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Interviewee: Joy (Ufema) Counsel

Interviewer: Jennifer Ott

Date: April 29, 2015

Place: Martin Library; York, Pennsylvania

Transcriber: Jennifer Ott

Abstract:

Joy (Ufema) Counsel was raised in Altoona, Pennsylvania. After completing high school, Joy began studies to become a nurse at the Altoona Hospital, and later completed a nursing program at Harrisburg Area Community College. Joy worked in numerous hospitals and medical facilities in New York, Maryland, and Pennsylvania. Throughout her career as a nurse, Joy developed an affinity for caring for patients who were terminally ill. Her work in the area of death and dying received considerable media attention. As a result, she was interviewed on *60 Minutes*, a TV movie titled *A Matter of Life and Death* (1981) was made about her work, she authored numerous publications, and she participated in many speaking engagements across the country. In her interview, Joy discusses her work and experiences during the height of her recognition. She goes on to discuss the AIDS hospice she operated in York, Pennsylvania — elaborating on some of her most memorable patients and her experiences running a non-profit. Joy talks about her family's reaction to her homosexuality, and her experiences as a lesbian in Central Pennsylvania. In the interview Joy goes on to discuss both challenges and the progress she sees as being significant to the LGBT community. Finally, Joy discusses the role of spirituality in her life.

JO: I'm Jennifer Ott and today is Wednesday April 29, 2015. I'm interviewing Joy Ufema at the Martin Library in York, Pennsylvania for the Oral History Project of the LGBT Center of Central Pennsylvania. Joy is it okay for me to ask you a few questions about your life and experiences?

JC: Yes.

JO: Could you please state your name and confirm that you're willing to be interviewed.

JC: Sure. I'm Joy Counsel Ufema.

JO: Okay.

JC: And yes, I'm willing to be interviewed.

JO: Can you sign your name just on this top line where it says narrator's signature?

JC: Sure. [Joy signs]

JO: Thank-you very much.

JC: You're welcome.

JO: Alright, if at any time you would like to have the recording stopped or if we come to a question that you don't want to answer, just let me know and we'll stop or move on.

JC: Well that's very thoughtful. Thank-you.

JO: Okay, you're welcome. Alright, so to start off can you tell me a little bit about your childhood, your family when you were young?

JC: Well, I'm 5 years younger than my sister, and we're the only siblings. Raised in Altoona [Pennsylvania]. My father worked for the railroad and my mother stayed home. And it was just this delightful childhood of the neighborhood with all the mothers who stayed home. So you could, run in and out of people's houses for lunch or cookies and — and of course I had a whole gang, and I was short and I was younger than they, and a lot were boys, and so I could sort of order them around, and that's probably where this assertiveness began, you know. It was — it was very stable, and secure. Very predictable with holidays and — and getting ready for school and then what the summer would be like. It was just a — I think it was a pretty delightful childhood actually, yes. Very independent, you know mother would say, "I want you to stay in this area of the yard." And of course within an hour I was you-know gone from that area. So, but really built a lot of self-esteem and self-worth and confidence in that — in that environment. The old — old kind of neighborhood with mothers around, you know.

JO: Nice, can you tell me a little bit about your education — both when you were a kid and then any post —

JC: Right. It was public school, and that was in Altoona. And you went first around the area of the neighborhood was the primary education one through six, and that was a pretty strong steady — pretty varied education. Reading was a big part of my life. Punishment actually was where you don't get to read for this afternoon, or you're not gonna have story tonight at bedtime, so that was —and that helped a lot I think in my enjoyment of English and —and — and school. Then into junior high it was my mother worked in the library after my father died at age 42, and so there was still that security around then into high school, I decided I wanted to play the drums. But I couldn't read music, so I sort-of had to fake it all along, you know. And in those days girls were not allowed in the band, in the marching band — just the orchestra. So I played snare drum and timpani so that was pretty good and again, just a real steady, secure kind-of, kind-of life. Then I started noticing girls, which was nice. [laughing] But then my grades started to fall, that was very interesting. So I was distracted and certainly graduated fine. Pretty immature, overprotected at home you know. And you're gonna be either a teacher or a nurse, you know. There was no option like you could be a physician— that was not in the works. And then I got accepted into nursing school at Altoona Hospital — a three year program, which was really what you did. You went from high school graduation afternoon into the nurse's residence. Again, pretty immature, and this was just a delight that you could be in this dormitory and play ping-pong and pool and you could go to bed when you wanted and there were all these other girls to play with and I'm not gonna study. I failed out within five or six months, I failed out. Which was a huge surprise. It was like, "Wait, I wanna be a nurse." Well, you have to do some other things, and that was very embarrassing because my chums from microbiology class and all around and in high school were in that nursing program. So I had to sling hash at (McCrery's ???) to get money to be tutored. My parents were very strict on this, "We're not gonna do this again unless you're committed and do something about why you failed. And that was embarrassing too

