Book review: ‘Illness as many Narratives: Arts, Medicine and Culture’

The book:

There could be no stronger sign of the coming of age of the critical medical humanities than Stella Bolaki’s Illness As Many Narratives. A piece of artistry as deft, intricate, and steadfastly complex as the astonishingly diverse range of artworks presented within it, Illness As Many Narratives at last moves us well beyond the canonical confines of what we might now start calling ‘first-wave medical humanities’. This book troubles the assumptions, privileges and discursive structures of the first wave, yet all the while preserves complete fidelity to its core project of ‘writing back’ to medicine-as-dominant-paradigm.

Bolaki’s opening position is a deceptively simple one: it is to ‘decentre’ the literary form as the paradigm for understanding narrative in health and medicine, and to explore what opens up when the multiplicity of artworks that have narrative elements are included. Illness As Many Narratives is a set of close studies of photographers and their photographs, artist books, performance art, theatre, collaborative film and animation, twitter poetry and more. The formal attributes of this array alone disrupt the smooth genre conventions of realist fiction and autobiography that have been paradigmatic for ‘narrative medicine’ – they instantiate all the diversity that the canon had made invisible.

But casting the narrative net widely does much more: it requires us to ask what demands these varying forms make of their equally varying audiences, and what ethical and political questions are raised in and by the works, and in and by academic and non-academic responses to them. In this book, Bolaki sets out to build a bridge between the medical humanities with its interest in pedagogy and in the therapeutic and humanistic value of writing about illness, and literary criticism and its cognate academic disciplines, with their theoretical incisiveness and their appreciation of indeterminacy and complexity. This, she asserts, will require the use of new tools that are actively fashioned for the job, and she proposes one very elegant tool here – a practice that she calls ‘critical interloping’. By juxtaposing and synthesizing otherwise separate practices and approaches, be they artistic or scholarly, critical interloping works in two ways: by inserting a variety of artistic and cultural representations to expand the repertoire of the medical humanities in one direction, and to
model the ways in which arts and arts/media scholarship can expand practices and critical approaches on aesthetics and ethics, and such subjects as the body, disability and death.

Chapters One and Two ‘stage’ a conversation between and across the works of photographers and writers with breast cancer, enabling a full and non-reductive embrace of the contradictions embedded in the visual culture of breast cancer. Exploring the questions asked by images of scars and breasts, revealed or hidden, present or absent, Bolaki can follow the politics of breast cancer in one direction, and the theory and politics of representations of the female body in the other. In the next chapter, she magically transports us to the ethics of touch, where breast cancer narrative is given to us anew through the exquisite artist books of Martha Hall. ‘Artists books’ were new to us: handcrafted, ‘part narrative, part object, part performance’ as Bolaki terms them, they may combine fine printing, papermaking (in one, the now-dead bookmaker’s hair is woven in the paper itself), experimental poetry, illustration or conceptual art (or more!), and were instantly evocative and unsettling, as intended. The ubiquity of the image in age of digital consumption is suddenly juxtaposed with an object created for one to one, sensual interaction. Bolaki’s analysis repeatedly asks questions about the ethics of witnessing, the performativity of non-performance art and the demands made on audience responsibility and care: How delicately one must unfurl fragile paper to read hidden words, how one must learn almost to ‘perform’ these books through touch as much as ‘read’ them.

Possibly the tour de force of the book is the middle chapter, which explores the work of border crossing Chicano performance artist Guillermo Gomez-Peña and his transdisciplinary arts collective, La Pocha Nostra. Performance art, with its deliberately provocative and extreme aesthetics, confronts and unsettles medical dominance in relentlessly discomfiting ways. Gomez-Peña’s central focus on the brutal politics of the brown body – in one work, collaborator Roberto Sifuentes is stripped, shaved and washed by a curator as if being prepared for burial, representing ‘the brown body of the universal immigrant’ – and on human rights, democracy and community care. This activist / collectivist vision of health and illness confronts the audience with ‘raw interstices of tolerance/intolerance,’ to further a dialogue on (often violent) intercultural relations, ‘instead of pretending that hollow gestures of sympathy and ‘empathy’ can transform the human condition’ as Gomez-Peña himself put it. Inviting readers to see ourselves as part of Gomez-Peña’s ‘mainstream bizarre’, Bolaki deftly draws us into the globalized world, requiring us to share her protagonist’s struggles and suffering, whether from US border officials, the cage in which he exhibited himself to American audiences, the eliding and suffocating injustices of corporate multiculturalism, or from steatosis, treated in a poorly resourced Mexican hospital. In Chapter Five, Bolaki has a quieter muse about theatre’s capacity to show the ‘messiness’ of the ethics of illness via a critical analysis of ‘Well’.

Chapters Four and Six discuss filmmaking as an intersubjective and collaborative project and the sorts of methodological, aesthetic and political engagements that stories of illness, death, and dying generate. Discussing Wim Wenders’ cinematic handling of director and friend Nicholas Ray’s illness and death in Nick’s Film/Lightning over Water and its attempts (and perceived failure) to adequately respond to the experience of illness and dying, Bolaki juxtaposes aspects of filmic and medical knowledge and practice as a means of challenging and reorienting them in the ways they treat death and dying. Bolaki then puts a new spin on these questions by exploring animation as an unconventional non-narrative form well-suited to capturing radical embodied experiences in Chapter Six, especially experiences of mental distress. The tension between animated documentary’s evocative power and its potential to
objectivise and instrumentalise subjects encourages viewers to reflect on the kinds of identification these films produce.

Failure, testimony, indeterminancy, witnessing, ambivalence, moral responsiveness, the postmodern subject, duality, social justice, the body, authentic enactment – only a very good writer could do justice to the multiple themes that Bolaki asks the reader to retain a grasp on, and fortunately she is an excellent one. The book synthesizes an extraordinary breadth of theory, but remains an accessible and pleasurable read. She may write of indeterminancy and radical uncertainty, but her touch is both deft and assured, while the empathy and respect with which she treats her subjects affords a greater depth of analytic understanding of their work for her reader, while simultaneously provoking questions about how empathy is itself constructed.

Those who would like an introduction to, or updated education in, theoretical perspectives from gender and cultural studies, performance studies and visual arts, will find this book a rich, immersive means to those ends. It will be an oft-reached-for text for scholars who want to explain how and why we should challenge the internal assumptions, genre conventions, models of selfhood, politics and repertory within the medical humanities and ‘arts and health’ more generally. We hope that Bolaki’s book-bridge will also be trodden over (perhaps trampled on!) by humanities scholars.

Illness As Many Narratives is rich scholarship in keeping with the new wave of creative explorations in care, in pedagogy, and in health and illness, a book at last adequate to their demands.

Reviewed by Dr Claire Hooker and Dr Scott Fitzpatrick.

Claire is Senior Lecturer and Coordinator, Health Humanities, at the University of Sydney. Her research and teaching interests are in arts and health and in many of the varied lands of the medical humanities; her recent output includes articles on empathy, dignity, and several concerning risk communication and disease control. Her students explore various aspects of doctors’ experience and workplace relations in health and medicine.

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