

Independent Study/ The Labor of Care Archive

Monica Ortiz-Suloway

Interviewed by

Dolores Urena

October 15, 2018

CWE, City College, NY

### Narrator

Monica Ortiz-Suloway is currently an Adjunct Lecturer at CCNY/Center for Interdisciplinary Studies, where she teaches Intro to Developmental and Intellectual Disabilities, Medical Aspects of Disabilities, and Sociology of the Deaf Communities. She has a Master's of Science in Education from Hunter College, New York City and is a Certified Rehabilitation Counselor for persons with intellectual and developmental disabilities. Ms. Ortiz-Suloway is a candidate for a Master's in Clinical Social Work from Fordham University, in the field of gerontology and bereavement counseling. Ms. Ortiz-Suloway is fulfilling her clinical hours at an assisted nursing home and palliative care facility.

### Interviewer

Dolores Urena (43) is a graduate student at City College (CUNY) enrolled in an independent study about the Labor of Care in America with Professor Kathlene McDonald.

### Restrictions/ Consent

Signed: The Labor of Care Archive Informed Consent Form

Signed: Labor of Care Archive Oral History Interview Release Form

### Format

Interview recorded on October 15, 2018 in Wav format using aTascam DR-05. One file  
43 Minutes 15 seconds

Transcript

Transcribed for clarity by Dolores Urena, waiting for Monica Ortiz-Suloway to review  
and approve.

**Monica:** So, My name is Monica Ortiz-Suloway and I teach in City College and I am of  
Puerto Rican descent I am a native New Yorker, born and raised in New York. Or as  
they like to call us, New York Ricans. I am 58 years old, and my mom is 85

**Dolores:** That was going to be my next question; your care situation is your mother?

**Monica:** Yes, mom is 85 and she has Osteoarthritis, Osteoporosis, Parkinson's  
disease, Dementia, and Depression.

**Dolores:** How long have you been taking...

**Monica:** So, this is going to sound very strange but I am 58 and I have been taking  
care of my mother for 34 years. Because when she was 50 my father died, very  
suddenly of a vehicular accident, and, um, and my mom totally lost it. And although  
she was in her own apartment I became her caretaker for everything. So, my son is  
34, so that is when I started taking care of her so, 34 years ago when he was a baby.  
so, I took on my mom, my aunt who was intellectually and undeveloped, severely

incapacitated that I inherited from my grandmother's death. So now I have a 60 something-year-old aunt, my 50, only 53-year-old mother, a ten-year-old niece, that my sister has mental issues, I ended it up with and a baby with no husband yeah, and that was 34 years ago and all this time, so now obviously for the last good ten years with these compromise medical situations that she has really, I just came from being with her for a couple of hours, yeah.

**Dolores:** Do you rely on paid caregivers?

**Monica:** I have three fulltime home attendants that are with her 24 hours a day, otherwise I would not have much of a life but still like I have their texts and their phones and you know I am there twice a week I call her twice a day, every day and I rely on them for food the cleaning, and food shopping and keeping an eye on her because she is what you call a wanderer so if you turn your back she walks out the door but won't, sometimes she knows where she is but sometimes she doesn't

**Dolores:** Do you have other family members that are part of (hesitation) I am going to open this...

**Monica:** yes, I do have other her family members they are not part of my mother's care management team, I have power of attorney health care proxy, I am the go-to person. It does not matter if I am on vacation in Portugal like I was this summer when I got the phone call I have to be hands-on, I have a sister that leaves 15 minutes from her but I leave in Ossining, two hours from her but I am it. Essentially I am an only child, yeah

**Dolores:** okay. um, so, two hours away and you do see her twice

**Monica:** Um, while I teach here (City College), while I do three days of clinical practice while I take four classes at Fordham back to back and then Saturday and Sunday I read and write catch up on my papers, dash to Brooklyn. I like to you know what, I love my mother but it is a lot of work, but I just like to put my eyes on her I like to see her you know, she still knows who I am but is going to come the day that I am still going to know who she is but she is not going to know who I am so it is not easy

