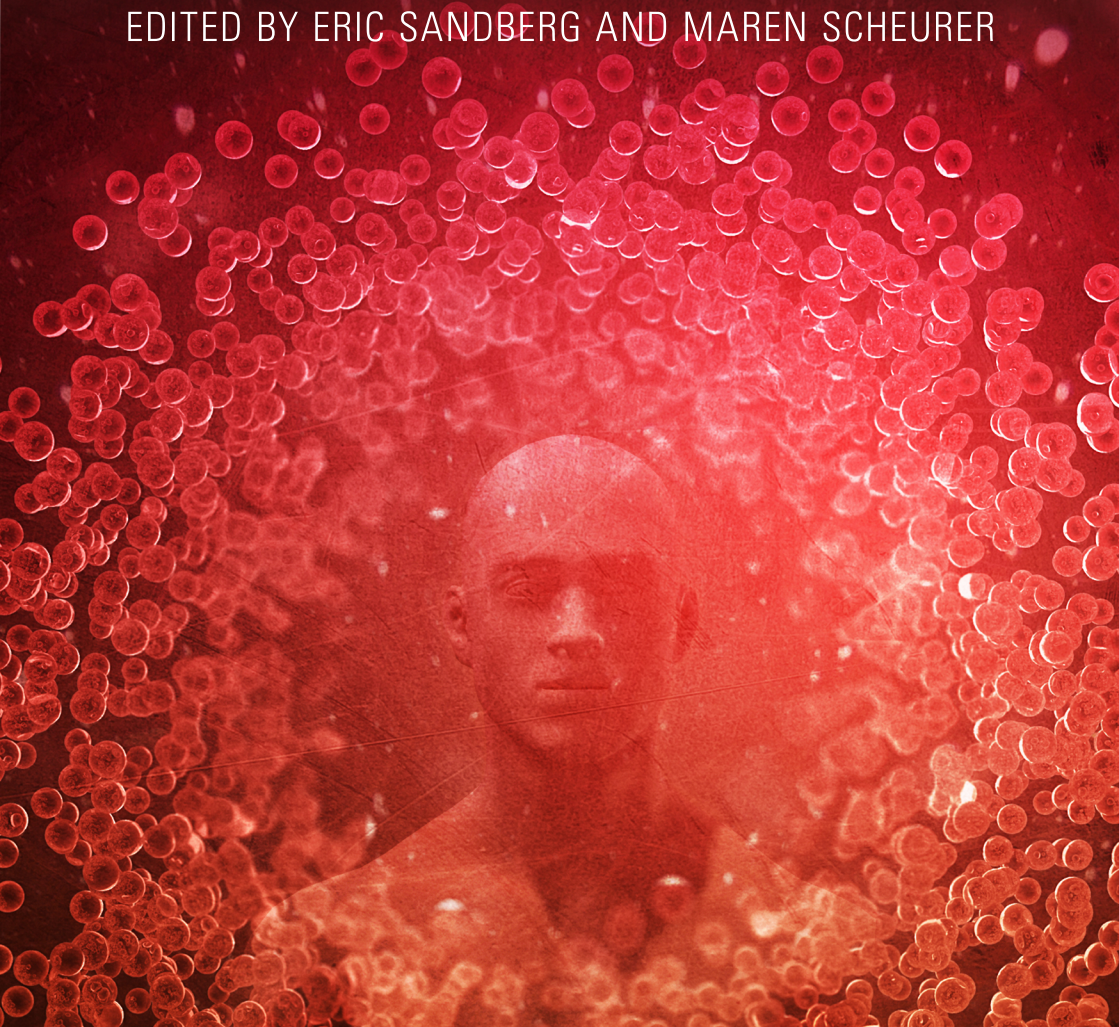# CULTURE, EXPERIENCE, CARE:

(RE-)CENTRING THE PATIENT

EDITED BY ERIC SANDBERG AND MAREN SCHEURER

Culture, Experience, Care

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(Re-)Centring the Patient

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Introduction

Eric Sandberg and Maren Scheurer

1. The Patient under Consideration

In her 1926 essay 'On Being Ill,' Virginia Woolf wondered over the surprising lack of importance accorded to the experience of being a patient: 'Considering how common illness is,' she wrote, and 'how tremendous the spiritual change that it brings,' it is difficult to understand why 'illness has not taken its place with love and battle and jealousy among the prime themes of literature.'[1] We have our great novels of war, she points out, our great poems of romantic love, even our narratives of the quotidian mundane, but not, despite its ubiquitous centrality to the human experience, a substantial literature of illness. To a certain extent, this lacuna in the cultural matrix has been filled since Woolf wrote, and the experience, analysis, and theorisation of illness has come to occupy a more important position in both letters and life. Susan Sontag's claim that 'everyone who is born holds dual citizenship, in the kingdom of the well, and the kingdom of the sick' is not a controversial one.[2] We have learned to acknowledge that while 'we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.'[3]

The chapters collected here are based on papers delivered at the Fourth Global Conference on The Patient, held in Prague in March of 2014, which brought together scholars and students from diverse fields, health care professionals, and many others, from around the world for an intense and rewarding three-day discussion of the many ways in which the idea of the patient can be conceptualised in different cultural, professional, intellectual, and emotional contexts. The diversity and range of the topics dealt with at the conference, and the sometimes conflicting, sometimes converging, perspectives offered by the participants, indicate clearly that issues of patienthood are both urgent and current

These chapters can thus be seen in the context of an on-going, multidisciplinary and international attempt by scholars, health care professionals, and indeed patients themselves to rectify precisely the problematic omission of the patient's experience Woolf identified so long ago, and to place illness, suffering, and mortality at the centre not just of literature and other forms of cultural expression, but of the way we think of ourselves as living beings, incarnate, vulnerable both in mind and body, and inevitably the objects of care. Without seeking to medicalise the entirety of human experience, this approach acknowledges that we are, all of us, at some point, or indeed at many points, in our lives, patients, and thus seek to explore, explicate, and expand our sense of what this means, this state of patienthood, in a variety of intersecting and overlapping contexts. These chapters attempt to put the patient at the centre; not just (although clearly not least) at the centre of the processes, institutions, and ideologies of medical care, as in the now at least theoretically ubiquitous, or at least 'widely advocated' concept of patient-centred

care, but of a wide range of intellectual and social practices.[4] Here, then, we find a focus on the patient as represented in various forms of cultural expression, from literature to TV, to film; on the patient's experience of medical practices; on the wide range of vital ethical issues which surround the patient and his or her care; on the politics of patienthood; and finally on innovative therapeutic approaches involving collaboration and cooperation. While these are clearly diverse topics, arising out of the specific issues, approaches and traditions of different bodies of knowledge, they are bound together by a belief that the patient and the patient's experience represent a point of fundamental importance in human life.

2. Patients at Centre Stage

Experiences within Sontag's 'kingdom of the sick' are bound to differ widely. Each illness, each injury involves different symptoms, different sufferings, and each individual patient will respond differently to them. Even definitions of what being a patient means, and who is or is not a patient are fluid, subject to change, and unstable across cultural and social boundaries. Part of adopting a patient-centred approach in medical and social practices involves acknowledging the variety of experiences patienthood inevitably has in store. How we see ourselves as patients, and are treated as such, depends on innumerable factors such as ethnicity, gender, sexual identity, age, therapeutic setting, care politics, and patient involvement. The chapters in this section remind us of this diversity of patient experience by discussing patienthood and care in fictional renditions of therapeutic encounters (construed in the widest sense).

In recent years, scholars working within the overlapping fields of Medical Humanities and Narrative Medicine have argued that art may provide a unique insight into patient experience, and it is thus an invaluable tool in teaching future medical health professionals to respect the patient's perspective.[5] These chapters show that literature, film, and television have their own claims to make as they put the patient at centre stage and investigate the underbelly of medical practices, that which remains underdeveloped and seldom discussed in therapeutic discourses: the transgressions, the failures, and the ironies of care.

In 'The Human Body as a Construct in Pedro Almadóvar's *La Ley del Deseo* (1987) and *La Piel que Habito* (2011)' Jytte Holmqvist details the Spanish filmmaker's sustained interest in identity politics in two films depicting voluntary and forced sex change. Gender and body emerge as two interrelated but not necessarily coinciding coordinates of a patient's identity. Eric Sandberg's chapter '"Unbearable Conjectures": The Failure of Care in Hilary Mantel's Axon Diptych' is concerned with the breakdown of care along the axis of age, most specifically at the beginning and end of life. Maren Scheurer, in 'The Art of Group Therapy: Satire and Renegotiating Patienthood in Film and Television,' reads the satiric representation of group therapy in a number of television series and the films *The Art of Negative Thinking* and *Fight Club* as a serious engagement with the

theatricality of treatment and with patient agency. Taken together, these chapters represent a first step in examining the diverse ways the patient, and the patient role, can be represented.

3. Centring on Patient Experience

How is it possible to return our focus to the patient? As Joanna Bourke has recently argued, current medical practice all too often tends to rely on its own professionalised discourses, which are subject to what she describes as the 'emotional and aesthetic "thinning" of clinical languages,' and in doing so ignores or elides the patient's own narratives of suffering.[6] For some time, scholars and practitioners have argued that narrative provides a powerful means to partake in the patient's experience, although this was not always properly acknowledged. Rita Charon claims: 'Sick persons and those who care for them become obligatory story-tellers and story-listeners. Hippocrates knew this, Chekhov knew this, Freud knew this, and yet knowledge of the centrality of storytelling was obscured in medicine throughout much of the last century.'[7] A 'rise of interest in the humanities' and 'narrative theory' has, however, helped to strengthen therapeutic disciplines today.[8] The chapters in this section seek to expand the potential of narrative and attention to a patient's experience in medical and pharmaceutical practices.

In 'From the Inlands of Brazil, Healing in Literature and Film,' Davina Marques discusses three ways of approaching the patient in the short story 'Campo Geral' by writer-physician João Guimarães Rosa, and in Sandra Kogut's 2007 film adaptation *Kotum*: a purely medical approach, a narrative approach, and a combined approach to healing. Fabiana Carelli and Davina Marques present a theoretical framework for approaching these patient narratives in 'How to Change Lives with Words.' Aristotelian poetics, narratology, and performative and narrative identity theory provide the means not only to analyse patient narratives, but also to understand why stories do in fact have a therapeutic effect. By paying attention to the narrative acts of both patients and practitioners as more than mere factual claims, we can begin to achieve better patient care. As pharmacists, Djenane Ramalho de Oliveira and Mateus Rodrigues Alves also seek new ways to shift their centre of inquiry to the patient. In 'Understanding the Patient's Medication Experience: Collaboration for Better Outcomes' they use a duoethnographic, dialogic approach to think about how patients' experiences with medication influence their treatment outcomes and how pharmacists can learn to pay attention to these narratives. As all of these chapters indicate, a renewed focus on language, both that of the patient and of the medical practitioner, and on careful and attentive listening, may provide a way to put the patient experience at the centre of therapeutic relationships, and thereby to improve health care outcomes.

4. Patient-Centred Ethics

Centring on patient experience is by no means an easy task, and it is also one which raises a number of important ethical considerations. Who assigns patienthood? Who decides on a treatment? On what grounds? Perhaps the central question is that asked by Ramalho de Oliveira and Rodrigues Alves in this volume, regarding what is more important to consider in a therapeutic environment: the patient's will or the practitioner's superior, that is, more knowledgeable and thus putatively more beneficial, professional opinion. Patient-centred ethics must indeed decide, as Richard Ashcroft points out, whether it puts 'respect for autonomy' first or understands autonomy 'as the end to which the principles of beneficence and non-maleficence are directed.'[9] Unreflective patient-centeredness may easily turn from paternalism to a careless, 'isolationist and consumerist delivery of medical services.'[10] If it is to provide an answer to clinical dilemmas, we must therefore carefully discuss its philosophical foundations, predecessors and alternative models, its practical feasibility and potential consequences for individual patients and institutions.

The question of patient-centred ethics, and of the ethics of patient-centred care, is approached in this section from three different angles. Through a close reading of Shakespeare's *Hamlet* Peter Bray interrogates the ethical dilemmas involved in institutional care in his chapter 'Hamlet Is Sick: Patient Care in the Total Institution.' He uses Shakespeare's tragedy as a springboard to discuss the difficulty of diagnosing and treating a reluctant and maybe even questionable patient, as well as the tragic consequences of the disempowerment of inmates in institutions. Iva Apostolova's chapter '"When I'm Afraid I Will Trust In...?"' uses Kant's ethics to argue against another disenfranchisement of patients in a controversial area: euthanasia. This is a discussion that goes to the heart of the ethical questions involved in the concept of the patient and patient autonomy. M. Jane Markley's chapter 'Reluctance and Resistance: How Do We Break the Cycle?' shifts the focus towards advance care planning, but also argues for education, open dialogue, and proper legislation to assist patients in having a say in their own care up to and including their deaths. What is indicated here is the centrality of ethical considerations, and the consideration of ethics, to the whole range of questions surrounding the notions of the patient and patient-centred care.

5. Patients and Politics

The insight that patient-centred care can only be achieved within a sound ethical framework calls for political action whenever this framework is found lacking, as Markley's chapter indicates. Health care is not simply shaped by the players directly involved in therapeutic relationships. Frederico Toth suggests that different factors such as government ideologies, the institutional organisation of medical professionals, culture, and national values shape healthcare policies, and the actors in this field may include the state, health care practitioners, insurance

companies, trade unions, the pharmaceutical industry, and other influential interest groups.[11] This means that the act of care is as much political as it is medical, and that effective conceptualisation of the patient is impossible without due consideration of the political contexts within which care is delivered.

Within this maelstrom of conflicting interests and policies, patients have often found it difficult to assert themselves. Health activism and patient interest groups have developed, in part, in response to this. Their demands, however, must eventually find an institutional response if they are to contribute to solving the patients' predicaments, and must be discussed in fields as varied as sociology, anthropology, pedagogy, and law. Proper medical care, as envisioned by the chapters in this section, is buffered by trusting patient-doctor relationships, cross-cultural collaboration, mindful legislation, and thorough education.

In Ana Maria Borlescu's 'Negotiating Identity in the Patient Role: Tales from the Romanian Medical System,' the interaction of corruption and cultural beliefs is identified as a complicated substrate of the Romanian health system. The overlap of two different cultural approaches to health care are also the focus of Andra le Roux-Kemp's 'Mental Health and Ethno-Etiologies in Southern Africa: Towards Collaborative Therapeutic Relationships.' Discussing the beliefs and practices of traditional healers, she argues for a stronger collaboration between traditional and Western medicine to ameliorate the dire situation of mental health care in Southern Africa. Ana Lúcia Abrahão, Dalvani Marques, Marcos Antônio Albuquerque de Senna, Sérgio Aboud, Marilda Andrade and Ândrea Cardoso de Souza introduce the teacher's perspective in 'Working within Groups of Teachers: Teaching and Learning Implications in Health Services' and give an outline of a pedagogical approach designed to improve mental health services via the education of both students and teachers. Overall, these chapters offer a picture of the many complexities involved in thinking about the patient and patient care in differing cultural contexts, and of some of the ways pedagogic practice can respond to these complexities.

6. Collaborative Therapeutic Approaches to the Patient

As the previous sections have already suggested, putting the patient at the centre of medical and social practices cannot simply be accomplished by re-shifting the focus within individual relationships between doctor and patient, or by shifting the emphasis from the delivery to the consumption of medical care. Cultural, political, ethical, and institutional factors determine the extent to which patient-centredness in medicine, psychology, and pharmacy can be achieved. What is more, dyadic therapeutic relationships are no longer the norm in our highly specialised medical facilities, where patients and groups of patients interact with a variety of specialists and care personnel. The final section thus presents two different models of collaborative therapeutic approaches in which patients are

encouraged to take an active part in their healing while interacting with medical practitioners.

Ann Fantauzzi, Patricia A. Fennell, Kelly A. Bertrand and Sara Rieder Bennett present a practical application of the Fennell Four Phase Treatment in two inter-related chapters. 'A Programme for Helping Others as We Help Ourselves' focuses on Ann Fantauzzi's personal experience as a volunteer in Uganda and as a sufferer from reverse culture shock upon her return. It points out some of the ways in which artistic practice can assist in integrating traumatic experiences into normal life. The companion chapter 'Volunteerism, Culture Shock and Trauma: Making the Transitions Easier Using the Arts and the Four Phase Model' adds an outline of a collaborative therapeutic approach to effectively deal with culture shock and trauma. In 'Compassionate Communication,' Nancy Billias describes the benefits of another collaborative approach: the Schwartz Centre Rounds, a holistic and participatory health care practice which destabilises traditional hierarchies within medical institutions and emphasises an attentive mutual openness to the other. The attentiveness proposed by these chapters to both the individual self as it experiences and recovers from trauma, and to the other members of a caring community offer a potential way forward through some of the dilemmas of care.

7. The Patient in Question

Patient: '[I]t seems a modest / word,' muses Eve Kosofsky Sedgwick at the beginning of her psychotherapy memoir *A Dialogue on Love*, 'that makes no claim / to anything but – wanting / to be happier / and wanting, it's true, someone else to shoulder a lot of agency in the matter of my happiness.'[12] Even as Sedgwick embraces the term for herself, she points out its etymological and contextual ambivalence. In the patient role, the fear of passive suffering meets with the hope of being taken care of by loving hands, the reluctance to submit to authority with the temptation to give up responsibility. The claims made for a more patient-centred form of care surely carry their own ambivalences, including the shortcomings of the disputed term 'patient,' but not solely resting on them. Where do agency, responsibility, and, indeed, happiness, shift to when we realign our practices and our thinking on the patient? Where does patient-centredness leave medical and non-medical staff, human beings with needs and claims of their own? Can patient-centred ethics and politics accommodate supraindividual concerns, such as social, cultural, and ecological problems arising within increasingly complex medical communities? It seems we have only just begun to comprehend who the patient is, whom and what he or she interacts with, and where we may sensibly place our centre within this vast field. In this spirit, we want to understand these contributions not as final statements on patient-centred care but as an invitation to extend the debate even further.

Notes

[1] Virginia Woolf, *On Being Ill with Notes from Sick Rooms by Julia Stephen* (Ashfield: Paris Press, 2012), 3-4.

[2] Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus & Giroux, 1978), 3.

[3] Ibid.

[4] Paul Little et al., 'Preferences of Patients for Patient Centred Approach to Consultation in Primary Care: Observational Study', *BMJ* 322, No. 7284 (2001): 468, accessed 25 June 2014, http://www.bmj.com/content/322/7284/468?view=long&pmid=11222423.

[5] Rita Charon et al., 'Literature and Medicine: Contributions to Clinical Practice', *Annals of Internal Medicine* 122, No. 8 (1995): 599.

[6] Joanna Bourke, 'Our Anaesthetic Times', *Aeon Magazine*, 14 May 2014, accessed 1 July 2014, http://aeon.co/magazine/being-human/why-it-helps-to-put-pain-into-words/.

[7] Rita Charon, 'Narrative Medicine: Attention, Representation, Affiliation', *Narrative* 13, No. 3 (2005): 261.

[8] Ibid.

[9] Richard E. Ashcroft, 'Teaching for Patient-Centred Ethics', *Medicine, Health Care and Philosophy* 3 (2000): 290.

[10] Lois Shepherd and Mark A. Hall, 'Patient-Centred Health Law and Ethics', *Wake Forest Law Review* 45 (2010): 1429.

[11] Frederico Toth, 'The Choice of Healthcare Models: How Much Does Politics Matter?', *International Political Science Review* 34, No. 2 (2013): 169.

[12] Eve Kosofsky Sedgwick, *A Dialogue on Love* (Boston: Beacon Press, 1999), 1.

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Part 1

Patients at Centre Stage

The Human Body as a Construct in Pedro Almodóvar's *La Ley del Deseo* (1987) and *La Piel que Habito* (2011)

Jytte Holmqvist

Abstract
This chapter explores the representation of the human body, with a particular focus on *transgenesis* and *transgenderism*, in Pedro Almodóvar's *La Ley del Deseo (Law of Desire)* (1987) and *La Piel que Habito (The Skin I Live In)* (2011). Although released 24 years apart, both films represent the female body as a construct that mirrors the fluid reality of the postmodern era in which this body is found. Thus, as the physical space of our global habitat has become ever more artificial, fragmented and unfixed so, too, the screened individual is a 'floating and drifting self,'[1] a being that has become increasingly hard to define. Known for his unconventional themes and plots, Almodóvar here challenges traditional notions of what is male and female and the two concepts merge. The viewer explores a fluid corporeal and gendered territory as the once biologically male protagonists are subjected to either voluntary or forced sex change, leaving them physically transformed into a female although their thought patterns are still partly male. Gender and body are open to new interpretations as the filmmaker demonstrates how the human body (and skin), in a sexually permissive, socially and culturally less rigid era, can be surgically and bio-medically altered through a number of procedures, a process which by its end result at times reminds of a Deleuzian *becoming*. The screened individual is physically changeable, body and mind unfixed concepts, as one identity is left behind and another is adopted. Almodóvar's man/woman/construct resembles what Zygmunt Bauman has called 'denizens of' a 'postmodern habitat' that 'have a rootless and inconclusive existence.'[2] The argument is inserted into a Baumanian and Deleuzian framework and the fluidity of the human being is analysed from a partly postmodern perspective.

Key Words: Transgenesis, transgenderism, postmodernity, fluidity, body, gender, male, female, Almodóvar.

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1. Introduction

In focus in this chapter is Pedro Almodóvar's representation of transgenesis and transgenderism in *La Ley del Deseo* (1987) and *La Piel que Habito* (2011), the latter based on Thierry Jonquet's 1984 book *Mygale*. Both films represent the female body as a construct that mirrors the fluid reality of the postmodern era where this body is found. Thus, as the physical space of our global habitat has become increasingly artificial, fragmented and unfixed, so too the screened

postmodern individual is a 'floating and drifting self,'[3] a being not always easily defined. Known for his unconventional themes and plots, Almodóvar here challenges traditional notions of what is male and female and the two concepts merge into one. The viewer explores a fluid corporeal and gendered territory as two of the once biologically male protagonists undergo an either partly voluntary or forced sex change, leaving them physically transformed into a female although their thought patterns are still, to some degree, male. Gender and body are hence open to new interpretations as Almodóvar demonstrates how in a sexually permissive, socially and culturally less rigid era, the human body and skin can be anatomically transformed through *vaginoplasty* and other body-altering surgical procedures, a process which by its end result at times reminds of a Deleuzian *becoming*. The screened individual is physically changeable, body and mind unfixed concepts, as he leaves one identity behind and adopts another. Almodóvar's man/woman/construct resembles what in Bauman's words are 'denizens of' a 'postmodern habitat' with a 'rootless and inconclusive existence.'[4] The upcoming argument is inserted into a Baumanian and Deleuzian framework and the fluidity of the human being is analysed in a partly postmodern light.

2. The Fluid Narrative Development of Almodóvar's Filmic Oeuvre as Reflective of a Transient, Unfixed Society and Human Gender

Almodóvar's sixth and eighteenth feature films share a number of commonalities and are part of a more than three-decade long coherent repertoire that reflects the transformative times Spain has undergone ever since the beginning of democracy from the late 1970s to the beginning of the 1980s. Thus, the early films *Pepi, Luci, Bom y Otras Chicas del Montón* (1980) and *Laberinto de Pasiones* (1982), shot on a shoestring budget and featuring cameo performances of Almodóvar himself, represent the city of Madrid as a concrete fun-filled space to which the characters relate in a manner that reminds of the notion of urban space as incomplete without the energy conferred to it by its people. Specifically from a Lefebvrian perspective, 'physical space has no "reality" without the energy that is deployed within it.'[5] These two light-hearted films released in the wake of Franco's death in 1975 were followed by the essentially anticlerical *Entre Tinieblas* (1983), which delivered a not overly veiled pun on the Catholic Church and mirrored the increasing rift between church and state in contemporary Spain. In 1984, the neorealist *¿Qué he Hecho yo Para Merecer Esto!!* was released. *Matador* (1986) and *La Ley del Deseo* (1987) appeared subsequently. In conjunction with the latter, Almodóvar's own production company *El Deseo* was established and both the film and the company inspired by its name capture the essence of Spain's liberating 1980s and the sexually frivolous *Movida* years. This film is also the first to fully explore and normalise homosexual relationships, in the sense that they are here treated in a respectful and generally nuanced manner. Come the 1990s, Almodóvar entered his so-called 'blue period' of filmmaking,[6]

where Paul Julian Smith's Picasso-inspired reference mirrors a move into a more problematic, ever more postmodern urban space. In an era that is gradually more forward-looking and global in perspective, the film characters still often appear to be lost in a metropolis battling issues like drugs, sexual violence (not uncommonly rape) and AIDS. In a number of these more recent films, the urban ordeals faced by the protagonists are symbolically witnessed by an omnipresent, voyeuristic film camera (they are thus doubly screened, also by Almodóvar's own camera) and the media becomes an intrusive force which relentlessly lays bare the now openly publicised fate of these individuals. As the cineaste has embarked on his journey through the 21st century his films are gradually less concerned with the city as such. While the geographical setting is still generally Madrid, the plots now largely unravel within internal spaces (mainly apartment buildings). The Spanish capital is instead often represented by way of scale replicas which imitate the city without being equivalent to the real space. As a simulacrum of the real, this mock version of the metropolis becomes a construct rather than a concrete environment. The notion of external Madrid thus lingers within a space where the recreated, inauthentic urban environment is rich in postmodern pastiche.

In line with the partial artificiality of the urban space, Almodóvar's protagonists themselves become more multi-facetted and less easily defined as the filmmaker experiments with the representation of the human body and an increasingly fluid human identity. As part of this, the cross-dresser or the transvestite gains prevalence in the filmic narrative, as does the transsexual already introduced in *La Ley del Deseo* through character Tina Quintero (played by Spanish veteran Carmen Maura. Real transsexual Bibiana Andersen, aka Bibiana Fernández, stars also in this film). Thus, as contemporary society has become more globalised, there is an ensuing social and cultural fluidity that also includes less easily defined gender roles and representations. In a Butlerian manner, gender has become increasingly performative in character and Almodóvar's now postmodern Madrid reflects these transformative societal changes. In his films, city and citizen become unfixed urban versus anatomical landscapes which, experimental in character, are also partly constructs.

Further reflective of the screened distancing from Madrid as an external space are a number of 21st century films whose plots develop in other parts of Spain or in the fluid airspace above the Iberian Peninsula – as seen in Almodóvar's most recent highflying feat *Los Amantes Pasajeros* (2013). Laden with political metaphors, the film seems to conform to Bauman's definition of our postmodern era as one of *perpetuum mobile*.[7] Similarly, in the preceding multiple award-winning *La Piel que Habito*, Madrid does not generally feature either, apart from in a few brief scenes. Instead, the cinematic narrative develops largely within a rural mansion in the province of Toledo. Here, as shall be seen, the 'housed gender'[8] of the human body is visually embraced throughout and seemingly considered more important than any purely geographical landscape.

Rather, a both physical and mental human map is created on screen. What is important is no longer the visual portrayal of the city but the exploration of the human mind and the postmodern, unfixed body experimented on.

3. Positive and Negative Screened Representations of Transsexuality

This chapter holds that an individual held captive within the walls of this rural residence shares commonalities with aforementioned, all the more mobile Tina Quintero in *La Ley del Deseo*. Both Tino/Tina, and Vicente/Vera in *La Piel que Habito* are subjected to an ordeal as transformative as the global era of which they are a part. However, Vicente's complete physical and possibly also mental alteration contrasts starkly with the essentially voluntary, more positive sex change undergone by Almodóvar's 1987 male/female protagonist. While Tino's sexual reassignment surgery in this earlier film was the result of an incestuous childhood relationship with a father who approved of his son undergoing a sex change that transformed him from male into a female, as an adult Tina fully embraces her female persona. Tino has thus become Tina and *desire* runs like a governing idea throughout the entire movie. It is not only envisaged in the platonic fraternal bond between the man turned 'woman' and her playwright brother Pablo, but desire also comes to (homo)sexual fruition in a number of graphic sex scenes between Pablo and his two male partners. Ultimately, Tina's own celebratory attitude to her now female existence is also characterised by a zest for life and an appreciation of her acquired sex. Her largely asexual relationship with both men and women and her full identification with her transformed gender becomes yet another platonic love affair – no longer between siblings but with regard to an individual ultimately proud of her new body and of her somewhat altered identity. Tina Quintero could be regarded as a 'sexual intermediary.'[9] As such, she inhabits a fluid territory between male and female, and although she sometimes nostalgically reflects on her previously male persona she dedicatedly performs her femininity in a double sense of the word: not only as a man turned woman in a film that largely explores Tina's gender and identity but also when she plays the main female part in Cocteau's 1930 play *La Voix Humaine*, a staged performance that Almodóvar represents on-screen, thus merging theatre and film.

While Tina's character thus adheres to Judith Butler's theories of gender performativity in the sense that she repeatedly performs her gender (not only on stage but also in her own everyday life), the screened merging of body and mind means that her acquired gender is, after all, perhaps more natural than constructed. As she moves comfortably within her surgically enhanced body, Tina often comes across as a more fully-fledged woman than several others around her and her body becomes an '"event" of becoming.'[10] Deleuze has defined this verb as one 'with a consistency all of its own; it does not reduce to or lead back to, "appearing," "being", "equalling" or "producing."'[11] While this 'event' of having entered a new body is always in focus in the film, Tina's organic relationship also with her urban

environment – which in one acclaimed street scene becomes eroticised – means that she has voluntarily become 'the other.' In other words, as an individual not born a woman 'she has to pass through this difference, she has to appreciate this difference as being at once symbolic and artificial.'[12] Almodóvar's bold protagonist becomes symbolic of (post)modern fluidity, a society which is not as much fixed and predictable as changeable and in constant motion. Guided by such a fluid identity, Tina Quintero feels at home or 'chez soi'[13] everywhere – not only within her urban environment but also within her transformed body and, to a certain extent, her mind. She also apparently exchanges 'a portion of' her 'possibilities of security for a portion of happiness.'[14] Because, although troubled, Tina embraces life and change on a number of levels.

4. *The Skin I Live In:* A Transformed Body and Identity?

As highlighted earlier, in the all the more dark and unsettling *La Piel que Habito*, the viewer partakes in an anatomical and mental exploration of the human body and mind. It is anything but a pleasant experience. Indeed, the film is said to be '[d]rawing on aspects of the thriller, *film noir*, science fiction in its medical version, and psychological terror' and it 'explores extremes of vengeance, abuse of power, madness, amorality, and unhealthy passion, expanding on themes introduced in much more attenuated form in *Matador* (1986) and *La Ley del Deseo/Law of Desire* (1987).'[15]

A film ripe with literary and cinematic references, it is thematically and technically inspired by, perhaps primarily, Georges Franju's 1960 horror *Les Yeux sans Visage* and it also resembles James Whale's *Frankenstein* (1931), as well as Hitchcock's *Rebecca* (1940) and *Vertigo* (1958). Bergman's *Persona* (1966) additionally comes to mind in Almodóvar's repeated use of doubles or mirror images. His screened *doppelgänger* not only reminds of characters in Jonquet's harrowing novel but the double also serves to fully replace an individual mourned after her suicide triggered by an accident that leaves her facially and physically unrecognisable. By contrast, the later surgically successful transformation of another individual also trapped within an unrecognisable skin leads to a new female physique which, when visualised on screen, adds a contradictory sense of aesthetic appeal to the scenes.

While the filmmaker remains faithful to Jonquet's text, he also takes cinematic liberties. His film is distinctly Almodovarean with regard to the sleek cinematography, the vivid colour scheme and the narrative pace as well as a set of characters that represent a number of basic human traits. Through the use of flashbacks and flash-forwards the spectator is taken from present to past back into the present again. As part of the journey back in time, Almodóvar paints a more complete picture of the protagonists before and after a narrative turn of events crucial to the storyline. But these flashbacks also allow us to explore the human mind – in a visual sense (in Jonquet's original narrative, Vincent Moreau's ordeal

predominantly unravels in a manner similar to a Joycean stream of consciousness).
The English translation of Jonquet's book as *Tarantula* – with a clear reference to
an insect also known as 'wolf spider' or *Lycos tarantula*[16] – places the initial
narrative focus on a 'master' whom Vincent secretly refers to as 'Mygale.' In the
text, Richard Lafargue is indeed equalled to a spider:

> [...] slow and secretive, cruel and ferocious, obsessed yet
> impenetrable in his designs, hidden somewhere in this dwelling
> where he had held you captive for months: this luxury web, this
> gilded cage where he was the jailer and you the prisoner.[17]

Almodóvar's film title, on the other hand, rather gives immediate preference to
the human captive within a second skin, a concept or scenario which a number of
critics have compared with Didier Anzieu's notion of *le moi-peau*. Thus, e.g. Gayle
Salamon argues that

> [i]n *The Skin Ego,* Anzieu takes Freud's formulation of the
> bodily ego as a starting point and postulates the ego as an
> envelope that contains the psyche in the same way as the skin
> contains the body.[18]

Indeed, human and an artificially enhanced second skin become key words in a
film that revolves around a series of events triggered by the nocturnal abduction of
a man presumed to have raped the daughter of a Toledo-based plastic surgeon. To
avenge this 'deed,' Doctor Robert Ledgard (or Richard Lafargue in the French
novel) subsequently sets out to transform the young man into a woman by forcing
him to undergo vaginoplasty, breast implantation surgery and
xenotransplantation,[19] which involves providing him/her with a second skin that is
resilient to any external threats, through *transgenesis* – by which 'genetic
information from a pig cell'[20] is transferred to a human cell:

> I've given the name "Gal" to the artificial skin I've been working
> on in recent years [...]. This skin is resistant to every insect bite,
> which means a natural barrier to malaria, for example. Naturally,
> I've carried out a rigorous quality control on the tissues
> implanted in mammals, specifically in Athymic mice, and the
> results have been spectacular. This leads me to suppose they
> would be equally positive in human mammals.[21]

While the transsexuality in *La Ley del Deseo* thus resembled a Deleuzian
process of 'becoming woman' and the individual transformed seemed to
comparatively effortlessly embrace a new female appearance while at the same

time she welcomed a corresponding partly altered persona and personality, in *La Piel que Habito* '[t]ranssexuality [...] is imposed as a punishment, as an instrument of domination and revenge.'[22] This is particularly true in terms of the facial reconstruction surgery that becomes an intrinsic part of Vicente's ordeal and that deeply uproots this individual from a previously male existence. Through this complete physical makeover, Vicente's male attributes vanish altogether and Vera appears as his metamorphosed alter ego. It comes as no surprise that Vera is strikingly similar to Dr. Ledgard's dead wife Gal (and, again, a further sadistic twist comes when the new skin forever to be inhabited by Vera is also given the name Gal).

