Transcript of Interview with Virginia Chang by Kit Heintzman

Interviewee: Virginia Chang
Interviewer: Kit Heintzman
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Location (Interviewee): New York City, New York
Location (Interviewer):
Transcribed By: Angelica S Ramos

Some of the things we discussed include:
Working as a certified end-of-life doula. Pre-COVID working primarily with the dying person; post-COVID supporting the caregivers of dying people. People dying alone during the pandemic. Providing individual support to multiple family members and group support. Increased demand for end-of-life doulas in late 2020; supporting those who were supporting loved ones of the sick and dying. Dying well. Losing a friend to COVID in May 2020, not knowing that the last time you see someone might be the last time you see them; getting access to his body so he could be cremated; goodbye ceremony outside of the crematorium. Going through a divorce, children going off to college. Taking new directions in life.

Kit Heintzman 00:02
Hello

Virginia Chang 00:03
Hello Kitt.

Kit Heintzman 00:05
Would you please start by stating your full name, the date, the time and your location?

Virginia Chang 00:09
Okay, my name is Dr. Virginia Chang, and I am in New York City, New York. It is Monday June 27 2022. At approximately eleven fifteen am Eastern Standard Time.

Kit Heintzman 00:28
And do you consent to having this interview recorded, digitally uploaded and publicly released under Creative Commons License attribution noncommercial sharealike?

Virginia Chang 00:38
Yes.

Kit Heintzman 00:40
Could I just start by asking you to tell me a little bit about yourself? What would you want anyone listening to this to know about you?

Virginia Chang 00:53
What would I want someone to know about me? I'm a born and bred true New Yorker. I probably the most relevant information with regards to why we're having this interview is that I am a certified end of life doula.

That's probably how I identify myself recently, although it's only a profession and a role that I've come into more recently in life. But it's become a major part of my life and my identity right now and the work that I do and the way it has impacted me in the last few years. So but, um, but it's not the sum total of who I am. But we'll just leave it at that.

Kit Heintzman 01:46
Would you tell me a story about your life during the pandemic?

Virginia Chang 01:53
Tell you a story about my life. Well, let me back up and say that for people who are not familiar with what an end of life doula is, okay? And end of life doula is a non medical professional, who guides, supports, educates companions, dying people and their family and loved ones to approach end of life in a positive, meaningful, and affirming way. At least, that's my definition of what it is that I do. I actually came into this role in 2017, because of personal tragedies that I had experienced. And it turned out it was a rather fortuitous with COVID, occurring in 2020. Because when I decided to step into this, sort of like, I don't really want to say it's like a career, it's a job, it's really sort of a role of service of like, being in service to other people. And I wasn't doing it for the money, I was really doing it because I saw a need in society, that humanity, people weren't dying well. And there wasn't a awareness of, of death and dying in society, and that I realized there was such a fear in approaching these topics, and that we as humans weren't dying. Well. I mean, and, and these were just conclusions I'd made from my own personal story. And so I sort of started this journey myself to like bringing awareness of better dying, and you know, get over my own fears and concerns about what and develop, you know, a more positive attitude to what death and dying meant in society nowadays. And so I sort of started that own personal journey and then by the time COVID, occurred in 2020, I mean, I have to say it was rather fortuitous. So I spent basically 2017 to 2000, beginning of 2020, sort of training, learning and gaining clinical experience to really learn what it means to be in service to people at this stage of their life. And what it is that DYING PEOPLE NEED or looking for, or how do they achieve a peaceful state of mind where they can die peacefully. Calm and accepting, not afraid, not alone. I'm feeling like they've had some purpose or meaning in life. So I sort of spent those two, three years training myself, I did a lot of multiple, I did multiple trainings. And then I spent a year doing clinical experience working in hospice, getting a lot of exposure to people who were dying. And in this case, they were obviously not dying of COVID. But they were dying more of like, cancers, terminal illnesses, congestive heart failure, old age, frailty, things like that. But I saw a wide variety of patients illnesses, disease, progressions, different settings. And so I think it really set me up very well to sort of understand the wide range of emotions, situations, feelings. And, you know, if you want to go to even extend it to like, sort of like even the range of motions that one might experience when people are afraid of death, despair, regret, loss, loneliness, and those types of things. And so then, by the time COVID, happens in March of 2020. You know, at first my first reaction was like, oh, like, my work has stopped. Because I thought I couldn't see people anymore, right? I mean, the whole thing was, we were isolated. We were not having contact with people. I mean, we weren't even supposed to talk to strangers.

