

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

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SPEAKERS

Danny, Grishma, Jeetendra, Mumtaz, Dharmendra, Rekha

(Suspenseful music begins)

Mumtaz 00:07

How do you Desis disability? There's a lot of shame around it. Both being the person with a disability and your family, I think, And I'm speaking generally, you know, I don't think my family was ashamed me but, feel like everybody else, they minimized it, they weren't like, you know, let's figure out what you need (chuckles). They didn't do that. But generally, yeah, I think there's a lot of shame around it, because it's like, there's something that's wrong with you. Like, I don't think my parents ever said this out loud about anything. But I had the sense and then I think I learned, God is punishing you. Somehow, if you're, if there's something wrong with your child, God is punishing you.

Jeetendra 00:48

You know, growing up in India, I used to live in a very small town. And actually now that that, now that we're talking about it, there was a person with a disability. And the town's people would call them Gandyo. I don't know how to describe that in English. Stupid. Yeah. And they'll say, Oh, look, here's that Gandyo again, like it. Again, it's has a very negative connotation to it. And, you know, looking back, I'm like, that's, that was horrible. I mean, the town's people really took him as a joke, but never really understood, like, the science behind, like, you know, what is causing the disability. And it's almost sad, because I feel like, even if, in this time, people will still consider that person a Gandyo because that's just like, the way that they grew up, or that's just the

way that they've understood, at least from that perspective, what like a person with that type of disability is. And looking back, I'm like, that's, to have that nickname, I mean, that's horrible. But, that was the norm. You know, this is back in what, early 90s growing up in that town. I guarantee you, we can go back that time and if we see someone like that, they'll still say that. I don't think it has changed personally. But that's just from my perspective. It was an intellectual disability. I can't remember too much of it. I just, I do remember like, that was the name. And it was, almost like he was a joke of the town.

Grishma 02:40

(Suspenseful Music fades out)

Welcome to the episode on religion. We first heard from Mumtaz who's born in the United States into a Pakistani, Muslim family. Mumtaz has an invisible disability. And she's currently in her thirties. Hands down, she was one of the most successful storytellers I've had the pleasure of interviewing for this dissertation. And I've interviewed managers of Fortune 500 companies, folks in IT, entrepreneurs and folks in the medical field. If I told you what Mumtaz did, you can easily Google. To respect her privacy, I'm not going to. We then heard from Jeetendra who's also in his thirties and works for yet another Fortune 500 company. Though he came to the United States when he was a kid from India, he was able to share with us one of his memories from childhood. (It) was a memory for Jeetendra. for that person that was called stupid, that was his life. And wherever that person went, the town's people made fun of him. You're probably wondering which lens I'll be looking religion through? Good question. I'm going to be using the framework of loss (Ganz, 2020). What I took away from my professor Marshall Ganz's teaching is that loss can come in many forms, like the loss of a job, person candidacy, loss of belief in God, or in my case, loss of normalcy, or "ability". We heard Mumtaz tell us how she feels disability is perceived from her lived experience. We then heard from Jeetendra about how people in his town looked at someone with an invisible disability as stupid. Remember Dharmendra, that guy that said, throwing out the garbage and cooking for 1.5 hours don't cancel each other out. In our interview, I asked him, *How do you think Desis view disability?* And this is what he had to say.

(Guitar heavy, soft music begins)

Dharmendra 04:55

Not, not nicely. How to think through (voice cracks). Let me drink some water (audio of drinking water). And I'm being emotional because I think people choose to behave that way. Because it's a preconceived idea, or the belief they have based on their religion. You

are disabled because you did something wrong. You have a kid with disability, because you must have done something in the past life. And my wife and I, we are not religious people at all. And I think the, the main thing that hurts me is people not able to see ability, versus they're trying to find out the cause. And even though you are so educated, people are saying, not mean stuff, but so so backwards stuff, you know. So for example, we know that when a kid is born, you have... chromosomes and if something goes wrong, you're not going to have this (chuckles).

(Guitar heavy, soft music ends)

They try to find answer in those religious books, why it happened to me. They, they don't understand that, hey, how many kids are getting born? What is the probability that can happen? I normally don't interact with people or try to educate them. But that's a piece if I get an opportunity, I definitely help them out to understand, if the person is able to understand that piece. So if they're willing to understand that piece, you know.

Grishma 06:27

(Fast beat music begins)

Dharmendra got emotional, because he has a close family member with a disability. And he's not the only one to push religion away. I myself pushed religion so far away, that I began to boycott temples and I come from a very religious family, listener. In my family, God got to have a whole bedroom while I had to share. I guess I got lucky, because I had a good roommate, my sister. But growing up, I told God many times, it wasn't fair that I had to share my room, and God didn't. You know how kids tend to have imaginary friends growing up. For me, God was my friend. And when your community tells you over and over again, that God is punishing you. And that's why you have a kid with a disability, or that's why you have a disability. It can create a loss of belief in God, a loss of belief in self, or even a loss of belief in your community. Like Mumtaz said, over and over in her interview...

