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Published

2013

Journal Title

Narrative Inquiry in Bioethics

DOI

[10.1353/nib.2013.0074](https://doi.org/10.1353/nib.2013.0074)

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Commentary

Crafting and Retelling Everyday Lives— Disabled People’s Contribution to Bioethical Concerns

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Conflicts of Interest. The authors report no conflicts of interest.

Abstract: This commentary draws out themes from the narrative symposium on “living with the label “disability”” from the perspective of auto/biography and critical disability studies in the humanities. It notes the disconnect between the experiences discussed in the stories and the preoccupations of bioethicists. Referencing Rosemarie Garland-Thompson’s recent work, it suggests that life stories by people usually described as “disabled” offer narrative, epistemic and ethical resources for bioethics. The commentary suggests that the symposium offers valuable conceptual tools and critiques of taken-for-granted terms like “dependency”. It notes that these narrators do not unproblematically embrace the term “disability”, but emphasize the need to redefine, strategically deploy or reject this term. Some accounts are explicitly critical of medical practitioners while others redefine health and wellbeing, emphasizing the need for reciprocity and respect for the knowledge of people with disability, including knowledge from their experience of “the variant body” (Leach Scully, 2008).

Keywords: Bioethics, Disability, Ethics, Health, Narrative

The stories in this edition of *Narrative Inquiry in Bioethics* offer the reader privileged access to some of the varied experiences of people living with a disability. The essays demonstrate the resources people with a disability offer in terms of knowledge and theory development, as they reframe bioethical debates around concerns central to disabled people’s lived experiences. In this sense, the collection is a departure from biomedical and research paradigms which largely define people with a disability as “other”. In this commentary, we identify the ways in which we believe the writers assert their agency over their own bodies and lives

in the narratives, and comment on the contributions these stories make to the study of bioethics.

Disability Narrative as a Resource

Rosemarie Garland-Thompson in a recent article in *Bioethical Inquiry* argues that the experience of disability offers many resources for not only people with disability but also for others. Garland-Thompson discusses in turn narrative resources (different ways of “storying” life experience); epistemic resources (new ways of knowing through the body); and ethical resources (alternative ways of thinking

about the good life) (Garland–Thomson, 2012). The stories in this symposium underscore the truth of this argument, not only offering powerful accounts of a diversity of experiences of living with the label “disability”, but also developing compelling conceptual frames through which we can understand these experiences.

Eva Kittay (2009) has argued that bioethicists such as Peter Singer—in the habit of making pronouncements about the fates of disabled children—should have a little more “epistemological modesty”, acknowledging the limits of their understanding of the lives and experiences of people with disability. While both our working and personal lives have offered us many encounters with narratives of disability, we are very aware of the need for epistemological modesty. Even as we draw out themes and make connections between these narratives based on our own disciplinary trainings in social work and social policy, media and cultural studies, we acknowledge that these expert accounts don’t merely exemplify or illustrate bioethical ideas but also theorise them. Many of these writers are well equipped, not just by their lives, but by their status as scholars of disability studies, to offer sophisticated abstractions from their own experiences. The specific voices in these English–language written narratives are American and Australian voices, mostly female, often highly educated. Some contributors make similar observations of the need for epistemological modesty in their own stories—Samantha Merriwether for example comments on the difficulty of finding out information about experiences of disability outside Anglophone world. By acknowledging the specificity and limits to understanding disability from the papers presented here, we are also wary of reiterating the illogical message of the letter received by Jillian Weiss: ““Due to the subject’s advanced education, the subject is no longer disabled.”

Bioethics in Everyday Life

One of the most important contributions of these stories is their disconnect from the typical preoccupations of bioethical writing “about” disability. None of the themes that are returned to repeatedly

when bioethicists discuss disability—genetic testing of fetuses; euthanasia and end of life issues; women with disabilities’ control over their own fertility—are mentioned by any of the authors in this symposium. This disconnect between the “bioethics of disability” and disabled peoples’ bioethical concerns has been noted by bioethicists with disability such as Christopher Newell (2006, see also Sara Goering, 2008), and indeed is highlighted within this symposium by Alessia Minicozzi in her account of discrimination and marginalization in her search for employment as a bioethicist. In place of the usual preoccupations of bioethics, the narratives in this symposium instead focus on and analyse what Lorna Hallahan has called “the disabled everyday” (Hallahan, 2009): childhood, relationships, pain, work, changing bodies, identity, technology, discrimination, labelling and misrecognition. Sara Goering argues that “bioethics has typically not been able to understand impairment and limitation, even disability, as a regular part of human life” (2008, p. 128). These stories resituate disability as part of the experience of “regular folks” (Goering, 2008, p. 128).

