Subjectivities and Afflictions in Medical Anthropology

Subjectivities and Afflictions in Medical Anthropology

Edited by

Angel Martínez-Hernáez
and Lina Masana

**Cambridge
Scholars**
Publishing

Subjectivities and Afflictions in Medical Anthropology

Edited by Angel Martínez-Hernáez and Lina Masana

This book first published 2022

Cambridge Scholars Publishing

Lady Stephenson Library, Newcastle upon Tyne, NE6 2PA, UK

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN (10): 1-5275-8341-4
ISBN (13): 978-1-5275-8341-2

To Susan M. DiGiacomo, *in memoriam.*

TABLE OF CONTENTS

Section One. Negotiating Knowledge and Subjectivities: Illness Narratives and the Biomedical and Social Construction of Disease

Section Two. Hospital Ethnographies and Subjectivities: Encounters between Health Professionals, Patients, Families, Clowns, and Ethnographers

Section Three. Negotiating Subjectivities: Body, Substances, Biopolitics and Health Practices

Section Four. Mental Health Narratives, Embodiment, Healing Practices and Subjectivities

LIST OF ILLUSTRATIONS

INTRODUCTION

LINA MASANA
AND ANGEL MARTÍNEZ-HERNÁEZ

Subjectivity can be understood as the meeting point where the experienced and experiencing body intersects with micro and macro level contexts and processes, such as local social worlds, power relationships and biopower; (mis)encounters between lay medical knowledge and expert systems; and persistent political-economic inequities (Biehl, Good and Kleinman 2007). Nevertheless, subjectivities still receive little attention in Western biomedicine. Despite some recent changes aiming at humanizing medical care by taking a more person-centred approach (McCormack et al. 2017), biomedical representations and practices continue to focus mainly on diseases rather than on the patient's illness experience. Biomedicine largely relies on evidence produced by biomedical technologies—evidence-based medicine (EBM)—excluding, to some extent, illness narratives as a rich source of evidence that provides significant insights into the complex social worlds of affliction. Is there a place for subjectivity in biomedical routines of cure and care? If so, can medical anthropology provide an alternative approach for those practices focusing on a politics for life instead of a politics of biological life that detaches subjectivity from health policies and practices?

These questions are addressed in this edited book, which is the result of the X Medical Anthropology at Home (MAAH) Conference held at Poblet Monastery (Tarragona) in October 2018. It is a unique international contribution on subjectivities and afflictions from a medical anthropology perspective. It contains fourteen contributions from different authors who discuss current medical anthropology debates through ethnographic data from different contexts and countries, such as Canada, Chile, Egypt, France, Kazakhstan, Spain, and the United States of America, among others. The anthology aims to develop some of the themes emerging from the conference's sessions to contribute and stimulate further anthropological debates on subjectivities in health and illness. The chapters of this book address, with an international lens, the experiences of illness, the dilemmas of care, the politics and biopolitics of health and the ethical dilemmas related to subjectivity and afflictions. Each chapter is built upon a specific methodological approach. However, being anthropological contributions, they share the ethnographic method and a qualitative approach.

The different chapters can be organized along four main sections that explore the profound relationship between, on the one hand, the social world with its health care systems and institutions, and, on the other, suffering as an expression of the human condition.

Negotiating knowledge and subjectivities: Illness narratives and the biomedical and social construction of disease

People's experiences of illness, suffering and affliction are expressed through their narratives (Kleinman 1988). Illness narratives are presented to different audiences in the social, medical, and professional arena: relatives, friends, co-workers, other people in the social arena, clinicians, anthropologists, and other kinds of researchers. On the one hand, people's accounts of illness—"what" and "how"—are presented in different ways according to "when", "where", to "whom", and "why" they tell their illness stories. On the other hand, the illness narratives might be overshadowed by the dominant biomedical discourse of the disease, which might or might not legitimate people's subjective illness experiences and knowledge. According to different audiences and situations, people decide whether they want to reveal their subjective experience of suffering, provide an "objective" and biomedically informed account of their illness or affliction, or offer a combination of both. Consequently, the social construction of disease and the illness experience are mediated and shaped by the hegemonic biomedical point of view. Is subjectivity changed, shaped, or negotiated in those different narrative encounters? Are the subjective worlds of affliction mere accounts of symptoms and ailments, or do they serve other purposes? How is illness expertise and experiential knowledge negotiated in the biomedical and social arena? To what extent does the social construction of the disease come from the original illness account or from an official discourse? In this first section of the book, the following three chapters will attempt to respond to these questions by analysing three chronic conditions—cancer, chronic fatigue, and AIDS—in different contexts and from the points of view of the diverse actors involved.