The question around which the narrative revolves is whether or not a complete physical transformation will irrevocably lead to an equally transformative identity change. While Ledgard himself proclaims that 'Our face identifies us. For burn victims, saving their lives is not enough. They need to have a face, even if it's from a corpse,'[23] and the name 'Vera' suggests an association with the Latin word *verus*, meaning 'true'[24] and also 'faith,' the only truth to which she remains faithful is her own memories of whom she initially was. By staying true to her original identity after six years as a hostage, an ordeal which has left her physically transformed into a woman, Vera who is still Vicente deep inside, seems to conform to Deleuze's notion of becoming as something that is 'always double, that which one becomes becomes no less than the one that becomes – block is formed, essentially mobile, never in equilibrium.'[25] Thus, although Vera is anatomically a construct that perfectly resembles a real woman, her original identity ultimately remains intact. Or rather, it has become a dual identity, one which is partly male/Vicente and partly female/Vera (this seems to conform with Deleuze's notion of identity as one 'always in motion, no matter how rooted it seems or how fixed').[26] Through years of resilience (on her bedroom wall each day of her captivity and the repeated, charged word 'respiro' are elaborately inscribed) and a mental refuge found in yoga, a final turn of events leaves Vera able to shoot dead her captor, escape and regain her freedom. Her final voiced identification of herself as Vicente when reunited with her mother in the city as the film draws to a close seems to indicate that a person's identity is not as 'readily' transformable as the body s/he inhabits. And an uprooted, de-territorialised individual is now finally re-territorialised.

5. Conclusion

This brief chapter has sought to highlight the complexities of the postmodern individual characterised by an unfixed body and identity that breaks away from male and female gender stereotypes. Pedro Almodóvar has encapsulated these human complexities in two films that are both similar and radically different. Through representing the screened transsexual as alternatively an individual undergoing a fluid, seemingly positive, process of becoming a woman (while the unscreened surgical operation is bound to have been intrusive also in *La Ley del*

Deseo, it results in a female who seems so at ease in her new skin that she cannot be considered a construct through and through) and a victim to forced gender reassignment surgery, Almodóvar leaves us with one last question: Is our human identity so closely connected to our body that it can become as transformed as this physical shell or can our identity be regarded as separate from the body and, thus, remain more or less intact despite a complete physical transformation? While the filmmaker himself has established that '[a]lthough Vera has changed skin, she hasn't lost her identity,'[27] an ultimately open-ended film seems open to suggestions.

Notes

[1] Zygmunt Bauman, *Postmodernity and Its Discontents* (Cambridge, England: Polity Press, 1997), 21.

[2] Dennis Smith, *Zygmunt Bauman: Prophet of Postmodernity* (Malden, MA: Polity Press, 1999), 150.

[3] Bauman, *Postmodernity and Its Discontents*, 21.

[4] Smith, *Zygmunt Bauman*, 150.

[5] Henri Lefebvre, *The Production of Space*, trans. Donald Nicholson-Smith (Oxford, England, and Cambridge, MA: Blackwell 1991), 13.

[6] Paul Julian Smith, *Contemporary Spanish Culture: TV, Fashion, Art and Film* (Malden, MA: Polity Press, 2003), chap. 6.

[7] Zygmunt Bauman, *Culture in a Liquid Modern World* (Cambridge and Malden: Polity Press, 2011), 19.

[8] Giuliana Bruno, *Atlas of Emotion: Journeys in Art, Architecture, and Film* (New York: Verso, 2002), 64.

[9] Magnus Hirschfeld, *Die Transvestiten* (Berlin: Pulvermacher, 1910), 7.

[10] Julia Coffey, 'Bodies, Body Work and Gender: Exploring a Deleuzian Approach', *Journal of Gender Studies* 22, No. 1 (2013): 6.

[11] Gilles Deleuze and Félix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. B. Massumi (London: Athlone Press, 1988), 239.

[12] Damian Sutton and David Martin-Jones, *Deleuze Reframed*: *Interpreting Key Thinkers for the Arts (Contemporary Thinkers Reframed)* (London and New York: I.B. Tauris, 2008), 47.

[13] Anthony Elliott, ed., *The Contemporary Bauman* (Oxon, NY and Canada: Routledge, 2007), 261.

[14] Bauman, *Postmodernity and Its Discontents*, 3.

[15] Francisco A. Zurian, '*La Piel que Habito*: A Story of Imposed Gender and the Struggle for Identity', in *A Companion to Pedro Almodóvar*, eds. Marvin D'Lugo and Kathleen M. Vernon (Malden, MA: John Wiley & Sons, 2013), 263.

[16] 'Online Etymological Dictionary', Douglas Harper, last modified 2014, accessed 25 November 2013, http://www.etymonline.com/index.php?term=tarantula.

[17] Thierry Jonquet, *Tarantula: The Skin I Live In*, trans. Donald Nicholson-Smith (London: Serpent's Tail, 2011), 50.

[18] Gayle Salamon, 'The Bodily Ego and the Contested Domain of the Material', *Differences: A Journal of Feminist Cultural Studies* 15, No. 3 (2004): 106.

[19] Juan Jorge Michel Fariña, 'Almodóvar con Sófocles: Responsabilidad Trágica y Fábrica del Cuerpo Humano. *La Piel que Habito*. P. Almodóvar, 2011', *Ética y Cine Journal* 1, No. 1 (2011): 18.

[20] Pedro Almodóvar, *La Piel que Habito* (Spain: Canal+ España, Blue Haze Entertainment, and El Deseo S.A., 2011). DVD.

[21] Ibid.

[22] Zurian, '*La Piel que Habito*: A Story of Imposed Gender and the Struggle for Identity', 271.

[23] Almodóvar, *La Piel que Habito*.

[24] 'Behind the Name', last modified 2013, accessed 1 December 2013, http://www.behindthename.com/name/vera-1.

[25] Deleuze and Guattari, *A Thousand Plateaus*, 305.

[26] Sutton and Martin-Jones, *Deleuze Reframed*: *Interpreting Key Thinkers for the Arts*, 45.

[27] 'EL DESEO presents a film by ALMODÓVAR:THE SKIN I LIVE IN', last modified 2013, accessed 30 March 2014,
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'Unbearable Conjectures': The Failure of Care in Hilary Mantel's Axon Diptych

Eric Sandberg

Abstract

Hilary Mantel is perhaps the preeminent writer of the human body in distress and the social repercussions this distress entails. This focus on the corporal and on the social and conceptual structures that circle around it is clear in both her historical fiction and her non-fiction, as well as in a number of her contemporary literary novels. This chapter focuses on Mantel's first two published novels, the 1985-1986 diptych *Every Day Is Mother's Day* and *Vacant Possession*, in which Mantel begins her exploration of the horrific potential of human corporality by inverting the network of meanings frequently associated with two types of caregiving: care for children and care for the elderly. This occurs through the intertwining of two superficially very different families and two different literary genres. Evelyn Axon and her malignant, and according to the social services mentally sub-normal daughter, Muriel inhabit a world of gothic horror. Central to their story is a persistent failure of caring manifested in, for example, Muriel's status as a fundamentally 'wrong' child who eludes and deceives the hapless attempts of her institutional caregivers, and her pregnancy which results in both infanticide and matricide. Parallel and connected in terms of plot is the bleak social realism of the 'normal' Sidney family, whose own failures of care (a miserable domestic life, petulant children, extra-marital affairs, and neglect of their aged relatives – all the familiar material of mid-century realist literary fiction) are given a terrible slant by their proximity to, and gradually increasing involvement with, the horrific tale of the Axons. Mantel thus envisions a world in which 'normal' processes of caregiving, both biological and social, are seen as fundamentally tainted.

Key Words: Hilary Mantel, Booker Prize, body, infanticide, matricide, evil, childcare, pregnancy, senility, senior care.

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1. Introduction

Hilary Mantel has earned considerable attention for her Booker Prize-winning historical novels *Wolf Hall* and *Bring up the Bodies*. This double award was unusual on a number of levels: Mantel is the first woman and the first English writer to have won the prize twice; the 2012 award was the first given to an overt sequel; and finally while the Booker had previously been awarded to historical novels, there nonetheless persists what Merritt Moseley describes as 'a small but insistent critical voice that decries this fact, arguing that historical fiction is escapist [...].'[1] Unfortunately, this attention and controversy has obscured the

contours of Mantel's oeuvre, much of which can be placed within the realist tradition of the contemporary novel described by Margaret Atwood, amongst many others, as central to the twentieth and twenty-first century's vision of the literary.[2] This element of Mantel's work has attracted little attention. Her only other brush with fame arose from an essay on the Duchess of Cambridge's pregnancy. Mantel described the duchess as 'a shop-window mannequin, with no personality of her own' whose 'point and purpose' is 'to give birth.'[3] Perhaps predictably, this aroused the ire of the tabloid press, which misinterpreted her comments as 'a bitter attack.'[4] This furore, while not itself particularly interesting, reveals one of Mantel's primary interests, for her discussion of royal bodies and the ways in which historical tragedy can be inscribed upon them acts as a bridge between her historical fiction and her contemporary novels: both are preoccupied with the body, the biological processes that transform it, and the social implications of these changes. This interest is clear in Mantel's memoir, *Giving up the Ghost*, in which she writes of her own body's failures and society's reactions to them. Naturally, much of this response is medical: 'I complained I had a pain in my legs,' Mantel writes, 'and I went to the doctor: that was my big mistake.'[5] However, Mantel is also concerned with the social interpretation of illness and the ways it impinges upon identity, reducing the self to 'a thing done to, a thing operated on.'[6] In this chapter I will examine the way this preoccupation is articulated in Mantel's 1985-1986 diptych *Every Day Is Mother's Day* and *Vacant Possession* as a failure of care for children and the elderly.

2. Two Worlds: The Axons and the Sydneys

Every Day is Mother's Day and *Vacant Possession* are set a decade apart in the 1970s and 80s, and deal with two very different families, the Axons and the Sydneys. Evelyn and Muriel Axon live in a dilapidated house on Lauderdale Road. The widowed Evelyn is a retired medium; her daughter Muriel has been assessed by social services as 'subsisting at a marginal level of social adequacy' resulting from seclusion and 'subaverage intellectual functioning.'[7] Evelyn's assessment is more direct: she believes her daughter is 'a hopeless idiot.'[8] The Axons are almost totally isolated, disturbed only by the harassment of a legion of unwelcome and uncanny spirits who seemingly haunt the house and make Evelyn's life a misery. Yet Muriel has somehow become pregnant: this is one of the primary facts of *Every Day Is Mother's Day*, and its consequences are central to *Vacant Possession*.

So bizarre and unpleasant is the Axon's life that it might be seen as a gothic intrusion into the realistic fabric of the novels embodied by the Sydneys, a more traditional family whose story tends towards bleak social realism. The unmarried Florence Sydney has given up work at the Department of Health and Social Services to take care of her elderly and demented mother, while her brother Colin lives with his wife Sylvia and their three (later four) children. Colin is a history teacher, Sylvia a housewife; their marriage is not a happy one, but it is normally

unhappy: their jerry-built modern house with its 'tiles coming loose'[9] is haunted by nothing more than the squalid emptiness of modern life. Their family problems – adultery, teenage pregnancy, the angst of the modern individual – are the very stuff of the twentieth-century literary novel.

Nonetheless, the Sydneys and the Axons exist in greater proximity than their differences might seem to imply. The novels' plots revolve around the gradual intertwining of their lives, but even before these plot developments occur, there are indications that the 'normal' Sydneys and the 'abnormal' Axons are more closely related than might seem probable. An initial textual sign of this is the fact that although the Sydney family home is on Lauderdale Road, and the Axon's on Buckingham Avenue, the Axon's house is, as Colin realises with some surprise, 'next door, in fact.'[10] This 'hidden' proximity is a sign of the unexpected closeness of the nightmarish world of the Axons to the everyday world of the Sydneys, who indeed eventually buy and move into the Axon home, thus in a way uniting the two textual realms. This is particularly important because it is through this conflation of two seemingly irreconcilably different worlds that Mantel's vision of the failure of care receives its fullest development.

3. The Failure of Care: Childcare

One of the most fundamental forms of care is that of adult for child, and in these novels it is represented as persistently failing both socially and domestically. In *Vacant Possession*, for instance, the vicar Francis deals with his son's delinquency through fatuous and ineffective psychological theories, and schoolteachers 'know that there's nothing to be done with young people.'[11] Within the Sydney family, childcare is desultory. Florence Sydney finds 'the antics and the shrieking' of her nieces and nephews irritating, and Colin is not particularly concerned with his children beyond wondering why they couldn't be 'gifted.'[12] He figures in their lives only as an 'obstruction to their view'[13] of the television. While listening to their 'shrieks and curses, the kicking and slamming of doors'[14] he quotes a line from Philip Larkin's 'This Be the Verse.' No blunter critique of the parent-child relationship is imaginable:

> They fuck you up, your mum and dad.
> They may not mean to, but they do.
> They fill you with the faults they had
> And add some extra, just for you.[15]

If Colin is a failure as a parent, Sylvia offers no better model of care, and this in spite of the fact that the figure of the mother has in twentieth century western culture been loaded with a tremendous significance, particularly under what Sharon Hays describes as the 'ideology of intensive mothering'[16] with its emphasis on the unique irreplaceability and significance of the mother as a dedicated,

nurturing care-giver. Sylvia is indeed her children's primary caregiver, but an uninterested, ineffectual, and unfulfilled one. When she discovers that she is pregnant with her fourth child, her first reaction is despair: '[…] another baby, what for, when the three were too much for her […].'[17] Years later she sees herself as 'bubbling and thwarted' because 'the children no longer needed her,' but this is an erroneous interpretation: one is a glue-sniffing delinquent, another pregnant with a married man's child, a third is a bully, and the fourth constantly wears her Brownies uniform as a totalitarian talisman of identity.[18] Sylvia is simply not interested enough to provide them with the care they so patently need. Her ineffective attempts to help care for her grandchild, motivated by a maudlin, mammalian love of the baby *qua* baby with its 'formless undersea face' is counteracted by her daughter Suzanne's complete indifference: 'I don't have any feelings.'[19] This is confirmed by her willingness to commit the child to Muriel Axon's care, a decision that can have only the most terrible results.

All of this is bad enough but the connections between the Sydneys and the Axons add another layer to this failure, for the Axons represent a terrible inversion of childcare. When Evelyn, for example, first told her husband Clifford about her pregnancy, 'he said that no doubt the child could be trained to be not much inconvenience'[20] and she remembers Muriel's birth with horror:

> She had been left alone to scream, on a high white bed. The landscape of her pain had been her high, knotted, purple stomach. The parasite was straining to be away. A woman with a clamped mouth had stuck her head around the corner, and asked her to please have some consideration.[21]

The medical practitioners here are certainly failing in their duty of care, but Evelyn herself can conceptualise birth as nothing but an excruciating and alienating experience of disease; her reaction to her baby 'dangling from the doctor's hands, upside down and blood-smeared, like someone horribly executed'[22] is similarly indicative of her attitude. This is an experience at some remove from the notions of the sublime that have frequently been associated with parturition.[23] It is also an example of what Leigh Gilmore has described as Mantel's rejection of the humanist notion of suffering as ennobling: here birth is not beautiful but horrible, and it produces not nobility but more horror.[24]

Although Evelyn wonders 'who would look after Muriel' if she 'took some sort of fit,'[25] her motivation for taking care of her daughter (giving her tinned food to eat, maintaining minimum standards of hygiene, and 'protecting' her from the intrusive visits of social services) is less maternal than this might imply. Muriel's presence is her last line of defence against the creeping horrors that haunt her house, a sort of 'fat bait, something to lick their lips over' if 'they get too close.'[26] When Muriel has her own child, Evelyn becomes convinced that it is no human

baby, and that 'that misbegotten, that changeling, that demon-food' must be returned to its proper owners by drowning it in the stagnant canal that runs through town.[27] Part of her horror arises from the infant's resemblance to her dead husband. When she looks at it, 'Clifford stared back.'[28] Traditionally, as Valeria Finucci has argued, an unrecognizable baby 'was not just a bastard [...] but a monster.'[29] Yet the reverse is true of Muriel's baby, whose monstrousness lies in its very similarity to its family, in Evelyn's eyes a clear indication of the transmission of evil. This infanticide, and Muriel's attempt to re-enact it years later with Suzanne Sydney's child, represents the nadir of the diptych's vision of an inverted childcare.

4. Care for the Aged

The social worker Isabel Field is another point of connection between the Sydneys and the Axons: she is Muriel's caseworker and Colin's lover. As a social worker, she is particularly troubled by the very young and the very old: 'At the two poles of birth and death, she sniffs unbearable conjectures in the wind.'[30] Old age again renders us dependent on social or familial care, and here Mantel depicts another catastrophic failure occurring socially, within the 'normal' Sydney family, and in a more horrific form with the Axons.

Throughout the novels a negative social attitude towards the elderly is clear. When Florence is almost knocked off her feet by her nephew Alistair, he tells her to 'Eff off, you old cow,' and when another character retires, she realizes that this means her extinction as a full person: 'Her life was over, she thought: she was entirely slipping from view.'[31] The ultimate destination of the elderly in these novels is geriatric hospital, yet so 'depressing' and 'futureless' are the inmates of these institutions that the only way staff can cope is by viewing them as existing on 'the outer edge of whatever could be taken for sentient and separate life.'[32] And even this grudging level of social care is under threat: the hospitals are being shut down, their patients returned to the care of their families.

This is what happens to the elderly Mrs Sydney. The Sydneys welcome their mother home with trepidation if not outright horror: as she arrives, Colin's face is 'drawn with apprehension' while Sylvia and Florence look 'like women' who know 'exactly what to expect.'[33] This is nonetheless better than it might be. The ambulance drivers who drop Mrs Sydney off have encountered ghost families, 'like the *Mary Celeste*' who have fled rather than taking care of their elderly.[34] Colin and Sylvia dedicate as little time as possible to caring for Mrs Sydney, while Florence, burdened for the second time in her life with the care of her mother, is 'at the end of her tether, a woman appalled by her own thoughts.'[35] In desperation, they sedate her 'into a twilight world, sleeping for twenty hours out of the twenty-four,' but even this does not help: 'We can't take any more, any of us,' Florence claims.[36]

The Sydney-Axon connection exacerbates this failure, elevating it from the quotidian to the horrific. Muriel Axon's own relationship with her mother (who at

sixty-eight is by no means young) is an inversion of care. She delights in her ability to think private thoughts in front of her mother, such as 'I will kill you,'[37] without detection, and in general, while appearing to require the admittedly inadequate care of her mother, is in fact dedicated to tormenting her. Indeed, the demons that haunt the Axon home are, at least in part, Muriel's work (Mantel is careful to preserve the ambiguity of the supernatural elements of the text, which are never clearly demarcated as real or fantastic). This plot line concludes when Muriel throws her mother down the stairs in an act of sudden and seemingly unmotivated matricide.

Ultimately, the Axon's anti-care infects the Sydneys. When Muriel is released from mental hospital she becomes the Sydney's cleaning woman (under an assumed name), a position that allows her to disrupt and taint their family life – the house itself becomes 'horrible' under her malign influence.[38] Her culminating acts are the attempt to murder Suzanne's child, and the murder of the elderly Mrs Sydney. This is horrible enough, and of course represents a clear inversion of care for the young and the old, but the Sydneys assume that the murder was carried out by Florence, whose failure to cope with her mother's return has not gone unnoticed. Despite her protestations of innocence, the family is tainted, as Colin recognises. 'Murder now,' he thinks, without surprise.[39]

5. Conclusion

One of the primary topographical features of the unnamed city in which *Every Day Is Mother's Day* and *Vacant Possession* are set is the polluted canal which runs through it, covered in 'an inch of scum' and emitting an 'awful smell of rotten eggs.'[40] This is the canal in which Muriel's infant is drowned, and from which its skeleton is dredged years later to play its part in the horrible inter-plotting of the Axons and the Sydneys. As Sylvia points out, 'there could be literally anything at the bottom of that canal.'[41] It thus can be seen as a sort of master sign of all the horror and evil that lies below the surface of the normal world, the malign substratum of the everyday. More specifically, it would be possible to identify the canal as a symbol of a number of textual realities: it can, for example, be seen as representing the persistent effects of a seemingly vanished past in an oblivious present, or as being linked to the inscrutable depths of self that underlie the placid surface of our social personae. While the stagnant canal is thus a polysemous symbol, open to multiple interpretations, it is clearly associated with some sort of fundamental problem underlying the modern world.

My reading of Mantel's novel would seem to indicate that what lies drowned beneath the canal's stagnant surface is a systematic and comprehensive failure of care, most particularly for children and the elderly. *Every Day Is Mother's Day* and *Vacant Possession* figure a society which fails to offer an adequate level of care to its most vulnerable members, the very young and the very old. The family, as represented here by the Sydneys, is no more successful in caring for its children and parents. The Axons in turn represent a more extreme form of this failure,

embodying an inversion of care, an alternate textual reality in which care becomes not just indifference but hostility. It is through the collision, superimposition, and eventual merging of these three levels or types of failure that Mantel's Axon diptych explores the 'unbearable conjectures' associated with the vulnerability of the young and old, and it is this systematic failure of care that lies beneath the surface of Mantel's novels.[42]

Notes

[1] Merritt Moseley, 'Bring on the Books: The Man Booker Prize for 2012', *Sewanee Review* 121, No. 3 (2013): 474.

[2] Margaret Atwood, *In Other Worlds: SF and the Human Imagination* (New York: Anchor, 2012), 58.

[3] Hilary Mantel, 'Royal Bodies', *London Review of Books* 35, No. 4 (2013), accessed 24 April 2014, http://www.lrb.co.uk/v35/n04/hilary-mantel/royal-bodies.

[4] Francesca Infante, '"A Plastic Princess Designed to Breed": *Bring Up the Bodies* Author Hilary Mantel's Venomous Attack on Kate Middleton', *MailOnline*, February 19, 2013, accessed 24 March 2014, http://www.dailymail.co.uk/news/article-2280911/Duchess-Cambridge-plastic-princess-designed-breed-Booker-prize-winner-Hilary-Mantels-venomous-attack-Kate.html.

[5] Hilary Mantel, *Giving up the Ghost: A Memoir* (New York: Picador, 2004), 158.

[6] Ibid., 192.

[7] Hilary Mantel, *Every Day Is Mother's Day* (New York: Picador, 2010), 19.

[8] Ibid.,15.

[9] Ibid., 68.

[10] Ibid., 188.

[11] Hilary Mantel, *Vacant Possession* (New York: Picador, 2010), 102.

[12] Mantel, *Every Day*, 32 and 42.

[13] Ibid., 42.

[14] Mantel, *Vacant*, 5.

[15] Philip Larkin, 'This Be the Verse', lines 1-4.

[16] Sharon Hays, *The Cultural Contradictions of Motherhood* (New Haven: Yale University Press, 1996), 9.

[17] Mantel, *Every Day*, 117.

[18] Mantel, *Vacant*, 8-9.

[19] Ibid., 199.

[20] Mantel, *Every Day*, 106.

[21] Ibid.

[22] Ibid.

[23] Francisca Noguerol Jiménez and Christopher Winks, 'Driven up the Wall: Maternity and Literature in Contemporary Latin American Women Writers', *Review: Literature and Arts of the Americas* 46, No. 1 (2013): 15.

[24] Leigh Gilmore, 'Agency without Mastery: Chronic Pain and Posthuman Life Writing', *Biography* 35, No. 1 (2012): 89, accessed 23 October 2013, http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/biography/v035/35.1.gilmore.html.

[25] Mantel, *Every Day*, 11.

[26] Ibid., 60.

[27] Ibid., 197.

[28] Ibid.

[29] Finucci, Valeria 'Maternal Imagination and Monstrous Birth: Tasso's *Gerusalemme Liberate*',in *Generation and Degeneration: Tropes of Reproduction in Literature and History from Antiquity to Early Modern Europe*, eds. Valeria Finucci and Kevin Brownlee (Durham: Duke University Press, 2001), 42.

[30] Mantel, *Every Day*, 54.

[31] Mantel, *Vacant*, 61 and 66.

[32] Ibid., 89-90.

[33] Ibid., 161.

[34] Ibid.

[35] Ibid., 173.

[36] Ibid., 184-185.

[37] Mantel, *Every Day*, 22.

[38] Mantel, *Vacant*, 186.

[39] Ibid., 198.

[40] Ibid., 184.

[41] Ibid.

[42] Mantel, *Every Day*, 54.

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The Art of Group Therapy: Satire and Renegotiating Patienthood in Film and Television

Maren Scheurer

Abstract

At the beginning of David Fincher's *Fight Club*, the narrator has become a 'tourist' in several support groups to alleviate his own, less palpable suffering. His trips, however, become increasingly ludicrous as he fights over groups with fellow tourist Marla. Although portrayals of group therapy abound in cinema and television, they are rarely favourable. A therapist's attempt to brighten a new member's day by arranging a group visit results in her expulsion and the group's orgiastic dissolution in Bård Breien's *The Art of Negative Thinking*. In *X Files* episode 'Hungry,' an Overeaters Anonymous member falls prey to another participant with a secret penchant for human brains. On a more sombre note, *The Sopranos* focuses on the damaging and dangerous aspects of relationships forged within a therapy group, with drug addict Christopher Moltisanti killing a rehab companion and relapsing during an affair with a fellow Narcotics Anonymous member. While most of these portrayals are apparently satirical in nature, the depicted interpersonal dynamics between group participants also point to something more: the complicated texture of relationships within a group, power struggles between therapist and group members, and the numerous ways in which group therapy can be exploited. However, interpersonal learning and group cohesiveness, which Irvin Yalom considers to be the most important therapeutic factors in group therapy, are also evaluated. Thus, the ability of patients to become their own therapists by engaging in new relationships and assuming agency within the group offers new perspectives on patienthood and the nature of therapeutic relationships. By examining several examples of cinematic and televisual representations of therapy and support groups, and by weighing them against Yalom's principles of group therapy, this chapter discusses the critical potential of these portrayals.

Key Words: Group therapy, support groups, therapeutic relationships, film, television, satire.

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1. Satire and Group Therapy

In the third season of *Breaking Bad*, drug dealer Jesse Pinkman uses his drug rehabilitation group as a foundation to build a new client base.[1] He is not the only dangerous participant in group therapy on television. In *X Files* episode 'Hungry,' Overeaters Anonymous cannot keep a patient with an insatiable hunger for brain tissue from eating another group member.[2] These hazardous clients are frequently

paired off with dubious therapists such as the abrasive guru GJ in Jane Campion's *Top of the Lake*.[3] Sometimes, the entire setup of a therapy group is ridiculed: In *Ally McBeal*, an all-male group seeking therapy for misogyny use their meetings to reinforce their chauvinist values.[4] While realistic, solemn, or even celebratory depictions of support groups are not unheard of (CBS's *Elementary*, for instance, takes Sherlock Holmes's rehabilitation very seriously, be it with the help of his sober companion Dr. Joan Watson or his Alcoholics Anonymous meetings[5]), it seems that bitterness, absurdity, and exaggeration dominate portrayals of group therapy in television and in film.

Therapy has long been the target of satirical invectives, as, for example, Michael Freund's extensive collection of psychoanalytic cartoons from *The New Yorker* demonstrates. 'Precisely because psychoanalysis is so serious, and a business, and deals with the more uncomfortable aspects of our lives, it has become a classic target for gag cartoonists,' Freund claims.[6] However, the failings of group therapy are not simply explored for their comic effect, providing welcome relief from the seriousness of illness or exacting revenge on powerful therapists. These portrayals launch an attack against group therapy by exposing it as a site for exploitation and regression, dangerous not only because it involves opening up to a group of supposedly disturbed strangers but also because of the failure of the therapeutic approach, the incompetence of therapists, or the malicious intentions of group members.

Embedding criticism in humorous fiction, these attacks on the institution of group therapy partake of satiric modes of writing.[7] Fredric Bogel claims that satire always arouses resistance in readers and viewers: Instead of simply falling into alignment with the satirist's judgements, they need to go through the uncomfortable process of negotiating their relationship with the object of satiric attack.[8] Especially if satire hits close to home, it would be easier to dismiss it as just another silly parody. However, apart from indicting defects, satire has something to say about the underlying dynamics of therapy that is all too easily missed when the discomfort caused by the attack tempts us to look away. Or, to put it another way: satiric interventions against group therapy not only tell us why it does not work but also why it does.

In this chapter I will discuss the most pressing concerns voiced by a selection of cinematic and televisual portrayals of group therapy and compare them to Irvin Yalom's description of the operating modes of group therapy in his textbook *The Theory and Practice of Group Psychotherapy*. Finally, by analysing one further example, David Fincher's *Fight Club*, in more detail, I will explore not only satiric insights into therapeutic agency but also the relationship between entertainment and group therapy.

2. Ridiculous Routines

When *Ally McBeal*'s misogynists are introduced, they are immediately recognisable as a therapy group by the classroom setting, the confessionals, and the didactic aphorisms. After a first testimony, Billy, a new member, is asked to introduce himself. 'You need to say it,' the group leader urges him to state the group formula, and so he does: 'Hello, my name is Billy, and I am a male chauvinist pig.'[9] When he subsequently details his inability to accept his wife's independent life-style, his companions, whose eyes are filled with tears, shower him with approval upon this self-revelation.[10]

In Bård Breien's film *The Art of Negative Thinking*, therapist Tori leads a disability acceptance group, which relies heavily on her guidance, her 'goal-oriented' strategies and slogans. The participants full-throatedly intone 'I choose the positive way' and are asked to talk into a 'barf bag' whenever negative thoughts surface.[11]

Staged confessions, empty slogans, prop-assisted exercises: Both examples ridicule the all-too-well-known routines of group therapy. The participants are given lines to speak while natural dialogue and self-expression are suppressed. The routines infantilise the group members, reinforce bigotry and obfuscate pressing and painful issues. Therapeutic success, however, does not depend on specific techniques or rituals, in contrast to what many group leaders believe.[12] Instead, according to Irvin Yalom, it is the 'interpersonal interaction [that] is crucial in group therapy.'[13] Thus, the most successful groups are engaged in free interaction, whereas rigid routines cripple the therapeutic process.[14] Effective therapeutic factors such as sharing advice, providing support, the improvement of social skills as well as interpersonal learning and group cohesiveness can be encountered in any setting.[15]

3. Dangerous Re-Enactment

When therapy in film and television fails to stop members from repeating their maladaptive patterns, the group becomes a hazardous place. In *The Art of Negative Thinking*, a new group participant, paraplegic Geirr, is so resistant to therapy that he attacks the other group members both physically and verbally, causing several emotional crises throughout the meeting.

Even more dangerous is the influence of the drug-addicted mafioso Christopher Moltisanti in the HBO-series *The Sopranos*. Rather than transporting useful coping mechanisms from therapy into his daily routine, Chris introduces his work environment into his group. Thus, an affair with a fellow Narcotics Anonymous member leads them inevitably into relapse,[16] and the involvement of a rehab companion in Chris's gambling operation results in his death.[17] White argues that '[f]or [...] Christopher therapy is a prelude to violence,'[18] but even if this is true, then therapy does not differ much from Chris's other regular activities.

All Geirr and Chris do in their groups is reproduce their customary behaviour. Therapy groups, however, depend on this kind of reproduction and are deliberately set up to provide a room for re-living negative experiences and harmful relationships in order to change them. The group constitutes a playing field where tensions such as struggles for dominance and conflicting values can be explored.[19] According to Yalom, a therapy group will develop 'into a social microcosm' in which patients 'will interact with the group members as they interact with others in their social sphere.'[20] Recreating their 'interpersonal universe[s]'[21] in the here-and-now of therapy enables members to analyse their behaviour by working through their group relationships. Thus, the group's microcosm also turns out to be 'a laboratory,'[22] in which meaning-making, experimenting with and learning new ways of dealing with conflict are made possible through interpersonal encounters. Theatrical enactment is not only a useful basis for therapeutic intervention[23] but also one of the reasons why group therapy is such an attractive fictional device: it creates a microscopic environment where individual stories can be shared and re-enacted in front of the audience, whose reactions are mirrored in group members and therapist. Despite its risks, the re-creation of interpersonal behaviour is the motor of group therapy and its fictionalisation, especially when dangerous activities fuel exciting storylines and critical commentary.

4. Hostile Leaders and Group Strife

Group members are not the only participants who may encounter difficulties throughout a therapeutic process. Jane Campion's mini-series *Top of the Lake* features a resistant therapist: A group of lovelorn women have established a 'halfway recovery camp' around 'enlightened' GJ,[24] but the brusque guru refuses to be their group therapist: she interrupts and insults them, shatters their hopes, and eventually leaves to 'get away from these crazy bitches.'[25]

In *The Art of Negative Thinking*, the therapist is quickly established as the group's enemy. Tori is endlessly cheerful on the surface, but when Geirr tells her to 'stop acting,'[26] he accurately exposes a tense and artificial group environment. When her patients refuse to comply to group norms, Tori often insults or threatens them to force them into agreement. But only after Geirr has punched her and turned the other members against her is she finally expelled from the group. Without her, the participants turn her therapeutic objectives upside down. They banish all non-disabled members and act out their anger and sorrow through drug consumption and the destruction of Geirr's furniture. However, what at first appears to be an example of a group disintegrating turns into a positive bonding experience for everyone involved. A final, staged confrontation with death in a game of Russian roulette, as much as their shared negativity throughout the night, welds them together. Their résumé after a night dedicated to self- and group-destruction is surprising: 'Maybe we could invite others to this. It was a big success.'[27]

In the complicated relational texture of a therapy group, power struggles are not infrequent, especially with the group leader. As the person responsible for the group's maintenance and for containing the above-mentioned dangerous behaviour, she is often seen as 'the personification of parental images, of teachers, of authority, of established tradition, of incorporated values.'[28] Aggression against or idealisation of the authority figure are common results of such transference reactions.[29] However, therapists as well as patients struggle with the roles they are assigned. This struggle, both through what it brings to the surface and through what it resolves, encourages change: Tori, forced to give up her role as leader, is integrated as a group member upon her return.

While individual therapy focuses on the patient-therapist-dyad, the therapeutic relationships in groups involve not just the therapist but the other members and the group as a whole.[30] Therapy groups are often depicted as fighting, members despising, blaming, and attacking each other, but as they fight, they also engage intensely with each other, learn about the others' weaknesses, and share experiences, or even a common enemy such as the therapist. Conflict seems to be an almost indispensable step towards group cohesiveness. This feeling of belonging to a group turns into an important therapeutic factor since it facilitates intimate exchange, greater acceptance, open expression of conflict, and thus further development.[31]

5. Fight Therapy

When the narrator of David Fincher's *Fight Club*, Jack, seeks medical assistance for his insomnia, his annoyed doctor refuses to prescribe sleeping pills and tells him to 'see the guys with testicular cancer' for a taste of real pain.[32] So Jack visits his first support group, 'Remaining Men Together.' Jack is mesmerised by the uncomfortable emotional outbreaks, which offer glimpses into someone else's life and suffering, the therapeutic routines, the thank-yous and flat, reassuring lines. Eventually, when everyone is supposed to pair off, hug and cry, Jack meets Bob, in whose massive body he can bury his face and finally let go, 'lost in oblivion – dark and silent and complete.'[33]

Jack becomes addicted to this 'vacation' and visits a group every night until the presence of Marla, another group 'tourist,'[34] destroys the calming effect of these therapeutic excursions. Openly smoking in a tuberculosis group, the only female member of 'Remaining Men Together,' Marla irritates many other group members besides Jack. Her explanation for her attraction to the groups is simple: 'It's cheaper than a movie and there's free coffee.'[35] When Jack offers to split up the week with her so they will not meet each other again, their exchange of groups as if they were commodities stands in sharp contrast to the suffering of the actual target groups: 'I'm gonna take the organic brain dementia,' Jack insists in a comically exaggerated scene, 'You can't have the whole brain.'[36]

At first glance, these commodified groups with their routine provision of hope, advice, and human contact offer not much more than entertainment. Jack studies group names like cinema showtimes and enjoys the programmes they offer: stories after stories, guided meditation as well as guided emotional release. *Fight Club* satirizes both therapeutic rituals and a society dependent upon them for stimulation. Close-ups on unusual displays of emotion, the confessional voice-over narration, and a montage of name tags, doughnuts, coffee machines, and overly positive group designations demonstrate the groups' forced intimacy, their stereotypical nature, and their exchangeability. However, in conversation with Marla, it turns out that group therapy is more than entertainment: 'When people think you're dying, they're really, really listening to you.'[37] As routinised and compartmentalised as they have become, behind the rituals and the masquerade and beyond free coffee and name-tagged acquaintants, these groups still offer more human contact than anything else in Jack's isolated existence. In his everyday life, he is trapped, as Lynne Layton argues, in 'a narcissistic world' without meaningful relationships.[38] Seen in this light, the routines console and protect Jack[39] and provide him with an easy means of establishing relationships. Jack is thus supported by the group conventions but also kept from further development. The cohesiveness of these groups is based on exclusiveness since they are specifically geared toward dealing with particular illnesses and imminent death. To enter the groups, Jack must pretend to be sick – act rather than therapeutically re-enact. What he needs is a group that addresses his specific problems, and he finds it in 'Fight Club.'

