more interactive and dynamic path.25 Friedman, Riggio and Casella demonstrated how expressive nonverbal skills contributed highly and significantly to initial likeability, independent of physical attractiveness:

However, in face-to-face interactions as well as in movies and television, we receive many dynamic cues from others: we see people in motion. [...] Such cues might have a great impact on first impressions - an influence beyond physical attractiveness.26

This research project takes this more dynamic and interactive path to investigate how botulinum toxin facial treatment affects facial expression and thus interpersonal communication.

Like the discourse analysis on botulinum toxin, another aspect not included in this project is the specific gender perspective. The illustration of cheerfulness amongst flight attendants mentioned above is an example of a profession that involves caring for others; a profession mostly performed by women. For them, positive emotional expressions are almost crucial to successfully carrying out the job. The effects of botulinum toxin on women are marginally discussed and should be at least mentioned to acknowledge the gender dimension:

Despite all the progress for women’s rights and against rigid gender roles, it’s chilling to take a fresh look at routine depictions of women in the mass media. [...] Endless media messages convey the stubborn presumption that women can never be good enough but should live and buy - and ultimately die - trying. First Barbie, then Botox.27

Long’s comment on botulinum toxin facial treatment links this perspective nicely to the aesthetic dermatologist’s portrayal of facial appearance and its report as how ‘negative or unpleasant’ emotional expressions are disregarded.
The old proto-feminist movie *The Stepford Wives*, in which troublesome, independent housewives in a Connecticut suburb were replaced by compliant, cheerful robots, clearly needs a remake. These days, sisters are doin’ it for themselves.  

5. **Guiding Research Questions in the Interaction Study**

This chapter presents the work in progress of an interdisciplinary project joining communication studies and psychology, as well as cosmetic dermatology. Recognizing the public discourse on expressivity, aging, attractiveness, and aesthetic medicine, the project aims to investigate the effects of botulinum toxin treatment on dyadic communicative processes. To this aim, the facial expressivity of women treated with botulinum toxin will be assessed within a standardized interaction task before and after the treatment. Two facial regions are treated with botulinum toxin: the lateral eye region and the glabellar between the brows. Thus, the muscles are relaxed and frown lines as well as crow’s feet are reduced or erased. The treatment will be checked by before-and-after photos of facial mobility (that is asking the subject to frown or to laugh in the same way as they are asked to when deciding on specific injection sites). Before and after the treatment about 60 female subjects will participate in a conversation (5-10 min standardized interaction situations) with an un-treated female confederate. We will allow for a 14-30 day period for full physical response of the treatment between the interactions. Both will be videotaped and assessed with questionnaires on interactive behaviour, interpersonal attraction, and well-being. Selected cases will be assessed with micro-analytic coding techniques. We are interested in the following questions:

1. How is the individual’s well-being affected by botulinum toxin treatment?
2. How is interpersonal attraction affected by botulinum toxin treatment? Are impressions of others affected by the treatment? We ask specifically for physical, social, and task-oriented attraction.
3. Will the interactive behaviour be evaluated differently before and after the treatment? The interactive behavior is conceptualized along the two relationship dimensions ‘status’ and ‘love’. Will one or both be affected by the treatment?
4. Will dynamic aspects like interactional synchronicity, mimicry or affect-transmission be affected by the treatment?
Notes

3 Carruthers and Carruthers, 2002.
4 Figures provided by the American Society of Plastic Surgeons, 2003
12 Giese, 2003, 16.
20 LaFrance et al., 2003.
21 LaFrance and Hecht, 1999.
22 Ibid. 45.
23 Ibid. 45.
24 Rubinstein et al., 2002. For a general overview, see Rhodes and Zebrowitz, 2002.
25 Knapp reported that ‘there seems to be a movement toward a new paradigm for the investigation of physical appearance - namely social interaction.’ Knapp, 1985.
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Evaluating Risk and Pain in Elective Cosmetic Surgery

Ashley Morgan

Abstract
This chapter will address a number of issues faced by individuals when undergoing elective cosmetic surgery. Drawing on wider research that examines the relationship between consumerism and cosmetic surgery, I will convey the way in which individuals perceive and evaluate risks associated with cosmetic surgery, as consumers of a service. Findings suggest that individuals tend to concentrate on the positive outcome of their surgery rather than the mechanics of the procedure. Cosmetic surgery is currently considered to be a form of cosmetic enhancement for which there may be a number of motivations, such as the desire to improve appearance. Cosmetic surgery is medical in nature, involving elements of surgery such as cutting into tissue and muscle, removing skin, or implanting prosthetics. Yet this type of surgery is set apart from the rest of biomedicine, since the ability to bestow health through cosmetic surgery is limited. Cosmetic surgery is widely advertised: many cosmetic surgeons practice independently, get paid directly, and are unregulated. Any medical doctor can practise as a cosmetic surgeon, and the incompetence of many surgeons is notorious. Unlike the traditional doctor/patient relationship, where boundaries and expectations of both parties are well established, people may perceive cosmetic surgery to be a consumer service, and consequently their expectations of surgeons differ. Information regarding cosmetic surgery is available in a number of locations including the popular press, and individuals make important decisions based on their evaluation of such information. Findings suggest that people who undergo cosmetic surgery tend to perceive the risks involved as being part of the process, and that choosing a surgeon who can guarantee a positive outcome is often the result of luck rather than judgement.

Key Words: Cosmetic surgery, risk perception, motivation.

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This chapter will focus on the manner in which individuals deal with a conscious form of risk taking and pain when undergoing elective cosmetic surgery. The chapter draws on wider research that examines the relationship between consumerism and cosmetic surgery. Risk is considered to be an important aspect of this type of surgery as it involves medical procedures being carried out on healthy people. While all surgery carries a modicum of risk, the hazards associated with cosmetic surgery may be considered to be qualitatively different from general surgery.
Cosmetic surgery differs from other medical procedures in a number of ways. It is widely advertised, marketed and purchased as a product. In contrast to the traditional doctor/patient relationship, where the boundaries and expectations of both parties are well-recognised, cosmetic surgery might be considered a consumer service, and expectations of surgeons may differ. Moreover, cosmetic surgery is unregulated; any medical doctor can practice as a surgeon, which has meant that the incompetence of many cosmetic surgeons is notorious. Arguably, performing surgery on healthy individuals contravenes the Hippocratic Oath, and the ‘health’ benefits are questionable.¹

There may be beneficial elements to voluntary engagement with risk that will only become apparent through the examination of individual testimonies. Pain is often explicitly associated with the experience of cosmetic surgery, and is often cited as one of the reasons why many people choose not to undergo it. The way in which individuals experience pain seems to be related to the prospective outcome and pain might be considered to be another aspect of cost. This chapter has two parts. As the quality of surgeons may be variable, the first part will address the manner in which surgeons are evaluated. The second part will explore perceptions of pain. Evidence from interviewees suggests that there are many different types of pain experience, and that pain may be considered to be part of the process of surgery - a necessary outlay in order to achieve the desired outcome.

1. Risk and Cosmetic Surgery

Undergoing elective cosmetic surgery involves consciously engaging with high profile risks. Arguably, cosmetic surgery is largely associated with two phenomena; danger and celebrity. Thanks to the well-publicised controversies surrounding silicone breast implants, the public are now well aware of the potentially damaging and disfiguring effects of cosmetic surgery. Such surgery is also associated with celebrity excess, symbolised in the bodies of Pamela Anderson and Michael Jackson. Media portrayals of cosmetic surgery are generally negative and suggest that it may be detrimental to health, and is only really undertaken by capricious celebrities. Research suggests that the two main sources of public information about cosmetic surgery are the media and cosmetic surgeons themselves, and access to impartial information is limited.

2. Evaluating Surgeons

One of the more notorious controversies surrounding cosmetic surgery is cosmetic surgeons’ perceived lack of qualifications and inexperience. Regulation of cosmetic surgeons is not mandatory either in the UK or US, and is, at best, sporadic. Dull and West have noted: ‘By law, any licensed medical doctor may perform cosmetic surgery’.² More recently, Orton argues that because cosmetic surgery is partly removed from the
medical profession, it is likely that many organisations that offer cosmetic
surgery ‘are not staffed by accredited surgeons’.

The public is also well aware of these issues and qualifications and experience are of great concern when choosing a surgeon. As one of the interviewees remarked: ‘I would want somebody that I knew was professional with a good reputation, and was actually a bloody surgeon!’ This uncertainty about professionalism and degree of qualification was also evident in other interviews, and individuals used a number of strategies to judge who would be the most appropriate surgeon for them.

Respondents indicated that their choice of surgeon was influenced by recommendations from both General Practitioners and lay people. Information gained from others was used to form expectations of surgeons. One interviewee suggested that a surgeon should ‘know what he’s talking about’, a comment which could indicate that there are many cosmetic surgeons who do not. Some interviewees also suggested that surgeons who advertise in magazines might be less reliable than those who advertise privately. ‘The thing is, I didn’t want to just apply to one of these, you know, that you see advertised in magazines and things,’ said one interviewee. Another stated, ‘I mean, all these columns you see in the back of these comics [women’s magazines], I don’t know that I would just go to like a supermarket one there’. This suggests that reliability and professionalism might be equated with a bespoke, individual service. This is in contrast to a so-called ‘supermarket’ type of surgeon, whose accessibility and relative ubiquity might undermine professionalism. The ‘supermarket’ type of surgery might be interpreted as meaning a number of things: a standard rather than customised service, cheap price reflecting inferior work, and an element of a production line implying impersonal service. In a number of cases, surgeons were chosen because they seemed to fit into a popular, positive stereotype: the good-looking, masculine surgeon, ‘everything a surgeon should be’.

A number of the interviewees suggested that surgeons’ expertise could be quantified by assessing concrete achievements such as qualifications and professional status. Yet, the actual criteria that they used to assess expertise tended to consist of a combination of attractiveness, physical appearance, pleasant manner and a vague ‘feeling’ of liking the surgeon.

There are a variety of locations in which it is possible to shop for a surgeon, compounds the lottery-like nature of choosing a surgeon. Some interviewees suggested that surgeons might be measured by cost as well as status. One person said that choosing her surgeon was like going to a restaurant and looking at the menu. The menu analogy is important here as it suggests that, as in a restaurant, there is a range of services on offer, and also that different things will appeal to certain individuals. Making a decision about where to find a cosmetic surgeon is very much a matter of personal
preference. This preference may be informed by a number of different variables, not all of which are the result of thorough investigation or evaluative research, such as a sense of personal liking. While attempting to minimise risk seemed to be the main motivation for choosing a surgeon, the interviewees explored many different ideas about risk.

3. Voluntary Risks and Gambling with Health

While the majority of the interviewees were generally aware of the range of potential risks involved in undergoing cosmetic surgery, they tended to identify physical disfigurement as being the most problematic. This is in contrast to the well-publicised medical risks and actual harm that may occur as a result of cosmetic surgery.

Evidence from some individuals suggests that in order to undergo cosmetic surgery, they were willing to gamble with their health despite the known risks. Individuals who had made up their minds to undergo surgery were seldom swayed, even by known health risks. As most of the risks involved with cosmetic surgery might be described as physical rather than psychological, what emerges from interviewees is their willingness to gamble with their physical health in search of self-improvement. One person even risked undergoing cosmetic surgery while suffering from high blood pressure. Gambling with health in this instance seemed to rely on the interviewee’s speculation that the outcome of surgery would be positive, and that change would be beneficial. However, whilst she was willing to risk her health before this operation, this interviewee also said that she would never undergo cosmetic surgery again as the risk of high blood pressure would be too great. ‘I wouldn’t have it done ever again, knowing what I know now and what I went through, no, I wouldn’t have that again.’ This implies that direct knowledge concerning risks gained through experience may have greater impact for lay people than knowledge acquired from reputable information sources. Knowledge acquired in this way may be considered to be embodied knowledge: understanding of experience through physical memory. The determination of some interviewees to undergo surgery despite the fact that they knew they were gambling with their health, suggests they believed such surgery was a calculated risk. … or - suggests they believed that risks undertaken consciously are less precarious than those they perceive to be beyond their control.

Beck argues that individuals are affected by risk indiscriminately. In these uncertain circumstances, it is difficult for individuals to know what action to take. Risks associated with cosmetic surgery are well-publicised, but evidence from interviewees suggests that some individuals seem to apply a cost-benefit analysis to cosmetic surgery, both in financial terms - spending a great deal of money in the hope that the outcome will be positive, and also in the projected physical risks - hoping that cosmetic surgery will improve
appearance, and that at the very least they will look no worse. Interviewees commonly commented, ‘I knew it would be ok.’

A. Breast Implants

Cosmetic surgery has acquired a reputation for being risky and, frequently, unsuccessful. This seems to be especially true of breast implants. Davis notes that many cosmetic surgery operations, especially breast augmentation, have to be redone. This may be due to the relatively short life of implants, or because the body may reject the implant. Despite the apparent perils of breast augmentation, many interviewees believed that this evidence was not clear-cut; one interviewee conveyed a general scepticism about the risks involved with breast implants and made an analogy with the scare over the beef crisis. Moreover, she implied that the validity of media publicity regarding such risks is questionable.

Whenever there was a scare about it, people would say, ‘oh, you don’t want to have that done,’ you know. I would say to people at work or my friends that I was interested in going for a consultation. They were like, ‘don’t you ever get worried about these scares and things?’ And I was like, ‘no.’ Same as I’m still eating beef after all that Mad Cow thing. So maybe I’m just the kind of person who doesn’t believe everything I read.

As risks seem to lurk within every area of people’s lives, she suggests that there is no reason to suspect that engaging with risk on a voluntary basis, armed with an awareness of the potential consequences, might cause any greater problems than not engaging with the hazard. Additionally, this interviewee proposed that there is an element of scare mongering implicit in the media representation of cosmetic surgery. At least two of the interviewees had heard about the risks associated with breast implants from the popular press or the television rather than through consultation with surgeons or other health professionals.

Evidence from interviewees indicates that they are knowledgeable about the risks involved in cosmetic surgery but nevertheless submit to it voluntarily. Often, motivation behind choosing a surgeon was the desire for a positive outcome with minimal risk. However, as many of the interviewees relied on an instinctive liking of the surgeon as well as a positive reputation, these things alone may not be sufficient to guarantee successful cosmetic surgery.

It might further be argued that there are degrees of risk inherent in cosmetic surgery. While there seem to be a number of well-known consequences of cosmetic surgery such as numbness, implants being rejected
or facelifts dropping, individuals may not interpret these as being harmful, but rather as being part of the process which they are aware of. In this research, individuals were conscious of the risks that undergoing cosmetic surgery entails. Indeed, some were very knowledgeable. This knowledge is informed by the research that many people conduct prior to undergoing surgery. Yet, they seemed convinced that not only would the benefits outweigh the potential hazards, but also that engaging with cosmetic surgery voluntarily, in some way, reduced the possibility of harm. These views are held despite clear evidence to the contrary.

While some of them placed their trust in surgeons to carry out the work successfully, a large proportion of interviewees showed a willingness to gamble with their own health as well as accepting individual responsibility for the outcome of the surgery. One of the better known consequences of cosmetic surgery is the risk of pain. When undergoing cosmetic surgery, pain might be another hazard to be endured and traversed; the price to pay for the desired outcome.

4. Pain Experiences

The data collected from the interviewees raises a number of issues surrounding the pain experienced when undergoing cosmetic surgery. There appear to be considerable differences between what surgeons say about the painful aspects of cosmetic surgery and the way that individuals themselves experience such procedures. While surgeons seem to make light of both the risky elements of cosmetic surgery and the pain involved, interviewees often described their physical and emotional feelings very explicitly. Others were keen to play down the pain experience, preferring to concentrate on the wider, medical implications involved in surgery. Some people seemed to echo surgeons’ words by saying that they experienced ‘discomfort’. Others suggested that it was not as bad as they had anticipated. It has been established that preoperative knowledge of impending pain and outcome of operations might not only reduce the anxiety of the patient but also the experience of pain itself. Moreover, imagined pain may be constructed as being far more unpleasant than real, embodied pain. It might be argued that images of pain, such as those represented in novels or in the media, are more available to individuals than real pain experiences. There is evidence to suggest that there is increasing public interest in medical issues, which is reflected in medical dramas depicting hospitals and surgery. The plasticity of the body is also being taken to extraordinary limits in the work of Gunter Von Hagens and magician David Blaine, for example, yet, arguably, experiences of pain are obscured by technical feats and artistry. Pain is therefore the imagined rather than the real, to be represented in metaphor, or
through symbolic representation. In the context of cosmetic surgery, pain seems disparate and acute rather than localised or chronic.

People who choose to undergo cosmetic surgery report widely differing experiences. For some people, their encounter with cosmetic surgery may be more medical than anticipated. Many of the interviewees described incidences of excessive bleeding, high blood pressure and having drains removed as being more problematic than the actual surgery.

5. Conclusion
When individuals make the decision to voluntarily put themselves at risk, they do so knowing the diversity of risks involved. Voluntary engagement with potentially risky behaviour feeds into ideas of self-actualisation and identity creation. Engaging with risky behaviour may be progressive; it becomes a 'practice of the self.' Furthermore, that people are choosing to undergo cosmetic surgery despite myriad warnings and conflicting information about the safety of cosmetic surgery suggests a sense of 'taking charge of one’s life.' Taking control itself is risky, Giddens argues, because it offers a wide number of possibilities that may be overwhelming. From the evidence of interviewees, the decision to undertake cosmetic surgery is both a practice of the self and a unique opportunity to take control of a physical situation.

Notes
2 Dull and West, 1991, 55.
3 Orton, 2002, 1229.
5 Beck, 1998, 12.
6 Davis, 1995, 28.
7 Ibid, 27.
8 Sofaeer, 1993.
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PART V

Disability and Desirability
Genetics, Disability and Symbolic Harm

Elisabeth Gedge

Abstract
In this essay I analyse the claim that the expanding practices of prenatal genetics testing constitutes a threat to the status of persons with disabilities. First, I consider whether genetic testing sends the message that persons with disabilities are not welcome. Drawing from the literature on the politics of recognition, I then identify the harms associated with subordinate status, showing how the symbolism of our reproductive genetic practices contributes to these harms. Finally, I consider ways to reconceptualise political entitlements in terms of dignity and equality so as to resist the subordination of persons with disabilities.

Key Words: Genetics, disability, harm, recognition, symbolism, dignity.

In a recent issue of the Canadian public policy journal ISUMA (which is the Inuktut word for ‘idea’), Timothy Caulfield, Michael Burgess and others use the term ‘genohype’ to refer to the excessive preoccupation with genetic medicine, the exaggerated claims made on its behalf, and various associated dangers. Genohype is not a new phenomenon. From its inception, supporters of the Human Genome Project have represented it as the key to population health, overlooking both the complex interaction between genetic predisposition and environmental and social determinants of health, as well as the uncertainties associated with both the expression and prediction of genetically related conditions. More significantly for my present topic, the foregrounding of genetic health, when combined with an analysis of health based on species normalcy, presents a grave threat to the status and well-being of persons with disabilities. Kerry Taylor and Roxanne Mykitiuk have argued, in the same issue of ISUMA, that although, paradoxically, notions of genetic health as statistical normalcy have led to internalised and essentialised identities, with disability constructed as deviance. Furthermore, argue Taylor and Mykitiuk, when health as normalcy is linked to political liberalism’s ideal of equality, an implicit justification for genetic intervention and ‘correction’ emerges. For this reason feminist philosophers have called for a scrutiny of the identity construction presupposed in much genetics discourse and have called attention to the limitations of the anti-discrimination approach to protecting
persons with disabilities in the current medical and political climate. In this paper I consider in turn the claims: 1) that prenatal genetic testing for disability sends a message that persons with disabilities are unwelcome and their lives not worth living; 2) that this message is harmful to the status and identity of persons with disabilities, and 3) that a notion of political equality based on dignity offers better protection for humans in our diverse identities than an unrevised notion of equality.

1. The Message of Genetic Testing

Criticism of the medical model of disability in general, and its genetic version in particular, is substantial. While much of the criticism focuses on the need to recognise the interactivity of social, environmental and biological factors in the classification and degree of disability, attention has also been paid to the link between genetic diagnosis and our reproductive practices. Currently, the primary function of genetic medicine is the screening for genetic ‘anomaly’, with reproductive counselling and the offer of selective implantation or termination as its corollary. Many persons with disabilities claim that this function, and the conceptualisation implicit within it, not only stigmatises them as deviant but sends a message that their lives are not worth living and/or that they are not welcome. This has been labelled the expressivist argument. Examples of its advocates are:

Susan Wendell: ...the widespread use of selective abortion to reduce the number of people born with disabilities ... sends a message to children and adults with disabilities, especially people who have genetic or prenatal disabilities, that ‘we do not want any more like you.’

Laura Hershey: ‘I believe the choice to abort a disabled foetus represents a rejection of children who have disabilities’.

Marsha Saxton: The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are ‘too flawed’ in our very DNA to exist; we are unworthy of being born...

Notwithstanding widespread sympathy amongst commentators for the concerns of persons with disabilities, many writers challenge the expressivist argument. Laura Purdy, for example, claims that we can separate the trait from the person, and in testing for a disease we are not passing judgment on the worth of the individual who might bear that trait. Bonnie Steinbock concurs, adding that in fact the rise of prenatal screening has
coincided with greater inclusion of persons with disabilities - a paradoxical result if the expressivist argument is sound.⁷

Most significantly, Eva Feder Kittay, a philosopher and the mother of a severely disabled daughter, carefully analyses but ultimately dismisses the expressivist argument, in a moving published dialogue between herself and her adult son.⁸ Kittay bases her rejection of expressivism on her understanding of the necessary conditions for the meaningfulness of an act. According to Kittay, for an act to convey meaning six conditions must be met: there must be a speaker, a hearer, a message (or mediating ‘depiction’), a channel of communication, a context and a code. A woman’s decision to terminate a pregnancy because of disability, she argues, fails to meet some of these conditions: in particular that there be a code (a widely shared set of meaning conventions) and channel of communication. She invites us to consider, by contrast, the thumbs-down in the gladiatorial arena, or the display of the Confederate flag in the deep American South. Both of these actions convey meaning not only by being visible (thus operating in a channel of communication) and being situated in a supporting context (of imperial authority, of slavery), but also because they exploit a common code: each can be understood as performative (condemning to death; exalting white supremacy, respectively). Although acknowledging that the act of selecting against disability takes place in a context of ableist discrimination, Kittay finds such acts fail to meet the conditions for unambiguous meaningfulness, because they lack a clear channel of communication and a common code.

James Lindemann Nelson agrees with Kittay that singular acts of selective abortion for disability fail to send an unambiguous message; however, he considers that the social practice of expanded prenatal genetic testing may meet the semantic conditions Kittay sets out. A reproductive practice such as prenatal genetic testing is public (indeed, in places routinized), and hence is mediated through the channels of communication which generally convey medical information (television programs, pamphlets in doctors’ offices, educational courses and materials). It is embedded in a medicalised and geneticised ideology of health, and hence enjoys the authority of medical experts, whose utterances, in the context of ableism, provide the code (i.e. disability as deviance). Thus whereas individual acts may be ambiguous in meaning and hence poor vehicles of any message, a social practice, by contrast, may succeed in conveying a determinate meaning. However, Nelson argues that prenatal genetic testing, as a social practice is not one such act - its meaning is not unambiguous. Rather than sending a derogatory message about disability, he says, it may reflect a concern for women’s autonomy, a desire to reassure pregnant women, or a commitment to population health.

Nancy Press, however, is not convinced. Press, who with her research team has conducted studies of attitudes and behaviours of
practitioners and ‘consumers’ of prenatal testing, draws attention to further features of the practice that support the expressivist claim. She notes the type of language used (e.g. the language of ‘risk’), the routinization of maternal testing without statistical justification; the asymmetries of authority between clients and physicians or counselors, and the background attitudes of all participants towards disabilities. She argues that these features imply settled goals (of termination and cost saving) at odds with the stated (and approved) goals of enhanced maternal and infant well-being. As she notes, the routinization and medicalisation of prenatal testing have arguably compromised both reassurance and expanded choice for women; and prenatal testing only serves population health by reducing the population of the disabled.

If Press is right, the practice of prenatal genetic testing can be understood as sending the message that persons with disabilities are unwanted. The ‘success’ of its message relies on a combination of the normativity of medicalised understandings of health and the social authority of physicians. The dominant ideology of health and its embeddedness in routinized, hierarchical health care delivery and a broader ableist culture ensure a stability of context, code, and channel of communication in which the negative message about persons with disabilities can be sent and received, albeit without conscious intent by ‘senders’ or even explicit recognition by ‘receivers’.

