

Review of Heidi M. Altman's *Agency and Bodily Autonomy in Systems of Care* (Lexington Books, 2024)

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Agency and Bodily Autonomy in Systems of Care, edited by Heidi M. Altman (2024), weaves an impressive international tapestry to raise awareness of intercultural factors that restrict or eliminate agency over one's body in systems of care. It is not often that a book seamlessly strings together stories of people from such seemingly diverse walks of life, including fishermen in the coastal states of Georgia and South Carolina in the U.S., patients in an Italian psychiatric hospital, and people who are deemed overweight in Japan. The merit of the book is that it delivers more than an opportunity for the reader to vicariously visit with different people and places. It ultimately points out the common denominator of the different groups of people it studies, which is their "minoritized social location" (p. 103) as people whose bodies do not meet their societies' normative expectations and are, therefore, subjected to control. This control may be applied in different ways, but it always demonstrates the fundamental premise of the book, which is Michele Foucault's view of "the human body as an element under the control of outside structures, whether they be carceral, military, or medical" (p. 15).

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The book is a collection of seven essays, focusing on "individuals who submit (or refuse to submit) to medical institutions where their agency is curtailed or usurped" (p. 19). However, I would argue that the essays offer a more complex analysis of how the restriction of agency works. In some of the cases, personal agency and bodily autonomy are restricted through the institutional structures of the systems of care, whereas in other cases, they are restricted through internalized social norms that cut off individuals from the care they need. Sometimes, these external forces collude.

In Chapter 1, Jacqueline Berger reviews and examines how the remains of patients in the San Niccolò Psychiatric Hospital in Siena, Italy have been historically used. This chapter provides the clearest case of institutional violation of bodily autonomy. The treatment of corpses may at first seem to be relatively harmless, since it does not impact quality of life. But, as Berger explains, for Catholic patients, the dismemberment of their corpses constitutes the violation of a sacred belief in the possibility of resurrection and eternal salvation. Often, the corpses used for medical research belonged to patients who were committed to the hospital because of mental illness and had, therefore, limited agency over their bodies in their lifetime; this limited agency enabled further violation of their bodily autonomy after death.

Chapter 2, written by Anne O. Odusanya, focuses on children—especially children and youth with special healthcare needs (CYSHCN). As Odusanya points out, while all children are dependent on adults for care, CYSHCN "require health and related services of a type or amount beyond that required by children generally" (p. 61), yet many do not have access to the healthcare they need. To qualify for the care available, CYSHCN are diagnosed based on a "five-item screener" that assesses a wide range of needs, from use of prescription medications to need for special therapies (p. 62-63). Yet healthcare providers often present a barrier to healthcare due to "lacking knowledge of disability, not providing appropriate accommodations, eliciting implicit bias, assuming children with disability have a low quality of life, and displaying apathy" (p. 63). Thus, the application of medical criteria is significantly impacted by the cultural assumptions of the healthcare providers.

Chapter 3, written by Cindi SturtzSreetharan, examines how cultural shifts impact biomedical models by which the health of the body is measured and lead, in turn, to the internalization of negative messages about one's character. It focuses particularly on Japan, a country which "boasts one of the lowest adult obesity rates in the modern world" (p. 80) and where large bodies, therefore, occupy a particularly minoritized social location. The chapter focuses on health policies that target large bodies under the guise of "protecting people's health" (p. 80). Implementation of the policies depends on the definition of the healthy body, so

SturtzSreetharan takes a close look at both the language and the criteria the government uses to identify or diagnose problematic bodies. The most insidious of them—because it carries the cachet of scientific credibility—is the term “*metabo*” which is often used in place of the word “obese” and literally means “metabolic syndrome.” According to this biomedical model, metabolic syndrome (or MetS) is “understood as a condition that combines the measurement of visceral fat (as determined by BMI, hip, and waist circumference) with high blood pressure, high blood sugar, and abnormal lipid metabolism” (p. 83). To monitor these values in its citizens, the Japanese government relies on employers who require their employees to submit themselves first to annual check-ups and then to “guided health interventions” if they test at risk for *any* of the factors, such as a BMI greater than or equal to 25. While there is no consensus in the medical community as to the value of BMI as a health indicator, adherence to these strict body measures in Japan is tied to employment, which increases the pressure on individuals to try to conform and significantly reduces their agency over their own bodies. As one of the subjects SturtzSreetharan has interviewed says, “I wish people would leave me alone” (p. 91).