Virginia Chang 06:52
I mean, so I mean, you can imagine you weren't going to be invited into someone's home. And so I literally thought my work had stopped, like, and it was like for, March to July. My work stopped, and I was isolated at home and living this world of like, I don't want to say fear. But there was an element of fear and isolation. And like, uncertainty, I think that uncertainty was the biggest thing in the early parts of the COVID days. It's just like, we didn't know what we were dealing with. But then, you know, people started to die. A lot. A lot of people

started to die, and in really, really horrible ways. Right? Gasping for air alone, without any family or loved ones. And even the health care professionals who are, you know, obliged to take care of them. It was such a lack of personal connection, because they themselves were afraid. They were not knowing what was happening dealing with COVID. And then to be masked up, like, you know, in these contamination suits. I mean, there isn't just that element of connection that was so important to give death a more personal touch a more final elements of meaning and purpose in like, I've been seen in this world before I die, right. I mean, people were dying. People were dying in the didn't even know that. They were never going, that they weren't going to die, that they were never going to have a chance to see their loved ones again. People died without ever having to say goodbye to people.

Virginia Chang 09:10
I mean, I'm not telling I'm not saying anything new that everybody who has lived through this time period knows. Of how much uncertainty and how much fear and ugliness and just how difficult it was how challenging how, how, how heartbreaking it was, during that time. I actually, I actually had a personal friend myself who died of COVID. So and he died in May of 2020. And yeah, It was it was not it was not a good time

Kit Heintzman 10:07
Okay. Would you share something about the friend that you lost?

Virginia Chang 10:11
Oh. Well, he did have an underlying condition. So he had a comorbidity but you know, before COVID, there was always the thought that he would get better, that he just needed time to get better. He just needed time. And so his family, all his friends, myself included, we were just waiting. We were waiting, we were waiting for the time for his body to heal, and to get better. He was in a private room. His mom was a devoted caretaker. I mean, he was in a private room in a rehab facility.

Virginia Chang 11:13
But his mom was a devoted caretaker, you know, visiting every day, for five years. Being with him all the time. And one day in March of 2020, she said she had to leave, they forced her to go. She didn't know she was never going to see her son again. I didn't know that I would never see my friend again. I can't recall the last visit I had with him before that because you know, it was just one of so many visits. And you never thought it was going to be the last one, right. And COVID was brought to him in his private room. And he died in May 29, of 2020. His mother called me in the early afternoon, soon after she had gotten the phone call from the facility that he had died. I mean, he she didn't even know the oldest sequence of events he had actually contracted a COVID. And because the rehab facility wasn't equipped to deal with COVID patients, they sent him to the hospital and he ended up dying in Jamaica hospital. And she called me in the early afternoon after she found out and you know, I mean, there was such anguish in her voice. Such heartbreak, right. She never even got to say goodbye to her own son. She never thought that when she left the facility when she was forced to leave the facility in March of 2020. She didn't know that she was never going to see her son again.

Virginia Chang 13:22
Yeah, to hear her voice when she called me that was really difficult. But I knew it like as soon as I saw her name on my cell phone, I knew that's why she must be calling me. I can say that I was fortunate at that time to be an end of life doula, because I knew what was happening to his body. And of course, we also heard what was happening

in the news. And he was one of one he was just like one of hundreds and hundreds of bodies in these refrigerated trucks out and parked in front of the hospital in Jamaica Boulevard, right? With a tag on it. I mean, hundreds and trucks, just hundreds and hundreds of 1000s of bodies just jam packed full in these trucks to just house enough people who are dying so fast. And fortunately, by that time, I because there was an end of life doula and I had started to practice and I I had a lot of connections in the death care space. I asked the mother I said, you know, the mother was in Tennessee. And they had I mean, they had they were not he, my friend lived in New York City, but his family was from the south originally and so the he had no family in New York and they could not travel to New York City. And so I asked the mother I said, Would you like me to try to get his body out of there, find his body and claim it. And she couldn't have been more grateful. And between myself and a colleague of mine, who was a funeral director, we managed to find his body that evening it was, yeah, it was difficult it was. And we, and for that, like, just to know that he wasn't one more last body in the 1000s and 1000s of people who were dying, especially in Queens, New York at that time, was really it was it was it was grateful to know that we had been able to pull his body out of that mass of humanity.

Virginia Chang 16:03
You know. I mean, he was just one, he's just one person. And he's just my friend. He's also, you know, one son, one brother, one uncle, one close friend to many people, but you know, there were 1000s and hundreds of 1000s of people who, you know, they didn't have good ends. But, um, we were fortunate because I was in the death care space as an end of life doula, I knew what to do when we were able to, and even though his family was not able to come to New York City, and we were not able to have any gathering, we were able to give him a very meaningful and beautiful send off. And we had his body cremated in Greenwood Cemetery in Brooklyn, New York, in a beautiful, beautiful simple service in the in the loading zone area of the crematory because, because we couldn't gather, like, in a reception area, we couldn't gather at a funeral home. We couldn't we weren't allowed in the crematory. And so just in that split second, in which his body was being transferred, transported from the cold storage at the funeral home where my colleague was keeping him to the crematory we had like 10 minutes in that parking load zone outside the back of the crematory. And it was beautiful. It was enough was that there was myself and two other really good close friends of his and my colleague, the funeral director, but what was really beautiful was in the intermittent time between his death and when we've had him cremated. You know, his friends and family network had all been gotten in touch with and everybody mailed beautiful letters and notes and photographs, and what I call olds of love and laughter. And we plastered his casket with all the images on the outside and sent him into the flames with all our love

Kit Heintzman 19:06
Who was supporting you throughout that process?

