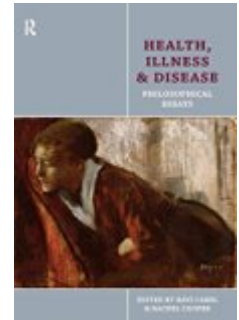


Havi Carel, Rachel Valerie Cooper, eds.. *Health, Illness, and Disease: Philosophical Essays*. Durham: Acumen, 2013. xi + 255 pp. \$75.00, cloth, ISBN 978-1-84465-543-4.



Reviewed by Hannah Tweed

Published on H-Disability (July, 2014)

Commissioned by Iain C. Hutchison (University of Glasgow)

Havi Carel and Rachel Cooper's *Health, Illness and Disease: Philosophical Essays* is the product of a multidisciplinary conference organized by the newly founded Research Networks Council on Concepts of Health, Illness and Disease. Topics of study include connections between disability and chronic illness, the influence of social factors on public acceptance of illness and disability, and the phenomenology of illness, disease, and health. Accordingly, the articles in the Cooper's volume cover a broad range of topics and areas of expertise, drawing on work from within psychology, biomedical research, disability studies, health philosophy, and the medical humanities, and should be of interest to scholars from a variety of disciplines.

The text is structured in three sections. The first, "Concepts of Health and Disease," provides an overview of key philosophical approaches to health, disease, and illness, drawing on work from within bioethics, medical practice, and sociology. It makes repeated reference to naturalistic and normativist approaches to health and illness,

and the work of Christopher Boorse in particular, questioning the feasibility of value-free accounts of illness and disease. The second section, "The Experience of Illness," focuses primarily on the significance and role of patient-orientated analyses of medicine and health. "Illness and Society," the final portion of the volume, analyses socio-political concerns around health, discussing cultural reactions to a variety of health-related topics, from contemporary attitudes to intersexuality to the relationship between health and beauty in Nazi society and medicine. This last section is more eclectically structured than the rest of the volume, but the breadth of topics conveys clearly the interdisciplinary potential nature of the field. Carel and Cooper introduce the collection with a detailed discussion of key questions and debates in health philosophy, and the potential methodological challenges to the field (especially from disability studies). Although at times subject-specific language can present a potential barrier to understanding, this is generally a meticulously

edited and structured introduction to philosophies of health.

In the first essay in the collection, Lennart Nordenfelt outlines two approaches to health and disease: a naturalistic, biostatistical theory of health (BST), and a holistic theory of health (HTH). Nordenfelt unpacks the challenges and problems associated with each position, discussing them against three test cases--grief, pregnancy, and the division between human and animal health. The article provides a clear introduction to these contrasting health philosophies, and while the argument in favor of HST is understated rather than evangelic, Nordenfelt's article provides a useful introduction to key concepts that are returned to throughout this collection--especially for readers who are not familiar with the terminology of health philosophy. In the subsequent chapter, Elsiljn Kingma's contribution furthers this discussion of the role of naturalism and normativism in philosophies of health and illness, proposing "social constructivism" as a possible third option, drawing on material from both camps. Kingma begins by asking fundamental questions for the field--"What is health? What is disease?"--and suggests that within sociology, the accepted claim that "health and disease are socially constructed" has not been analyzed philosophically (p. 37). Kingma unpacks the language surrounding philosophies of health and illness before concluding that the social constructivist viewpoint offers a potential middle ground between naturalistic and normativist approaches, and prompts others to explore further the consequences of that viewpoint. This article makes a particularly interesting crossover with disability studies theory and the role of society in framing and defining disability, and encourages further exploration of the effects of the social constructivist mode on the concept of a disability/impairment social binary.