2. The Harms of Misrecognition

What is the significance for persons with disabilities of the foregoing analysis of the meaning and message of expanded prenatal testing? Apart from the serious eugenic implications of the practice, it exacerbates the existing harms of misrecognition within a context of ableism. The literature on the politics of recognition highlights the role of appropriate recognition in affirming the status and entitlements of persons and in providing the semantic tools and authority to develop and effect strong self-understandings. Misrecognition, by contrast, occurs in what Misha Strauss has labeled harms of exclusion and of demoralisation. In the absence of appropriate recognition, she says, persons may be devalued or rendered invisible, and this lack of status reduces their ability to shape the meanings of their community, to be heard, and thereby to secure the social goods that are available and needed. Misrecognition can also compromise the personal goal of developing a strong identity and an effective agency. Where the dominant semantic world offers no appropriate iconic images, or, worse, contains derogatory ones, persons may lack the resources to develop a positive self-understanding - may indeed internalise the dominant, derogatory ones - thus undermining the possibility of articulating their own reality and being effective agents within it.
The message of genohype may well have just such a subordinating impact on persons with disabilities. Not only does genohype reflect a narrow, medicalised understanding of health; it also dichotomises and essentialises identities. Because of the grandiose claims made on behalf of genetics - in particular, that genetic discoveries are discoveries about what it really is to be human - and because genetics research takes place in an allegedly therapeutic context, essentialised human and healthy identities overlap. ‘What is it that distinguishes the human from the non-human?’ merges with ‘What is it that distinguishes the healthy from the unhealthy?’ so that to deviate from genetic human normalcy is to have a questionable human identity. This may have two undesirable consequences: the subordination of the ‘deviant’ group, and either its neglect or ‘therapeutic’ intervention in the name of equality to raise its members to an acceptable level of humanness.

Arguably, then, as genohype impacts on the semantic world, particularly as it is mediated by the social practices of reproductive monitoring and manipulation, it both expresses and effects the reduced status of persons with disabilities, by sending the negative message that they are deviant and unwelcome, by problematising their inclusion, identities and agency, and by putting them at risk of corrective medical intervention in the name of equality.

3. Equality and Dignity

I noted earlier that critics of genohype see anti-discrimination approaches to securing equal status for persons with disabilities as wrong-headed, and it should now be obvious why this is so. Anti-discrimination approaches frame equality as sameness, leaving underlying norms unchallenged, and often operating to applaud or even impose conformity. Traditional arguments from equality thus see disability as a deviation from species normalcy demanding remedy. Furthermore, in legal and political contexts, traditional equality arguments operate with a narrow concept of harm, one which focuses on welfare interests and cannot accommodate the mediated, symbolic harms of exclusion and demoralisation described above. By contrast, recent attempts to frame equality in terms of equal moral worth and dignity have the potential to support diversity. For example, Meir Dan-Cohen offers the dignity principle as more effective than its utilitarian predecessor - the harm principle - as a means of defending the unique moral worth of every human being. In a complex argument, Dan-Cohen captures the intuitive idea that dignity is foundational to the moral point of view, and that a concern for dignity underlies our legal and political priorities. For example, he finds in our refusal to countenance consensual slavery or punitive castration, evidence that our moral and legal priorities are not reducible to welfare- or autonomy-based concerns, but rest on human dignity.
The dignity principle contributes in two ways to the present project of critiquing genohype. First, it invites us to understand harms as conditions that undermine human worth rather than merely setting back welfare interests. This broader understanding will reflect the stake persons have in recognition and its associated political and personal goods: semantic authority, appropriate self-understanding, and effective agency. A community committed to respecting equal worth and dignity must recognise the harmfulness of the normative paradigms of humanness and health, and must work to remedy them by ensuring the diversity of cultural and semantic space. This may involve positive measures - such as foregrounding alternative identities in the media and diversifying health services - or negative measures - such as the censoring of derogatory representations and utterances in public space. All such measures should be prompted and guided by disabilities activists who obviously have epistemic privilege. Further to the diversification of health services and the protection of semantic space, remedial measures should include recognising affronts to dignity as bases for alleging unequal and harmful treatment.

The second way in which Dan-Cohen’s dignity principle supports the critique of genohype is in its understanding of how meaning relates to dignity. The application of the dignity principle, argues Dan-Cohen, requires that persons be respected; but whether an ‘...action, practice or institution is consonant with dignity is a matter of that action’s meaning...’ he says, and when actions are parts of practices ‘...the reasons for ascribing to an action-type its symbolic significance as expressing disrespect and the tokens of that action need not be tight.’

In other words, particular acts within practices take their symbolic significance from the practice of which they are a part, notwithstanding innocent intentions or welcome outcomes in particular cases. This observation is useful in supporting the expressivist argument, since it reduces the peculiarity of describing a practice such as prenatal genetic testing for disability as harmful, even though practitioners may have benevolent intentions and individual ‘consumers’ of genetic services might consider themselves better off for them. As expressivism maintains, the message of such services may nevertheless be harmful, where practices are seen as conveying meanings and where harm is understood to include affronts to dignity.

4. Conclusion
The potential for genetic testing and intervention to reinforce essentialised norms of health and humanity is significant, especially when combined with a narrow understanding of harm and an uncritical understanding of equality. As I have argued, the routinization of genetic testing in the reproductive context risks subordinating persons with disabilities by sending a message that they are unwelcome, and by denying
them semantic authority in the cultural space where identities are formed and agency strengthened. While a welfare-based understanding of harm will not be able to capture these inequalities, the dignity principle, which targets affronts to moral worth through subordinating practices, is more promising. In identifying such affronts and in devising and evaluating remedies, persons with disabilities or their designates should be granted privileged status. And finally, a finding of symbolic harm does not necessarily mean a practice must be curtailed. For policy-making is ethically complex, and the ethical weight of a derogatory message, when measured in relation to other relevant ethical concerns such as individual freedom, the reduction of suffering, and distributive justice, may not trump. My goal has simply been to ensure that it is acknowledged.

Notes

4 Hershey, 1994, 30.
6 Purdy, 1996, 57.
7 Steinbock, 2000.
8 Kittay and Kittay, 2000, 165.
10 Dan-Cohen, 2002, 150.
11 Ibid, 161.
12 Ibid, 162.

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Making Sense of Disease, Disability and Trauma: 
Normative and Disruptive Stories

Valerie Raoul

Abstract
This chapter will report on some of the issues raised by a major collaborative project conducted at UBC over the last five years, for which I was Principal Investigator, entitled ‘An Interdisciplinary Inquiry into Narratives of Disease, Disability, and Trauma’. This project brought together a dozen specialists from the Humanities, Social Sciences, and Health Sciences, to look at how narratives of disease, disability, and trauma are used and analysed. We also attempted to bridge the divide between academics undertaking research in these areas, community advocates and people representing their personal experiences through the arts. Some of the results will soon be published in a collection of essays provisionally entitled Unfitting Stories. The book is divided into three sections, focusing on what we came to see as the three major functions of narratives of disease, disability, and trauma: the aesthetic, therapeutic, and polemic. Bridging sections deal with methods of narrative analysis across the disciplines, and the intersections of these three functions as well as the overlap between disease, disability, and trauma. This presentation will focus on problems that arise when engaging in cross-disciplinary discussions involving very different uses of the term ‘narrative’ and a wide range of methods of dissection and interpretation of stories told by both patients and health care professionals. I will illustrate one way in which we managed to engage in effective dialogue by summarizing a multi-disciplinary approach to the way narrative functions in Margaret Edson’s highly successful play about a woman dying of cancer, Wit. Using a model for the functions of communication developed by linguist Roman Jakobson, we were able to better understand how this play can provoke very different reactions from the perspectives of cancer patients and their families, health care professionals, those with a religious faith, and academics engaged in literary or feminist research. It also serves, as a drama, to illustrate the differences between performance and performativity, when narrative representations deal with issues of identity and agency in relation to communication through language or other means.

Key Words: Narrative analysis, representation of illness, cancer, literature.

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This presentation describes a collaborative project conducted at the University of British Columbia, funded by the Peter Wall Institute for Advanced Studies. A collection of chapters arising from that project will be published soon by Wilfred Laurier University Press, under the title *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma*. The example of the play *Wit* by Margaret Edson serves here to illustrate one way in which we undertook a cross-disciplinary analysis of a text/performance/pedagogical tool that deals explicitly with meaning-making through words/literature in the face of death and a deficient medical care system. The points of view represented are from nursing, medical history, women’s studies, and rhetorical analysis of literature.

Whereas twenty-five years ago there were relatively few published personal stories of ill health or suffering, in English or other languages, there is now an extensive list that can be divided into several categories, including accounts of disease, disability, and trauma. Research on these narratives has been undertaken in North America from a wide range of different disciplinary perspectives. Cross-disciplinary inquiry was the focus of a collaborative research project on such narratives recently completed at the University of British Columbia (UBC), funded by the Peter Wall Institute for Advanced Studies. The initial team from UBC was composed of ten faculty members from the Health Sciences, Social Sciences, and Humanities, and as many postdoctoral fellows and graduate research assistants. Our collaboration over five years included interaction with scholars from elsewhere, as well as with advocacy groups in the local community and people engaged in representing their own experiences through writing, film, and the performing arts. At the outset we acknowledged the problem of distinguishing between disease, disability, and trauma, engaging in debates over definitions including ‘illness’ as personal experience, as opposed to ‘disease’ as scientific classification, and constantly encountering the overlap between mental illness and physical suffering. We came to the conclusion that conceptualising disease, disability, and trauma as distinct categories is not useful, or even possible, and that it is more valuable to focus on elements common to all three. Questions concerning the gendered aspects of these experiences and cultural differences in their interpretation became central in our attempts to clarify possible approaches to narrative analysis, when the stories concerned not only try to make sense of shattering experiences, but challenge what we mean by ‘making sense’.

Three assumptions held our group together, and provided common ground for discussion. The first is that disease, disability, and trauma, while often having physical or biological causes and effects, are socially and psychologically constructed and part of a life story. The second is that the exchange of stories is central to treatment, therapy, and advocacy for change. The third is that the stories exchanged (whether medical or personal accounts,
of an aesthetic or didactic nature) are governed by cultural meta-narratives that vary according to time, place, and socio-political context. Normative or disruptive stories can be used in various ways, fulfilling functions of which the teller may be more or less aware. They can also be analysed from a range of methodological perspectives that raise academic and ethical issues regarding what can or should be done through or with personal narratives.

The members of our team all deal with narratives of various kinds in the course of our work, whether they are published literary or historical texts, or in-depth interviews and oral histories related to health care. One frame that enabled us to bring our various approaches together was Roman Jakobson’s linguistic model of the different functions of communication. This model made us aware of the interconnections between the aesthetic, therapeutic, and polemical functions in narratives of ill health or suffering. Our forthcoming volume of essays entitled *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma* is divided into three sections illustrating the relative importance of each of these aspects, not only in the various stories told but in the approaches adopted in analysing them.

The first section, on ‘Narrative Aesthetics’, deals with polished and published stories that have wide appeal. Academics trained in narratological or semiotic analysis illustrates various methodological approaches to narrative developed in the Humanities but increasingly applied in other disciplines. They look at how the therapeutic and polemical aspects of storytelling are integrated into works constructed to appeal to an audience, and sometimes to raise funds for a specific cause. In the second section, ‘Narrative Therapeutics’, the chapters focus less on the effect of the story on others than on what telling the story does to and for the teller. The contributors include several people with expertise in qualitative research and some who are themselves personally engaged with disease or disability. They bring out the value of sharing stories as a way to build a mutually supportive community, as well as aspects of the self-reflexivity required for this type of research. A different type of exchange takes place in sharing these stories, requiring a different type of discourse analysis with less emphasis on artistic merit. The third section broadens to engage with the ‘Narrative Polemics’ that occur when competing collective frame narratives clash in the professional and political realms, looking beyond individual stories to consider the larger context of their production and reception. These essays draw attention to the ways in which public policy decisions are made, and how gender and race or ethnicity play a role in access to attention and to resources. Medical research frames disease, disability or trauma in ways that define what stories about them are expected and therefore heeded. Two chapters in particular, by team members who live with cerebral palsy and bipolar disorder respectively, address the difficulty of defining ‘personhood’
in terms of the ability to communicate or to ‘make sense’ in ways that are easily recognisable.

The volume concludes with a collective dissection of Margaret Edson’s play *Wit*, about an academic woman dying of ovarian cancer. Our analysis illustrates the cross-disciplinary communication that took place throughout our project, using Jakobson’s model of communication. This example conveys the inextricable overlap between disease, disability, and trauma, when life-threatening illness and a traumatic delivery of a terminal diagnosis render the patient’s previous identity obsolete, resulting in a type of objectification and denial of agency that are frequently experienced by people with disabilities.

Our discussion of *Wit* pulls together several central issues that arose throughout our project, in relation to the six functions of communication in Jakobson’s model. These are: (1) the relationship between the story and the narrator who constructs and conveys it (Jakobson’s emotive, expressive or therapeutic function); (2) the relationship of the content (what is told) to a context recognized by the audience (Jakobson’s referential or documentary function); (3) the impact on the audience’s ideas and behaviour (what Jakobson calls the conative: a didactic or ‘reader response’ function); (4) the role of the form given to the story (the crafted stylistic or poetic function); (5) awareness of the effects of the medium of narration, in this case language and drama (the metalinguistic, self-referential function); and (6) the elements that ensure that the line of communication is open, in this case interaction between the actor/character and the audience (Jakobson’s phatic function). Four of us commented on aspects of the play that seemed particularly relevant to our discipline, in relation to these functions.

Two of us, myself and Gloria Onyeoziri, a colleague in francophone African Studies, are specialists in literary analysis, gender and ethnicity in relation to life-writing. We focused on the expressive, aesthetic, and metalinguistic functions: the role of the author-narrator-actor in relation to the text, when what Philippe Lejeune calls the ‘autobiographical pact’ is not evoked. In the case of Edson’s play, the author does not have cancer, and the actors make no claim to be expressing their own personal experience. The name assigned to the central character, fifty-year-old English professor Vivian Bearing (played by Emma Thompson in the film version) indicates that she is a representative of those who want to live (Vivian) and who are ‘bearing’ suffering, rather than an actual individual. Issues of authority, authenticity, and protection of privacy that might arise with an autobiographical narrative are set aside by the audience’s willing ‘suspension of disbelief’. Any catharsis or therapeutic effect will be experienced by the spectators rather than the narrator, and we are dealing with issues of transference rather than ‘lived experience’. The playwright, and the actors, may be considered to be ‘speaking for others’, but this constitutes a gesture
of advocacy rather than abrogation of the other’s voice or story. Paradoxically, the actual presence on stage of a body that appears to change as the illness progresses brings home to us the corporeal, material reality of disease and dying, although we know that the actor will arise from the dead to respond to applause at the end of the play. The dramatic form of this narrative draws attention to issues of aestheticisation or literary value, in relation to documentary or technical knowledge. The plot does so emphatically by making Vivian a specialist in the poetry of John Donne, with specific reference to his sonnet ‘Death be not proud…’. She is forced to confront not only her own death but a competing, physical rather than metaphysical, biomedical story about the meaning and value of pain and suffering, and what ‘conquering death’ might mean: immortality through literature, or through finding a cure for cancer.

What constitutes the value of life is also called into question by other aspects of Vivian’s existence, since she is depicted as a successful but lonely intellectual career woman who has apparently chosen not to have a family or close friends. Her ovarian cancer (occurring as Bearing arrives at menopause and can no longer ‘bear’ children) could be interpreted as indicative of failure to perform as a ‘normal’ woman. In contrast, Vivian’s mentor and only visitor, an older female professor, has managed to combine motherhood with a successful academic career. She is present near the end (along with a homely nurse who is racialised in the film version) as a maternal figure, to comfort Vivian when her intellectual knowledge is no longer of any use. The last book Vivian has read to her is a children’s story about a rabbit trying unsuccessfully to evade his mother (or a maternal God?). This straightforward fable promises the comfort of unconditional love, in contrast to Vivian’s constant attempts to gain paternal and academic approval by tackling the most difficult tasks. These aspects of the text lend themselves to a psychoanalytic reading, especially as this fiercely independent and intellectual woman is infantilised in the clinical environment - she is attached to umbilical drips, washed and cared for, wheeled about, and finally offered a Popsicle as a soother.

These elements are part of a broader and more obvious critique of the impersonalised treatment of patients in hospital, which was the focus of two other colleagues, one from the School of Nursing, the other a specialist in the history of medicine. They concentrated on the depiction of medical personnel and the use that has been made of this play in many American medical schools to raise awareness of the patient’s perspective. This approach throws light on the referential, documentary aspects of the play, and its conative function as a teaching tool. These aspects are inextricably entwined, albeit with an acerbic irony that depends for its effect on the metalinguistic function.
Dr. Bearing’s self-esteem is initially boosted by the respectful presence of a clinical fellow, Jason, a former student of hers who failed to achieve top marks in her course. However, her dominant discourse is forced to enter into competition with that of the oncology specialist, Dr. Kelekian, who abruptly informs her in the opening scene that she has advanced metastatic ovarian cancer, in a satire of the worst way of breaking bad news. The challenge to her is, at first, to master his vocabulary, like another intellectual puzzle to be solved. Similarly, her response to the invitation to take the ‘full dose’ of chemotherapy, however tough, is an uncompromising readiness to try. Vivian assumes that, as a Donne scholar, she knows ‘all about life and death.’ However, her attitude as a student was already criticized by the ‘great’ Professor Ashford, her role model, who accused her of choosing an interpretation of the end of Donne’s sonnet on death (‘Death, thou shalt die!’) based on ‘hysterical punctuation’; an exclamation mark that implies Death (personified by a capital letter) as the end, rather than death as simply a pause or transition, a comma (or coma?) indicating entry into life everlasting. While this play has been seen as useful in showing the value of kindness to patients (as demonstrated by the nurse), and Vivian learns that she should herself have been kinder to her students, it also conveys a challenge to intellectual arrogance in both Medicine and the Humanities. Vivian is forced to concur with the grandmotherly Professor Ashford that when it comes to life and death, ‘simple human truth’ may outweigh academic verbosity and conceit.

From this perspective, as Edson pointed out in an interview, it is Vivian Bearing’s illness or ‘fall’ that redeems her, forcing her to rediscover her own humanity, as she finally ‘bears’ her soul at the end of the play, literally rising silent and naked in the final scene from her abandoned and derelict body. However, the irony and paradox that dominate the play’s text leave it open to interpretation: it may be seen as a tool for the enlightenment of medical practitioners, forced to accept the power of literary words and drama, or as a critique of a literary/humanistic view of the world, since the medical practitioners remain in control at the end and Vivian is dead. Her flight into another world or life may convey a spiritual ‘truth’ for those with faith, or represent literally a flight of fancy, an escape from the stage on which her life and death are played out.

What Jakobson calls the ‘phatic function’ ensures that the line of communication is open. It works differently in a theatrical production than when reading the dramatic text or watching the film. The dramatic devices deployed in Wit enable the principal actor to address the audience directly, reminding them that this is a play, and that the pain, suffering, and death depicted are representations - copies simulated to provoke reactions. Illness is performed in the sense of a masquerade, a metaphorical theatrical show-and-tell, by stand-ins who replace real patients and hospital staff. The
selective action is arranged in a specific order to illustrate certain points. We are told the outcome at the beginning: the heroine will die. At the same time, the playwright’s words, spoken by the central actor who is also the commentator, speak for or represent, in a metonymical sense (the part for the whole), all those who face death in alienating surroundings. The story is relayed, amplified by the actors’ voices. They impart a textual message open to interpretation, as we interactively co-construct the story. Our reactions show that the meanings assigned to the play may vary, according to what we look for or expect to find, based on our disciplinary training and personal beliefs. The story we extract from the performance also reflects the cultural narrative templates (to use Arthur Frank’s term) that we choose to apply. Vivian can be seen as a victim or a survivor, a pawn or a warrior in an epic confrontation between Science and the Humanities; or as a woman who missed out on life in spite of her career success.

If Vivian were a real person, this would not be a performance in the theatrical sense. Rather, her designation by medical specialists as a patient with terminal cancer would be performative, in the sense developed by speech-act theorist J.L. Austin, popularised by Judith Butler, and adapted to narrative analysis by Kristin Langellier. The diagnosis would turn her into a patient/case rather than an individual person, abolishing her past identity, affecting her present precarious situation, and predicting (or prescribing) her future prospects. Vivian says early in the treatment, ‘I just hold still and look cancerous. It requires less acting every time,’ but by the end she cannot hide the effects on her body. The pronouncement of ‘stage four ovarian cancer’ is a death sentence, changing utterly her life (as) story. Her only survival (since she has no children) will be through a record of her experience as told, not by herself but by someone else. In this sense, Wit can also be read as a tribute to all those who have died in silence without leaving a trace, with no witnesses or spectators. However one interprets it, this play provides an exceptional example of narrative possibilities in the depiction of illness, illustrating many of the central issues discussed throughout our project and at this conference. These include whether it may be justified to prolong a life as an experiment in the hope of finding a cure, in spite of an individual’s suffering; whether, when facing death, significant human relationships are generally assessed as more important to having lived a satisfying life than other achievements; and whether faith in an afterlife is a useful fiction to sustain hope when all else fails. The play illustrates the limits and the power of ‘wit’ in terms of both knowledge and humour, as it evokes and contests the meanings assigned to suffering and death.
Notes

1 See, for example, works by C Caruth, R Charon, T Couer, A Frank, A Hunsacker Hawkins, S Henke, A Kleinman, H Lindeman Nelson, C Mattingly, S Sontag. An extensive bibliography is available (contact valraoul@interchange.ubc.ca).

2 For our first attempt to apply this model we considered a personal memoir: see Raoul et al., 2001.


5 Ibid, 32.

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Disability, Reproductive Interventions and Moral Consistency

Stuart Oultram

Abstract
Advances in medical and reproductive technology and understanding now allow women who are both pregnant or who are seeking to become so to influence what sort of child they have in one of two ways. The first is directly through technological interventions such as ultra-sound and amniocentesis, followed by selective termination. The second is indirectly through such things as dietary and lifestyle advice and subsequent alterations to their behaviour. However, it is only the direct form of influence that commonly seems to attract both suspicion and objection. In this chapter I argue that it seems impossible, or at the very least incredibly difficult, to be opposed to the first kind of intervention without being opposed to the second. In doing so I will examine (and reject) the objection that there is a moral difference between the first and second interventions because the first involves the termination of an existent foetus while the second does not.

Key Words: reproductive technology, ethics, morality, health interventions, foetal screening, disability

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1. Introduction
The aim of this chapter is to examine the problem of moral consistency that arises from disability discrimination based objections to modern reproductive interventions such as amniocentesis, ultra sound or pre-implantation genetic diagnosis (PGD).

The chapter itself is split into two halves. In the first half of this chapter I shall describe how objections to modern reproductive interventions that are based on appeals to disability discrimination generate the problem of moral inconsistency, with particular reference to PGD. I shall then in the second half of this chapter move on to examine whether or not there are any solutions to the problem of moral inconsistency.

2. Section One: What is the Problem?
Advances in reproductive science and technology now allow women who are pregnant, or who are seeking to become so, the option of avoiding, through detection and termination, having children who are disabled or impaired in some way. For example, in the case of PGD, viable embryos can be screened with the ‘healthiest’ one going forward to be implanted.
However, far more common interventions are low-tech, such as the use of *ultrasound scans* at 18-20 weeks to determine the possibility of the foetus carrying Down's Syndrome.

Yet, in many people’s opinion, the development and application of reproductive interventions such as *PGD* represent an ‘advancement gone too far’. At this point, it should be noted that although there are a number of different objections to techniques such as PGD, the one I want to concentrate on in this chapter is what I shall refer to as the ‘disability discrimination objection’. The objection itself is fairly straightforward and revolves around the following question, which Schwartz nicely illustrates as follows: ‘Does screening for particular conditions mean that we devalue those who are eventually born with it?’

Proponents of the disability discrimination objection believe the answer to the above question is yes. That is to say that to its proponents, reproductive interventions such as PGD encourage and perpetuate eugenic and discriminatory attitudes towards disability and the disabled.

The notion here is that the ability to screen and detect disabilities will result in the termination of those children, foetuses or embryos that are afflicted with disabilities or genetic conditions and which, as a result, are deemed imperfect or impure, as these statements on PGD by the campaign organisation Human Genetics Alert nicely illustrate:

> The campaign against Human Genetic Engineering believes that the prevention of the birth of disabled children is often driven by misinformation and prejudice. We would therefore question whether it is right to promote the availability of personal screening and PGD.

> PGD has a far greater eugenic potential than prenatal genetic testing because the availability of multiple embryos creates an in-built imperative to select.