**Dolores:** no, it is not. How do you deal with it?

**Monica:** (Nervous chuckle, holding back tears) a little sample

**Dolores:** I might get a little personal

**Monica:** no, it is all right

**Dolores:** how do you deal with that?

**Monica:** Everyone deals with it differently, you know what I have a masters in rehab counseling and I have a lot of ways to tweak my days and my hours and my time is not always easy um, I also I think you meet people where they are at you know if something doesn't get done something doesn't get done, I have learned to let go of a lot of my control issues yeah so basically Monday so I get up I get myself together and organize I pick my notes from my class tonight that I prepare yesterday um I head to NY I get on the train so I work on the train and I read and work on the train and I get to and I stopped because I get her flowers every week because she says she can't smell them when is dead, you know the Latinas, you know how they are (laughter between Dolores and Monica)

**Dolores:** There is even a song that says that right

**Monica:** yeah, yeah, I can't smell them when I am dead, so I get her flowers at Grand Central, I jump on the train I get to Brooklyn I stay with her, I was there today for two hours I wasn't there long time, I was there for two, two and half hour and then I jump on train to come and meet with you and then when I am done with you I go and teach my class which is what bring me some, so that I enjoy and I enjoy my students so then I can detach because at some point you have to stop.

**Dolores:** Yes

**Monica:** Um, like the day before yesterday I got a call from the home attendant my mom kind of fell but she didn't fell all the way, she got a little hurt, nothing with the ambulance, the week before that she took too many pills they thought she was having a stroke 10 o' clock at night okay, I have to go to Brooklyn because the ambulance is coming for my mother. To answer your question I do it one day at a time I don't, as I left her I am not worried that she is going to fall again I just wait for the phone call but I put it kind of over there somewhere (chuckled)

**Dolores:** Is a lot of self-therapy sounds like

**Monica:** yes, I need more therapy (laughter between Dolores and Monica) you know what, is you know like if you had children and you have had a husband or you've had listen this is a very interesting sidebar, I was interpreting in government offices for my grandmother and my aunt who was severely incapacitated when I was 10 year old that would never happen now so once you got into that mind set to me is second nature to pick a phone and make a phone call because if you don't ask you don't get I learned that from the time I was 10 years old when we were in agencies and people would be talking "esa gente"(those people)"they are lazy they are

coming in here for a hand out", not knowing, like, they knew that I was Spanish and I was interpreting and this was for my grandmother whom I loved dearly and took care of her until she died and then with my mom too even now is like I get everything that is going on my focus is even though is exhausting my focus is my mother because one is going to come a day when she would not be here like I told her today "cuidate" you know to take care of your self because I only have one mom

**Dolores:** Is she able, because you said she is suffering from all these...is she able to understand, she is able to

**Monica:** you know

**Dolores:** being able to tell her

**Monica:** this is very interesting my mother still very clear in some sections and then she is not clear in others. Like I made a list of every day where I am at so she can look at it and see where she can find me, he can always find me on my cell phone she is very clear, she is very vain, her hair is done, the nail everything, (smiles) there you go. My mother understand a lot still, she is not completely gone I would say in a scale of 1-10, dementia being the worse at 10 my mom right now is about 3 or 4so for 85 I think she is still pretty clear, yeah, yeah. Trust me that I sound good but this wasn't as good like a couple years ago until I figure out how to handle everything and is really time management, I tell my student is time management it doesn't always work but is time management

**Dolores:** realizing it and trying to apply it

**Monica:** you know what if, I usually get her flowers but if something happens that I can't do this it doesn't get done and then I say I am sorry you know, I can't do that

for you she wants to go to the cemetery to my father's grave can't do it I have to write a paper I have to say I am sorry I'll pay for an Uber so she can still go with her home attendant so you let go of some of the control because otherwise, I would be dead

**Dolores:** wow, you can teach a class on that,

**Monica:** Well,

**Dolores:** really, that is wonderful, really

**Monica:** is control, you know. when you become the caretaker and I have really been thinking about that so interesting that Kathy suggested it we talk about it a little bit I have been a lot about handling my mom because is not what you do is how you do it is not what you say is how you say it so you just have to is not always easy there are tears there is lot of crying in between but then I look at her and by the grace of God go on I don't know what is coming for me I doing clinical hours with a nursing home and I am meeting amazing people amazing, and everybody has a narrative, everybody has a story good bad or different wonderful whatever there is issues in every story that you are going to hear and so with my mom, now, I just have been trying to videotape and audiotape her and get her to talk about the old day get her to talk about stuff because that is my personal archive