While they do not directly address typical bioethical concerns, some of the stories here do offer an implicit rebuttal of arguments that emerge from conventional bioethical preoccupations about, for example, “quality of life”. A powerful example is Emily Hutcheon’s refiguring of the notion of dependency. In acknowledging the “exquisite care” of her mother, she tells us of her mother’s response when Emily expresses her fear of being “a burden”: “Em, I will take care of you now, *only* if you change my diapers when I’m old, kay?” This writer firmly resituates “being a burden” as a fear not just of people with disability but of “everyone I know”. She asserts: “I have come to learn that this dependency, along with those other shades of vulnerability, are an inevitable consequence of being human, and to deny this is to relinquish our capacity to connect with others” (Emily Hutcheon).

This analysis recalls Sharon Snyder and David Mitchell’s argument for “the disabled body’s reintroduction as the more appropriate paradigm for a mutable humanity (2001, p. 386). A perspective, like this one, in which dependency is a central

dimension to human existence is deeply challenging to accounts of the self that, as Christopher Newell has said, idealise the isolated individual (Newell, 2006, p. 278).

Emily Hutcheon's argument in this symposium that denying human "dependency" is to disconnect from others points towards a recurring theme in these narratives. Most of these accounts explicitly discuss the social organization and formation of the category of "disability". Jillian Weise, for example, in answering the question "Are you disabled?" responds: "It depends. I need contexts." Gabrielle Hodges describes the "graduated, contingent, and dynamic manifestation of disability" very precisely: "deafness as disability tends to be an emergent characteristic of my interactions with other people, rather than a constant feature of all interactions."

This writer's observation that it is in encounters with strangers that she is most emphatically "disabled" is repeated in many of the stories collected here. Stephanie Birmingham and Douglas Kidd, for instance, offer strikingly similar stories of being approached, to their discomfort, by unfamiliar, religious people who offer to pray for them. Stephanie Birmingham notes, as many other storytellers do, the contrast between her sense of selfhood and the way some strangers see her: "It's still a painful experience when I'm reminded that some people only see me for 'my label'."

These encounters also provide examples from storytellers of how non-disabled people assume that the experience of disability is ontologically intolerable and inherently negative (Kumari Campbell, 2005). The narratives at times serve as a medium for an explained ontology—that is, the authors contest the experiences of being treated as "other" or being objectified. This sharing of everyday lived experiences seems to call on the reader to recognize a shared humanity regardless of bodily differences. As Emily Hutcheon asks: "As opposed to being *something*, can I not just be? Seriously."

Deploying, Analysing and Contesting Narratives of "Disability"

There is not a single narrative in this symposium that unproblematically embraces the term

"disability". Jillian Weiss's mock interview response depicts this shared ambivalence beautifully: "Q: The name *disability* is important to you then? A: It is important. It is very, very important. No, it is not important. I hardly think of it. It vexes me and I need it and I should not say it that often." Other writers view the label "disability" in distinctly performative ways: distancing themselves from the idea that it accounts for them, but at the same time acknowledging the value of what the label "disability" can do. Emily Hutcheon notes, in the vein of much US critical disability studies, what the category "disability" does for non-disabled people: "the category of disability is really a way to neatly manage the notion of vulnerability—to label others 'disabled' is to render one's own body, mind, and even social location, stable and invulnerable." Other narrators note the things that the category "disability" can do in their own lives: provide access to services or early educational interventions, "prime seating at sporting events . . . and front row parking almost everywhere I go" (in the words of John Hermanek). The relationship that several writers here describe with the label "disability" (often kept within querulous quotes) is not one where the label either "fits" or "doesn't fit", although some, like Emily Hutcheon, explicitly refuse that label. Rather it is a relation, which is actively worked on and managed. Samantha Merriwether describes herself "taking ownership" of the label "disability" for instance, despite the fact that "labels are embarrassing". Emily K. Michael advocates "developing a resilience to the commonplace reading" of labels like "disability" and "expanding the space" around them.