This secret society organising underground fights among its members functions like a therapy group.[40] Protected by strict confidentiality, its rule structure mimics therapy: every new member, for instance, has to fight, very much like a new member is asked to introduce herself in a therapy group meeting. That 'Fight Club' is perceived as therapeutic is proven by Bob, who claims that he no longer needs his cancer group since he has 'got something so much better now.'[41] Thus, 'Fight Club' is just another and more intense version of 'Remaining Men Together,' a way of seeking relief from isolation and restitution for damaged masculinity.[42] In this case, a problematic form of therapy and bonding is literally achieved through fighting. Tyler Durden, their idealised, increasingly dominant leader and, unbeknownst to Jack and the audience, Jack's alter ego, asks members to vent their frustrations in 'Fight Club' and to apply the group's interpersonal lessons (liberation through violence) to their daily lives. However, Jack does not truly change until he liberates himself from Tyler and takes action against him in the final minutes of *Fight Club*.

6. Renegotiating Patienthood

The importance of free interaction, interpersonal learning, and group cohesiveness that arises out of the critique of ridiculous routines, dangerous re-

enactment, hostile leaders and group strife points to a single conclusion: '*[I]t is the group that is the agent of change.*'[43] Thus, many mechanisms of group therapy remain active even when the leader fails to create a beneficial '*group culture,*'[44] since this failure forces patients to become their own therapists. They have to engage in new relationships, assume agency within the group, and solve their own problems. Patienthood is renegotiated as therapeutic relationships are established in multiply charged directions across group members: a patient may be both agent and recipient of healing, thus escaping the passive, patiently suffering state implied in the term 'patient.' Therefore, both satiric and scientific explorations of group therapy go further than transforming the patient into a consumer, a user, a client, or even a customer,[45] and *Fight Club* actually criticises the commodification of therapy. The group participant is not a consumer, however decisive, of therapy, but the agent, the provider of therapy within a relational setting. Since therapists and patients may be seen 'as players tentatively performing on a complex non-linear stage,' David Kernick concludes that '[b]oth patients and doctors should be known as actors.'[46]

Yalom points to the necessity that a group 'assume responsibility for its own functioning.'[47] Otherwise, it will remain ineffective, which Yalom illustrates with an illuminating analogy:

> I often experience the members of the group as moviegoers. It's as though they visit the group each week to see what's playing; if it happens to interest them, they become engaged in the meeting. If not, "Too bad, Irv! Hope there'll be a better show next week!" My task in the group then is to help members understand that *they* are the movie. If they do not perform, the screen is blank; there is no performance.[48]

That therapy groups and films do not make strange bedfellows has already been made sufficiently obvious by the numerous allusions to theatrical devices and entertainment throughout my examples. In the movie theatre as well as in group therapy, stories can be shared, roles enacted and discarded, and entertainment turned into interpersonal learning, provided patient recipients are willing to turn themselves into active participants. Basically, every text requires an engaged reader: '[M]edia texts acquire meaning [...] at the moment of reception, and [...] audiences actively produce meaning from media by decoding and interpreting such texts from their particular social and cultural positions.'[49] However, satires in particular ask viewers to become active. *Fight Club*, for instance, leaves many viewers uncomfortable, asks to be discussed in groups, and may even induce members of the audience to take action. In an afterword to the novel on which the film is based, Chuck Palahniuk claims that in response to the film, fight clubs have been established all around the United States and 'men still ask where to find the

fight club in their area.'[50] Can movies even be turned into a form of group therapy? The success of Cinema Therapy Groups[51] seems to point in this direction. Viewed actively, they may certainly open a discussion about the role of the participant in group therapy, film, and television.

Notes

[1] *Breaking Bad*, 'Abiquiu', S3.11, dir. Michelle MacLaren (AMC, 2010).

[2] *The X Files*, 'Hungry', S7.03, dir. Kim Manners (Fox, 1999).

[3] *Top of the Lake*, 'Paradise Sold', S1.01, dir. Jane Campion (BBC2, 2013).

[4] *Ally McBeal*, 'Seeing Green', S3.03, dir. Peter MacNicol (Fox, 1999).

[5] *Elementary*, 'Pilot', S1.01, dir. Michael Cuesta (CBS, 2012).

[6] Michael Freund, Foreword to *On the Couch: A Book of Psychoanalysis Cartoons*, ed. Michael Freund. ([New York?]: The Cartoon Bank, 2006), i.

[7] For a discussion of several definitions of satire see: Brian A. Connery and Kirk Combe, 'Theorizing Satire: A Retrospective and Introduction', in *Theorizing Satire: Essays in Literary Criticism*, eds. Brian A. Connery and Kirk Combe (New York: St. Martin's Press, 1995), 8-9.

[8] Fredric V. Bogel, 'The Difference Satire Makes: Reading Swift's Poems', in *Theorizing Satire: Essays in Literary Criticism*, eds. Brian A. Connery and Kirk Combe (New York: St. Martin's Press), 44-45 and 52.

[9] *Ally McBeal*, 'Seeing Green', S3.03.

[10] Ibid.

[11] Bård Breien, dir., *Kunsten å Tenke Negativt* (Ahrensfelde: Capelight, 2009), DVD, my translation.

[12] Irvin Yalom, *The Theory and Practice of Group Psychotherapy* (New York: Basic Books, 1995), 2.

[13] Ibid., xiv.

[14] Ibid., 111.

[15] Ibid., 1.

[16] *The Sopranos*, 'Kaisha', S6.12, dir. Alan Taylor (HBO, 2006).

[17] *The Sopranos*, 'Walk Like a Man', S6.17, dir. Terence Winter (HBO, 2007).

[18] Rob White, 'No More Therapy', *Film Quarterly* 61, No. 3 (2008): 68.

[19] Yalom, *The Theory and Practice of Group Psychotherapy*, 25.

[20] Ibid., 28.

[21] Ibid.

[22] Ibid., 38.

[23] See Ibid., 29.

[24] *Top of the Lake*, 'Paradise Sold', S1.01.

[25] *Top of the Lake*, 'No Goodbyes Thanks', S1.06, dir. Jane Campion (BBC2, 2013).

[26] *Kunsten å Tenke Negativt*, my translation.

[27] Ibid., my translation.

[28] Yalom, *The Theory and Practice of Group Psychotherapy*, 44.

[29] Ibid., 196.

[30] Ibid., 48.

[31] Ibid., 63.

[32] David Fincher, dir., *Fight Club* (Leipzig: Kinowelt, 2010), DVD.

[33] Ibid.

[34] Ibid.

[35] Ibid.

[36] Ibid.

[37] Ibid.

[38] Lynne Layton, 'Something to Do with a Girl Named Marla Singer: Capitalism, Narcissism, and Therapeutic Discourse in David Fincher's "Fight Club"', *Free Associations: Psychoanalysis and Culture, Media, Groups, Politics* 62 (2011): 123.

[39] Brigitte Ziob, '"Wir Sind Doch Immer Noch Männer?" Eine Psychoanalytische Betrachtung des Films "Fight Club" von David Fincher', *Psyche* 59 (2005): 364.

[40] Ibid., 367.

[41] Fincher, *Fight Club*.

[42] Ziob, 'Psychoanalytische Betrachtung', 367.

[43] Yalom, *The Theory and Practice of Group Psychotherapy*, 109. Italics in the original.

[44] Ibid., 110. Italics in the original.

[45] All these designations are discussed in: Raymond Tallis, 'Commentary: Leave Well Alone', *BMJ: British Medical Journal* 318, No. 7200 (1999): 1757.

[46] David Kernick, 'Both Patients and Doctors Should Be Known as Actors', *BMJ: British Medical Journal* 319, No. 7222 (1999): 1437.

[47] Yalom, *The Theory and Practice of Group Psychotherapy*, 118.

[48] Ibid., 119. Italics in the original.

[49] Laura Fingerson, 'Active Viewing: Girls' Interpretations of Family Television Programs', *Journal of Contemporary Ethnography* 28 (1999): 391.

[50] Chuck Palahniuk, Afterword to *Fight Club* (London: Vintage, 2006), 217.

[51] Birgit Wolz, 'Why Cinema Therapy Works', accessed 17 January 2014, http://www.cinematherapy.com/whyitworks.html.

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——. 'No Goodbyes Thanks'. S1.06. Directed by Jane Campion. BBC2, 2013.

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Part 2

Centring on Patient Experience

From the Inlands of Brazil, Healing in Literature and Film

Davina Marques

Abstract

Can a song make you feel better? How strong is a narrative in the process of healing? This chapter explores an episode in literature and cinema where an encounter between a healer and a sick child changes his condition. In the short story 'Campo Geral' (1956), João Guimarães Rosa, a writer who was formerly a physician himself, denounces the critical situation of the inlands of Brazil, as he presents us with characters that perform healing procedures where there is no other possibility of treatment. Presented as strong in the story, these characters will fill pages with local knowledge and tradition. At first, there are two male healers: there is one who deals with herbs and advice; there is another who does the same but also explores the gift of storytelling, laughter and dancing. The second one has better results when treating Miguilim, an 8-year-old boy, the main character. Miguilim gets better when he meets this second healer. Not only does he feel better, but he learns from this experience and starts exploring storytelling himself. When his dear brother falls ill, we will see him trying to 'treat' his brother with stories as well. His life, however, will be changed by a third man, a 'real' doctor, from far away. This doctor, who passes by the place where the boy lives with his family, will offer him a new possibility in life. The story was presented in the film *Mutum* (2007) by Sandra Kogut, and it deals with the healing process differently. Both film and literature, nevertheless, show us distinct ways to deal with a harsh reality in Brazil.

Key Words: Representations of healing, patient perceptions, childhood and change, literature and film.

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1. Introduction

João Guimarães Rosa (1908-1967), one of the most important Brazilian authors, presented us with *Corpo de Baile*[1] (Corps de Ballet, in English) in 1956, an amazing book, written in seven 'blocks' that can be read in any order, or even separately. They are seven novels-poems-short stories (as characterised by the author himself), which are so related and non-related to each other that the publishing company was able to disassemble the seven pieces into three different books a few years later. The first of the stories, 'Campo Geral,' (General Plane/Overview, in English) has always been placed as the opening piece in the first volume of the several publications and translations of *Corpo de Baile*. It is the piece I have been studying.

João Guimarães Rosa is well known for his style, for his experimentation in language, because he brings to his writing elements of the many languages (more than twenty) he himself was fluent in. He also refers to a people who co-exist on multiple social strata in a country traversed by social problems and prejudice: his characters are anomalous and crazy people, outlaws, poor Brazilian children, ordinary women and men in the inlands, in the backlands of the *sertão*, a huge central area in Brazil. And even though there is such a Brazilian geographical area called *sertão*, there is a virtual appeal to it in Rosa's writing. He states that the *sertão* is everywhere and also nowhere (no-where and now-here); that the people who live in the *sertão* are fabulists by nature, great storytellers; and that one must come from *sertão* in order to tell good stories (therefore, the language spoken in the *sertão* is the language spoken by Goethe, Dostoevsky, Flaubert…). In order to become an alchemist with words, a sorcerer with words, one must come from *sertão*.[2] And his stories and characters tell us about universal issues that affect us all.

In 2007, Sandra Kogut (1965-), a prominent video artist and director of documentaries in Brazil, surprised Rosa's readers with an adaptation of 'Campo Geral.' *Mutum*, as it is called, is her first feature film, and it was shot in the inlands of our country, mostly with non-professional actors, with a careful approach to image and sound.

In this chapter, I will approach the novel and the film aiming at bringing forth the healers, the medical characters and practices of the story.

2. A Boy and His Family in a Plot

The narrator tells us the story from the perspective of a boy, Miguilim, who lives in Mutum, in the middle of the state of Minas Gerais, in an area surrounded by mountains and woods, in a valley; a place he was once told was beautiful, in between mountains, with lots of rocks and greens, far away from everything. After he hears that Mutum is beautiful, Miguilim wants to tell his mom about it, as if it is a secret. He wants to tell her that Mutum is pretty, for she has never said so; she only talks about the place with and between sighs and woes.

Miguilim has three brothers and two sisters. His older brother lives in the city, far from them. The others live in Mutum, in the company of Father, Mother, Vó Izidra (his grandmother's sister), his uncle – Tio Terêz – his favourite person, and the house workers: the middle-aged single Rosa, and two black women, the old Mãitina and the young Maria Pretinha. The work on the land and the animals (which were not the property of Miguilim's father) demand the assistance of two other men: the cowboys Salúz and Jé (the first was his father's partner in taking care of the land for someone else).

Mutum, the land, is the source of affections and conflicts, it affects all beings. The young Miguilim is charmed by his mother's beauty. So is his father. But this one, raw and crude as he is, broken by the lack of resources and poverty, is rude

and harsh. In contrast to his brother, uncle Terêz is gentle towards Miguilim and his mother, a situation that makes Father brutally jealous. Miguilim senses there is something wrong, but he is too young to understand it. Tio Terêz has to leave the land after Miguilim's father beats his wife for his interest in her. Miguilim decides to protect his mom and is then also beaten up.

They have no school. This is one of the many things that troubled Miguilim's father, who wants to find someone who can at least teach his children the first letters and some math. Furthermore, Miguilim's health is fragile, and there is no doctor nearby.

In his 130 page story, Rosa is able to construct love stories, family relations, friendship, jealousy, death, murder, suicide, dance, music, storytelling, fights, descriptions of small, happy and sad things, love stories, and a reminder for us all: '[...] that we should always be happy, be happy, even when all the bad things happen to us. We must then be happier, happier, inside!'[3]

There are many issues presented in this single piece of literature on very many levels of depth. My focus will be, however, on patient-healer relations, both in the book and the film.

3. Storytelling and Healers

According to Friedrich Nietzsche, artists and philosophers are 'physicians of our culture.' For Gilles Deleuze, a reader of Nietzsche, authors and artists are symptomatologists, just like doctors and clinicians. Deleuze goes even further and reminds us that, because writers are less worried with the causes of a symptom, the work of art may give them new means of expression, allowing them to go deeper into a symptom.[4]

It is interesting to think of the healing powers of storytelling. Walter Benjamin has a small text, 'Storytelling and Healing,' where he mentions the common sight of a mother telling stories to a sick child who is in bed. At one point he asks himself '[...] whether every illness might be cured if it could only float along the river of narrative – until it reached the mouth.'[5]

Our research group at the University of São Paulo – GENAM (Medicine Narrative Study Group) – has been dealing with finding a proper approach to working with the way the narrative of a patient is reconfigured by doctors and their assistants in the clinic of our School of Medicine. We know how a doctor, looking at a tomography scan, produces a 'description' of what is presented before him or her. We also know that the diagnosis, given orally or in writing, is a descriptive or a structured text based on the 'facts' that the specialist chooses to select and organise for others to read. From the patient's point of view, there is a narrative to be told, even if the doctors do not really listen to them and act upon the story being told. We have found that narrative cohesion is not only related to the past but also organises the present and projects a future – a happy ending or, maybe, a tragedy.

We have also often seen that, in several cases, there is a silence of the patient, who may even become voiceless in the process of treatment.[6]

   When the patient is a child, it is obviously harder to 'hear' this narrative. An adult will need to tell another adult how the child feels at the beginning of the process. In the story 'Campo Geral' Miguilim, aged 7-8, learns that his health is not very good. As a baby, the family even imagined he was not going to survive. He was very skinny. One could count his back bones just by looking at him. He is also not very competent in games, especially in those that required throwing balls, for instance.

   He is a gentle, sensitive and respectful boy, however. And he cares for his mother. A few days after a violent incident in the family,[7] we have the first healer in the story: Seo Deográcias comes to the house (his name meaning Deo = god; gracias = thanks: thanks God). He is an older man who lives in the area and occasionally visits the families. We learn from Dito, Miguilim's brother, that this man is a sort of collector, who visits people to see how they will pay their debts. Miguilim's father is in debt. Nonetheless, as he has traditional knowledge of herbs, he assists the people in need. He is old, his teeth are ugly. He sees Miguilim and tells his parents that he must have some medication; as weak as he seems to be, he could get a fever or even a serious disease. He is, in fact, looking for a disease. Seo Deográcias says he will send them the medication soon, and he does. But the family does not think it is good enough – just plant syrup and oil Miguilim is supposed to drink. The boy takes them, but he really feels he should live with Seo Deográcias. There, he will have access to every medicine and then he will be able to one day come home healthy and fine. Miguilim is very sad, probably due to his parents' situation and the fact that Tio Terêz is not around anymore. He does not feel like eating, playing, or even going out. But he takes the medicine they give him.

   His mother wants to call someone else to see Miguilim: Seo Aristeu. He also understands herbs and healings, but Father and Vó Izidra does not think much of him, because he plays the guitar and likes playing and dancing. Miguilim decides that he will have to get better on his own. After long consideration, he makes a deal with God: if he does not die within ten days, he will not die at all. For nine days he pays careful attention to every little detail of his ordinary life. He notices how close he is with his brother Dito, and how beautiful the plants and animals are.

   On the tenth day, Miguilim, crying softly, does not want to get out of bed. Everyone tries to talk to him and to understand what was going on. Only Dito has a different idea. He has seen Seo Aristeu riding his horse far away and he runs to call him to see his brother.

   This man comes, strong, tall and handsome, bowing to people and moving around just like an artist, a dancer. When he talks, he rhymes the words and makes all of them smile and laugh. He is not looking for a disease in Miguilim. He *looks at* Miguilim. He *sees* a sad boy; a boy who is dealing with 'the insanities of the

grown-ups.'[8] He asks Miguilim what his problem is and the boy tells him he has hectic fever. Seo Aristeu is so certain that there is no case of hectic disease in the area and talks so self-assuredly with the boy that Miguilim stands up and dances around the house with him.[9] Seo Aristeu stays for lunch and tells many stories, and everyone has fun. The boy is 'cured.'

Seo Aristeu turns Miguilim into a storyteller himself. Later on, the boy will use a narrative to help make a decision that could affect his family life, and when his dear brother is ill, he tells several stories to make him feel better.

Not everything is saved by storytelling though. An episode that does not concern Miguilim's health, but his brother's, does not end well. Dito falls ill because he has cut his foot. Tragically his infection is untreated, no one from 'outside' comes in time to see him, and he dies.

The third healer comes at the end of the story. A lot had happened. Dito and Father are dead. This man is a real doctor and he is passing by because he has an acquaintance, a relative, in the region. He notices that the boy is short of sight and needs to wear glasses. The doctor invites Miguilim to go to the city with him, get glasses and go to school. He is not sure about going, because everything seems so big. But Mother helps him make up his mind. She promises that the rest of the family might meet him there in the following year.

Leaving, in this case, should function as a solution for the difficulties: leaving in hope it will be different somewhere else, or in the future. And this is why, fifty years later, it is possible to tell this same story over and over again, in film.

Brazil has come a long way to change the situation of poverty and access to health and education countrywide. We are a huge country though, the fifth biggest country in the world, and there is still a lot to be done. One may still find places with no electricity or running water. When Sandra Kogut decided to tell the story of Miguilim on film, she knew it was a challenge. She did not want to make it romantic, historical, outdated; she wanted to show the relevance for our contemporary world, but she was surprised at the worldwide response to the story.

With an eye for detail, she had to select fewer passages to show. Only the doctor, the third healer, appears in the film. The whole magic of Seo Aristeu is lost in the adaptation. I am not in favour of discussing film adaptation in terms of what is lacking in the film when compared to a book. My doctoral thesis argues that the film must stand alone as art, as difference, and not as repetition of the book.[10] Besides the fact that the film is just shorter, one could also speculate that the fantastic healing power of storytelling simply did not fit into Kogut's film, which has almost a documentary approach to life. When she decided to tell the story of Miguilim in the year 2007, Kogut showed its possible connections to contemporary life, starting from the plot, but never constrained by it.

It is beautiful to notice, however, how the director expands the scene where the doctor meets the boy, slowly and calmly talking to the boy, when he was first only asking him for directions. He notices Miguilim has difficulties talking about things

that are far away, and he asks to talk to his mother. Only then does he offer Miguilim his glasses, and the boy becomes extremely happy: he is finally able to see things around him.

4. One Last Note on Storytelling and Changing Lives

Stories may save our lives, as we have learned with Scheherazade in *One Thousand and One Nights*. Patients' stories, when told to their doctors well, may also save their lives.

In the episodes described in this chapter, a boy has his life changed by healers in two different ways: once by a doctor who diagnoses he is short-sighted and takes him away from his family in order to give him the eyes only God had been able to give him before (that is how his mother sees his moving to the city); and another by a man who changes the way he sees himself, by giving him the ability to tell stories.

I argue that the book gives us a glimpse of possible doctor-patient relations, of possible treatments for patients. Lack of treatment kills people (his brother's death). No one wants children to die from lack of medication. Some treatments make people sad – the bitter medicine that does not cure (Seo Deogracias – looking for diseases). Some treatments work but force people to make choices that will affect them forever – having to leave one's own family in order to see better (the doctor passing by – the technical approach). And some treatments will make people feel really better and will affect them positively for the rest of their lives. Here the healer needs to really look at the patients and understand what they really need (Seo Aristeu – the doctor who listens, observes, cares, and gives back the joy of life).

As patients, we do not always have a choice; these are possibilities we face in our lives. I believe that if we fight for this last kind of doctor – who listens, observes, cares and is able to give us back the joy of life – we, as patients, would be much better.

The artists here, author and film director, provide us with an opportunity for thinking about health in our country, but these reflections go beyond local Brazilian concerns. World-wide we still have a long way to go before we have no more children who need glasses and do not know it; and especially children who are in some aspects forced to leave their homeland in order to get a better life, education, and health care.

Notes

[1] João Guimarães Rosa, *Manuelzão e Miguilim* (Rio de Janeiro: Nova Fronteira, 1984). Also João Guimarães Rosa, *Corpo de Baile: Edição Comemorativa 1956-2006* (Rio de Janeiro: Nova Fronteira, 2006).
[2] Eduardo F. Coutinho, ed., *Guimarães Rosa* (Rio de Janeiro: Civilização Brasileira, 1993), 86.

[3] Rosa, *Manuelzão e Miguilim*, 108.

[4] Gilles Deleuze, *A Ilha Deserta e Outros Textos*, ed. Luís B. L. Orlandi (São Paulo: Iluminuras, 2006), 171-174. Also Gilles Deleuze, 'Mysticism and Masochism', in *Desert Islands and Other Texts*, ed. David Lapoujade, trans. Michael Taomina (Los Angeles, New York: Semiotext(e), 2004), 131-134.

[5] Walter Benjamin, *Rua de Mão Única* (São Paulo: Brasiliense, 1987). Also Walter Benjamin, *Selected Writings: 1931-1934*, trans. Rodney Livingstone (New York: Harvard University Press, 2005), 274.

[6] See Fabiana B. Carelli and Carlos E. Pompilio, 'O Silêncio dos Inocentes: Por um Estudo Narrativo da Prática Médica', *Interface (Botucatu)* 17, No. 46 (2013), accessed 22 January 2014, http://dx.doi.org/10.1590/S1414-32832013005000020.

[7] Rosa, *Manuelzão e Miguilim*, 116.

[8] Ibid., 28.

[9] See Gabriela Reinaldo, 'A Cura pela Palavra', *Ângulo* 115 (2008): 82-88.

[10] See Davina Marques, 'Entre Literatura, Cinema e Filosofia: Miguilim nas Telas' (PhD diss., Universidade de São Paulo, 2013).

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How to Change Lives with Words

Fabiana Carelli and Davina Marques

Abstract

Since 2011, the GENAM, Group of Studies in Narrative and Medicine at the University of São Paulo, Brazil, has been searching for a better comprehension of the narratives that permeates every medical encounter. With an approach that comes from the narrative/literary studies and philosophy and has points in common with the so-called Narrative Medicine, our research tries to focus on the narratives that embody the building of meaning across healthcare practice, whether these narratives are told by patients to doctors, by doctors to patients, by doctors to doctors, etc. We consider narrative as an aesthetic phenomenon, understanding 'aesthetic' in the broad sense of (any) language production that aims to conceive a form for the purpose of enhancing expression. In this direction, and based on the concepts of peripeteia or reversal of circumstances;[1] mimesis (I, II e III), emplotment and narrative time;[2] illocutionary and perlocutionary acts;[3] and narrative identity,[4] this presentation aims to propose the concept of narrative act, preliminarily defined as a narrative action, by the narrator or the listener/reader, that, deliberately or not, conscious or unconsciously, effectively changes the meaning of the story told and, consequently, the course of the events. This concept is clearly inspired by the Aristotelian concept of peripeteia and by the process conceived by Paul Ricoeur as configuration, 'the capacity of poetic composition to re-figure… temporal experience.'[5] Within the life and death contexts of the narratives produced in the healthcare practice, this so-called narrative act may, ultimately, change the outcome of a lifetime.

Key Words: Narrative act, reversal of circumstances, GENAM, literature and medicine.

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1. Aristotle, Start and End

In the Chapters X and XI of his *Poetics* (IV B.C.), Aristotle postulates an important concept for literary theory and narrative analysis: that of *peripeteia* or reversal of circumstances, related to the threading of the story's actions:

> Of stories, some are simple and others complex, for the actions too, of which the stories are imitations, are directly from the start from these sorts. I mean by a simple action one in which, while it comes about as continuous and one in the manner defined, the change takes place without a reversal or discovery; and a

> complex action is one out of which a change involves a
> discovery or reversal or both together,[6]

says the philosopher. And he continues, in the following chapter:

> A reversal is the change to the opposite of things being done, just
> as has been said [by others], and this, as we are saying, in accord
> with what is likely or necessary… And a discovery, as even its
> name implies, is a change from ignorance to recognition, leading
> toward even friendship or hostility in people bound for good or
> bad fortune. A discovery is most beautiful when it happens at the
> same time as a reversal [...].[7]

As a good example of a complex action, as defined above, Aristotle, in the cited
chapter, mentions the well-known tragedy *Oedipus Rex* by Sophocles, more
specifically the scene where the messenger announces to Oedipus the death of
Polybus, revealing to him that the latter was not his father. Says the philosopher:

> For example, in *Oedipus*, one who has come intending to make
> Oedipus happy and set him free from his fear about his mother,
> by revealing who he was, does the opposite.[8]

In fact, what the audience sees happening in the *Oedipus*, in a pathetic and
tragic way, the discovery of a fact or past condition previously unknown and that
radically transforms what is to come, is actually a usual, even ordinary event in
common lives. In the case of the king of Thebes, to this discovery corresponds to
the acknowledgement that his foster-father was not his biological father, with the
well-known consequences in the myth and the play. In everyday life, there are
numerous other examples: for an elder child, for instance, hearing that he/she was
not the first pregnancy of his/her mother; the discovery of hitherto unknown
siblings; the discovery that the former resident of your house for a time was
someone famous; and so on. These and many other facts or conditions formerly
'concealed,' once revealed, transform more or less radically the life story of those
involved after this 'recognition.'

Speaking of the field of healthcare, the same can be said of the 'discovery' of a
severe disease. Once diagnosed, the disease changes the course of a patient's life in
many ways: has the power to change his routine (in other words, the facts and the
chain of facts that make up his own story); introduces new characters in that story;
offers alternatives for its deployment and outcome very different from the
previously conceived ones.

Therefore, the rather unknown and suddenly revealed fact or condition
obviously modifies the *future* of a story, i.e., the events that will come after the

disclosure. It promotes, as Aristotle says, a turnaround. But not only that. If we ponder about this phenomenon in depth, such 'recognition' may also change the *past* radically – certainly not in the concreteness or the verity of the events that took place, but in its *meaning*. The past turns out to be completely different after a recognition of this kind! In other words, in an attempt (albeit precarious) of a synthesis: 'recognition' is when a *future* (something that had never happened before), made *present*, can abolish and radically modify a *past*, not in the concreteness of the facts, but in its *meaning*. And *meaning*, in the way we understand it here, is the result of the interpretation of a selection of facts enchained in time. Life, or the specific story of the existence of this or that person, his/her *narrative*, gains another *meaning* after the recognition.

Thus, for example, in the *Oedipus*, as we have seen: learning that his biological father was Laius, who he has murdered at a crossroad, and not Polybus, who he always accredited as his genitor, makes Oedipus' *past* change: he was no longer Oedipus, son of Polybus and Periboea, born in Corinth, but rather Oedipus, son of Laius and Jocasta, born in Thebes. Some unknown facts, then revealed, were included within the timeline of Oedipus's life story. This phenomenon alters his past – and also changes the concreteness and the meaning of what will come next.

We believe that the diagnosis of a disease, especially of one considered severe, often occurs as a kind of discovery, in Aristotelian terms, certainly modifying the future, and, in some cases, also the past. Acknowledging that someone is diabetic, for example, may establish some forms of previously unthought-of family bonds within the general sense of a patient's life, a kind of network of meaning somewhat inexistent in one's life story until then, and it certainly changes the events and the order of the events of his life from there on. Discovery and reversal. Aristotelian *anagnorisis* and *peripeteia*. New (or unknown) facts are incorporated within the facts of the life narratives of these protagonists, and completely change the general meaning of these narratives. How does this occur?

In *Time and Narrative*, Paul Ricoeur recovers and revisits the Aristotelian concept of the poetic work as a threading of actions, of which both *peripeteia* and recognition are part. Synthetically, we might say that, for Ricoeur, every narrative fabulation occurs as a *prefiguration* of the 'world of life' ('a pre-understanding of the world of action, its meaningful structures, its symbolic resources, and its temporal character;'[9] a *configuration* ('emplotment' or 'organization of the events;'[10] and a *refiguration* ('intersection of the world of the text and the world of the hearer or reader').[11] Schematically, we would have:

Table 1: Paul Ricoeur's Theory of Mimesis

Kind of Mimesis	Operation	Universe to which it refers
Mimesis I (M1)	Prefiguration	'world of life' – empirical facts, symbolic and cultural categories
Mimesis II (M2)	Configuration	text itself (narrative)
Mimesis III (M3)	Refiguration	listener/reader

In the construction of any narrative, the passage from prefiguration to configuration confers focus, order and meaning to the referentiality articulated by it. In the end, the listener/reader that listens to/reads this narrative refigures it according to his/her own points of view, beliefs and cultural universe. Within our argument, we might say in Ricoeurian terms that the configuration of the life narratives which we have been addressing here changes before the change of its prefiguration, i.e.: the 'pre-understanding of the world of action' of the one who configures the narrative is transformed, due to the introduction of new or unknown facts, which modifies, therefore, the configuration (and meaning) of the narratives informed by them.

When we consider the narratives produced within the health contexts within this dynamic, we understand that a patient only makes sense, within the clinical context, when he is configured by him/herself, and configured and reconfigured by the health professionals that assist him/her. In this sense, to consider narratives as forms of knowledge within the clinical practice is to recognize its mediating character as a 'synthesis of the heterogeneous.'[12] Also, in Ricoeur's words,

> every poetic text [in the broad sense of an expressive articulation of language], whether it be lyrical or narrative, [...] speak[s] *of* the world, even though they may not do so in a descriptive fashion.[13]

According to the French philosopher, this would correspond to 'a more radical power of reference to those aspects of our being-in-the-world that cannot be talked about directly,' that is, to the eminently *ontological range* of these narrative configurations.[14] Ricoeur develops the idea of an identity between being and acting in his book *Oneself as Another*, where he discusses the dialectical relation between *sameness* and *selfhood*.[15] Through this relation, it would be possible to speak of a 'human action ontology,' rooted in our being-in-the-world and, therefore, tellable. This would be one of the possibilities of an epistemic valorization of narrative within the medical context.

2. John Austin and the Speech-Acts

Briefly speaking, in his book *How to do Things with Words*, a compilation of lectures given at Harvard University in 1955, John Austin, under the Pragmatics point of view, postulates two series of concepts:

(1) that not all statements are made by their locutor in the sense of 'describing' certain state of things or 'simply to *state* something, but in the sense of doing something.' With this affirmation, Austin criticises certain philosophical points of view according to which every statement would be a declaration, testified as 'true' or 'false,' according to empirical parameters. As he says:

> We were to consider [...] some cases and senses [...] in which to *say* something is to *do* something; or in which *by* saying or *in* saying something we are doing something.[16]

According to this consideration, he will distinguish between 'constative speech-acts' (those which envision to indicate or report something related to reality or to inform something)[17] and 'performative speech-acts,' those which

> do not "describe" or "report" or constate anything at all, are not "true or false"; and the uttering of the sentence is, or is a part of, the doing of an action, which again would not *normally* be described as, or as "just" saying something;[18]

and (2) the distinction among locutionary acts (which have intention to refer to or to mean something); illocutionary acts (which have a certain *force* in saying something); and perlocutionary acts (which are the *achieving of* certain *effects* by saying something).[19]

As examples of performative utterances, instead of constative ones, Austin mentions the promise (as in a wedding ceremony – 'I take this woman as my wife' – or a will – 'I give and bequeath my watch to my brother'), the baptism of a ship ('I name this ship the *Queen Elizabeth*') and a bet ('I bet you six pence it will rain tomorrow'),[20] emphasising that 'many performative are *contractual* or *declaratory*'[21] and that '[t]he uttering of the words is, indeed, usually a, or even *the*, leading incident in the performing of the act.'[22]

Regarding the distinction among locutionary, illocutionary and perlocutionary acts, Austin clarifies that the first 'is roughly equivalent to uttering a sentence with a certain sense and reference;' that the illocutionary acts correspond to actions like 'informing, ordering, warning, undertaking, etc., i.e., utterances which have a certain (conventional) force;' and that the perlocutionary acts are those by which we achieve some kind of purpose, 'such as convincing, persuading, deterring, and even, say, surprising or misleading.'[23]

Within the fields of health sciences, especially in the medical field, the distinction between constative and performative utterances and, beyond that, the distinction among locutionary, illocutionary and perlocutionary acts is more than important, as long as the medical science seems to us to be pervaded by a Cartesian vision of the phenomena and, consequently, of language. The physician, in his/her clinical practice, often believes him/herself to be uttering eminently constative statements in constative speech-acts. Nevertheless, in the clinical practice, the patients come to the doctor's office uttering illocutionary and perlocutionary statements, which speak little or nothing about the empirical reality of his health condition, but are mainly intended to *do* something and/or to *achieve* certain effects. Likewise, the health professional that attends him utters, in his/her professional practice, performative speech-acts in a way that Austin considers a 'descriptive fallacy,' with little or no awareness at all of what he/she is doing.[24]

As discussed later by Paul Ricoeur in *Oneself as Another*, the theory of speech-acts was developed from Austin to Searle and originated in the distinction established at the first part of *How to Do Things with Words*, that of constative speech-acts *versus* performative speech-acts. As Ricoeur puts it, the speech-acts, or discourse-acts, as he prefers, fulfill themselves according to a dialectics between transparency and opacity:

> If, with the ancients and again with the Port-Royal grammarians, the sign is defined as a thing that represents some other thing, then transparency consists in the fact that the sign, in order to represent, tends to fade away and so to be forgotten as a thing. This obliteration of the sign as a thing is never complete, however. There are circumstances in which the sign does not succeed in making itself absent as a thing; by becoming opaque, it attests once more to the fact of being a thing and reveals its eminently paradoxical structure of an entity at once present and absent.[25]

According to this passage, one of the circumstances of the 'sign opacity,' e.g., when the word is worth it for itself, and not for what it supposedly represents, is in the Austinian circumstances of the illocutionary and perlocutionary acts, which are crucial for our argumentation.