**Dolores:** that is wonderful

**Monica:** yeah, is hard sometimes this stuff is really hard it is hard

**Dolores:** yes. You mentioned son,

**Monica:** yes

**Dolores:** is your son involved at all



**Monica:** yeah, you know he is a guy (laughter between Dolores and Monica) when I got the phone call for the hospital situation I called him he is Brooklyn. he said "I live near that hospital, I go check if you don't need to come then you just stay home and finish your work and that is exactly what was able to be so he came he went to the hospital he checked her he spoke to the home attendant he called me and said "you know what she is sleeping it off she took four pills instead of one they got her on two IV they flushing out of her system she is fine don't come" so he was able to articulate be very clear I got on the phone with the doctor he said the same thing and so(deep breath). I breathe, I went back to my work and I finished my paper

**Dolores:** so he is supportive?

**Monica:** he is supportive, the best he can, he is a boy(Laughter from Dolores) he is a young man

**Dolores:** is there anyone else aside from your son that takes that role that you can count on

**Monica:** no, no. I basically do 98% he does 2%

**Dolores:** he probably doesn't do any, but is just so that when...

**Monica:** no, you looking at it I am chef, cook and bottle washer

**Dolores:** so, what happened when you went to Portugal, you mentioned Portugal, give me a little bit of what happened

**Monica:** (Chuckled) I call her when I am on vacation every day, so I called her and she was feeling very poorly and she layout the guilt and then the home attendant sent me a text in Spanish, they are all in Spanish they don't speak English "ella esta

bien, ella esta bien, no venga!"so she does it every vacation last year I was I think in California

**Dolores:** so she contacts you and says I am not okay

**Monica:** right, yeah, yeah, she is very manipulative

**Dolores:** okay (Surprised tone)

**Monica:** and she can stick you with the guilt, and I basically access by asking her a series of questions and then I ask the home attendants to be on speaker phone in Spanish and then I ask again the questions is there a fever is she bleeding is the pressure over 200, you know this are the questions I ask once I get the dynamics of it I say you know mom I am like a seven-hour plane ride away so, I am going to ask you other daughter "no, no, no la llames que estoy bien"(no, no, don't call her I am fine) so as long as I access and the home attendant don't get to pay the money that they are worth

**Dolores:** no, they don't

**Monica:** they seriously, they don't they are I got three one is better than the other I trust that they are giving me proper information and so I digress because I wanted to mentioned that I do have another support system is not fair not to mention my niece whom I raise who lives near me, if I have to call her and ask her to go down there and take a look at what is going on she will do it for me but she got two small children so I don't like to ask her but in a pinch if I call her she knows she has to go because I never call her

**Dolores:** and you were in the situation right, because you were the sandwich generation, I was reading about it

**Monica:** yeah, the sandwich generation... I have been doing that for so long, so she will rise to the occasion

**Dolores:** you are so considerate to think of niece in that situation to not get her to involve, because you thinking of her as well, so caring doesn't only happen towards your mother you are looking at a bigger scope of things here

**Monica:** you are looking at the mother to the world, I take care of everybody which is something I working on stop doing as much and to rely on other people for help because you know what none of us can do it is a big job no one can do it by themselves

**Dolores:** the next question that I have is was it by choice that you taking care of your mother obviously there is love...

**Monica:** I don't want to take care of my mother I learned to love her and I learned to take care of her no, I don't have a choice is either a nursing home which I will not do that to her or o take care and have these services for her I ...(hesitation) this is very conflicting my mom was not a good parent, she was not a good mother. My father was not a good father so I come from a very violent domestic violent child violence I have a damaged ear a broken nose I suffered abuse in the hands of my father who was an alcoholic and so these are components that I look at and go really " you didn't protect me from that son of a bitch and now look where you are and look where I am I am taking care of you but I go back there for the grace of God she is my mother she is my only mother like I told her today and is conflicting but I had, if I don't take care of her she is going to be where? like destitute

**Dolores:** is your sister, not an option?

**Monica:** no, my sister would stick her on a nursing home, my sister doesn't talk to her she does not like her because she was the oldest so she got the brunt of the abuse because she was six when I was four so my brother and her do not talk to my mom