For proponents of the disability discrimination objection the implications for disabled people are two fold. Firstly, any increase in the ability to screen will result in an imperative to select. This in turn will send out strong social messages about the status of those disabled people who already exist in society. The notion here is that by screening for, and selecting out, disabled people, society is in effect saying that those disabled people who do exist are less important than non-disabled people, or that the disabled should not exist. That is to say such technologies will serve to accentuate, and even create, social prejudice against the disabled.

Secondly, as well as the fear that disabled people will face increased prejudice and discrimination from society as a whole there is also the fear
that the existence, and the encouragement to use, screening techniques and the subsequent imperative to select out disabilities may have a negative psychological impact in the way in which disabled people perceive themselves.

However, these methods of selection are not the only means of reproductive influence or intervention, which are available to women who are or are seeking to become pregnant.

Today pregnant women receive, and can seek out, a plethora of dietary and lifestyle advice all of which is designed to ensure and enhance the foetal and thereby future health of any prospective child. Examples of such advice includes increasing the intake of folic acid (to 400 micrograms per day) as this can reduce the chances of neural birth defects such as spina bifida and Downs’ Syndrome; avoiding excessive doses of Vitamin A, which in turn will lower the risk of heart defects and cleft pallets; and not exceeding 300 micrograms of caffeine a day so as to avoid, among other things, low birth weights. However, unlike the methods of intervention I began this section by discussing, these methods seem to receive no such hostility or ringing denunciations. Indeed mothers who do follow such advice receive praise and are thought of as being good mothers. Or to put it more bluntly pregnant women who take folic acid, or give up smoking, are never accused of being party to the promotion of eugenics in our society. It is this fact therefore which for me seems to generate the problem of moral inconsistency.

This is because these interventions are designed to do, or perform, the same role and function as those I described at the beginning of this section. Therefore, all things being equal, they should be subject to the same objection, that is that they are eugenic and discriminatory because the aims of these interventions are to bring about ‘healthier’ embryos, foetuses and children than would other wise have been the case.

Indeed it would seem that unless there are any moral differences between these two types of intervention it is incredibly difficult, from the perspective of moral consistency, to be opposed to the first kind of intervention without being opposed to the second.

This brings me to the second part of my chapter.

3. Section Two: Is there a Difference?

For the purpose of this section I am going to restrict myself to what I believe to be the three most significant potential differences between these interventions.

The first potential difference which could be appealed to is that much of the dietary and lifestyle advice given out to pregnant women is advice that is beneficial to everyone. That is to say that drinking less caffeine and giving up smoking are things we should all be doing because of the
beneficial effects it has upon our health. By contrast, interventions of the first
type carry no such general health benefits.

However, the problem with this response is that some of the dietary
and lifestyle advice given to pregnant women and those seeking to become
pregnant does not fall into this category of being ‘universally good advice’.
Fitting examples of this are the recommendations that pregnant women
should avoid un-pasteurised dairy produce or that they should eat more folic
acid, actions which can only really be of benefit to the foetus.

The second potential difference is that interventions such as PGD
are inherently far more successful in avoiding and selecting out disability
(and therefore disabled people) than changes to lifestyles and diets are. So,
for example, even if a pregnant woman were to increase her folic acid intake
with the intention of reducing the chances of having a baby with Downs’
Syndrome, her actions will not be able to guarantee that this disability will be
avoided. However, screening through PGD followed by the implantation of
only healthy embryos, ensures a far greater success rate. As a consequence,
dietary and lifestyle based reproductive interventions will not result in the
elimination of disabled foetuses.

Yet the problem is that while the odds of avoiding a disabled child
may differ between say eating folic acid and PGD screening, dietary and
lifestyle alterations still remain vulnerable to disability discrimination based
objections. This is because while the odds of success may differ between
PGD and lifestyle and dietary alterations the intentions do not; namely the
intent to avoid having children with certain disabilities.

This then brings me to the third and final potential difference, and it
is one which originates from a particular difference between the two types of
intervention I have been discussing: dietary and lifestyle interventions consist
of enhancing what is already there while PGD involves the termination,
‘death’, or replacement of one sort of potential child, foetus, or embryo with
another entirely different one.

There can be no doubt that in terms of method there is a difference
between how both these different types of practice seek to avoid the birth of
disabled children. But with regards to the problem of moral consistency that
arises from disability discrimination objections there is no difference.

Let us recall that the thrust of the disability discrimination objection
is not that embryos are being terminated per say, but rather that techniques
such as PGD will reduce the number of disabled children and this in turn will
have a negative social impact upon disabled people. As we have seen, this
can also be said of things like dietary alterations such as eating extra folic
acid to avoid neural tube defects in foetuses.
4. Conclusion

I began this chapter by describing two ways in which pregnant women, or those who are seeking to become so, can seek to avoid the birth of a disabled child either through reproductive technologies such as PGD or through dietary and lifestyle alterations.

As was noted, some critics object to the use of certain techniques on the grounds that they will create adverse social conditions for disabled people by encouraging discriminatory attitudes towards disability, as well as potentially leading to adverse psychological effects upon the self-esteem of disabled people themselves. However, as was also noted, while it is common for critics to find the first kind of ‘disability avoiding’ option objectionable on disability discrimination grounds the same objections are never applied to the second type of ‘disability avoiding option’ (dietary and lifestyle changes). It was this difference that generated a problem of moral consistency for me, as the same disability discrimination objection appeared to be applicable to both types of intervention.

I then, in section two, examined three potential solutions to the moral consistency problem however all of these proved unsatisfactory. Therefore, in conclusion, unless there is a meaningful difference between the two methods of avoiding disability, I would argue that from the perspective of the disability discrimination objection, all things being equal, the problem of moral consistency would appear in principle to hold true.

Notes

1 Schwartz et al, 2002, 147.
3 Ibid.
4 All information taken from the following two web sites; BBC NEWS, 1998; BBC NEWS, 2001.

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Desirability and Its Discontents: Young People’s Responses to Media Images of Health, Beauty and Physical Perfection

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Abstract
In contexts where the entertainment media focus on selling dreams of successful lifestyles linked to images of attractive young men and women disporting themselves in healthy abandon, those who do not fit these ‘norms’ often come to be seen, and also come to see themselves, as the other. This situation is particularly problematic for young people who suffer from physical disabilities, but it is also critical for those who think of themselves as too fat or too thin, not beautiful and so on. This chapter reports on data from focus group interviews with 195 young people (aged 14 to 25) living in Malta, and examines the extent to which attitudes to body image can be shown to be changing as a result of young people’s complex engagements with the media. The main focus is on how teenagers and young adults themselves speak about their own bodies and physical appearances, and how their self-worth and perceptions of others relate to recurring projections of desirability in the media. Advertisers’ views of what body images are appropriate for use in advertising are compared with young people’s changing perceptions of desirability. The chapter suggests that though young people often resist and ridicule media stereotypes of physical perfection, their self-images are inevitably inflected by the commercial imperatives of the entertainment industries and advertising.

Key Words: Body image, advertising, media, youth, health, disability, physical perfection, Malta.

1. Introduction
As is the case in other aspects of media influence on behaviour, ascertaining how media consumption may be affecting young people’s attitudes to body image is anything but clear-cut. However, there are strong indications that the value systems propagated through popular media images can have a profound influence on how young people perceive their own bodies and appearance. Elizabeth Bird, for instance, describes an anthropological study of the cultural impact of the recent introduction of television and ‘the arrival of images of blonde, thin, imported beauties’ into a Fijian culture:
In a society that traditionally valued generous female proportions, young girls quickly learned disgust for their bodies, discovered the binge/purge syndrome, and told interviewers: ‘I want their body, I want their size. I want to be in the same position as they are… We have to have those thin, slim bodies…’ Certainly, these young girls derived great pleasure from this new medium. But we cannot ignore the negative impact of the globalizing economic forces that ensure that Fijian girls’ first media experiences are of Baywatch and glamorous soap operas.¹

This chapter explores how young people’s attitudes to body image are inflected by their exposure to commercially oriented and increasingly globalised media images. Drawing on data from focus group interviews with 195 young people (aged 14 to 25) living in Malta,¹ I examine how they speak about their own bodies and physical appearances, and how their self-worth and perceptions of others relate to recurring projections of desirability in the media.

On a billboard at a busy intersection in Malta, a triptych of images advertises Versace soaps and body lotions. I saw this billboard while I was on my way to meet students at Malta’s Institute of Business and Commerce, and again when I was coming back from interviews with young factory workers. What struck me most was the positioning of the billboard and this particular poster. Standing prominently behind the billboard are a Catholic Church and a monastery, while on the other side of the street facing it stands Malta’s only (as far as I know) mosque and minaret. Towards the back of the Church and adjacent to the monastery there are also the remains of a prehistoric Neolithic Temple. A secondary school stands not far down the road, with the post-secondary College of Arts, Science and Technology beyond that. In the opposite direction lies the industrial estate, with its range of factories and production plants. An eye-catching symbol of global glamour and commercialised sexuality appeared here to have reached the gates of the centres of learning, labour, heritage, tradition and organised religion, and incongruously assumed the role of guardian at the gates.
In the first image, in stark shades of blue, a young blond woman and a dark haired young man tilt their heads and shoulders against each other as they lean up and forward from a reclining position, smiling broadly at whoever happens to glance at them from the busy street. What can be seen of their young and well-trimmed bodies indicates that they are totally naked, though their decency (as they used to say) is strategically protected by the angle of their postures and the positioning of their arms. Next to this image, in the centre of the triptych, is a picture of the young woman by herself. The
dominant colour here is red, and the model is again looking straight at the viewer (through the camera), her arms partially covering her breasts, with one of her hands slightly touching her lips, as she sits cross-legged and naked behind three bottles of ‘Time for Pleasure’ body products. The third image is in green. The couple are together again, but this time they are caught in an embrace, with his arms around her shoulder and back, their legs interlaced with each other. Here too they are naked, and here again they look straight at the viewer, but this time they are looking sultry rather than smiling.

Lines from W.B. Yeats’ *Sailing to Byzantium* spring to mind:

The young
In one another’s arms
[....] commend all summer long
Whatever is begotten, born, and dies.
Caught in that sensual music all neglect
Monuments of unageing intellect.

There is clearly nothing particularly technologically advanced or innovative in the messages projected by an advertising poster like this one. What is striking about it are the qualities it shares with the countless similar images which appear so frequently in the popular media: the technical virtuosity with which it has been posed, composed, and airbrushed; the eye-catching way it has packaged its banal equation of success and happiness with physical appearance and sexual attractiveness; its endorsement and propagation of stereotypical norms of enviable body shape, youthfulness, looks and sexual orientation. In this respect, as indeed is the case with most commercial media, the poster is selling more than a brand of soap and body lotions - it is selling a whole way of life. Judging by the ways in which many young people talk about themselves, their bodies and their relations to others, the sales pitch appears to be working.

2. **Commercial Media and ‘Beautiful People’**

The advertising agents I interviewed in Malta spoke of their awareness and use of young people’s concern about image. At the same time, however, they were also insistent that in locally produced advertisements they usually use ‘ordinary’ people rather than professional models. One agent stressed that in her campaigns she chooses models who look healthy rather than seeming ‘unrealistically beautiful or unrealistically thin’. She pointed out that, in recent years, young Maltese people have become more concerned about their appearance, body weight, and physical fitness, and that this might well be one positive outcome of what they see in the media, particularly in the types of models used in advertising. I asked whether she would consider using somebody who is chubby or fat in an advertising campaign for a
product not specifically related to body size or appearance (as in an advert for jewellery she had produced). Her answer, predictably perhaps, was no, and she saw this as a matter of promoting better health consciousness:

*Advertising Agent 1:* ‘The young couple in this advert are good looking, but not abnormally so. They’re not ’supermodel’ types, and they’re not unrealistically thin either. I believe that an advert should portray an ideal situation, so ideally you’re healthy, you’ve got a good physique, even if you’re not particularly beautiful, but you know how to keep yourself well groomed. So for me that is the image that I should be giving with my advertising. If you’re healthy, you should be looking like that.’

When I put a similar question to two other advertising agents, they made it clear that for them it was more a matter of aesthetics and good sales technique:

*Advertising Agent 2:* I wouldn’t use a chubby or fat person in an advertising campaign - not because it’s not healthy, I wouldn’t do that because it’s unattractive. You have to make an advert look as appealing as possible.

*Advertising Agent 3:* In one particular campaign in which we aimed at young adults, the people we used were attractive, very attractive, but nothing that intimidated, nothing that made you feel: ‘Oh my God, I can’t go next to that crowd of people because I’m going to be inferior…’ They were normal people, people anyone could relate to. In our local adverts, we very rarely use models or model agencies. We use well people. It’s different when we import adverts from overseas of course.

The specific campaign aimed at young adults referred to here involved what sounded like a relatively uncomplicated procedure:

*Advertising Agent 2:* We got a local group of friends, who happen to be my group of friends, who happen to be quite a good looking bunch of people, and we just put them on a sofa in a nightclub, lit them up, and just told them to sit down and have a good time. We got a certain image, an image which was young, cool, trendy. We called them the beautiful people.
So how are these recurring images of ‘beautiful people’ perceived by young consumers themselves? And how are young people’s self-images and attitudes to their own appearance affected or inflected by such material? What happens, for instance, when young people perceive their own bodies and appearance as failing to match those of the ‘beautiful people’ whom advertisers project as ‘normal people, people anyone could relate to’?

3. Young People with Disabilities

The problems created by the media’s insistence on idealised ‘norms’ of physical health and attractiveness are perhaps most pronounced in the case of a segment of the population whose body images can never hope to match the ‘ideal’ or ‘healthy’ looks so deliberately espoused and propagated in popular films, TV programmes, magazines and advertising.

Eight percent of Malta’s population is officially registered as disabled. However, the exact number is difficult to pinpoint because registration in Malta is voluntary, and the vast majority of those who do register as disabled are older people, i.e. those who have become disabled in old age. The figures can thus be expanded or minimized depending on how disability is defined or measured. According to the National Office of Statistics’ 2003 Lifestyle Survey, for instance, ‘nearly a quarter of the population have a long-term health problem or disability’\(^3\) but what exactly ‘long-term health problems’ and ‘disabilities’ involve, or indeed how they differ from or overlap with each other, is not explained. The World Health Organisation estimates that 10% of the population of any developed country are likely to be disabled. The figure for non-developed countries is estimated to be higher, and it is also estimated to be higher than average in highly developed countries, simply because countries with stronger economies can afford to broaden their definitions of disability, and presumably their financial support, to include cases which would not be defined as such in other countries.

In a context where advertising and entertainment media focus primarily on selling dreams of successful lifestyles linked to images of attractive young men and women disporting themselves in healthy abandon, people with disabilities are either simply ignored or else portrayed in stereotypically damaging ways.\(^4\) Society’s norms, often reinforced by repetitive media images of what we should all look like if we are healthy, or attractive, or desirable, create a situation where those with disabilities come to be seen (and also come to see themselves) as ‘the other’.

One of my older interviewees described his recollections of growing up with severe physical disability, and of how his self image was influenced by what he saw on the media. He felt that it is portrayals of allegedly ‘normal’ and ‘unexceptional’ people and body types (as distinct from supermodels) which caused him the greatest problems. Supermodel-type
adverts, he noted, were always ‘Peter Pan fantasy worlds’ as far as he was concerned; too distant from personal reality to invite comparison. It was the less fantastical images, programmes and films which helped to forge his self image. Films and soap operas, for instance, ‘provide your imagination with the stories that just stay there, and stay there, and stay there. And they create images of what you would like to be.’ Referring to his own recollections of what it was like to grow up as a disabled teenager, he remarked that he used to have the same sort of hopes and ambitions as other teenagers. His idols were the stars; he played in a band, and hated the fact that he was small, that the electric guitar he played seemed bigger than he was:

It’s terrible when you’re young. I mean, I hated being short, I hated having very thin limbs, you know, like Kermit the frog. All the images come out. And for years and years and years you just think you’re a freak, and ‘why are you alive?’ and if you are alive, why is your mind not messed as well so you don’t know what’s happening to you? And every time I tried to speak about how I felt, people would say: ‘Oh, you’ve got nothing to worry about. You’ve got nothing to be unhappy about!’ What they were saying was ‘Please shut up, don’t talk about it. It’s too painful.’ So you shut up.... But then it’s difficult because you don’t open up to anybody.

A lot of films, TV programmes and advertisements play on images of sexuality, ‘beautiful young people’, as well as happy families and healthy parenting. People with disabilities are not usually seen as (or even encouraged to think of themselves as) sexual beings, and they are usually patronisingly assumed to be incapable of being independent or raising their own families. In this context, they are (often unconsciously) encouraged to think of themselves as being asexual - ironically within a global media context which is increasingly sexually oriented. Most commercially-dominated media contexts thus encourage the disabled to think of their identity as being totally defined and confined by their ‘disability’. In other words, by refusing to get close enough to see people with disabilities for who they really are, society is also insisting on seeing and defining them exclusively in terms of the characteristics which it has itself determined to be ‘abnormal’ because they ‘deviate from the norm’. The disabled become the perennial ‘other’ - to be ignored or else treated as curiosities or as objects of pity.
4. ‘Healthy’ Young People’s Perceptions of Body Image

Many of the young people I interviewed spoke of the ways in which the images projected through the media create stereotypes of sexual attractiveness which encourage girls to wish for a slim figure, and boys for a muscular one.5

The links between girls’ desire to have slim or thin figures and the images of female beauty most frequently projected in films, television programmes and advertisements have frequently been documented in the international research literature. Several cross sectional studies have found ‘an apparent link between level of media exposure and likelihood of having an eating disorder or eating disorder symptomatology’.6 One study found that young women with eating disorders report that magazines and newspapers influence their eating habits and their concept of beauty.7 Studies of college women in the US found that the ones who are most dissatisfied with their bodies and are most prone to bulimia are those who most ‘internalise the cultural bias toward thinness’.8 Similar patterns of dissatisfaction and levels of eating disorders have been found with younger girls ‘whose devotion to fashion magazines leads them to compare their bodies with fashion models’.9

In the course of one of my interviews in Malta, 15 year-old Mark described young people’s perceptions of the ‘ideal’ body types in language coming straight out of popular magazines and advertising media:

Every girl I’ve ever met, however thin she was, always said that she’s too fat! Some boys I know who are fat often get depressed because of their body and do everything to lose weight, not eating, etc. But it’s much worse with girls. Girls go for the perfect shape. The perfect shape à la American style: perfect shape meaning a Size C cup basically and a small rounded ass. Either one or the other: backside or ‘What a girl!’ if you see what I mean. For guys as such, they want to be well built, so their aim is to have a six-pack, muscles, and to be tall - taller than the girls they want to date.

It is ironic that such perceptions are prevalent in a context which also encourages young consumers to eat unrealistically glamorised fast foods. Throughout the interviews, whenever McDonald’s and Burger King were mentioned, the interviewees’ eyes tended to light up, even though they frequently referred to such food as ‘junk food’.

Echoing comments made by the advertising agents cited above, several of my interviewees insisted that young people want to look slim or muscular because it is healthy. According to one sixteen year old girl:
I was watching a debate on TV lately, and someone stood up and said, ‘But let’s be realistic. Do we want to see fat slobs on TV, or people without hair, or something of the sort?’ And it’s true. And the media do affect us to want to look good or to eat better food, and if it doesn’t get excessive, it’s good, because after all we feel good, and if we’re what we want to be, we’re OK with ourselves.

Feeling good about oneself in this context presumably means not being ‘a fat slob’ or losing one’s hair. The ‘norms’ against which these negative perceptions are measured are not hard to identify. Sandra, a 25 year-old factory worker, summed up the situation as follows:

“When you look through the magazines, all you see is young women with great figures, and everywhere you look you see stuff about dieting. And the men all have amazing bodies! And then you look at yourself in the mirror, and you say: My god! What a bloody mess!”

Though perhaps not always expressed as colourfully as this, these sentiments were voiced by many of the young women interviewed, irrespective of their age. Several spoke more specifically of their own or their friends’ experiences of dieting, or of eating disorders like anorexia and bulimia nervosa. One 16 year-old girl described her own experience and that of one of her friends as follows:

“There are thin people who are so affected by how, like... like you have to have a perfect body, you have to be thin, and you can’t. Like, my hips are huge; I still want them to be smaller, but.... I had gone through a phase when I didn’t eat. Like, you lose three or four kilos in a week, but you put them on again, so it’s a waste! But I had a friend, she’s tall, very thin, and she still wasn’t eating anything. Another friend of mine blacked out last week....

According to Malta’s National Office of Statistics’ 2003 Lifestyle Survey, 7.6 per cent of Maltese females aged between 18 and 24 are underweight.¹¹ According to an earlier report published by the Health Promotion Department, the overwhelming majority of patients suffering from anorexia nervosa and bulimia nervosa in Malta in 2003 were female; almost half were aged between 18 and 29, and more than a quarter were under 17 years of age.¹² These figures are particularly striking when compared to the
Lifestyle Survey’s revelation that 60 per cent of the Maltese population are either overweight or obese, and that 56.3 per cent of these are males.

How then do boys fare in this regard? According to one 15 year-old girl: ‘Lately boys have become very vain, almost as much as girls!’ Similarly, a group of 16-17 year-olds commented on the growing number of boys going in for fashion modelling, having facials and pedicures, and spending more and more time in the gym. The fact that young men have become more fashion-conscious and apparently more concerned about their physical appearance is not a phenomenon that is unique to Malta, of course. Indeed, changing attitudes towards fashion and personal grooming among young Maltese men can be read as indicators of how the young perceive and construct their own emerging identities in an increasingly globalised media environment.

Several international researchers and commentators have over recent years become interested in men’s relationship to consumption and in the ways in which perceptions of masculinity have been changing in consumer society. According to Tim Edwards, since the 1980s it has become ‘more socially acceptable for men to be consumers per se and, more importantly, to be consumers of their own masculinity or, in short, to look at themselves and other men as objects of desire to be bought and sold or imitated and copied.’ The perception of male sexuality as a consumer product suggests that masculinity is coming to be perceived as something to be displayed, gazed at, envied and groomed. In many ways, these qualities have traditionally been more stereotypically associated with femininity. But these changing perceptions, again according to Edwards, do not appear to have radically affected traditional sexual behaviour.

The ways that different boys and young men react to the perceived pressure to ‘look good’ vary considerably. One 17 year-old described his reactions to recurring media images of ‘perfect bodies’ as follows:

About the impact on me: OK, I’m a bit fat and so on, but not too much. OK, if you see a pretty girl, it’s all right, because it’s a girl. But if you see a young man, then you say, ‘Why am I not like him?’ sort of. Personally, that’s what I say. It doesn’t get me down that much, however, because then I turn, and say, ‘I’ve got a lovely character; at least for me it’s very good.’ But still....

In some cases, building muscles and showing them off becomes almost obsessive. 18 year-old Pierre noted that there has been ‘an enormous boom in gym memberships’, that many of his school friends go to the gym, and that they do this because they want to look sexy: ‘I think the majority go
to the gym so as to pick up girls, not for the sport itself, to have a good figure!’

But gym attendance, or even concern about body size, does not appear to be so common among young men coming from lower socio-economic backgrounds. According to a number of young women in this category, for instance, men are not usually as worried about their appearance as women are. Girls will diet so as to stay slim, they pointed out, but in the Maltese context, boys and men are not as worried about their body weight or looks, and many think that it actually looks better for a man to be stocky in build. One 15 year-old girl remarked that ‘if a guy is a bit fat we’re not going to take much notice; we’re not expecting to go out with a model or something!’ Many of the young people I interviewed appeared to assume that it is girls and women who are most concerned about attaining the ‘ideal’ body image. Indeed, some young men seemed to think that such concern is ‘natural’ or even biologically determined where women are concerned! Women were thus assumed to ‘naturally’ want to improve their image by fitting the stereotype of sexual attractiveness in order to attract the male gaze. According to 24 year-old Cliff, for instance, women are always obsessed with their figures anyway, irrespective of what the media or advertisers throw at them.

But the claim that boys are not really worried about their appearance is of course misleading. They might not be concerned about the same aspects as girls, but there is no doubt that ‘looking cool’ is very much a young male preoccupation. One area where this is very pronounced is in the way young men talk about their hair. Several comments were made to the effect that boys have become more concerned about hair grooming and appearance than appeared to be the case in the past. Hair gel was frequently cited as a young male obsession.

5. Conclusion

What came across to me very strongly in the course of my research was the fact that young people are often very skeptical about exaggerated media stereotypes of physical perfection. Young people often appear to enjoy drawing attention to, and even ridiculing, what they see as unrealistic portrayals of super-bodies and super-beauties. This observation is in line with Wray and Steele’s account of how the girls they studied were critical of the ways teenage girls are portrayed in teen magazines like Seventeen and YM (describing such portrayals as ‘unrealistic,’ ‘mindless’ and ‘horrible, but in a funny way’). But, as the evidence I have presented suggests, it is media images of allegedly ‘normal healthy ideals’ which most frequently act as measures against which young people assess their perceptions of themselves. These are precisely the types of images which the entertainment and advertising industries now frequently describe themselves as ‘responsibly’
projecting. In this sense, the ways in which young people’s self-images are being inflected by the commercial imperatives of the media can be argued to be as complex as they are insidious.