3. The Narrative Act

In *Time and Narrative (II)*, speaking of the articulation of narrative actions in time, or, in other words, of the narrative configuration, Paul Ricoeur affirms:

> The enrichment of the concept of emplotment and, correlatively, of narrative time [...] is more certainly a privilege belonging to

fictional narrative, rather than to historical narrative…. This privilege is due to the remarkable property narrative possesses of being split into utterance [*énonciation*] and statement [*énoncé*]. To introduce this distinction, it suffices to recall that the configuration act presiding over emplotment is a *judicative act*, involving a "grasping together". More precisely, this act belongs to the family of *reflective judgments*.[26]

From these reflections on, Ricoeur offers a footnote in which he aims to clarify the concept of 'reflective judgment,' based on Kant:

A determining judgment is wholly caught up in the objectivity it produces. A reflective judgment turns back upon the operations through which it constructs aesthetic and organic forms on the basis of the causal chain of events in the world. In this sense, narrative forms constitute a third class of reflective judgment, that is, a judgment capable of taking as its object the very sort of teleological operations by which aesthetic and organic entities take shape.[27]

From Ricoeur's statements, we can postulate a parallel between the Austinian concept of 'performative speech-acts' and – not in the slightest and linguistic level of the sentence, but in terms of the narrative fabulation – the Ricoeurian concept of 'configuration act,' for both can be considered as judicative acts. As long as configuring a narrative, in Ricoeurian terms, is a judicative action, i.e., an action over the causal chain of events in the world and a way to act upon the 'teleological operations whereby aesthetic and organizational entities take shape,' narrating can become, not only a constative action (i.e., related to the expression of a referentiality, or to the intention of 'saying something'), but also a performative action, i.e., a way of doing something through the action of narrating itself. In Austinian terms, as previously mentioned, the narrative configuration act may ultimately become an action of 'informing, ordering, warning, undertaking' and, within the limits of their perlocutionary traits, also 'convincing, persuading, deterring, and even, say, surprising or misleading.'

In this sense, we can say that the configuration of a health professional's narrative about his/her patient relates to the concept of narrative identity as developed by Ricoeur in *Oneself to Another*. Just as the speech-act, according to Austin, has an impact on the enunciation and its agents, the configuration act directly modifies the course of the previously configured narrative and its meaning – present, future, and past – hence the considerable and often unconscious responsibility, the eminently ethical character, in a broad sense, it exercises in the context of health practices and, for that matter, life in general. After configuring

his/her story and having it reconfigured by a health care professional, the patient is no longer the same – he/she is *another*, an identity in process that will never become identical to that he/she had built for him/herself before the illness, and that depends, for its continued reconfiguration, on the configuration acts – performative, not just constative – of the healthcare professionals that will take care of him/her from there on.

Based on these reflections, this chapter asserts that:

(1) many of the utterances made within the health care context, even though strictly scientific rationality postulates the contrary, are performative utterances and, according to this, sometimes illocutionary, other perlocutionary acts – which includes narrative utterances, e.g., those emitted in order to configure the stories told by patients to the health professionals and vice-versa;

(2) grounded on the Aristotelian concept of peripeteia, we may say that the introduction, in a certain story, of an unknown fact or of an intervention that happens to establish a reversal on the meaning of the story itself is something that is able to change the course of the events and prepare another kind of ending. This act, in our consideration, can assume the nature of a perlocutionary speech-act, that kind of action that aims to achieve certain effects by saying something, and that we can define as *narrative act*.

In our opinion, this kind of narrative act undertaken by health professionals in contact with their patients can be considered, and as we have seen throughout this chapter, as the offering of a new perspective to them and, therefore, of new possibilities of future and past. Built within the doctor-patient relationship, it is their mutual chance of a reversal of circumstances, aiming to new – and hopefully healthier – outcomes.

Notes

[1] Aristotle, *Poetics* (New York and London: Penguin, 1997).
[2] Paul Ricoeur, *Time and Narrative* (Chicago: University of Chicago Press, 1984), 1.
[3] John L. Austin, *How to do Things with Words*, eds. Marina Sbisà and J. O. Urmson (Cambridge: Harvard University Press, 1975).
[4] Paul Ricoeur, *Oneself as Another* (Chicago: University of Chicago Press, 1995); Fabiana Carelli, 'The Other Who Is Me: Literary Narrative as a Form of Knowledge', paper presented at the Conference 'A Narrative Future for Healthcare', London, 21 June 2013.
[5] Ricoeur, *Time and Narrative*, 1:xi.
[6] Aristotle, *Poetics*, 34.
[7] Ibid., 34-35.
[8] Ibid., 34.

[9] Ricoeur, *Time and Narrative*, 1:54.
[10] Ibid., 64.
[11] Ibid., 71.
[12] Ibid., 66.
[13] Ibid., 80.
[14] Ibid.
[15] Ricoeur, *Oneself as Another*, 140-168.
[16] Austin, *How to do Things with Words*, 12; author's italics.
[17] Ibid., 3.
[18] Ibid., 5; author's italics.
[19] Ibid., 121; author's italics.
[20] Ibid., 5.
[21] Ibid., 7; author's italics.
[22] Ibid., 8.
[23] Ibid., 109.
[24] Ibid., 3.
[25] Ricoeur, *Oneself as Another*, 41.
[26] Ricoeur, *Time and Narrative*, 2:61; the last two italics are ours.
[27] Ricoeur, *Time and Narrative*, 2:174.

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Understanding the Patient's Medication Experience: Collaboration for Better Outcomes

Djenane Ramalho de Oliveira and Mateus Rodrigues Alves

Abstract

The patient's medication experience is concerned with the patient's feelings, thoughts, wishes and concerns associated with taking medications in daily life. While these experiences influence people's attitudes towards medications, they most probably influence their medication taking behaviour. Research developed in the last 10 years suggest that these experiences are an important portion of the patient's illness trajectory and especially significant in the context of medication management services. In order to assist patients to obtain the most benefits from their medications, the practitioner must create spaces during the encounter with the patient for the medication experience to emerge so that it can be understood and acknowledged. Uncovering these experiences from patients' narratives is a challenging task that requires the establishment of a strong therapeutic relationship between practitioner and patient and openness to patients' perspectives. We contend that capturing and utilising these experiences is a crucial component of an integral, ethical and patient-centred health care practice. This chapter will draw upon several research projects that explored the experiences of patients taking chronic medications and how medication management pharmacists utilise those experiences in their daily practices to prevent or resolve drug therapy problems. Thus, the patient's medication experience is a type of knowledge that should be understood by and taught to those who claim to care for people in need of medication.

Key Words: Patient's medication experience, medication management services, medication management pharmacists, therapeutic relationship, health outcomes, patient-centredness, qualitative research, duoethnography.

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We are pharmacists, or, as we like to say, social pharmacists, educators, researchers as well as patients that choose a different venue to share our thoughts, concerns and ideas related to patient care. We deem our trajectory as non-traditional because most pharmacists are usually focused on the technical issues associated with medication use instead of being attentive to the meanings ascribed to being ill and of taking medications in daily life. We have been influenced by qualitative researchers, especially those who advocate for collaboration in the research process.[1] Researchers can enter a dialogue and write together from different perspectives about an experience, an event or a social process. As a result of this collaboration, we can achieve multiple understandings of the world and,

hopefully, a more comprehensive one. Here we use duoethnography to reveal our diverse experiences in the process of understanding the patient's medication experiences. Duoethnography is a collaborative research methodology that allows us to juxtapose the meanings we give to our experiences so that the research act helps us to discover new meanings. New narratives emerge in the process, allowing the audience to relate to the topic and better understand the phenomenon under investigation. Interestingly, duoethnography questions the legitimacy of the metanarrative of the Self as no one representation holds supremacy in the dialogue. The meanings are constructed and reconstructed and they oscillate from one person to another.

We want to use our own experiences as researchers of the patient's medication experience and our situated knowledge as patients taking medications to invite readers to think about their own experiences with medications as patients or as professionals.

> Djenane: To start with, I think we should attempt to answer a few questions. Firstly, what do we understand by the patient's medication experience?
>
> Mateus: I like Cipolle, Strand and Morley's definition of the medication experience as 'the sum of all the events a patient has in his/her lifetime that involve drug therapy. This is the patient's personal experience with medications.'[2]
>
> Djenane: What does it mean?
>
> Mateus: It means that we, as patients, have our own experiences of taking medications. These experiences can be direct or indirect. I can take a medication for depression and gain some weight. So, I will associate that drug with weight gain, which can lead to a negative feeling toward that medication. On the other hand, I can witness my mom starting taking insulin and experiencing renal failure just after that. I might associate injecting insulin with worsening of the symptoms of diabetes or dying because of my mom's experience.
>
> Djenane: You are saying that a patient might have an experience, or a feeling towards a medication, not because of a direct experience with taking it, but because he witnessed the experience of a loved one.
>
> Mateus: Exactly!

Djenane: That's interesting. So, besides having his own experience to which he might attribute some meaning, the patient can also attach meaning to a medication because of what he witnesses. I should underscore that the patient can also give meaning to an object, such as a medication, due to what she sees on the media. This means that patients can have an experience with a medication or a certain feeling toward a medication even before they use it. We could call this an indirect experience.

Mateus: Yes, this can be seen as the beginning of the trajectory of the medication experience. It can start before the patient receives a prescription or when he gets a prescription. When the patient receives a prescription for the first time, he might already have a feeling about that medication due to past experiences, or he might question the need for it, or he might be concerned about what that drug can do to his body or mind.

Djenane: I guess we should contextualise this type of knowledge. Why do we care about this? I would say that as social pharmacists we are very critical of the pharmacy profession, as we believe that pharmacists, with their vast knowledge of medications, could have a bigger impact in health care. We believe pharmacists can have a more active role in the health care team. The pharmacy profession has a theoretical framework and a well-described professional practice at its disposal that provide all the necessary resources for pharmacists to apply their unique knowledge in order to make sure patients are getting the highest benefit from their medications.

Mateus: That's what we call pharmaceutical care practice and medication management services.

Djenane: And we must emphasise that these services have a philosophy of practice that is patient-centred. This means that in the context of this practice, the medication experience becomes a very important type of knowledge.

Mateus: Some say that the medication experience is the heart and soul of this practice. Capturing and acknowledging this experience is what makes the pharmacist truly focused on the patient, not only as a patient but also as a human being.

Djenane: Going back to the trajectory of the medication experience… After getting a prescription, the patient starts taking the medication and observes the effects in her body. The effects can be positive or negative, which will influence the meaning it will have for the patient. For instance, the patient can see the medication as a saviour as it allows him to have a normal life with diabetes or depression. On the other hand, the medication can cause a side effect that upsets the patient, such as weight gain.

Mateus: Interestingly, after using the medication for some time, the patient can get accustomed to it, better understand its effects on his body and can take control over it. In this phase, the patient can rigorously follow the professional's recommendation, or she can test the medication, changing or even skipping some doses, taking more control of her treatment.

Djenane: This is what Peter Conrad calls 'medication practices.'[3] Patients create their own ways of taking medications, which might differ from what health professionals recommend. These practices result from patients' unique experiences, their perceptions and feelings towards medications. This is the medication experience.

Mateus: Shoemaker and Ramalho de Oliveira have been studying this for a long time. Through their qualitative research projects with people living with many chronic illnesses, they help us to understand what the most common experiences are and how these experiences surface in patients' narratives. According to their metasynthesis, patients associate taking a medication chronically with getting old, with feeling like a failure, and with disturbing changes in their bodies. They question the need for it, they deem taking medications a burden, and they may eventually take control over their regimens.[4]

Djenane: Another metasynthesis indicates that patients are usually reluctant to take medicines. They argue that peoples' resistance to taking medicine needs to be recognised and that the focus should be on developing ways of making medicines safe, as well as evaluating the treatments that people often choose in preference to medicines.[5] Even though these experiences are individual, subjective and situated, the published studies assist us

in becoming more attuned to the most common ones, so that we can better listen when the patient talks about them.

Mateus: This is the hardest part. The professional has to listen well during the encounter with the patient to capture these experiences. It requires the professional to have an open attitude towards the patient's perspectives and motives that influence her or his behaviour.

Djenane: This is very difficult to do because of the way we are trained as health professionals. We are bombarded with evidence-based medicine, or with the voice of medicine. It is still unusual to find curricula that honour the voice of the patient, or the voice of the *lifeworld*. Unfortunately, we do not look for this balance in our professional schools. Professionals are acculturated in an environment in which the hard sciences represent the final truth and what is subjective or associated with the human sciences is considered less scientific.

Mateus: This is incomprehensible to me! There is so much knowledge out there to guide us towards a more humane and integral medicine. There are so many authors teaching us about the importance of attending to patients' narratives, of understanding patients' illness experience, and of communicating in a patient-centred manner.

Djenane: However, it is my understanding that all of this is still seen as soft science and not a priority in the curricula of the health professions.

Mateus: In the profession of pharmacy, we have been talking and writing about this for several years. But how much of it is reflected upon and taught in pharmacy schools?

Djenane: We have started paying attention to this in the 90s when the profession of pharmacy decided that its new mission is to care for patients to ensure the best possible results of the medicines they use.

Mateus: And pharmaceutical care practice was born!

Djenane: Yes! This should have completely changed pharmacy! The focus would change from the product to the human being. But I guess this change was much more challenging than we expected!

Mateus: I guess so. But we have seen some change, haven't we? Truly, it was in the context of pharmaceutical care practice and medication management services, as pharmacists take care of real patients, that the concept of the patient's medication experience emerged.

Djenane: We were not looking for that. It transpired when we were listening to patients that were receiving these services. Qualitative methodologies allowed us to uncover the unexpected. Patients started talking about their illness trajectories and how pharmaceutical care practice impacted those. The medication experience was there, hidden, between the lines in patients' narratives.

Mateus: Then it emerged over and over again both in patients' and pharmacists' stories. It became something real and meaningful in the process of caring for people taking medications.

Djenane: The work conducted by Ramalho de Oliveira et al. provides us with good advice on how to listen for the medication experience and some questions professionals can ask to invite patients to talk about their individual experiences.[6]

Mateus: An interesting thing we have learned about these experiences is that they are not static. They change over time as patients live through new experiences. Therefore, every time we meet with the patient we must listen for that and act accordingly.

Djenane: Yes. Previous work showed that it is essential to understand these experiences because they affect patients' behaviours in a way that can impair their health outcomes. For instance, these experiences can be the cause of drug-related problems, and by addressing them medication management pharmacists are able to prevent and resolve these problems.[7]

Mateus: We cannot forget that medications are the main therapeutic tool utilised to control most chronic conditions and, therefore, we do need to pay attention to how patients feel and manage their medications on a daily basis.

Djenane: The truth is that patients make decisions every day, or several times a day, about taking or not taking their medications. We, as health care providers, need to acknowledge that and work with our patients to help them to make the best decisions for them.

Mateus: That became very clear to me after conducting my PhD work with patients living with HIV-Aids.

Djenane: Tell me about that.

Mateus: Interestingly, all of my participants considered themselves compliant to their treatments, although from a biomedical perspective most of them were not. They followed the regimens as closely as possible, but some events in their lives affected how and when they took their medications. For example, if they had to leave and stay out for a period of the day and the medication could produce diarrhoea, they would skip a dose. In another instance, a woman would not take her medication because she had a fight with her fiancé.[8]

Djenane: It is fascinating! We can be so naïve to believe that patients will do everything we tell them to do. Their lives are so much more than having diabetes, or hypertension, or HIV-Aids. The context and events of their lives shape their actions and we must understand that.

Mateus: We need more than understanding. We need to accept that we cannot be effective professionals if we ignore that. We need to see the medication experience as key knowledge to assist us in making the best possible decisions with our patients.

Djenane: This is what patient-centredness is all about. Making decision *with* the patient and not *for* the patient. It means to contextualise our decisions in terms of the patient's reality, wishes, and needs.

Mateus: We must listen better, negotiate, share the decision-making process, and not judge.

Djenane: This is all great, but I think it is more complicated than that. I remember that a colleague of mine and I had an interesting conversation about the complexity of understanding and using the medication experience in our clinical practice. We questioned if we could be colonising patients' lives as we attempt to capture the patients' feelings, values, concerns about their health, about their medications and even about the treatments they use without prescription, and if we could use that to educate (persuade?) them to follow our recommendations. How do we reconcile being patient-centred with respecting the patient's autonomy? Can't it be that the preferences of the health professional differ from the preferences of the patient?

Mateus: I think that sometimes the sense of beneficence of the professional can be in conflict with the autonomy of the patient. Reach proposes that the education of the patient by the professional presenting different alternatives to resolve the patient's problems can empower the patient to make an informed decision. Moreover, this author claims that as education is delivered as an invitation for the patient to reflect on his situation and desires, the professional's intervention might go beyond manipulation. The patient can be given the option to move to healthy preferences or not, but hopefully he will do so in a more conscientious mode. The goal would be that the educational process promotes the patient's autonomy.[9]

Djenane: That's an interesting way of looking at this. For a long time I have been concerned with the possibility of manipulating the patient or colonising his or her life. Even though we have been talking about adherence, concordance, and patient-centredness, I struggle with the fact that we are always trying to convince people to do what we believe (know?) it is better for them. And we use our knowledge to do so.

Mateus: But if we gain the patient's trust, the relationship will become a more balanced one and it will be easier to negotiate with the patient. As stated by Reach, 'the whole medical practice supposes the existence of trust: how can the patient accept to answer the physician questions, the clinical examination of her

body, and the proposed therapy? [...] [A] relationship of trust cannot be assumed and has to be earned and gained.'[10]

Djenane: So, we can presuppose that to understand the patient's medication experience and use that knowledge to educate the patient, we must have earned the patient's trust. I think I would feel more comfortable with that.

Mateus: It is important to remember that it can be hard for people to take medications.

Djenane: This conversation reminds me of my own medication experience.

Mateus: Would you be willing to share it with me?

Djenane: Sure! I never had to take a medication until I was diagnosed with depression. This was after I had lost my younger brother and moved to the USA to pursue my PhD. I was not doing well even after months of psychotherapy. I also had a hard time with the Minnesota winter, not much sun for a Brazilian. So my therapist and psychiatrist recommended that I start an antidepressant.

Mateus: It makes perfect sense to me. It looks like you really needed that!

Djenane: As a clinical pharmacist I could see that, but as a patient I felt overwhelmed by the thought of taking a medication every day. And the worst part: a medication for depression. I always saw myself as a happy person. I would say that I have a pretty positive outlook on life. Thus, it was strange to accept I had depression. Even though I had been doing psychotherapy for depression for over a year at that point, the prescription of an antidepressant meant failure and weakness. I felt ashamed.

Mateus: I can understand that.

Djenane: To make things worse, I called my father one day and mentioned I had been prescribed an antidepressant. He started laughing and said: 'But, depression does not suit Djenane. You have always been a happy person.' Then I started explaining to

him why I thought I really needed the medication. I guess I was trying to convince myself…

Mateus: So, did you take it?

Djenane: Yes, but I questioned the need of it and considered not taking it. This happened at the same time as I was doing interviews with patients taking chronic medications. I felt ridiculous when I realised that several of my participants had severe depression and were taking medications. Was I different from them? As a health care professional, how could I educate patients on the importance of taking a chronic medication and not do it myself? I think I understood the importance of the medication experience then. Up to that point it was an abstract concept for me.

Mateus: I also have my own medication experiences…

Djenane: I would love to talk with you about them so that we can broaden and deepen our understanding of this concept. That's why we engage in a duoethnography! We could share several stories about how we react, feel, think and act towards taking medications. And I think that we, as health care providers, should do that as a way to get closer to our patients and to become better teachers.

Mateus: That is an important exercise for us, and for our audience.

Djenane: Thus, we invite you to reflect on how you make decisions every day about your health and about accepting or not accepting the advice of your health care provider. How do you feel about taking medications? What is it like for you to adhere to even a short-term treatment? It is more complicated than we admit it to be, isn't it?

Notes

[1] Marcelo Diversi and Claudio Moreira, *Betweener Talk: Decolonizing Knowledge Production, Pedagogy, and Praxis* (Walnut Creek: Left Coast Press, 2010), 13-29; Joe Norris, Richard D. Sawyer and Darren E. Lund, *Duoethnography: Dialogic*

Methods for Social, Health, and Educational Research (Walnut Creek: Left Coast Press, 2012), 15-22; Carolyn Ellis and Jerry Rawicki, 'Collaborative Witnessing of Survival during the Holocaust: An Exemplar of Relational Autoethnography', *Qualitative Inquiry* 19 (2013): 366.

[2] Robert J. Cipolle, Linda M. Strand and Peter C. Morley, *Pharmaceutical Care Practice: The Clinician's Guide* (New York: McGraw-Hill, 2004), 103-104.

[3] Peter Conrad, 'The Meaning of Medications: Another Look at Compliance', *Social Science & Medicine* 20, No. 1 (1985): 29-37.

[4] Sarah J. Shoemaker and Djenane Ramalho de Oliveira, 'The Meaning of Medication for Patients: The Medication Experience', *Pharmacy World & Science* 30 (2008): 86-91; Sarah J. Shoemaker, Djenane Ramalho de Oliveira, Mateus R. Alves and Molly Ekstrand, 'The Medication Experience: Preliminary Evidence of Its Value for Patient Education and Counseling on Chronic Medications', *Patient Education and Counseling* 83 (2011): 443-450.

[5] Pandora Pound, Nicky Britten, Myfanwy Morgan, Lucy Yardley, Catherine Pope, Gavin Daker-White and Rona Campbell, 'Resisting Medicines: A Synthesis of Qualitative Studies of Medicine Taking', *Social Science & Medicine* 61 (2005): 133-155.

[6] Djenane Ramalho de Oliveira, Sarah J. Shoemaker, Molly Ekstrand and Mateus R. Alves, 'Preventing and Resolving Drug Therapy Problems by Understanding Patients' Medication Experiences', *Journal of American Pharmacists Association* 52, No. 1 (2012): 71-80.

[7] Ibid., 75.

[8] Mateus R Alves, 'The Medication Experience of People Living with HIV: From the Understanding of the Meanings of Medications to the Development of a Conceptual Framework of Medication Experience' (PhD diss., University of Minnesota, 2012).

[9] Gérard Reach, 'Patient Autonomy in Chronic Care: Solving a Paradox', *Patient Preference and Adherance* 8 (2014): 15-24.

[10] Ibid., 21.

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Part 3

Patient-Centred Ethics

Hamlet Is Sick: Patient Care in the Total Institution

Peter Bray

Abstract

William Shakespeare's play *Hamlet* is conceived as an exploration of one patient's experiences of the power of a total institution. In the unethical and unsuccessful processes of healing his step-son's melancholia, Claudius the chief executive and senior consultant of Denmark's Elsinore Castle transforms Hamlet's condition from princely protégé to patient. As a noncompliant inmate Hamlet goes about creatively finding ways to both resist his helpers and assemble evidence that will prove the institution's power base is corrupted by its new leader. His increasing reluctance to see the world as the state sanctions it gives the institution reason to treat his personal challenges as attacks on its integrity. Thus, Shakespeare's play exposes the sickness of total systems that vest power in a single individual. It also shows how a diagnosis of complicated mourning, experienced as a difficult personal process of intra-psychic transformation, might be reframed by its onlookers as 'madness.' By showing the tragic consequences of withholding or intentionally ignoring the true source of a patient's disease, Hamlet's case demonstrates the difficulties of making correct diagnoses and giving appropriate treatment. At best there is a fragile symbiosis between a doctor and patient. In *Hamlet* the institution misdiagnoses, threatens, renders incompetent, and denies Hamlet the patient a say in his own healing processes. However, in his institutionally inconvenient condition he is provided with opportunities for the kind of unsupervised self-analysis and experimentation that ultimately risks his life and those of the community. After his assault on the body politic, steps are taken to fully remove him from the public gaze. Hamlet's case serves to illustrate how a unitary approach to patient care that disenfranchises and disempowers, tragically disables the service relationship and totally restricts its staff in their work.

Key Words: Doctor-patient relationship, Shakespeare's *Hamlet*, Erving Goffman, madness, total institution.

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1. Introduction and Background

Since its appearance at the turn of the sixteenth century William Shakespeare's colossal theatrical version of the bloody legend of Amleth has continually challenged the academy to curiosity about the motivation of its main protagonist.[1] In the psychoanalytical tradition, for example, Hamlet has become the everyman of patients – and these powerful objectifications and examinations of Hamlet have illuminated his seemingly infinite interiority and reductively 'bounded' him 'in a nut-shell.'[2] Possessing 'a consciousness that seems to over-hear itself,'

Shakespeare's incarcerated prince invites his audience to 'pluck out the heart of my mystery' and examine his disease.[3] Subsequently, for centuries writers and thinkers have attempted to solve him and by some impossible alchemy cure him. Impossible to fully know and projected onto time and time again, Sigmund Freud and Ernest Jones finally confined Hamlet and transmuted him into a *bona fide* oedipal neurotic patient – an object for hypothesis, assessment, and treatment.[4]

This chapter suggests that *Hamlet* might be conceived of as a play whose organising principles are similar to those later elaborated upon in Erving Goffman's description of traditional patient care in the self-protective total institution, 'the epitome of organizational tyranny and coercion.'[5] *Hamlet* describes a unitary approach to social life that has become tainted by corruption and therefore beyond individual control. It shows how this infection impacts upon the institution's community and negatively influences the ways in which it cares for its members. Hamlet's symptoms of traumatic mourning are genuinely problematic to the patient but they also offend the institutionally constructed perception of what it is to be a prince, and therefore threatens the stability of an organisation that has plans to move on. Under these circumstances even a return to baseline functioning is tragically impossible. Through supernatural intuition Hamlet understands that his institution is sick. However, as Claudius the therapist is reluctant to allow Hamlet the agency to make his own changes to Denmark's social order, he exploits his symptoms of mourning to further the patient's mortification and to force him to 'go a progress' through the intolerably 'rotten' guts of the institution.[6] In this extraordinary passage Hamlet, in order to protect himself from Claudius, feigns madness but gives the institution a further excuse to assess, diagnose, and treat him.

2. '[...] Think of Us as of a Father': The Patient, the Paternalistic Institution and the Cure

Elsinore fully embraces Erving Goffman's four 'common characteristics' of total institutions, particularly prisons and mental hospitals, suggesting that,

> All aspects of life are conducted in the same place and under the same single authority; Daily activity is carried out in the immediate company of a large *batch* of others; Activities are tightly scheduled [...] by a system of explicit, formal rulings and a body of officials; Activities are brought together into a single *rational plan* purportedly designed to fulfil the *official aims* of the institution.[7]

As such, Elsinore's custodial environment provides the seat of institutional and hierarchical power and its paternalistic chief executive has a mandate to organise clinical, custodial, and administrative inmates in 'healing' confinement that

guarantees protection and freedom from infection for the wider community. Subject to the values, structures, and rules of a total institution Hamlet acknowledges that his home is 'a prison [...] one o'th'worst.'[8] In order to be cured, he must accept the reduced circumstances of institutional life and endure the dissolution and removal of his 'domestic existence' for a subtle version of the mortifying regime of 'batch living,' segregation, observation, analysis, experimentation, and constraint.[9]

Unravelling this relentless game of doctor and patient in *Hamlet* draws attention to how one might doctor one's own solutions whilst simultaneously learning to be good patients to other medical and social 'doctors' whose service ministrations teach us to serve themselves.[10]

A. The Patient

Hamlet's traumatising losses make him extremely vulnerable. Exchanging one father for another, a playground for a prison, Hamlet's assumptive world has become an unpredictable and dangerous nightmare where nothing fits.[11] Held in the institutional grip of a 'forcing house for changing persons,' and condemned to a life of unmet needs or imminent destruction, Hamlet still has the freedom to acquiesce or withdraw into himself but does so at the risk of this being mistaken for a deeper form of mental illness.[12]

From Claudius's pragmatic perspective, before he can complete Hamlet's treatment he must consider the patient's potential to spread the epidemic of civil war, which also justifies his containing the patient's infection at its source. Thus, Hamlet's condition rather than Claudius's act of regicide provides the threat to the institution. Claudius restricts the patient's freedom, places him under surveillance, and sifts him using those he trusts the most. Meanwhile, the patient becomes increasingly aware of the wrongness of the institution's world view and his own impending diagnosis and provides the motive power to further investigate the underlying truth of his complex position. Constantly watched and having to guard his feelings, other than to his long-time friend and confidante Horatio, there is no secure transitional object that can replace Hamlet's multiple losses of father, mother, kingdom, and thwarted expectations in the world. His interaction with the Ghost, a tangible symptom of his spiritual crisis, forces him to contemplate issues previously hidden in the shadow of his unconscious.[13] No longer sharing the same communal understanding and sense of the world as he believes others do, the Ghost confirms his worst fears about Claudius and provides a motive to powerfully resist his institution.

B. The Institutional Diagnosis

Highly visible to the institution's gaze, the patient's discomfort with his father's death and mother's remarriage at first presents as melancholy. Later, if education or psychiatric treatment fails to transform him into a compliant and

largely sane member of this society, his recalcitrant condition will be cynically manipulated to create the impression that he is mad and an object to be cured or removed. Since the Middle Ages it had become a common and lucrative business to expeditiously remove the mad by ship to other countries where they might be disembarked, and quietly and conveniently disposed of.[14] As Claudius's diagnosis confirms, 'Madness in great ones must not unwatched go.'[15]

According to Goffman the 'social beginning' of the patient's career is the 'betrayal funnel.'[16] This is described as a conspiracy of trusted and concerned family and friends who report behaviours to professional helpers and other members of the 'circuit of agents' who will ultimately make important decisions about their inmate status in the institution. Aside from Horatio, the other characters fulfil their roles admirably well. As senior 'complainant' and concerned family member, Claudius is the first to question Hamlet's brokenness and introduce him into the funnel. Summoned back to court, Claudius offers Hamlet persuasive therapeutic advice over his grief and directs him to conform in his dress and worldview by publically suggesting that his step-son's self-indulgent grief is 'unmanly' and unnatural.[17] Placed under informal house-arrest he is to 'remain here in the cheer and comfort of our eye,' under surveillance.[18] Already experiencing losses and 'out of contact' with the world beyond the institution, the patient's mortification process meticulously disposes of any further 'previous self conceptions,' identity and resources in order that he might be '"rebuilt" with an organizationally appropriate identity' that 'produces an acceptable inmate self in the eyes of the staff.'[19]

At this stage in the treatment in Act I, given the inequitable power relationship between patient and doctor, Claudius resorts to emotional blackmail to be seen to gain the patient's fragile compliance. However, to retain his 'executive competency' Hamlet establishes an alternative 'under-life' that engages his energy in a search for evidence.[20] Fraternising with other inmates and directly practising 'amoral arts of shamelessness' against them permits him to covertly offer a resistance that honestly rails against the institution without exposing his true purpose.[21]

Hamlet tantalisingly suggests a number of possible diagnoses to explain Hamlet's condition. Polonius and Gertrude are convinced that Hamlet's true madness is either due to Gertrude's 'o'er hasty marriage' or that he is love-sick for Ophelia.[22] Ophelia too, on her own pathway to institutional insanity, questions Hamlet's stability after his vicious rejection of her. However, it is Claudius's first and cynically misdirecting diagnosis of a melancholy that leads to madness that is most relevant here. In the therapeutic project both parties share the same terrible intent, making it impossible to accommodate a therapeutic outcome. Beginning with the Ghost, associated in the Elizabethan mind with disruptions in the institutional relationships between king and cosmos, reality and unreality run

together and the combatants are left 'watching one another, forming theories about one another, listening, contriving, full of anxiety.'[23]

Finally realising that Hamlet's behaviour is both a personal and an institutional threat Claudius dispatches Polonius, his senior consultant and spy-master, to observe the patient and to undertake a number of tests, and his friends Rosencrantz and Guildenstern to ascertain the extent of his 'madness.'[24] Thus, Hamlet's curious behaviours are 'transformed from defiance [...] into mere symptoms of sickness.'[25] Much of Acts II and III finds the institution bending themselves to the difficult task of covertly collecting evidence of Hamlet's symptomology and analysing it, whilst Claudius works to reveal the extent of Hamlet's awareness of his culpability.

C. In Practice

In ethical practice expert helpers rarely work with close relatives and in this case the therapeutic challenge to work with Hamlet momentarily falls upon Polonius who is totally self-assured in his knowledge of the human condition. Taking the form of an assessment, Polonius in his role as pre-Freudian analyst and spin-doctor undertakes his first session with Hamlet quite spontaneously by posing questions that confirm his preconceived hypothesis. Unfortunately, in his fumbling attempts at a therapeutic relationship he fails to note that the patient is mocking him. However, he does have the wit to momentarily see that Hamlet is rational: 'how pregnant sometimes his replies are!'[26] Duping Polonius into thinking that he is 'mad for love,' and later detaching himself from Ophelia and her father's spying, the patient is able to signal his losses and condemnation of the love/lust that has infected his mother's new marriage.[27]

In the character of Polonius is found the genuine tension that exists in the server-served relationship that typifies all institutions. His allegiance to his chief executive prevents him from acting in the best interests of his patients. He makes cursory judgements and poor assessments of patient needs and withholds confidentiality. He impugns his daughter's character and reputation by revealing and reading personal letters sent by the patient to her and has no hesitation in devising an experiment that will see her unethically employed as a humiliated decoy.