**Dolores:** how is your relationship with your siblings?

**Monica:** none, I don't have a relationship with them I decided self-preservation so I decided to go into therapy and I did a long-term analysis and I did some therapy with my mom and we worked on fixing that mess and that gap, not 100% because she's in denial but she did enough work that is helped me to take care of her

**Dolores:** your mother was willing to take the fault of

**Monica:** no, no, she was busy working and putting food on the table and clothes on our back so she doesn't know what I am talking about she is on denial or whatever is that expression is. so, is conflicting but really, even I may sound very clear on my description of taking care of my mother there was a lot of resentment for a lot of years until I did the actual work because I knew that A. I needed therapy for myself B. I needed therapy to take care of her otherwise it was going to be very angry dynamics and so that was through my thirties, the forties and it wasn't until I turned about maybe 10 years ago 48 because I am 58 now so it took a good 10 years to go (deep breath)okay this s when you think about your mother I always try to think about three positive things about her and even with my father as abusive I try to think about three positive things because the intergenerational issues is that these abuses and these issues weather is incest or alcoholism or violence comes from generation to generation generations, and to break that cycle you have to

understand where those people came from not just to be angry at the person who is in front of you, yeah.

**Dolores:** I want to take a class thought by you

**Monica:** yeah

**Dolores:** wow, that is really

**Monica:** but that was learned

**Dolores:** it is but wow, really, we are strangers but I have to commend you because that is really

**Monica:** it was hard work and I tell people that are going through this with their parents, yeah you are going to get angry yeah is exhausting yes, but you know what? (Holding back a tear, the voice is breaking) when my mother dies and I lay my head at my pillow I will not have a guilty conscious I do this work now not so much that I don't have a guilty conscious you know guilt is terrible but is a waste of emotional I wont have a guilty conscious I made peace with all of the stuff with her I will say that I have done the best that I could as daughter to someone that is very damaged and who came from being very damaged and I understand why my mother is who she is and that is a gift that not many people have because when my sister gets the phone call that my mother is gone she is going to be on medication I feel sorry for her I feel bad for her but there is nothing I can do for her because she is on her own trajectory she is on her own path so you know "cuando mi mama se muera yo me quedo" (when my mother dies I will stay) I mean it will be hard of course she is my mother but I don't

**Dolores:** peace of mind

**Monica:** yeah, like you do the best you can and with something or someone(deep breath) and then you say.. you put the rest to bed because even if you have like my friends say they have a perfect relationship with their mother(incredulous look)

**Dolores:** does that exist? Laughter between Monica and Dolores

**Monica:** oh yeah, blah, blah, okay(laughter, incredulous looks between Dolores and Monica)is your narrative

**Dolores:** correct. I am ....a lot of the questions that I had for you-you have covered, is great

**Monica:** aha,

**Dolores:** this interview evolve organically

**Monica:** sometimes interview can happen that way

**Dolores:** is really wonderful

**Dolores:** you told me about a little bit already about your daily routine and so forth. Um, with your responsibilities you really have covered everything so I am not going to ask you to repeat what you already said it so beautifully I do want to talk about what inspired you, how do you want to contribute you already doing so much on the personal side but it sounded as if you wanted to contribute to the archive, you mentioned already you want this to be out there and you want to make an imprint. What do you think can be done here at CUNY or in New York state to support the caregivers you talked about how wonderful your paid caregivers are and by the way so are you as a family caregiver because what you are doing...

**Monica:** Um, starts with me

**Dolores:** is amazing I was just wondering..

**Monica:** (big sight)

**Dolores:** a lot of what I wanted to asked you, you covered it in so many ways

**Monica:** right,

**Dolores:** you are so passionate and I know you don't think so(laughter) so well put together

**Monica:** I try to get it together

Dolores: you really are, and I will ask you again when do you ever take the time off and really (deep breath)

