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## Whose Story is it? Narrative Humility in Medicine and Literature

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***“Stories matter. Many stories matter. Stories have been used to dispossess and to malign. But stories can also be used to empower, and to humanize. Stories can break the dignity of a people. But stories can also repair that broken dignity”***

***- Chimamanda Ngozi Adichie***

### ***Stories Matter***

I am on a panel. It is at a college, a conference, or a literary festival. It happens on almost every panel I am on; particularly when we are discussing representation and diversity in children’s literature – the importance for young people to see protagonists, families and story lines representing their own identities and their own lives. Someone – usually white, and/or straight, and/or cis-gendered -- raises their hand in the audience and tells us about a story they feel compelled to write, a story they love, a story about a protagonist unlike themselves. “Can I tell this story?” they ask, “Is it alright?”

Although this question usually comes from a sincere desire to do what is right by young readers, sometimes there is a palpable undertone of anger that comes with it. Behind this anger are false perceptions of censorship (just to clarify, critique doesn’t equal censorship) as well as resentment toward the #weneeddiversebooks and #ownvoices movements. Behind this anger is also the gnawing acknowledgement that perhaps good intentions aren’t always enough, and a discomfort with how social privilege operates in all our lives.

Of course, no one can grant someone else carte blanche to tell any story, in the same way that no one can guarantee for 100% sure that a writer’s story will not create hurt or garner criticism. But perhaps it is useful, instead of asking another person ‘may I write this story?’, to ask oneself, ‘why do I want to write this story?’ and ‘whose story is it?’

### ***Whose Story Is it?***

As a pediatrician with a public health background who has worked almost two decades as a teacher and scholar of narrative medicine, the question of ‘whose story is it?’ is one that has framed all my careers – as a doctor, as a scholar, and now, as a children’s fiction writer. In the courses I teach - in things like illness and disability narratives and narrative, health and social justice -- I constantly ask my undergraduate and graduate students to ask themselves this question as well as the related questions: ‘who speaks?’ and ‘who is spoken for?’ Because these questions of stories and their relationships to power are as important in medicine as they are in fiction.

As feminist philosopher Linda Martín Alcoff argues, part of the problem of speaking for others is that none of us can transcend our social and cultural location: “The practice of privileged persons speaking for or on behalf of less privileged persons has actually resulted (in many cases) in increasing

or reinforcing the oppression of the group spoken for,” she writes. Yet, she goes on to say, this doesn’t mean that people in privileged positions shouldn’t speak out against injustice. Rather, the effort must be made to create spaces to speak *with* the Other whose injustice you are opposing. This framing can be called a position of solidarity rather than saving.

### ***Indigenous Absence***

But how do we get ourselves to a position of solidarity and ‘speaking with’ in medicine or in fiction? Sometimes, it is by naming and then re-framing our own motivations. Take, for instance, the parachute model of global medicine, which basically consists of swooping into a foreign country to save the day. This sort of model of paternalistic ‘saving’ as opposed to health partnership is often based on what anthropologists Arthur and Joan Kleinman call the narrative of indigenous absence – the idea that local people have neither the skill, ability nor interest to help their own. The end result of such an assumption is often culturally inappropriate or ineffective care that actually undermines local medical authority and infrastructures. Simultaneously, narratives of indigenous absence not only feed the egos of those doing the ‘saving,’ but serve to legitimize ongoing economic, military and political exploitation of those countries deemed needing of rescue.

Whether the narrative of indigenous absence (‘no one is writing stories about this community, so I must do it’) plays into fiction writer’s choices is something important to examine, and dismantle. Is the desire to tell a story out of one’s own cultural, ethnic, gendered, etc. experience coming from a desire to ‘save’? Will this story in fact silence the community it seeks to represent? Will the story, for instance, take the opportunity from another teller – one with less social access due to marginalization – who might be told by a publisher, ‘we can’t publish your novel, we already have a [insert identity] novel in house’? Ultimately, writing outside one’s experience cannot be to ‘give voice to the voiceless.’ As the novelist and activist Arundhati Roy has said, “There’s really no such thing as the ‘voiceless’. There are only the deliberately silenced, or the preferably unheard.” Therefore, before telling, perhaps our actual job is to listen better, listen more justly, and help create systems that will do so as well.

### ***Narrative Humility***

All writers – whether we write directly outside our experiences or not -- might benefit from what we in health humanities/narrative medicine call a ‘narrative humility’ lens: the recognition that our subject positions cannot be transcended and our own biases must constantly be examined. For doctors and nurses, practicing narrative humility means recognizing that no matter how good of a listener we are, how sincerely we elicit, attend to and honor a patient’s story, there will remain elements unknowable of that patient’s life. As one of my students once said – a medical student with a chronic illness herself, “Try to understand. Recognize that you will never understand. Try anyway.”

For authors writing outside of our experiences, practicing ‘narrative humility’ may mean recognizing that no matter how good of a writer we are, how sincerely we represent and honor the story of a community unlike our own, there may be elements outside our grasp, elements of our own privilege that place road blocks in the path of our empathy. This is where diverse critique groups, sensitivity readers and a good deal of self-study and self-examination may come into play. Assertions that writers can write whatever they want, or that a novelist’s job is to imagine do not change the fact that stories can do damage, and that imagining is for all of us a political act.

***Writing Toward Freedom***

Stories, whether those of fiction or those of the medical interaction, do not exist outside of power structures. To decolonize either medicine or literature as a field, we all have to be conscious of our own biases and work from a stance not of assuredness, but of humility, not of knowing, but of asking, again and again, ‘whose story is it?’ These questions are not easy, but our work demands it of us. Those we work with, care for, and write for deserve it of us.

Writer and educator bell hooks describes the classroom as a ‘location of possibility.’ So too, perhaps, is the room of literature. In her words, “In that field of possibility, we have the opportunity to labor for freedom, to demand of ourselves and our comrades, an openness of mind and heart that allows us to face reality even as we collectively imagine ways to move beyond boundaries, to transgress.”

Let us not be afraid of the hard questions. Let us collectively decolonize our imaginations, uplift one another in gestures of solidarity. In doing so, let us, word by word, story by story, write our way toward freedom.

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## Author Biography

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Originally trained in pediatrics and public health, Sayantani DasGupta teaches at the Graduate Program in Narrative Medicine, the Center for the Study of Ethnicity and Race, and the Institute for Comparative Literature and Society, all at Columbia University. She is the author, co-author or co-editor of several academic books, most recently, *Globalization and Transnational Surrogacy in India: Outsourcing Life* (Lexington 2014) and the award winning *Principles and Practices of Narrative Medicine* (Oxford 2016). Her academic work is widely published and anthologized, and she is also the author of the middle grade fantasy series, *Kiranmala and the Kingdom Beyond* (The Serpent's Secret 2018, Game of Stars 2019, and The Chaos Curse 2020, all from Scholastic). Learn more about her work at [www.sayantanidasgupta.com](http://www.sayantanidasgupta.com) or follow her on twitter @sayantani16.