Notes

1 Bird, 2003, 168. The anthropological studies described by Bird are Becker, 1995 and Becker et al., 2002. Becker et al. report that, in the Pacific isle of Fiji, the proportion of teen girls scoring abnormally high scores on a test for disordered eating doubled three years after the introduction of television. There was also a significant rise in cases of teenage girls reporting that they had vomited to control their weight and in the numbers of girls reporting that they felt ‘too big or fat’.

2 The interviews were part of two research projects commissioned by Malta’s Broadcasting Authority in 1998-2000 and 2002-2004. For full reports on the projects see Grixti, 2000 and Broadcasting and the Young Adult Consumer, 2004.


5 For a recent critical overview of research on the media’s impact on women’s body image see Wykes and Gunter, 2005. On men and body image see Pope et al., 2002, Pronger, 2002 and Olivardia, 2002.

6 Strasburger and Wilson, 2002, 264.

7 Murray et al, 1996.

8 Thompson et al., 1999.

9 Strasburger and Wilson, 2002, 264.

10 See Hofschire and Greenberg, 2002, 126-7, who report several content analyses and questionnaire-style surveys which stress that ‘the mass media presents a narrowly defined body type - ideal’ and that ‘[a]dolescents are particularly at risk for experiencing body dissatisfaction’ because they ‘consume large quantities of media that emphasise these standards of attraction’.


13 Edwards, 1997, 73.

14 Wray and Steele, 2002, 198.
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Selling the Social as Object: Online Donor Banking and the Standardisation of Semen

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Abstract
This chapter explores the history of human sperm banking from the late 1970s to today’s online market. Of special interest are the ways in which semen is now categorised online, due largely to meaningful negotiations among actors within social worlds. The chapter reflects on how the optimal health of the donor is predominantly translated through their social rather than medical histories, as these are crucial characteristics in determining the marketability of the materials themselves. Objective markers for healthy sperm have come to be constructed as such largely due to shifting negotiations between doctors, donors, and patients. Examples of the classification, standardisation, and objectification of these materials will emphasise the multi-layered negotiations involved in the construction of meanings while describing the semantic evolution of semen through a cultural history of sperm. As the market for human reproductive tissue flourishes, reproductive materials gain value beyond their basic life-giving properties. The major attributes reflecting the value of sperm include race and ethnicity, beauty, sexuality, intelligence, and athletic competence. How does the sperm of someone beautiful, young, smart, athletic and heterosexual, come to elicit a certain price on the market? Or more specifically, how is a biological material personified and marketed as technosemen? A hierarchy of reproductive materials is most often created through classification, where a higher price is paid for the most finely negotiated balance between differences and standards. Social and cultural constructions are ultimately deemed important nexuses for the online exchange of sperm, which in turn paradoxically sells the social through the re-creation of semen as a standard, categorised unit, rendering it an object in the aperspectival imagination.

Key Words: Sperm banking, donor banking, semen standardisation, technosemen, reproductive materials.

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This chapter explores some ways that semen is categorised online due largely to meaningful negotiations amongst communicative actors. I will reflect upon optimal donor fitness as predominantly translated through his social rather than medical history, as these are crucial characteristics in determining the ‘marketability’ of the materials themselves. I will also
explore some of the ways that seemingly objective markers for healthy sperm have come to be constructed as such, as well as how these constructions thrive within shifting negotiations between doctors, donors, and patients. Emphasis is placed here on semen as simply biological material until it is infused with social and political meaning. Definitions of ‘good’ and ‘bad’ reproduction are questioned, as social meanings are increasingly entwined into the expanding market of fertility services. Examples of the classification, standardisation, and objectification of these materials will emphasize the multi-layered negotiations and contexts involved in the construction of meanings while describing the semantic evolution of semen through a cultural history of sperm. What emerges is an intricate system for predicting the health of a unit of sperm, where social characteristics fuse with objective understandings of biological health.

1. The Industry

By 1977, the Minister of Health and Welfare in Canada had decided that artificial insemination techniques, which were becoming increasingly popular, would continue to expand mostly due to ‘the reduced availability of infants for adoption, and because of the desire of a woman to bear her own child.’ Prior to this statement, however, in the fall of 1974, the annual meeting of provincial health ministers resulted in a recommendation to the Canadian federal government to prohibit the storage of sperm until research and control studies could be carried out. The federal Minister of Health soon assembled an advisory committee which offered suggestions on ethics, standards, and protocols for the use of frozen human semen. More recently, the Assisted Human Reproduction Act received Royal Assent in 2004, prohibiting Canadians from selling their reproductive materials, but offering the possibility of purchasing foreign ones. Semen is now widely stored, shipped, and exchanged in Canada.

Reproductive materials are discursively transformed into sites that offer insight into the cultural norms and values they have absorbed. Besides the fact that an online bank can cut fertility costs by providing detailed database information pertaining to donors without a prior meeting with a physician, and can reduce travel times for fertility treatments - which was otherwise a problem of controlled testing for fertility success rates - they also offer the possibility of perusing many different kinds of donors from a variety of facilities at once. The suppliers of these materials often tailor their services to the wants of their clients/patients through finely tuned categorisations, which includes the standardisation of reproductive materials through various techniques that ultimately translate in terms of price to the customer. Among the more routine forms of standardisation are semen screening for both genetic and infectious diseases, motility testing, and washing and suspension in standard fluids. Lisa Jean Moore and Matthew
Schmidt have named the physically manipulated end product ‘technosemen’, and assert that ‘Marketing technosemen can alter the assumed inelasticity of the semen market by convincing, or better yet guaranteeing, the general public that technosemen is fertile, uncontaminated, and genetically ‘engineered’ for desirable traits’. 4

The production of physically standardised semen operates in conjunction with socially produced classifications, resulting in blurred constructions of health. 5 The first signs of ‘technosemen’ in Canada can be found in the 1977 report on the storage and utilisation of human sperm by the advisory committee to the Minister of National Health and Welfare. In this report, the first ‘standards for the acquisition, preservation, and importation of sperm’ are outlined, including genetic and infectious disease screenings and several psychological evaluations of the donor. A physical examination of the donor is also recommended, where ‘non-trivial malformations’ 6 such as cleft lip, cleft palate, and clubfoot among many others are deemed medically unacceptable. Standards were also extended to the family members of donors, with family traces of asthma, rheumatoid arthritis, and psychosis being unfavourable indicators of donor health.

The efficiency with which these new techniques operate is exemplified through donor search engines aimed at facilitating the reproductive process through online semen-selection. Models include the Power Search, available from California Cryobank Inc., 7 which offers a quick route to the acquisition of ‘technosemen’. Specialised features such as the Power Search offer consumers of these materials convenient types from which they may attempt to manage genetic risk by selecting categories on a pull down menu. They also propose screening for nine genetic diseases, as well as for eleven sexually related infectious diseases. Interestingly, the social is woven into the medical discourse of semen selection here, with a noteworthy emphasis on religion as noted with the advanced search tool which allows users to view a list of donors with at least one Jewish ancestor. Religious possibilities are juxtaposed with objective scientific screening, and act as auspicious indicators of health. Through marketing semen in this way, the basic properties that make up the actual material, ‘a mixture primarily of prostaglandin, fructose, and fatty acids combined with 10 percent sperm cells’ 8, is disciplined and infused with social standards. Smart semen, gay semen, beautiful semen, and religious semen may not only vary in price, but will be held to objectively possess these qualities as they are observed as categorised standards.

Fertility specialists have come to understand that their patients are not simply patients, but consumers of technology, as well as educated research subjects who are willing to experiment with their bodies as long as their opinions regarding treatment are taken into account. Fertility practices have evolved with those whose bodies they are used on, and standards have
shifted to meet new criteria of health as defined by customers, and not only patients and research subjects.

2. Standards
Some of the most sophisticatedly marketed online reproductive materials and accessories are offered through fertility centres. These often have the most thorough donor screening available, and might charge extra for tailored services such as donor videos or audiotapes, or detailed biographies. At these sites, prospective online parents are offered the same services as the clients who physically enter their facilities, such as the chance to examine donor summaries, which consist of what constitutes as standardised medical, physical, and psychological profiles. The Fairfax Cryobank located in Fairfax, Virginia, claims to provide ‘a large selection of the most up-to-date genetic and infectious disease tested donor semen’. Their massive offerings of variously categorised semen samples allow them to remain competitive on a global scale. They will encourage their online clients to take advantage of discounted shipping with the purchase of 6-11 units of sperm, offer free delivery for 12-17 units, and waive overnight-shipping charges with the purchase of more than 18 units. Of course, a schedule of fees posted on their website warns that an $825 deposit is required for a liquid nitrogen tank to deliver the frozen materials, all part of a discourse of ‘convenience over cost in making lifestyle decisions’.

Selling the sperm in units such as this furthers its travel into realms of convenience and standardisation by offering the promise of perfectly measured doses for optimum success potential with impregnation.

More often than not, ‘Donors who do not rate highly within these categories are not included in these catalogues, nor presumably is their semen stored in banks as sellable inventory.’ Most importantly, the ‘sellable inventory’ does not emerge on its own, but is a product of socially, politically, and culturally specific discourses which then coalesce with genetic materials to form value and meaning. This meaning is further constructed and re-constructed by the tools and practices that make it possible. Although commercial sperm and egg banking have led to new ways to manage genetic risk, these practices would not be feasible without the co-evolution of cryogenics, information technology, and women’s health movements.

Marc Berg has explored the ways that tools and practices are produced together, and not separately, finding their ways through points of convergence in intertwining networks. These points are crucial in understanding how tools like cryogenic freezing tanks and information technology have transformed the practice of artificial insemination. He explains, ‘convergence also points at the fact that characteristics of ‘tool’ and ‘practice’ are not pre-given but rather emerge in and through the
The intertwining of the networks.  

The networks, however, are not static, fortified grids, but are instead imagined as constantly shifting, multi-dimensional, open-ended arenas of activity. Of special interest here are the ways in which tools such as cryogenic freezing and information technology have converged with fertility clinic practices, and the ways in which women have negotiated their needs within a culture of consumption and convenience. Following Berg, I will not consider these convergences as imperative ‘successes’ for the online reproductive exchange industry, but instead contemplate the temporal context for their emergence within intertwining networks.

Of special interest is the degree to which patients are included in the scientific processing of semen. Heightened standards are used as a form of marketing in itself, indicating that increased standardisation is indeed a step in the right direction to higher quality semen. One bank proudly states that screening for cystic fibrosis goes beyond ‘25-37 mutations as most labs do’, to ‘more than 1300!’ Interestingly, the bank even tries to standardize lifestyles and infections for which there is no medical testing available. When lifestyle choices bleed into standards, a cultural situatedness is necessarily at work.

3. Culturally Embedded Notions of Sperm

The cultural embeddedness of online semen selection is inescapable, and the shifting semantic structure which supports the objectification of sperm is necessarily contingent upon it. Indeed, the language involved dictates ‘donor selection’, implying that the actual donor is what is being selected and not simply a unit of his frozen semen. Lisa Jean Moore has explored the way that books about human reproduction for children and teenagers emulate social notions of gender. Likewise, Emily Martin has taken the position that ‘scientific accounts of reproductive biology rely on stereotypes central to our cultural definitions of male and female.’ Both tell of culturally embedded notions of sperm, and of the scientific discourses that enforce gender roles.

Moore emphasizes that ‘coming of age’ books in general ‘ease’ children ‘into science, a marker of maturity’. Fairy tales, fables, and sex education books are all part of this rhetoric, and are important structures for the dissemination of information concerning the science of reproduction. While motility, morphology, and sperm count are key elements in the production of ‘good’ sperm, discourses of ‘relationships’ between the egg and sperm are consistently woven into elementary explanations of reproduction. Sperm comes to take on an active role in self-referential meaning construction, adhering to social laws that are undoubtedly framed in time and space.
The use of socially and culturally normative language in science extends beyond the learning that is carried out through children’s books. Learning through scientific textbooks is also a heteronormative process of language use. Emily Martin says that these textbooks ‘celebrate sperm production’, and goes on to say that ‘We need to understand the way in which the cultural content of scientific descriptions changes with biological discoveries, and whether that cultural content is solidly entrenched or easily changed’. She finds that stereotypical language prevails in scientific textbooks. These views are re-written and reproduced, supporting her claim that these are solidly entrenched notions which are difficult to change. While American narratives in the 1950s insisted upon reproduction between a man and his wife, the late 1990s have brought about some (although limited) discussion of artificial insemination. This is done by introducing the egg and sperm to each other in laboratory dish, which continues the language of personification and the social relationship of these materials to one another. Narratives of reproduction are interwoven into the collective conscience and facilitate the work of classification.

4. Classifying Semen

The classification of semen might be largely due to what Geoffrey C. Bowker and Susan Leigh Star refer to as convergent bureaucracy. They assert, ‘Throughout this century, in general, people have become more and more used to being counted and classified’. Others cite a decrease in the physician’s control over institutional practices which leads them to more profitable and controllable ventures: ‘Semen banks are industrial sites in which health care providers attempt to stake professional claims’. Efficient communication through a global online network of patients has become fully integrated as a result of both increased profitability and controllability. The exchange of wombs, sperm, eggs, and embryos online is incalculable, and continues to grow in diverse ways through a range of convergences between medical fertility practices and information technology. The meanings exchanged here are diverse, but are all socially co-constructed, embedded, and coevolving.

If we are to consider that meanings are contextually embedded, it is worth considering constructed notions of childbirth by comparing cross-cultural practices. Lesley Sharp offers insight into the different social worlds inhabited by reproduction as she explores the economic meanings created for childbirth by Bangladeshi and Western women. For the Western women, these would most often include ‘a host of medically valued by-products, including the umbilical cord, placenta, and foetal brain matter and other tissues from neonates who did not survive’. A Bangladeshi activist for women’s rights however, reads the code for these much differently, choosing not to absorb capitalist influences from the economic environment.
She would read the ‘Western feminist constructions of the body as property as mirroring capitalist, patriarchal interests’.

This view is enabled by a code that translates economic impulses from the environment into the understanding that the sale of reproductive materials is a step towards the diminishing of the body into ‘a reproductive factory’. A woman such as this would not peruse online donor lists of sperm, categorised by race, ethnicity, and level of education, because the world that these qualities inhabit is not hers. Coding the body is a semantic project that can only be undertaken within specific social contexts. The semantics involved in the reproductive process itself have been theorised as inherently a product of patriarchal forces according to many feminists. Lisa Jean Moore has expressed this view, with reference to the reproductive process in children’s books that perpetuate social norms for courtship and dating.

The meanings that embed reproductive materials inevitably lead them to become personified, allowing consumers of these to search for the ‘right’ materials for them, i.e., ones that fit their lifestyles, tastes, and sometimes prejudices. As Moore and Schmidt have noted:

Compatibility and socially desirable properties such as evidence of upward mobility, intelligence, and social integration are portrayed as important in choosing the right semen. Efforts are clearly made to convince the woman that she is choosing a man rather than wriggly little cells. Sperm may be disembodied, but they are vividly personified.

The construction of categories then, lends something tangible to the personification of these materials, allowing patients to recognise them as simultaneously standard and unique.

Every reproductive tissue service will offer information pertaining to the race of their materials. These are classified in similar ways by the banks themselves, and are often based on the self-reporting of individuals prior to donation. In terms of the racial embeddedness of these materials, it seems obvious that racial classifications are constructed based on a variety of social discourses. Above all, these banks are perpetuating what Melbourne Tapper has described as outdated anthropological beliefs in racial markers through ‘physiognomy (what does the patient look like?) and genealogy (who are his or her ancestors, and where did they come from?). Categories are confusing, as well as confused, both blurring and separating lines between race, ethnicity, and religion for the purposes of classification. More often than not, these categories permit concepts of racial purity and impurity.
Physiognomy plays a huge part in semen exchange, most notably due to the recipients desire to have a child appear as though it is most ‘naturally’ theirs. Religion, too, has come to play a part in the social infusion of semen, - a product of the patients need to create a child that most closely related to themselves. However, religion was not always considered a marker of ‘good’ sperm. For example, in May, 1975 the Ninth Report of the Royal Commission of Family and Children’s Law: Artificial Insemination put forth a model agreement form for donor use, of which one of the statements is ‘I understand that no consideration will be given to the religion of either the donor or the recipient.’

Sperm donor lists display how these can become problematic markers for genetic speculation, and how individuals might be ‘squeezed’ into categories for the sake of categorisation, and nothing more. One cannot help but wonder how accurate genealogical knowledge is overall. Again, as Tapper points out, racial purity is being constructed that simply does not innately exist. Clearly, this form of categorisation aims for user-friendly donor selection, resulting in various social implications for the donor. Inevitably, the invisibility of this procedure is what makes it work. The fact that racial categories are so finely classified with sub-categories of ethnicity insinuates that racial ‘purity’ can somehow be determined and managed through the careful selection of materials. While the gayspermbank.com does not list any African American Donors at this time, they do stress the fact that they are ‘especially interested in finding African American and Jewish Donors’ considering this kind of plea, one has to wonder how much lineage exactly would constitute African Americaness, as well as how exactly Jewishness gets passed through genes. While someone who is of a certain faith might want a spiritual connection to his or her offspring, it is extremely interesting that religiosity is implemented as a category in this way. The especially intriguing thing here is the way in which the categories of race and ethnicity for ‘Caucasian’ are used. It seems that again, this is in line with what Tapper would call ‘informed by the discourse of ‘racial’ distinctiveness and purity which dominated medico-anthropological thinking in the late nineteenth and earlier twentieth centuries.’

Also typically listed are categories for education and sexual orientation. Interestingly, one donor list with especially delineated categories was taken from a gay sperm bank. This demographic is not typically accounted for by most fertility centres, and specifically offers more gay and bisexual donors than heterosexual ones, customizing a unit of frozen semen enough for potential consumers of this service to feel comfortable with the person that they choose to procreate with. A category for sexual orientation is often not included in the marketing of sperm to infertile heterosexual couples. When it is, heterosexuality is all too often
clearly implied as what can be thought of as marketable. By engaging in this kind of embedded personalisation to the marketing process, banks are able to narrow in on new markets for their services as the materials are semantically transformed, then ironically observed through an aperspectival objectivity that ‘opposed the subjectivity of individual idiosyncrasies, which substituted for the individual interests and ‘situations’ analysed by the eighteenth century moral perspectivists.’\textsuperscript{35} All this ‘for the collective - if not for the collective good, at least for the collective comprehension.’\textsuperscript{36} Sperm banks market collective standards, based on presumably common interests, however these standards are not averages at all, but situated ideal types.

It is obvious that sperm and eggs are objects discursively transformed into categories enabling the efficient management of genetic risk. All kinds of social worlds construct different kinds of risk and deal with these accordingly, but how do these discursive meanings lead to understandings of desirable and undesirable reproductive tissue? Geoffrey C. Bowker and Susan Leigh Star assert that:

> Assigning things, people, or their actions to categories is a ubiquitous part of work in the modern, bureaucratic state. Categories in this sense arise from work and other kinds of organised activity, including the conflicts over meaning that occur when multiple groups fight over the nature of a classification system and its categories.\textsuperscript{37}

Materials are literally transformed for the process of categorisation. Sperm is washed, suspended, and screened, eggs are multiplied, retrieved and frozen before they age. A hierarchy of technologically produced, risk-free products is then produced and marketed as such. The extent to which sperm donors are asked to fit criteria in order to meet standards of good health is often indeterminate. Interestingly, the first criterion might be ambiguous enough to require the donor to be in general good health. Also of importance might be the social, rather than medical requirement that the donor ‘practice safe sex’. By listing these requirements together with other indicators like having no genetic family diseases, the lines between sperm as object and sperm as socially acceptable mating tissue are blurred.\textsuperscript{38}

New technologies increasingly provide the patient with additional dimensions of standardisation that would not have otherwise been imagined. These new dimensions include both the physical and social manipulation of seminal fluid in order to carefully construct reproductive possibilities. Once introduced and consensually accepted, procedural standards are often repeatedly expected. Rayna Rapp refers to the rise of amniocentesis and observes that while choices are mostly increased through the introduction of new technologies, they are often not without hard decisions or social
consequences. Lord Kilbrandon, a British Legal authority, had referred to semen donor testing in 1973, acknowledging ‘most of us when we get married take our chances on genetic history.’ There is conceivably more room for error when nature is involved in reproduction, but science is expected to yield predictable results, hence expectations for semen are inevitably higher when it arrives from a lab rather than directly from a body. It is clear that the increased standardisation and categorisation of these materials leads the consumer/patient to perceive these new risks to a greater extent. Ironically, the consumer/patient would not know about the realm of genetic risks to manage if not confronted with them in this way.

I have focused on some of the social and cultural constructions that have enabled the online exchange of sperm to paradoxically sell the social through the re-creation of semen as a standard, categorised unit, rendering it a constructed object. More specifically, I have explored the social meanings which infuse these materials and enable categorisations. Sperm and eggs, as reproductive commodities, are not simply biological materials, universally meaningful on their own, but rather, they are socially and politically infused with meaning, categorised, and standardised with the end result being a site from which we are able to construct a viable social image through the codes that are used in the process. Meanings of healthy semen vary within the worlds in which they are created. From sexual practices to race and beauty, the health of a donor is embedded in the language that is used to classify reproductive tissue. This language is linked to social and political discourses, by which semen both forms and is formed by the social on a consistent basis. Desirability references for semen recipients and donors are derived through social, rather than medical criteria. All understandings of health in this way are reflexively created through the classification, standardisation, and objectification of semen. When sperm banks create delineated social categories of sperm out of seemingly similar reproductive materials, a temporally situated classification system surfaces, in this case, within a paradigm of convenient online consumption.

Notes

1 Health and Welfare Canada, 1981.
2 The AHR Act was passed on March 29th 2004, and came into effect the following month. While the act makes it clear that Canadians are prohibited to sell their reproductive materials, it is also clear that the Canadian government does not intend to hinder Canadians from receiving assisted reproduction. The government intends to move towards a system of ‘altruistic donation’, where ideally sperm banks would consist of donors without financial motivation. In the meantime, Canadians are not permitted
to sell their reproductive capital but they are free to browse the world market and import sperm from other countries.
3 Richardson et al., 1980, 150. The often considerable distance between a woman’s domicile and the fertility center was seen as an obstacle to overcome for early fertility treatments.
5 I owe the distinction that I make here between physically standardizing semen in terms of motility, units, washing, etc., and socially standardizing it in terms of markers such as race, beauty, and intelligence to Thomas Schlich.
8 Moore and Schmidt, 1999, 334.
13 Ibid., 167.
14 For a more detailed list of the kind of donor standards available, including serological screening, genetic testing, sexually transmitted disease testing, and freeze-thaw recovery rates visit: www.nwcryobank.com/donor_standards.html.
18 Martin, 488.
19 Ibid., 492.
22 Moore and Schmidt, 1999, 333.
25 Ibid.
26 Ibid.
27 Moore and Schmidt, 1999., 343.
29 Creighton, 1977, 66.
30 See www.gayspermbank.com/donorlist.htm, for an example of this kind of confusion. See the category racial category ‘Latino’, with ethnicity listed as ‘Mexican/Lebanese’ at: at Rainbow Flag Health Services
www.gayspermbank.com/donorlist.htm, for an example of this kind of confusion.
31 Ibid. See the category ‘Education.’
32 Ibid.
33 Tapper, 1999, 59.
34 Ibid.
36 Daston, 1992, 613.
38 www.gayspermbank.com/donorlist.htm. See ‘What are some of the requirements to be a donor?’
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Alcoholism: Correction and the Changing Notions of Recovery

Donavan Rocher

Abstract

Consuming alcoholic beverages is a common practice in Western societies and is routinely associated with leisure time. At the same time, frequent excessive consumption, otherwise known as alcoholism, is most commonly described in popular discourses as being a disease. The ‘loss of control’ typified by the alcoholic with respect to drinking is described as being symptomatic of an ‘alcoholic identity’. These ideas are informed by the organisation of Alcoholics Anonymous and the considerable influence that this organisation has had on health care professionals and the institutions that work with individuals that are believed to suffer from this dependency. With respect to alcoholism, popular discourses of this ‘disorder of desire’ are presently shifting in Western societies due to recent scientific research and theory. Nikolas Rose argues that these new discourses of alcoholism describe it as a disorder requiring ‘correction’ for genetic errors, rather than being a symptom of a deviant identity or, in the terms of Marianna Valverde, a ‘disease of the will’. This presentation will explore and support Rose’s argument by illustrating how contemporary scientific discourses about alcoholism are entering into popular discourses. By examining self-help literature, it is possible to trace the emergence of new medical theories and regimes of treatment for alcoholism as they begin to appear in popular culture. This chapter will specifically examine the books: The Sober Kitchen: Recipes and Advice for a Lifetime of Sobriety, The Craving Brain - A Bold New Approach to Breaking Free from: Drug Addiction, Overeating, Alcoholism and Gambling and The Serotonin Solution. By exploring these texts, the intersections between the successful popularisation of the serotonin hypothesis of depression and prescribed anti-depressants and current theories about alcoholism will be analysed. Similarly to depression, alcoholism is now being theorised in terms of malfunctions in the neurotransmitter system.