The collection of stories here discusses a wide range of experiences for those with "visible" and/or "invisible" disabilities. For example, for the writers with so-called "visible" disabilities, such as Stephanie Birmingham, there is no real choice in the matter of disclosing their disability to others, and for Emily K. Michael, the use of the white cane is considered an "emblem" of her blindness. Both Birmingham and Michael report benefits to being visibly identifiable as a person with a disability, in addition to the many misunderstandings from strangers they encounter. Annette Chacos and Katherine Schneider write about acquiring "invisible"

disabilities alongside their “visible” differences, and being discredited by others as not having a “true” disability. The story by Kerry Magro is an example of someone who grows up with an “invisible” disability of autism, whose impairment was invisible to him until he was around eleven years old. Although all of these stories describe different experiences, it is difficult to make a binary between living with a “visible” or “invisible” disability, because all writers speak of being devalued by others on the basis of their impairment. This discrediting has common elements of stereotyping and cognitive distancing from others into “us and them” categories (Lucas & Phelan, 2012).

These storytellers draw on a range of genres in their writing: Katherine Schneider, Kerry Magro and Annette Chacos’s accounts use quite different variants of a “how to” instructional genre, for example, while some writers with acquired impairments like John Hermanek, and Douglas Kidd offer a narrative that bears similarities to clinical notes with accounts of dates and diagnoses. Some, like Kerry Magro, Alessia Minicozzi, Angela Moore and Emily Hutcheon, tell stories beginning in childhood that evoke the bildungsroman. As writers like Arthur Frank (1995) and G. Thomas Couser (2009) have compellingly argued, such genres, alongside story-types or “emplotments” in Frank’s terms, play a powerful role in shaping what should and can be said, while making other things difficult to say.

Several of these storytellers, we note, engage consciously and critically with the role of narratives around disability in defining identity, often drawing explicitly on the ideas of critical disability studies. Emily K. Michael, for instance, describes the deficit models and tragedy narratives that shape stereotypical understandings of the lives of people with disability. She argues for the importance of “resilience to the commonplace reading” of terms like “disability”. Samantha Renee Merriwether, like Angela Moore, explicitly contests the powerful narrative of recovery, of being “fixed” through medication. She notes the power this narrative offers to “those who are prescribing the treatment” and the way it implies that one treatment should cure a diversity of people. However she also observes a similar narrative of control and cure in her own

way of thinking when she comes to discussing her encounters with disability studies: “For me, finding my ‘authentic voice’ began with this course and, of course I wanted immediate results. This is what I have been conditioned to expect. If I study, then I will get an A. If I take this pill, I will not be in pain.” (Samantha Renee Merriwether)

By drawing on and reworking a range of narrative resources, these writers allow new ways of knowing and describing identities. In particular Samantha Merriwether’s analysis and critique of her own narration recalls Garland-Thompson’s argument that “disability and illness frustrate modernity’s investment in controlling the future” (2012, p. 352).

The Power of Experiential Knowledge

One of the strongest themes across the accounts within the symposium is the knowledges that can be learned from, in Jackie Leach Scully’s term, “the variant body” (Leach Scully, 2008). Stephanie Birmingham describes this idea neatly: “my short stature allows me to see things from a different vantage point (figuratively and literally).” Many of the narrators here remark on the insights offered by their embodied experiences, contesting the authority of medical knowledges over their bodies. Katherine Schneider’s account of her response to being diagnosed with fibromyalgia in her 40s, however, offers a wry corrective to the somewhat utopian accounts of theorists who emphasise the body as a source of knowledge:

The first issue I had to deal with was fairness. Wasn’t one disability my fair share? Why two? I had comebacks ready for comments like, ‘This will make you a better person.’ If that was true, I’d be better already! ‘God will walk beside you in this.’ What about when I’m too tired to walk? ‘You will learn from this.’ Can’t I learn some other way? (Katherine Schneider)

