

Who speaks for whom? Health humanities and the ethics of representation

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ABSTRACT

The medical or health humanities are in essence a form of advocacy, a means of addressing a problem of underrepresentation. They focus on suffering, rather than pathology, and on sociocultural understandings of illness and disability, rather than a narrow biomedical perspective. The health humanities thus analyse and attempt to recalibrate the power imbalance in healthcare. This article reviews health humanities scholarship that addresses underrepresentation through the analysis of illness and disability narratives. It examines the ethics of representation by exploring how literary representation functions, its aesthetic as well as political dimensions, and how it operates as a relay mechanism for power. The mechanism of representation is further explored through a reading of Eli Clare's narrative *Exile and Pride*. Donna Haraway's notion of *articulations* is proposed as a tool for a more ethical approach to representation. The article suggests that transparency about the power health humanities scholars stand to gain through representation may contribute to a more ethical health humanities practice.

Definitions belong to the definers—not the defined.

—Toni Morrison, *Beloved*¹

INTRODUCTION

Who speaks for whom, and how is the other represented? The medical humanities, or, in a more inclusive configuration, the *health* humanities, are in essence a form of advocacy. Focusing on suffering rather than pathology and recognising the social determinants of that suffering, the health humanities advocate on behalf of the person who seeks healthcare and whose biological manifestations of illness and disability may be addressed by healthcare but whose psychic and social suffering are not. I am using the term *health humanities* deliberately here to more fully recognise professions other than medicine and to recognise the authority of non-professionals, patients themselves and their intimate circles of support and care. Scholars and educators such as Paul Crawford and colleagues have theorised this revision of terminology and its democratising agenda, seeing it as part of the evolution of the field of the medical humanities.² The terms may mean different things to different people, and the debate about terminology is beyond the scope of my analysis here. I am using *health humanities* to signify a field that includes but extends beyond the scope of the patient-provider relationship, while recognising the significance of the work done to address power,

ethics and interpersonal complexities within that dyad. Much of the medical humanities' focus has been trained on the experience of the individual—in pointed opposition to biomedicine's focus on diseases, disorders and populations—and this discipline has emphasised narrative as a necessary and neglected dimension of data.^{3–8} The need to represent those who had not been represented, or not represented fully enough, led to the emergence of a field in which literary representations (and literary critical analyses) of illness, disability, healthcare and dying became required texts for clinicians. Narrative in general is a significant aspect of this approach, and some health humanities scholars deliberately focus on first-person accounts written by people who are disabled or chronically ill, rather than on representations of clinicians or clinician writing.^{9–19} Making these autobiographical texts central to theory and pedagogy is a way of advocating on behalf of the authors and the categories of people they represent, those who have less power and privilege in the clinical setting and in society because they are ill and disabled and may have other marginalised identities or social conditions.

REPRESENTING THE PATIENT THROUGH NARRATIVE

To provide some examples of the way the health humanities represent the underrepresented patient, it makes sense to begin with sociologist Arthur Frank, whose groundbreaking work, beginning with his 1995 book *The Wounded Storyteller*,²⁰ helped forge the discipline. This book challenges the paradigm in which seeking medical care involves 'a narrative surrender' to a medical narrative of illness (p. 6) and offers an alternative paradigm in which people's stories of illness are no longer secondary to the medical narrative "but have their own primary importance" (p. 7). The patient and her or his illness narrative continue to be central in Frank's more recent work, as is his emphasis that "the medical history is not the ill person's story" (p. 15).²¹ Frank insists that healthcare must involve a sociocultural approach (eg, one that recognises the stigma associated with certain kinds of illness) rather than a narrowly biomedical approach to achieve the fullest sense of healing. The health professionals who cared for Frank when he was ill "suffered from an illusion—that what they were learning about me [by taking a medical history] was equivalent to knowing me as a person" (p. 15). Without knowing him as a person, his health professionals were incapable of helping him to heal, in terms of his psyche and identity as well as in terms of physiology. Frank sees the health humanities as offering a remedy for this gap in



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understanding. He sees “the humanities as therapeutic” (p. 17), as capable of facilitating a “narrative therapeutic” (p. 20) by enabling the prompts for patients’ stories and by “offering appreciations that reinforce aspects of the selves displayed in storytelling” (p. 21). To address medicine’s tendency to depersonalise and biomedicalise the patient, Frank represents the patient by facilitating her or his narrative authority and expertise and through his recognition of published accounts of illness and disability as expressions of identity sustained in the face of crises.