The posthumous chapter[1] by Susan M. DiGiacomo ‘Healing and Wholeness: Cancer Survivors’ Embodied Experience of Illness as a Source of Expertise’, contributes to the theoretical discussion on subjectivities and afflictions in the biomedical context. Her paper revisits data collected during 1988-1990 on cancer survivors (including the author) which volunteered in the Patient Network group in a tertiary-care university teaching hospital in the United States. Those volunteers aimed to accompany persons newly diagnosed with cancer through their treatment proces. Volunteers understood themselves as experts, not as medical experts but as experts on the lived experience of cancer, challenging, thus, the biomedical undestanding of “expertise” and negotiating a legitimate source of knowledge.

In her chapter ‘“We Are All Tired”: The Social Construction and Negotiation of Chronic Fatigue’, Lina Masana analyses the narratives of people suffering from chronic fatigue in Spain and discusses how the chronically fatigued body and self is conceptualized, and how it is biomedically and socially constructed. Drawing from her ethnographic research on chronic conditions (2009-2013) and taking a phenomenological and cultural hermeneutic approach, together with a social interactionist perspective, she examined the communication interactions on fatigue between chronically fatigued people and healthy ones. The results showed three common archetypal narratives (sentences) which the author considers to be communication strategies serving specific purposes related to the negotiation of the intersubjective experience of chronic fatigue in the social arena.

In her chapter ‘Navigating HIV Discursive Practices and Positive Subjectivities in Egypt,’ Wesam Adel Hassan examines the dominant

---

[1] This chapter is shorter than the rest because it is the primary version used for the conference. Unfortunately, Susan could not expand her chapter afterwards for this volume since she passed away in June 2019.

discursive practices and the personal narratives of another chronic condition—AIDS—and how they are produced and shaped by the dominant biomedical discourse on HIV within the political context of Egypt after the 2011 revolution. Through ethnographic research conducted (2014-2015) in Greater Cairo (Egypt) with mothers living with HIV in their mid-thirties, the author shows how the dominant discourse on HIV and AIDS produces different forms of knowledge and attitudes towards it, shaping HIV-positive subjectivities and, therefore, their narratives.

Hospital ethnographies and subjectivities: encounters between health professionals, patients, families, clowns, and ethnographers

On the one hand, hospitals, nursing homes and other institutionalized environments are specific settings for anthropological inquiry about the interplay between the professional and lay subjectivities. How do clinicians respond to patients' and families' suffering? How do they deal with subjectivities? How do they discuss or negotiate treatment? In this section, we explore how subjectivities are presented, treated, or placed at risk in four different biomedical settings.

On the other hand, it is worth acknowledging that when conducting hospital ethnographies, and because the ethnographic encounter is intersubjective in nature, the ethnographer is vulnerable to afflictions deriving from that encounter. This is especially relevant in medical anthropology inquiries dealing with sensitive topics including illness and suffering, life and death, end-of-life care, and degenerative diseases, among other topics. How does ethnographic research affect anthropologists? How do the anthropologist's subjectivity and presence in the health setting affect research and clinical encounters? How do researchers deal with emotions encountered in the field? Can the researcher's emotional responses be mobilized for analytic purposes? In the following chapters on diverse clinical settings, the authors also reflect on and discuss the notions of subjectivity, reflexivity, and emotions in ethnographic work.

In her chapter 'Re-Experiencing Medical Care Routines Through the Work of Hospital Clowns' Claire Bodelet studies the work of hospital clowns with hospitalized children (on paediatric wards) in France. Through participant observation, this hospital ethnography (belonging to her PhD research from 2016-2020) explored how clowns come to cooperate and work with the medical staff during medical care routines. Particular attention is brought to subjectivities and interactions among the actors involved—medical staff, children, family, clowns and the ethnographer—and the kind of strategies that clowns use to help both staff and patients, quickly acting on and reacting to situations, or managing emotions in the field.