**Monica:** (deep breath, laughter) I am doing it right now just being here

**Dolores:** I know that is wonderful(laughter)

**Monica:** the thing about the archives and the care givers I think the one great thing about the archive is for other people to hear other people experiences like a person that might be walking in my shoes 3 or 4 years from now because they are just starting the process with their parents is a good thing if they are in CUNY or the archive lets people say hey you should listen to this, this is going to be a little bit of a disconnect I am giving you this information is going to be in the archive who is going to look at who is going to view it ,read it who is going to listen I think that younger woman especially that are going through this I have a lot students who are amazing, amazing and a lot of them are almost starting to be in my shoes because a lot of our students are not that they are older they are not young so I think that they need to hear some stuff that will give them hope because you always have to have hope so I think that if the archive or social media however you come to bridge that gap and to let students hear this see or hear the interviews, see it in a play format, um which is

an amazing therapy for people I think I wouldn't say it should be mandatory but think people the students in disabilities studies and the people that have parents and children with disabilities should be going to the performance and hearing because not everyone learns the same way and sometimes is tactile, sometimes is visual sometimes what have you so I think that would be great um having a dialogue, you know, like put out the word to CUNY, SUNY, or however the archives are not SUNY but CUNY have a day where you get the students to come in and I don't want to call it a bitch fest because that is not the correct word especially because we are woman but to have like a town home meeting kind of thing where woman can come together and man because man are caretakers too let me not leave the guys out that they can come together in a forum and if I had the magic wand to get 30 or 40 people in a room like me who are doing caretaking and with people with disabilities, older with senior, aunt uncle whatever and be able to give shoot out ideas like a forum of some kind and they can talk about the different things that they are feeling and the different ideas that they can use to help their parents or themselves like self care. Like I learned self-care through therapy and I am learning now more self-care now that I am doing social work master at Fordham um, I always knew about self-care and every once in a while I cheat, like I am going to go and get a massage before the week is out maybe, um

**Dolores:** you call that cheating (laughter)

**Monica:** yeah well, I try, like I have a hot bath every night with the salt, you know, almost every night but not every night um I did not mention my wonderful husband who is incredibly supportive to me, he is my chef, cook and bottle washer and



sometimes he goes all the way to Brooklyn to see my mom and he does not speak Spanish and she does a little bit of English but she adores him and he loves her he is my support system and he cooks for me I might look put together but his is doing all the shopping all the cooking he works he pays bills he does the budget puts gas in my car he is my support system at home to allow me to then go and take care of my mom so I don't have this demanding person at home that I have to go and do laundry and cook and clean so that is a huge help some people don't have that. some people do this and they don't have that (hand signals) that is a person that is going to be at the ledge (laughter from Dolores) to answer your question I don't know how you guys are dealing with the archives but I think a lot of people need to hear this stuff because baby boomers are the fastest aging population and pretty much one of the last baby boomers I was born in 60 but I think 57 so that would be my sister who is older than me. so we are the fastest growing population and we have the highest disposable income we are not all going to end up in nursing homes but we are probably able to afford to be in our own homes as we age out and so the archives might be a way to start thinking about to interview other baby boomers because there is going to be some kind of gap in there somewhere because we think we can do it all and we can't, yeah

**Dolores:** very well said

**Monica:** we can't, I told my mother someone is interviewing me about you and she said why? (Laughter from Dolores) because you don't behave, she said what? no, no, they are working,...and I tried to explain it to her and she said "that is very interesting" and I said, and she said "what are you going to say? And I said you are a

pain in my...(laughter between Monica and Dolores) " " no te atrevas"(don't you dare).. (Lamenting with laughter) yeah, you know, you have to do it organically, yeah, figure out what to do when to do it, how to do it sometimes it doesn't pan out the way you want it to because you want to wave, I want to wave the magic wand that said if things were different my mom will be, of course, she would be but things are not different this is what is front of me so think also for the archives or for people that are listening it will be maybe like some kind of a survey as to what they felt when they heard this what brought up feeling up for them what would they wanted to know more about, things like that

**Dolores:** yeah, because you are experiencing, I mean really, I am really impressed by you. I have to say

**Monica:** hesitation) yeah, thank you

**Dolores:** no, I have interviewed many people and I think they all have their stories, their own narratives and they are all impressive in their own way, but as I have said before this self-therapy and the stages of it

