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Transcript of an edited interview with

Jaya Dantas

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INTERVIEWER:	Rita Alfred-Saggar
TRANSCRIBER:	Luisa Mitchell
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NOTE TO READER

INTRO: Death. It's the most inevitable part of life. Some might say it's the only guarantee. But it's also a topic that many people shy away from because it makes us feel uncomfortable, scared or upset. It's often swept under the rug, not acknowledged or talked about, until of course, we come face-to-face with it ourselves. We hope to end this taboo through a series of interviews with many different people from all over Western Australia. We talk to ordinary people about their views on the grief, loss, love and celebration that *is* death and dying. This is a conversation on death.

JAYA: My name is Jaya Dantas and I'm Professor of International Health at the Curtin School of Population Health at Curtin University in Western Australia. My research has been on refugee and migrant populations and vulnerable and priority groups. I focus a lot on women and on gender and on young people. And basically, in recent times, especially in the last two years, it has focused on COVID and vulnerable populations with the focus on the social determinants and health inequalities.

RITA: So, we do know that COVID has disproportionately played a very important role in those communities. How do you think governments around the world have dealt with that or not dealt with that?

JAYA: So often what happens is that, with governments, when there's an emergency public health situation like the COVID pandemic, the measures in place did not consider certain priority groups. So, throughout the world, the elderly were impacted; the indigenous populations were impacted; and the refugee and migrant groups were impacted. And groups that worked in the informal economy, because often in those informal economies, if you didn't work, you couldn't put food on the table. And this impacted people, not only in developed countries, but also in developing countries. Even now we see that our indigenous populations have a lower vaccination rate than the other wider population. In the United States, they have been looking at the African, the Hispanic and the Native American population and how they have fared. Now, these groups also had poorer health indicators, poorer health literacy. So, their impacts are significant also.

In Australia, with our government, when they closed borders and they put forward very strict public health measures. In isolation, when people are in isolation, when they live in smaller houses, when they don't understand what it actually means, when they may not have sufficient computer literacy, they have multiple disadvantages that impact them. And that is what has happened significantly in Australia. The first thing is, [Indigenous Australians] like a community model of health where there's the community health workers going into the community, talking to them and inviting them to take part in health programs, immunization, etcetera, all this was lost because of lockdown. You know, they like to go on a walkabout and meet with other families. They could not do that. You know, then when it came to messaging, it is really important within Indigenous communities to use their own countrymen. So, you would need someone from that particular tribe, or mob as they call it, and the government was missing that. So, although there were indigenous health organisations that were consulted, this was missed. And at the same time, in terms of vaccination, everything that was rolled out was online. So, you book online, this actually impacts people who might not have internet on their phone, or the elderly, like my mum, who're not computer literate. She relies on us and we are able to help her.

But in the Indigenous communities, that was lost and the Indigenous communities do not do telehealth well at all. The government was rolling out telehealth and wanted telehealth, but Indigenous communities don't do that well. One, you need access to a phone and sometimes they are surviving from pension to pension and might not have credit on their phone to actually do a telehealth consult. There's a factor of trust [too], because they can't see the health professional, and this impacted them. So, there were these multiple layers that you can't take for granted, it's not one size fits all at all in terms of health. And that is why health equity is so important because that's what's happening in the world.

RITA: I was interested that you termed that as an ableist culture. Tell me a little bit about how and why you term [it] that?

JAYA: So, the term ableism has often been used in the disability sector, because with ableism, when you actually make certain choices for the person, you actually disempower them in many ways. So, in the case of COVID, there were multiple forms of ableism that were happening. There was institutional ableism, and that was very much seen within the aged care sector, because basically by locking down or shutting down aged care facilities, that ableism was given to the institution, and you had to actually depend on whether the institution did something right or wrong.

Then at the same time, with respect to vaccines, as we called it, there were certain vaccination centres, but in many places, and especially in many parts of the developing world, there are community health workers going in mobile vaccination clinics or scooters, or even in canoes in the Amazon, going out to the communities to give [them] that. So, in some ways you are assuming that all people can do this: book online and then go to a vaccination hub and stand [in line]. Not many people can do that. So, in the case of the vaccination rollout you needed to actually roll out the vaccination to the elderly over the age of 65, then you needed to roll it out to the immunocompromised. So, you know, people on transplant medicine, people who are having cancer treatments, people who are having immunotherapy. So these were our priority groups and then our indigenous populations, because they have high rates of chronic disease and comorbidities. So, it was important to roll out the vaccination first to them. And we missed that.