Virginia Chang 19:17
Not very much. But after that I had to escape from New York City for a while too. It was that was a really intense time for me. So I actually escaped to New York City and went upstate to a cabin and actually took the month to, as you say, to process what happened to take care of myself. And I wrote about what happened. And funnily enough that story was actually just published last month by a medical humanities journal One of the leading medical humanities journals. Yeah, it didn't start out as something that I wanted to write or to share with the world. But I wrote, To process to help myself, come to grips with what had happened, and to try to make sense of it and try to understand. But then, you know, it turned into something rather powerful. And people said, oh, you know, you have a good way with words, this is so powerful, and I had a slightly different perspective on it. And I

think that's partly because of the work I do in working with dying people. And trying to understand things like this, but turn it into what can we learn from it to do better? How can we, as humans learn to do better? How can we learn to die better? How can we bring more awareness into ourselves into living and dying to just bring more richness and fullness into our lives. And so I wrote this story. And then I've been reading it, I wrote this huge, I added more and more and more to it, but then it turned out that in order to get published, I needed to cut back and back and back and back. So it's, it's gone through about like five major revisions. But it was just, I think, all of that work and all of that writing and all that processing really helped me and it finally got published in one of the leading medical humanities journals intima it's the Journal of Narrative Medicine out of Columbia University. And it came out last month and so that was thrilling because the week it came out, is my friends family. Finally traveled to New York City and gave the memorial for their son to his New York City, friends community. A one week after that, and when I spoke at his memorial, I read my story. So that was it just seemed like everything was coming into place just falling into place. And for myself, I'm I have a really good sense of closure about everything. And it's still miss my friend, but that's okay. i That's just that's that's part of grief. That's what love will live with me. And I only have good memories now.

Kit Heintzman 22:58
How did the pandemic impact your practices as a death doula?

Virginia Chang 23:03
Okay, yeah, so, so I'll go back to that. So, um, as I said to you before, like in that first few months, I felt like I wasn't going to be doing any work, because like, even though many people were dying, there was no place to have contact with people. We were everyone was too afraid. But towards the end of the summer of 2020, I started getting a lot of inquiries. People were just desperate. People were just desperate. People were dying. People weren't dying well, and and not only all of that, but all the people who were supporting the people who were dying, or people who were ill. They had no services available to them, right. There weren't home health aides, there wasn't support services coming into the house. I mean, I mean, people were still people were too scared. And all the services had either been cut off, or cut back. And, you know, families who often had had 24/7 hours support, now had nothing, and they had to completely fill those roles themselves. And so they were being forced into roles that they were not accustomed to, or expecting to fulfill. And they were completely unprepared, unskilled, and, you know, overwhelmed, to say the least, I mean, and so towards the end of the summer of 2020, I started getting desks. Britt calls from caregivers family, people just saying like, Help me, help me. And so my work as an end of life doula then shifted really from pre COVID, where I really been working with the dying people, the dying person as my focus really shifted to working to the caregivers as my focus. And in fact, it really makes sense. Look, as an end of life doula, all I'm interested is helping you, the dying person to find a path to a positive, meaningful and affirming death, I believe in your capacity to find and determine what's best for you. My goal has always been to empower you in your own end of life journey to create an ending that is personalized, meaningful, and peaceful for you and your loved ones in those last months, weeks, days, moments, up until your last breath. Now, before COVID, my work had been strictly almost exclusively with the dying persons, the ill persons. But when COVID happened, I realized that I can achieve the same thing by empowering the people who care for them. And so by working through the caregivers, the family members, the loved ones who are supporting the person who is dying, by helping them to be to be helping them in their role as caregivers, to making sure that they're taking care of themselves, to make sure that they have knowledge about the end of life process, to make sure that they have support, that they feel like they have, you know, someone to ask questions to resources, that they feel guided and supported. If they're supported and feeling better about themselves, and the role that they're

in as caregivers, then they will be able to be a better caregiver to the person who was dying, and be able to offer a more positive experience for that dying person.

