

The South Asian Perspective(s): Desi & disabled*

Podcast Dissertation by: Dr. Grishma Shah

Preface • 12:46 mins

SUMMARY KEYWORDS

dissertation, stories, community, Desi, india, disability, feel, study, participants, storytelling, identifying, mom, storytellers, non traditional, shared, communitarian, listener, parents, hope, compelling

SPEAKERS

Grishma, Dr. Marshall Ganz, Committee Member

(Upbeat, piano music begins)

Grishma 00:04

Once-upon-a time, there was a girl who asked her mom a question. She said, *Mom, what do you wish for me?* Her mom said, *I wish, I wish to outlive you by one day.* The daughter was surprised. So she asked her Mom, *Why is that your wish for me?* Her mom looked at her and said, *I used to have a cousin in India and she had a disability. She outlived everyone but her mom. Her mom passed away one day after she did, till her last breath, the cousin knew she was loved. That is why I wish to outlive you by one day.* The daughter told her mom to change the wish. *I want you to wish that I'm extremely successful, and that I find love and that I'm truly loved. And that I marry a gorgeous man.* Maybe you're wondering what happened to that girl? She became an artist who fell in love with storytelling and she constantly wondered if there were other moms out there who are wishing to outlive their disabled daughter, by just one day. And if there were stories, that she could tell those moms, so that they can rethink their wishes. So much so that she asked her dissertation committee if she could do a non-traditional dissertation, a dissertation that had storytelling in it. At first, she didn't succeed. But she kept trying. By the second or third attempt, her committee had this to say to her.

Committee Member 01:50

The way in which you were able to make your case today and back it up with examples and evidence and, and present it and a logical argument is the best I've ever seen, that

you've been able to, to make that case. You've shared ideas in pieces at different times through different conversations. But in today's presentation, you were able to put it all together in a way that's really compelling. And so, I just want to applaud you for that. It's compelling in a way that is creating questions and discomfort in me. And that's a good thing, right? Because that's how we change. So I'm really impressed. And I think that, that I think that this is all great. So that's the biggest thing that I want you to, to walk away, with feeling really good about what you've shared with us. And that, you know, you're, at least in me personally, causing me this type of discomfort that leads to change.

(End of upbeat, piano music)

Grishma 02:58

What I wanted to convey to my dissertation committee was that dissertations are full of amazing stories, stories that can change minds and hearts and policies. But traditionally, dissertations were hundreds of pages long, and written in such a way that it was difficult to digest. Oftentimes, these stories stayed contained within the scholarly community, and then ended up in a story graveyard. I thought I'd also bring in the big guns, I'm talking Harvard University here. Let's listen to what Dr. Marshall Ganz's said about storytelling, and how important it is and why I wanted to do my PhD dissertation focusing heavily on storytelling.

I do hope that this is the beginning of something where not just my institution, but other institutions as well start to realize that we really want to be able to share data with communities so that communities can thrive. We need to be able to do it in a way that makes sense. And for me, I feel like stories make a lot of sense. Stories teach me go to hate, who to hate, who to respect, who to love, who gets my love. And if we can just tap into that at a really early age, it can really flip the way that we tell stories.

Dr. Marshall Ganz 04:22

Yeah, of course, there's all kinds of stories. And I mean, there's stories that lift up life giving value and there's stories that lift up the opposite. And so because it's such a powerful form of communication, and because it's essentially a form of values, communication, in the language of emotion, not all values are equal. It's not like narrative's the answer to everything. I mean, there's some pretty vicious narratives out there that are based more on fear than they are hope and they're more on identifying, identifying evil than others as opposed to finding hope in ourselves. And so it's a form of moral communications, not moralistic... but Charles Taylor, I think helps a lot with this the moral philosopher that teaches at McGill and sort of a father of communitarian

philosophy, communitarian theory... Communitarians argue that values are rooted in communities that we are part of. And so we are shaped by them, and we shape them. And so Michael Sandel's work is in this area, certainly, and there are others. Michael Sandel teaches Justice here at Harvard. His teacher was Charles Taylor, who is a Catholic moral philosopher that writes about the significance of articulation of moral sources. And what he means is not what's the moral argument, he's saying the stories. What are the experiences that shape us and from which we can learn? So it's consistent with that kind of approach. Course, again, that kind of approach has been certainly used by political leaders and by religious leaders and by movement leaders and by parents for thousands of years (chuckle). So it's not exactly news, but there is, there certainly is a sound, academic grounding for a lot of this.