Unaware that Hamlet is conducting his own experiment, his university friends Rosencrantz and Guildenstern are instructed by Claudius to find out 'Whether aught to us unknown afflicts him thus.'[28] Hamlet bluntly asks if they have been sent to spy on him. Their obfuscation and transparent denial press him to suggest that they are being manipulated by Claudius and he satisfies them with a self-diagnosis and symptoms of melancholy that will serve to convince Claudius of his vulnerability: 'I am but mad north-north-west: when the wind is southerly, I know a hawk from a handsaw.'[29] Gertrude hopes that an imminent stage performance to the inmates will prove a distraction that will literally change her son's mind. Meanwhile, in his under-life in the institution Hamlet uses his celebrity status to

discreetly prepare the actors to perform 'The Murder of Gonzago' as a means to
check the Ghost's veracity, create a visualisation of his father's murder, challenge
the institution's story, 'catch the conscience of the king,' and wring a guilty
confession from him.[30]

As all the inmates and staff of Elsinore are available to be used in forwarding
the needs of the institution, Polonius hastily arranges a spontaneous clinical
encounter for the patient with his daughter as bait where he and Claudius can
secretly observe Hamlet's reactions and verify Polonius's hypothesis. Hamlet
enters '*in deep dejection*,' as he begins 'To be, or not to be' soliloquy.[31] In a
painfully self-conscious altercation, the patient's treatment of Ophelia is further
distorted by his disappointment in her dissembling. A shocked and bemused
Ophelia is left to pray 'Oh what a noble mind is here o'erthrown!'[32] Intuiting that
the patient has been goading them, Claudius is convinced that 'Love! His
affections do not that way tend.'[33]

Having hijacked the performance, the patient energised by the approaching
fruition of his plan indiscriminately fires caustic puns at the assembled staff and
inmates in such a way as to confirm the institution's continuing prognosis that his
'wit's diseased.'[34] On cue at the climactic moment of the performance Claudius
bursts from the hall. For a moment a triumphant Hamlet has proved the
authenticity of his spiritually inspired evidence and out-witted his therapists.
Unfortunately, Claudius's abrupt exit from the play whilst inconclusively a public
disclosure of guilt might be interpreted as an attempt at managing a dangerous
patient who, prior to the performance, made a death threat.[35]

Summoned to face a concerned Gertrude by Rosencrantz and Guildenstern,
Hamlet savagely vents his frustration on them and implicates them as agents of the
institution, 'Why...how unworthy a thing you make of me!'[36] Joined by Polonius,
he resumes his scatological performance before sinking into a soliloquy that,
though it briefly threatens emotional violence to his mother, also counsels against
losing control – to 'be cruel not unnatural.'[37] Claudius's fears for his own safety
should he let Hamlet's 'madness range,' reinforced by Hamlet's sixth soliloquy,
are confirmed by his staff's confidential reports of the patient's growing
excitement.[38]

Hamlet keeps his appointment with his mother, whilst Claudius, preserving 'his
reputation as a kindly therapist,' follows Hamlet's treatment plan to its inevitable
conclusion by referring him to a similar institution in England that prevents further
contamination to a sensitive population.[39] In the meantime, Polonius is hiding in
Gertrude's room taking notes.

The patient begins to scourge his mother over her marriage – suggesting that it
is her mad lust that must be cured. Gertrude, anxious as the patient '*[seizes her
arm]*,' cries 'murder' and startles Polonius in his hiding place.[40] Thinking it is
Claudius, Hamlet blindly stabs and kills him. Undeterred, he continues his self-
righteous interrogation, and it is at this point that the Ghost appears, unseen to

Gertrude, to caution Hamlet against violence. Instead Hamlet lectures Gertrude, in the language of the institution, on her future chastity with Claudius and challenges her to test his sanity: 'lay not that flattering unction to your soul, that not your trespass but my madness speaks.'[41] The patient's final speech is coldly self-assured as he informs her that he knows of Claudius's plans to have him silenced.

As the institution rallies to search for its violent inmate, Gertrude's diagnosis on Hamlet's state of mind is unequivocal, 'Mad as the sea and wind when both contend which is the mightier.'[42] Claudius admonishes himself for the institution's failure to restrain and correct the patient's fatal behaviour by caring too much. Notably, his language in subsequent scenes is peppered with ironic descriptions of 'disease' in connection with the patient, and his proposed intervention is ominous:

> Diseases desperate grown by desperate appliance are relieved, or not at all [. . .] Do it England, For like a hectic in my blood he rages, and thou must cure me; till I know 'tis done, howe'er my haps, my joys were ne'er begun.[43]

In his final soliloquy the patient carefully summarises what he has learned from his time in the institution and, about to embark, puzzles over his progress through the institution. In this he 'weighs' his painful personal losses 'against humanity's capacity for self-destruction and deception.'[44] Metaphorically and literally severed from the institutions of his childhood and motherland he is free to embark upon an uncertain future.

3. Killed and Cured

In the final stages of *Hamlet* providential occurrences now shape the design of the play revealing a Hamlet symbolically and freely rebirthed to the institution via its graveyard. No longer a patient, Hamlet appears markedly 'normal.' Even though he remains convinced of Claudius's guilt, his thoughts are no longer so overtly inclined to revenge. Nor does he seem afflicted by madness. Hamlet has achieved an understanding of the self, a paramount human task for early Elizabethans which, rather than 'egoism,' provided 'the gateway to all virtue.'[45]

Encouraged to take part in a fencing bout with Laertes, with whom he now believes he is reconciled, Hamlet is wounded by a poisoned rapier. Fatally wounded and forced to defend himself he watches his mother die from a drink meant for him and witnesses Laertes confession to his part in Claudius' elaborate murder plot. Finally justified in confronting Claudius 'with all his crimes broad blown' he stabs him with a poisoned blade.[46] It could be said that having explored the roles of a 'patient,' and a 'doctor' to the institution, he has achieved a level of psychic balance that enables him to fearlessly accept his own death and serenely reconcile himself to a reality that he cannot completely change.

4. The Tragic Institution

This work has examined Hamlet as a patient and an object for psychological analysis in a total institution. Hamlet's objectification by the institution illuminates the tragic dimensions of Hamlet in *Hamlet* whilst exploring the belief that the mortifying confinement and reconstruction of patients serves the greater good. However, as the roles of patient and doctor are blurred, almost interchangeable, it poses questions about the fitness of one group to work upon the other. Shakespeare's parable of *Hamlet* reveals a service relationship that is so functionally skewed that its flawed autocracy serves nothing but itself.

There is no happy ending to Hamlet's condition – this is a tragedy. It illustrates how the institution can pass on its own sickness through the patient's reconstruction process. It also raises one very subtle and important question: Are we implicated in Claudius's guilty scheme? As scholars and audience we relish *Hamlet* in the asylum, not because Hamlet requires healing, but because he unwaveringly and enigmatically taunts us with his mystery.

Notes

[1] Although its provenance is problematic, it is generally agreed that Shakespeare's *Hamlet* was first performed in 1602, or thereabouts. John Dover Wilson, Introduction to *The New Shakespeare Hamlet* (Cambridge: Cambridge University Press, 1972), vii-lxvii.

[2] *Hamlet*, 2.2.255: The bloody tale of Amleth is described in the late 12th century Danish historian Saxo Grammaticus's third book of history entitled *Historia Danica*.

[3] Harold Bloom, *Shakespeare: The Invention of the Human* (New York: Riverhead Books, 1998), 410-411: *The New Shakespeare Hamlet*, 3.2.368-369.

[4] Sigmund Freud, 'Some Character-Types Met within Psycho-Analytic Work'. In *Standard Edition of the Complete Psychological Works of Sigmund Freud* Vol. 14. Translated by James Strachey (London: Hogarth Press, 1957 [1916]): 316-324; Ernest Jones, 'Hamlet and Oedipus', in *Shakespeare, Hamlet: A Casebook*, ed. John Jump (London: Macmillan, 1949), 51-63.

[5] Greg Smith, *Erving Goffman* (London: Routledge, 2006), 71; Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (London: Penguin Books, 1991 [1961]).

[6] *Hamlet*, 4. 3. 29-30.

[7] Goffman, Asylums, 17: See also Erving Goffman's paper 'On the Characteristics of Total Institutions,' presented in April 1957 at the Walter Reed Institute's *Symposium on Preventive and Social Psychiatry*.

[8] *Hamlet*, 2.2.246-50.

[9] Goffman, *Asylums*.

[10] Michael Taussig, 'Reification and the Consciousness of the Patient', *Social Science Medicine* 14.B (1980): 5.

[11] Ronnie Janoff-Bulman, *Shattered Assumptions: Towards a New Psychology of Trauma* (New York: Free Press, 1992); Bray Peter, *Hamlet's Crisis of Consciousness: The Deeper Dimensions of Adolescent Loss* (Saarbrucken: VDM Verlag, 2008).

[12] Goffman, *Asylums*, 12.

[13] Ronald David Laing suggests that 'No one who has not experienced how insubstantial the pageant of external reality can be, how it may fade, can fully realise the sublime and grotesque presences that can replace it, or exist alongside it.' Ronald David Laing, 'Transcendental Experience in Relation to Religion and Psychosis', in *Spiritual Emergency: When Personal Transformation Becomes a Crisis*, eds. Stanislav Grof and Christina Grof (Los Angeles: J. P. Tarcher, 1989), 53.

[14] Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason*, trans. Richard Howard (Cambridge: Routledge, 1995), 8-9.

[15] *Hamlet*, 3.1.192.

[16] Goffman, *Asylums*, 123-135.

[17] Paul A. Jorgensen, 'Hamlet's Therapy', *The Huntington Library Quarterly* XXVII (1963-64): 244, suggests that Claudius is following the advice of Robert Burton: '[...] gentle persuasions are to be used, not to be too rigorous at first, or to insult over them [...] but if satisfaction may not be had, mild courses, promises, comfortable speeches, and good counsel, will not take place; then [...] handle them more roughly, to threaten and chide.' Hamlet, 1.2.94-97.

[18] *Hamlet*, 1.2.115-117.

[19] Smith, *Erving Goffman*, 72-74.

[20] Ibid., 43 and 305.

[21] Ibid., 155.

[22] Polonius is referring to 'heroes' a term that describes a 'melancholy anguish caused by love for a woman. The cause of this affliction lies in the corruption of the faculty to evaluate [...] [men forget] all sense of proportion and common sense [. . .] it can be defined as melancholy anguish.' Ioan P. Couliano, *Eros and Magic in the Renaissance*, trans. Margaret Cook (Chicago: University of Chicago Press, 1987), 20.

[23] Clive Staples Lewis, *Selected Literary Essays* (Cambridge: Cambridge University Press, 1980), 99.

[24] *Hamlet*, 3.3.2.

[25] Eliot Freidson, 'Celebrating Goffman, 1983', *Contemporary Sociology* 12, No. 4 (1983): 359-362.

[26] *Hamlet*, 2.2.210-213.

[27] For further references to concepts of erotic melancholy such as lovesickness and 'heroical' love in the Middle Ages, see: Angus Gowland, 'Burton's *Anatomy* and the Intellectual Traditions of Melancholy', *Babel Litteratures Plurielles*, 221-257. accessed 16 June 2013, http://babel.revues.org/2078#bodyftn21.

[28] *Hamlet*, 2.2.17-18.

[29] Ibid., 2.2.382-83.

[30] Hamlet's re-working of Old Hamlet's account of his poisoning in the garden and subsequent seduction of his wife by his brother. *Hamlet*, 2.2.609.

[31] *Hamlet*, 3.1.56-90.

[32] Ibid., 3.1.153.

[33] Ibid., 3.1.165-7.

[34] Ibid., 3.2.322-323.

[35] Ibid., 3.1.151. Hamlet's suggestion to Ophelia in Claudius's hearing that, 'Those that are married already – all but one – shall live,' might easily be interpreted as a death threat.

[36] Ibid., 3.2.366-373.

[37] Ibid., 3.2.398-399.

[38] Ibid., 3.3.2.

[39] William F. Bynum and Michael Neve, 'Hamlet on the Couch', *American Scientist* 74, No. 4 (1986): 391.

[40] The Ghost's individual appearance to Hamlet but not to Gertrude defies the logic of the previous group encounter but this incongruity does serve the plot and subsequent diagnosis perfectly. In this context Gertrude is able to claim that 'Alas he's mad.' *Hamlet*, 3.4.106-135.

[41] Ibid., 3.4.145-146.

[42] Ibid., 4.1.7.

[43] Ibid., 4.3.9-67.

[44] Peter Bray, 'Men, Loss and Spiritual Men, Loss and Spiritual Emergency: Shakespeare, the Death of Hamnet and the Making of *Hamlet*', *Journal of Men, Masculinity, and Spirituality* 2, No. 2 (2008): 10-14.

[45] Eustace Mandeville Wetenhall Tillyard, *Shakespeare's History Plays* (New York: Macmillan, 1946), 79.

[46] *Hamlet*, 3.3.81.

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'When I'm Afraid I Will Trust In…?'

Iva Apostolova

Abstract
In my chapter I will explore the possible moral attitudes toward a patient, with a focus specifically on the attitude of trust. I will make the strong case that the only morally viable attitude toward a patient is one of complete *trust*. By 'patient' I will understand a 'person who is in need of medical attention'. This puts the patient in an immediate and direct relationship with a professional who is *entrusted* with the care for the patient. I will look more specifically at the cases of terminally ill patients and their relationships with the caring health care professional. I will argue that a terminally ill patient's will is to be respected even if it is a will to terminate one's life. For this I will argue that the professional entrusted with care is under the obligation to not withhold any information from the patient that will help the patient make an informed decision about his/her fate. I will argue in favour of this on grounds of Kant's deontological principle of self-determination, complemented by the underlying principle of ethics of care where a *caring relationship* is understood as the foundation of morality. In line with this, I will argue against Bioethical conservatives such as Leon Kass who uses Kant's principle of autonomy combined with Kant's argument against suicide, to reject voluntary active euthanasia as a viable and valid moral attitude. I will discuss several cases of intervention under the presumption that the patient's decision is not voluntary and/or lucid in which I will attempt to draw the line between morally competent and incompetent patients to satisfy the condition of personhood.

Key Words: Ethics, patient, health care professional, care, trust, assisted suicide.

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The original quote from my title comes from the Bible, Psalm 56:3 and it reads: 'When I'm afraid, I will trust in you.' 'You,'of course, refers to God. The irony here is intentional.

Two caveats: for the purposes of this chapter I will assume that the generic term 'euthanasia' encompasses such procedures as 'assisted suicide,' 'starvation and dehydration' (a method of ending one's life that is gaining popularity in Canada), and all other methods that could go under the definition of 'voluntary active euthanasia' where the patient has explicitly made a wish to end his or her life due to unbearable pain and suffering, or extremely low quality of life resulting from terminal or chronic illness and/or other medical conditions.

1. Main Argument

My main argument is that the decision to euthanise is a moral decision which requires or even demands an attitude of complete trust between the person to be euthanized and the person euthanising. I will call the person requesting euthanasia the patient, and the person euthanising, the health care professional (most likely a physician). By 'patient' I will understand a 'person who is in need of medical attention'. This puts the patient in an immediate and direct relationship with a professional who is *entrusted* with the care for the patient. I find that what most arguments in favour (or against, for that matter) of euthanasia omit or simply take for granted is that there *is*, as there *should* be, a relationship of *complete trust* between the patient and the health care professional when it comes to decisions concerning the end of life.

On the one hand, I will argue that a patient's will to die due to the aforementioned conditions is to be respected. For this I will provide a few 'positive' arguments exclusively in the form a refutation of the bioethical conservative Leon Kass's arguments against euthanasia. On the other hand, I will argue that the professional entrusted with care is under the obligation of *care*. In other words, the two most important characteristics of a health care professional are *competence* and *care* (which involves such virtues as compassion, forbearance, tolerance, courage, etc.), care coming strongly into play when end of life decisions are concerned (where competence may be exhausted and thus, not playing an active role). I will argue for both arguments on grounds of Kant's deontological principle of *self-determination*, complemented by the underlying principle of ethics of care where *caring relationship* is understood as the foundation of morality.

I will start with the latter. When a patient is entrusted to the care of a health care professional, a few things happen: a special *bond* is formed between the health care professional and the patient. This bond is inevitable since the relationship between the patient and the health care professional is one that goes beyond professionalism. The health care professional knows the patient in a very *intimate* way. He/she has most likely seen and talked about parts of the patient's body that are normally not exposed to any other professional. If a life threatening medical condition is involved the health care professional is the person the patient trusts with the diagnosis, a diagnosis that involves the patient's life. This, however, puts a tremendous *burden of responsibility* on the health care professional which goes well beyond his/her medical competence.

Without any claim for comprehensiveness, here's an improvised list of what this burden of responsibility might look like: first, the health care professional must learn to trust another professional with the diagnosis and the suggested treatment. Second, the health care professional must *attentively listen* to the patient and his/her concerns. Third, it may be required that the health care professional make house calls and be attentive to the needs of the patient, whatever they may be. Fourth, he or she must not withhold any information that the patient might need to

make an informed decision. Fifth, the health care professional must make an effort to learn as much as possible about the patient's beliefs, views about life and death, etc. All of these, but especially the last one, will ensure that the health care professional who will be assisting with the making and the execution of the end of life decision, is well prepared to stand up for the patient's wish to terminate their life (in cases where the patient is meeting resistance from family members, friends, etc.) None of these are really taken seriously by the Canadian Health Care system.

2. Arguments for and against Euthanasia

There are two types of arguments regarding euthanasia provided in this chapter, a 'positive' and a 'negative' one. The 'positive' argument, which is my original position, is, in a nutshell, that there is *no* moral barrier toward a voluntary decision to euthanise. The decision to end one's life is grounded in the right to enjoy one's meaningful life, which right originates in the self-governing will. It will be argued, however, that a decision to euthanise is a context-based decision and should remain as such. Even though I will not make arguments for or against legalising euthanasia (the reasons being purely practical), I will argue that laws banning forms of euthanasia, are hardly wise.[1]

The main line of the 'negative' argument is that first and foremost, we need to distinguish carefully (no matter how difficult at times it proves to be) what I will call the *a priori* from the empirical moral argumentation concerning the decision to euthanise. Many arguments for or against euthanasia conflate the empirical with the *a priori* positions. I will argue, then, that there is no *a priori* moral barrier against the voluntary decision to euthanise. As for the empirical reasons against euthanasia, I will suggest, without offering an exhaustive list of all possible and actual case scenarios, that they have, in fact, weaker grounds than those proffered by their authors.[2]

Due to considerations of space, I will not go into the positive arguments in favor of euthanasia. I would just like to mention that I share James Rachels's and Dan Brock's conviction that there is no moral distinction between active and passive euthanasia.

2.1 An Argument against Euthanasia

I will consider now the most serious anti-euthanasia argument proposed by Leon Kass, who attempts to prove that there are no *a priori* moral grounds for supporting a decision to euthanise.[3] In other words, his claim is that a decision to euthanise cannot be a voluntary decision. This makes Kass's argument an *a priori* one and the main 'threat' to my original position. For ease of handling it, I have divided it into a few sub-arguments as follows:

A. Kass Perceives and Presents Death as *Unavoidable Evil*
    I object to this as an oversimplification of death and our experience of and with

death. Death plays a pivotal role in what we call 'meaning of life' in the sense that it defines the boundaries and limitations of our lives. In addition, we make all kinds of arrangements to organise our deaths (e.g., we purchase, sometimes very costly, life insurance policies, which often cover the cost of funerals; we leave wills where we express wishes about how to be handled in death, etc.), so it is not really fair to say that death is the epitome of the unavoidable, eminent evil in the Western culture to which Kass seems to be referring when describing death.

B. Kass Asserts that We Misconstrue the Right to Die

Kass argues that, on the one hand, we generally misconstrue *right* as desire, and on the other hand, that every right entails a set of obligations. Thus, when we talk about the right to die (with dignity) we actually express nothing more than our desire to die in a certain way, but this desire for Kass does not translate into a right to die in a certain way (e.g., with dignity). In addition, in our desire to die with dignity, that is, to terminate our life before its 'natural' end, we impose an impossible moral obligation on another person, the person assisting with the death wish, which we are, in fact, not allowed to do.

A proper response to Kass's anti-euthanasia argument would require a careful analysis of the concept of moral obligation as well as moral right, an analysis hardly fitting for the limited scope of this chapter. Instead, I would like to point to the fact that there is a lot of rationality involved in the way we think about and handle death. Kass seems to completely ignore this aspect of human life and instead, overemphasises the negative side of our experience with death, namely, that we, humans, have an ever-present fear of death (since often death is accompanied by pain, for example). From here, Kass argues that euthanasia decisions are based on fear, that is, on an irrational emotion rather than on a rational decision. It seems to me, however, that ignoring the rational handling of death and vilifying it, is nothing more than fear-mongering. Death, as well as our attitude toward death, deserves a due consideration which Kass does not seem to give.

As for the notion of right, I think it is worth pointing out that there are at least two different ways of defining right, both of which, however, consistently lead to endorsing euthanasia as a possible and legitimate 'natural' end of life, in opposition to what Kass considers a 'natural' end of life. One of the ways of defining right is through the concept of *interest* (as in conative interest).[4] In other words, I have a right if I have a *claim* to something. This claim needs to be recognised by me as something good for me. In other words, in order for me to have a claim, I need to have an *interest*, including an interest in living meaningfully, without pain and suffering, as well as planning for the future. If there is a loss of all meaning of life, including no prospect for any future plans, then, it is only natural for me to claim an exit from life as the most meaning-preserving move.

The second way is to define (moral) right in terms of *moral equality*.[5] In other words, every entity with interests, understood as conative interests, that is, interests that include future goals and plans for future activities, anticipation of future events, etc. should be treated equally with the like interests of any other entity. Thus, if avoiding suffering is part of my conative interests, there is no contradiction in arguing that in cases of unbearable suffering, it is in my best interest, hence, it is my right, to alleviate this suffering, even if it means, terminating my life.

It seems to me that Kass's use of 'natural' in the 'natural end of life' is poorly reflected upon. The use of 'natural' here is similar to the use of the term 'human nature' understood as a 'desire to live.' As I have already suggested, however, the desire to live should not be interpreted as a desire to live at all costs, but as a desire to live a meaningful and fulfilling life. We must assume, then, that humans have the possibility of ceasing to desire to continue living if life is not meaningful any more. A 'natural' end of life, then, would be considered an end of life devoid of any meaning. Such a life could be described, on the second understanding of right, as a life full of unbearable pain and suffering.

C. Kass Compares Euthanasia to *Self-Enslavement*

Following Hobbes's famous argument, Kass claims that we cannot enslave ourselves. The analogy between death and self-enslavement is suspicious, to say the least. Even if we accept Hobbes's argument that one cannot enslave oneself, Kass needs to labour a lot harder than that to prove that death is the same as self-enslavement. Of course, Kass's premise that death is always an unavoidable evil supports the self-enslavement analogy (enslavement, understood as taking away one's freedom and possibly, one's life, too, cannot be interpreted as anything but evil) but if we deem this premise weak as I hope I have at least suggested is possible in the previous section, then the analogy collapses.

D. Kass's Strongest Argument against Euthanasia Based on Kant's Ethics

Kass bases his strongest argument against the right to die on Kant's ethics, specifically on the dynamics between the autonomous will and the moral goodness which is dictated by the ultimate moral duty. In other words, the will which is a rational will, cannot rationally endorse its own self-destruction. And thus, there is no such thing as a right to die. While the move is certainly clever and on the face of it, delivers a deadly blow on the right to die argument, I believe Kass's interpretation of Kant's principle of the autonomy of the will is misguided, if not mistaken.

The first important thing to note is that Kant does not question the constitution of the human mind, that is, of human rationality. He accepts it as a given. Rationality is part of who we are as humans. Here is what Kant writes in the preface of *The Groundwork of the Metaphysics of Morals*, 'When applied to man,

it [moral philosophy] does not borrow in the slightest from acquaintance with him (in anthropology), but gives him laws *a priori* as a rational being.'[6] This does not mean that rationality is to be equated with human nature. Kant rejects the claim that human nature should play any role in deciding on the moral law.

It is clear that Kant wants to separate human nature from human rationality. However, this does not mean that rationality is not *typical* for humans like other traits such as walking erect or fearing danger. These traits make us who we are as humans. Thus, I think it is important to note that Kant not only never questioned that humans are rational, but also that he never proposed that we should have had a different kind of rationality compared to the one we already have. In other words, Kant did not think that human rationality is a weaker version of, let us say, a divine rationality which is perfect and unbounded.

This will also mean that, following Kant's logic, it is up to us, the members of the moral community, that is, all rational agents, to decide when one's rationality is fading or not present altogether (which we, no doubt, have already done by deeming certain individuals 'incompetent'). I think that if we bring out the subtle but very important point that what Kant means by rationality is human rationality and not a weaker version of a divine rationality, we could then, ask ourselves: how much of that rational constitution does an end-stage Alzheimer's patient really have? If suffering is so great that it impairs one's ability to think *rationally*, then is it not only *rational* to make the decision about one's end of life based on a *different maxim* (than the maxim that the will cannot rationally endorse its own destruction)? Consider the following maxim: 'When I am to lose my ability to reason and fulfill my obligations, I will act as to 1) avoid imposing duties on others and 2) reduce net suffering in the world.'[7]

This maxim is not in any way at odds with the way Kant describes the functioning of the human rational will. It also seems to exclude the possibility of killing the incompetent – who would have already lost their reason; it would also not require that all terminal patients end their lives, since there are some whose death would increase the net suffering in the world (e.g., the suffering of their families).

To sum up, it seems to me that Kass has missed Kant's point about rationality, namely that for him human rationality is not treated as a weaker divine rationality. It also seems to me that in looking at the definition of the moral law in Kant, one needs to discuss the origin of moral duty which is somewhat problematic for Kant, by his own admission. Although it is worthy of discussion and an important topic in itself, for space and time considerations, I will not go into it here.

3. Conclusion

In conclusion, I believe that one of the implications of my original position is the need to emphasise the inherent moral obligation to become a better person, which means better health care professional, better patient, and better member of

society which includes a better health-care system. For me a better health care system is not possible outside of a *relational ontology* where the patient and the health care professional are seen in a relationship, and an intimate one at that.

Notes

[1] I believe that the scope of this chapter does not allow for getting involved in issues surrounding legalising euthanasia, which is a topic in its own right demanding a careful consideration of the country's social, political, and health context.

[2] The authors whose points of view will be taken into consideration as representing the for- or against- euthanasia positions are Gay-Williams, Dan W. Brock, Daniel Callahan, James Rachels, John Lachs, John D. Arras, and The Philosophers' Brief (Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith Jarvis Thomson), James L. Bernat, Bernard Gert, and R. Peter Mogielnicki, James V. Lavary, Bernard M. Dickens, Joseph M. Boyle, and Peter A. Singer, Susan Wolf, Leon R. Kass, Mark R. Wicclair, and last, John Hardwig.

[3] See Kass' two main claims as exposed in his essay 'Is There a Right to Die?': 'Most generally, then, having a right means having a *justified* claim against others that they act in a fitting manner: either that they refrain from interfering or that they deliver what is justly owed. It goes without saying that the mere assertion of a claim or demand, or the stipulation of a right, is insufficient to establish it: making a claim and actually having a rightful claim to make are not identical. In considering an alleged right to die, we must be careful to look for a justifiable liberty or claim, and not merely a desire, interest, power, or demand. Rights seem to entail obligations: one person's right, whether to noninterference or to some entitled good or service, necessarily implies another person's obligation'. Leon R. Kass, 'Is There a Right to Die?', in *Biomedical Ethics: A Canadian Focus*, ed. Johnna Fisher (Canada: Oxford University Press, 2010), 197. And '[...] the right to die, especially as it comes to embrace a right to 'aid-in-dying', or assisted suicide, or euthanasia, will translate into an obligation on the part of others to kill or help kill. Even if we refuse to impose such a duty but merely allow those to practice it who are freely willing, our society would be drastically altered. For unless the state accepts the job of euthanizer, which God forbid that it should, it would thus surrender its monopoly on the legal use of lethal force, a monopoly it hold and needs if it is to protect innocent life, its first responsibility'. Ibid., 205.

[4] I have borrowed Joel Feinberg's definition of right as expressed in his 'The Rights of Animals and Unborn Generations'. Feinberg approaches the definition of right through *conation*: the presence of conscious wishes, desires and hopes, urges and impulses, drives, aims and goals, direction of growth, and natural fulfillment.

[5] This is how Peter Singer treats rights in *Animal Liberation*.

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[6] Immanuel Kant, *Groundwork of the Metaphysics of Morals* (London: Hutchinson's University Library, 1951), vii.

[7] This maxim was actually formulated by Christopher Parr, at the time a student in my Bioethics course in 2010.

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Reluctance and Resistance: How Do We Break the Cycle?

M. Jane Markley

Abstract

It is no wonder people do not discuss death; each is waiting for someone else to bring it up and feeling that they cannot. In America death is almost considered optional. But these people are not alone, as few take the lead and we continue the cycle of silence when it comes to advance care planning and death. So many different disciplines are involved in this space that challenges are compounded with much finger pointing and very little progress. Historically, involved entities worldwide have included: government legislation, the legal community, faith based organisations, acute care medical facilities, senior living advocates, hospices, palliative care centres, and many others. They each have a role but, much like the blind men examining an elephant, they all have varying success in describing the issues and then dealing with the whole. As a result of the lack of forward progress, many grass roots initiatives have been established, increasing the discussions; encouraging patients to talk with family, friends, and their healthcare providers; and getting advance care directives competently completed. Some have been more successful than others but, to date, we have been unable to significantly increase the percentages of completed advance directives and many that are completed are absolutely useless to the patient, family, and provider. There are new initiatives underway and other options available to us which I will discuss. What are our options for moving forward and how can we break the cycle of reluctance and resistance? Let us explore alternatives and seek to work together to enhance the end of life quality of care for people everywhere. This is an issue that crosses race, culture, gender, religion, etc. It is a universal issue with a universal need.

Key Words: Advance directive, living will, death, advance care planning, conversations, patient, end of life, quality of care.

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1. How Did We Get Here?

As technology progresses and new treatments are available, humankind seems to have become more unwilling to face their mortality. Let us consider why that might be. Back at the turn of the 20th century life expectancy in the U.S. for both men and women was under 50 years.[1] Death was a part of daily life and people had little or no control over it. They were injured or became ill and with the healthcare available at that time, they died; usually at home, cared for by family and friends who knew them well. Death was viewed as inevitable and was familiar to most as part of the family experience. During the 20th century, significant breakthroughs in science and medicine occurred and over time people began living longer. Their

children and sometimes they themselves left the insular family unit travelling far and wide for a variety of reasons. As the century progressed, more people were cared for in hospitals, which went from places where people went to die to places where people went to get well. There were miracle drugs, replacement of body parts, cancer remissions, and sometimes cures. It became as if death was an alternative that could be avoided rather than a natural progression of life. Because people were going to hospitals seeking a cure, death, when it came, was no longer occurring at home but in hospitals and people became insulated from it. Also disappearing towards the end of the century was the family doctor who cared for patients from cradle to grave and knew the patient and their family very well. Today, many people do not have a family doctor or, if they do, that person changes frequently due to transfers, insurance changes, or other mobility issues. People who used to view their providers as a family friend now do not know their family physician or even if they do, once they get sick they are shuttled off to a myriad of specialists whom they do not know. These providers all expect someone else to bring up the subject of advance care planning and thus it does not happen. Is it any wonder that people today are reluctant to talk with their providers about their death and advance directives? When you think everything is curable and you do not know or identify with your healthcare provider why would you bring the subject up? By having the conversations, developing a plan, and being proactive your desires will be known and can be readily shared with others. Effective communication is essential with so many players and so much distance involved.

Providers have a similar problem. They may not know their patients well either and they are pressured for time by our current medical system. They also do not manage emotions well as that is not a skill they have historically learned in medical school. Talking about advance directives is not comfortable for them and it is not a two minute conversation. If they bring it up they are unsure whether they will be able to cover what needs to be covered in the time available. They wonder if they will leave their patient fearful that their condition is worse than they thought or that they will lose hope. So what frequently happens is that no one brings the subject up because they are each waiting for the other party to do so. It usually takes a patient's untoward experience with a loved one for them to address the issue or a significantly negative medical event before the doctor brings it up. Thus: our conundrum.

It is important to remember at this point that this scenario is a generic one. No one should think that everyone in the U.S. falls into this pattern. There are family units who still address death at home but they are no longer the norm. And, there are individuals who seek out their autonomy documenting their wishes without any prompting. There are also physicians who are adamant about the need to address this type of planning and who do so with skill and compassion. Unfortunately, that is not the norm either. So, the question remains of how to break the pattern and encourage the conversation that needs to occur.

2. Historical Attempts

In the United States by the 1960s, advancing technology, coupled with the patient rights movement resulted in a hue and cry for people to be able to have a say in how they were treated. The years of healthcare paternalism, based on the concept of beneficence, were being overridden by the call for patient autonomy. This resulted in the earliest advance directive known as the 'living will.'[2] It was not until the 1970s that states and federal jurisdictions became active in legislating these 'grass roots' efforts. The first legislation in the United States in 1976 was the Natural Death Act in California which gave legal authority to living wills.[3] In the 70s, 80s, and 90s, the fates of three young women caught the attention of the U.S. and others worldwide. These women were Karen Quinlan, Nancy Cruzan, and Terry Schiavo, all in their 20s when stricken. Each had different conditions yet they were similar in that none of them had put anything in writing regarding how they wished to be treated if they could no longer speak for themselves.[4] This resulted in significant discussion, discord, press, and litigation regarding end of life decisions which played out in the media. While this was going on, states were taking their own initiatives and the federal government passed the Patient Self Determination Act (PSDA) of 1990.[5] Meanwhile in the 90s, Canada, the United Kingdom, and Australia each had similar activities emerging.

The PSDA was a start that increased awareness regarding advance directives and the importance of their use. These began as very medical/legalistic documents which included a living will and a durable power of attorney for healthcare. The living will outlined the type of care a terminally ill patient would or would not want to have if they were no longer competent. The durable power of attorney is a legal document that identifies someone else to speak for the person and make healthcare decisions for them when they are no longer able to do so themselves. Following implementation of the PSDA, the American Bar Association became pro-active by educating their lawyers regarding living wills and durable powers of attorney for healthcare. Thus when lawyers worked with their clients preparing legal wills and legal powers of attorney they naturally included the healthcare components as well. In some cases this became just a paperwork exercise with no involvement of any healthcare provider and little, if any, conversation between all the involved parties. Fortunately, they now encourage the conversation between parties including the healthcare provider.[6] Other initiatives were also started during the same time period with funding made available by the U.S. government. Many of these initiatives were established with the intent of educating the community and developing tools and programmes to support the training while drawing attention to the need for advance care planning and documenting one's wishes. Meanwhile states were exerting their authority to develop their own laws.

Unfortunately, even with all these efforts, the PSDA did little to increase the number of people who had completed advance directives. Numerous studies through the years report very little statistical change in the number of advance

directives completed and depending on the research study used, the percentage of people who have some form of advance directive still hovers around 25%. This compares with the fact that more than 80% of people queried believe having their end-of-life wishes in writing is important.[7]

Another thing that has naturally happened as a result of these multiple initiatives is that the terminology used to address the concepts of advance care planning is now very extensive and the requirements and policies are variable from one jurisdiction to another. People, patients and providers alike, who are averse to addressing death as a component of life, also have difficulty with this myriad of terms used, often interchangeably, to address this subject. An excellent example is the durable power of attorney for healthcare which is used interchangeably with the healthcare agent, healthcare proxy, medical durable power of attorney, proxy, and substitute decision maker, thus adding additional complexity with which to deal.