The proceeding chapter is another ethnographic study, this one carried out (from 2016-2017) in a paediatric hospital in Montreal (Canada). It too investigated the subjectivities and interactions between medical staff, children, and their families, however, in a more critical scenario than the one reported in the previous chapter on hospital clowns. 'Prolonging Life or Envisioning Death' by Sylvie Fortin and Josiane Le Gall discusses the decision-making process (or lack thereof) when facing a poor prognosis and the change of therapeutic trajectory from a curative to a palliative perspective. In that context, invasive treatments and furthering life at all costs compete with palliative medicine, bringing into discussion the notions of quality of life and death, and the moral role of physicians, contributing to a complex and contemporary debate regarding medical progress and practice, and non-abandonment of duty.

As part of her ongoing PhD research (2014-current), Sabrina Lessard's paper '"If I Understand Correctly, You're Waiting for One of Us to Die?": An Ethnography of Disorientation in a Geriatric Environment,' contributes to the debate around end-of-life care practices but deals with the opposing age-group to children, the elderly, in two geriatric (institutionalized) environments in Montreal. She discusses her position within the field as an observer and how the researcher's subjectivity can benefit the analytical process. Lessard suggests exploring the notion of anthropology of disorientation proposed by Pandolfi (2016) as an alternative to comprehend researcher subjectivity in the field.

Negotiating subjectivities: body, substances, biopolitics and health practices

In recent decades, the government of life has acquired a central position in medical anthropology. Rooted in the Foucauldian and neo-Foucauldian tradition, notions such as biopower, biopolitics, and anatomo-politics have been used to understand the role of the state and health policies in the management of human life and diseases, including the production of subjectivities or the subjectivation process. In this approach, subjectivities are treated as entities “subjected” to a social order in the post-disciplinary society, such as Byung-Chul Han’s concept of achievement society (Han 2017) where agency loses its capacity and is often envisioned as a mirage that conceals the forces of domination. What is the relationship between biomedical knowledge, health practices and afflictions? Is there a place for agency in the biopolitics framework? Is the notion of biopolitics useful for ethnographic inquiry in the domain of subjectivities and afflictions or do we need new notions such as psychopolitics for dealing with the new social orders? In this section, two chapters explore how subjectivities and agency are negotiated within the biopolitics framework of medication.

In her chapter ‘Subjectivities and Semantic Variations Around the Concept of Dependence on Medicines’, Sylvie Fainzang aims to contribute to the reflection on subjectivities by re-questioning, from an anthropological lens, the two oppositions in which they are generally considered: one between the subjective and the collective, and the other between subjectivity and objectivity. Based on her extensive research in the Paris region (France) on the lay management of medicinal risks—i.e., patients’ choices to adjust or modify their medication—she examines the notion of (and fear of) dependence on medicines from an emic point of view, its various meanings for users, and its relation to reluctance to take some medicines.

Medicalization is a common issue in psychiatric pharmaceutical treatments, something further explored by Nicolás Morales in his chapter ‘Pharmakon, Commodity and Dystopia: Three Approaches to the Pharmaceutical Self in Neo-Communitarian Mental Health.’ The aim of the paper is to understand the interrelation between subjectivation processes and psychiatric medications, the use of psychiatric medications in commodified clinical practice, and the dystopian narratives found in groups and societies. Grounded in the analysis of how psychiatric practice has evolved in the Southern Area of Santiago de Chile since 1968, with a focus on the post-dictatorship period from 1990 onward, the author argues that the pharmaceutical imaginary is inseparable from the pharmaceutical self, and that this case allows us to discuss the psychopolitical demands in neo-communitarian mental health times.

In his chapter entitled ‘Ecological Subjectivity: A Case of Chemical and Other More-Than-Human Sensitivities,’ Franz Graf presents the case of a person in the UK suffering from an environmental illness that clinical ecologists understand as a "physical" condition in which small amounts of industrial substances can cause severe trauma. In contrast, the biomedical mainstream views environmental illness as a "mental" illness. Given the difficulty of describing allergic symptoms in simple dichotomous categories, the author uses Thomas Csordas' understanding of environmental illness as a prototypical disorder in the sense of Foucauldian biopolitics. For the author, emerging subjectivities are based on intersubjective processes in which places play an important role because they confront us with agencies and structures, only some of which are human.