Grishma 06:13

I think there are some parallels with communitarianism and community psychology, which is what I'm getting a PhD in. If the title doesn't say enough, community is before psychology. Then let me tell you this. Oftentimes, in the real world, we need to show our communities how indispensable we are, whether our community is inside an office building, or in our friends circle. But in community psychology, our goal is to leave the community (or) organization better off than when we found them and to focus on assets of what the community brings. So that we can work through concerns with community members. After my committee greenlit my non traditional dissertation, I closed my laptop and danced with joy. After that celebratory dance was over. a surge of anxiety crept up inside of me. Fuck. What did I get myself into? I hope I don't fuck this up. listener. Have you ever felt like this was it? Your make it or break it moment? That's how it felt for me, with this dissertation. I would have dreams that Michelle Obama heard my dissertation and she loved it. Not only that, she would invite me to be her guest on her podcast. Then we wouldn't become Facebook friends. The anxiety grew as time went by. High blood pressure, cholesterol and acid reflux were frequent visitors. So I made a decision, focus on just you, listener. I wanted to bring my dissertation alive for you.

This dissertation has been deeply personal and painful for me. When I became an amputee, it felt as if I was no longer part of my ethnic community. People from my community would tell me, my sister and my parents, that I was not worthy of things like marriage or success. They would do so in subtle and not so subtle ways. At first, their comments made me laugh, because I thought they were so ridiculous. As years passed, these comments made me feel hopeless and somewhere deep down, I started to believe them. What I would give to roll back the clock to that eighteen year-old me and say to her, there is light at the end of this painful tunnel. And you will be more than okay. I wish I could hug my parents and sister and tell them the same thing. But time doesn't

work like that. At least not yet. So I dedicate this dissertation to my parents and sister and to all those families that have a daughter with a disability.

(Upbeat music fades out)

So now that you know listener, why I decided to do a non-traditional dissertation. I want to give you a heads up on a few things. My dissertation is on Desi culture. And the word this e de si can mean many things. Just Google it and you'll see what I mean. I have read articles where the term Desi can feel restrictive (Sircar, 2021). Sometimes it's linked to a specific country like India, or it's linked to a specific group of Indians like North Indians or upper caste Indians. In order to qualify for my study, people had to self-identify as Desi, meaning they had to tell me that they were Desi. Though, it was easy for the participants to see themselves as Desi. It took them a good minute to tell me what it meant to be Desi and how they would define this term. Some participants define Desi as someone who is from the same region as them in India, while others define it a bit more broadly, as anyone from India, Pakistan or Bangladesh.

There are also some study participants that define Desi as someone native to the South Asian region of Asia, like the Indian subcontinent, but they're living abroad. For the purposes of this dissertation, Desi will be referred to as people from India or Pakistan for the simple reason that the people from my study, were either born in Pakistan or India or have ancestors from there. If I continued interviewing more people that self identified as Desi it is highly likely that this dissertation definition of Desi would have included many more South Asian countries. Listener from time to time, you're gonna hear a bell ring. It means I'm referencing a study article or book. And if you want to get more information about that reference, you can check out the episode's transcripts. You may hear me call the study participants, storytellers. That's because I want to emphasize that dissertations are full of amazing stories and to respect the privacy of these storytellers, I've not only changed their names, but also their voices. Throughout this dissertation, we're going to hear stories of people who tell us how skin tone, religion, gender and caste hierarchy can affect perception of self and perception of others, keeping beauty, worth and disability in mind. Hold on to your seat as we explore my PhD dissertation as the podcast mini series, packed with stories, to encourage dialogue and change so it can reach more communities, and not end up in a story graveyard.

End of Preface Transcript

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