Focusing on bioethics, Antonio Casado da Rocha and Aranta Etxeberria concentrate on "autonomy-within-illness." They question whether an

individual who is ill or in pain can be considered fully autonomous, and explore how that autonomy may differ from that of someone who is healthy. Within discussions of patient-led narratives or disability studies, this line of enquiry seems problematic, suggesting the possibility that physical atypicality or mental illness limits the authenticity of individuals' choices. Casado da Rocha and Etxeberria make clear that they do not "deny that ill people can be autonomous," stating that "that would be tantamount to advocating an unacceptable return to paternalism" (p. 67)--but they suggest that it remains necessary to acknowledge and analyze the consequences of ill health on cognition and independence. Among several examples, they highlight that people without any current health problems frequently assess the lives of those who are ill as more "unliveable" than the ill people in question (p. 67). This contrasting assessment is also evinced more problematically within clinical contexts, where issues like patient non-compliance (defined as "behaviour incongruent with the treatment plan") can be understood as either an "autonomous refusal of the physician's recommendations" or an indication that the patient's ability to make decisions had been significantly impaired and needs to be managed (p. 70). Yet, as Casado da Rocha and Etxeberria set out, some patients with chronic illnesses may indicate comprehension of their treatment plan, yet appear noncompliant if they are unable to carry out the necessary steps. Such a proposition warrants further attention, and would benefit from more detailed case studies (here included in references), but makes a pertinent comparison with later articles on patient-led understanding of experiences of illness.

In the final article in "Concepts of Health and Disease," Valérie Aucouturier and Steeves Demazeux analyze the concept of "mental disorder," outlining the history of the term, and discussing poorly constructed examples of early terminology--especially the 1973 "round table" debate concerning whether homosexuality should be classed

as a mental disorder. Aucouturier and Demazeux raise several provocative questions about authority and diagnosis, which beg further comparison to contemporary attitudes towards diagnostic terminology; their use of homosexuality as a case study is effective in highlighting the historical problems in institutional language. I would have been interested to see this critique extended into contemporary medical history, perhaps with examples—such as the contentious (if less extreme) rearrangement of the latest edition of the DSM (e.g., the altered classifications surrounding "autism spectrum disorders") in order to extend contemporary relevancy to a well-constructed and socially pertinent argument.

"The Experience of Illness" contains three essays, all of which provide a useful methodological comparison to the essays in the first section of the collection. Fredrik Svenaeus's opening article, "What is Phenomenology of Medicine?," usefully bridges the gap between the conceptualization of illness and personal accounts of ill health. Svenaeus's conception of illness as an uncanny experience, rendering the individual ill at ease in their body, is both interesting and potentially problematic. He describes illness as an experience where the ill body "has a tendency to call for our attention since it is unhomelike in character" (p. 103). This focus on bodily experience, and the focus on the uncanny in particular, introduces a logical contrast between short-term experiences of illness or disease and the experiences of individuals with chronic illnesses or disabilities for whom impairment or the medically atypical may be normal. Svenaeus outlines possible scenarios where phenomenological definitions of illness may classify individuals with chronic illnesses or disabilities as healthy. While he appears to view this contrast as a possible flaw in phenomenological attitudes towards illness, it is a perspective that meshes well with communication from within a number of disabled communities and disability studies criticism. Those areas that Svenaeus highlights as the "blind spots" (p. 111) of contemporary

medicine (embodied experience, disability, social attitudes to medical technology, dying) are all usefully explored alongside phenomenological approaches to illness and invite further study from both medical philosophy and disability studies, drawing on the expertise of both fields.

Angela Woods's contribution, "Beyond the Wounded Storyteller: Rethinking Narrativity, Illness and Embodied Self-Experience," also engages with firsthand experiences and accounts of illness. Woods begins by highlighting the culturally accepted importance of narrative in disseminating knowledge, and the significance of narratorial authority. She then states that her intention is to challenge two "dogmas of narrative: ... the claim that we are narrative selves," and the proposal that the "most healthy way to respond to illness is through narrative" (p. 114). Using Galen Strawson's article "Against Narrativity" as a starting point, Woods argues that the medical humanities' prioritization of narrative is inherently restrictive, devaluing silence as a response to experience, and sidelining the communicative potential of other forms of artistic expression, including music, poetry, painting, and photography. Woods convincingly argues for the potential usefulness of these other forms of expression for individuals who are ill or undergoing medical treatment, and pertinently criticizes the drive towards the oversimplification of illness narratives, particularly "quest stories" (p. 119), as praised by Arthur Frank in *The Wounded Storyteller* (1995). However, Woods does not critique Strawson's analysis of narrative as closely as she does Frank's, and at times, this interrupts the coherency of the article. For example, Woods introduces Strawson's statement that the "narrative tendency to look for a story or narrative coherence in one's life is ... a gross hindrance to self-understanding" (quoted, p. 117), and suggests that narrative is irrevocably connected to a drive for "structure, coherence and unity" (p. 125). She concludes that narrative is thus potentially dangerous to ill individuals, who may be pressured to rewrite their accounts to fit