REPRESENTING THE PATIENT IN CONTEXT

Health humanities scholar Susan Squier²² also critiques medicine and its tendency to biomedicalise patients, suggesting that the “lack of awareness or ignorance in medicine...can be remedied by the medical humanities” (p. 334). Observing that “medicine too often has a narrow conception of the patient’s identity” (p. 337), Squier argues that, “In its increasing focus on positivist measures, biomedicine has not been fully able to grapple with those aspects of experience that can’t be expressed in scientific or quantitative terms” (p. 335). Squier takes as a starting point the argument for the importance of the patient’s narrative in the healthcare encounter and for clinicians and healthcare educators to study narrative accounts of illness and disability, but she moves quickly beyond the personal to the social. In her discussion of two book-length graphic narratives of cancer (Brian Fies’s *Mom’s Cancer* and Harvey Pekar’s and Joyce Brabner’s *Our Cancer Year*), Squier challenges the health humanities, as well as healthcare, to more fully represent patients by rejecting a tendency to take an instrumental or mimetic approach to literary texts. She critiques a tendency to reductively represent medical procedures and practices in literary texts, especially those used in healthcare education. Squier describes as a problematically narrow ‘mimetic’ approach to health humanities, which looks to literary representations that can illustrate a ‘preselected’ medical issue, thus implicitly endorsing the medical frame (p. 338). According to Squier, rather than focusing exclusively on texts that represent specific aspects of medicine, a tendency that often neglects representation of the larger sociocultural context of health and illness, health humanities scholars should work towards an epistemological expansion: representation of “the social and political threats to human health” (p. 342) and the intersubjective nature of illness, in addition to attending to the experience of the individual who suffers.

Through the comparative analysis of the two graphic narratives that follows, Squier distinguishes between narrow and expansive representations and epistemologies to propose a more ethical practice of health humanities scholarship and education. She identifies *Mom’s Cancer* primarily as a ‘conventional narrative’ that explores a family’s experience of cancer but does not expand far beyond the ‘medical frame’, focusing on a narrow notion of patient autonomy and treating social issues as extrinsic to the treatment and even experience of cancer. For Squier, *Mom’s Cancer* fails to challenge medicine’s authority and thus fails to fully represent the patient in an expansive, and thus ethical, sociocultural context. Pekar and Brabner’s *Our Cancer Year*, on the other hand, displaces medical authority and patient autonomy in its interweaving of Pekar’s and his partner Brabner’s stories about his cancer (which is redefined as ‘our cancer’) with the stories of the gentrification of their urban neighbourhood, Brabner’s relationships with student activists, the first US war in Iraq and the struggles of Pekar’s African-American home health aide (p. 343). Squier observes

how the cancer narrative is intersubjective and interwoven with narratives that illustrate a range of social issues involving race, economics and warfare. For Squier, the health humanities need to move “beyond the walls of the clinic to consider how race, gender, class, ability, ethnicity, and nationality—to name but a few of those mutually imbricated, intersectional identity categories—shape the healthcare we receive” (p. 346). For Squier, it is not enough to simply represent the patient who is ill and seeks treatment. For the representations to fully challenge medical authority—as they are interpreted through Squier’s specific reading practices—they must encompass the sociocultural dimensions of health and healthcare, including complex webs of social relations and social forces.

REPRESENTING THE PATIENT IN HEALTHCARE EDUCATION

Health humanities educators draw on literature and illness narratives as a means of addressing the power imbalance in healthcare by exploring the subjective experiences of patients. Delese Wear has long advocated for the humanities in medical education because they provide “the benefits of perspective...brought about by the content and methods of the humanities inquiry, in particular the perspectives of patients as unique persons living with an illness as only they can, as members of very particular cultures or communities, or as caregivers themselves” (p. 212). For Wear, the health humanities are essential to healthcare education and practice because they embody patients’ perspectives in relation to ‘social, cultural, and political contexts,’ including the US insurance industry, government and the law (p. 212). Similarly, Arno Kumagai’s ‘Family Centered Experience’ programme for medical students at the University of Michigan draws on the premise that literature and the arts—and narrative in particular—as a part of medical education can facilitate students’ moral development and empathy.¹⁷ For Kumagai, “[patients’] narratives have the ability to foster identification with the other” (p. 655). Kumagai’s students read narratives of illness and disability to come to a deeper understanding of those subjectivities that can be obscured by difference (usually difference determined by disability, ethnicity and race, sexuality, gender and class). For Kumagai, the health humanities represent underrepresented identities and perspectives.

In our research and pedagogy, health humanities scholars and educators attempt to speak for the underrepresented, for those who are marginalised in our societies and cultures and in the healthcare setting. We make the experiences of less privileged individuals—embedded within webs of social, political, economic, historical and cultural factors—the centre of attention. However, the role of the advocate involves the recognition of unequal power and an assumption of power. Health humanities scholars and educators need to begin to explore this question of representation, of who speaks for whom. To do this involves first asking a related question: How does representation work?