Some of these narrators, particularly those drawing on disability studies and its skepticism about a medical model of disability, choose not to engage with medicine and its languages. Others offer critical accounts of medical and health professionals. Sometimes these stories of inadequate medical care

are explicit and detailed accounts of incompetence or poor treatment—as in the case of Angela Moore’s narrative, entitled “a medical mishap” which emphasises the botching of a procedure undertaken on her as a baby; Douglas Kidd’s description of his brother Richard’s terrible treatment while in a residential aged care facility; and Annette Chacos’ anecdote of being passed over for surgery even as she slipped into unresponsiveness. Other contributions foreground inaccessible clinics or ill-informed or insensitive specialists, or identify professionals who underestimate the capabilities of people with disabilities. Emily K. Michael describes “slippage” in which non-disabled people including medical and health workers slipping from an observation of a person’s specific impairment to an assumption of general incompetence.

Contestation of the power relationship between medical and health professionals and the narrators often emerges in these stories in a subtle way, for instance through Emily Hutcheon’s comic memory of “being doped-up before invasive surgery at the age of ten and calling my favourite surgeon ‘So cute!!’ .” Several of these writers are evidently very aware of the figure of the good, “compliant” “brave” recipient of medical services, even as they map out their differences from this figure. Katherine Schneider for instance, flags up her gratitude for medical care, but makes clear that she is an “impatient patient” as well as a former provider of health services. Angela Moore notes the way she is read as “constructive” by doctors even as she refuses their attempts, while treating breast cancer, to frame other parts of her body as needing repair.

Jillian Weiss’s witty request to be permitted control of her own prosthetic encapsulates this demand for medicine to cede control:

This is my leg. It is an Otto Bock C-Leg. But I bought it. So it belongs to me. I think I should have the right to change the settings in my software. For example, if I want my knee to flex slower on the step, I have to drive to the prosthetist’s office, take off my pants, and hook up with his computer. He has the special software for the leg. Since it is my leg, it is my software. Does this make sense? How can I bring you closer to me? Let’s say you purchase a BMW convertible, which costs the same as an Otto

Bock C-Leg. Let’s say you want to put the top down. But to do that, you have to drive to the shop, talk to the mechanic, take off your pants, and then he, with his key fob, puts the top down. It is still a sunny day outside. Are you happy? (Jillian Weise)

The emphasis on fitness and the pursuit of physical health by several of the symposium authors might also be seen as a way of reframing understandings of people labeled with the term “disabled”. The emphasis on sports and wellness in these stories emphasizes that the narrators’ control of their own bodies and lives. John Hermanek talks extensively about his involvement in boxing after the amputation of his leg, noting that his return to sport confounded the predictions of his prosthetist. Equally, Gabrielle Hodge’s frames her account of her experiences as a learner and practitioner of yoga to offer a powerful message for health practitioners. She describes one yoga teacher insisting on exact compliance to instructions, not accounting for the writer’s need to adjust her position to observe the class visually. This teacher consequently humiliates her deaf student, “disabling” her by failing to accommodate what she needs to safely and fully access the class’s activities. Another teacher, effective at communicating not just through the spoken word, but through touch and the body, recognises Gabrielle Hodge’s understanding of her own body, valuing and engaging with her somatic, gestural and visual strategies for communicating. This yoga practitioner is willing to negotiate with her student to, “facilitate interaction” allowing them to “accommodate each other.” Gabrielle Hodge summarises: “Health and wellbeing professionals expect to work with their clients, as well as for them.” This story, like many within the symposium, stresses the importance of respect, reciprocity and negotiation in relationships between health workers and the people with whom they work.

Conclusion

This symposium has illustrated the ways in which people with a disability play an important role in the field of bioethics. The authors in this collection have provided reflections on everyday life that are

of relevance to many. The stories speak of equalising the power imbalance in relationships between people with and without disabilities. They also contribute to theory and practice development in the areas of disability studies and health service provision. The experiences captured in these stories may prompt reflection on practice and an understanding of “journeying with” not “doing to” people with disabilities. We hope that this collection will evoke more stories from people with disability, so that the voices of experiential authority can reach and influence wider audiences.

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