Mumtaz 07:42

They are making this shit up. Yeah, this is all made up.

Grishma 07:47

And who is *They*? That's the billion dollar question, listener.

(Fast beat music ends)

I think they are the people in our community that are the influencers, the people with the money, the people with the power. They get to tell us how we should feel. There was a study that explored perceptions of disability among Pakistani families living in the UK (Croot et al., 2008). Even those folks expressed that judgment and stigma from extended families and folks from the Pakistani community affected where they took their kids with disabilities. They were comfortable taking their child to a mall, but hesitated taking that same child to a Pakistani wedding or a funeral. Some of these parents saw disability through a medical lens similar to the way Dharmendra sees disability, while others saw this as a punishment, or a test or a blessing from God. Though these parents had rejected the negative views that their community had on disability, it certainly affected them and impacted their children's lives.

As for me, I just couldn't understand how a God like that could exist, a God that punishes instead of loves. Around that time, I met Dr. Mayank Shah that is his real name. He's a physician and part time (Hindu) priest. I began asking him hard questions like, do people deserve to be raped? If we blame women for being out too late or how they're wearing their clothes, how about a baby that's being raped? Many religious folks have been turned off (chuckles) by these questions that I've asked, but surprisingly, Dr. Shah welcomed them. I quickly learned that most of these answers were complex. But at the heart of Hinduism, we need to understand that we are the soul and that the soul is pure and divine (Hinduism Today, 2021). The soul has no gender or age. And it's only the body that has these things. At the end of the day, all of us are equal. And if we have this awareness, we would be able to understand what things we can control and what things we can't. While there are factors that we have no control over, like discrimination, or disability, what we can do is choose to respond to the events that influenced our lives. Psychologist Carol Dweck (Dweck, 2006), mentions in her writing that she's seen many folks who are always consumed by the goal of proving themselves, whether it be at school, in a relationship, you name it. When I read that, I felt like she was talking to me, because I constantly question if I will succeed or fail, if I will be rejected or accepted. If I say x will people think I'm smart or dumb. And I feel like I have to prove myself over and over again.

Then she shared a nugget of wisdom with me, that I'd like to share with you. If you think listener, that the cards that you're dealt with are the starting point of your development instead of your ending point. Then you have a growth-mindset. Dweck uses the example of a game of poker. She says that you don't need to pretend that you have a flush if you only have a pair. As she put it with a growth-mindset, you can learn and grow and get better. Because a growth-mindset is pregnant with possibilities. And according to Dweck, if you stretch yourself, especially when things aren't going well, in her eyes, that is the hallmark of growth-mindset. Dweck even gave us an example so that we can really

understand the difference between fixed-mindset and growth-mindset, going to class finding out that we got a C+ on a midterm exam in a class that we really enjoyed. And then we got a parking ticket. All of this was happening on the same day. So then you pick up your phone to call your BFF and they're totally dismissing you. Her research suggested that the folks who were in fixed-mindset took all of these things as a negative reflection of their worth. In other words, they were labeling themselves. I'm not smart enough, why bother trying? And the folks that had a growth-mindset said things like, I got to study harder, or study differently for the next test, I need to be more careful where (chuckles) I parked my car. And I need to call up my friend to see if they're okay, because I didn't like the way that they were dismissing me. So were they okay? In other words, they didn't label themselves. Instead, they were ready to confront the situation, even though they weren't happy about it, and work through it. I'd like to argue that rather than reacting to the situation, the growth-mindset folks were responding to the situation at hand. And according to the loss framework (Ganz, 2020), when you react, you don't have agency. It's when you respond that you have agency. Listener, which one are you?

Danny 13:50

(Soft, Sitar heavy music begins)

Desi culture is like, varied and rich and colorful. And, and again, I think Desi culture does have certain Hindu and some maybe Muslim color to it. In the sense that Christianity is such a small part of India that I don't think it's well documented, or explored. Even though Christianity is you wouldn't believe almost 2000 years old in India, most people don't know that. So when most people talk about Desi culture, I think they're mostly looking at like, Hindu culture. You know, and most people talk about Indian weddings, oh, seven days, elephants. And when I explained my wedding to them, their like *What?* My wedding was four hours long, no elephants involved. So same thing, you know, our conversation about caste, it does not feature, right, so it's almost like a bubble within Desi culture. The only similar Desi parts would be like, family oriented, like head of house or native places, language.