Virginia Chang 27:56
And so my goal, as an end of life, doula shifted to caring for the caregivers. So that they can then support the dying people or the ill people in their best, to their best positive selves. And so I don't need to work with the dying person directly, I can use the caregivers as conduits. And in fact, it's almost a more powerful experience, because what ends up happening is that after that loved person loved one dies, the people who remain behind the survivors, they have such a shifted, positive perspective of the whole dying experience. The journey, leading to final death, that it changes their whole outlook, on their own lives, their own deaths, and their whole path moving forward. Until they're actually I've the ripple effect is actually tremendous. It's more than just dealing with one person whose experience you have impacted and changed and then that person dies and goes away. You've impacted everybody in the circles around them. And so, so I've gone from this idea of like an end of life doula is not just about the dying, but it's really about the dying and all their loved ones and all the people that they've touched and impacted in their lives and to have that possibility and that potential to shift people's whole outlook and perspective about death and dying. It's like a It's a tremendous gift you can give to people

Kit Heintzman 30:03
Would you be able to give an example of what some of those shifts you've witnessed have looked like?

Virginia Chang 30:19
Um family, or loved family members or loved ones of people, of people who I know who have died. So now it's like I support the family as opposed to the dying. They have consequently gone on to become end of life, doulas themselves. And so their potential to impact other people has just grown from the fact that I supported their loved one. So, okay, just to be more specific, I was hired by a family. The grandmother was dying. I supported the family, the grandmother and her extended family of 10 members. So I supported each one individually, as well as the family as a unit, and the grandmother, as well. One granddaughter was so impacted by my work and how I impacted her family and the death of her grandmother's. She has gone on to become an end of life doula, and she is thinking of opening up a holistic death center in her hometown. And she wants to partner with like palliative care doctors and funeral directors and holistic practitioners such as acupuncturist and physical therapists to create this sort of like holistic death center. It's a pretty tremendous ripple effect. Like, because I helped her family in the death of her grandmother, she has changed her whole career path to now wanting to enter the death care space, and the number of people she will impact is also like incredible. And that was just from work that I did with her family.

Kit Heintzman 32:27
In addition to COVID-19, what else has been on your mind and heart over the last couple of years?

Virginia Chang 32:43
Well, besides COVID-19, actually, this has been a tremendous amount of a lot of personal change for myself as well. So I actually got divorced on both my kids grew up and went to college. So I've kind of re I'm taking this time, as a whole, like rediscovering of who I am, what I want, and what kind of life I want to live in this next stage moving forward. And I actually have to say, for me that I know COVID was a tragedy, a global tragedy. And without a doubt, I mean, I've seen it firsthand as an end of life doula, but also as an end of life, to love being

exposed to all that death. It has pushed me into positive ways of changing my own life personally, and using the lessons of death from COVID to really bring more positive change in the death care space. And so things that I think about is learning to feel comfortable living with uncertainty. Learning to be flexible, adaptable, going with the flow, living in the moment, right reinitiation for what we have now. You know, offering gratitude to other people. just acknowledging the good that you see right now. And letting people know, because you never know what's gonna happen tomorrow, but if you can just thank them, appreciate them. Notice the good that's happening right there in that moment. And you give that person that little spark of joy or you feel that little spark of joy, you know, that feels pretty damngood. And so, I'm I've, my whole personal life has shifted to one Where I try to live like that every day. And I can say that I'm no longer afraid of death. I don't know if I was ever I don't I don't want to say what I was ever afraid of death. I don't know if I was ever afraid of death, I can honestly say that I never thought about death. Right? So, I don't want to say that I was afraid of death. It's just that I never thought about it. But I can say now that I'm not afraid of death and that if I die, I'm okay with where I am.

Kit Heintzman 35:35
Well, I thank you so much for the generosity of your time, and the beauty of your answers. I just want to open up some space if there's anything you'd like to share that I haven't made room for. Please take the last word and

Virginia Chang 35:49
I'm not sure I mean honestly, I'm kind of like surprised where this is where this ended up. But that's what often happens people ask me and I, I mean, honestly, I can just talk a lot I can just go on and on and on. And I'm and I appreciate your questioning and the direction it's taken. But I think there has been a lot I've also learned to embrace that what you cannot control you have to let go. And there were so many things about COVID that we could not control but those things that you can control embrace your power to do so. And and use it to power yourselves forward in a positive manner. And those things are you know, your thoughts, your own actions, and your small community around you.

Virginia Chang 37:17
And I can honestly tell you, I was never like this my entire life. So what would people like to know about me? I mean, you probably just listened to me for like last 45 minutes and maybe you think like, oh my god, I sound so sage like, but honestly, I was never like this the majority of my life for you know, 50-55 years of my life. So I'm living proof that it's you have the power, you have the ability, you have the capacity within yourself to make positive change and to redirect your life in a way that you know, makes you feel good makes you feel like you have a reason for being here on Earth. And that you know, you still can do good in this world or and that even out of great human tragedy, you know, good can still come I don't know what else to say. Thank you so much Kit.

Kit Heintzman 38:39
Thank you