So, how can we move forward to break this cycle of reluctance and resistance? It appears that there are options. Enhancing the conversation between individuals and their healthcare providers as well as between individuals and their key family members and friends would be a start in the right direction. Another option would be making advance care planning a basic standard of good health care and not something that is belatedly tacked on as almost an afterthought. This might go a long way towards finding acceptance if these types of discussions were a normal part of every healthcare visit. From what has gone before, there appears to be no single panacea but perhaps a combination of multiple interrelated efforts to address the challenge would work.

3. Current Initiatives Showing Progress
A. Respecting Choices Model

Initiated by Gunderson Health System, Respecting Choices began as a collaborative effort in LaCrosse, Wisconsin, in 1991, involving major health organisations and the community. Their goal was different than many others as their focus was not only on increasing the number of advance directives completed or increasing education. They focused on providing both community training and trained staff to offer personal assistance to individuals throughout the community. This was a coordinated effort for which they sought buy-in throughout the local community and it paid off. Not only was there a significant increase in the number of people who completed advance directives, but those directives were also located in their medical chart, families and providers were well aware of them, and they were typically followed. This systematic, coordinated community effort of providing professional education and developing and using solid standards of practice has been a successful model. It is being replicated throughout the United States and overseas in countries such as: Australia, Canada, Germany, Singapore, and Spain. This type of effort requires buy-in from all community interest groups; a champion and staff who are hired to focus their full attention on ensuring that

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standards are maintained and that the programme is successful; and the professional resources to provide the required, community-wide educational component. This model incorporates professional training, buy-in, enhanced communication, commitment to the process, and integration across multiple disciplines and facilities.[8]

B. Aging with Dignity's *Five Wishes*

The non-profit company, Aging With Dignity, is one of the few programs developed in the 90s that is still active, fully functional, and growing. They started small, focusing on developing a mechanism for the people of Florida to address and actualise their advance directives. They introduced the *Five Wishes* in Florida in 1997 and to the nation a year later as a result of the interest its introduction generated. It is an easy-to-understand document that addresses more than just the medical/legal issues of advance care planning. It also addresses personal, spiritual, and family components that people say matter most when they are facing serious illness or impending death. Its emphasis on the total person is what makes it different and its ability to address how a person wants to be treated, what he wants others to know, and how he wants his pain managed in order to maintain his dignity is unparalleled. Working with the American Bar Association, Aging With Dignity sought to obtain legal buy-in at the state level for its use nationwide. Today, *Five Wishes* can be used in all states. It is also published in 27 languages and Braille and has been implemented in many nations worldwide. The *Five Wishes* is a legally sound document that is easy for people to use and better meets their needs.[9]

C. Medical and Nursing Training Programmes

Through the years, medical and nursing training programmes focused heavily on the technical aspects of medicine and nursing. Limited time was devoted to end of life care or to the art of communicating with patients and their families. Fortunately, this is changing as it becomes obvious that it must in order to meet the needs of today's patients and their families. More and more professional schools are incorporating ethics, end of life, and communications courses to better prepare their students to meet the reality of their professions.

D. Medical Home Model

In the United States changes are afoot to modify the delivery of care and focus more attention on preventive healthcare. This Medical Home Model seeks to educate patients to encourage behaviour changes. Including advance care planning routinely with all patients and building it into the standard of care will make discussing it much less threatening.

E. Death and Dying Dinner Parties

   Although this may appear whimsical, these parties are gaining a foothold in the United States as a way to allow people more comfort in addressing death while they are in a social setting with others. It encourages the conversation that is sorely needed to help people deal more effectively with death, whether their own or that of others. A multitude of models are currently in use and Alexis W. Foster even suggests having the conversation over breakfast.[10]

4. Moving Forward

   These initiatives demonstrate effective options for breaking down the reluctance of both patient and provider to address the subject of death and dying. One is far less fearful of something that he discusses and better understands. All these initiatives, in one way or another, support that opening up of the discussion and breaking the cycle of reluctance and resistance.

Notes

[1] UC Berkeley Department of Demography, 'Life Expectancy in the USA, 1900-98', accessed 16 December 2013,
http://demog.berkeley.edu/~andrew/1918/figure2.html.
[2] U.S. Department of Health and Human Services, 'Advance Directives and Advance Care Planning: Report to Congress', August 2008, accessed 16 December 2013, http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm
[3] Ibid.
[4] George J. Annas, '"Culture of Life" Politics at the Bedside: The Case of Terri Schiavo', *New England Journal of Medicine* 325 (2005): 1710-1715.
[5] The Library of Congress Thomas, '101st Congress 2nd Session H.R.4449 Patient Self Determination Act of 1990', accessed 16 December 2013, http://thomas.loc.gov/cgi-bin/query/C?c101:./temp/c101XsaMRA.
[6] Robert Fleming and Rebecca C. Morgan, 'Advance Directives: Ten Topics to Discuss with Clients', July/August 2002, accessed 16 December 2013, http://www.americanbar.org/content/newsletter/publications/gp_solo_magazine_index/flemingmorgan.html.
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[10] Alexis W. Foster, 'Bacon, Eggs, and Advance Directives: The Patient Self-Determination Act 20 Years Later', accessed 27 December 2013, http://www.law.uh.edu/healthlaw/perspectives/2011/Foster.pdf.

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Part 4

Patients and Politics

Negotiating Identity in the Patient Role: Tales from the Romanian Medical System

Ana Maria Borlescu

Abstract
Starting from Talcott Parsons' 'sick role' and Michel Foucault's 'biopolitics,' and on to the medicalisation of society, the patient has been theorised as a receiver of medical care in an unequal medical power structure. Although the patient is sometimes discussed as reluctant and even dismissive of the manifestations of medical authority, this power structure remains in place when discussing the doctor-patient interaction. Present day changes in the organisation of the medical system, increasingly market-oriented, have had an impact on this building block of medicine. No longer is the doctor an uncontested figure of authority, even in a place where many still see themselves at the mercy of medical practitioners. Patients do not leave their Self at the door when entering the doctor's office; they bring with them a complex set of social and cultural knowledge on who a doctor is and should be, how a patient can gain his favours and how much one can trust a doctor's orders. One of the main social problems in present day Romania is the malfunctioning, poorly managed, corrupt, state-funded medical system. Despite the many insufficiencies, patients and doctors generally find ways to treat the problem at hand. Informal payments – a common practice in the Romanian medical system – seem to sustain a patient's inclination to ignore or challenge in an informal setting the medical advice received. Even when a patient follows the prescribed treatment, this is often accompanied by other treatment methods inspired by the media, family or friends. My chapter is based on ongoing in-depth interviews with medical practitioners and patients which so far reveal a complex set of negotiated identities that take the doctor-patient relation beyond a simplistic power structure.

Key Words: Identity, doctor-patient relation, patient construct, power.

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When it comes along, illness acts as a breach in our daily lives and activities, an obstacle in the way of our forgetfulness. Be it severe or passing, chronic or acute, illness pulls us back into our bodies, forcing us to take notice of what we so often take for granted: our health. Illness is the star of the medical world, not health, not even the patient. Modern medicine continuously moves towards an ever more personified notion of disease which becomes the focus of medical investigation. Researchers are not looking for a cure for individuals suffering from cancer, they are looking for a cure for cancer itself. Disease occupies the main stage in medical care, pushing the patient to the background. This is at least the mainstream discourse of modern medicine set forth by the media and medical research which

client-oriented approaches are currently placing under pressure to shift to a more patient-friendly medicine.

Medicine also has a more daily, routine side which brings its actors face to face with the individual, human aspects of disease: the patients. The doctor-patient encounter is the core of meaning formation on the subject of disease and modern medicine at large. This encounter is the formal, socially constructed setting in which the two actors come together. Sociological analysis of this setting has mostly focused on the authority of the doctor and on the power structure of the encounter. Therefore, patients are assumed to bring their ailments to the encounter looking for a scientifically sanctioned remedy which can only be provided by the doctor, the keeper of scientific medical knowledge. Due to this knowledge, the doctor is believed to hold a superior position in comparison to the patient. The latter is supposedly expected to submit to any procedures and treatments prescribed by the doctor. This is the general line of argument followed by one of the most well-known sociological explanations of the medical encounter, Talcott Parsons' concept of the *sick role*. In short, by adopting the *sick role* an individual is exempted from his functions in society for the duration of his illness with the confirmation and support of the medical profession. Patients must then comply with the indications of doctors and respect their dominance, the position of the latter being granted by their extended knowledge of the inner workings of disease. Also, the doctor now acts as a sentinel meant to ensure that the patient does not unnecessarily prolong his stay in the sick role, and resumes his social responsibilities as soon as he is 'cured.' The functionalist perspective argues that patients are not resilient to surrendering control to medical practitioners, due to the stress and uncertainty of disease which sometimes might require reassurance from an authority figure.[1]

Another perspective key to the sociological understanding of the medical encounter is that of poststructuralist and postmodern orientation inspired by Michel Foucault's concepts of *clinical gaze*, *surveillance* and *biopower*.

> Foucauldian approaches stress that power in the context of the medical encounter is not a unitary entity, but a strategic relation which is diffuse and invisible. Power is not necessarily a subjugating force aimed at domination which itself is vulnerable to resistance, but rather is closer to the idea of a form of social organization by which social order and conformity are maintained by voluntary means. Power is therefore not only repressive, but also productive, producing knowledge and subjectivity. Discipline acts not only through punishment, but through gratification, with rewards and privileges for good conduct.[2]

This perspective does not see the medical dominance as coercive but rather as expected and accepted by individuals because they have been socialised to do so. Also, from a social constructionist approach influenced by Foucault, power relations are dynamic and constantly negotiated during the medical encounter, with the patient playing an active role in evaluating the authority of the doctor.

The illness narratives perspective takes the patient's role in the medical encounter a step further. This interdisciplinary view of illness includes contributions from a variety of actors: from doctors, previous and current patients to sociologists and psychologists,[3] all have added to the significant progress of a perspective that allows the patients to have their own voice. The focus now shifts to the social construction of illness and, consequently, to the construction of patient and doctor identity during the medical encounter. This perspective sees patients adopting a variety of stances towards their treatment and their doctor and focuses on patient agency in the medical decision making process. They are more involved in every step of their diagnosis and feel more entitled to ask for a second opinion; they are shown to openly reject a treatment due to the side effects and, most significantly, we now 'hear' the patient's side of the story. This is in line with a focus on increased patient autonomy in medical ethics, with a doctor now 'caring with,' not 'caring for' a patient.[4]

This chapter argues that the medical encounter is a context which the actors enter with a set of pre-existing notions of health, illness, medical care and the body. These notions are culturally determined and thus contribute to the formation of particular constructs which guide the actors through the medical experience. Here I will focus on what I call 'the patient construct,' a set of notions about who one should be and how one should act as a patient, what the expectations of the doctors, other medical staff, family and other groups are – as perceived by the patient – when one becomes a patient, and what the appropriate ways to perform the patient role are. The whole of these notions defines and at the same time guide an individual prior, during and after the medical encounter. This construct forms the basis of a patient's identity and can be outlined by a researcher based on patients' illness narratives as well as doctors' discourses about the medical encounter and their patients.[5]

There is a specificity to the patient construct for any given medical system. The availability and distribution of resources, formal organisation and efficiency of the medical system as well as the patterns of use that individuals have for such a system influence the doctor-patient interaction and a patient's identity. Thus, a few words on the current situation of the Romanian medical system are necessary.

The public Romanian medical system is based on a mandatory social health insurance system implemented in 1998 which guarantees the insured population a set of health services, pharmaceuticals and medical devices.[6] The private health services market has grown constantly at a national level from 80 million euros in

2008 to 131 million euros in 2013.[7] Government spending for health services rose in 2011 to 732.2 dollars (per capita, PPP), still one of the lowest rates in the EU.[8]

The migration of Romanian doctors and nurses to other countries which offer superior working conditions and pay is becoming a significant social problem. Only last year approximately 3 000 doctors left Romania[9] while data shows that there are currently 2.4 doctors for every 1.000 individuals.[10] Young doctors and nurses receive low salaries and are the ones most inclined to leave the country for better positions.

The insufficient remuneration in the medical system is linked to a variety of issues, besides workforce emigration. For example, in a recent study 18% of those questioned say that they give money, presents or other small tokens of appreciation to doctors because the latter are paid badly and deserve more, while 35% say they do this because otherwise the doctors would not pay them any attention.[11] The practice of informal pay is deeply entrenched in the Romanian medical system and has occasionally spurred extreme cases of corruption, which sometimes reignite public outrage towards the practice and the doctors who support it. This type of informal pay also sustains a more private level of interaction between a patient and a doctor. Giving money or gifts to doctors is not perceived as contract payment, but more as an insurance policy or superstitious practice to ensure a proper treatment. This subject often comes up when discussing medical procedures undergone by patients and it is perceived as a burden, particularly in difficult cases. None of the patients I have interviewed so far questioned the practice. Some have simply acknowledged its inevitability in a country where 'no one looks at you if you don't give them something.'[12] Even if the procedure goes well and nothing has been given in advance, patients seem to not want to risk falling out of a doctor's graces or being forgotten by the latter, if they ever need him again. The patients I chose to interview underwent some type of surgery which implies recurrent doctors' appointments. These are the type of patients in it 'for the long run' that Arthur Frank sees as forming what he calls the 'remission society.'[13]

One does not go back to the realm of the unconcerned healthy society after certain procedures, but joins those who have to constantly be reminded of their health's shortcomings. Frank argues that this kind of patients never actually leave Parsons 'sick role.'[14] Thus, an individual must live with this new status and integrate the patient identity. Illness is rarely accepted or perceived as a normal occurrence in one's life. When discussing it, patients go back and forth between disassociating themselves from their bodies and talking about illness as something that affects their entire selves. A seventy-year-old woman seems helpless and betrayed by 'this head of mine that won't listen to me anymore' while for others their 'stomach troubles' are just a daily – sometimes powerful – but negligible nuisance.[15] So far, all my interviews and discussions with patients fall mostly under what Arthur Frank calls the restitution narrative, with a touch of chaos narrative.[16] A restitution narrative implies an end to illness, a moment in the future

where all present trials will end with the help of others, particularly doctors, while a chaos narrative is a fragmented, immersed expression of ongoing illness. One sign of the chaos narrative I encountered is the temporal narrative structure a particular interview had. The respondent went back and forth between past illness occurrences and present ones, specifically to her state on the day of the interview. Her current health issues had been diagnosed unsatisfactorily in the patients' opinion, and while relating past medical interventions and illness episodes she always came back to her current signs of illness in an attempt to find an explanation for these in past experiences.

Some interviews also revealed an unstructured mixture of elements that were discussed by respondents when talking about illness. All discussions around health issues involve a variety of emotional, psychological, social and financial elements. Illness is not simply represented by bodily signs and symptoms, it implies a set of social and emotional reverberations as well as financial costs. This 'illness package' is also signalled by doctors when discussing the process of taking a patient's medical history: 'If you have the time, you let them talk. If not, you steer them towards what you need,' that is enumeration of the physical signs of illness.[17]

Some doctors find that letting the patient tell his side of the story gives them more details about the affliction than simply asking for the symptoms straight away. This strategy is, however, limited by the time allotted to a consultation and sometimes by the patient's and/or doctor's characteristics. Although it seems unwise and counterproductive, some patients fail to mention certain symptoms or afflictions to certain doctors. For example, a doctor's sex or age seems to sometimes be relevant to the type of information a patient is willing to share.[18] A patient admitted to hospital for cardiac problems revealed his previously undisclosed inguinal hernia to a resident doctor because the latter was also male.[19] Moreover, a recurrent criteria for discerning a doctor's abilities encountered in patient interviews is the doctor's age. The older a doctor is, the more they are automatically considered to be more experienced and capable, even before there is a chance to put their abilities to the test. It is one more reassuring sign that the procedure a patient has to undergo will have a positive result. Being operated on by a professor, head of the hospital or a doctor who also works in Belgium gives us a greater chance of success, especially after the doctor's sympathy has been ensured by a fair informal payment.

Patients have a self-determining approach to illness. According to a recent study on Bucharest residents, 30% of those who have minor health issues first ask family members for advice and 20% ask a pharmacist, while 23% consult their family doctor.[20] Also, 37% declare that they have not gone to the doctor during the previous year, although they should have.[21] This tendency toward self-treatment also emerged in the interviews conducted with patients and doctors. Individuals postpone seeking professional medical advice for as long as possible, even if subjected to severe pain cause by kidney stones or other clear signs of illness.

None of those interviewed so far give any clear indication of why they delayed a medical consultation. A variety of reasons could be inferred, though; financial issues, fear of surgery based on previous experiences or fear of an as-of-yet unknown diagnosis, as well as the primacy of other elements in one's life. So patients go on a search for a quick fix: myrrh for eliminating kidney stones, vitamin injections, a variety of plant and honey mixtures to increase bodily strength, spa treatments and painkillers in bulk. Eventually, it comes time for the unavoidable doctor's appointment where the illness signs or general un-wellness become disease symptoms and a diagnosis.

A recurrent motif in the patient interviews is the 'unwell' feeling, a general sickness state which, if aggravated, sends an individual to the doctor's office. This state constantly reappears in discussion when patients talk about initial illness signs or how they felt immediately after the anaesthesia wore off. But even with a diagnosis in hand and an ongoing treatment, 'feeling unwell' is still the expression preferred by individuals when referring to their symptoms. At first sight, it might seem puzzling why someone who now knows what is wrong still prefers to express his ailments through this general, 'fuzzy' term. However, if we look at illness as a social event in one's life, it sheds some light on the recurrent use of this term. An individual is not simply expressing his physical signs of distress but seems to integrate in this 'unwell' state the social inadequacy he feels and an acknowledgement of the strain his condition brings to those around him. The medical diagnosis, as a name and/or description of disease, does not seem to have the same reach and is rarely used when talking about health issues. Illness that does not obstruct the daily course of one's life and allows one to continue as if nothing is wrong is not 'really' an impacting disease. Illness becomes relevant to the individual when it has social consequences, when the symptoms are no longer manageable without some sort of outside intervention. Admitting the loss of control over illness and its consequences on one's body and activity leads to efforts to regain at least some sense of control and independence. Going back to work sooner than the doctor recommended, adding different types of possible cures and adjuvant therapies to the prescribed treatment are only a few of the ways individuals try to regain a perceived sense of control over an identity in crisis.

Patients do not seem to settle easily into a passive stance in regards to illness. All patients interviewed so far have deviated in one or more ways from the prescribed treatment and recommendations made by their doctor. None of them seem to give their actions a second thought and discussing these changes or additions reveals the 'normality' of such practices. Patients take an active, hands-on approach to illness even if this is rarely done during the medical consultation. Only one of my interview subjects so far has openly asked her doctor to refill a prescription for a blood pressure treatment – thus following the advice of her daughter – which he discontinued due to a feared interference with a different prescription. She also asked for a certain kind of sleeping pills, disregarding the

doctor's comments that 'these are pure drugs.'[22] Usually resistance or disbelief towards a doctor's recommendations is manifested outside the medical consultation by seeking a second opinion when one feels the first doctor didn't do a good job because they have not asked for any tests or used any special equipment during the consult and he might have even prescribed the wrong kind of drugs.

The prescribed treatment suffers changes in most cases due to a variety of factors. When a patient takes a prescription to a pharmacy he is either directed towards a 'sponsored' drug, or he can choose a cheaper version of the drug. But in most cases, the changes appear after acquiring the treatment: changing the frequency or the duration and even eliminating a drug from the treatment because we have reasons to believe it is not good for us, without consulting a doctor. Relying heavily on self-monitoring her blood pressure, one interviewee decided to give up taking a particular medicine after only one pill. The perceived immediate control over her blood pressure given by the numbers of the at-home measuring device seemed more trustworthy in this case than the long term effect of a particular treatment. This tendency to take a treatment according to momentary symptoms has been recurrent in patients with chronic afflictions like high blood pressure or diabetes. Doctors are aware of such practices, but don't seem to have a way of persuading patients to follow the prescribed treatments. Although admitting that in certain chronic afflictions like high blood pressure not following the treatment sometimes leads to serious consequences, a resident cardiology physician does not go beyond recommending the treatment as 'good' to patients who manifest resilience.[23] On the other hand, interviews with patients seems to indicate that individuals would prefer to receive more complex information about their diagnosis, as they search for such clarifications from other sources like media, family or acquaintances with similar experiences.

Doctors do occupy a superior and respected position in the patient's view, but only as long as they prove knowledgeable and capable of giving the treatment that is expected from them. Some Romanian patients take a detour towards receiving proper medical care, and, instead of seeking only biomedical treatment, they have adopted a different approach which includes any means believed necessary and useful to regain health. Negotiating one's identity in the patient role is a complex process of presenting the 'proper' illness story to a doctor by respecting his recommendations for long enough in order to look good on the next check-up, while at the same time allowing yourself the liberty to 'adjust' the treatment, adding or removing different elements often based on a non-professional second opinion. The health impact of such changes to the patients is unknown, but they do bring the added bonus of offering a slight sense of control and activity in an uncertain situation which redeems some of the social inadequacy brought on by illness.

Notes

[1] Deborah Lupton, *Medicine as Culture*, Second Edition (London: Sage Publications, 2003), 114.

[2] Ibid., 120.

[3] For example: Arthur Kleinman, *Illness Narratives. Suffering Healing and the Human Condition* (USA: Basic Books, 1988); Michael Stein, *The Lonely Patient: How We Experience Illness* (New York: Harper Perennial, 2007); Arthur W. Frank, *The Wounder Storyteller: Body Illness and Ethics* (Chicago: The University of Chicago Press, 1995).

[4] Sandeep Jauhar, 'When Doctors Need to Lie', *The New York Times*, February 22, 2014, accessed 26 February 2014, http://www.nytimes.com/2014/02/23/opinion/sunday/when-doctors-need-to-lie.html?smid=fb-nytimes&WT.z_sma=OP_WDN_20140225&bicmp=AD&bicmlukp=WT.mc_id&bicmst=1388552400000&bicmet=1420088400000&_r=0.

[5] I look at the doctor-patient interaction through a set of three constructs: the patient construct, the doctor construct and the illness construct. Only the first will be discussed here.

[6] Cristian Vlădescu, Gabriela Scîntee and Victor Olsavszky, 'Romania: Health System Review', *Health Systems in Transition* 10, No. 3 (Copenhagen: World Health Organization, 2008), xvi.

[7] Mednet Marketing Research Center, 'Medibus Study', 'Un Pacient Pentru Fiecare', *Business Magazin*, 27 October 2013, 38. Data is not available at a national level for the time before 2008.

[8] 'Românii şi Starea de Sănătate', *Business Magazin*, 27 October 2013, 34.

[9] 'Migraţia Medicilor Români: Aproximativ 3.000 de Doctori ne-au Spus "Adio" Anul Trecut', *Ziare.com*, 11 February 2014, accessed 20 February, 2014, http://www.ziare.com/social/spital/migratia-medicilor-romani-aproximatix-3-000-de-doctori-ne-au-spus-adio-anul-trecut-1282171.

[10] 'Românii şi Starea de Sănătate', 34.

[11] Sociology Department, Faculty of Political Sciences, SNSPA, *Cartografierea Socială a Bucureştiului 2013: Bucureştenii şi Sănătatea*, 67, accessed 20 February 2014, http://www.cfsmr.ro/fisiere/module_fisiere/665/Raport%20Sanatate%20Integral.pdf

[12] Research interview with P3, 20 January 2014.

[13] Arthur W. Frank, *The Wounded Storyteller: Body Illness and Ethics* (Chicago: The University of Chicago Press, 1995), 27.

[14] Ibid., 28.

[15] Research interview with P1, 23 April 2013 and P3, 20 January 2014.

[16] Frank, *The Wounded Storyteller*, 116.

[17] Research interview with D1, 19 July 2013.

[18] See for example for gender differences: Steven C. Martin, Robert M. Arnold and Ruth M. Parker, 'Gender and Medical Socialization', *Journal of Health and Social Behavior* 29, No. 4 (1988): 333-343; for social status differences: Florian Menz and Ali Al-Roubaie, 'Interruptions, Status and Gender in Medical Interviews: The Harder You Brake, the Longer It Takes', *Discourse and Society* 19, No. 5 (2008): 645-666.

[19] Research interview with D1, 19 July 2013.

[20] Sociology Department, *Cartografierea Socială a Bucureştiului 2013*, 47.

[21] Ibid., 69.

[22] Research interview with P1, 23 April 2013.

[23] Research interview with D1, 19 July 2013.

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Mental Health and Ethno-Etiologies in Southern Africa: Towards Collaborative Therapeutic Relationships

Andra le Roux-Kemp

Abstract

Multi-culturalism and -ethnicity are key features of African societies and an understanding of traditional belief systems and cultural perceptions about health, illness and healing is therefore pivotal on the African continent. This is all the more true when it comes to mental health. Despite neuro-psychiatric disorders ranking third (after HIV/AIDS and other infectious diseases) in contributing to the overall disease burden in South Africa, mental health is still acutely stigmatized and is generally seen as a peripheral and isolated issue. This is partly due to the various cross-cultural causal explanations and perceptions that exist amongst Africans with regard to their mental health. In many of the indigenous languages, no equivalent words for concepts like 'counselling,' 'therapy' or 'depression' exist and traditional beliefs in supernatural causes of, and remedies for mental conditions are rife. It is furthermore not uncommon for people to accept biomedical explanations and treatment for their condition, even while espousing more traditional and cultural (ethno-etiological) perceptions about their mental health, and utilising the traditional treatment options and rituals provided by traditional healers. This chapter will consider some of these mental health ethno-etiologies in Southern Africa and will show how cultural, religious and spiritual beliefs about mental health can colour perceptions and influence communication. An argument will be made for a culture-sensitive understanding of mental illness in Southern Africa, the fundamental principles that underpin African beliefs with regard to health and illness will be considered, and a collaborative therapeutic approach that is culture-sensitive, pluralistic and patient-centred will be advocated. The primary example that will be explored in this chapter is *kufungisasa*, a cultural construction of the mental illness generally known as depression in Western biomedicine.

Key Words: Mental health, ethno-etiologies, Southern Africa, culture-sensitive, therapeutic relationship, patient-centred approach, pluralistic health systems.

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1. Introduction

Traditional healers, local health professionals and nurses from Zimbabwe were presented with the following case study and asked to suggest a possible diagnosis:

> A 40-year-old woman has been looking very sad and miserable, has been unable to look after her home and children, and is slow

> in speech and movements. She says that her life is not worth living. Nothing seems to cheer her up. She does not eat or sleep well and lies on a bed for days without doing anything. Once she even tried to take her own life.[1]

Most of the health workers who took part in the study recognized the woman's condition, but contrary to what is generally expected in the realm of Western biomedicine, cited social or spiritual causes for her condition. It was suggested that the woman was 'thinking too much' about her husband's infidelity, or 'her neighbour's jealousy of her son's success in university and the use of witchcraft to make her unwell.'[2]

This case study is an example of how cultural norms are implicated in the presentation of psychological distress. The health workers in this example were not convinced that the patient suffered from a medical condition that required biomedical treatment other than for the relief of somatic symptoms. The patient's affliction, the cause thereof, and the appropriate treatment were rather seen as social and spiritual.

This chapter is about the cultural experience and presentation of mental illnesses on the African continent. First, an argument will be made for a culture-sensitive understanding of mental illness in Southern Africa, whereafter the fundamental principles that underpin African beliefs with regard to health and illness will be discussed. *Kufungisasa* will then be considered as a cultural construction of the mental illness generally known as depression in Western biomedicine. The chapter will conclude with a motivation for a collaborative therapeutic ethic of care that is culture-sensitive, pluralistic and patient-centred.

2. Towards a Culture-Sensitive Understanding of Mental Illness

Two approaches to cross-cultural psychiatric research and the treatment of mental illness exist: The etic approach claims that the diagnosis, experience and treatment of mental illness are universal and that Western 'psychiatric taxonomies, their measuring instruments, and models of health care [...] are globally applicable.'[3] The emic approach, on the other hand, advocates for more cultural sensitivity and emphasises the need and importance for the evaluation and treatment of mental illness to be generated within cultures.[4] It is argued that such a culture-sensitive approach is necessary as 'diagnoses of mental illness are given based on deviations from sociocultural, or behavioural norms' and is therefore, by its very nature, deeply tied to a particular social and cultural context.[5]

Culture, in this context, refers to 'shared beliefs, values, and norms of a given racial or ethnic group [...] that influence their customs, norms, practices, social institutions, psychological processes and organisations.'[6] And, although it is trite that all people of the same race or ethnicity do not necessarily share the same cultural identity, it is also recognised that for many people, 'the cultural

commonalities related to ethnic background are deeply entrenched.'[7] Abdullah and Brown even suggest that 'some people may not [...] realise the link between their cultural values and their ethnic background, but [that such] lack of insight does not diminish the importance of this link.'[8]

It is for this reason that many scholars advocate for equal value to be ascribed to culture-specific beliefs about mental illness, and its categorisation in the Western biomedical system of psychiatry.[9] This is not only important for an improved understanding, correct diagnosis and appropriate treatment of mental illness, but it is also useful in understanding the differences in stigmatisation of mental illnesses among cultural groups.[10]

Ethno-etiologies are examples of such a culture-sensitive (emic) approach and refer to anthropological studies of community attitudes and cross-cultural variations in the causal explanations of illness and other health related problems.[11] Ethno-etiologies is also often referred to as 'explanatory models' and refers to the multiplicity of illness and disease concepts as it relates to a particular cultural context and socio-cultural environment, influenced by 'time and the historical development of traditional cultural knowledge.'[12] In the context of mental health and illness specifically, ethno-etiologies offer descriptions of 'psychological constructs as part of a culturally specific system of beliefs and practices.'[13]

It will be shown in this chapter that these studies are important 'if we are to analyse the role of culture in shaping illness experience and behaviour' especially since 'most of what we know about [...] illness, we know through [the] stories [that] we are told.'[14] Peter Ventevogel described the importance of a culture-sensitive approach to, and ethno-etiologies of mental health care as follows:

> Elucidating popular nosologies of mental disorders not only can help health workers to better understand their patients, it can also prevent the imposition of categories that are meaningless to the patient and his social environment. This is important when health planners wish to address mental problems in non-Western cultural settings, such as in sub-Saharan Africa, where formalised mental-health care is often limited to hospital-based services in major urban areas and where existing resources are insufficient, both in terms of human resources, as well as in terms of coverage.[15]

3. Traditional African Cultural Beliefs about Mental Illness

The African continent is inhabited by many different cultures, each with a rich diversity of beliefs. However, within this diversity shared cultural values like collectivism, communalism, kinship-like bonds, role flexibility[16] and spiritualism exist.[17] And, a number of shared concepts with regard to disease causation and classification also exist.[18] In this section, the three pillars that underpin traditional

African cultural beliefs about mental illness will be considered. It is important to note, however, that 'culture,' traditional cultural beliefs, and local knowledge systems about health and illness are not static and are continually reproduced and evolved. Yet, the three pillars discussed here are generally regarded as fundamental to African philosophy and identity and variations thereof can be found in most African cultures and belief systems.

A. A Holistic Approach to Health and Well-Being

First, it is generally accepted that traditional African cultures view health and illness in a holistic manner.[19] Ebigbo explains that for traditional African cultures the 'body is the mind, and the mind is the body, and physical images are often used to describe feelings of the mind […] [while] dispositions of an external mind (as in witchcraft) [...] [are] attributed to the body.'[20] This interconnectedness of mind and body is especially evident in the context of neurotic illnesses, as symptoms of neurotic afflictions tend to present with somatic symptoms and not emotional symptoms, and is therefore more difficult to identify and diagnose cross-culturally.[21]

Examples of this interconnectedness between mind and body can be found in the ethno-etiologies of many traditional African cultures. In a 1994 focus group study in Zimbabwe the participants spoke about 'when someone thinks a lot, the heart becomes heavy' and when someone steals, 'it is the heart which decides it, and the brain which works out how to do it.'[22] The Baganda peoples of Uganda generally regard the heart as the centre of emotions, including fear, anger, joy and jealousy and Xhosa peoples consider the soul, which resides in the blood and heart, to be the seat of feelings.[23]

B. Continuity between the Living and the Dead

In traditional African culture, disease exists in relationships, not within persons, and these relationships also extend between the living and the dead. Patel describes it as follows: '[A]fter death, though the body may disintegrate, the spirit lives on and plays an important role in maintaining the wellbeing of its descendants.'[24] It is furthermore generally believed that spirits are the primary cause of mental afflictions.[25] Some spirits like the spirits of family members and community ancestors are generally associated with good health although they can also cause illness or misfortune when angered, for example when a social taboo is broken. Alien and evil spirits, on the other hand, 'cause illness in a random and malicious manner.'[26]

C. The Cause of a Mental Illness Is More Important than Its Effects (Symptoms)

Finally, the cause of an illness (whether physical or mental) is generally regarded as extremely important and possesses more power than its effect.[27] The causes of mental illnesses are furthermore not always apparent from the perceived

symptoms and are usually, as was evident from the previous pillar, attributed to the spiritual world.[28]

For example, the AmaXhosa tribe in Southern Africa attribute mental illness to external causes like the 'failure to propitiate the ancestors with the necessary sacrifices or rituals; non-observance of taboos and consequent ancestral displeasure; bewitchment; intrusion of evil spirits sent by sorcerers; and excessive worry over matters' kept concealed from others.[29] And while hereditary illnesses are recognized, these types of illnesses are also regarded within a spiritual context.[30]

Illness and misfortunate can, however, also be caused by human agency, through witchcraft and by a witch who is a living person with evil powers. The mental illness caused through human agency is generally believed to be far more serious than those caused by ancestral spirits.[31]

4. Depression or *Kufungisasa*[32] as an Example of a Cultural Construction of a Mental Illness

Depression is particularly interesting to study cross-culturally as it is generally regarded as a major global public health problem. Yet, stark differences in the experience and presentation of depression exist across different cultural groups.[33] In fact the diagnosis of depression has been singled out as 'the one [psychiatric diagnostic classification system] that raises significant issues of cultural validity and which poses special problems as a universally valid disorder.'[34] This is particularly due to:

- cross-cultural variations in definitions of selfhood,
- differing local categories of emotions,
- cultural variations in the language used to describe symptoms and the concomitant problem of translating emotion-related vocabulary, and
- the absence of a universal biological specification for the diagnosis of depression.[35]

In Western biomedicine depression is generally regarded as a 'disorder of the mood that rests upon a pathology of key emotions considered arising from within the mind.'[36] The disease model of depression as articulated in the DSM-IV[37] furthermore defines emotions as 'internal, often biological, un-intentional, distinct from thinking and cognition and above all a feature of individuals, rather than situations, relationships or moral positions.'[38]

In African languages, however, no specific term for 'depression' exists and people from traditional cultural backgrounds generally regard the biomedical symptoms associated with depression as the 'consequence of identifiable contextual factors' or 'life situations'; a 'normal reaction to severe social or

personal threats and losses.'[39] Non-western societies are therefore also less likely to seek biomedical treatment for depression compared to western societies, as the cause of the psychological distress for non-western societies is contextual, external and subject to ordinary human intervention.[40]

But that certainly does not mean that traditional African cultures do not know or recognise depression as a psychological state. *Kufungisasa* relates to the biomedical construct of depression or anxiety and is often described as the affliction of 'thinking too much,' 'the nerves' or something that 'makes the heart painful.'[41] *Kufungisasa* furthermore rarely presents with any emotional symptoms, but rather presents in terms of physical or somatic symptoms like headaches and fatigue.[42]

Possible reasons for the manifestation of *kufungisasa* as a social and cultural affliction rather than a mental illness include that there is no term for 'depression' in most African languages, and while the spiritual dimension of health and disease is emphasized in traditional African medicine, the presentation of somatic symptoms is often the only reasonable option available to patients to obtain biomedical health care in sub-Saharan Africa where mental health care services are scarce.[43]

5. Towards a Collaborative Therapeutic Ethic of Care

It was evident from the discussion above that the understanding of mental illnesses in Southern Africa still has a strong cultural base and it is therefore important to not only view mental illness in terms of a Western biomedical perspective, but to accommodate diverse cultural and social perspectives. However, the potential benefits of indigenous knowledge systems in the realm of health in Southern Africa have, to date, largely been ignored and true medical pluralism between Western biomedicine and African Traditional Medicine remains a mere pipedream. This is regrettable as a national survey conducted in 2010 in South Africa showed that a notable percentage of patients suffering from mental illness consulted traditional healers and/or religious or spiritual advisors, and often did this in combination with western biomedical services.[44]

It is therefore submitted that a collaborative therapeutic ethic of care, that embraces and expands medical pluralism by not only offering patients access to both Western biomedical health services and African Traditional Medicine, but that also allows and promotes collaboration, is pivotal for effective mental health service delivery in Southern Africa.