Mental health narratives, embodiment, healing practices and subjectivities

In phenomenological approaches, embodiment has been envisioned as the existential ground of culture and as a productive starting point for an anthropological inquiry into subjectivities and the self. Challenging the well-known dualities of subject and object, mind and body, the study of the embodied experience of illness highlights how illness is not merely the result of a biological imbalance affecting the body or the mind but a subjective experience affecting the lifeworld (*Lebenswelt*). In recent years there has been a growing interest in the nature of knowledge generated from the notions of illness experience and embodiment. This has served to counter the biomedical paradigm, and function as a corrective to biomedical reductionism and the hegemonic normative ideas on how bodies and minds are, or should be, expressed, socially (re)presented, understood, treated or healed. What is the relationship between body and subjectivity? How can the embodied experience of illness be turned into evidence? How might this serve to improve health care and healing practices? The following chapters of this section address those questions and serve as a starting point to reflect on the normative ideas on how subjectivities are perceived socially, medically, religiously, and spiritually.

In her chapter ‘Uncharted Sensations: Autistic Subjectivities, Affective Language and Unexpected Senses,’ Soula Marinoudi explores autistic subjectivities through modes of embodiment, communication and sensibility—i.e., socially unexpected sensory experiences—which transcend intelligible forms of logocentric cognitive sociability, thus, questioning the hegemonic ableist modes of communication and empathy. Based on ethnographic research conducted in Greece and published autobiographical narratives of autistic people, this chapter brings attention to the anthropology of the senses and suggests deconstructing the cognitive and logocentric accounts of sociability, exploring the unexpected emergence of autistic creativity by adopting a critical phenomenological perspective of autistic embodiments, sensations, and perceptions.

Angel Martínez-Hernáez explores the intersection of myths and life stories in his chapter ‘The Son of the Tiger Hunter Who Never Killed a Tiger: Myth, Violence and Masculinity in a Life Story.’ Through the reconstruction of the biographical story of Rajin—the tiger hunter’s son, a middle-class Konkani from Bombay (India)—gathered through in-depth interviews conducted along two years in the early nineties (1991-1992) in Barcelona, the author argues that myths offer us an imaginary content in a realistic structure that places us between strangeness and affinity, and that biography shows us a realistic content in a structure that ends up being imaginary and that places us between affinity and strangeness. This chapter deals with a life story that resembles a myth and a myth that seems like a biography, in such a manner than fable invades the biography, and the biography turns into myth.

In their collective chapter ‘Narratives of Violence and Alterity of a Psychonautic Woman,’ Patricia Cocchi, Ismael Apud, Juan Scuro and Adriana Molas examine the notion of alterity through spiritual practices such as neo-shamanism and its concurrence with the biomedical system. Using the theoretical frameworks of medical anthropology and religious studies, the authors describe and analyse the biographical narrative of the Uruguayan woman Patricia, her health seeking trajectory, and how that trajectory impacted her subjectivity. The participant suffered different forms of violence from a neo-shamanic group and, afterwards, in a psychiatric institution. Her case, garnered from in-depth interviews, is used to analyse how the alterities she embodied were treated within different spiritual and health systems.

The chapter by Danuta Penkala-Gawęcka, 'Illness Experience and Its Translation: The Case of a 'Shamanic/Healer's Illness' in Post-Soviet Kazakhstan and Kyrgyzstan', analyses the illness narratives of shamans and other traditional healers by looking at both their subjective and intersubjective experiences. Based in ethnographic materials gathered through longitudinal research conducted in Kazakhstan (Almaty, 1995-2000) and Kyrgyzstan (Bishkek, 2011-2013), the author shows how this specific kind of 'shaman/healer illness' experience—which is known in the literature as a prerequisite for becoming a shaman and which might be considered by biomedicine as a mental disorder that requires psychiatric intervention—is also crucial for the career of shamans or other spiritual healers in Kazakhstan and Kyrgyzstan nowadays.

In the final chapter, 'Possession and Psychopathology, Faith and Reason,' Thomas Csordas analyses the ritual of contemporary exorcism practice in the Roman Catholic Church, focusing on the relation between psychiatry and religion. The author states that exorcism raises not only the issue of how scientific medicine and ritual healing interact but also, and especially for its practitioners, an abiding concern with the relationship between faith and reason. Moreover, exorcism can be understood not only as a thriving form of religious practice but also as a dynamic social phenomenon. Csordas concludes that exorcism anthropological inquiry opens up the discussion of the relations between personal and impersonal entities, endogenous and exogenous causes, and natural and preternatural sources of affliction.