Key Words: Alcoholism, correction, recovery, therapy, self-help.

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The discourses of the new public health have shifted many of the responsibilities of the state to the individual. For example, this shift becomes apparent in the new campaigns for prevention of certain medical conditions in which the public is informed about what lifestyle changes may be made in order to either prevent or reduce one’s risk. In this manner, the strategy of
public health campaigns is to position the individual as being capable and having the rationality to operate in a fashion that will ensure one’s health. Discourses such as these are rarely challenged in today’s society since they promote the idea of the autonomous individual - an ideal that is also extolled through most social and cultural institutions in North American society.¹

1. **Responsibilisation of the Individual**

The mid-1970s may be viewed as the beginnings of the term ‘lifestyle’. During this time period, academic and professional writing began to focus on aspects of ‘lifestyle’ that were instrumental to poor health. The opinion that ‘lifestyles’ such as: being sedentary, eating poorly, etc. caused individuals to fall ill, resulted in the creation of a multitude of educational projects that aimed to inform people that it is possible to avoid illness if they modified certain behaviours.

This idea of ‘lifestyle theory’ is the basis for the emergence of the concept of the ‘entrepreneurial self’.² This self has come into existence as welfare interventionism has decreased and the ‘markets’ as the regulators of economic activity have been normalised. In this manner, this self is ‘the product and target of ‘neo-liberal’ forms of rule that employ technologies for ‘governing at a distance’ by seeking to create localities, entities and persons able to operate a regulated freedom.’³ With the rise of ‘neo-liberalism’, the citizen is now faced with a multitude of discourses about his/her individual responsibilities and obligations in order to remain a ‘healthy’ citizen. This new ‘will to health’ is increasingly ‘capitalised by enterprises ranging from the pharmaceutical companies to food retailers.’⁴ Moreover, the ‘will to health’ has been extended in present day society to include the maximisation of an individual’s corporeality with respect to ‘a kind of overall ‘well-being’ - beauty, success, happiness, sexuality and much more. It was this enlarged will to health that was amplified and instrumentalised by new strategies of advertising and marketing in the rapidly developing consumer market for health.’⁵

2. **The Molecular Gaze**

The molecularisation of biology is a profound event that has had numerous ramifications and is implicated in projects that are attempting to understand the ‘code of life’, DNA. This scientific change in focus that has occurred in the past three decades has shifted attention towards the molecular level, and in order to study life at this level, complex and expensive equipment is necessary. Since most of the research in the life sciences today is conducted in labs that are funded by pharmaceutical companies and biotech enterprises, profit becomes the primary motivation for continuing research and development of knowledge. This motivation does impact upon
the direction of research and influences the theoretical framework for the
development of knowledge in the life sciences.

With the scientific gaze at the molecular level, all life processes
appear to have the possibility of being studied and replicated in the lab
whereby these processes may be engineered and re-engineered in order to
understand the chain of events that formed them. One example of this would
be in biological psychiatry in which mental illness and mental health are
being revamped by the ability to now view molecular images of the mind and
the creation of drugs that are specifically manufactured to target and modify
molecular reactions in neurones and synapses. Theoretically, it is now
assumed that in most and maybe all cases, it may become possible to identify
biological risks. Medical interventions at the molecular level will then be able
to treat these potential medical conditions.6

Now, how does this relate to alcoholism? Contemporary psychiatry
is enthralled with the new developments in neuroscience that explain
variations in mood, cognitive state, affective reflexes and behaviour in terms
of anomalies in the brain - specifically malfunctions in the neurotransmitter
system. One example of this is the condition of depression that may be
diagnosed as the result of an anomaly in ‘just one of the many subtypes of
one of the seven sub-families of receptors for the neurotransmitter
serotonin.’7 As a further stage in this molecularisation, the new genomics
‘seeks the precise polymorphism in a particular sequence of bases in a locus
in a particular gene that is correlated with a precise type of disorder of
thought, emotion, or conduct’.8 This further stage in molecularisation has
resulted in a shift in the way a ‘disease’ such as alcoholism is conceptualised:
alcoholism is now discussed in terms of a ‘disease’ of the brain, rather
than and no longer as a ‘disease of the will’.9 One example of a new
treatment for alcoholism (or as termed in the DSM IV - alcohol dependency)
is the use of Naltrexone. This new class of drugs is particularly of interest
since it operates differently from past treatments for alcohol dependency,
such as Antabuse. They act on the craving for a drink rather than making the
drinker feel sick after consuming alcohol:

[In this new] ‘neurochemical’ account of personhood,
psychiatry no longer distinguishes between organic and
functional disorders. It no longer concerns itself with the
mind or the psyche. Mind is simply what the body, what
the brain, does. And mental pathology is simply the
behavioural consequence of an identifiable, and potentially
correctable, error or anomaly in some aspect of the brain, in
its neurotransmitters or receptors.10
These new developments in research with respect to alcoholism demonstrate a fundamental shift in psychiatry and inherently advocate that they have finally overcome the Cartesian dualism of body and soul.

3. Popular Discourses of Alcoholism and Brain Chemistry in Self-Help Books

Self-help literature is a resource utilised by individuals in order to understand topics that generally affect them in their own personal lives and/or the people that surround them. In addition, the latest scientific research about the specific topic being investigated is included in an accessible manner that is accessible for a lay person. Generally, new books also receive a great deal of media fanfare and if they become successful, their contents begin to be reflected in public consciousness. The first case study in this analysis depicts the emerging popularisation of the neurotransmitter understandings of the brain examined is *The Serotonin Solution*, by Judith J Wurtman, published in 1996. Wurtman discusses how carbohydrates operate within the human body and explains their importance in the production of serotonin. In addition, she describes how serotonin operates like a stress-management system. She claims it:

soothes our emotional turmoil and, by doing so, stops the urge to binge. Eating carbohydrates is the only way to boost serotonin levels in the brain - because even if serotonin could be put in a pill and swallowed, it cannot get into the brain from the bloodstream. For this reason carbohydrates are considered a ‘psychoactive’ food. When they are eaten in the correct ‘dose’ and without other foods that might interfere with their effect, they have the power to bring about substantial changes in our mood. 11

This self-help book is intended for an audience that suffers from binge eating, specifically addressing stay at home parents, pre-menstrual women and ex-smokers. In particular, this self-help text informs the reader of the connection between eating carbohydrates, the production of serotonin and the resulting changes in individual mood and/or behaviour. Moreover, it is imperative to highlight that the serotonin hypothesis and depression had already begun infiltrating the public consciousness through the best selling books of previous years - Peter Kramer's *Listening to Prozac* and Elizabeth Wurtzel's *Prozac Nation*. The next text examined incorporates many of the recent developments in scientific research with respect to theories about addiction, entitled *The Craving Brain - A Bold New Approach to Breaking Free from*
Drug Addiction, Overeating, Alcoholism and Gambling, written by Ronald Ruden. Ruden describes how the neurotransmitters dopamine and serotonin are involved in cravings. Ruden states that:

If dopamine is the ‘gotta have it’, serotonin is the ‘got it.’ It is the rising dopamine that motivates us to action, and it is the attainment, the full belly, the safe place, the completed sexual act that raises serotonin. The brain is in a high dopamine and high serotonin state. Contentment floods our being. We feel safe, satisfied, and secure. The craving is gone. The ability of our brain to motivate behaviour is gone. We call this a biobalanced state.\footnote{12}

This explanation of the mechanisms behind addiction in the brain is very simplistic, however, it is accessible for individuals who are not educated in the life sciences and offers a basic understanding of the neurotransmitter system.

In addition to providing a basic understanding of the neurotransmitter system, Ruden discusses the recent research into naltrexone. Although he does not elaborate on the possibilities of treatment that naltrexone may offer as knowledge about this drug expands, he does note that ‘by reducing the euphoria of alcohol and dampening the craving for another drink, it helps patients feel better and encourages them to remain abstinent.’\footnote{13}

Moreover, Ruden does articulate that the advances in psychopharmacology are exciting. However, he stresses that scientific advances in theory do not always translate into practice with the anticipated results.

The philosophy of Alcoholics Anonymous (A.A.) with respect to alcoholism,\footnote{14} and the theory that alcoholism is a disease, have had a tremendous influence upon medical discourses during the twentieth century. For example, the majority of rehabilitation centres for individuals who suffer from drug and alcohol dependence in North America offer programs that are based on many of the tenets of A.A. Furthermore, as stated by Barry Stimmel, ‘almost everyone involved in treating alcoholism now considers it a disease’. This includes groups such as the American Medical Association, the American Psychological Association, the American Psychiatric Association, the American Society of Addiction Medicine, and the World Health Organization.\footnote{15} The first step of the program of A.A. is: ‘We admitted we were powerless over alcohol - that our lives had become unmanageable.’\footnote{16} Therefore, alcoholics by definition are and will always be powerless over alcohol. In this sense, A.A. challenges the tenets of the discourses of the entrepreneurial self. A.A. members instead concentrate on trying to achieve inner peace and remaking their souls through the ethical techniques described above.\footnote{17}
It is also important to note that many of the individuals who suffer from alcohol dependence may not choose to become members of A.A. This is seen in Barry Stimmel’s research when he states that ‘the dropout rate can be high. In one study of people who attended an A.A. meeting one month after being discharged from a detoxification unit, only 11 percent were still participating a year later. In other studies, 68% dropped out before the tenth meeting. But of those who attended regularly, an estimated 26% to 50% remain abstinent after one year.’

For many individuals the support that may be offered through organisations such as A.A. may not be viewed as a viable option. Part of this reason might be that the logic of A.A. is unfamiliar to individuals due to their socialisation in liberal societies that praise the values of autonomy, independence and choice.

Since naltrexone has been FDA approved, new programs have been developed that include a combination of naltrexone and cognitive therapy. Although such programs are very recent and the long-term effectiveness of these new treatment approaches are still to be determined by future research, these programs are noteworthy in terms of how alcoholic identity may be reconfigured by these innovations in practice. These new treatment strategies do offer individuals a sense of autonomy and choice (a familiar way of operating in a contemporary liberal society) in terms of choosing to undergo a regime of treatment rather than give one’s will to a higher power and completely abstain from imbuing alcohol.

Liz Scott’s The Sober Kitchen is touted as being the first book on alcoholism and nutrition. She describes the importance of proper nutrition specifically in initial recovery when individuals who suffer from alcohol dependence are likely to be malnourished and the difficulties of adjusting to a life in sobriety can be eased by nourishing the body and ensuring that depleted vitamin and mineral reserves are replenished. Scott explicates how previous books offered very little if any nutrition advice for the vast majority of those in recovery. Moreover, Scott articulates her belief that scientific research will be useful in the development of innovative approaches in the treatment of alcohol and drug dependencies. This is evident when she states that:

We are now lucky to live at a time when it is possible to explore the human body and mind in vast technological detail, particularly with advanced tools that allow us to witness neurochemical activity as it happens…As studies continue and results are analysed, the connection between brain chemistry, addiction, genetics, and behaviour will thankfully be much better understood, paving the way for better treatment and ultimate prevention.
Similarly to the previous self-help books examined, she discusses the neurotransmitters dopamine and serotonin. For example, she describes how ‘by drastically reducing the amount of carbohydrates they eat during early recovery, some people report an increase in alcohol craving. I have heard this over and over from recovering alcoholics who, in an attempt to fix everything at once, diet early on and experiment with extremely low-carbohydrate eating plans.’

Scott does address the recent development of using naltrexone for treatment of alcoholism but only discusses the use of this drug with respect to individuals who require morphine for medical purposes. She describes the recent studies that ‘have shown that if Naltrexone, the FDA-approved drug that blocks parts of the opioid-reward pathway and has been successful in reducing craving in some abstinent alcoholics, is administered with morphine for pain, the patient is less likely to become dependent.’ It may be assumed that since her entire book is about abstaining from consuming any amount of alcohol during recovery that she would not discuss naltrexone treatment programs and the possibilities of new treatment strategies with respect to alcoholism. Such a discussion would be controversial due to the stance of A.A. members, audience members that she does not wish to isolate. However, this inclusion of recent scientific research does illustrate the strong influence of scientific discourses.

In terms of recovery from alcoholism, recent studies indicate that much of the damage due to active drinking is reversible and new techniques in recovery may be possible in the future. This may explain why many alcoholics say that after several years of abstinence, it somehow ‘feels easier’ to stay sober. Dr. Nancy C. Andreasen, in *Brave New Brain*, suggests that tracking our brain improvement through the use of imaging techniques could serve as a powerful motivator to remain abstinent. The possibility that future treatment strategies may include imaging techniques is encouraging and may also be useful in the development of new psychopharmacological therapies in alcoholism. Moreover, these developments will certainly be utilised in the theoretical framing of scientific discourses about the logic of ‘correction’ for neurochemical reactions in the brain, and aid in the successful marketing of these ideas to an awaiting populace.

4. Conclusion

In conclusion, this essay attempts to summarise how scientific developments in the study of alcoholism are entering into the popular discourses in contemporary society. Recent scientific developments are impacting upon current understanding of alcoholism and as Nikolas Rose has argued, shifts in thinking with respect to this condition are beginning to influence possible treatment strategies. I would like to suggest that the work
of Liz Scott is the beginning of a new market phenomenon in which diets, food products and behaviour modifying procedures will soon be sold and utilised for ‘persons in recovery’. As Judith Wurtman describes in her text, food products or ‘nutraceuticals’ that are able to not only nourish the body but also enhance certain chemical processes in the brain. These products have become available in supermarkets and health food stores (for example nutritional bars that state they boost memory, water that contains vitamins and minerals). I would venture to guess that ‘nutraceuticals’ for ‘persons in recovery’ will soon be hitting the grocery shelves, and books describing the ways that individuals may make ‘corrections’ to their brain chemistry by monitoring and adjusting for the levels of certain neurotransmitters in order to arrest cravings will be published in the near future. These types of products will be very profitable and the scientific research and development required to create them is most likely already occurring. In addition, the knowledge that has been produced from this scientific research is already influencing how alcoholism is now perceived - as an imbalance in the neurochemical structure of the brain rather than a ‘disease of the will’ and the treatment options of pharmaceutical regimes will be available in the near future as they are already being tested in rehabilitation centres in North America.

Notes

1 Lupton and Petersen, 1997, 175.
2 Lupton, 1995, xii.
3 Ibid., xii.
4 Rose, 2001, 16.
5 Ibid., 18.
6 Ibid., 21.
8 Ibid., 410.
9 In Diseases of the Will: Alcohol and the Dilemmas of Freedom, Mariana Valverde develops a socio-historical analysis that describes alcoholism as being a ‘disease of the will’. She argues that the genealogy of alcoholism should be traced back to the early studies of J.E.D. Esquirol and his collaborators. She states: ‘J.E.D. Esquirol and his collaborators were interested in pursuing studies of that grey area between madness and reason conceptualized in the early nineteenth century as partial insanity. ‘Monomania’ was the main term employed in France, and to some extent elsewhere, to initially map and occupy that liminal zone. In the English-speaking world, a similar move was effected through the category of moral insanity.’ Valverde, 1998, 45.
Valverde describes how the ideas about alcoholism in A.A. have influenced medical discourses such as the work of E. M. Jellinek. She specifically notes: ‘What is perhaps the most famous text in the history of alcoholism in English-speaking countries, E.M Jellinek’s 1960 *The Disease Concept of Alcoholism* (still widely cited today), has a number of different ways of defining alcoholism, but the main criterion distinguishing those people who drink heavily but are not ‘addicted’ from those who are truly diseased is that the latter group suffers from ‘loss of control’. Jellinek states that there are several types of alcoholics who drink as much as the worst addict, even to the point of suffering from cirrhosis of the liver; but they drink because they want to, not because they feel compelled to do so. Since they do not suffer from ‘loss of control’: they are therefore not diseased, even though they are alcoholic.’ Valverde, 1998, 25.

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PART VI

Ethics, Autonomy, Justice and Rights
On My Own: Where Autonomy Ends and Justice Begins

Alison Roberts Miculan and Lisa Schwartz

Abstract
It is an interesting irony that the Hippocratic Oath does not contain the words ‘First Do No Harm’, yet it remains the most commonly ‘cited’ phrase from the oath. Perhaps this is because physicians, in fact do harm all the time. They cut into the body, administer foreign elements, poke, prod and otherwise intrude. But all of this is justified by the fact that the physicians’ ‘harms’ are sought out by autonomous agents, and by the greater good of health that these harms are intended to procure. Indeed, the intention behind most of the treatment is assumed to be restoring autonomy to the recipient. Autonomy, then, is fundamental to the ethics of healthcare provision. This move is well intended but flawed because it places the burden of complex decision-making on the individual seeking help and implies that her choices will be exclusively self-regarding with limited relevance to the impact of the decision on others and the impact of others on the decision. Individuals are thus being asked to act autonomously when they are at their most vulnerable and in the face of highly complex information. Moreover it is assumed that the individual is able to act voluntarily, rationally and free from social necessities such as responsibilities to loved ones and colleagues, or economic and social pressures. We maintain that even a relational-autonomy model does not go far enough in reflecting the complexity of the patient’s context and that a social-justice model would be more appropriate. We also maintain that the multi-faceted obligations of healthcare providers not only to individual patients, but broader communities requires the expanded perspective that a social justice model would facilitate. Certainly the most serious concern with a social-justice model may be that patient autonomy will be compromised in favour of an overarching social good, but we argue that, by including a comprehensive notion of rights, individuals can be protected from the tyranny of the majority.

Key Words: Health ethics, autonomy, justice, Hippocratic Oath, healthcare provision.

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I will keep them from harm and injustice.
The Hippocratic Oath

It is an interesting irony that the Hippocratic Oath does not contain the words ‘First Do No Harm’, yet it remains the most commonly ‘cited’
phrase from the oath. Though the classical version of the oath does embrace a similar sentiment, these words never appear. Perhaps this is because physicians, by the very nature of their occupation, in fact DO harm all the time. They cut into the body, administer foreign elements, poke, prod and otherwise intrude. But all of this is justified, of course, by the ‘greater good’ of health that these harms are intended to procure, and, by the fact that the physician’s ‘harms’ are sought out by autonomous agents needing care. Indeed, the intention behind most of the treatment is often said to be to enhance and restore autonomy to the recipient of treatment. Autonomy, then, is fundamental to the ethics of healthcare provision, in terms of its aim as well as to grant authorisation. Without it, the actions of the physician would constitute assault. But should autonomy be the only, or even the dominant value governing the ethics of healthcare? The translation of the Hippocratic Oath quoted above indicates that justice is another principle prevalent in health ethics, and one which we will argue can accommodate respect for autonomy in a more realistic manner.

1. Autonomy

Traditional approaches to ethics in health care education draw their theoretical foundations from Principlism first described by Beauchamp and Childress in the early 1980s. This approach nominated four moral principles that the authors took to be the guiding principles for ethics in health care. They argued that attention to these four guiding principles would lead decision makers faced by ethical dilemmas to making the right choice in any given situation. Since its first publication, The Principles of Biomedical Ethics has withstood many critiques. Despite this it is embraced by most health professionals and has defined the language of health ethics dialogue. Most health care practitioners, and even some patients, freely use its terms for the principles of autonomy, beneficence, non-malfeasance and justice. These four principles have engendered policy and theory of patient centred care, especially in North America and the UK where autonomy is arguably the defining principle of patient-centred health care provision.

Autonomy has historical origins in political theory of governance of states. Early modern conceptions, influenced mainly by Immanuel Kant, introduced autonomy as a personal trait. Under this understanding, autonomy is seen as relational but only as it pertains to freedom from others and a capacity for independent decision-making. Sherwin among others have demonstrated how this conception of autonomy is flawed and why it has been criticized. To clarify, Kant claimed autonomy was an essential criterion for moral action. Without it actions would not be voluntary or intentional but overly influenced by directives or the will of others. As a result of this external influence we would be prevented from assigning individual praise or blame in a meaningful way. As Ranaan Gillon states, ‘...autonomy - the
ability and tendency to think for oneself, to make decisions for oneself about the way one wishes to lead one’s life… is what makes morality, any sort of morality, possible.’ This is how we separate ‘autonomous choice from mere choice.’ However, independence taken to an extreme can be cast as atomistic, and even self-centred or selfish.

The most significant contribution this understanding of autonomy offers is protection from the tyranny of others or of the majority. Autonomy so conceived protects liberty and the freedom of self-determination. This vision of the concept has been enthusiastically appropriated in health ethics as a response to medical paternalism. It is meant to move the locus of decision-making in care from the doctor to the patient and protect patient freedom to act autonomously by seeking informed consent for health related interventions.

This is well-intentioned but flawed because it places the burden of complex decision-making on the individual seeking help and implies that her choices will be exclusively self-regarding with limited relevance to the impact of the decision on others. It is no surprise then that the classical Kantian image of patient autonomy is one which has been criticized for its limited correspondence to the realities of individual experience. The clearest example of respect for individual autonomy is informed consent, a process all health practitioners struggle to enact daily. Anecdotally, health professionals describe feeling uncertain about whether and to what degree the information they have provided to patients has been understood. They also express concern about the degree to which the person they seek consent from is acting autonomously. Is the patient too vulnerable in the state of ill health to give adequate consent? Is the patient responding to subtle coercions by the health team or family members or wider social pressures limiting the voluntary choice of the patient?

Individuals are thus being asked to act autonomously in the form of giving informed consent just as they are at their most vulnerable and in the face of highly complex information. Moreover, it is assumed that the individual is able to act voluntarily, rationally and free from social necessities such as responsibilities to loved ones and colleagues, or economic and social pressures, to name a few. Moreover, epidemiology and social studies of health portray the patient as not existing in isolation and without context. Rather new conceptions of the study of health show health to be causally defined by the social and economic context in which we live. Numerous factors impact on health. Many of these are not biological, but a good proportion is outside the realm of what is traditionally considered to be part of medical practice. We cannot overlook how socio-economic factors determine the health of individuals and populations. All of these concerns reflect a post-Kantian, feminist conception of autonomy that arguably better accommodates the realities within which individuals make choices.
2. **Autonomy and Relational Autonomy**

In her article ‘A Relational Approach to Autonomy in Health Care’, Susan Sherwin points out that there are a number of criteria we have traditionally considered to be necessary conditions of autonomy:

1) **Rationality**: the autonomous agent must be capable of understanding and assessing options.

2) **Reasonableness**: the autonomous agent must be capable of determining his/her own interests and the interests of others.

3) **Information**: the autonomous agent must have sufficient information to make a decision.

4) **Freedom from Coercion**: the autonomous agent must not be forced through threat or reward into making an unwanted decision.

Sherwin argues, however, that the criteria associated with autonomy are embedded in a notion of individualism that she finds unsatisfactory. Perhaps the most obvious of these is that the autonomy model makes assumptions about the decision-maker that may or may not be true, for instance that they are intelligent, not coerced, practiced decision-makers. She describes this position as ‘not only false but impoverished’. She also argues that a strict autonomy model engages with an ideal moral environment that probably never exists, namely, that there are no financial, legal, social, political or practical constraints that may interfere with the autonomous decision of individuals. This can create a context in which false or partial autonomy can prevent genuine autonomy, giving individuals the impression that they are free to make choices that they really are not free to make at all (or at least, they are free to make these choices with consequences far wider and complex than the straightforward consequences of their actions).

A striking feature of most bioethical discussion about patient autonomy is their exclusive focus on individual patients; this pattern mirrors medicine’s consistent tendency to approach illness as primarily a problem of particular patients. Similar problems are associated with each discipline. Within the medical tradition, suffering is located and addressed in the individuals who experience it rather than in the social arrangements that may be responsible for causing the problem. Instead of exploring the cultural context that tolerates and even supports practices such as war, pollution, sexual violence, and systemic unemployment - practices that contribute to much
of the illness that occupies modern medicine - physicians generally respond to the symptoms troubling particular patients in isolation from the context that produces these conditions.  