AN ANATOMY OF REPRESENTATION

In order to examine the degree to which literature is a ‘representation of life,’ literary theorist W J T Mitchell discusses two different but connected understandings of representation: (1) the aesthetic and semiotic (where things, such as words, stand for other things, such as ideas) and (2) the political (where people ‘act for’ other people) (p. 11).²⁴ Literary representation merges the political with the aesthetic and semiotic aspects of representation. Rather than being purely mimetic, an unmediated mirror image of life, literary representation is a political phenomenon, where values and power come into play. Because literary representation involves *play*—creativity and room or

space for interpretation—it cannot fix or control meaning. According to Mitchell, “Representation is that by which we make our will known...and, simultaneously, that which alienates our will from ourselves in the aesthetic and political spheres” (p. 21).²⁴

Representation can facilitate communication, but it can also create a barrier to communication, because creating a representation involves “the possibility of misunderstanding, error, or downright falsehood” (p. 12).²⁴ Representation is necessarily complex, and literature and other artistic forms of representation are necessarily political and ideological, involving life in all its “social and subjective complexity” (p. 15).²⁴ Mitchell further explains that representation is not a thing or an object but rather “a kind of activity, process or set of relationships”. It is the “relay mechanism in exchanges of power, value, and publicity.”²⁵ This relay mechanism is up for grabs through interpretation; it is “an inherently unstable, reversible, and dialectical structure,” and power and value may flow to or drain from either the representation or the represented “but inherent in such an understanding would be the assumption that the power/value quotient originates with the represented, that it has been (temporarily) alienated, transferred, and may always be taken back.”²⁵

THE JAGGED EDGE OF REPRESENTATION

A striking example of this play of power and value within representation—where it is ‘drained’ from the represented and where it is ‘taken back’—is found in engagements with the labels and definitions that represent identities outside the mainstream. The narrative essays of Eli Clare, who identifies as *genderqueer*, that is, neither man nor woman, as disabled, and as an activist whose commitments encompass gender, class, disability and the environment, challenge identity categories through complex renderings of intersectionality. Intersectionality involves “the analysis of the differential ways by which social divisions are concretely enmeshed and constructed by each other and how they relate to political and subjective constructions of identities.”²⁶ Clare, who comes from the rural North-west and has cerebral palsy, as well as presenting as someone of ambiguous gender identity, creates representations of intersectionality in writing about the language used to describe people like him and that people like him sometimes use to describe themselves, to different effects. Clare writes:

I think of the words *crip*, *queer*, *freak*, *redneck*. None of these are easy words. They mark the jagged edge between self-hatred and pride, the chasm between how the dominant culture views marginalized peoples and how we view ourselves, the razor between finding home, finding our bodies, and living in exile, living on the metaphorical mountain. Whatever our relationships with these words—whether we embrace them or hate them, feel them draw blood as they hit our skin or find them entirely fitting, refuse to say them or simply feel uncomfortable in their presence—we deal with their power every day. I hear these words all the time. They are whispered in the mirror as I dress to go out, as I straighten my tie and shrug into my suit jacket; on the streets as folks gawk at my trembling hands, stare trying to figure out whether I’m a woman or a man; in half the rhetoric I hear from environmentalists and queer activists, rhetoric where working-class people get cast as clods and bigots. At the same time, I use some, but not all, of these words to call out my pride, to strengthen my resistance, to place myself within community. *Crip*, *queer*, *freak*, *redneck* burrowed into my body.²⁷

Invoking exile and pride, Clare reflects on the fluidity of representation and shapes the force of stigmatising language in part

by reappropriating it through declarations of pride. Reminiscent of the chant “We’re here! We’re Queer! Get used to it!”—created by Queer Nation and other activist organisations to locate the power of community and connection with allies in the street demonstrations of the 1990s—this sort of repurposing of a slur or epithet into a term of endearment or badge of honour begins a transformation of representation. It is a way of ‘taking back’ a mode of ‘power, value, and publicity.’²⁵ Clare’s analysis reveals the instability of representation in his repeated invocations of a sharp fulcrum or pivot—the ‘jagged edge’, the ‘razor’—which constitutes an uneasy balance over two fields of interpretation: with power and pride on one side and oppression and violence on the other (the ‘jagged edge’ and ‘razor’ can ‘draw blood’). There is danger involved in representation, the danger of unstable channels of power, value and publicity. Given the health humanities agenda of representing the under-represented, the danger also involves misrepresentation, getting the other’s meaning or story wrong or even claiming the power of that story for one’s own purposes or benefit.