Individual freedom, especially from government control, is fundamental to the American constitutionally protected principle of “life, liberty, and the pursuit of happiness.” Yet the next two chapters puncture this illusion of autonomy by showing how coercive control is sometimes exercised through the internalization of the dominant culture. Chapter 4, by Stacey W. Smallwood and Dorcas Ama Adom, examines the barriers to accessing PrEP, “a medication that lessens the risk of contacting HIV through sexual intercourse or drug injection” (p. 100). As Smallwood and Adom point out, many “public health interventions are developed with the expectation that various publics will automatically gravitate toward them based on novelty and the support of an authoritative, often governmental, voice” (p. 103). However, these approaches underestimate the cultural factors at play and can lead to underuse among the populations that need them the most. For example, “men and women in the South accounted for 52 percent of US HIV infections in 2017,” but “only 27 percent of PrEP users were from the southern parts of the United States” (p. 103). A powerful barrier to access is the stigma associated with the use of PrEP, which is not limited to clinical settings, but is often rooted in social attitudes. As Smallwood and Adom explain, PrEP stigma can take many forms. For example, those who need it may be afraid that they will be misidentified as people who live with HIV, or they may be concerned about being perceived as individuals who engage in risky sexual behaviors (p. 105).

The impact of internalized stigma on personal agency is also evident in Chapter 5, authored by Jennifer Sweeny Tookes, Tracy Yandle, and Bryan Fluech who examine what impedes access to healthcare among fishermen in South Carolina and Georgia. Through personal interviews, the chapter paints a harrowing picture of the injuries sustained not only by the fishermen themselves, but also their children and spouses. And yet, most fishermen forgo health insurance and rarely seek medical assistance, even when family members are injured. In one particularly startling account, when a child loses part of his finger, his father wraps it up with a dirty deck rag and duct tape, tells him he doesn’t need that part of the finger for shrimping, and continues with the trip instead of turning around to seek medical help (p. 138). It is striking that all of these stories are told in a seemingly nonchalant way, as if they were just a fact of life. They are often accompanied by a shrug or an off-hand comment such as “[j]ust

one of those things you have to deal with” (p. 133). As Tookes, Yandle, and Fluech point out, fishermen “consent to pain and suffering as evidence of dedication to their profession” (p. 138) and see refusing medical care for their injuries and chronic pain as “an opportunity to perform a type of masculinity that refuses to acknowledge pain” (p. 139). They are “fiercely independent and resist efforts to encroach on their autonomy” (p. 138), especially efforts that take the form of government regulations. However, the traditional construct of masculinity they have internalized is part of “the health assemblages”—i.e. social determinants of health—that restrict their agency when it comes to providing their bodies with the health care they need.

The interaction between institutional structures and social determinants of health is also evident in the last two chapters, which examine, respectively, the restrictions in agency during breastfeeding and maternal healthcare. Chapter 6, written by Cassandra White, looks at how the internalized stigma of breastfeeding combined with discouragement by medical professionals, especially pediatric dentists, prevents the normalization of extended nursing as recommended by the American Academy of Pediatrics which supports continued breastfeeding “as long as mutually desired by mother and child for 2 years or beyond” (qtd. in White, p. 149). The interviews White has conducted show that what is desirable to the women often conflicts with what is medically or socially prescribed.

The last chapter, co-authored by Heidi M. Altman and Tobi Oloyede, is likely to particularly resonate with women who have experienced traumatic pregnancy and childbirth. As Altman and Oloyede’s analysis shows, the trauma is rooted largely in the lack of knowledge of and agency over one’s body during pregnancy and childbirth. The Georgia women Altman and Oloyede interviewed recount feeling not seen or heard by their doctors or having doctors make impactful decisions for them—such as inviting all family members into the delivery room while the patient is still being treated (p. 184). But what’s particularly striking is that even after their hard-gained knowledge, some women, much like the Georgia and South Carolina fishermen described above, struggle to acknowledge their experience and to assert agency of their bodies because they cannot reconcile their will with the gender constructs they have internalized. The fishermen recount breaking various bones and parts of their bodies, but they refuse to acknowledge the pain in order to perform masculinity in culturally acceptable ways. The women Altman and Oloyede interviewed describe several no less harrowing injuries they have suffered during childbirth, yet at least one of them, Helena, struggles to acknowledge them as bodily harm. As she says, “I don’t like to call it breaking my body because it is what we’re meant to do, and I don’t think that’s conducive to my message of being pro-life, but, secretly, I don’t really want to break my body again” (p. 183). The fact that she perceives her instinct to protect her body from further harm as contradictory to her pro-life stance can only be explained by an internalized model of femininity that not only rewards, but also demands self-negation.

It is difficult not to notice that the same gender construct that denies women in Chapter 6 agency over their bodies is used to help women in Chapter 5 assert their bodily autonomy. While Helena in Chapter 6 is reluctant to acknowledge that she does not want to get pregnant again because she believes “it is what we’re meant to do” (p. 183), Anna in Chapter 5 finds it comforting and encouraging to know “*that a woman’s body is meant to do that*” (p. 178, emphasis in original). The belief “empowers” her to breastfeed even though she does not enjoy it. This may at

first appear contradictory, but the common thread of all essays in this book is that they invite readers to recognize the veracity of Foucault's premise that "the body is an element under the control of outside structures" and consider what those outside structures are. Perhaps the greater merit of this collection lies not only in the insights each article provides, but also in the questions it raises and invites the readers to pursue.

References

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