The other problem Sherwin identifies with the autonomy model is that it prioritizes autonomy over all other moral values such as justice, and there is no justification for retaining this notion of primacy and, in fact, there may be some very good reasons for rejecting it.

For these reasons, then, Sherwin adds the following criteria to the autonomy model, to create a ‘Relational Autonomy Model’:

4a) Freedom from Oppression: as a special category of Freedom from Coercion, Sherwin maintains we need to add Freedom from Oppression since some oppressive conditions can conceal the fact that coercion that is taking place.

5) Autonomy-Skills: Sherwin claims that the skills required for autonomous decision-making (assertiveness, clarity of expression, etc.) cannot be assumed and may need to be developed.

6) Structural conditions: though these are covered indirectly by other categories, Sherwin insists on the importance of understanding that certain structural conditions (economic conditions, educational conditions, conditions of conflict, etc.) can be barriers to autonomous decision-making.

6a) Opportunity: Sherwin also insists that the opportunities for structural conditions to be met must also be taken into account. People may need encouragement for autonomous decision-making. They need ‘the experience of being respected’.

Sherwin maintains that there are a number of advantages to her relational-autonomy model, specifically:

1) Decision-making is seen as a transformative process - rather than a static or final activity.

2) Relational-autonomy, as opposed to individual autonomy, clarifies the relation between social location and autonomy, thus clarifying what may (or may not) be adequate condition for autonomous decision-making.

3) The range of ethical responsibility extends beyond the individual to society and public policy at large.
4) Relational autonomy highlights, rather than obscures the wider social and material scope of ethical relationships.
5) Relational autonomy helps those in positions of power to examine their own biases, and to work at eliminating those biases.11

3. Rationale for a Social Justice Model of Health Ethics
While we agree wholeheartedly with Sherwin’s criticisms of the autonomy model, we maintain that her relational-autonomy model does not go far enough in overcoming the difficulties she has described and that a social-justice model would be more appropriate. Freedom from Oppression, as primarily (though not exclusively) social and structural, for instance, would be far more viable in a Social Justice model that highlights the power relationships of individuals and organisations than in an autonomy model (even a relational-autonomy model) where the focus on one individual and her relationships is central. Also, the appropriate structural opportunities and conditions for decision-making, identified by Sherwin, are most frequently socio-economic in nature and would be best facilitated under a Social Justice model. We also maintain that the multi-faceted obligations of healthcare providers, not only to individual patients but broader communities, require the expanded perspective that a social justice model would facilitate. The WHO definition of Health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ also supports a social-justice model for ethics in healthcare delivery.

Certainly the most serious concern with a Social Justice model may be that patient autonomy will be compromised in favour of an overarching social good, but this need not be the case. As members of a social environment themselves, the basic needs and interests of individual patients may, in fact, be more realistically and better served by taking their broader social environment into account. One of the factors that Sherwin’s model does not take into account is that oppressed people do not always recognise that they are being oppressed and a comprehensive account of fundamental human rights can compensate for this situation.12

Alison Miculan argues elsewhere that existence is a necessary condition for goodness. While this point appears initially trite, her next move is more significant. Miculan maintains that because existence requires a ‘will-to-exist’, human flourishing is necessary for existence, and, hence, goodness. That is, ethical behaviour requires the assurance of human flourishing, and, for Miculan, that engenders a fundamental human right, namely that no one ought to be placed in a position that makes non-existence more appealing than existence. It is a matter of social justice that each individual have fair access to the basic conditions that accompany human flourishing.
A central criticism about deposing the primacy of autonomy in favour of justice is that the values inherent in autonomy could be lost; specifically preserving the liberty of the individual even in the face of broader social goods. The most familiar way of protecting the individual from the tyranny of the majority is to appeal to the ideal of rights of individuals for protection. Social Justice frequently does incorporate the language of rights to do just that. However, the greatest concerns with respect to Social Justice models are invariably: Who gets to decide what constitutes ‘Social Justice’? How do you guarantee that your ‘Bill of Rights’ is truly equitable and representative of all? While we acknowledge that this kind of declaration must flow from a continuously evolving process, we do believe that we must do our very best to ensure human flourishing, and offer the following as a tentative starting place for a list of human rights. This list has been developed from a combination of Martha Nussbaum’s Capabilities Index; the United Nations ‘Universal Declaration of Human Rights’ and the ‘Canadian Charter of Rights and Freedoms’, as well as the authors’ experiences in clinical and cross-cultural settings:

All people should have the right to:

1. *Life* - Does this person value his/her life? Does s/he experience pleasure? Can anything be done to improve this person’s quality of life?
2. *Freedom from violence* - Has this person been subjected to any unnecessary harms, cruelty, humiliation or degradation?
3. *Emotional freedom* - Does this person have the freedom to think and feel towards others as s/he chooses? Does s/he have the opportunity for relationships with others?
4. *Freedom from discrimination* - Is this person being discriminated against on the basis of race, sex, sexual orientation, religion, caste, ethnicity, national origin, association, politics, language, property, wealth, mental ability, physical ability, age, birth or other status?
5. *Privacy* - Is this person’s right to privacy being maintained?
6. *Freedom of conscience/opinion* - Does this person have freedom of opinion, thought and expression? Does s/he have the opportunity to change his/her mind?

What a Social Justice model can offer, then, is a set of minimal standards that are necessary to human flourishing. It highlights, rather than obscures, power relationships that may compromise human flourishing, and seeks to prevent oppression under any of its various guises.
4. **Social Justice Assistance Tool for Decision-Making in Ethics**

While we acknowledge the limitations of all ‘tools’ of this kind, the intention of this model is to expand the context of ethical decision-making to more adequately reflect the ‘real’ contexts of people’s lives and to provide a ‘check-list’ of fundamental rights that we believe cannot be violated. We hope that it can facilitate some direction of thought in the decision-making process.

**Notes**

1. From the *Hippocratic Oath*, classical version, translation from the Greek by Edelstein, 1943.
7. Ibid., 34.
8. Ibid., 24-25.
9. Ibid., 75.
10. Ibid., 36-37.
11. Ibid., 42-44.
12. The resistance of women to the Women’s Suffrage movement is one of a multitude of examples of this phenomenon.

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The Production of Health and Illness in Discourses: The Case of the German Healthcare System

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Abstract
In this chapter I will discuss some aspects of the historical development of the German healthcare system. Focusing on the discursive production of ‘health’ and ‘illness’, I will ask how both concepts are institutionalised in the public healthcare insurance system. I will limit my discussion in this chapter to the constitution of the German social security system. As such, the chapter will provide a useful angle for understanding current healthcare reform debates in Germany. The German health insurance system was developed at a time fundamentally different from today. The strong historical link to accident insurance and thus the close connection to the working environment led to a concept of health which was based upon the ability to work. As a result, illness meant inability to work. With the invention of occupational risk and the acknowledgement of accidents as standard, illness became a fate to be accepted by the worker. However, this means that the right to illness is recognised only in relation to professional activity and recovery is seen in terms of the obligation to return to work. In short, the obligation of treatment is the reverse of the right to illness.

Key Words: Health, illness, social policy, healthcare insurance, discourse analysis, Germany.

1. Introduction
Welfare policy is usually seen as a response to functional needs or as the result of conflicts of interests. However, such views usually neglect the influence of discourses on policy. There is neither only one response to functional needs nor only one possible outcome of conflicts of interests. Welfare policy is also a result of the definition and interpretation of social problems. Welfare policy is never objective, being instead a social construct. Historical-comparative research supports this. Because the English defined the ‘social question’ differently, their approach to welfare policy by the end of the nineteenth century contrasts that of Germany. Instead of establishing a social security system like the German model, in England the government intensified employment safety regulation and improved ‘poor relief’.

This chapter is concerned with the historical and cultural context of employment and welfare policy. It will consider how the different discourses surrounding health determine the definition and interpretation of related
problems, and examine how such issues became integrated into social knowledge. In this chapter I will look at the constitution of the German health insurance system from a modern historical perspective. This will shed light on the constructed nature of our current understanding of ‘social security’.

2. Industrial Accidents and the Birth of the German Healthcare System

The German social security system is usually seen to originate from the health insurance law (Krankenversicherungsgesetz) of 1883. However, one must also consider that before 1883 a system of sick funds had already been in existence. The legislator had tried to regulate this system, which was inconsistent and organised on a regional level, with a low standard of benefits provided, and that for only a small part of the population. In today’s sense it was not modern. Therefore the question arises why at the end of the 19th century with the introduction of the healthcare insurance system, the system of sick funds was regulated on a national level and a compulsory coverage was introduced, but remained selective. One finds the answer in the political handling of industrial accidents.

3. The Political Handling of Industrial Accidents

In the course of industrialisation in Germany and other European countries, industrial accidents became an ever more urgent social problem. At that time they were the main cause of disability and subsequent poverty. The problem of industrial accidents had two dimensions: how could industrial accidents be prevented, and how, in the case of an accident and resulting illness, could compensation for the worker be provided? Germany, unlike other countries, neglected the protection of workers and the regulation of industrial relations, but tried to resolve the issue of compensation. The 1871 Liability Act (Reichshaftpflichtgesetz) provided corporate liability for accidents where the corporation was at fault. However, the worker had to prove the employer’s responsibility for the accident. Thus, the compensation had to be ensured via legal liability. If the employer was found responsible for the accident they had to compensate the worker.

In practice though, the Liability Act (Reichshaftpflichtgesetz) could not sufficiently solve the question of compensation, and was disapproved of by all parties involved. There were innumerable legal cases, compensation was rarely paid, and when it was the sums were so huge the workers could retire. The employers criticised the arbitrariness of the judges’ decisions. They argued that it was impossible to correlate guilt with specific levels of payment. They also criticised the legal process which demanded that workers had to prove the employer had not taken every possible precaution to prevent industrial accidents, as this practice meant that poor working conditions were
made public. Employers rejected the legal liability solution of industrial accidents for economic and political reasons. How could these problems be resolved? Two possibilities emerged: aggravation of the liability law and reversal of burden of proof, or the introduction of a general insurance for all accidents.

In fact, accidents cannot be compensated for because they are accidents. They can only be compensated for if one returns them symbolically into the human sphere of influence. In the case of the legal liability solution, this is achieved by assigning the employer a degree of power over both humans and machines. Employers were thus seen to be responsible for both working conditions and the behaviour of workers. The employer is therefore responsible for the prevention of industrial accidents, and consequently will be held accountable in case of such an accident occurring. This view corresponded with employers’ own views of themselves at that time.

4. Industrialisation and Occupational Risk

Industrialisation led to an accumulation of borderline cases of corporate responsibility, which could not be solved with existing liability logic. With industrial development, accidents which eluded the will of the employer or could not be traced back to any cause began to accumulate. The result was that workers remained without compensation or employers were unjustifiably held responsible. In short, the liability laws seemed at odds with industrial development even though such industrialisation seemed to benefit society at large.

In the long run these borderline cases led to an epistemological shift, the invention of ‘occupational risk’, which viewed industrial accidents and employers in a rather different way. The issue of profit became important. There were damages which workers, although not being at fault, simply had to suffer; indeed they were required to bear bravely those conditions of work which were obviously dangerous, even from the outset. The situation was unacceptable for those workers who fell victim to the increasingly dangerous conditions of industrial production from which others drew profits. Such profiteering at the expense of worker health seemed unacceptable.

This new conception of the world took leave from the question of guilt crucial to liability law. It therefore became necessary to create a new rule regarding compensation in the case of industrial accidents. This rule consisted in the mental separation of the fact of the accident and its cause. The allocation of the damage costs was organised independently of will and cause. Accidents were seen once again to be outside of the sphere of human influence, and the adjustment of damages changed from the objective principle of causality to purely social references which were thought of in terms of occupational risks. Thus, there were people sustaining the damages
of industrial development from which employers and society drew profit. Therefore, re-establishing the equilibrium between both had to be the task of the legislator. While the liability law covered the principle of compensation, the idea of occupational risk referred to the principle of social equilibrium.

The idea of occupational risk was institutionalised in the social insurance system and promised a solution to all the problems the employer connected with the liability-legal solution and their labour force. Since the question of guilt was not asked, in-plant conditions were not open to the public. In addition, the social costs of industrial production were distributed on many shoulders and were calculable for the employer. Industrial accidents were acknowledged as normal, as standard. In other words, the workers had to endure accidents silently but were, nevertheless, financially protected. This guaranteed that the industry could rely upon workers who were capable and willing to work.

5. The Meaning of the Social Insurance System

In its concrete form, occupational risk is institutionalised in the social insurance system. There, we see detailed evidence for its fundamentally new meaning. Damages could be awarded on the basis of an accident taking place without inquiring about the behaviour of the employer or the worker. Compensation corresponded to the extent of disability, though it was generally low and paid as a lump sum, only partially covering lost wages. Instead of comprehensive payments for damages, scanty compensations were made with the intention of covering initial lost wages whilst also forcing the worker to return to work, even in case of reduced ability. This was in the interest of the employers since they were interested in a pool of healthy, employable and willing workers.

Generally, the social insurance system signalled the abandonment of ‘poor relief’ and worker politics. The social insurance system was at the beginning a worker insurance only. The worker being valuable for industry should not fall into discriminating poor relief. Social security was an insurance for privileged social classes: all those persons who were productive for industry. This differentiation of workers however was a double separation. If there had been interest in the poverty question (as in England) and not in the worker question (whose aim was to maintain a productive and willing labour force), then social security would have had to have been introduced, initially for the most socially disadvantaged and not for highly qualified persons in better positions. Social security therefore cannot be seen as a functional replacement for the unsatisfactory poor relief as some authors claim.
6. The Definition of Health and Illness

What does this mean for the health insurance system? The health insurance law (Krankenversicherungsgesetz) of 1883 was a law preceding accident insurance. It was intended that the first thirteen weeks of medical expenses incurred following an accident should be paid for by health insurance. This regulation led to the introduction of compulsory health insurance policies.\[^1\]

In general, the benefits comprised payments in cash and free medical treatment. Initially payments in cash were more widespread, as at that time it was not common to visit a physician following an accident since patients usually self-medicated. Also, from an institutional perspective, health insurance funds only provided insurance for the risk of the inability to work. Equating illness with the inability to work meant that patient control and the suspicion of simulated illnesses became the organising principles for health insurance funds. This was supported by the traditionally high threshold for the definition of illness and the inability to work.\[^14\]

The permanent suspicion of simulated illness was intended to test the willingness to work, and control mechanisms were designed to re-establish the working ability as fast as possible. Illness (and the patient) was at that time a relational category being based on the criteria of ability to work. The sick person was either a patient, because he was unable to work, or he was not a patient, because he was able to work. Workers who were old or almost unable to work would no longer be insured.

Parsons develops this view of the patient some fifty years later.\[^15\] He suggests that illness is used as the legitimate basis to relieve the ill person from the obligations of their everyday social role, in particular with respect to employment. In turn, the patient must recognise illness as a condition which is socially undesirable. Hence, he has the obligation to make all efforts to return to fitness. Finally, the sick person must recognise that they are in need of help, and should seek and follow the advice of a qualified physician.

7. Conclusions

The German health insurance system was developed at a time fundamentally different from that of today. The strong link to accident insurance and thus the close connection to the working environment led to a concept of health which was defined as the ability to work. As a result, illness was seen as the inability to work. With the invention of occupational risk and the acknowledgement of accidents as standard, illness was then also a fate to be accepted by the worker. However, this means that the right to illness is recognised only in relation to professional activity and recovery is seen in terms of the obligation to return to work. In short, the obligation of treatment is the reverse of the right to illness.
Notes

3 Albrecht, 1990 and Schetsche, 1996.
4 Foucault, 1971 and Foucault, 1981.
6 Reidegeld, 1996.
9 Cf. the bad working conditions in Machtan, 1981.
10 Ewald, 1993.
12 In the 19th century individual countries defined social problems completely differently. The social question was designed characteristically in each case: in Germany as a working class question, in England or Ireland as a poverty question, in France as a family question or in Sweden as a question of social inequality. The results of these entirely different views on the core of the problem, its causes and its solution, are completely different institutional solutions for similar social problems - differences in organisation, extent and way of national intervention. Cf. Adshead and Millar, 2003, Kaufmann, 1986, Kaufmann, 1991 and Münch, 1986.

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From Policy to Practice: Recruitment of African Nurses in the UK

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Abstract
The international recruitment of nurses is a major issue with implications for health, ethics and public policy. The 2004 United Kingdom Code of Practice on International Recruitment of Nurses prohibited the active recruitment of nurses from developing countries with nursing shortages of their own. Studies commissioned by the Royal College of Nursing indicate that the United Kingdom continues to recruit nurses from Africa. Private agencies and the acceptance of unsolicited applications from individuals have become more common as methods of recruitment. The Code of Practice covers the NHS but places no legally binding restrictions on private agencies. Africa’s loss of nurses is problematic, especially now that the greatest social and economic burden facing sub-Saharan Africa, HIV/AIDS, has increased the need for nurses. Little is known about the experiences of nurses during recruitment, their transition from African countries to the UK and their experiences in the UK. Using focus group interviews, this research explores the reasons why African nurses leave their home countries to work in the UK, their expectations and the realities once in the UK. The paper assesses the ethical issues surrounding migration from the nurses’ personal perspectives.

Key Words: International nursing, nurse, recruitment, Africa, employment, agencies, policy, UK, NHS.

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1. Introduction
The recruitment of African nurses in the United Kingdom (UK) takes place in the context of wide-scale international recruitment. For the first time in 2001, the UK Department of Health (DH) recruited more foreign than British nurses. There is evidence to suggest that a good number of these nurses came from Africa. Recruitment from developing countries continues, despite the DH 2004 update of their Code of Practice for the International Recruitment of Healthcare Professionals, which states:

Developing countries will not be targeted for recruitment, unless there is an explicit government-to-government agreement with the UK to support recruitment activities…

There is no active recruitment of healthcare professionals
The 150 countries covered by the Code include all African countries except Libya, all Caribbean countries and many others. The emphasis of the Code is on discouraging active recruitment by NHS employers. Although private recruitment agencies are expected to abide by the Code, compliance is not compulsory and there are no mechanisms for monitoring and enforcing the Code. This has resulted in ongoing passive recruitment into NHS hospitals via recruitment agencies. In other words, nurses hired by agencies begin working in private non-NHS nursing homes, but subsequently apply and obtain jobs in the NHS. The NHS also accepts unsolicited applications from individual nurses, whether they are already in the UK or in their home countries. These findings are consistent with those in a recent DFID report.4

2. Methodology

We chose to use focus group interviews as the research method in order to facilitate an in-depth exploration of the nurses’ experiences.5 These interviews were conducted in two English cities.

The participants were nurses from sub-Saharan Africa, who were identified through word of mouth. One nurse from a Caribbean country joined one of the sessions. We decided to include her experiences because they were similar to those of the African nurses. In total, we interviewed six African nurses and one Caribbean nurse, whose ages ranged between 29-42 years and who had worked in nursing between 6-26 years. The two interviews took place in May, 2005 and were recorded with an Olympus DS330 Digital Voice Recorder. At the beginning of each interview session, the researchers explained the purpose of the interview and ensured that the participants were relaxed enough to be able to participate effectively in the discussion. The respondents gave their consent to participate in the research and were assured of confidentiality and that tapes would be destroyed after transcription. Both interviews lasted about ninety minutes.

3. Results

A. Expectation of Nurses before Coming to the UK

When asked about their expectations before leaving their home countries, most of the nurses responded that they expected better pay, working conditions and standards of nursing; better quality of life, professional development opportunities and educational opportunities for their children.
My major expectation was to advance myself in my nursing skills and knowledge. In Malawi we lack equipment, and it was difficult to teach students, not teaching proper nursing because of lack of resources. We were doing theory but practice was difficult. And to further myself in education, like get a Masters degree.

B. Recruitment

When asked how they were recruited, some participants reported coming to the UK through recruitment agencies based in the UK or in their home countries.

I was recruited by my former employer, the doctor at the hospital where I was working at. He has an agency in which he took nurses.

However, the majority of the nurses contacted former colleagues, already in the UK, about job opportunities. Often this occurred because agencies were slow to process recruitment documents.

I registered with the agency while in Malawi. It was taking a long time. [My] friend got a job. She was working here. She said ‘Where I’m working, they want someone else as well, just wait for [the agency] to process.’ So I came and the agency processed.

From the participant’s point of view, the recruitment process can be tortuous. For example, after two years of corresponding with the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC), one nurse applied for an adaptation course from a list supplied by the UKCC. She then had to fly to another African country to attend the interview. After the interview, she never heard from the recruitment agency again but eventually she found an adaptation place through a personal contact.

It is usual for most nurses trained outside the EU to undergo an adaptation course before being registered by the UK Nurses and Midwives Council (NMC). However, only two of our participants did the adaptation course. The rest were registered by the NMC before leaving their home countries. This could mean that either the nurses were well qualified or that the NMC is helping to carry out the government’s agenda by fast tracking the nurses so they can find employment as Registered General Nurses (RGNs) right away.
For one participant it was simply a question of applying for a position advertised on the Internet, after which she was told come to work, even before being interviewed.

I applied for this job which was advertised on the Internet. The agency was looking for a staff nurse, working in a nursing home... I had to be interviewed when I got to the airport. My first day of work was the day I had the interview. The nursing agency had to get in touch with the nursing home, telling them they had someone to take up the position. I had to come straight into that job.

When asked whether they had paid any fees, some nurses reported that they had paid recruitment agencies £300-£1,500. One nurse did not know that she would be expected to pay.

They [the agency] were demanding this money, which they never asked in advance. They wanted money for my air ticket, which I said I would find on my own. So they needed a way to make money. I did not know that they needed money to process my work permit. I had to tell them that I did not have the money right away and I would not give them. We had to make arrangements. I said I was going to give them in about two months. They wanted £500. So I told them I would give £250 per month after I had worked for two months.

Some participants reported being exploited by their employers because of their lack of familiarity with the system.

They [the nursing home] offered me a job while still in Malawi…. I was paid less than the other nurse because they said that they had offered me a job whilst still in Malawi, £7 and some of the nurses £10 or £9.50.

C. Experiences in the Workplace

There was a distinct difference between experiences of nurses in the independent sector and in the NHS. Most of the nurses indicated they received better support in the NHS.

Some of the participants complained about the way that they were treated by the care staff in the nursing homes, and said that they did not receive adequate orientation before they were expected to assume serious responsibilities: ‘In the nursing home, they said I’d be given an orientation
Within the NHS, some participants expressed concern about the attitude of some foreign nurses towards them:

With my colleagues, out of ten of us, eight of us are from different countries. Mainly Indian. It is unfortunate, because sometimes they think that you are inferior to them and they are superior to you. It took some time to be able to come across to them that I could do the same things. Like a phone rang and someone stood there and said what I was supposed to say like I don’t know what to say. Intimidating.

Another participant concurred.

They’ll speak English when it’s convenient. They’ll speak in their language, and I’ll ask what they’re saying, and they say it is nothing to worry about.

One nurse felt that this attitude was in part due to the different ways that Indian and African nurses were recruited. Indian nurses are recruited under a ‘Recruit and Retain’ policy and the African nurses felt that they were not. The African nurses felt that the differences in recruitment processes contributed to the feeling of superiority among the Indian nurses.

Several nurses expressed similar concerns with the attitudes of some of their white colleagues.

If I’m doing something not in the right way…like a light switch and you’ve forgotten the way it’s supposed to be…and you’d find that instead of anybody showing you what to do, they go together and talk about it, which is not good for you, the patient or the equipment. Instead of coming to my aid…they go to the corner and start talking about it. If it was one of their own, they’d be very supportive.

The participants in this study generally reported good experiences with patients, but there were some instances of rejection.

Some of the residents accepted me, but some of them were not happy being looked after by a black person. I was told by the manager of the ward that Room 43 and Room 18 didn’t like to be looked after by a black person, that a
Senior Care Assistant could do it. It was very strange but because I was new, it was very difficult. One of the residents became poorly. When I went there she refused me to come into the room. I had to call the Ward Manager to sort her out and take her to the hospital.

D. Benefits of Living in the UK

For most participants, affordable, good education and medical facilities were the most important benefits of living in the UK.

The children. I’m happy for the children. They are able to express themselves and communicate better. Having been a single mother since they were 2 and 4 years old, financially it’s been easier than back home. I have been able to [help] my family back home...The experience has been quite positive for me. If I go back, I have a lot of experience to share with people.

E. Challenges of Living in the UK

The nurses indicated that the greatest challenges of living in the UK had to do with the children. Respondents were concerned about the racism their children faced at school.

When my son got into school, he got into problems. Serious problems. He did not even know he was black. He did not even understand why they were saying he was black. That’s when the behaviour problems started. At home he was all right. He has got into this problem of racism. [Everything is] ‘…racist, racist’. Now I’ve got a problem on my hands, just because of the differences.