Such a collaborative therapeutic ethic of care holds the following advantages to health care users in Southern Africa:

- First, the manner in which patients perceive their treatment will be improved, which will also have a direct positive

influence on their treatment compliance and their overall
experience of therapeutic relationships.

- A culturally sensitive explanatory model of mental illness
  will also help in reducing social stigma that often
  accompany a diagnosis and will make it easier for patients to
  negotiate their social and professional life.[45]

- Given the shortages of biomedical human resources on the
  African continent, a collaborative therapeutic ethic of care
  will also ensure greater access to health care services,
  especially in rural areas.

But it is not only patients that stand to gain from such a collaborative
therapeutic ethic of care. Health workers themselves are 'not immune from cultural
influence' and they also 'hold a range of cultural beliefs which affect their
interpretation and use of [...] [biomedical models of care].'[46] African traditional
healers have already been significantly influenced by Western biomedicine. For
example, despite the traditional mind-body interconnectedness that underpins
traditional African beliefs about health and illness (see section 3 above), the mind-
soma dichotomy of Western biomedicine has already had an impact on traditional
African medicine and is especially evident in the existence of traditional healers
who are said to specialise in the diagnosis and treatment of mental illnesses or
illnesses of the spirit.[47] It is furthermore noted that traditional African peoples now
consult either traditional or Western biomedicine, but once an abnormal aetiology
manifests or when an illness becomes chronic, abnormal or terminal, traditional
medicine is preferred.[48] And, already in 1987, did Good note that while traditional
healers offer a broad interpretation of the cause assigned to illnesses, urban
traditional healers – compared to rural traditional healers – generally place less
emphasis on spirit-caused illnesses and the role of ancestral spirits.[49]

Practitioners of Western biomedicine and the movement towards patient-
centred care also stand to gain from a collaborative ethic of care. For example, the
relationship between the healer and patient in African Traditional Medicine is more
egalitarian compared to equivalent relationships in Western biomedicine. The
traditional healer is viewed as a 'guide who will help in the [patient's] total growth
and not just in the narrow confines of illness.'[50] The patient-centred approach in
Western biomedicine can therefore be informed by the shared cultural values of
collectivism, communalism and kinship, discussed in section 2 of this chapter and
reflected in the relationship between traditional healer and patient.

It can therefore be concluded that while biomedical models can be used cross-
culturally to effectively treat mental illnesses, careful attention must be paid to the
conceptual translation of biomedical frameworks to particular cultural contexts, as
well as particular cultural presentations of psychological distress.[51] This can be
done in a number of ways and can include the following micro-level strategies:

- Medical students and other health care workers should be encouraged to acquaint themselves with the local idioms of their particular social and cultural context in order to participate effectively in their community.[52]
- The involvement of family and community members in the assessment and treatment processes of mental illnesses can furthermore play an important role in the effective treatment of mental illnesses in a cultural context.
    - Family and community members can assist health care workers in distinguishing between commonly held beliefs in, for example witches and spirits, and 'idiosyncratic explanations of psychotic experiences,' thereby reducing the risk of potential false diagnosis.[53]
    - It can also have a positive impact in reducing stigmatization.
    - And, the involvement of family and community members in the assessment and treatment of *Kufungisasa*, will improve the social support available to patients and strengthen social cohesion and social capital within communities. It is important, however, to ensure the early detection of risk factors and symptoms of mild and/or moderate depressive states before they develop into more serious psychiatric conditions.[54]

6. Conclusion

Ethno-etiologies or explanatory models of mental illness are constitutive of culture, in that they shape 'experience through symbols and categories reflecting larger scale disease taxonomies and categories' and also act as a mirror reflecting cultural realities.[55] Peter Ventevogel submits that '[w]hile cultural categories [like *kufungisasa*] may be closely aligned to mainstream psychiatric categories, it is important to realize and understand its social and cultural meaning.'[56]

In this chapter, an argument was made for a collaborative therapeutic ethic of care that utilises ethno-etiologies or local explanatory models of mental health and illness as 'heuristic concepts [...] to bring order to chaotic and disturbing experiences and to assist in the quests for meaning and solutions to end suffering.'[57] The advantages of such a collaborative approach were considered and it was highlighted that such an approach can assist in identifying the contextual and social factors that shape and influence the mental illness experience. And, it can also serve as an important resource for the therapeutic treatment of patients.[58] This is particularly important on the African continent where biomedical sources (including human resources) in the realm of mental health are scarce. The effective diagnosis and treatment of mental illness in Southern Africa therefore necessitate

that we make optimal use of the scarce (human) resources available and that we do this in a culture sensitive manner by incorporating African Traditional Medicine, and involving African traditional healers in the mental health framework of health systems and practices.

Notes

[1] Vikram Patel, 'Recognition of Common Mental Disorders in Primary Care in African Countries: Should "Mental" Be Dropped?', *The Lancet* 347, No. 9003 (1996): 742.

[2] Ibid.

[3] Vikram Patel, 'Explanatory Models of Mental Illness in Sub-Saharan Africa', *Social Science Medicine* 40, No. 9 (1995): 1291.

[4] Ibid.

[5] Tahirah Abdullah and Tamara L. Brown, 'Mental Illness Stigma and Ethno-Cultural Beliefs, Values, and Norms: An Integrative Review', *Clinical Psychology Review* 31, No. 6 (2011): 934.

[6] Ibid.

[7] Ibid., 935.

[8] Ibid., 934.

[9] Patel, 'Explanatory Models of Mental Illness', 1291.

[10] Abdullah and Brown, 'Mental Illness Stigma', 934.

[11] Ibid.

[12] F. Napo, A. Heinz and A. Auckenthaler, 'Explanatory Models and Concepts of West African Malian Patients with Psychotic Symptoms', *European Psychiatry* 27, No. 2 (2012): 45.

[13] Abdullah and Brown, 'Mental Illness Stigma', 935.

[14] B. J. Good and M. D. V. Good, 'In the Subjunctive Mode: Epilepsy Narratives in Turkey', *Social Science Medicine* 38, No. 6 (1994): 835-842.

[15] Peter Ventevogel et al., 'Madness or Sadness? Local Concepts of Mental Illness in Four Conflict-Affected African Communities', *Conflict and Health* 7, No. 3 (2013): 2.

[16] Abdullah and Brown, 'Mental Illness Stigma', 942. Role flexibility refers to the ability to 'change roles within a family such as grandparents taking on roles traditionally held by parents or a child taking on the role of parents in a child headed household.' For a discussion of child headed households and therapeutic relationships see Andra Le Roux-Kemp, 'Child Headed Households in South Africa: The Legal and Ethical Dilemmas When Children Are the Primary Caregivers in a Therapeutic Relationship', in *People Being Patients: International, Interdisciplinary Perspectives*, eds. Peter Bray and Diana Mak (Oxford: Inter-Disciplinary Press, 2013), 119-131.

[17] Abdullah and Brown, 'Mental Illness Stigma', 942.

[18] Patel, 'Explanatory Models of Mental Illness', 1291.

[19] Ibid., 1292.

[20] Peter O. Ebigbo, 'The Mind, the Body and Society: An African Perspective', *Advances: Institute for the Advancement of Health* 3 (1986): 45-57.

[21] Patel, 'Explanatory Models of Mental Illness', 1295.

[22] Vikram Patel et al., 'Concepts of Mental Illness and Medical Pluralism in Harare', *Psychological Medicine* 25, No. 3 (1995): 485.

[23] John H. Orley, *Culture and Mental Illness: A Study from Uganda* (Nairobi, Kenya: East African Publishing House, 1970), 1-15; R. W. S. Cheetham and R. J. Cheetham, 'Concepts of Mental Illness amongst the Rural Xhosa People in South Africa', *Australian and New Zealand Journal of Psychiatry* 10, No. 1 (1976): 41.

[24] Patel, 'Explanatory Models of Mental Illness', 1293.

[25] Robert R. Franklin, 'Cultural Response to Mental Illness in Senegal: Reflections through Patient Companions: Part I. Methods and Descriptive Data', *Social Science Medicine* 42, No. 3 (1996): 325.

[26] G. B. Fosu, 'Disease Classification in Rural Ghana: Framework and Implications for Health Behaviour', *Social Science Medicine* 15, No. 4 (1981): 471-482.

[27] Patel, 'Explanatory Models of Mental Illness', 1293.

[28] Ventevogel et al., 'Madness or Sadness', 9.

[29] Patel, 'Explanatory Models of Mental Illness', 1294.

[30] Ibid.

[31] Ibid.

[32] A Shona term that can be compared to the South African term *amafufunyane* and to the Rwandan term *guhahamuka*, both refers to a feeling of despair, hopelessness, worthlessness and can lead to attempted suicide. Mark Tomlinson et al., 'Manifestations of Affective Disturbance in Sub-Saharan Africa: Key Themes', *Journal of Affective Disorders* 102 (2007): 195.

[33] Alison Karasz, 'Cultural Differences in Conceptual Models of Depression', *Social Science and Medicine* 60, No. 7 (2005): 1625.

[34] Sushrut Jadhav, 'The Cultural Construction of Western Depression', in *Anthropological Approaches to Psychological Medicine: Crossing Bridges*, eds. Vieda Skultans and John Cox (London: Jessica Kingsley Publishers, 2000), 41.

[35] Ibid.

[36] Ibid., 45.

[37] *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition (DSM-IV).

[38] Karasz 'Cultural Differences', 1632.

[39] Ibid., 1626; Ventevogel et al., 'Madness or Sadness', 13.

[40] Karasz, 'Cultural Differences', 1625.

[41] Enid Schatz and Leah Gilbert, '"My Heart is Painful": Physical, Mental and Social Wellbeing of Older Women at the Times of HIV/AIDS in Rural South Africa', *Journal of Aging Studies* 26 (2012): 20; Tomlinson et al., 'Manifestations of Affective Disturbance', 195.

[42] Karasz 'Cultural Differences', 1626; Tomlinson et al., 'Manifestations of Affective Disturbance', 192 and 195.

[43] Ibid., 195.

[44] Katherin Sorsdahl et al., 'Traditional Healers in the Treatment of Common Mental Disorders in South Africa', *Journal of Nervous and Mental Disease* 197, No. 6 (2009): 434-441.

[45] Napo et al., 'Explanatory Models', 45.

[46] John Reynolds and Leslie Swartz, 'Professional Constructions of a "Lay" Illness: "Nerves" in a Rural "Coloured" Community in South Africa', *Social Science and Medicine* 36, No. 5 (1993): 658.

[47] Patel, 'Explanatory Models of Mental Illness', 1291.

[48] A. O. Odejide, L. K. Oyewunmi and J. U. Ohaeri, 'Psychiatry in Africa: An Overview', *American Journal of Psychiatry* 146, No. 6 (1989): 708-716.

[49] Charles M. Good, *Ethnomedical Systems in Africa: Patterns of Traditional Medicine in Rural and Urban Kenya* (London: Guilford Press, 1987).

[50] Varma K. Vijoy and Nitin Gupta, 'Doctor-Patient Relationship in Psychiatry: Traditional Approaches in India versus Western Approaches', in *Psychiatrists and Traditional Healers: Unwitting Partners in Global Mental Health*, eds. Mario Incayawar, Ronald Wintrob and Lise Bouchard (Oxford: Wiley & Sons, 2009), 25.

[51] Tomlinson et al., 'Manifestations of Affective Disturbance', 195.

[52] Patel, 'Recognition of Common Mental Disorders', 743.

[53] Napo et al. 'Explanatory Models', 47.

[54] Ventevogel et al., 'Madness or Sadness', 14.

[55] Karasz 'Cultural Differences', 1633.

[56] Ventevogel et al., 'Madness or Sadness', 14.

[57] Ibid.

[58] Ibid.

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Working within Groups of Teachers: Teaching and Learning Implications in Health Services

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Abstract

In Brazil, the Ministry of Health has been encouraging change in the way teaching and learning takes place in undergraduate health programmes. One such program is the Teaching Program at the Workplace in Health (PET-Saúde). At Universidade Federal Fluminense, in Niteroi/Rio de Janeiro, we have chosen multidisciplinary groups (a tutor – professor; two students from each of the following professions/teaching programmes: medicine, nursing, nutrition, odontology, pharmacy and physical education; and six professionals from different areas in health). The objective of this chapter is to describe the experience of multidisciplinary groups as we approached teaching in an interdisciplinary way. Methodologically, we have proposed, within the PET groups, a diagnosis of that given region, with the intention of developing devices to deal with the population's health. This study began in 2009 and has been developed in the last four years. We have had professors of different faculties teaching and coaching students of other areas such as medicine, nursing, nutrition, odontology, pharmacy and physical education. Teaching took place in service, and not in the classroom. The professional who is in practice participates in the student's preparation while acting, caring for health system users. Professors, students and professionals have thus been working in multidisciplinary groups for training and practicing in interdisciplinary health care. Our intention is that our students', professors' and health professionals' preparation is enhanced simultaneously, while health assistance is improved as well. We have concluded that the process of teaching must be understood in a participatory way, focusing on the daily work of health services. That is why it is necessary to leave the protected environment of the classrooms and aim at the world of the workplace, where professional, individual and collective behaviours and actions are consolidated. Interdisciplinarity has become an important concept in pedagogical approach in the development of our health professionals.

Key Words: Teaching, health interdisciplinary team, health care.

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> *As any other object,*
> *groups are susceptible to various levels of analysis.*
> René Lourau[1]

1. Introduction

Health professional education in Brazil has dealt, in recent years, with the idea of change in the way teaching and learning are conceived. The intention is to lead to curricular changes in the courses in the area of health, with encouragement from the Brazilian government, through projects/programmes that stimulate the adoption of new guidelines. One such programme is the Teaching Program at the Workplace in Health (PET-Saúde), organised in groups of students who have been introduced to the workplace as a major source of learning, as they are accompanied by a professor-tutor and other health professionals.

At Universidade Federal Fluminense, in Niteroi/Rio de Janeiro, we have chosen multiprofessional teams, aiming at the interaction of different forms of knowledge of the professions involved in treating the users, a way of seeing patients as a whole, not separately in specialties or discipline areas. PET-Saúde Niterói is organised with a professor-tutor who follows a group of about twelve students, two students from each of the following professions/teaching programmes: medicine, nursing, nutrition, odontology, pharmacy and physical education; and also six professionals at the workplace, from different areas in health.

We led the development of this project for four years. It was an experience that started from the elements that are present in everyday services and from the idea that teaching and practicing become an ongoing process of production and a constant dispute between the professions. The objective of this chapter is to describe the experience of these multidisciplinary groups with the objective of interdisciplinary teaching.

2. The Way

The PET groups – composed of professors, students and professionals from different areas – became part of the public health services and started to work on the population's health. The work began with the diagnosis of a given health region built by both the university team and the health service professionals. An analysis of the problems was necessary in search for clues that would include biological, social, economic, environmental and political features that were present in the focus population and that shaped the area's health issues. The collection of problems related to the health status of the population, expressed by the distinct subjects involved in the process, became the materialisation of a continuing effort to create conditions for the development of a situational analysis of the population's health with pedagogical potential of teaching and learning.

In this project students were invited to fully participate, without prerequisites such as years of training, thus allowing a circulation of knowledge among the students within the groups. For instance, there was a pharmacy student in the beginning of his education working with a medicine student who was already halfway through his course. The perspective was that by acting on health the

students', professionals' as well as professors' trainings were enhanced, while at the same time improving the users' health assistance.

In our experience the students composed multidisciplinary groups and the tutor had to find ways to teach in an interdisciplinary fashion. For instance, we had a professor of pharmacy teaching and guiding students in medicine, nursing and other fields. This teaching took place in practice, in service, not in the classroom, and it was shared with the health professional at his/her workplace. The health professional who is at work participates in the college education of the student, teaching as he/she works, attending the public system users. Therefore, the professor, the students and the professional team members consolidate multidisciplinary groups for an interdisciplinary education and practice within the health care system provided for the users.

The programme points out that the learning process should be viewed in a participatory way, with the central axis based on the daily work of the health services. That is why it is necessary to escape from the closed classrooms of our universities in order to find the real context of the workplace where behaviours and forms of professional, individual and collective action are consolidated. At the workplace the paradigm of interdisciplinarity becomes the structural axis of teaching and pedagogical practice in health services. It becomes the space in which the understanding of the complexity of relationships and institutions is facilitated; it integrates theory and practice, as well as the actors from the scenes of teaching, professor-student-user-health worker, creating a process of multiprofessional teamwork.

3. The Groups and Teaching, Learning at the Workplace

Forming study groups or working teams is a common practice in health education in Brazil. Getting closer to each other, getting in contact with the other, this moves collective practice. As Heliana Rodrigues et al say, we must abandon our 'deadly specialties and begin to build knowledge and practices [...] that may initiate other ways of knowing, doing and being [...] in favour of difference and life.'[2]

When analysing the relations among groups and institutions, René Lourau contributed effectively to build a new theoretical approach for groups in Institutional Analysis, which he named 'groups of interference,' which

> [...] have the characteristic of being in the crossing and the
> becoming of numerous other groups, past, present and to come.
> They refuse boundaries and they are rebellious to analysis
> models in which the group is closed on itself. They work on a
> permanent inside/ outside dialectics, and this dialectics, hardly
> noticeable, hardly perceptible by the participants, is much more

interesting than the problems of regulation, cohesion, leadership
and so on.[3]

Thus, the group event 'in action' can be understood as an institution, that is,
while maintaining a certain 'stability,' the whole group is traversed by
transforming forces and even by forces of self-dissolution, in an uninterrupted
contradictory movement: balanced forces are revealed at times and, in others, they
are completely disequilibrate. Accordingly, in each group there are several
institutions at stake, and conflicts are expected to come up permanently within the
distinct instituted and instituting issues that go across the group and have the power
to bring about change.

We understand that group practices, in healthcare in general and particularly
within the PET group, have great relevance in the team work process, contributing
for the construction of a way to assist that is not focused on the disease. However,
in order to do so, such practices must consider the group as a real device that
tightens, moves and changes caring, as 'machines that make us see and talk.'[4] It is
a process that takes place in the plane of flows and forces arising from the network
of different institutions, with the possibility of incorporating different processes of
subjectivation under construction.

The PET group members became great speakers and were involved in distinct
directions hardly perceived by its participants before. However, in this process
some groups came closer to the proposed changes in the way teaching and training
health professionals should function and others remained focused on the disease,
with little change in the process of teaching that originated from the workplace
experience. Still others were open to unusual processes of experimentation in
education. This last group was able to orally reconstruct the social, environmental
and political history of the area studied – through testimonies and in films of the
people who were being treated at the health service. This experience helped
students realise that health care is related to the form of political, social and
environmental organisation. It is not just about the disease.

4. The Gatherings and the Meetings with the Coordination

The PET group meetings in which the process of teaching and learning were
discussed and planned had the participation of the tutors and the coordinators. The
tutors for each group of students/ health professionals/ tutors met with the objective
of monitoring the activities in health services. These meetings were usually tense;
they were weekly meetings and lasted three hours.

In these gatherings the practices and experiences of each workplace were
monitored, and we evaluated the progress and the difficulties of simultaneously
teaching and acting (working) within the services. It was a procedure that required
participants both to provide care for the people who were seeking health services
and, at the same time, was intended to prepare future health professionals.

The encounters led to collective actions. These were not easily constructed. Every moment the 'established' presumptions of the medical profession were present, with its institutionalising discourses. The dialectical movement between the 'institutionalised'/ 'established' and the 'institutionalising' process of new practices raised issues that led to questioning the foundation of the institution itself, that is, the truth that supports what is 'institutionalised' in biomedical practices, which is present in every healthcare profession. In other words, the 'institutionalised' reacted with false speeches:

> [...] this dialectical logic can analyse how the will and strength of truth in relation to the plea must be dismissed permanently falsified, to avoid the risk of dissolution within the social.[5]

The institutions which were present in the PET groups either created small established false ideas, shifting the focus from issues that might affect their survival, or they sought, in a movement of re-institutionalisation and by means of inauthentic discourses, to maintain, without distress, the mission and goals of their foundations. One example is the idea of offering the student a clinical evidence based practice. The principle of acting on 'evidence' seems to be something that questions the biomedical establishment, but it is centred on the same basis of disease signs and symptoms that leads practices and assistance. It was constantly necessary to consider this issue and articulate it in the professional role of coordination, which strongly preserves the truths that underlie and constitute the biomedical institution. We are all subject to this process. We must all understand that it is part of what we are. In order to achieve change, we have to realise that it happens in the daily routine of our professions.

This movement is of great importance when the objective is to give the student a background in health that can lead the future professional to work with different and multiple forms of knowledge that the health practice and care enclose. It is teaching how not to teach: *Unteaching* that the disease must be the starting point of health actions; *Unteaching* that there is only one valid kind of knowledge; *Unteaching* that emotions and affections are not present when we are healing or providing care for a user. In this sense *unteaching* is an approach to mobilize the whole group.

The challenge of deconstruction is enormous. We have questioned the institutionalisation of the practices in the health arena and we are constantly surprised at how addicted we are to our truths and implications; we have had quite busy weekly meetings with the intention of learning how to work in an interdisciplinary way. Having the role of the coordinator of a proposal which is based on a set of groups is not an easy task, among all of those roles we have at the university. Students, professionals and teachers have all implicitly brought in their bodies and actions, the theory and practice of biomedical institution.

In this project one is implicated in a net of relationships which are inevitably present there; neither good nor bad, this injunction leads to involvement with the guiding proposal of PET, exploring the libidinal, political, historical and professional conditions that emerge during meetings. It is a complex practice, not on easy one, aimed at the construction of a new necessary way of teaching and learning focused on changes.

5. The Comings and Goings of *Unteaching*: Tutoring

Each tutor developed – with his/her twelve-student group from different undergraduate programme and the six preceptors, health professionals, also from different backgrounds – *unteaching* health work activities. This job was incorporated into the other activities already performed by the university professor.

How can one to be a tutor who *unteaches* in PET-Health groups when he/she remains institutionalised as a professor, working in specific disciplines, sometimes at the undergraduate, others at the graduate level? Being a professor at a public university involves working in teaching, research and extramural activities, producing, publishing, and preparing new health professionals The PET-Health group tutors developed several activities related to their role as a university professor, but these are complemented by occupying various positions in the institution.

In the movements of approaching the PET-Health proposal, we have constantly had to deal with whatever traversed us – our own education, our ideals, our desires – and we interacted with our group and the group of tutors. In these comings and goings, we were building a new/old or an old/new practice, other ways to look at something.

The same way? Different? New? Maybe! But we know that we have developed teamwork, interdisciplinary, focusing on the field of Public Health and Health Care; even as we continue teaching in some places and *unteaching* in others. The challenge for tutors was learning to be a professor/ tutor who can *unteach* even when he/she is institutionalised.

Was it possible? In comings and goings, we may answer affirmatively: the productions of various PET-Health groups in Niterói have shown it. From now on only time can show whether we have incorporated *unteaching* in our daily life in the institution.

6. Final Words

The work with groups of professors who seek to bring about changes in health education has been a complex and dense movement, especially when this process happens at the workplace in health services, a space that is very different from the classroom environment. There are many tensions along the way; and leading the group discussion on the implications has shown how powerful a distinct form of teaching and learning can be.

We understand that the practices created by the PET-Niterói group in healthcare in general have contributed to the construction of a way of caring for patients, one that is not focused on the disease. We believe that it is necessary to leave the protected environment of the classroom and aim at the world of the workplace, where professional, individual and collective behaviours and actions are consolidated. Interdisciplinarity has thus become an important concept in the pedagogical approach to the development of our health professionals.

Notes

[1] René Lourau, 'Grupos e Instituição', in *René Lourau: Analista Institucional em Tempo Integral*, ed. Sonia Altoé (São Paulo: Hucitec, 2004), 176.

[2] Heliana B. C. Rodrigues, et al., *Grupos e Instituições em Análise* (Rio de Janeiro: Rosas dos Tempos, 2000), 118.

[3] Rene Lourau, 'Grupos e Instituição', in *René Lourau: Analista Institucional em Tempo Integral*, ed. Sonia Altoé (São Paulo: Hucitec; 2004), 181.

[4] Regina Duarte Benevides de Barros, 'Dispositivos em Ação: O Grupo', *Saúde e Loucura* 6 (1997): 34-41.

[5] Rémi Hess, *La Socianalyse* (Paris: Éditions Universitaires, 1975).

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Part 5

Collaborative Therapeutic Approaches
to the Patient

Addressing Reverse Culture Shock with the Fennell Four Phase Model and the Arts

*Ann Fantauzzi, Patricia A. Fennell, Kelly A. Bertrand
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Abstract
Life-changing experiences, cultural stress, and unexpected encounters may result in trauma for many who travel outside their homeland to work in the global south. Upon entry, culture shock may cause disequilibrium for those in the field not prepared to witness what they encounter, for example, the photojournalist embedded with the army, or the volunteer working in a refugee camp. Upon re-entry, reverse culture shock may also occur after returning from many weeks of stressful work and difficult living conditions. Individuals may develop symptoms of chronic depression, grief, PTSD, disappointment, and conflict with their home culture and family. Reverse culture shock may occur when the home country cannot be tolerated and the 'other' culture is desperately longed for. This trauma can be effectively treated, and in fact integrated, using the arts. The empirically validated, multi-phased Fennell Four Phase Treatment (FFPT™) model recognises the influences of cultural and psychosocial factors in assessing and treating those with cultural shock or trauma. The system provides a narrative framework and a clinical map for the medical volunteer, non-governmental organisation (NGO) volunteer, or embedded journalist to respond to traumatic visual and experiential events. It is through the FFPT™ that the traveler's life can reorder and possible trauma can be successfully addressed. A pilot project has been initiated combining the images of a photojournalist-NGO worker with the phase narrative intervention. The work and results will be reported. This phase approach is grounded in clinical practice to help travelers help themselves and fellow travelers integrate their life changing experiences and create positive change. Consequently, the discipline of photography, accompanied by recollection and reflection, descriptive writing and countertransference, can help the 'wounded warrior.'

Key Words: Trauma, culture shock, reverse culture shock, PTSD, volunteerism, FFPT

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1. Volunteering: Many Changes

Countries in the Global South depend on volunteer personnel to bring projects to development stages for economic, educational, and infrastructure improvements for the future.[1] Children and families are the focus of these nonprofits's programmes and their efforts to bring sustainable living conditions to families, nutritional improvements through agricultural projects,

sanitation, education, and clean water for better health. USAID reports that about one million Americans volunteer overseas each year.[2] There are about 139 countries that qualify as developing countries that receive the services of people giving their time, expertise, work, and money.[3] Volunteers serving in severe poverty areas with high childhood mortality rates, various types of diseases, and extreme hunger and poor water, can experience trauma from what is seen and experienced during the time there. The Antares Foundation notes that as many as '30% of returning aid workers report significant symptoms of PTSD returning from an assignment.'[4] A programme of preparation for the pre and post experience can prevent many problems for the volunteer. When the volunteer comes home to experience reverse culture shock or PTSD, an intervention using the Fennell Four Phase Treatment model can take the volunteer's experience from crisis through integration and resolution in an empirically validated programme using the arts as an agency of sharing and talking about what happened.[5]

Image 1: Arriving in the village of Wairika to work. © 2013/Ann Fantauzzi. Permission granted by copyright holder.

2. A Personal Journey

Anticipating the return home before leaving my volunteer experience in Uganda was very difficult, knowing that reentry would be a time of expected sharing and explaining. Events carry such colorful yet emotional memories that it can be next to impossible to describe to someone who has never been part of a service trip, or even a visit, to Africa. Photographs can certainly supply telling images, but the real human story does not emerge from within oneself easily. Much of the trip's dramatic recall may be superficial, consisting only of details of general interest. To build characters and events into a meaningful account from memory snatches takes hours, and a special understanding beyond that of the average listener.

Image 2: Youngster in Kagoma Gate Village. © 2013/Ann Fantauzzi.
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The retelling of the volunteer's experience, then, can become a stressful and anxiety ridden event. It is possible that no one can comprehend what has happened in terms of emotional impact and personal change. A dedicated and involved volunteer has come home a reinvented person with the mind's windows dressed very differently. The change can be very noticeable to those around the volunteer, yet they may not understand it.[6] A situation can then churn or become agitated and this can push the volunteer into isolation, silence, depression, and a feeling that the experience was not genuine in its intended outcome and integrity. This emotional state becomes a crisis the returning volunteer has to allow a place in his or her current life. It may become a 24/7 living condition that cannot be set aside, even for a moment. Using the meaningful intervention phases of the Fennell Four Phase Model (FFPT[TM]) to move from identifying the facets of the crisis to seizing a mode of personal control to integrate the memories and life changes into a new life, also addresses the social, emotional, and psychological domains of the trauma imbedded within.[7]

My journey back and adjustment to my privileged home world was much more traumatic this past year than when I worked with The Giving Circle previously. It seems more days were spent thinking about what I experienced, what I did during the time I was there. I had to ask myself the big question: did I make a real change in anyone's life. Africa, and Uganda in particular, is so rife with poverty in so many ways.

Image 3: Downtown Jinja, Uganda. © 2013/Ann Fantauzzi.
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One situation that I observed daily was the overall vision of what people saw every day. I was overwhelmed with the trash, plastic bags, paper wrappers, water bottles, and easily disposed of items that people used and discarded, caring nothing about where it ended up. That cluttered and dirty scene became a wearisome sight for me as we headed out to work each morning. Uganda is a beautiful country, often called 'The Pearl of Africa,' but to see such trash thrown all over was very depressing for me, and I would suppose for the citizens who noticed it as well. Pride of place, pride in where one lives, is I think a universal feeling. Where you live can establish a mood and perhaps develop a feeling for the future of where a community is going. The visual and mental exhaustion of the defaced landscape gave me the feeling of not having much hope for future development. The landscape seemed to have no promise as it stood there! Perhaps that is the inner spirit that I took home and could not really separate myself from for so long. My love for the work we do, the children we build schools for and encourage to get an education for their future, the families we help establish a sustainable existence, makes for many big questions to mull over and search for reasonable answers. None of these challenges, however, would keep me from going back.

3. Sorting the Experiences

My therapist and I discussed the helpless, frustrated, and ultimate sad feelings I had from the experiences with the children I could still visualise in my daily thoughts. I struggled through tears to tell of how it seemed even worse to me than it had on my previous volunteer excursion three years before. Different events happened while there that seemed to have a stronger emotional impact on me. These made me deeply depressed and totally silent when I came home. I could not begin to share with anyone what I saw and felt. Tears and an emotional wave continued on a daily basis for weeks. I did not know what to say about the events to make me feel better or to make them disappear from my at-home reality. I had

seen more than I could process in many cases, death and dying, to be specific. Those instances took me back to unsettled issues of my own life. Recently, I had been dealing with personal issues of being adopted and searching for my birthmother. I became a midlife orphan as my parents and only, also adopted, brother died. His death, revealing his previously unknown HIV+ status, and the dissolution of his life, made me hypersensitive to the HIV/AIDS condition in children, their orphan status, and the lack of family in these circumstances. Furthermore, as a new grandmother, I found this a particularly difficult time to see so many youngsters hungry and suffering. Unlike previous trips, I was not stabilised in a number of personal ways to the prevalent situation where I was working. When I came to understand these underlying conditions and their impact, I was better able to take a rational perspective on how I now felt. My place in the volunteer world of Uganda now made sense to me as a short-term helper in a limited way.

Image 4: Busoga Junior School. © 2013/Ann Fantauzzi.
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Daily writing and a travel log is a facet of my life I find to be not only reflective, but an asset in remembering the details of the photographic experiences. The details of the stories and personal interactions, when home, provide comfort and joy at times, as well as a stimulus to discuss with others work being accomplished in an under-acknowledged area in Uganda. Accepting this precept, my therapist and I decided that chosen photos would aid in my acceptance of what I had witnessed and been a part of for two weeks. So my therapist and I decided that I would choose eight to ten photos from those I had taken that stood out to me as in some way meaningful, and to create a scrapbook in which I would write a cohesive narrative about each picture. I went back to my 2,000 plus photos from the trip (for which I was the official photographer). Spending some hours looking at them all, I thought about what was important, about why I had taken each photo.

Considering my purpose, I chose about twelve photos that were particularly meaningful to me. In each case, I thought back to the circumstances and the person I had photographed, and now, how I felt about them once home. The photos I chose had deep meaning for me in some way, both then and now. That was the ultimate criteria I applied when selecting the pictures for me to write about in order to try to retouch my feelings and experiences with people and places.

Taking a blank scrapbook, I placed the first photo on the third page, leaving a place for an introduction to what this project was all about. The individual photos took on a life when situated in their Ugandan context: at school, in the village, at the Koi Koi orphanage, playing with children, helping to write a letter, or listening to someone talk to me. I recalled, in many cases vividly, what I was doing when I took each photo and why it was important for me to remember that moment. I took time to actually sit and visualise the experience, to remember the sounds, to feel the warmth of the Ugandan sun, and of the people around me. Was it important to capture the face as beautiful or cute, as a survivor of hunger or sickness, or as a victim of AIDS? Did I fall in love with this child because of the potential I saw in him or her? More often than not, the shot was one that captured my heart in the middle of nowhere, when so much seemed to be about suffering and deprivation and lack of basic comforts.

Image 5: Sponsorship day in Wairika Village. © 2013/Ann Fantauzzi. Permission granted by copyright holder.

4. Bringing the Crisis into Meaning

For some reason, I had to bring their faces home with me so I would not forget them and they would remain in my heart. After snapping a photo, I always showed them the photo and told them that I was taking them home with me. I suppose I thought knowing somebody cared for them – wherever they might be – might help them get through their daily struggles better. Maybe, I felt their faces would help me remember who I was, and what I had in my life when I looked around my world at home.

