

**ANGEL MARTÍNEZ-HERNÁEZ & LINA MASANA (eds) 2022. *Subjectivities and Afflictions in Medical Anthropology*.**

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Over 30 years after ARTHUR KLEINMAN's (1988) seminal work on illness narratives, subjectivities still receive little attention in Western biomedicine. The editors of this volume argue that

[d]espite some recent changes aiming at humanizing medical care by taking a more person-centered approach [...], biomedical representations and practices continue to focus mainly on diseases rather than on the patient's illness experience (1).

They understand subjectivity as the intersection of the experiencing/experienced body with micro- and macro-level contexts (local social worlds, power relations, conflicts between lay knowledge and expert systems, etc.). Accordingly, as the result of the X Medical Anthropology at Home (MAAH) Conference held at Poblet Monastery (Tarragona) in October 2018, the authors of the 14 chapters explore spaces of subjectivity in routines of cure and care and the possibility of medical anthropology providing alternative approaches "focusing on a politics for life instead of a politics of biological life that detaches subjectivity from health policies and practices" (1). The chapters are organized into four sections, investigating suffering as an expression of the human condition and its relatedness to social worlds with its healthcare systems.

Section I (Negotiating Knowledge and Subjectivities: Illness Narratives and the Biomedical and Social Construction of Disease) addresses the following questions:

Is subjectivity changed, shaped, or negotiated in [...] different narrative encounters? Are the subjective worlds of affliction mere accounts of symptoms and ailments, or do they serve other purposes? How is [sic] 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? (2f)

Three chapters on chronic conditions (cancer, chronic fatigue, AIDS) attempt to respond to these questions, partially integrating autoethnograph-

ic accounts. In chapter 1, SUSAN M. DIGIACOMO (Healing and Wholeness: Cancer Survivors' Embodied Experience of Illness as a Source of Expertise) reports her experience as a volunteer in the US-American Patient Network where "survivors" of a cancer diagnosis guide newly diagnosed patients through the ongoing transformations of body- and self-experiences. They develop "expertise" different from the biomedical one but crucial to negotiating states of ongoing liminality and the "sudden shift from one mode of being to another" (15). Participants become "acutely aware of their bodies" (15) beyond mere coping and develop a form of re-embodiment understood as new somatic modes of attention and ways "how to live" (16). In this regard, the author also criticizes "immunological metaphors that predispose us to think in terms of war, victory and defeat [because] getting the status quo ante back after cancer is all but impossible" (18). She suggests asking "[w]hat have you learned from having cancer?" (19)

Another example of the need for new modes of awareness is introduced in chapter 2 by LINA MASANA ("We Are All Tired": The Social Construction and Negotiation of Chronic Fatigue). Presenting a Spanish case study of a woman suffering from chronic fatigue and certain incidents during a hiking trip, she illustrates how social responses may relativize, delegitimize, and contest ill-body experiences due to a lack of empathy even of very close fellows and relatives. Whereas the previous chapter has affected me because the author passed away during the publication process (a piece of information shared by the editors) and I personally mourn for good friends who in similar circumstances would have profited a lot from such an approach, this second chapter makes me (as a passionate hiker) aware of my ignorance of and impatience with the needs of others. The author stresses the factor of (ill) communication, but to me, her study also illustrates the interdependence of the categories of illness (personal experience), disease (medical diagnosis), and sickness (social implications) and how the latter may affect the former. We currently observe similar challenges

with the affliction of Long Covid, as we did in the past with HIV/AIDS.

WESAM ADEL HASSAN, in chapter 3 (Navigating HIV Discursive Practices and Positive Subjectivities in Egypt), draws our attention to the latter context with the particular ethnographic example of Egypt and the social and medical exclusion HIV “positive” patients suffer from. The author focuses on a particular group of mothers living with HIV, some of them also helping newly diagnosed patients (compare chapter 1). Her main interest is in how they enact “their agency and their will to live through their maternal subjectivity, and their impressive daily negotiation of the dominant political, medical, and social surroundings” (45). She touches upon religious and moral convictions and related stigma driven by fear and ignorance policies, the categorization of patients, and strategies of othering / blaming others in social interaction and media productions (a strategy also well-known from the COVID-19 pandemic). A case study illustrates the struggles, hopes, and fears in everyday life, particularly regarding the social role of a mother and caretaker for their sometimes also “positive” and, differently, for their healthy children.