Some participants felt that UK government policies were taking away their ability to discipline their children.

The kids, the influence, the peer pressure...in this country at 16 you’re an adult. In Kenya at 16, you are a child. Discipline, the way we are not allowed to discipline our children. At home we smack them. It is discipline. We should be able to discipline them, as long as we know we are not going to harm them. I heard on the radio about discipline in schools, and they were saying ‘If only teachers were allowed to smack a little bit.’ And you get into bad
behaviour, smoking and the bad stuff, and pregnancy for girls. That is what I am afraid of.

Another major concern was that many spouses had difficulties in finding employment commensurate with their professional qualifications. As a result the men are forced to work as unskilled labourers and to depend on their wives’ finances. This is not consistent with African culture, where men are expected to be the breadwinners.

My husband… he came here and could not get a job… Eventually he got into odd jobs, working at M&S and that kind of thing, working at nursing homes…and as you know, African men…they don’t even look after babies at home. He was a draftsman back home.

F. Future Plans

When asked about their future plans, nurses reported a desire to keep their options open. One nurse said:

I have an open mind. The children need me here. I’ve got to stay here and give them the support they need, and once they finish school they can give me support…so I don’t think I can stay forever, that’s what my position is.

It was evident that pay was a big factor in the nurses’ decisions not to go back to their home countries in the near future. Some of them said that they would go back if they were offered better pay and working conditions. All the nurses wanted to go home eventually, however, because they dreaded the prospect of getting old and being put into a nursing home.

G. HIV Testing

When asked whether they were required to undergo HIV testing, one nurse said:

Yeah, I was tested. You had to go. And when I came here, there was a very high incidence of HIV [in my home country]. And the Nursing Director told me that he didn’t want to do it, but for the safety of the patients, I was tested. I didn’t sleep that night.

Some of the nurses were concerned that the practice of testing African nurses was unfair, because not all of the HIV patients in hospital had contracted the disease in Africa.
H. The impact of Nurse Migration on Host Countries.

The magnitude of the problem of nurse migration is illustrated by one of the Malawian participants, who reported that all 27 members of her BSc nursing class of 1999 from the University of Malawi were now in the UK. One nurse from a different country concurred and remarked:

I think in our hospital if I went back today, I wouldn’t know anybody. Everybody is out: the UK, US. The UK has taken quite a few. All the nurses are newly qualified without much experience. I can say that it is being drained of the cream of nurses. More of the senior nurses are here. Whoever is left in charge is junior.

Nurses pointed out that wards in their home countries were left short staffed. One nurse said that there were five nurses for 30 deliveries in a 24 hour period on a maternity ward. Another nurse said that on a TB ward with 200 patients, there were seven nurses in the day and two at night.

4. Discussion

Our research indicates that African nurses come to work in the UK for financial, family and professional reasons. The motivation to come to the UK is sometimes so high that nurses are willing to pay large fees to private agencies. Once in the UK, however, nurses realise that there is clearly a mismatch between their expectations and realities in the UK. Their quality of life is often undermined by racism and discrimination in the workplace. They are also affected by the racism that their children face at school. Although salaries are higher, the high cost of living takes the benefits away. Their expectations regarding professional development are generally met but information about development opportunities is not always readily available.

The UK government continues to recruit nurses from countries with nursing shortages of their own, despite the UK Code of Practice. According to DH, the number of new registrations from some sub-Saharan countries has risen, while others have remained stable. Although the Code of Practice covers Malawi, Kenya and the Caribbean, the nurses we interviewed reported that they knew others who were making arrangements to come to work in the UK, and that private agencies continue to actively recruit from there. It appears that the Code of Practices is difficult to enforce. In part, this is due to the inherent weakness of Codes of Practice as policy instruments. As Bach states, ‘Voluntary codes of practice...are relatively weak regulatory mechanisms because they have no legal basis’. The difficulty of enforcing and monitoring the Code of Practice also stems from an ethical dilemma. The International Council of Nurses (ICN) describes this dilemma in its position statement.
The ICN recognises the right of individual nurses to migrate... The Council acknowledges the adverse effect that international migration may have on health care quality in countries seriously depleted of their nursing workforce.

While individual nurses have the right to seek employment wherever they wish, when nurses migrate, home countries lose the nurses as well as the resources invested to train them.

Our research shows that personal factors such as better pay, better working conditions and better quality of life for them and their family, all play a major role in nurses’ decisions to come to work in the UK. However, these decisions, made on a personal level, have a major impact on the health care systems of their home countries.

For example, Dugger observed that 10 nurses delivered more than 10,000 babies per year in Malawi’s capital city labour ward, and that a single nurse often looks after more than 50 or more desperately ill patients. Forty-six of the fifty countries with the highest HIV/AIDS adult prevalence rates in the world are African or Caribbean countries on the DH list. At the same time that aid is being increased in the fight against HIV/AIDS, the nursing shortage compromises the ability of those countries to utilise that aid effectively. But the problem is not just HIV/AIDS. Men, women and children in need of all kinds of nursing services will continue to die if the situation is not reversed.

5. Conclusion and Recommendations

Due to the glaring imbalances between the economies of developed and developing countries, the migration of health workers and other professionals will continue to take place. As long as nursing shortages continue, developed countries like the UK will continue to recruit nurses from overseas, including from developing countries with nursing shortages of their own. This is problematic because by recruiting nurses from developing countries, the UK and other developed countries are exacerbating health care problems in developing countries. In particular, the nurse recruitment undermines global initiatives aimed at combating HIV/AIDS and other treatable diseases.

Although the UK has a Code of Practice in place, evidence suggests that the Code has not been effective. Difficulties of enforcement and monitoring are due in part to the ethical dilemma between the freedom of individuals to seek employment, and the needs of developing countries to hold on to health professionals they have paid to train. The nurses experience their own dilemmas. On the one hand, nurses are attracted for personal reasons to come to work in developed countries. On the other hand, they are aware that their governments would like to retain them because their services
are crucial to the health systems in their countries. The words of one participant could not have put it better:

    Our government has invested in us. It is time to give back what they invested, really. It is really difficult for the government now because they have lost most of their trained nurses, registered nurses to countries like the UK and Australia. It is good to give back to the country at some point.

The main recommendations of the study are:

1. Establish measures to make nursing more attractive as a profession to the British people
2. Cover private recruitment agencies in the Code of Practice
3. Establish systems of compensation and make agreements to fund nursing education in countries that have lost a substantial proportion of their nurses to the UK

Notes

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Health and Ethical Choices in Economics

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Abstract
Economists have used different strategies to introduce the notion of health into economics. Notable examples include the integration of some of the characteristics of health into economic concepts and the referencing of intermediary concepts, such as the demand for health care or health determinants, as echoes of health. These strategies, which could be qualified as indirect conceptualisations of health, reveal the difficulty economics has in conceptualising health. This presentation shows that the absence of a conceptualisation of health in economics leads to implicit ethical choices in economic analysis which shape health policies. In this discussion, we develop three dimensions of health and the inherent ethical choices economists make when working on health:

1) The choice of a life norm: Health can be conceived of as a personal norm expressing the conjunction of biological and psycho-social norms in a dialogue between the individual and his or her environment. By often ignoring this complex personal normative space, economists implicitly introduce a specific personal norm into the assumptions upon which they base their economic models.

2) The choice of social ends: Health is a collective norm, a justification of the Welfare State through its bio-pouvoir, and a relative universal right. That a degree of priority is attached to health as a social end is often implied in economic models without being discussed.

3) The choice of a particular allocation of resources: Economists refer to different social representations of health which carry inherent criteria for resource allocation. However, when choosing a specific representation, economists often fail to recognise the allocative consequences of this choice.

This presentation enlivens the dialogue between the interdisciplinary approach to health and an economic theoretical framework which tend to overlook the multidisciplinary dimensions of economics.

Key Words: Health economics, health ideals and norms, ethics, policy making.

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This chapter shows through three examples how an economic perspective on health could lead to implicit ethical choices. It will demonstrate that these implicit choices are the result of the fragmentation of knowledge inside the discipline of economics. It will also show that these choices are the result of boundaries between disciplines.

This chapter considers three normative aspects of health and identifies their treatment in economics. First, health is understood as a norm of life; when modeling rationality, economics does not consider some dimensions of this norm, thereby leading to an ethical choice. Second, this chapter shows the influence of economics in defining health as an economic and social end. Finally, it shows how different conceptions of health lead to problematic choices in the allocation of resources.

1. **Health as an Individual Norm**

   When considering health as a norm, it is possible to keep the social sciences distinction between the individual and collective levels of analysis. Health as an individual norm is a norm of life expressing the interaction between the individual and his/her environment. In economics, this norm of life has been captured partially through the notion of rationality and particular norms of life have been selected.

   According to Canguilhem, the relation between the living (i.e., a biological living form, such as a body or a cell) and its milieu is characterised by a biological norm which corresponds to ‘what must be,’ the living either adhering to a specific norm or creating new norms when facing particular events. Normality corresponds to the usual state that the majority of persons have adopted or to the ideal state: the one that must be. The living is thus normal if it can live and function within the milieu when evolving. But the living is also normative in the sense that it itself institutes new norms. In its relation with the living, the milieu will be also organized and transformed by the living, which does or does not submit to some constraints of the former. This notion of normativity is similar to the concept of autonomy of the living, where the living, by creating its own norms, constructs itself.

   When pathology appears, a living being becomes unable to function in its milieu and to interact appropriately with its environment; this means it cannot realise its normative state anymore and thus is no longer normal. In that case, the biological norms characterising a person’s relationship with his or her milieu cannot endure. New norms will impose on and characterise the normal state. The difference between health and disease lies in the normative capacity of the living, which gives the living a profusion of means for creating the power and the temptation to exceed its limits, and thus make itself ill. According to Canguilhem, this normativity is the key to understanding how health is intertwined with the idea of creation. Through normativity, the living acquires an identity of its own; the living creates itself and becomes unique.
The theoretical construction of health can be understood at two levels: the biological and the psychosocial. This biological approach, based on norms, can be examined at the psychosocial level. The psychosocial individual is in good health when he/she is normal, that is, realising projects according to the rules of his/her group. But he/she is also normative when creating new norms when completing projects. Through norms, a person constructs and realizes him- or herself as an autonomous individual.

But when biological and psychosocial levels are combined in the concept of health, the creative sense of a human prevents him or her from finding the most secure situation because, according to Dubos, this creation is nourished by the reactions of a human who faces danger. Health must be understood as a creative movement specific to a human being in his or her entirety. Health consists of creating norms, of creating life, and creating the person. Considering health is reconsidering each person in his or her entire individuality and, at the same time, in his or her attachment to the world.

This integration of the biological and psychosocial levels in the concept of health leads to the representation of health as a personal normative space, structured by norms, and characterising the relationship between the individual and his/her milieu. This inherently ethical space, where the biological and the psychosocial are integrated, is where the ethics of the individual and society are constructed. But it is first a space where the person constructs his/her identity and dignity.

Economics relies on a scheme of viewing emotions in terms of wants, which will determine action. But when considering the biological level, researchers have shown the intimate interdependence between body and mind. Worry, fear, despair and abandonment of and by oneself and others hurt the body. For example, in a simplified deterministic perspective, emotions determine the biological, which in turn influences individual and collective actions. If a person accomplishes an action that is not the most appropriate for him or her, and where it is impossible for him/her to be normative, the person’s body can react and he/she can become sick. It is in disease that he/she will be ‘liberated’ from this action by no longer being physically able to accomplish it. Moreover, his/her relatives and social environment may no longer want or be able to impose the action on him/her.

The economic point of view implies a perfect rational choice in an action, whereas the biological level shows a dissonance between the individual and his/her environment. An act must be regarded in terms of interaction between a person and his/her environment: if a shift cannot be expressed by a social act, it can be expressed by a biological act.
2. Health as a Collective Norm

At a collective level, we can also question the influence of the specificities of economics on the statement that health is an economic and a social end.

A. Bio-power and Right to Health

At the collective level, health is a vector of power inside a nation. Foucault deduced a bio-power through which the living becomes the value, the richness to preserve, to favour and to encourage. A bio-politics follows which, for regulating the living, sets up interventions and controls on people and their bodies. This bio-policy is not only the tool of the government or the administration but also of institutions and social groups at a more local level. In many civilizations, life has and could only be managed through the emergence of specific state structures. The bio-power has found its ultimate expression in the welfare state. In fact, health has always been an object of interest for politics and the means for the state to legitimise its power by imposing it in the personal sphere of individuals.

This collective norm is taken over at the individual level by the notion of a right to health. The Universal Declaration of Human Rights has identified some health determinants like food, housing, health care, economic security, and social services as fundamental rights; these rights are reaffirmed in the United Nations Charter. Health is not itself an absolute fundamental right - that is, a juridical norm which can be applied and respected - but a relative right because the definition of health is not precise enough to produce some specific criteria by which the State could be condemned if it does not respect this right to health.

The analysis of health in terms of bio-power and human rights reveals that health is at the core of people’s (and sometimes power’s) aspirations. Maintaining the project of health at the core of society requires strong mechanisms such as power and rights. But often economics omits these mechanisms in its frameworks because of an over-cautiousness regarding the introduction of concepts from other disciplines. By neglecting these vectors, a project of health relies more on its financial feasibility and is thus weakened when it loses the dimensions by which it was given its priority.

B. Health as an Economic and Social End

The organisation of economics makes the identification of ends for the economic system complex. One of the main reasons is the set of boundaries within the discipline.

Economics is divided into sub-disciplines and health economics is only one sub-discipline among others, such as monetary economics, economics of education, or spatial economics. If improvement of health is the logic attributed to the health system and individuals in health economics, it is
replaced by other objectives in other sub-disciplines - for example in industrial economics, the objective is the health of industry. This phenomenon of segmentation reveals why it is difficult for economics to have a general point of view, since a positive policy in one sector can have negative effects in another. A policy in one sector that is to the detriment of another has certain similarities with a decision of an inter-sectorial allocation. For example, the policy of liberalisation of capital had some negative effects on the well-being and health of people in some developing countries.17

Another important boundary is the distinction between what is economic and what is social. This distinction in economics often leads to the assumption that the economy is the driving force of the social sphere. In the discipline of economics, analysts have argued that wealth creates health. Hirshman18 has noted the common assumption that it is the growth of the GDP that leads to the improvement of social factors (e.g., diet and housing) and that economic growth will therefore have positive impacts on health. Improving health and economic growth are synonymous. Health has been simultaneously considered as a key element for the improvement of the labour factor and consequently as a boost for economic growth.19,20 Health appears more as a means than an end of the economic system. While this point of view seems restrictive, it may be the only argument for investment to be directed towards the improvement of health.

It appears that the organisation of the discipline, based on fragmentation and specialisation, leads to implicit priorities in terms of allocation.

3. Representations of Health and the Allocation of Resources

The concept of health is complex, with multiple dimensions at the root of different conceptions. Intuitively, it seems that economics has retained different conceptions of health, which could lead to very different allocations of resources. The approach here is to use a categorisation of conceptions of health already validated in the social sciences as a guide for identification in economic literature. The social representations of health among the French population identified by Herzlich will be used.

The first representation of health is ‘health-in-a-vacuum’. Health here takes the form, on an individual level, of an absence of disease or of consciousness of one’s body and its functioning. Illness is thus the only point of reference and the only experience for the individual.21 In the field of health economics, health has been first considered as a bi-variate state: an individual is either in good health or is ill. Since disease is the reference, it is on this basis that the sub-discipline of health care economics has developed. Individuals are overcome by an episode of morbidity and the economic analysis retains its demand and consumption of health care services. Most health economics
textbooks defined health as the absence of disease due to the complexity of working with a positive definition.

Herzlich’s study shows that health has also been captured through the notions of robustness, strength, and resistance to disease. This reserve of health takes the form of capital with which the individual is endowed at birth. It is permanent and can be restored to a certain point if there is deterioration due to disease or old age. The idea that a human being is a stock of capital - human capital theory - has been developed since the 1960s. Investing in health is profitable because it reduces workers’ mortality and morbidity and improves the capacity for working. At an individual level, in Grossman’s model of the demand for health care, individuals inherit an initial stock of health which depreciates over time at a growing rate, this stock being improved by some adequate investment in health care or the consumption of other market goods such as housing or diet.

Finally, health has been represented as an equilibrium which translates the state of the individual and his/her kind of life by considering both biological and social aspects of his/her life such as physical and psychological well-being, ease of engaging in activities, efficiency of doing activities, or good relationships with others\(^2\). In economics, measurement of health outcomes has retained this definition by measuring how the person functions in his/her environment, the physical and social functions, emotional well-being, pain and cognitive ability\(^2\). At a more conceptual level, health as equilibrium can be associated with the notions of capability and functionings constructed by Amartya Sen to better integrate ethics and economics and can offer a new perspective on allocation of resources\(^2\). Whereas functionings are acts of being and doing, capability represents the various combinations of functionings the person can achieve; functioning and capability can be assimilated by health. Both Herzlich’s health as equilibrium and Sen’s capability express the freedom for a person to live the life he/she has chosen.

Choosing a particular conception of health helps to define the problem of resource allocation by retaining specific dimensions of health. For example, if health is conceived of as an absence of disease, the allocation of resources must permit sick people to have access to health care services. But this definition of the problem already carries criteria for the allocation of resources, notably the type of resources that would be allocated, the beneficiaries, and the expected results. Often the choice of a particular conception of health is implicit in an economic framework and the allocation consequences are neglected. The choice of a conception of health therefore reveals itself as a real ethical choice. For a health policy aiming to improve health status, if health is defined as an absence of disease, policies will be oriented towards health care and cure. Only persons suffering from disease will be the beneficiaries of this allocation.
If health is defined as capital, policies will be oriented towards the allocation of health services and services improving individuals’ capacities, such as income, education, diet and exercise. This type of allocation may or may not lead to an absence of disease, depending on the biological constitution of the individual, his/her environment, and the events he/she faces.

If health is defined as an equilibrium, policies will be oriented towards the individual (for example, health(care) services, education, and other social services) and towards the collectivity (for example, the welfare state, conditions of work, or equality of income) to better achieve the adjustment between an individual and his/her environment.

Notes

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Qualifying for the Right to Die - A Dubious Privilege: Assisted Dying for the Terminally Ill

Michele Wates

Abstract
As long as societies have had laws, a central tenet has been to protect people, especially those who may be physically and/or mentally vulnerable, from being intentionally, or for that matter unintentionally, killed. Legislation has now been passed in some countries and is under consideration in others that represents a far reaching and fundamental shift in the moral basis of the law in relation to the taking of human life; establishing the principle that a person may invite others to lawfully kill them. This may be all the more dangerous a development given societal attitudes (including of course the attitudes of doctors and solicitors who respond to people's requests to die) regarding the quality of life, or rather the supposed lack of quality of life of people who have physical and/or mental illnesses. Who 'qualifies' within the terms of such legislation for the right to die is frequently disputable. Not only does this present doctors with impossible dilemmas in practice, but that ‘right’, once established, is liable to be extended over time to include more and more people, in the name of equal rights and nondiscrimination; as has already proved to be the case in Holland. Those who seek to legalise the right to ‘medical assistance to die’ frequently use the language of human rights, access to choice, and anti-discrimination. Whilst views on this matter differ among disabled people, as in the general population, it is argued that legislation upholding ‘the right’ to die potentially jeopardises the human rights, access to choice and freedom from discrimination of many more people who do not wish to die, or who are ambivalent about ending their lives, than it assists those who seek the right to end their lives.

Key Words: Euthanasia, assisted dying, terminal illness, medical legislation.

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As other chapters presented at this conference have reminded us, illness is a socially defined phenomenon as much as it is a physical reality. Over the course of the 20 years that I have lived with a progressive illness I have come to realise that society’s view of the value and acceptability of my experience as a disabled person is often at odds with my own perspective as someone who lives with that reality from day-to-day. A woman I hardly knew once said to me, with disarming honesty, albeit with an awesome lack of tact, ‘If I was suffering from an illness like yours, I would
probably kill myself.’ I was aware that she was voicing a view that may be widely shared, though seldom expressed.

It is not only that some people believe that it would be better to die than to become disabled themselves, but also their belief that many disabled people (including those still very young or unborn and those who are for one reason or another not physically in a position to express a view on the matter) would be better off dead.

In the United Kingdom a Private Member’s Bill on Assisted Dying for the Terminally Ill written by lawyer Lord Joffe and supported by the Voluntary Euthanasia Society (VES) has this year cleared the hurdle of consideration by a select committee at the House of Lords, passed its formal second reading and is now ready, as and when the government of the day decides that the time is right, to go to the House of Commons. If it is passed, this Bill will establish the legal right of terminally ill people to physician-assisted suicide. Throughout this chapter where I refer to legislation, unless otherwise stated, I am referring to the Assisted Dying for the Terminally Ill Bill here in the UK.¹

The tone and thrust of public debate, reflected in a number of articles, radio and television programmes, films and plays suggest that society is in favour of such a change in the law and that it may only be a matter of time before it happens.

I believe that it is both timely and necessary at this point to question the wider implications of such a far-reaching change to legislation. As someone with a long-term progressive illness and as a campaigner for the rights of disabled people I argue that we should regard with extreme caution the language of anti-discrimination, choice and human rights frequently used by those who promote the notion of legalising assisted killing.

It is necessary to question whose right to life might be undermined by establishing the right to die.

I should like at this point to summarise my arguments. Firstly, if physician-assisted suicide was once to be legally sanctioned then limiting access to such assistance to die could be said to be discriminatory. For this reason the right would be extended over time to more and more people in the name of equality and human rights.

Secondly, moves to legalise assisted killing for the terminally ill have to be seen within the context of society’s prevailing assumptions about disability and long-term illness.

Thirdly, the existence of assisted dying as a legal and relatively easily accessible option will have the undesired effect of undermining the provision of palliative care, treatment for depression and society’s commitment to support independent living.

Fourthly, the availability of assisted dying as a legal and relatively easily accessible option has the potential to place mentally vulnerable,
I start with the point that limited access to assistance to die to those who might be described as ‘terminally ill’ is inherently problematical.

At this point, late in the afternoon on the third day of a four-day conference, it would be understandable if delegates found their attention beginning to flag. On this particular occasion there may be a certain aptness in my presentation being assigned the so-called ‘graveyard slot’ given the subject matter. Allow me to put to you a hypothetical scenario that hopefully will help us all to focus.

If a non-disabled friend, who does not, as far as they are aware, have a serious illness, were at some point in the future to become depressed and suicidal, doctors would seek to treat them for depression. If I, as a person with a serious, progressive illness, were to become suicidal it would be a matter for debate, were the Assisted Dying for the Terminally Ill Bill currently under discussion in the UK to have become law at that point, as to whether I should be treated for depression or assisted to die at my own request. The difference is that I, unlike my friend, could argue that I was suffering unbearably as a result of my illness and that my illness is terminal. The argument would then come down to whether the professionals concerned agree with me at that point that my illness is ‘terminal’, that my ‘suffering’ is caused by my illness and that my suffering is indeed ‘unbearable’. In my friend’s case there would be no such discussions to be had. And so in opposing the proposed legislation I am, amongst other things, seeking to ensure that in the future I will have the same assurance as my friend that were I to become suicidally depressed, doctors would see it as their task to treat me for that depression and that if I was suffering they would see it as their task to relieve me of that suffering rather than seeing it as their task, or even their legal obligation, to assist me in carrying out my wish to die.

Incidentally, under the proposed UK legislation, if I were to ask that my partner, relatives and friends should not be informed of my desire to kill myself either at this point or during the ‘waiting period’ of at least fourteen days after I had signed the declaration of my intent, they would presumably know nothing of my suicidal intentions until after my death when they would be informed that doctors had assisted me to die. If you do not find that prospect an alarming one, allow me to assure you that I do.

The proposed legislation implicitly draws a line between those who ‘qualify’ to be assisted in committing suicide and those whom society would seek to prevent from committing suicide (even to the point of physically restraining or detaining someone who appears to be intent upon harming themselves). Some people would be seen as clearly qualifying within the terms of the legislation as framed whilst in other cases it would be arguable as to whether people qualified or not. Others would definitely not be covered
by the legislation. And, as I suggest in my hypothetical example, whether or not a person is seen to qualify determines how the medical profession is required to respond to their needs.

There is an inbuilt problem with attempts to limit legislation on assisted dying to the terminally ill. The more the checks and balances around who ‘qualifies’, the greater the chances that the legislation is construed as excluding certain categories and therefore discriminating against people who do not qualify. Ironically, in the very name of human rights it becomes necessary to include more and more people in the right to die. Herbert Hendin, medical director of the American Foundation for Suicide Prevention, and an opponent of physician-assisted suicide, argues that this has already happened in Holland:

According to the Royal Dutch Medical Association, it did not seem reasonable medically, legally, or morally to sanction only assisted suicide, thereby denying more active medical help in the form of euthanasia to those who could not effect their own deaths. Nor could the Dutch deny assisted suicide or euthanasia to the chronically ill who have longer to suffer than the terminally ill, or to those who have psychological pain not associated with physical disease. To do so would be a form of discrimination."