The last words of this introduction we would like to dedicate to Susan DiGiacomo. She was our beloved fellow anthropologist and friend, who sadly passed away in June 2019. Susan was an extremely generous person, a person of integrity, and a perfectionist in everything she did. Her courage in the face of human finitude will always remain in our memory.

Bibliography

Biehl, João, Byron Good, and Arthur Kleinman, eds. 2007. *Subjectivity: Ethnographic Investigations*. Oakland: University of California Press.

Han, Byung-Chul. 2017. *Psychopolitics: Neoliberalism and New Technologies of Power*. London and New York: Verso Books.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Free Press.

McCormack, Brendan, Sandra van Dulmen, Hilde Eide, Kirsti Skovdahl, and Tom Eide, eds. 2017. *Person-centred healthcare research*. Hoboken (NJ): John Wiley & Sons.

Pandolfi, Mariella. 2016. Livre 8. “L'ethnographie désorientée sur le terrain de l'humanitaire". In Les possédés et leurs mondes. Montréal, Canada: *Revue Anthropologie et Sociétés*. Accessed June 24, 2021. https://www.youtube.com/watch?v=WvMwT-aBOqo

SECTION ONE

NEGOTIATING KNOWLEDGE AND SUBJECTIVITIES: ILLNESS NARRATIVES AND THE BIOMEDICAL AND SOCIAL CONSTRUCTION OF DISEASE

CHAPTER ONE

HEALING AND WHOLENESS: CANCER SURVIVORS' EMBODIED EXPERIENCE OF ILLNESS AS A SOURCE OF EXPERTISE

SUSAN M. DIGIACOMO

Introduction

This paper is an effort to use the paradigm of embodiment (Csordas 1990) in order to understand the experience of persons who have survived cancer, in a rereading of postdoctoral research I did between 1988 and 1990. My research participants were 23 individuals (19 women and 4 men) plus one, myself, who had all been treated for various malignancies at the same tertiary-care research hospital in Boston, Massachusetts, and had offered their time to the hospital's social services to accompany newly diagnosed cancer patients. A social worker in search of a Ph.D. thesis topic saw in these 24 people a possible way to address the request of a patient whose lonely experience of treatment for non-Hodgkin's lymphoma gave her an insight: there had to be many others whose suffering, like her own, was augmented by the feeling that she was alone; not only alone in the world of healthy people, but alone among others undergoing treatment for cancer, isolated by their own particular anguish, an unnecessary exile from which they could be rescued. In response, the social worker proposed the creation of a group she called the Patient Network. Meeting others who shared their affliction would, she reasoned, allow them to resituate their own experience within a range of what she identified as "common, normal concerns…attitudes and stresses."

It is the experience of the volunteers as survivors that interests me here. Survivorship (see Mullan 1985) is often interpreted narrowly in terms of "coping" with the acute phase of illness and treatment; or, in still narrower biomedical terms, as five-year survival rates, five years beyond the end of treatment being the accepted benchmark for long-term remission. What is the experience of the formerly sick, who nonetheless face ongoing liminality and vulnerability for the rest of their lives? This is a question I cannot avoid posing, as one who has been treated twice, with all three standard forms of intervention, for Hodgkin's lymphoma. This kind of "medical anthropology at home", in which the ethnographer is a patient treated in her natal society doing fieldwork in the same hospital where she herself was treated, shortens the distance between the ethnographer Self and the ethnographic Other to the vanishing point. This collapsing of the central subject-object dichotomy that underlies much of anthropology is at the heart of the paradigm of embodiment, whose aim is to apprehend the existential grounding of cultural meanings in the experience of the body. What was at stake for the people I observed and spoke with was also at stake for me.

Bodily experience: from "organic innocence" to embodied knowledge

In his 1943 doctoral thesis in medicine, Georges Canguilhem wrote the following:

> Diseases are new ways of life. Without the diseases which incessantly renew the area to be explored, physiology would mark time on well-trod ground. But the foregoing idea can also be understood in another, slightly different sense. Disease reveals normal functions to us at the precise moment when it deprives us of their exercise. Disease is the source of the speculative attention which life attaches to life by means of man. If health is life in the silence of the organs, then, strictly speaking, there is no science of health. Health is organic innocence. It must be lost, like all innocence, so that knowledge is possible (Canguilhem 1989, 100-101).