RITA: What about the impact that migrants face when they have family who are overseas, who are also being impacted by the pandemic who pass away and the emotional impact on families who are not able to be with their loved ones at that time of passing? Is that something that has been widely recognised, do you think?

JAYA: I don't think it has been widely recognised. What we know is we live in a global world. So we had, for example, the Indian community, many elderly parents were in India and the Delta outbreak was considerably harsh in India. It was an outbreak that had a huge number of deaths and impacted everyone of all ages. But for the elderly, it was difficult. And with the borders closed, people actually could not go to see their family members. This impacted them significantly because they felt that from a human rights perspective, from a compassionate perspective, they needed to be able to travel and they were not able to do so. It was also there in Australia because people were not able to see their elderly parents in those homes because the homes were locked up, and people felt that this was a problem because their elderly parents actually relied on their family members coming two times a week, three times a week, to talk to them, to actually take them out for a coffee, and all that stopped overnight. They couldn't understand this. And when you are elderly, when you might have mild dementia, this becomes much more difficult and has a psychological impact.

So, I know several friends who have lost family in India, in Bulgaria, in Italy, not being able to go [and this] has been quite challenging for them here. Now they are able to go, but it means that they have not been able to go and grieve with the parent that has been left behind, not complete the rituals. So, they felt that they had to do the rituals after a year, but even after a year, they could not travel from Western Australia. So, people have actually had these experiences, having been in Western Australia, and not being able to be there for their family members. And that's been quite harsh, I feel. So, some people had not seen their families for up to two years. And I think that's not right. The government could have looked at it on a case-by-case basis, but it chose not to do that. The constant message was that we are protecting you. So, the onus was protecting you, so we have these closed borders. For those who had family in other parts of the world, this was harsh. They really wanted to go and see their family members and be able to do that. And in cases where they lost their family members or family members died, they could not actually be with the family members there to do the process of grieving.

RITA: There was a preponderance of online funerals. And in some ways, of course, we all adapt to whatever environment we have. But did you feel that that in any way alleviated actually being there in person?

JAYA: No. I don't think so. People would have liked to be there, but they knew they had no choice. So, they felt that looking at the funeral online is something that they've seen that someone has done something for them. So it's been challenging at so many levels.

RITA: So, you are from India. But you've lived in Africa as well. Sometimes when there are these populous communities, it's relatively easy to say that life becomes cheap because people die much earlier for all sorts of different reasons, and that death is not the great taboo that it is in modern societies, where people seem to now be able to live for a long, long time without any threat to their wellbeing. Do you think that in those countries where death is a part of life, there is a greater acceptance of death?

JAYA: Yes. There is definitely a greater acceptance of death because they feel death is a part of life, you know? And in some ways, they know that you could die of a disease, like in India and in Africa, infectious diseases were rampant. So not only COVID, but there are other infectious diseases. So, in India you have multi-drug resistance TB, and you still have that. You have severe infectious skin infections that people do get. During the rainy season, you have diarrhea outbreaks, during the floods, you'll have cholera outbreaks. So, people accept death, that this can be part of life, and they also grieve. But then they move on. So grieving is often loud. It's quite okay to cry and cry as a community and lament that person and share something about that person. Communities celebrate at weddings, but communities come together in death too. The whole community will come when there's a funeral, people will bring food to that family. And in the Hindu culture, they have to cremate the body within 24 hours. So we don't have a funeral parlour where the body goes to, but we dress the body, we order a coffin and the body lays in repose at home and people will come and there'll be a constant prayer that goes on. And if you can't go to the actual funeral ceremony, you'll actually go afterwards to pay a condolence visit, and you'll go with some food or you'll go and sit with a family and you'll say a prayer. So, it's something that you do. And we even do it here among our migrant communities.

But when I was in Africa, there were three or four world events that took place, you know. So, one was the HIV pandemic in Sub-Saharan Africa. I actually lived during another pandemic and my daughter was born during that HIV pandemic. So basically, in Uganda, you had conflict, two decades of violent conflict and brutal conflict, during the reign of Milton Obote and Idi Amin. People disappeared, students were decapitated, so it was quite brutal. And people had lived through that. You also had conflict in South Sudan and the refugees coming across the border into Northern Uganda. [And] basically, you had men and women being affected by HIV. There was still a lot of stigma. What they would call it is they called it ‘slim’, because people grew thin because there was no vaccine, there was no antiretroviral therapy.

And you had whole villages like Rakai village in Uganda [where] the youth were decimated with HIV. So, you had young children being looked after by grandparents. You had a generation lost, you had huge amounts of HIV among young military recruits.