(Soft, Sitar heavy music ends)

Grishma 15:19

What is important to remember is that Pakistan and India didn't exist until 1947. So 1946, they were one entity under British rule. Just imagine one day California becoming its own country, it will really shift things around. According to one study (Ahmed, 1995), 96% of people in Pakistan identify as Muslim or practice Muslim traditions. and about

1% of 210 million Pakistanis identify as Hindu (Abi-habib, 2019). In India, it's flipped. The dominant religion is Hinduism, which takes up 80% of the religion pie. And Islam is considered to be one of the minority religions taking up 14% according to the 2011 Indian census (Religious Census, 2011). Where does Christianity fall? Good question. In India, Christianity takes up about 2% of the religion pie. And in Pakistan, there are fewer Christians than Hindus (Fuchs & Fuchs, 2019). When it comes to disability in the United States, about 26% of the population has some kind of disability (CDC, 2020). India's disability statistics are less than 3% as of 2019, even after creating a more broad definition of disability (Iqbal, 2020). Maybe you're wondering what the disability statistics are for Pakistan? Well, in 2017, it was less than 1% according to one article (Rana, 2017). When they did a headcount in 1998 it was about 2.3%.

One of the reasons why disability stats are so low in both countries could be because of stigma. There is social stigma attached to disability in Pakistan (Ahmed, 2015), so families try to keep it in the down low. If disability is out in the open, then it can affect other people from their family getting married, because they may be suspected to have defective genes. More often than not, people with disabilities are perceived to be jinxers or folks that carry bad luck (Anees, 2014). These beliefs transcend through socio-economic classes and education, is found in urban and rural areas of India. What's interesting is that in Islam, and in Christianity, disability is considered to be God's will not a blemish on society (Anees, 2014). And that all people, regardless of ability, are God's children. How come Mumtaz who comes from a Pakistani Muslim heritage, although she was born in the United States, learned that if you're a person with disabilities, or you have a child with disabilities, God is punishing you?

Rekha 18:33

I think our culture's emphasis on goddesses and how they usually have an equal amount of power to their husbands right, like Parvati is called Adi Shakti (Pandey, 2016), that's half power. It's not a third of His (Shiva) power, you know. And I think our culture actually offers like, a very egalitarian view when it comes to religion and stuff of men and women. I think the, the societal constructs don't really go with it. And I think even our goddess of knowledge, right, it's not a man, it's a woman, yet people somehow within society contributed intellectual ability to men (Anees, 2014). But that's not what our culture teaches us. So I think, and also Lakshmi is wealth (I.T.V.N, 2015). So women bring wealth to the family, right? So I think these are all very important things. But I think people focused on the wrong aspects. Because, you know, it's very easy to be like, oh, like, they said, this, oh, my God, but then like, what about all the good things, you know? And I think that's one of the things like that's how negative interpretations come about, too, is because we tend to focus on the negative or tend to think, view things in a

more negative light when actually like, you interpret that same thing. And you could do it in a completely different way, if you go into it with a different mindset.

Grishma 19:57

In Hinduism, it is stated that one can look at a situation in multiple ways (Love, 2019). The Sattvic way of looking at a situation is what we should strive for. In this way, we're trying to find out what the situation is teaching us, whether it be a co-worker that's stressing us out, or a simple case of competition. *What can I learn from my co-worker that can strengthen my skills?* The Rajas way of looking at the same situation can be, you work so hard that you put the rest of your priorities to the side, and you end up beating your co-worker. But then fear creeps in because you worry that you're going to lose this position to someone, anyone. So you keep working harder and harder and harder. The Tamas (Tamsi) way looking at the situation would be by blaming the co-worker. *Oh, the co-worker's making me look so bad. I can't believe X, Y and Z did that. We all know how they got that promotion.* What we're doing is taking all of the energy that we could dedicate to the mission of living our best lives, and putting it into someone who may not even know that we exist.

Rekha 21:25

I'm gonna be honest, Desi culture hasn't really taught me a lot about disabilities. Which, I still see that as kind of a negative thing, because it didn't offer me as wide of a perspective as I would have liked growing up, on what it means to be human even. Because, like, disabilities are something that exists, you know, across every border, in society, and they've existed since like, the conception of society. And I guess, the way I see disabilities is that I don't think I view people with disabilities any different. Only, because like I said before, like, I see everyone as a soul. I also just feel like, you could be like an amazing person and have a disability. And you can be fully able and not be like a very morally righteous, or like, what people would describe as a good person. So I don't think like, physical ability to me especially through like our faith and stuff, it doesn't have to do with a person's worth and it doesn't have to do with how I view a person. So I think while culturally I wasn't taught a lot about it, I think my faith helped me view disabilities in a different perspective...We have a festival honoring Krishna, and he was known for being dark skinned (Pattanaik, 2019). And then we also, when we think about Ganapati dada, he's not completely human but people still see him as, like, an amazing deity. And I think that's like another example of just, you know, having positive examples. And with that, like, even if you don't believe in our religion to a huge perspective, a lot of Desis who aren't very religious still have like, a Ganapati dada statue in their house, just as decoration. And it's something that, you know, people in other cultures might be like, *Their God is like part animal?* (Encyclopedia Britannica). We're