We can make use of the power of this insight to develop an understanding of cultural meanings as emergent objectifications of bodily experience.

Susan Songag's essay *Illness as Metaphor* (1978) has made it impossible for us to be unaware of the widespread use of cancer imagery to characterize a wide variety of disorderly and disordering forces as social, economic and political pathologies. These images feed back into the illnesss experience of cancer patients, increasing their suffering by burdening them with the disease's stigmatizing "double" (Scheper-Hughes and Lock 1986, 137). But this "doubling" is a secondary process. The disordering force of cancer begins in the inchoate experience of that passage from "organic innocence" in "the silence of the organs" to the fall from grace, to physiologic "noise."

The language Patient Network volunteers used to convey this passage was richly evocative of the sudden shift from one mode of being to another. Sometimes they experienced it as a literal fall: "like I fell off a cliff." Others felt it as a crushing blow: "like my whole world caved in." The sudden loss of control was sometimes experienced in a manner analogous to physiologic shock. Much as the nervous system initially fails to register pain after a serious injury, so some participants recalled the first minutes, hours, or days following the communication of the diagnosis as a time of numbness. A volunteer who underwent a mastectomy for breast cancer received the news of significant lymph node involvement on the same day the Challenger space shuttle exploded in flight shortly after launch. She experienced the shuttle disaster not as a faraway catastrophe, as someone else's tragedy, but as her own, and as its destructive force reverberated through her own being she wept for the first time, confronting at last her own mortality not as an abstract idea but as a felt certainty: embodied knowledge, loss of "organic innocence," the definitive fall from grace.

Once the interior "silence" was broken, it could be difficult to screen out the noise. Participants spoke of becoming acutely aware of their bodies, hypervigilant, conscious of changes as minor as tenths of a degree of fever. This new somatic mode of attention (Csordas 1993) could be burdensome, even exhausting. A volunteer who had had two mastectomies followed by breast reconstruction explained that she felt both angry and "terrorized" by it. One possible (though not universal) response to the embodied knowledge of mortality was becoming dis-embodied. Some volunteers found a degree of relief in simply making explicit in everyday speech the separation of body and self through the use of the definite article in preference to the possessive pronoun: "the" instead of "my" (see Murphy 1987, 100). At its most extreme, this kind of dis-embodiment went beyond mildly dissociative states to something approaching a trance, as in the case of a very young woman whose ovarian cancer was diagnosed when she was in her late teens. She described how she had “handed over” her body to her parents and doctors and had “gone to sleep”, remaining in this state until her treatment ended. This was not so much a refusal to participate as a refusal to know, a rejection of the embodied knowledge of mortality that, at her age, was perhaps not a surprising reaction. When she “woke up”, the breaking of the spell also awakened an intense desire to know. At the time she joined the group, she was preparing for a career in social work, intending to specialize in working with cancer patients.

Volunteers spoke largely in terms of knowledge, of what they had learned in the course of their illness and wished to place at the disposal of those just starting out on the same journey. They had learned things about the human condition, beginning with their own bodies, that radiated outward into the social world. The youngest volunteer, who had been treated by bone marrow transplant for leukemia, offered, spontaneously, that had she been given the chance to go back, to rewind her life like a film and live it again but with cancer edited out, she would not accept it. I began to pose this question to the other members of the group, and they agreed that they valued their biographical integrity and what they had learned, both positive and negative, in the course of their illness too highly to be willing to sacrifice it in order to return to organic innocence.

None of these narratives were simple stories of overcoming adversity and emerging as a new and improved person with better values. In addition to moments of transcendence and even humor, they included elements of anger, loss, grief, fear, vulnerability and pain, a sense of having been betrayed by one’s own body and the hope of achieving renewed trust in it. It was this kind of knowledge that they wished to place at the service of others, and precisely because they framed it as knowledge they wanted the oncology department’s social services to recognize them as experts of a particular kind: not experts in medicine, but experts in how to live after the fall. This “how to live” is not “coping” – a thin description – or illness management, but existential. Service work such as this is one dimension of “how to live”, a way of crafting a life through the telling and sharing of stories in all their complexity (Frank 2003, 252).