**Monica:** Yeah, yeah because I did not have the mother, this might be very, very important to say because I did not have the kind of mother that I wanted as a child I always found myself moving towards older women some girls look out for an older man to date I was looking for older women for friends so I found safety with my grandmother who was 74 when I was born and I buried her when she was 101, my friend Violet who was deaf(From this time forward during the interview, Monica spoke using sign language as well)who changed my life completely and I learned sign language and went on to working with the deaf community and teaching

sociology of the deaf here at the center um she was 85 when she died and what I learned from her was massive. my friend Miriam who was in her nineties when she died, my friend Pierre who was 96 so I have like pull of this goodness and caretaking from people who wanted to love me and be good and kind to me and just because my mom is my mom but my grandmother raised me so when I buried my grandmother I really mourned my mother and my mom when she dies still my mom and I will mourn her too of course I will but I just surrounded myself with all these older people whom I learned so, I mean on the worse day all I have to do is think about Miriam, Violet my grandmother and I am fine. Because (voice tearing) I just like wrapped then around me and I go is going to be okay if Miriam would be here she goes ' honey, get on with it" (laughter) and if violet would be here she would say " have a drink"(laughter) she liked champagne, so you have to have a sense of humor

**Dolores:** so they provided care for you,

**Monica:** yes, they were my caretakers, they were amazing women, amazing. when you a]have a deaf woman who sues the city of Chicago for her driver's license because they say you can drive because you are deaf, yeah, and you get that pearl of wisdom from her. when you get a grandmother that gave birth to 8 children didn't speak English could not speak or write but divorce her husband in the '30s and left her remaining children with him because my grandmother was a feminist, when you get Miriam who is an older Jewish lady who lived through you don't want to know. Hey, if I live long enough I can fill these shoes.

**Dolores:** I think you already doing it

**Monica:** I rather have that then say or my god my life is so hard and my mother is this and I cant stand her, I don't want to take care of her when you get that negative and by the way my mother is a very negative person very negative(teary eye) I justify it so I know what she is negative I give her a lot of respect because this is a woman who survived horrors my mother had post dramatic shock syndrome at the age of 10 her father was murdered and castrated in front of her she ran away and they could not find her for three days she was catatonic under the church and in those days 1943 they weren't giving child therapy, the priest was talking to her and she is 85 now and she has been living with that and it wasn't until she was in her 60's that she had the nervous break down and we started with the therapist and psychiatrist and let me tell you my little Puerto Rican mother who is about 100 pounds soaking wet and 5 feet tall when into therapy with a psychologist and a psychiatrist in Spanish a Cuban psychiatrist and a Mexican psychologist for 15 years of therapy so I bow down to my mother

**Dolores:** absolutely

**Monica:** yeah, because you know the Puertoriquenas (Puerto Ricans) they are not going to go to therapy that is those blancas locas (crazy white women) and my mother to her credit said to me I need help that was the turning point so I kind of when all the way around to get to this point that I think for her and for me was the turning point in working, me working to help her I knew I had heard the story and I knew about it how my grandfather died but until you see it through the nervous break down and the trajectory that she had to go on herself horrific really tough one. you know, I am proud of my mother I give her I mean as my husband said what

she went through what she went through that she is still standing mira (look) she is good. yeah,

**Dolores:** she is standing and you are helping her stand which I think

**Monica:** yeah (hesitation)

**Dolores:** imagine

**Monica:** imagine, if I had disappeared as my siblings did, you know, I give them a lot of room I don't even deal with their craziness because they if you don't get the help you need then you can't help other people

**Dolores:** correct

**Monica:** and I know that if I had not gotten the help that I needed that I still need I wouldn't be here talking to you so clearly about how much I care about my mother you know and the early feelings of ambivalence versus now saying that is my mom and I am going to do right by her take her to task for something she could not because she did not have the skills right, you like at that and go okay, yap. It is what it is...

**Dolores:** I know you are press with time like I said you have answered all the questions organically, amazing thank you very much

**Monica:** you are welcome'

**Dolores:** is there anything else that you would like to add to, anything that you would like to know, that I could answer

**Monica:** I no, I just hope that moving forward that the archives and that you get more people really do this, I think you might really want to I don't know what the company or the organization doing for this but I think you might want to interview

younger women who are doing this because I have a lot of students in my class that are taking care of their parent either immigration DACA or moms that are depressed and they are only in their forties their mothers and the caretakers are the daughters at CWE there are a lot

**Dolores:** I think is not exclusively for older women, I think it includes all but I will reach out to professor McDonald and tell her about it

**Monica:** yeah, yeah