with a social norm. While these concerns seem valid, Woods and Strawson do not acknowledge the possibility of experimental forms of narrative, or engage with any postmodernist or modernist theory—both of which seem natural companions to any discussion of the limits of realist or overly determined narrative. I also find it problematic that Woods states that haiku, photography, and music do not engage with narrative, and would like to have seen further expansion on that argument. That said, the questions and concern that Woods raises are clearly relevant to the medical humanities community and should prompt further discussion.

Continuing the analysis of patient-led narratives, James Brennan explicitly focuses his discussion of accounts of adjusting to cancer on the contrast between realist and phenomenological narratives, including extracts from seven different cancer diaries. He proposes a "biopsychosocial ... model of adjustment" (p. 129) which draws on ideas of disease as a medical state, featuring physical abnormality, while ill health is equated with lived experience. Brennan offers David Seedhouse's definition of health as "equivalent to the set of basic conditions which fulfil or enable a person to work to fulfil his or her realistic, chosen or biological potentials" (p. 133), and focuses on sociological concepts of quality of life and disability studies approaches to impairment in order to analyze how people adjust from health to illness, and from illness to health (with disease a secondary consideration at each stage of development). This discussion makes for a pertinent comparison with the neighboring essay, which focuses on personal and social definitions of pain. Elisa Arnaudo's "Pain as Illness" posits that in Western culture, "pain is a medical problem" (p. 143), defined by charts and comparisons that originated within a medical framework. Arnaudo summarizes key ways of assessing pain levels before analyzing how contemporary medical practice and research handles pain, especially when it is classified as a chronic disease. Rather than relying sole-

ly on the definition of chronic pain syndrome as a psychosocial disorder, Arnaudo suggests that analyses of chronic pain should include the affected individual's lived experience, detailing several studies and accounts where the sense of being ignored was a significant contribution to patients' experience of "suffering" from pain" (p. 155).

Melanie Newbould opens the final section of *Health, Illness and Disease* with an article on the pathologization of intersexuality. Summarizing the changing medical and social treatment of intersex babies (and adults), Newbould offers a detailed history of intersexuality, explicitly avoiding the most contemporary medical definition of "disorder of sex development" (p. 161) because of the discriminatory associations of the phrase. Newbould uses intersexuality to illustrate the medical and social problems of naturalistic approaches to health, which would classify intersexuality as a disease based on its statistical atypicality, and discusses the psychological consequences of this approach for intersex individuals. She presents a cogent and compelling argument that the majority of medical interventions (particularly early interventions), while well-intentioned, ironically emphasized individuals' sense of abnormality. Newbould draws a clear distinction between the hormone deficiency that comprises one element of congenital adrenal hyperplasia (CAH)—which has serious, potentially life-threatening consequences if left untreated—and atypical genitalia. She classifies the former as a disease, but not the latter, challenging and cross-analyzing historically dominant medical discourse. While Christopher Boorse et al. propose that a naturalistic approach to medicine is value-free, Newbould's argument demonstrates how social influences render that ideal realistically impossible and outlines how social concepts of gender have consistently overlapped with clinical approaches to intersexuality. Examples of the latter include assessing whether an individual has an "adequate" or "inadequate" vagina—where adequacy is dependent on the ability to have heterosexual intercourse. Newbould concludes by ana-

lyzing the Gender Recognition Act, 2004 (England), which formally separates concepts of sex and gender. Following on from the systematic analysis of medical terminology, her conclusion begs the question of whether legal language can be any more successful than medical language in creating value-free terms.

