

WEEK 2 MEDICINE & THE ARTS – CHILDRENS VOICES AND HEALING
ISSUES OF CHILDREN'S VOICES

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Hello. Welcome back to week two of the course, Medicine and the Arts. This week, we will be exploring a theme that lies very close to my own research interests as a medical anthropologist, and that is the question of children's voices in the context of disease and chronic illness. If any of you out there are medical students, you'll know that when you do rounds in the hospitals, now whether it's in the paediatric ward or otherwise, you're not only asked to examine the physical, the biological markers of disease and illness, but also to know something about the patient, something about their history, something about their social circumstances, about their life world.

Something in medical anthropology, we call an illness narrative. That is what the patient has to say about his or her own life experience in relationship to that illness. You also know, if you're medical students or medical practitioners, that your time is quite constrained and limited to working in the hospital context, different kinds of regimes diagnosis, implementing care.

So often, in these cases, these space through which voices in hospital contexts gets limited or condensed into shorter narratives and what's possible in other kinds of disciplines, such as medical anthropology, or other kinds of Social Sciences, which has a greater latitude for time to really engage with patients and to elicit what we call the oldest narrative or the story of illness. What we're calling it this week-- voice, in particular in relation to children's voices.

This is the goal of the medical humanities, which is to bring disciplines into conversation, so that the medical, the social scientific voices emanating from the arts, and opening up other kinds of spaces for communication are brought together into a richer conversation and that can impact on patient care. To begin developing this new field of the medical humanities, we've brought together today three extraordinary individuals all of whose work focuses in one way or another on youth and young people.

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We have Dr Marc Hendricks. He is a paediatric oncologist at the Children's Red Cross Hospital. He's also a singer and songwriter. He is one of the most extraordinary caregivers I've seen in action with children and the children's families. He speaks to

the ways in which children's voices need to be heard in the context of illness and also in the context of death and dying. Something that medical anthropologists are rather attuned to are the ways in which children's illness inverts the usual logic of who dies first-- children, parents, grandparents.

So children's illness provides a very different kind of space in which to think about questions of mortality, death, dying, and letting go. Children themselves have so much to say about this. And often because of adults' fear around the question of how children might feel about death and dying, we don't broach the subject. So through the conversation with Dr Hendricks-- who we'll call Marc-- we'll begin to explore this very delicate area around paediatric oncology. There are also some wonderful survival stories that he'll talk about.

Kate Abney is a medical anthropologist. She was my former Ph.D. student here at the University of Cape Town; she's been working at the Brooklyn Chest Hospital with children living in a chronic care ward for tuberculosis. And she'll also be talking about the kinds of narratives the children themselves spin about the experience of taking medication, the nausea, attendant, kinds of feelings of dis-ease, being separated from their families in an institutional setting, and also some of the really liberating aspects of the hospital, such as the school that's on the premises of the hospital-- and really gesturing towards new ways of maybe thinking about the ways in which the medical humanities couldn't bring in different dimensions of care for children living in institutional settings.

We then move to a wonderful radio producer named Nina Callaghan, who works for the Children's Radio Foundation. And in some sense, Nina brings in the missing ingredient. We have the medical anthropologist. We have the paediatric oncologist. The question now is, what can the arts do to enliven and enrich the experience for children?

And here we have a wonderful example of using radio to tape record children's voices to tell their own stories. This has become painfully clear that we need to have spaces in hospital contexts and in home settings where children are living for children to be able to speak into a microphone and to be able to voice their own concerns about their disease and their own care.

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So I'd like to invite you to engage with the speakers—Dr Hendricks, Dr Kate Abney, and Nina Callaghan, and to think about your own experiences in your own context, your own life-- maybe the stories of your parents or grandparents, friends-- to think through these case studies that are being presented through a very personal space.

One of the emphases in the medical humanities and medical anthropology is to filter social scientific ideas through the lived, through the embodied experience. So we're going to ask you to maybe keep a diary, keep a journal, take down notes, share your thoughts on the online MOOC site, and begin to extrapolate new ideas.

You as the audience have so much to offer this new field of the medical humanities. You could bring your own insights into this virtual classroom. And to begin

generating new ideas, there are certainly projects beyond the kinds of radio projects that Nina has offered, beyond some of the musical interventions for doctors survival in the context for really stressful work that you might have at your fingertips that can contribute to this new and exciting field. Enjoy week two, and we'll see you next week.



Susan Levine, 2015

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