A further problem with interpreting the legislation has been expressed by the number of physicians who have articulated serious concerns that although the bill purports to be concerned only with individuals at the ‘end of life’, predictions about the nearness or otherwise of death are notoriously uncertain. Human beings do not come stamped with expiration dates. In saying that the person who wishes to die must be, ‘in a terminal phase of life’, Lord Joffe’s Assisted Dying for the Terminally Ill Bill glosses over these complexities in a way that many doctors find deeply worrying.

I find it almost inconceivable that the pro-euthanasia lobby would be unaware of the potential for a series of challenges in relation to the terms used in the bill and the likelihood that this would lead to the extension of the dubious privilege of the right to die once the initial principle has been established. I sincerely believe that the rest of us need to become savvier and not jump without question onto the ‘human rights’ bandwagon in relation to assisted killing.

Incidentally, as a further aside on the changing use of language, I have lived with multiple sclerosis for over 20 years without ever hearing it described as a terminal illness, until now, in an article on the Internet by an American writer promoting physician-assisted suicide and euthanasia. An
illness such as progressive multiple sclerosis, which many individuals live with for half a lifetime and more, may in this way come to be regarded as ‘terminal’ in popular imagination, in the media, in ethical debate and ultimately in the context of legislation.

My second point is concerned with the role played in ‘end of life’ decisions and discussions by prevailing assumptions about the reduced value of the life of a person who has a long-term illness or a life-threatening condition.

The point of view held by the doctor advising a patient with a serious, life threatening illness would inevitably have a bearing upon the information that they give to the patient and the extent to which they would be inclined to argue the case for palliative care measures, for example, or link the person up with appropriate care assistance or counselling for depression. The doctors advising the person who wishes to die, the solicitor required by the legislation to verify that they are of sound mind to make the decision, and the courts who might retrospectively be called upon to comment upon what had happened would all be operating from within the context of pathological societal assumptions and attitudes towards illness and disability.

A person who articulates a wish to die, perceiving that their life lacks dignity and value as a result of either a newly acquired or a longstanding illness or impairment, may find that they have either the open or the quiescent agreement of those around them. It is widely assumed that it is impairment and illness in and of themselves, rather than the social and physical environments in which impairment and illness are experienced, that lead to suffering and loss of human dignity. As a wheelchair user of many years standing, or rather sitting, I know from personal experience that a good wheelchair is a liberating piece of equipment and not a fate to be avoided at all costs. It has been my experience that the quality of my life as a disabled person has not been determined by the progress of my illness and the extent of my impairments so much as by the access that I have had at any particular time to sufficient money, appropriate assistance, equipment, accessible buildings, transport and so on.

This is what one might call a social model of disability rather than the pervasive medical model, which sees disability and illness as something that can be described in terms of physical characteristics and psychosocial responses more or less separable from social and economic contexts.

My third point has been emphasised repeatedly by the disability rights movement around the world expressing concern that the existence of physician-assisted suicide as a legal and relatively easily accessible option undermines treatment for depression, the development of palliative care and ongoing commitment to supported independent living.

Herbert Hendin makes the point that whilst the argument is frequently made by proponents that legislation sanctioning assisted suicide
upholds personal choice, it has been shown in the Netherlands that, ‘palliative care is one of the casualties and that hospice care lags behind that of other countries.’ Many disabled individuals argue that resources to support disabled individuals’ living choices are put at risk in the climate established by moves to promote assisted dying.

Marilyn Golden, a policy analyst writing for the Disability Rights Education and Defense Fund (DREDF) in the USA summarises the case against the legalisation of assisted suicide as follows:

While an extremely small number of people may benefit… large numbers of people, particularly among those less privileged in society, would be at significant risk of substantial harm. We must separate our private wishes for what we each may hope to have available for ourselves some day and, rather, focus on the significant dangers of legalizing assisted suicide as public policy in this society as it is today. Assisted suicide would have many unintended consequences.

My final point, relating to potential pressures upon vulnerable, elderly and ill people to end their lives in the interests of their caregivers, is heightened by the fact that my talk is between two others concerned with the relationship between ethics and the funding of health services.

With an ageing population, we have to face the fact that society can be said to have a vested interest in not having to pay to support increasing numbers of people who are disabled and/or sick. It is insufficiently acknowledged that those who are terminally ill and those who look after them (both individually and at the broader societal level of state services, health care related businesses, voters and tax payers) may be perceived as having competing and conflicting interests. Whether this is indeed the case is a matter for debate; however it is essential to recognise the social and economic context within which the debate about physician-assisted suicide is taking place.

It is possible to imagine a range of scenarios in residential care settings and even in nominally supportive families where there might be different views not only of what constitutes suffering but how that suffering might be brought to an end. Those who are receiving care and assistance may have different perspectives and, on occasion, conflicting interests from those who look after them. The Assisted Dying for the Terminally Ill Bill in effect wishes these complexities away, saying merely that ‘the physician should have satisfied himself that the request is made voluntarily’. I believe that the pressure upon those who find themselves ‘qualifying’ in the terms of the Bill for the right to be assisted in killing themselves, whether this pressure came...
from outside or had been internalised, would in some cases be intolerable and that people who did not want to die might nonetheless feel that they should seek death. It is not enough that the legislation says that the physicians concerned should have satisfied themselves the request is made voluntarily. The pressures that people are under may in some cases have become internalised to the extent that they no longer open to the necessary scrutiny.

Media attention has been overwhelmingly focused on a small number of exceptional cases of people (often highly educated and relatively well-off) who object that they are no longer in a position physically to control their own destiny and that they should have the legal right to be assisted in committing suicide. In focusing on real life cases and fictional stories highlighted such as, Whose Life Is It Anyway?, Million Dollar Babe and The Sea Within we are in danger of straining at a gnat of human rights and swallowing a camel.

To summarise, as long as societies have had laws, a central tenet has been to protect people, especially those who may be physically and/or mentally vulnerable, from being intentionally, or for that matter unintentionally, killed. Legislation has now been passed in some countries and is under consideration here in the UK that represents a far-reaching and fundamental shift in the moral basis of the law in relation to the taking of human life; establishing the principle that a person may invite others to lawfully kill them. This may be all the more dangerous a development given societal attitudes (including of course the attitudes of doctors and solicitors who respond to people’s requests to die) regarding the quality of life, or rather the supposed lack of quality of life of people who have physical and/or mental illnesses.

Who ‘qualifies’ within the terms of such legislation for the right to die is frequently disputable. Not only does this present doctors with impossible dilemmas in practise, but that ‘right’, once established, is liable to be extended over time to include more and more people, in the name of equal rights and non-discrimination, as has already proved to be the case in Holland.

There is a real danger that focusing upon the option of assisting sick and elderly people to die will supplant the focus of independent living aimed at ensuring that people who need assistance to live, whether rich or poor, have genuine living choices and control over their own lives.

Those who seek to legalise the right to ‘medical assistance to die’ frequently use the language of human rights, access to choice, and anti-discrimination. Whilst views on this matter differ among disabled people, as in the general population, it is argued by many that legislation upholding ‘the right’ of a small number of individuals resolved to die potentially jeopardises the human rights, access to choice, and freedom from discrimination of many
more people who are ambivalent about ending their lives or who have no wish to die.

Notes

4 Hendin, 1997.
5 Golden, undated.

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Michele Wates, Oxford, United Kingdom.
Reconciling Discretion, Jurisdiction and Equity: Funding of Health Services in Canada

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Abstract
In the allocation of health resources, demand exceeds supply and rationing is required. The ethical and legal debate has been taken to new ground recently in Canada, when the Supreme Court was asked in a class action case whether a province’s public health system must provide a behavioural therapy intervention. The argument is poignant because despite some inroads, the Canadian approach is predominantly based on a single public health ethos. In general, a Canadian needing health services turns first to the public system. Connor Auton is an autistic British Columbia child. His parents had self-funded ongoing behavioural therapy through an American provider, but the cost became prohibitive. The intervention involves 1-on-1 therapist-child interaction for several hours a day over several years. British Columbia’s health services commission refused to pay for the intervention, indicating that it fell outside the range of support services for autistic children. However, some provinces do cover the costs for up to 20 hours a week. The author will discuss the moral and legal principles in Auton’s case, which they argue raises questions not so much about fair opportunity of access and accountability for reasonableness, but about the very domain of what it is that could be accessed or rationed and who is to decide. In this, it expands the current rationing and prioritisation debates and has implications for Zeliotis v Province of Quebec, presently pending, where the plaintiff claims provision of private health service in Canada is a constitutional right.

Key Words: Public health care, autism, behavioural therapy, ethics.

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The Canadian health care system is somewhat of a misnomer. There are actually thirteen separate systems in Canada, one for each province and territory. This paper will first provide a brief overview of the legislative context within which health care is structured in Canada, with specific attention to how funding decisions are made. The variation in publicly funded services across Canada will also be discussed. Next, I will briefly outline the approach generally taken by individuals who wish to challenge funding decisions. Against this background, and using the recent Supreme Court of Canada decision in Auton et al v. British Columbia (Attorney General) et al as a case in point, I will explore some of the concerns that arise when services that are offered in one province are not available in another
province, and discuss whether such inconsistency gives rise to ethical concerns that go beyond those generally associated with resource allocation decisions.

1. The Political Landscape

In order to understand Canada’s health care system and the particular challenges discussed in this paper, one needs to understand something of Canada’s political structure. Canada has a federal constitution, with power divided between a central (federal) government and thirteen constituent (provincial and territorial) governments. This division of power is set out in sections 91 and 92 of The Constitution Act, 1867. The provinces have been afforded primary jurisdiction over health care under sections 92(7) (hospitals), 92(13) (property and civil rights), and 92(16) (matters of local or private nature). However, there is also room for federal involvement in health. Pursuant to section 91(27), the federal government has jurisdiction over criminal law, which includes a role in the protection of public health. In addition, the federal government has jurisdiction over all matters (including health) relating to specified groups, including First Nations people, inmates in federal prisons, and members of the armed forces. In addition to these specifically listed areas of jurisdiction, the federal government also has the general jurisdiction ‘to make laws for the peace, order, and good government of Canada, in relation to all matters not coming within the classes of subjects…assigned exclusively to the legislatures of the provinces.’ This seemingly empowers the federal government with the jurisdiction to enact legislation regarding health ‘where a problem has attained a national dimension (air or water pollution, perhaps) or where an emergency exists (such as an epidemic or pestilence).’

2. Canada’s Health Care System

Against this constitutional backdrop, Canada’s public health care system has developed into a single payer, publicly funded health care system, accessible to all without barriers based on ability to pay. The origins of the Canadian health care system as it is today may be traced back as far as 1919, when Canadians first discussed the idea of universal health insurance following the ravages of World War I. However, it was not until after the Depression and World War II that the idea really started to be developed. From the time Saskatchewan Premier Tommy Douglas implemented universal hospital insurance in 1944, the characterisation of health care as an inalienable right of citizenship and a public good, which ought to be accessible by all regardless of ability to pay, grew in strength and popularity.

The historical development of the Canadian health care system has not been smooth or easy, and there has been intense debate at every milestone. However, at each juncture, Canadians have opted to base access to
health care on need, and not on one’s ability to pay. The 1968 Medical Care Act enshrined four principles, which the provinces had to meet in order to obtain much sought federal funds (universal coverage; portability; comprehensiveness; and public administration). In 1984, the Canada Health Act was enacted, adding the principle of accessibility. In brief, the principles of universality, comprehensiveness and accessibility establish a health care system in which all residents of a province have equal access to all medically necessary health care services rendered by a physician or in a hospital, based on need and not ability to pay. More specifically, the accessibility requirement effectively removes the incentive for direct and extra billing by physicians, and discourages the development of a parallel private system with private insurance to cover services covered under the public system. The portability requirement ensures that residents of one province can move either temporarily or permanently to another province, and be insured in that province without an interruption in their medical coverage. Finally, the principle of public administration recognizes health care as a public good, and requires the provincial health insurance plans to be administered and operated on a not-for-profit basis, by an accountable public body. Where these criteria are not met, the provinces do not qualify for the federal financial transfers; consequently, each of the provinces has taken legislative steps to ensure compliance with the principles of the Canada Health Act. Although there have been significant changes in the amounts and structure of federal contributions since 1984, Canada’s health care system can still be classified essentially as one in which medically necessary physician and hospital services are covered under a public system funded by both federal and provincial dollars, and one in which the provinces must meet the requirements of the Canada Health Act in order to receive the federal contribution.

The Canadian health care system is an integral part of the Canadian identity and a source of intense pride for many Canadians. However, there is a long list of problems plaguing the system. Long wait lists at many intervals in the health care process (i.e., to be seen by a family physician, to be seen by a specialist; to undergo a medical intervention) and overcrowded emergency rooms are two oft-sited examples. As discussed above, the Canada Health Act protects the integrity of the public health care system by prohibiting private health insurance for publicly covered services. However, there has been growing discontent with the status quo as people are spending more time on wait lists, frustrated and often in pain, awaiting medical attention that they know could be available to them much sooner, although for a price, in the United States. The push for a solution is once again before the courts, and the country is currently awaiting the Supreme Court of Canada’s decision in Chaoulli et al v. Quebec (Attorney General). In the context of the current ailing public system, the Court is considering whether provincial legislation
which prohibits the development of a parallel private system constitutes a violation of a person’s constitutionally guaranteed right to ‘life, liberty and security of the person.’

3. ‘Medically Necessary’: An Elusive Definition

Canada’s health care system has been shaped in large part by the ever elusive concept of medical necessity. As noted above, the five principles at the foundation of the Canadian health care system are public administration, comprehensiveness, universality, portability, and accessibility. Pursuant to section 9 of the Canada Health Act:

In order to satisfy the criterion respecting comprehensiveness, the health care insurance plan of a province must insure all insured health services provided by hospitals, medical practitioners or dentists, and where the law of the province so permits, similar or additional services rendered by the other health care practitioners.

‘Insured health services’ are defined in the definition section of the Act as ‘hospital services, physician services and surgical dental services provided to insured persons.’ Definitions are in turn provided for hospital services and physician services, respectively. ‘Hospital services’ are defined as those specifically listed services provided to in-patients or out-patients at a hospital, if the services are medically necessary for the purpose of maintaining health, preventing disease or diagnosing or treating an injury, illness or disability. Finally, ‘physician services’ means any medically required services rendered by medical practitioners (themselves defined as persons lawfully entitled to practice medicine in the place in which they practice.) However, the terms ‘medically necessary’ and ‘medically required’ are not defined. Moreover, these terms are also adopted by the provinces in their health care legislation, without being further defined. The situation with respect to the elusiveness and role of medical necessity in the Canadian health care system is succinctly summarized as follows:

The term is not defined, nor is it susceptible of precise definition; individuals will advocate their preferred definition based on policy goals they seek to attain, so achieving a consensus in defining the term is likely impossible; and, ultimately, an undefined notion permits the health care system to evolve.

The lack of definition of the terms ‘medically necessary’ and ‘medically required’, combined with the comment in section 9 of the Act
that provinces may also insure ‘similar or additional services rendered by the other health care practitioners,’ means that ‘the scope of ‘medically required services’ and indeed all ‘insured health services’ is a policy decision’ largely left to the discretion of the provinces. As a result, what qualifies in one province as an insured health service may not be covered in other provinces. Moreover, and as has been noted by the courts and picked up by commentators, ‘the current legislative framework does not create a right to health care, since the content of insured services is decided as a matter of policy rather than law, and there is no guarantee of procedural fairness in the listing or de-listing of those services.’

4. An Exercise in Discretion

The principle of universality under the Canada Health Act ensures that all residents of a province have access to the insured health services provided for by the provincial plan on uniform terms and conditions. However, although the provincial health plans must cover everyone, they need not, and indeed cannot, cover everything. The reality that demand will always exceed supply of health care resources (in both quantity and scope) means that there will always have to be decisions made as to what services to include for coverage, and which ones to exclude. In its *Summary report: Fiscal Federalism and Health* (2002), the Institute of Intergovernmental relations at Queen’s University, noted ‘the five principles of the *Canada Health Act* and the inter-regional transfers embedded in our fiscal arrangements do sustain reasonably comparable standards for key health services across the country. At the same time, it has to be recognized that inter-regional variation is greater in Canada than in other federations.’

Moreover, the report also notes that although some variation was found within services covered by the Canada Health Act, there is a far greater degree of variation within the ever growing group of services that fall outside the ambit of the Act. As we have seen above, the principle of comprehensiveness means that the provincial health insurance plans must cover all medically necessary hospital and physician services, and that the provinces have a great deal of discretion in determining what constitutes an insured service, in large part because of the lack of definition of ‘medically necessary’ in the Canada Health Act.

The extensive discretion of the provinces and the resulting potential for significant variation in coverage of health services across the country makes transparency in the process by which services are included or excluded from coverage in the public health care system essential if Canadians are going to be satisfied and confident in their health care. Unfortunately, the way in which such decisions are currently made is far from transparent. The process generally involves negotiations between the provincial governments and provincial medical associations. Decisions
regarding which services to list and which services to de-list ‘rely on provincial governments to represent public values and on physicians to apply technical expertise. However, there are strong arguments that this is an impossible task…as the process for determining what is ‘medically necessary’ is too intimately connected to the process for determining compensation rates for physicians.’  One proposal to accomplish this is the establishment of a permanent, independent expert panel whose purpose would be to assess which services to consider medically necessary. Key to the success of this board would be its provision of an explicit, detailed account of the factors considered and relied upon in making its determination to list or de-list a service. Although this would provide a significant improvement over the current somewhat mysterious, ‘closed door’ approach, the logistics could prove challenging. Despite the inevitable difficulties, however, increased transparency is likely necessary if provinces wish to avoid future legal challenges regarding these decisions, especially where more and more health care services are falling outside the clear protection of the Canada Health Act.

5. Challenging Funding Decisions

Given the somewhat elusive manner in which determinations are made with respect to coverage of health services, it is not surprising that there have been cases in which insured persons have taken issue with what services are not covered, and for which they are left to pay for from their own pocket, or seek private coverage. Where these cases have made their way to the courts, they have been brought as constitutional challenges, primarily under section 15 of the Canadian Charter of Rights and Freedoms (the ‘Charter’). Section 15 reads as follows:

Every individual is equal before and under the law and has the right to the equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

In bringing a section 15 claim against the government, individuals who seek to have a certain service covered are essentially claiming that the government is discriminating against them by not funding service ‘x’ which they consider to be medically necessary. Although a detailed discussion regarding how section 15 claims are assessed by the Courts exceeds the scope of this paper, it is important to understand the role and potential impact that a successful section 15 claim could have on the publicly funded system.

One of the many papers submitted to the Romanow Commission (a major study on the future of Canadian health care), discussed the likely
impacts of a successful Charter challenge regarding funding decisions.\textsuperscript{21} The list includes shifting some power over health care reform from the legislatures to the judiciary with a resulting ‘homogenizing effect’ across the provinces. These impacts are a direct result of two facts. First, legislative and policy reforms made by the provincial (and federal) governments need to comply with the Charter, and it is the judiciary that determines this. Where the legislative and policy reforms do not conform to the Charter, they are held to be invalid and the offending portions are struck down. Second, the potential for increased consistency across the provinces (the so-called ‘homogenizing effect’) results from the force of judicial precedent. A decision, especially at the appellate level, in one province will be considered a persuasive authority by the judiciary in the other provinces and any decision from the Supreme Court of Canada is binding across the country. Hence, where a court rules that a province must cover a particular service, this will be a strong indication that other provinces may have to follow suit, though this is somewhat dependant on the specifics of the legislative schemes of each province.\textsuperscript{22} A further result of a successful Charter challenge in this context concerns the mix of public and private funding for health care. Where judicial decisions require a province to fund previously uninsured services, ‘they expand the scope of publicly funded services, shifting the balance between public and private funding.’\textsuperscript{23} Clearly, section 15 of the Charter is a powerful means through which government funding decisions may be challenged and, where successful, altered.

6. Concluding Remarks

Canada’s publicly funded health care system and the Canada Health Act were developed in a time where the realities of delivering medical care were quite different than they are today. Technological developments and an ever increasing diversity in health care practitioners has meant that more and more treatments and services are falling outside the ambit of the Canada Health Act because they are provided neither by a physician, nor in a hospital. The protective umbrella of the Canada Health Act, and the principles on which it is founded, have therefore become less effective at ensuring consistency across the country. Although the development of a more specific definition of ‘medically necessary’ with which the provinces would have to conform in order to continue receiving federal funding for health care has been suggested as one possible solution\textsuperscript{24}, it is not at all clear that this would be effective. There would undoubtedly be strong resistance from the provinces, who would likely view such a step as a serious infringement into an area that they consider to fall within their jurisdiction. In fact, given the ever decreasing amounts of the federal funds to the provinces, the result may be that many of the wealthier provinces determine that the limitations placed on their discretion is not worth the reward. This would leave the courts as the
only means of achieving or retaining some level of consistency with respect to coverage of health care services across the country. This in turn would likely result in more and more individuals being forced to step into the litigation arena in an attempt to obtain funding for services that the province decided were either too expensive or too inefficient or not in sufficiently high demand, to merit coverage. Although it is clear that choices will always have to be made when determining which of an ever expanding list of ever more expensive therapies, treatments and health care services to cover with ever limited resources, equity demands that the impact of such choices not be significantly more burdensome for specific groups depending on their province of residency.

Notes

2 Constitution Act 1867 (30 & 31 Victoria, c. 3. (U.K.)).
3 Constitution Act 1867 (30 & 31 Victoria, c. 3. (U.K)) s. 91.
5 Even in politically conservative Alberta, an informal television poll following the Supreme Court’s decision in Chaoulli et al v. Quebec (AG) et al., confirmed that 65% of respondents were opposed to reform that would allow purchase of insurance to expedite access to treatment for which waiting lists existed (A Channel News, Thursday, June 9th, 2004).
6 See, for example, Alberta Health Care Insurance Act, RSA 1980, c. A-24; Medicare Protection Act, RSBC 1996. c.286.
7 Chaoulli et al v. Quebec (Attorney General) 2005 SCC 35. Following the initial preparation of this paper, the Supreme Court of Canada handed down its decision. Briefly, the Court found that Quebec’s provincial legislation prohibiting residents in that province from purchasing private insurance for services already covered by the public system was in contravention of the Quebec Charter of Rights. The Court was split evenly on the question of whether or not the legislation also contravened the Canadian Charter of Rights and Freedoms. The result means that private health insurance for services covered under the public system is now available in Quebec; however, the situation is unclear for the rest of Canada. There is likely to be a series of constitutional challenges to the various pieces of provincial legislation across the country that limit or prohibit the development of a system of private health care insurance alongside the public system. The Supreme Court will likely find itself faced directly with the question of whether such legislation violates section 7 of the Canadian Charter of Rights and Freedoms in the not to distant future. Whatever the outcome, it is clear that Canada’s public health care system is on shakier ground that it has been
since its inception, and that the debate over its merits and shortcomings will only get louder.


9 See, for example, Alberta Health Care Insurance Act, RSA 1980, c. A-24, s.1; Medicare Protection Act, RSBC 1996. c.286, s.1.


11 These terms are generally used interchangeably in this context, and I will therefore not be distinguishing between them.


14 Although some minor exceptions do exist, these are very specific and are not relevant to our discussion here.

15 Lazar et al., 2002.

16 Ibid at p. 8. The report highlights the effect that the shift in types and sources of medical attention has on funding considerations: ‘when the country-wide framework was established in the postwar decades, hospital and physician services represented the core instruments in health care. In the contemporary period, however, drug therapies and home care are rapidly growing components of that sector. The fact that they also fall outside the scope of the Canada Health Act means that the extent of Canada-wide sharing in health care is shrinking with each passing year.’


18 Ibid at p.356.

19 Presumably any such board would operate along the ‘A4R’ (‘accounting for reasonableness’) lines suggested by Daniels and Sabin in their Setting Limits Fairly (Oxford, 2002).

20 Briefly, because the Charter is enshrined in Canada’s Constitution, all federal and provincial legislation must be consistent with the rights and freedoms it protects. Where a court finds that it is not, the legislation, or offending portions thereof, are struck. So called Charter challenges have also been brought pursuant to Section 7, which guarantees the right to ‘life, liberty and security of the person’. A discussion of these challenges exceeds the scope of this paper.


22 Ibid.

23 Ibid at 86.

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