And then I was in Uganda when the genocide took place in Rwanda. So, for me, that's what actually made my interest in post-conflict countries and nations so strong. And those three months in 1994, it was like the world just forgot Rwanda. It was the largest killing of people in the shortest span of time. So, you had 800,000 people, nearly a million people, who died in three months, and you had 2 million people who moved across borders due to that.

I had grown up in a conservative family, a Catholic family, where I was protected. You know, I lived in a place where the police had batons in Mumbai, to then come to Uganda, where there were soldiers on the street, and then hear of the genocide where essentially, it was tribal, where one tribe was killing the other. Like neighbors turned on each other. So that to me was very confronting.

RITA: How does a community, how does a society, recover from that? Is it just that we as living beings have this enormous ability to be able to go through such terrible trauma, but still survive, this survival instinct? What is it about the human psyche that allows us to survive these terrible incidents?

JAYA: What I have found, Rita, is that people are extremely resilient. Now, in Africa and in India, there is no social security system. You work and you eat. If you don't work, you beg or you live on the streets. So, one thing we found is people were resilient because they had to look after their families. I had women telling me this, always telling me [this].

I had one of my colleagues in Uganda, and I'll never forget her because she said, my husband used to be the deputy academic registrar of Makerere University. She said, I was a teacher and I had six children. And one morning the soldiers just came and shot him in front of me, but I had to live, Jaya, I had to live for the sake of my children. And she did, she didn't only live, her children grew up and became educated. So they were extremely resilient. So, for me, I use the term resilience quite a lot in my research, and empowerment, because people felt empowered. They felt that their needs were so little. All they wanted was a small plot of land to be able grow some food, have a meaningful job, and then look after their family. They didn't have these big ambitions because they had gone through so much.

You know, people would lose their siblings. Children would lose parents. The problem with the genocide was they couldn't find the bodies because the bodies were in mass graves, or in graves in churches. And that's what affected them more than that [death], because they feel that the grieving process had not ended. They had not seen the body of their father or their mother.

So that to me was quite challenging. When I was in Rwanda, it took me two years to go and visit a mass grave site, because what the government did is it had these genocide memorials so that the world doesn't forget that these atrocities were committed. Now they have a complete genocide museum, et cetera. But at that time, they had these churches where the atrocities took place that were left there.

RITA: What did that feel like? Did you feel death around you?

JAYA: Seeing that filled me with a deep sense of sadness that as human beings, we still can do this to each other. And in 2022, we are hearing about [the same] in Ukraine and I thought, you know, the world is not able to stop this. This is a problem. We shouldn't have this. We shouldn't have war full stop, but we keep having this in the Congo, in Somalia, in Afghanistan, in Syria, in Iran and in Iraq and now in Ukraine.

RITA: Can I ask you how you sleep at night?

JAYA: You know, these images often come back to me, but I often feel that listening, and giving people a voice is really important and you actually share stories of those who don't have a voice, they might never be heard. These are lived stories. They're real stories of real people who have lived through brutal regimes, the HIV pandemic, the genocide, the Balkan War, the conflict with the Tamil Tigers; people who have lived through that and continue to live through [that]. So I've seen death in all these multiple forms, Rita.

RITA: Last year, the WA government voted for voluntary assisted dying which allows a very narrow minority of people to be able to die at the time when they think that they need to be able to do that. Have you ever considered, or have you already planned, for how you would like your death to be?

JAYA: Yes. I have actually thought about this because I travel for work and I travel to conflict areas. So, for me, it's really important to have things in order, to have a will. And at the same time to decide if I die, then I definitely want to be cremated, but I also want to be an organ donor.

I know about the voluntary assisted dying and for a long time I've also read about euthanasia. Often, I would hear people in India say, who are in their nineties, they say, I'm just praying to God to take me away because I feel I'm a burden to my brother or to my son. You know, I have to be looked after and I'd be very happy to actually die. And if a person makes that choice, but their quality of life is really limited, then that's a choice, but we don't have that freedom yet of a living will to be able to do that. The other thing is I've heard many people say that if I'm in an accident, no resuscitation, or I don't want to be in an induced coma for a prolonged period of time, I'm happy to die.

But for me personally, from a health perspective, from a dignity perspective, from a quality-of-life perspective, voluntary assisted dying is a good thing, I think. It gives people that choice to make their own decisions about their own end of life.

OUTRO: Thanks for listening. This interview was recorded on the lands of the Whadjuk Nyungar people, and we pay our respect to their Elders, past, present and emerging. This oral history collection was commissioned by the State Library of Western Australia and produced by Luisa Mitchell from the Centre for Stories. Narration by Luisa Mitchell, editing by Mason Vellios and special thanks to executive producer and interviewer, Rita Alfred-Saggar.

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