Section II (Hospital Ethnographies and Subjectivities: Encounters between Health Professionals, Patients, Families, Clowns, and Ethnographers) inquires in three chapters about the interplay between the professional and lay subjectivities but also wondering

[h]ow 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? (4)

In chapter 4, CLAIRE BODELET (Re-Experiencing Medical Care Routines Through the Work of Hospital Clowns) observes the interaction of hospital clowns with the medical staff, family members, and patients in a French pediatric clinic, where “humour is not always the appropriate solution” (65). The author explores their subjectivities and specific situations where clowns either support the work of medical staff or the “patient’s work”. In the former case, medical staff members might call them to distract patients from medical interven-

tions; in the latter, they may initiate coping strategies and individual support for the child’s control of emotions such as fear and sadness. Accordingly, “clowns must learn the technical work, but they also must learn how to manage an unstable environment in which they must have the appropriate gestures” (66), linking “their performance to an exploration and understanding of their environment” (67). However, by presenting a case study, the author also reflects on the positionalities and subjectivities of researchers in hospital ethnographies and how their work may transform them. In her case, the clowns helped her by integrating her into their performances but also by transforming her perspectives on her research topic.

In chapter 5, SYLVIE FORTIN & JOSIANE LE GALL (Prolonging Life or Envisioning Death) direct our attention to another emotionally challenging context of pediatric care. It “was inspired by an encounter with a young man, at the end of his life” (81) and decision-making processes among the medical staff and his parents. The decision in question is when to stop with curative and begin with palliative treatments. The contribution thus (in the reviewer’s opinion) questions the contemporary biomedical practice of “furthering life at all costs” (82). The setting is a Canadian clinic for pediatric hematopoietic transplants where “different subjectivities are played out, modulating clinical practice, therapeutic relationships and finally, end of life care” (83). The authors describe decision-making spans “from a paternalistic perspective where the physician plays a leading role to an autonomist model, where the patient and their parents [...] take a leading part in care decisions” (84). They introduce the model of a partnership that promotes new configurations of therapeutic relationships in which patients and families develop expertise. However, in the context of the case study, it appears that families’ decisions either contradict medical expertise or put their hope in ever-new technologies and unnecessarily extend suffering. It is not necessarily the authors’ opinion but the reviewer’s impression.

Chapter 6 takes SABRINA LESSARD (If I Understand Correctly, You’re Waiting for One of Us to Die?) to another context regarding end-of-life discussions and deserves my full respect for publicly addressing the ongoing problem of what I would like to call the obligation to live. It also relates to

the Canadian context but addresses “the issue of dying with dignity” in elderly care. It further reflects the researcher’s ambiguous positionality in the field, located between personal empathy, the feeling of being voyeuristic, and the need for data collection: “The scenes I witnessed reminded me to overcome the urge to flee the suffering of others or turn them into spectacle” (101). The author shares her disorientation in the field, dealing with end-of-life situations, death, and the social and medical implications of “deliberating on extending life or choosing death” (104), particularly when patients are prevented from dying:

Their deaths were stretched out over time. The medical care they received was so effective that they could only die if their bodies didn’t respond to treatment [or] [...] if they said a final no to this culture of ‘you shall not die’. [...] I belong to a society where it is wrong to die (105).

Again, I feel myself reminded of COVID-19-related health policies where basic human rights have been dismissed for the sake of the government of life.

Section III (Negotiating Subjectivities: Body, Substances, Biopolitics and Health Practices), with three chapters on human-substance relationships, addresses this government-of-life aspect in the management of human affliction. However, even more important for the discussion throughout this edited volume is the question: “Is there a place for agency in the biopolitics framework” (6)?

In chapter 7, SYLVIE FAINZANG (Subjectivities and Semantic Variations Around the Concept of Dependence on Medicines) investigates the lay management of medicinal risks with the example of French patients’ fears of dependence on substances. The author reflects on their subjectivities at the intersection of two oppositions: “one between the subjective and the collective and the other between subjectivity and objectivity” (115). According to her, “discussing subjectivity does not necessarily involve taking an interest in the perceptions/representations/emotions/sensations of an individual. And [sic] therefore, does not necessarily involve only taking an interest in ‘subjective feelings’ [...], but also focusing on the subjective *constructions* of a phenomenon, that are simultaneously bodily, social and existential. Yet

these constructions are not exclusively individual” (116f).

