EDITORIAL: UN/MAKING HEALTH: REFLECTIONS ON WELL-BEING

by

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The present *Echoes* issue was inspired by an undergraduate course, "Approaches to American Studies: Health Topics in American Literature and Culture," which I taught to 3rd-year students at the School of English of the Aristotle University during the fall semester of 2018. This course encouraged students to deal with different genres and media, such as fiction, drama, memoir, film, documentary video, and visual art, under the theme of health and wellbeing; parameters of race, ethnicity, gender, sexuality, and dis/ability informed our approach to the various texts/artworks. From Charlotte Perkins Gillman ("The Yellow Wallpaper") and Jack London ("The Law of Life") to William Carlos Williams (*The Doctor Stories*) and Audre Lorde (*The Cancer Journals*); from film (*Philadelphia*; *Gattaca*) to drama (Margaret Edson's *Wit*), memoir (Kenny Fries' *The History of My Shoes and the Evolution of Darwin's Theory*), and several other media (documentaries, paintings, and popular art), this course touched upon health and medicine as rich areas of inquiry in 19th, 20th, and 21st-century American literature and culture: not only did it explore the changing nature of American identity, reflected in the various literary and artistic genres, but it also shed light on the broad spectrum of relationships among individuals and groups within American society.

The range of topics covered was wide and stimulating: the patriarchal underpinnings in the understanding of mental illness in the 19th century; the bioethics of ageism and the cultural dimensions of senicide seen through a social-Darwinist/naturalistic lens; the challenges of healthcare during the Great Depression given through a doctor's perspective; illness/disability and second-wave feminism; civil rights movements and the politicization of patienthood; medical practice and racial discrimination; the social stigma of homosexuality during the AIDS crisis; ethnic identity and its impact on doctor-patient relationship; dystopian prospects of eugenics, genetic engineering, and the role of medical ethics at the turn of the millennium; and the reconfiguration of disability according to the—inclusive and equitable—social model.

Another goal was to familiarize students with the rapidly growing interdisciplinary field of the Health Humanities—a field of studies that explores human health, illness, and disability through the methods and materials of the arts and humanities, including literature, visual and performing arts, film, drama, philosophy and history. Health Humanities studies nurture the capacity to critically approach cultural representations of human illness and its conditioning by society, ideology, and health policies; within the hospital setting and beyond. In the last two decades, Health Humanities has increasingly become a component of medical education, while undergraduate and postgraduate programs have been developed in North America and Europe, addressing students from a range of disciplines, including psychology, neuroscience, biology, languages, law, anthropology, social sciences, literature, and fine arts. Health Humanities reflects and expands on the thriving Medical Humanities field—the intersection of biomedical sciences, the arts and humanities, and social sciences with a clear orientation towards the exploration of the historical, social, ethical, and legal aspects of medical

practice.¹ It offers a more encompassing perspective, though, as it does not only "[align] with medical visions of healthcare" but also, and most crucially so, with "multiple and often complementary contributions to health and well-being which fall outside medicine per se" (Crawford et al. 2). My students had, thus, the chance to explore patients' and caregivers' perspectives as well, and contemplate on the nuanced illness narratives under discussion.

The course ended with an end-of-term project, where students were free to expand on syllabus material and critically explore new texts/artworks, even create pieces of their own, and present them in class. In this way, all participants were able to deepen their understanding on a topic of their choice and broaden their knowledge of the field by being introduced to the subjects their peers had worked on. Thus, critical and creative reflections on: smallpox and its impact on the indigenous population of the Americas starting in the early 16th century and for the next 200 years; 19th-century asylums and their harsh practices in treating mental illness; stigma and the biomedical model of mental illness in the 20th century; autism/mental disability and the debate on the right to parenthood; early-onset Alzheimer's and the challenges of caregiving; quadriplegia and quality of life; doctors' biases and their impact on their relationships with their patients and on the quality of treatment; reinvention of the body in postmodern/posthuman art; embodied experience expressed through dance; and American-culture inspired poems, video making as well as reflective drawing were the impressive outcome of these students' first venture into the politics and aesthetics of health, illness, and medicine.

Departing from humans' perennial pursuit of health and well-being and the perception of illness as a threat to the very essence of existence, the central problematic of the course—and of the present *Echoes* issue—boils down to the following question: What is health?