I went through my photos one by one, searching and writing about each one, telling a story about the photo and how I remembered it and how I related to it now, at home, among my family and my comfortable life. As time passed, I understood the great economic divide there was, and where I was, and how I was so fortunate only by the luck of the draw of nature and birth! It is from this point in the therapeutic process that one develops passion for others. Writing these thoughts in the book was a very emotional time – the faces and people came to life again as I felt their presence and heard their voices in my head. I found myself reliving some of the most emotional moments of my journey. I was not sure that this was helping me get rid of the emotions that were deeply invested in my time in Uganda. Gradually, I began to put the children in the photos into a larger picture of what would become their future. Thinking of what I, and we as a group, had done for the school, villages, and orphanage, I began to see positivity in what could be – not what was now.

Image 6: The Doll Project at Busoga School. © 2013/Ann Fantauzzi.
Permission granted by copyright holder.

As I sat for hours with the narrations forming next to the photos, I was beginning to move into the stabilisation phase of my outlook and what I did on my journey by revisiting the hardest of the experiences I could remember. The time came to share my photo journal aloud with my therapist in sessions we set up to work through my return back to life as a changed person. The photo journal gave a starting place to discuss what the emotional talking points were. I was an interloper, only passing through but with work to do and learning to accept how others had to live.

Image 7: Kagoma Gate Village youngster waiting for shirts.
© 2013/Ann Fantauzzi. Permission granted by copyright holder.

Image 8: A face in Kagoma Village. © 2013/Ann Fantauzzi.
Permission granted by copyright holder.

As I created the photo journal narrative, the isolation of the crisis phase, not being able to talk of my experiences with others, moved into stabilisation and then resolution. As I came to understand the bigger picture of where I fit into the journey just taken into the Ugandan world of extreme poverty and to believe that my work had worth, I could begin to understand that I would find ways to tell others about what our non-profit was doing. I came to see that sharing the purpose of our trips and accomplishments is fundamental to our ongoing work. My photography is the vehicle to transfer the message. My ability to find the most personally salient faces and situations in my photographs turned out to be the most effective way to share the work of our group. I went on to share my photos with others on social media, reproducing many for sale, and allowing the non-profit to

use them for publicity and website blogging. All of this made me feel very good about what I did. The stories, the faces and events, had meaning that could be shared.

5. Developing Passion

I have found the integration of these volunteer experiences, whether they are emotionally sad, or happy and joyful, to be a part of the entire journey's overall value. I was fortunate to develop compassion for others that will allow me to continue to work overseas and at home. Recording and documenting my experiences through photography is a way for me to share with all those who want and need to know how people live in a culture other than their own. The lives of those in severe poverty can be witnessed through pictures by those who will never see it first hand, yet have the opportunity to understand and contribute.

My personal journey each year with The Giving Circle is helping to tell the stories of these precious children, whose faces represent the desire and need for education, clean water, nutrition, and sanitation and opportunity in the developing world. My personal work leads to fundraising activities, speaking engagements to further the goals of our nonprofit awareness and work, and seeks to engage more people to become participants in our work for others.

Image 9: Becoming a teacher, Busoga School. © 2013/Ann Fantauzzi.
Permission granted by copyright holder.

Image 10: Learning at Busoga Jr. School. © 2013/Ann Fantauzzi.
Permission granted by copyright holder.

I will be traveling back to Uganda this summer to work as group photographer and educational consultant and teacher trainer for four schools, as well as doing work in the village and orphanage wherever needed for two weeks. The Giving Circle will continue to carry out its plans to educate children. I started an ambitious program last year in our poorest school, located on a sugar plantation, where our children are learning math skills through chess from a national chess teacher. It is one of the best projects for our schools to date, and will be part of an international study with the Gary Kasparov's Chess Foundation Africa.[8]

I hope to see people and scenes with new eyes this year, and to develop deeper relationships and insights. Most children I met last year will still be there, some may have died from malaria, dehydration, starvation, or AIDS and witnessing death and suffering is likely. While the grief is overwhelming at first, a programme to help volunteers move through crisis, stabilisation, and resolution to develop meaning, and into integration will address their needs both before and after their trips. In a true sense, I am helping to mentor the future of our nonprofit to continue its meaningful work in Uganda with children and families. I was the patient, I am the provider.

Image 11: Maths and chess with Minichess at Kagoma Gate Village School.
© 2013/Ann Fantauzzi. Permission granted by copyright holder.

Notes

[1] Share the World's Resources, 'The Brandt Report', accessed 29 March 2014, http://www.stwr.org/special-features/the-brandt-report.html.

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Volunteerism, Culture Shock and Trauma: A Programme for Helping Others as We Help Ourselves

Patricia A. Fennell, Ann Fantauzzi, Sara Rieder Bennett and Kelly A. Bertrand

Abstract

Life experiences, culture stress, and unexpected encounters may result in trauma for many who travel outside their homeland to work in the developing world. The empirically validated, multi-phased Fennell Four Phase Treatment (FFPT™) model recognises the influences of cultural and psychosocial factors in assessing and treating those with culture shock or trauma. It is through the phases of FFPT™ that the worker can move through crisis into stabilisation, through resolution and into integration, having successfully addressed their trauma. Upon arrival, culture shock may cause disequilibrium for those not prepared to witness and experience what they may encounter. Upon re-entry, reverse culture shock may occur after many weeks of stressful work and difficult living conditions. Individuals may begin to develop symptoms of chronic depression, grief, posttraumatic stress disorder (PTSD), and disappointment in home, culture, and family. Often, families suffer conflict. Reverse culture shock may occur when the home country cannot be tolerated and the 'other' culture is longed for desperately. An assessment, preparation, and debriefing programme is being piloted with The Giving Circle (TGC) for the medical workers, educators, and general non-governmental organisation (NGO) volunteers working in Uganda; the programme will be described and results reported. The FFPT™ phase approach is grounded in clinical practice to help participants help themselves and fellow workers integrate their life changing experiences and create positive change.

Key Words: Trauma, culture shock, reverse culture shock, PTSD, developing world poverty, first responders, FFPT™.

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1. Volunteer Workers at Risk

Much of the developing world is aided and supported by NGO volunteers helping to address the problems of hunger, clean water, education, housing, and medical issues that plague people not fully served by their government. Those with no access to necessities for survival suffer, have much shorter life spans, and do not reach their full potential. The incidence of AIDS, malaria, polio, and other infectious diseases in the developing world is significantly higher than in the developed and economically advantaged world.

Research indicates the following can be experienced by many volunteer workers: culture shock, reverse culture shock, PTSD, and a desire to return to the

host country given the difficulty readjusting to life at home.[1] The difficulty in returning to routine, community, and the developed world lifestyle are not expected. It is necessary, then, to screen and prepare these volunteers for what they may experience. The Fennell Four Phase Model (FFPM™) and the Fennell Four Phase Treatment based on the model (FFPT™) is a multi-phased, validated method of recognising the long-term effects of chronic experience together with cultural and psychosocial factors that can be applied in the assessment and treatment of those suffering from culture shock and possible trauma.

In contrast to paradigms or models which explore single conditions, rigid stages, or just aspects of chronic experience, FFPT explores the physical/behavioural, psychological, and social/interactive domains of chronic experience/trauma as well. Use of a phase, rather than stage, model recognises the dynamic nature of volunteer experience and the movement between phases due to changing circumstances in an individual's life. FFPT includes recognition of the loss or reduction of functioning in pain, fatigue, sleep, cognition, ambulation, mood, and sexual functioning which impact individuals across specific chronic conditions, such as the effects of trauma.[2] Treatment planning is matched to the particular needs of an individual or group, in each of the four phases, with the goal of adapting and improving quality of life rather than curing illness.[3]

In *Phase 1, Crisis*, the individual faces the onset of trauma, which may occur suddenly, upon arrival in the host country, gradually during the work visit, or upon return home. Onset of the Phase occurs with the recognition that events over the course of the trip have significantly changed the volunteer's life through impacting beliefs, attitudes, and perception of reality. As a result she or he may have difficulty talking about events and engaging in daily functioning. Perhaps it was something the person witnessed, such as the death of a child or overwhelming poverty. The individual enters crisis, a personal state of emergency, unable to manage unbidden, often disturbing thoughts and visions. The person feels trapped within the experience of the trip. During this Phase, the task of the volunteer, caregivers, and providers is to adapt to the urgency and trauma.

In *Phase 2, Stabilization*, the task is to restructure one's life through developing new norms, clarifying values, and modifying activity levels to current functioning. The volunteer recognises that normalisation of life upon returning home is not taking place. Volunteers may withdraw from immediate friends and family and need to associate with fellow volunteers and travellers who share similar experiences and potential traumas. Utilising Phase matched interventions, including the Phase/Arts Narrative and Seeking Others of Like Kind, volunteers develop perspective and begin to contextualise the possible contribution of their work within the larger picture of reducing global poverty and improving life in the developing world. As stabilisation of physical, psychological, and social spheres begins to occur, the volunteer moves into the Resolution Phase. During *Phase 3, Resolution*, individuals may experience grief and loss as they recognise that their

former worldview and sense of self is forever altered as a result of volunteer service. Tasks of this Phase include creating meaning for their suffering and the suffering they have witnessed, establishing an authentic new identity, and developing a meaningful philosophy of volunteerism.

As volunteers approach *Phase 4, Integration*, they have come to accept that traumatic experience does not go away and memories cannot be unlived. Instead, the memories, visions, and experiences have become integrated into a new reality, a new personal best, that integrates the pre-crisis and post-crisis lived experience. The volunteer now has context and perspective that can be utilised in their future service endeavours, including the support and training of other volunteers. Thus, the task of Integration is to define a new self, which includes the understanding that the volunteer's sometimes traumatic experience is a valued part of their identity.

2. Volunteerism and Trauma

Individuals choose to serve for various reasons, including being a positive influence in the lives of people that live in poverty and harsh conditions. Expectations are usually very high and the volunteer anticipates returning home with an increased level of life satisfaction, a new or renewed sense of purpose, and clarity regarding the state of the world and how they have contributed to improving it. Volunteering is a positive choice on the part of those in a position to 'give back.' What is not anticipated are the overwhelming thoughts, emotions, and physical responses to an alien environment and a task that may now seem too formidable to be able to effect positive change. Upon re-entry to the home country, volunteers, providers, family, and friends work toward stabilisation and all may experience disappointment and frustration with the slow resolve of symptoms. Trauma symptoms can arise from multiple sources, including:

- Volunteer Entry/Event Trauma: The disparity been the developed world and the developing world is acute and can have a traumatising effect on even the sophisticated individual. On arrival, the cultural impact of climate, food, lack of infrastructure and even water is immediate. Encountering overwhelming poverty, death, disease, violence, and hopelessness can have a profound impact on the volunteer and a realisation that life and reality, as they previously experienced it, will not return to what was once considered 'normal.'
- Reverse Culture Shock/Trauma: Often people come home suffering from what is known as Reverse Culture Shock (RCS). Volunteers expect to return to the same home they left and for life to easily return to normal. RCS can include

feelings of isolation, uncertainty, restlessness, boredom, depression, and confusion. Some indicate 'reverse homesickness' in which they fail to reconnect to an idealised sense of home. For those who are returning from the developing world, these symptoms are more pronounced. Some volunteers cannot stand to see food wasted or thrown away because they have witnessed so much hunger. Even a trip to the grocery store can be experienced as aversive and to be avoided until a readjustment to being home can be made. Home is often seen as too abundant and overwhelming. Re-adjusting to the realities and conditions of the developed world can be difficult, almost impossible, creating a deep desire to return to where they volunteered. As a result, volunteers experiencing RCS may seek to serve frequently in an effort to reduce their suffering, sense of isolation, and displacement. They feel more at home in the host country surrounded by others with shared experience.

- Iatrogenic Trauma: Trauma may result from medical and psychological treatments being provided by clinicians not familiar with enculturation, re-enculturation, and possible PTSD that are normal for volunteers serving in the developing world. Interactions with the health care system may be traumatic as volunteers feel pressured to prove and explain the reasons for their symptoms' chronicity.

- Cultural Trauma: Societal norms in the developed world may induce stigmatisation toward those living in the developing world. Traumagenic sociocultural factors include intolerance of suffering, ambiguity, and chronicity. Dominant narratives, such as 'belief in a just world,' typically serve to further marginalise people living in extreme poverty and harsh conditions. Those who care for marginalised populations are often on the receiving end of traumatic stigma from these cultural biases as well. Cultural trauma may also be induced by divergent values with those of the host country.

- Vicarious Trauma: Those who live with or provide care for the volunteer suffering from PTSD may also develop trauma symptoms through an empathic connection with the suffering of the individual. Mental images carried home by the volunteer can cause depression, grief, and flashbacks that involve a significant process of adjustment. It may be extremely difficult to share these experiences with families or friends who have no connection or framework from which to

understand them, and their caregivers and loved ones may suffer from similar trauma symptoms as they struggle to cope with these changes. Further, loved ones may suffer rejection as the volunteer withdraws due to the trauma. When returning home, many volunteers feel guilt for the sense of abandoning those they went to help. Volunteers may also feel loneliness and discomfort with family and friends, often avoiding socialisation because they struggle to integrate the lived experience of the developing world with their home life. The stress of trauma can cause family unrest, including possible separation or divorce. Lacking an outlet to process the experience leaves the volunteer and their loved ones subject to living in the long-term trauma. Often with the support of a qualified professional, integration of the experiences into one's life can take place and the volunteer and significant others can learn that the time and effort spent volunteering was meaningful.

- Pre-Morbid/Co-Morbid Trauma: Traumatic events occurring prior to or concurrently with volunteer experience may exacerbate symptoms. Survivors of abuse, war, natural disasters, accidents, and traumatic loss may struggle to cope with the unanticipated additional trauma of volunteer service.

3. Outline of Prevention and Treatment Programme for TGC

Individuals who desire the experience of working in developing nations with an NGO need to be well prepared for what they are about to encounter. Project leaders need to assess possible workers for an alignment of values and expectations with the project mission. Participants need to be assessed for trauma history, psychosocial history, and coping capacities, which moderate the impact of harsh working conditions and exposure to trauma during volunteer work. Pre-trip assessment focuses on determining readiness for providing service in the developing world and training for an appropriate skill set. Worker pre- and co-morbid trauma, and experiences and attitudes toward poverty, illness, dying, and death are considered in the process. Pre-trip sessions focus on techniques for personal coping and assisting fellow workers with coping, and psychoeducation about PTSD, enculturation, culture shock, and the Fennell Four Phase Model (FFPM™). Subsequently upon return to the home country, workers are debriefed and provided with a protocol for coping with re-enculturation and possible PTSD. Additional mental health services can be provided depending on the severity of the volunteer's symptoms. Ongoing participation in the community through post-trip sessions facilitates healing and integration of experiences upon return. Following is

an overview of the proposed Preparation Debriefing Programme grounded in the FFPT.

A. Pre-Trip Assessments and Training

Pre-trip assessment and training is comprised of two meetings with the volunteers that include screening questions, volunteer's comments about the screening process, and introduction to relevant psychoeducation and techniques to assist them on the ground. We will present data from our initial piloting of an NGO that is currently preparing volunteers for work in Uganda. The first pilot was held for experienced volunteers with the intention of utilising the volunteers' feedback for content validity, making meaning of their experience of chronic PTSD from repeated exposure, and to assist them in providing training and support to new volunteers.

First Meeting:

At the first meeting, volunteers were asked the following screening and psychoeducational questions. First, 'why go?' Why do volunteers self-select to go on these trips? Secondly, volunteers were asked to review their expectations regarding their experience in the host country – what they expected to do, how they expected to be a change agent, what they expected from themselves, and what they expected from the people in the host country. We reviewed the expectations and assumptions about how they would affect the home country and its citizens and their work, and how their work would be received. Volunteers answered questions about self-selection, expectations and assumptions, and what they saw as their strengths and interests, and difficulties and weaknesses. We then presented specific pre-screening items that would typically be relevant in a developing world volunteer worksite, including their experience with severe poverty, extreme living conditions, life threats, non-English speaking environments, religious and cultural belief systems that are divergent from the developed world, past work with women and children, and experiences and attitudes toward dying and death.

Second Meeting:

During the second meeting, we provided psychoeducation about enculturation, re-enculturation, PTSD, reverse culture shock (RCS), and the FFPT with the intent of preparing volunteers for what they may experience in the developing world. Within this frame, we work with them to understand where they are in the Phase model before they leave for volunteer work again. They are taught to self-assess daily using the Physical Capacities Awareness Tool (PCAT) to be mindfully aware of their pain, fatigue, sleep, cognition, ambulation, and mood symptoms and how they are coping. The Cultural Health Awareness Inventory (CHAI) is also being piloted to help volunteers appreciate the health attitudes and tolerances of their host country and how these attitudes impact them, their co-volunteers, and the people they are serving. Finally, volunteers are educated about countertransference and how empathic connection with people in the developing world may impact them.

Volunteers will be supported and facilitated by the NGO leadership in daily PCAT, daily journaling for personal support, and considering developing a personal tool for meaning development (e.g. photojournalism). Daily group meetings will be held and one-to-one facilitation will be provided as needed.

B. Post Trip-Debrief
First Meeting:
Following their return home, we will facilitate sharing of volunteers' experiences through a group debriefing within the first 10 days of return in which group leaders will model sharing of countertransference experiences, with the understanding that this has already been occurring during daily group meetings in the host country. Individual group debriefings will also take place to continue this exploration. Volunteers will reassess individual and group phase placement to take account of the changes that occurred while in the host country and in returning home.
Second Meeting:
A second group debrief will take place within a few weeks of returning home, once volunteers have had time to process the first meeting, with phase placement review for individual members and group. We will initiate stabilization interventions to move individuals into Phase 2. Ongoing volunteer training will be facilitated to engage returning volunteers in the continuing process of meaning development and the shared training of new volunteers.

4. Conclusion

Volunteering with NGOs is a challenging endeavour and may result in culture shock and trauma for some individuals. Being witness to seriously traumatic events calls for a treatment programme that integrates pre-screening and education, support and coping skills during volunteer work, and debriefing for prevention and treatment. The Fennell Four Phase Treatment (FFPT™) is a validated programme to help these people integrate the experiences into their lives and develop a new outlook on the encounters.

Notes

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Compassionate Communication

Nancy Billias

Abstract
Rapid strides in research and technology, while improving diagnostic and treatment capabilities, have also contributed to an increase in the 'silo-ing' of information and widening the distances both between patients and doctors and between members of multidisciplinary care teams. Often, as the pace of life in hospitals has increased, not only has the patient been left behind; so has the sense of compassionate care. Over the last twelve years, an exciting experiment in health care communication has been tried, first in the US and more recently in the UK. The Schwartz Centre Rounds (SCR) explores the impact of mutual listening as an important and effective tool for improving patient outcomes and staff satisfaction. By opening themselves to listening to one another, staff and patients begin to treat each other in a more human(e) fashion. The result is greater compassion, reduced stress, and a renewal of meaning in difficult situations. The real value of the SCR does not lie in improving problem-solving amongst professionals, but rather in allowing them to process emotions in a safe and neutral space. This shift is further enhanced by a second feature: the SCR is holistic and participatory. It looks at patient care in a completely 'new' way. The redistribution of power is a radical idea in modern health care, demolishing the paternalistic 'doctor knows best' paradigm. It has long been thought that power in medical care can never be equalised, because of the varying levels of expertise and training involved. And yet, the success of the SCR has proven that not only can power be distributed more evenly throughout a care team, it is actually beneficial to all concerned when this occurs. The SCR allows for – and demands – attentiveness, mutual openness to the other, and a certain amount of shared vulnerability.

Key Words: Compassion, communication, listening, multidisciplinarity, Schwartz Centre Rounds.

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1. The Power of Listening

My focus in this chapter is on one specific form of communication, one that is very low tech, yet seemingly cutting-edge. For several years, I have been involved in a wide variety of projects that focus on one activity. I have been a psychotherapist with hearing-impaired people, a translator, a practitioner of contemplative prayer, and a teacher of leadership studies. One pursuit links them all together: listening. In this chapter, I want to introduce another way in which this powerful tool is being used, and explore its application in health care.

Schwarz Centre Rounds (hereinafter SCR) is based on a brilliantly simple idea. Once a month, a multidisciplinary hospital team – typically of 100 – 150 people – gathers to discuss one aspect of patient care. 'Popular Rounds topics include delivering bad news, caring for a colleague, when cultural and religious beliefs conflict with medical advice, and dealing with spiritual crises in patients.'[1] A facilitator opens the rounds by reminding the group of the ground rules: confidentiality, listening without judgment and silencing pagers and cell phones. One person (usually, but not always, a doctor) provides a brief clinical overview of a case. For the rest of the hour, the team focuses on being together and creating a safe forum to share the challenges of caring for patients. During this time, the normally rigid hospital hierarchy is suspended: all can participate equally, from orderly to hospital administrator to (shockingly) patient and family. At the end of the session, the facilitator provides a formal conclusion.

The purpose of Schwarz Centre Rounds is simply to provide a space in which active and productive listening can take place. The Rounds are not M and M (Morbidity and Mortality) events, where doctors routinely discuss a case that has resulted in, as they say, a 'serious adverse effect' (i.e., death). Neither are they what are typically called Grand Rounds (a teaching tool common to all hospitals), where one doctor quizzes medical students with the aid of patients as 'show and tell' exhibits. The distinguishing features of Schwarz Centre Rounds are threefold:

1. the focus is on psychosocial issues, rather than strictly medical ones;
2. patients, not doctors, are seen as the instructors;
3. the goal is shared reflection as a precursor to individual action.

Kenneth B. Schwartz was a healthcare lawyer who practiced in Boston in the 1980s and early '90s. For the last year of his life, he was also a cancer patient. Shortly before his death, he founded a non-profit organisation dedicated to supporting and advancing compassion in health care. Based at Massachusetts General Hospital, over the past 13 years, the Schwartz Centre has established a toehold in just over 300 healthcare institutions across the U.S. In 2012, the model was introduced in the U.K., and as of 2013, it is being implemented as a major new initiative in the National Health Service.

From both a professional and a very personal perspective, Kenneth Schwartz saw that the ever-increasing commodification of medical care was resulting in an alarming decline in compassion. Rapid strides in research and technology, while improving diagnostic and treatment capabilities, also contributed to the 'silo-ing' of information and widening the distance between patients and doctors, and between members of care teams. Often, as the pace of hospital life increased, both the patient and compassion were left behind.

A number of studies have now established an astounding fact: if communication between patients and doctors, and between members of care teams, is improved, patients get better faster. How extraordinary! Better communication results in better care. Not only are patients' outcomes markedly improved (as measured by such variables as length of stay and patient satisfaction), burnout is lower amongst medical students and nurses, and turnover rates are reduced across staff lines.[2] A study commissioned in 2004 found that Schwartz Centre Rounds:

- Help caregivers connect better with patients emotionally
- Enhance their understanding of the effects of illness on patients and their families
- Improve communication among caregivers
- Decrease feelings of caregiver isolation and stress.[3]

More recently, Lown and Manning have demonstrated that SCR sessions help improve teamwork by allowing staff to empathise with colleagues, thereby creating more supportive work environments. Staff also report feeling less stressed at work. These findings were replicated in the UK pilot which involved the use of a similar tool to measure feedback.[4] The Schwartz Centre in Boston suggests that greater staff wellbeing improves patient care.[5] Their research is validated by the King's Fund claim that there is a clear link between staff wellbeing and healthcare.[6]

Clearly, this is a win-win situation for everyone, as the programme is virtually cost-free, or at least cost-neutral. Training is free, consisting primarily of observation. Most SCR sessions take place over lunch, for which insurance or pharmaceutical companies are generally delighted to pick up the tab.

What is most interesting about the SCR is how glaringly obvious its benefits are (to the 'market' of health care), and how much resistance it is finding as a movement within that market. I think these two aspects are linked. Although it was begun nearly 20 years ago, to date it is in use in less than 10% of the 5000 health-care institutions throughout the U.S. The resistance can, I think, be attributed to three main factors, which, I would suggest, are also its main advantages, and the reason I chose to speak about this program in the context of *The Patient* conference.

2. Shifting the Focus: Participatory Process and Vulnerability

First, the SCR promotes a major shift in the overall health care paradigm. For while its outcomes are real, measurable and desired, the SCR is not primarily about outcomes, but rather about process. As a communications tool, the real value of the SCR does not lie in improving problem-solving amongst professionals, but rather in allowing them to process emotions in a safe and neutral space. It puts aside the question of 'failure' – since ultimately all patients die – and focuses instead on the quality of care for both patients and caregivers.

A change in focus thus enables a major paradigm shift. Communication is not a by-product; rather, it is the medium of change. Beth A. Lown, medical director at The Schwartz Centre at Massachusetts General Hospital, suggests that The Schwartz Centre Rounds

> [...] are not like any other rounds in a hospital. [With] grand rounds, you come in; you sit down; it's a lecture; and people present technical material and data . . . [they are] a place for anybody who touches the care of a patient in a hospital or other setting where we have the rounds can come together and talk about some of the psychosocial, the emotional, the psychological aspects of care of patients and their impact on patients, on family members, and particularly on us.[7]

This shift is further enhanced by a second feature: the SCR is holistic and participatory. It looks at patient care in a completely 'new' way, as a team effort in more than name alone. The redistribution of power is a radical idea in modern health care, demolishing the paternalistic 'doctor knows best' paradigm. It has long been thought that power in medical care can never be equalised, because of the varying levels of expertise and training involved. And yet, the success of the SCR has proven that not only can power be distributed more evenly throughout a care team, it is actually beneficial to all concerned when this occurs. Patients take more ownership of their own care, improving compliance rates for post-surgical treatment. Expectations are lowered regarding decision-making, which reduces burnout rates, especially amongst medical students. A more mindful focus on the humanity of all involved results in greater respect throughout and across team results. In a 2011 UK pilot, an SCR workshop

> [...] found that barriers to compassionate care include: staff stress and burnout, conflict between perceptions of professionalism and compassion, a lack of systematic role modelling or mentoring, training that encourages professional detachment, as well as ways that staff naturally develop to cope with continuous exposure to patients in pain and distress.[8]

A third feature which is both key to the success of the SCR programme and a major source of resistance to its implementation is the introduction of a sense of shared vulnerability. Several studies have shown that an essential ingredient in the success of the SCR is visible buy-in at the highest levels of leadership within the institution. Seeing the CEO or director of nursing weep (or laugh) alongside third-year residents and physical therapists forges strong personal bonds. Many participants (in both the US and the UK) report that the SCR offered professionals

their first opportunity to share emotions at work. Several reports note that participants needed to be reminded to focus on the emotional, rather than the technical aspects of caring. They were initially much more comfortable remaining in their professional roles

> because people are used to attending grand rounds and mortality meetings, at which outcomes, rather than emotional experience and response, are scrutinized. We at first encountered a few staff, for example, who questioned the treatment approach but the facilitator steered the discussion in another direction.[9]

Over time, the emphasis on psychosocial concerns in patient care took root, but it necessitated people being willing to open themselves to a new level of relating to one another. The SCR offers a way for team members to encounter one another not only as professionals but also as persons. Thus, the SCR has been beneficial to treatment teams not only in increasing efficacy, but also in changing their perception of their co-workers, as united in a common cause.

As the barriers to communication fall, so too do barriers to compassionate care. Gradually, nurses and doctors reawaken to the fact of their common humanity. Given a forum for articulating the difficulties of dealing with high-stress factors like PTSD, chronic pain, and lack of resources, the distinctions between caregivers and patients dissolve into the common cause of improving the quality of care within what is possible.

3. Benefits: Hope, Openness, Renewal of Meaning

So philosophically, what might the SCR teach us about communication in the marketplace? I see three main intertwining benefits of the SCR programme which I believe can and should be explored in a wider market context: hope; openness to the other; and the renewal of meaning. These can all be summed up as the power of listening.

A. Hope

I want to argue that listening is central to the shift that the SCR makes possible, and that this shift can be understood not only in the context of the health care 'market,' but in any form of business communication. This is, in itself, no radical finding, but if we reconfigure listening as an act of hope, it takes on a whole new complexion.

> The very act of listening, generously listening while assuming nothing, holds hope in the relationship. A constructive relationship can't exist if listening doesn't happen. I think that sometimes we think of hope as setting the bar very high. I don't

think that holding hope requires any action at all. In fact, it's very passive but it requires very active listeners. It's not another thing to put on the to-do list but it is a way of being.[10]

This quote comes from a discussion between hospital chaplains and oncologists with regard to the ethics of hope in communication between doctors and patients. Some of the most fundamental ethical dilemmas in health care today have to do with open and honest communication. Most of the time, we imagine that the emphasis on communication is on what is or is not said. It may be time to re-introduce the notion of an ethics of hope based, instead, on listening.

Imagine what it would be like if one were to go through the day – not merely in a hospital setting, but in a workplace setting – with hope rather than competition or anxiety as one's primary mode of being-with-others. I want to suggest that a kind of ethics of hope could be a powerful and promising strategy for business communication.

B. Openness to the Other

Within the last ten years, the thought of French philosopher Emmanuel Levinas has been introduced into business ethics, as offering an alternative lens on our interaction and communication. Levinas argues for a truly inter-subjective ethics, one which is based on the encounter with the 'face' of the other. For Levinas, looking into the face of the other enables one – and requires one – to see the Other as an other Self.[11] This encounter can be seen either as a demand or an invitation: in either perspective, the encounter engenders an attitude of mutual responsibility. It also gives rise to an attitude of hope. It is a stance that is simultaneously active and passive. It is not an action so much as a way of being.

I think that there is no doubt that communication in health care can benefit from the kind of paradigm shift suggested by the SCR. Perhaps the real teaching of the SCR project is a reinforcement of the idea of open receptivity to the other, as a positive action. Perhaps what is needed is a renewed appreciation of the power of listening. The SCR project shows medical teams a different way to deal with patients, not by doing anything, but simply by the mediative act of listening, whereby caregivers 'witness their suffering, share in their journey, accompany them, and give them permission to own their joys and their fears, to hope, and to surrender…'[12] The process of active listening entails making oneself available and vulnerable, being present to the other on the level that Levinas suggests.

C. Renewal of Meaning

Above and beyond this mediative potential – which is, in itself, no small gift – the SCR seems to provide one more benefit: the renewal of a sense of meaning. The process itself is a shift away from acting on and towards being with the other, a shift in emphasis from the treatment of disease to the treatment of the person. The

point of the SCR is not to improve this or that technical process, but to facilitate the focus of attention on both patient and caregiver as people. The SCR frees the medical professionals from their Sisyphean tasks and roles to encounter their patients (and one another) in the common space of their mutual intersubjectivity.

In terms of existential philosophy, this moment of inactivity can be understood as tremendously important. It is a moment of spiritual transcendence of the here-and-now. It is a moment of suspension – and thus it touches the infinite. No decision is being made, so everything is possible. Thus each individual is completely free – in existentialist terms, free to create the next moment of meaning for both parties in its next choice of action. What occurs in this space of active listening is the moment between decision and implementation, which is full of virtualities, potentialities. Only one will issue forth in (or as) the new aspect of the self-interpretation in existence of the individual that we call meaning.

This moment can be called ethical in several ways. First, because it gives birth to the ethical agent, the subject who can then choose to act. Second, because as a moment of absolute freedom it is the ideal starting point for an ethics. Third, it is a moment that is saturated with responsibility, for, as Levinas reminds us elsewhere, 'every responsibility exists prior to freedom.'[13] Phenomenologically speaking, we know that in fact no action takes place in a vacuum, unrelated either to a history or a future. The moment prior to a decision already holds within itself the responsibility for an ethical outcome. A moment of attention-without-action, whether it precedes or follows an action, can be a moment of self-reflection on one's meaning within the whole. This is perhaps the greatest lesson of the SCR: the re-cognition through reflection on the part of each team member. The more this condition can be inhabited or cultivated, the greater the potential for meaning-giving will be enhanced.

4. Conclusion

The Schwarz Centre Rounds are just one example of a new way forward for communication, and research suggests that it may well be an enormously beneficial one. To conclude, I would like to invite all of us to think about what this idea of active, open listening might look like in your own contexts. Is your field ready for such a paradigm shift that encompasses a more fundamental orientation to the process of communication? These sorts of (in)activity are demanding stances requiring practice and support. The challenge for all us is to imagine how this idea might be introduced, implemented and supported in our own clinical contexts.

Notes

[1] Julie Rosen and Thomas Lynch, Jr., 'The Talking Cure: Schwartz Centre Rounds Foster Compassion and Collaboration', *Journal of Cancer Education* 23 (2008): 195-196.

[2] 'Resident-centred MDR (Multi-Disciplinary Rounds) is an effective process using no additional resources that simultaneously improves quality of care while enhancing resident education and is associated with shortened length of stay.' Steven O'Mahony et al., 'Use of Multidisciplinary Rounds to Simultaneously Improve Quality Outcomes, Enhance Resident Education, and Shorten Length of Stay', *Journal of General Internal Medicine* 22 (May 2007): 1073-1079.

[3] Rosen and Lynch, 'The Talking Cure'.

[4] Joanna Goodrich, 'Supporting Hospital Staff to Provide Compassionate Care: Do Schwartz Center Rounds Work in English Hospitals?', *Journal of the Royal Society of Medicine* 105 (2012): 117-122; Beth Lown and Charles Manning, 'The Schwartz Center Rounds: Evaluation of an Interdisciplinary Approach to Enhancing Patient-Centered Communication, Teamwork and Provider Support', *Academic Medicine: Journal of the Association of American Medical Colleges* 85 (2010): 1073-1081.

[5] Schwartz Center website: accessed 22 August 2012, http://www.theschwartzcenter.org.

[6] See Goodrich, 'Supporting Hospital Staff'.

[7] Lown and Manning, 'The Schwartz Center Rounds', 1074.

[8] Goodrich, 'Supporting Hospital Staff', 121.

[9] Ibid.

[10] Richard T. Penson et al., 'Connection: Schwartz Center Rounds at Massachusetts General Hospital Cancer Center', *The Oncologist* 15 (2010): 760-764.

[11] See Emmanuel Levinas, *Totality and Infinity: An Exercise in Exteriority* (Pittsburgh: Duquesne University Press, 1969).

[12] Penson, et al., 'Connection', 763.

[13] Levinas, *Totality and Infinity*, 34. It might be more accurate to say that responsibility and freedom are equiprimordial, in this schema. (My thanks to Agnes Curry for this observation.)

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CULTURE, EXPERIENCE, CARE:
(RE-)CENTRING
THE PATIENT

Susan Sontag claimed that 'everyone who is born holds dual citizenship, in the kingdom of the well, and the kingdom of the sick,' and while 'we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.' We are all, in other words, past, present, or future patients. This collection examines the many ways in which the idea of the patient can be conceptualized in different cultural, professional, intellectual, and emotional contexts as part of an on-going, multidisciplinary and international attempt by scholars, health care professionals, and, indeed, patients themselves to rethink and re-examine patienthood and patient care. These chapters attempt to put the patient at the centre: not just (although clearly not least) at the centre of the processes, institutions, and ideologies of medical care, but of a wide range of intellectual and social practices.

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