FROM REPRESENTATION TO ARTICULATION

Feminist science studies scholar Donna Haraway cautions against a representational practice that transfers power from the represented to the author of that representation, describing the “serious danger of romanticizing and/or appropriating the vision of the less powerful while claiming to see from their positions.”²⁸ This observation suggests a necessary caution for a field that claims to offer access to the perspectives of those marginalised in medical practice and education, as well as an effective means of inculcating empathy.²⁹ Haraway, in a discussion of the politics of representation in relation to environmentalism and conservation, problematises the rhetorical force of a question raised by an environmentalist writing about the Amazon: “Who speaks for the jaguar?” This particular phrasing of the question of who speaks for whom stops Haraway in her tracks. It reminds her of the rhetorical move made by some pro-life groups in the abortion debate. She observes:

Who speaks for the jaguar? Who speaks for the fetus? Both questions rely on a political semiotics of representation. Permanently speechless, forever requiring the services of a ventriloquist...in each case the object or ground of representation is the realization of the representative’s fondest dream (p. 311)...The effectiveness of such representation depends on distancing operations. The represented must be disengaged from surrounding and constituting discursive and non-discursive nexuses and relocated in the authorial domain of the representative. Indeed, the effect of this magical operation is to disempower precisely those—in our case, the pregnant woman and the peoples of the forest—who are ‘close’ to the non-represented ‘natural’ object. Both the jaguar and the fetus are carved out of one collective entity and relocated in another, where they are reconstituted...as the ground of representational practice that *forever* authorizes the ventriloquist (pp. 311–312).³⁰

The drama and rhetorical power of Haraway’s writing here illuminate the high stakes of claims about power and justice at work in representational practices and in our analyses of them. Haraway’s work on the concept of the ‘inappropriate(d) Other’ (which draws on the original formulation by feminist theorist Trinh Minh-ha), that is, the commitment to the agency of the represented, leads Haraway to argue for framing these questions as *articulations* rather than representations. Deliberately choosing to use the term *articulations* is in itself a reminder (in the way that using the term *health humanities* may serve as a reminder for some, at least until we grow used to it) that we

cannot speak for another (or perhaps even for ourselves) except in flawed and potentially dangerous ways, while at the same time accepting the risk of ethical pitfalls to open up channels for understanding and agency. Thus, through *articulations*, or whatever term one chooses to describe or redescribe acting on behalf of another, we might avoid the sort of ‘distancing operation’ that shifts authority from the represented to the representative. By foregrounding the social context, the people and contours of place, and the historical, political and economic conditions that shape that context, we keep the focus on the ‘collective entity’ and the social relations that co-construct the subject of representation.

The disability rights protest slogan “Nothing about us without us!” is a compelling but confounding charge for those working in clinical and academic settings. This notion urges us to advocate for diversity in clinical education and practice (for *self-representation* and *self-advocacy*), but it should not discourage educators and practitioners from addressing the inequities experienced by minority groups, which requires us to advocate for—to represent—the other. The slogan, like Haraway’s coinage of a new term to trigger social consciousness, reminds us to clarify *when* we are *speaking* for others, perhaps calling attention to the problem by recalling the history of objectification inherent in speaking for others. The notion of articulation reminds us to continually question *how* we represent others and who benefits.

NARRATIVE ARTICULATIONS

First-person narratives suggest a complex approach to the question of representation or articulation. In her autobiographical writing, disability studies scholar Nancy Mairs argues that “what is critical is an understanding of the realities disability imposes, and the only way finally to develop the necessary empathy is through knowing disabled individuals.”³¹ Narrative may hold the potential for another way of knowing the realities disability imposes, albeit one more mediated and thus open to losses as well as gains in power and value.^{13 14} The displacement from self-representation—which itself is flawed if one person’s experience is taken to stand for the experiences of others—to mediated self-representation through published narratives, blogs, vlogs, videos, films, images, performances, or zines creates the distance that Haraway cautions about. Writing and teaching *about* narratives (and thus speaking for the author or artist) creates the opportunity for the displacement of authority from the represented to the representative, whether it is the educator or the critic. An *articulation* of another’s experience, then, must involve transparency in terms of the role of the representative. Therefore, and by way of example, I must express to my readers that I do not identify as disabled and thus, in speaking about disability, I risk perpetuating (or in fact perpetuate) the historical objectification of disabled people through my use of the objectifying “articulated or implied third-person ‘they’”, as disability studies scholar Simi Linton puts it.³² Articulation involves thus situating my own knowledge and agency, as well as the conditions of representation at work in any given narrative, for example, revealing the social interests embedded in textual representations, such as the conventions of narrative and the pressures of the book market on published accounts of chronic illness and disability. This is not an injunction against drawing on the power of representation in narratives but rather an injunction to do so with caution and with an awareness that the

power and value of the representation is all too easily assumed or even usurped.

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