Let us examine the current definition the World Health Organization (WHO) has provided in response to this question. Formulated in 1948, it describes health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1). This definition of health as complete well-being was revolutionary at that time as it overcame the concept of health as absence of illness, which had hitherto rendered the two states mutually exclusive. What is more, the 1948 definition acknowledged the existence of the individual in a psychosomatic continuum, also conditioned by social determinants.

This description, however, poses certain limitations that are to be traced in the rigidity of the word "complete" with respect to well-being. With "disease patterns [having] changed, with public health measures such as improved nutrition, hygiene, and sanitation and more powerful healthcare interventions" and with an increasing number of people living (and ageing) with chronic diseases for decades (Huber *et al.*, 2), the presence of chronic illness or disability blurs the lines between health and illness. Disability, in particular, is now disengaged from the medical model that has reduced this non-normative, nuanced way of being to a mere disfunction that has to be medically fixed. Given the relationship with one's own body and their physical and mental environment alongside the increasing demand for the

Promotion" 662-64.

¹ Anna Whitehead et al., *The Edinburgh Companion to the Critical Medical Humanities* (Edinburg UP, 2016); Victoria Bates et al., *Medicine, Health, and the Arts: Approaches to the Medical Humanities* (Routledge, 2015). ² See Huber et al., "How should we define health?" 343:d4163; Sartorius, "The Meanings of Health and Its

disabling of biases and discriminatory policies, as the social model of disability suggests, one is capable of living a fulfilling life despite the presence of impairment.

A new definition of the term encompassing "the human capacity to cope autonomously with life's ever changing physical, emotional, and social challenges and to function with fulfilment and a feeling of wellbeing" even with a chronic disease or impairment (Huber *et al.*, 2) is, therefore, deemed necessary.

One of several suggested definitions that was adopted for the purposes of the course and the present issue comes from Norman Sartorius. Health should thus de defined as

a state of balance, an equilibrium that an individual has established within himself and between himself and his social and physical environment. . . . This means that those with a disease or impairment will be considered as being healthy to a level defined by their ability to establish an internal equilibrium that makes them get the most they can from their life despite the presence of the disease. Health would thus be a dimension of human existence that remains in existence regardless of the presence of diseases, somewhat like the sky that remains in place even when covered with clouds. (662-663)

In pursuit of such a sense of equilibrium, the students' reflections compiled here swarm around notions of health and well-being, of shifting perspectives and new trajectories as personal resources and coping capacities rise and fall, calling for pliability in order to restore one's inner balance and sense of well-being.

In the "Mad Look of Love," Sofia Skeva draws inspiration from the graphic novel supervillain Joker and his contested personality to capture in her drawing his controversial relationship with his psychiatrist Harley Quinn, and thus reflect on the muddled boundaries between sanity and insanity, good and evil, the "normal' and the "other"; the unsettling of roles between doctor and her patient and the doctor's loss of control; and the social stigma attached to the mentally ill, conveyed through the expressionistic details of her drawing.

In his poem "Psychomare," Aristeidis Kleiotis ruminates on the impact traumatic life events have on an individual's inner state and the struggle to cope with mental challenges and restore equilibrium. The rich intertextuality of his poem, echoing the works of Sylvia Plath and Lana Del Ray, as well as his experimentation with color symbolism and confessional poetry, render his piece a textured narrative of loss and restitution of the self; by relating his fragmented story, not only does he attempt to put its pieces back together and reach a deeper self-awareness, but he also hopes that others struggling with mental issues will find solace in it.

Vasiliki Kaditi's "A dance story" is an original choreography which also reflects on personal trauma. It narrates her own journey through health challenges, a numbing of her limbs in particular, which persistently eluded diagnosis and drained her from her ability to put thoughts and feelings into words; fear had deconstructed her linguistic deftness. She then recounts the fluent, spontaneous bodily vocabulary she discovered once she began to express herself through dance. By substituting words with movements, she observes, she rediscovered her body's expressive capacity and restored her optimism.

This *Echoes* issue on health and well-being closes with Mirsini-Anna Boni's poem "Could I?" and its focus on relatedness and empathy as a way of restoring balance. Its episodic structure and limited perspective on the disparate characters and situations it brings to life capture the complexity of human emotions and the unsettling effect the outside world may have on our inner organization. Here, the concept of health acquires collective proportions; it suggests a relational way of being which is essential to our ability to evolve not only as individuals but also as parts of a larger societal organism. Strewn with evidence on the devastating effects of biased thinking and ensuing stigma and the way they affect one's mental health, the poem points to the significance of empathic understanding of the other as intrinsic to humanity and as the path towards self-acceptance and wholeness.

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