She illustrates divergent discourses beyond the concept of bodily/mental addiction among “objective” medical professionals and “subjective” patients and strategies relating to social constructions of self-control and emancipation. Further, she observes an increasing fear of dependence in France in the last two decades. She relates it to an increasing impact “of Anglo-Saxon models of autonomy and the responsabilisation of the patient” (123).

In chapter 8, NICOLÁS MORALES (Pharmakon, Commodity and Dystopia: Three Approaches to the Pharmaceutical Self in Neo-Communitarian Mental Health) in a more historical and philosophical approach, continues to discuss the relations of patients to pharmaceuticals in the Chilean mental healthcare context. His account navigates from the “most ardent defenders as a panacea for the brain’s chemical imbalance [...] to those who denounce what has become ‘a sedated society’ [...] [and] a fragile balance between the healthy and the mortal” (132). The author explores “the use of psychiatric medications in commodified clinical practice through the commodity fetishism metaphor” (132) and “pharmaceutical imaginaries” in the form of the “pharmaceutical self” and dystopic narratives of large-scale sedation. The chapter contributes to the investigation of the history and critical practices throughout the Chilean dictatorship (including the German Nazi Colonia Dignidad), and more broadly, of psychiatry and community mental healthcare services.

With chapter 9, FRANZ GRAF (Ecological Subjectivity: A Case of Chemical and Other More-Than-Human Sensitivities) returns to anthropological research based on case studies and, at the same time, broadens our perspectives on human relations to chemical substances and other materialities. The author introduces the case of a woman in Britain who has developed a hyper-sensitivity to all kinds of artificial chemical substances (multiple chemical sensitivity) impacting her in an urban modern context and who seeks relief in natural environments and British Paganism. Instead of understanding her individual transformation as a symbolic representation in terms of denying the malcontents of modernity or an alleged nature-culture-antagonism, he focuses on

the emotional and sensory aspects of her experiences. Integrating the theoretical concept of embodiment, he argues that affliction highlights “a specific bodily relationship to the world” (159) and wonders about “the question of agency in the body-world relationships” (159).

Section IV (Mental Health Narratives, Embodiment, Healing Practices and Subjectivities) further investigates these aspects in five chapters, highlighting how illness is not merely the result of a biological imbalance affecting the body or the mind but a subjective experience affecting the life-world. It investigates how subjectivities are perceived socially, medically, religiously, and spiritually and how they may

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 (7).

It further addresses the intersection, and sometimes opposition, of sensory and cognitive aspects of healing, cure, and care.

In chapter 10, SOULA MARINOUDI (Uncharted Sensations: Autistic Subjectivities, Affective Language and Unexpected Senses) outlines related dissonances based on case studies on Autism, or to be more correct, on the interaction of so-called “neurotypicals” with “autistically” classified persons in Greece. Overall, the author stresses the fact of divergent ways of perceiving and interacting with the environment, exemplarily discussing nuances of cognitive/linguistic vs. sensory/bodily interactions and the need for empathy, patience, and goodwill to negotiate and intermediate between these spheres. This contribution, in the opinion of the reviewer, very much corresponds to an earlier issue of *Curare* (see Kurz 2019) on the Aesthetics of Healing but takes a further step: it not only refers to different ways of being in the world but to contexts and processes of mutual understanding and learning of each other, of stepping back from own subjectivities and providing space for the others’. Bridging and integrating experienced life-worlds might not only provide more agency to (alleged) patients but, overall, free them from a disease category and acknowledge divergent self-other orientations.

With chapter 11, ANGEL MARTÍNEZ-HERNÁEZ (The Son of the Tiger Hunter Who Never Killed a Tiger: Myth, Violence and Masculinity in a Life Story) takes a different stance that on an experiential and cognitive level connects individual biographical narratives with provided patterns of myth in a transcultural context. Introducing the case study of a person of Indian descent in a mental healthcare institution in Spain, the author develops a quite symbolical and philosophical argument on the patient’s experience that appears to resemble various Hinduistic, Christian, and even psychoanalytical myths and interpretations, transgressing these boundaries and giving space to individual subjectivities using social/public and mythical/religious representations as a sketch or draft to locate one’s own affliction.