This is powerful stuff, as the anthropologist Paul Stoller tells us. In the course of doing fieldwork on ritual language and local politics in Niger early in his professional career, Stoller was unexpectedly initiated into Songhay divination, sorcery and spirit possession. His subsequent 17-year apprenticeship to a sorcerer is an unusual but not unknown research strategy. Stoller produced an extensive body of work on Songhay sorcery, and thought he understood it…until he received a diagnosis of non-Hodgkin's lymphoma, a disease with an uncertain prognosis. On the day of his first chemotherapy treatment, as he struggled to take in his oncologist's explanation of the treatment protocol while maintaining a façade of confidence and in-controlness, "suddenly…the disruptive nature of my condition hit me like a Nigerien dust storm. Even if the chemotherapy treatments were successful, they would still change my life dramatically. Faced with these overwhelming circumstances, I struggled for strength. Slowly, I sensed a familiar tingling in my stomach – a sorcerous tingling. Blood surged through my veins. My senses finally began to wake up to the world in which I now found myself. I heard the soft voice of Adamu Jenitongo, my teacher and mentor: 'You've found your way back to the path,' he said. 'Step onto it and walk forward'" (Stoller 2004, 79). Stoller then reached for the hands of his brother, who had accompanied him, and his oncologist, and as they stood linked together in a circle he recited the *genji how*, a powerful Songhay incantation that harmonizes the powerful and dangerous forces of the bush. Many years earlier he had memorized it, repeating it after his teacher. At the time he saw it as a beautiful poem, and later as an important piece of data that revealed some key themes in Songhay culture. It was not until he found himself in the infusion room of the cancer center, inside the moment of danger, of fear for his life that Adamu Jenitongo had foreseen for him in the cowry shells, that the words of the *genji how* "surged like a current into my consciousness" (Stoller 2004, 97) and he began, finally, to understand the deep meaning of the incantation and of sorcery more broadly. Sorcery, he realized in that moment, was not about making things happen in the world. It was a way of being in the world, a strategy for living in chaotic and threatening circumstances.

Conclusion: the cancer survivor as sorcerer's apprentice

Surviving cancer is a process of re-embodiment that is not the same as the pre-illness state of "innocence." Canguilhem writes:

> Man feels in good health – which is health itself – only when he feels more than normal – that is, adapted to the environment and its demands – but normative, capable of following new norms of life. It is obviously not with the express intention of giving men this feeling that nature built their organisms with such prodigality: too many kidneys, too many lungs, too much parathyroid, too much pancreas […] But it has. always been so; man feels supported by a superabundance of means which is is normal for him to abuse (Canguilhem 1989, 198-200).

It is precisely the loss of the possibility of abusing our health, what Canguilhem (1989, 199) calls "the margin of tolerance for the environment's inconstancies," that Patient Network volunteers experienced as the salient feature of their recovery and the source of their continuing vulnerability. This shared experience of the body, and the ability to reconstitute a sense of self that includes this experience, is what defined them as experts in their own estimation.

Paul Stoller traces out the implications of life lived in that indeterminate space called "remission": the space self-consciously inhabited by the Patient Network volunteers. One of its lessons is that this state of "continuous liminality" (Stoller 2008, 28) is inherent in the human condition, which is located between "contingent birth and certain death". Taking this seriously means abandoning the restitution narrative (Frank 1995) of cancer and incorporating illness into our lives rather than struggling to defeat it; living with remission, rather than against it. Following David Napier's (2003) argument that we live in an "immunological age" in which the Self/non-Self opposition is foundational, Stoller argues that immunological metaphors predispose us to think in terms of war, victory and defeat of the alien intruder. This immunological/war metaphor underlies the restitution narrative of cancer. The problem, however, is that getting the status quo ante back after cancer is all but impossible.

Shifting the metaphoric field to embryology opens up a very different set of strategies and attitudes. In embryology, "the mother – the self – accepts the presence of the fetus – not-self – in her womb" (Stoller 2008, 31). For cancer patients, this suggests that the possibility of incorporating illness into our lives and treating it not as the enemy but as one of the "forces of the universe" (Stoller 2008, 38) rather than trying to eliminate it can be a