just like, no, this is someone who's divine because the outside doesn't matter. And I think that's one of the most important lessons. You know, within the Desi community, a lot of people have misconceptions about what our faith says about someone who's been sexually assaulted. But there are stories like the story of Tulsi and the story of Ahilya (Ritu, 2017; Merriam, 2019), which, when if you actually look behind them, like, these bad things that happen to them become a reason for their upliftment. And it doesn't make God say, Oh, this is a bad person. He's actually like, No, you're ready to be uplifted. Right. So I think those are just examples of like, we have so many things that can be interpreted to just be such positive contributions to our culture. But I think, like I said, like, those things get lost within like the bigger fabric of things.

Grishma 24:32

Another way that we can look at loss is through contamination scripts, and redemption scripts (Ganz, 2020; McAdams, 2001). And that is where Dan McAdams research comes in. What I learned from McAdams is that people tend to create stories about their experiences. And if we look deep enough, we can find out what the scripts are of these stories, if they're redemption scripts or contaminated scripts. Imagine a great event about to be happening like the birth of a baby, and you're on your way to the hospital. But when you're at the hospital, the baby ends up dying. So a good event turned bad. That would be an example of a contamination script. On the flip side, if there was an accident, and the car burst into flames, but the driver was able to get out with just a few minor bruises, a very bad situation became a good situation. That would be an example of redemption scripts. The UK study (Croot et al., 2008), had folks with varying beliefs. Some thought that disability was a punishment from God, which could lead to more contaminated scripts about their worth affecting how they see their lives, and their children's lives. While others considered the disability to be a gift from God, which could mean that it was God's will, and that there's a divine reason for this. Maybe the child was sent by God for a purpose. And this child is destined to do great things. As Rekha mentioned, if we see things from a different perspective, it can change how we live our lives. According to the framework of loss (Ganz, 2020), these scripts can influence our outlook in life the same way that Sattvic, Rajas and Tamas (Tamsi) thinking can too. I was listening to The Happiness podcast (Industries, 2021), the other day and learned that Judaism focuses heavily on gratitude. And by being grateful for what we have, we can be more happier. I would argue that gratitude, redemption scripts and Sattvic thinking all fall under the same umbrella. umbrella of growth-mindset.

Jeetendra 27:04

(Soft, piano heavy music begins)

Growing up and how I mentioned, we used to go to temple or mandir every Sunday, the men and the women were split. It's interesting, because the boys always sat closer to the Swamis or gurus or whoever. And the women were always in the back. And that's interesting, because, you know, how do we come to that point where women can't be closer, or, you know, anytime a Swami used to walk to the hallway they would have two or three guys or boys in front of them, two in the back, there was no way to get around without it, there's a, there's a woman in front of them. For me, at a very young age, I just didn't understand that. And I think most of my friends who also, you know, went on mandir. I think that was just like our religion. Like that's just, it is what it is. You just got to do it, right. And I think that pushed me further away from my religion. And like, it's, we take a step back and we look at under the umbrella of Hinduism, right, you have all these different deities, you have all these different sub-religions. Overall, overarching theme here is like togetherness, wholeness, right. There's no segregation of men and women. Somewhere between when Hinduism was created, to this point in time there was some disconnect from the actual deep understanding of being a Hindu. And I think we've got to that point here, with all these different little mini rules that we had set in place, because in Swaminarayan we can't have women sit in the front, you can't eat onion or garlic, right. That's, that sounds crazy to me. But like, where did those come from? And I think not understanding that piece has pushed me away from religion, specifically. But I think to your point, I think I need to understand why like where these things came from.

Grishma 29:12

Jeetendra made a great point, we really need to explore if traditions make sense. Like, where did the tradition of women sitting in the back at temples come from? And does it still hold true today to its purpose? Especially in Danny's perspective about Desi culture being influenced by Hinduism holds merit.

(Soft, piano heavy music ends)

Rekha reminded us that in Hinduism, Saraswathi is the goddess of wisdom and yet in this culture, we often equate intellect with men. Then there's Lakshmi, the Goddess of wealth that Hindus pray to a woman yet again, and somehow we've equated men as the breadwinners or the financial supports of the family? Rekha also spoke of Lord Ganesha, who she lovingly referred to as Ganpati dada. Ganesha is the god you go to if you want obstacles to be removed. It matters not that he has the head of an elephant because as Reka eloquently stated, in Hinduism, it doesn't matter how a person looks on the outside, they are divine on the inside. This goes for Gods like Ganesha, as well as people. And that concludes our episode on religion.

End of Religion transcript

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