In chapter 12, PATRICIA COCCHI, ISMAEL APUD, JUAN SCURO & ADRIANA MOLAS (Narratives of Violence and Alterity of a Psychonautic Woman) discuss the case of a woman in Uruguay who suffered abuse and mistreatment in both a neo-shamanic spiritual community and a psychiatric clinic. The authors explore her biography starting with her “quest for new emancipatory models against Western materialistic modern life” (219), illustrating experiential and subjective processes of alterity at the intersection of medical anthropology and religious studies. They describe trajectories “related to different health, religious, artistic, and educational contexts, with their own social dynamics and cultural backgrounds” (220). They “analyse how these trajectories impacted her subjectivity, and how the process of subjectivation was not passive, but active and creative” (220). A very interesting aspect is the comparison of sanctioning non-conformity in neo-shamanic groups with their use of psychedelic substances and biomedical psychiatry. In the end, only emancipation from both and following her subjective needs has provided sustained relief.

In chapter 13, DANUTA PENKALA-GAWĘCKA (Illness Experience and Its Translation: The Case of a ‘Shamanic/Healer’s Illness’ in Post-Soviet Kazakhstan and Kyrgyzstan) continues to explore the relationship between shamanism, spirituality, and mental healthcare but on the complementary level of healing cooperation in former Soviet republics. The author focuses on the experience of “ini-

tiation illness”, a recurrent concept in studies on shamanism and other spiritual-religious healing practices, but in a different alignment. She illustrates that different from historical accounts, “[s]uch encounters and revelations often happened after unsuccessful biomedical [and/or psychiatric] treatment” (245). Accordingly, the author investigates how experiences are “translated” from one healing profession to the other, stressing subjective and intersubjective (and intercorporeal) aspects. In particular, she focuses on “the role of experienced healers, mediators between spirits and individuals chosen to become healers, in the process of translation of ‘mental illness’ into the ‘call of spirits’” (247). However, it raises the problem that in contemporary contexts, “the asymmetries in the shaman’s (or another spiritual healer’s) and the patient’s knowledge are much greater” (249) than with biomedical and psychiatric health professionals.

Corresponding to the fact that many authors in this edited volume refer to the concept of embodiment, the final chapter 14 gives the word to THOMAS CSORDAS (*Possession and Psychopathology, Faith and Reason*), even though his contribution refers more to the relation of medicine and religion and the subjectivities of respective therapeutic experts. The author refers to exorcism in the Roman Catholic Church and how exorcists and biomedical / psychiatric professionals of the Catholic denomination cooperate. After providing a historical account of exorcist practices and their regulation by the Vatican, he focuses on the subjective narratives of a Spanish psychiatrist engaging with exorcist explanatory models and practices in cooperation with two priests. He shares three case study vignettes: “The first is a case he ascribed to mental illness, the second to demonic possession, and the third at the time of his narration was still ambiguous and as yet to be determined” (273). The reading of these accounts produces very critical feelings in the reviewer because of the revealed inconsistencies and, from a medical perspective, misjudgments.

In line with the declared orientation of this volume, I, as the reviewer, can only present a subjective evaluation of the several chapters and the overall composition. Some contributions harmonize with my medical anthropological perspectives whereas others do not but still present rich

data to be further analyzed. I want to stress that I enjoyed reading every single contribution of this volume that, in its entirety, negotiates and integrates divergent perspectives on the subjectivity of affliction in medical anthropology and, in its majority, focuses on the agency of patients (apologizes for the oxymoron). The reviewer regards this volume as a delightful and necessary reading for medical anthropologists and therapeutic professionals to overcome their long-standing ignorance toward individual and social aesthetic experiences and evaluations in biomedical/psychiatric health-care, postulating a more empathetic integration of divergent experiences, interpretations, and solutions to human suffering and to-other-than-human relations. It is an essential contribution to the medical anthropology of emotional, sensory, and aesthetic aspects of cure and care. Particularly medical students and health professionals will gain a lot from this impressive composition of divergent accounts of (inter)subjectivities and experiences of affliction in various settings and environments. I further recommend the volume as a textbook in courses of (medical) anthropology, psychology, (transcultural) psychiatry, nursing training, and other health-related professions.

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## References

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