In "Stigmatizing Depression: Folk Theorizing and 'The Pollyanna Backlash,'" Charlotte Blease analyzes the significance of sociocultural pressure on individuals with depression. Despite the prevalence of depression, Blease outlines the continued and widespread bias still attached to the condition. Questioning why depression, in particular, is publically stigmatized, Blease suggests that a "folk model" of cognition, where people instinctively attempt to "uphold a core common-sense set of optimistic beliefs about the world" explains the backlash against depression (p. 181). She posits that people want to believe the best of their circumstances and when an individual challenges that worldview, they are ostracized--sometimes instinctively--to protect the optimistic philosophy of others. I would suggest that if one is to apply this "Pollyanna Principle" (p. 190) as an explanation for the discriminatory language surrounding depression (even, in some cases, by those with depression), then it could also logically be applied to other forms of illness and even disability, rooted as it is in fear of the abnormal. Such a possibility invites further exploration, particularly with regard to the idea of being "temporarily able bodied." This concept is especially pertinent given the penultimate essay in the collection, Britta Pelters's "Doing Health: A Constructivist Approach to Health Theory." Pelters focuses primarily on healthy women who are classified as being at high risk of developing breast cancer, introducing terms such as the "healthy sick" and the "unpatient" to summarize the position of women who have been identified as having BRCA1 or BRCA2 genes, and linking back to earlier discussions in the volume about contrasts between experiences of illness and asymptomatic disease.[1] Including

a variety of extracts from interviews with BRCA-positive women, Pelters explores this ambiguous zone of health and potential disease, and the psychological impact it has upon the women in question. As well as offering a cogent account of the variety of responses to a BRCA-positive test result, Pelters's study also prioritizes constructivist approaches to health over either holistic or naturalistic models. Pelters demonstrates that neither of the latter are appropriate to the experience of asymptomatic (and currently disease-free) women, who are faced with changes to their lived experience because of a serious and monitored future threat to their health.

The final article in the collection has a more specifically historical focus. Sophia Efstathiou's "Beauty and Health as Medical Norms: The Case of Nazi Medicine" offers an analysis first of the use of beauty and idealized aesthetics in Nazi propaganda, and then of the eugenical consequences of those philosophies. Efstathiou highlights both the progressive elements of Nazi medicine--the campaigns encouraging healthy eating, early research into links between smoking and cancer, and the ensuing anti-tobacco adverts--and the discriminatory processes by which they classified and targeted those who were considered "unfit" (p. 220). In doing so, she outlines both the validity of references to Nazi "medicine"--which did aim to "secure health and cure disease" (p. 226), despite associated, morally repugnant actions--and stresses the continued relevance of such research. As Efstathiou states, medicine can still be framed by discussions of beauty and the ideal (such as the valorization of the "norm"), and is thus open to social and cultural manipulation. The few contemporary examples that Efstathiou offers of public discomfort with disabled bodies (reactions to *Alison Lapper Pregnant*, and the late introduction of and mixed reactions to the Paralympic Games) give added social relevance to her discussion of idealizations of beauty and aesthetics. Within popular

contemporary culture and media, additional comparisons abound, and invite further analysis.

In conclusion, *Health, Illness and Disease* presents an eclectic but rigorously structured selection of essays on a variety of connected topics. These philosophical reflections on and challenges to accepted and new conceptions of health, illness, disease, and disability are clearly relevant to contemporary discourse in the medical humanities, and Carel and Cooper's volume is a useful resource for disability studies and health philosophy scholars alike.

Note

[1]. A. R. Jonsen, S. J. Durfy, W. Burke and A. G. Motulsky, "The Advent of the 'Unpatients,'" *Nature Medicine* 2, no. 6 (1996): 622-24; and C. Scholz, "Biographie und molekulargenetische Diagnostik" [Biography and molecular genetic diagnostics], in *Welche Gesundheit wollen wir?* [Which health do we want?], ed. E. Beck-Gernsheim (Frankfurt: Suhrkamp, 1995), 33-72.

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Citation: Hannah Tweed. Review of Carel, Havi; Cooper, Rachel Valerie, eds. *Health, Illness, and Disease: Philosophical Essays*. H-Disability, H-Net Reviews. July, 2014.

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