because I had this stupid yellow [gestures a hat and outfit] (McCrery's ???) counter girl outfit, and they would come in and you know I'd have to wait on them. It was just awful. But it was a good lesson for me. And then I got accepted at Lewistown Hospital, another three year program. And went there, and really adapted well, and loved it. But really, got into the girls. And lot of pressure from my parents, church, society that this is way, wrong, and, "You're not okay." That was the message — "you're not okay." But I knew inside there was this other whole part of me that was great, you know but — but I remember my father gave me a watch for graduation and I wore it down low like boys do, and he said to me move your watch up on your wrist, so he had this concept of the expression that was gonna be more masculine and that terrified them. So again the pressure was building, I was kissing girls in the dorm and that's what I wanted to do and dancing with them and it was good, but boy there was this scary thing about getting caught, and maybe you'd get thrown out. So, I went to a birthday party and there was this handsome guy and I'd never really dated much in high school, and so he was interested in me and the feeling was, "This is what you need to do, cause this other pressure is off." So, we dated and I got pregnant, and when I told my parents, they were actually more relieved than if I was gay. And then we had to get married and it was just awful. I — and I had two daughters, and it was just — I was — I was gonna kill myself cause this is — I couldn't quite put in how to escape and what would the ramifications be, because I had these two little children, but I knew that mentally and physically I can't do this. So I ran away. Ran away. And I lived with my aunt in Steelton [Pennsylvania], the big Italian family that you know they love ya, and it doesn't matter. And I worked at Holy Spirit Hospital as an LPN, I took boards, and even though I hadn't completed the three years I was strong in certain areas, you know, you pass boards — and then I left there and went to New York state and worked at the crazy hospital, Warren State Hospital. And got fired for being gay. One of the — the evening nurses was very seductive with me and of course she went home and prayed to Jesus about this, that she was too tempted and she got me axed. So this message is still, "this is not okay." And these are penalties if you try to be who you are. There are gonna be serious ramifications, so I'm toying — playing with it a little and then I'm back. Very difficult. This is like around age 29 now. So, one day, I was living in Jamestown, New York and working at the dentist office. And that evening I got a cab and just said to the cab driver, "Take me to the gay bar." And he did, and there, "I'm home." [laughing] And certainly got involved with women and had relationships. Then there was a fire in my apartment from the guys downstairs that were smoking pot and everything else, so they set fire to their ironing board, and it forced me to move to Harrisburg again to get this LPN job, and I though wait a minute, I can finish my nurse — I can get a two year degree from HACC [Harrisburg Area Community College] which I did. Just flew through because this huge part of me was now satisfied and I could focus on studies and I just loved it. I was a really good little nurse. Then I was working at Harrisburg Hospital — loved it, doing fine, in a relationship which was sorta okay, you know but — and I had this affinity for dying patients. It was almost identification with suffering and pain and — and loss. And I created the job. First one in the country of a nurse specialist in death and dying. And the whole gay thing sorta just dissolved and I just focused on this. And created an entire career out of it. With — it was hot then. Elisabeth Kubler Ross was hot. This was early seventies into the eighties. That was all death and dying time. And lots of publicity. Got on the front page of the Washington Post — just launched this career. Had a national lecture circuit, wrote books, did video— the whole thing just went. That— so it was like

once that part of me was secure and solid I could just fly, which I did. It was really, really good. Made a big impact on death and dying, lot of assertiveness for patients, that was another part. That all came out again. And then built my own house. And got into that wonderful project—that was fun. And was still at Harrisburg, and *60 Minutes* called, and Phil Donahue, and Washington [Post], all of that and so we did this—and Linda Lavin for this movie of the week. Which was an interesting thing. [laughing] I was on this farm, on my farm, and it had snowed and I couldn't get my tractor started and I was so frustrated and snowed in and I went in the house and to get my pistol to shot this tractor, and the phone rang and it was, "Yes, yes!" [imitates herself answering the phone annoyed] "Is this Joy Ufem" [imitates person saying her name wrong]. "Yes, what is it." "This is Linda Lavin." "Oh, yeah sure." But it was she. And she had a contract with CBS to do a movie of the week, which was just a thrill, the whole filming — she came to Harrisburg for the filming — it was just wonderful. But, the writer had everybody riding off into the sunset, there was no death. And I said, "No, this — that's not my story. That's not my patient's story." So, we got another writer whose child had been killed by a drunken driver — little boy. And he had the empathy and the experience of loss and death and he wrote a pretty good script. So that was — that was a neat thrill to have — have that. So I was still pretty much in the lecture circuit and teaching York College, death and dying course which was very popular and still really enjoying this and AIDS started coming along. And I was working at a hospital in Baltimore, small hospital, and — I never liked Hopkins and univer— I liked my little hospitals where I could really make a difference. And got my referrals and I knew everybody and I could you know call down and say she's too sick for an x-ray bring the portable—I had a lot of clout within that system. And they closed it and Hopkins bought it. So, I was without a job and that was pretty traumatic because I had this farm and mortgage and I decided the worst thing was I'd be able to work a regular nurse, so I gave myself six months and if I didn't find death and dying work, which was very popular still, so I couldn't understand it, you know why I — oh I had 15, 20 interviews all over the co — all over the — all over the state. "No, we don't—I don't think we need that right now. We know who you are, and that'd be neat, but we just can't," you know. So, one day I was at my farm pretty, pretty leery, and not trusting spirit and digging around in the dirt under my favorite pine tree and out came a plastic letter A. you know, like the kid have on the refrigerator. And it was [hits self in head and makes "a-ha" face] its AIDS, you're supposed to be working with AIDS. Okay. And off we went. And I found this beautiful brownstone in York [Pennsylvania], went to the mayor, and said, "I'm gonna create a non-profit and I'll have three bedrooms, I have a board of directors, I have Dr. Hawk as our medical director, it's all up. But I need the building." And he said, "Okay, you can buy it for dollar." So we did that, and — and that was a wonderful project. That was ninety to ninety-five. And I just had volunteers come in and the art academy took us as an art project and they designed all the rooms and wallpaper and at that point, York was number three in the state for the highest number of AIDS cases. That was a lot of IV drug abuse. So this was my baby. And this was where again that whole focus and energy went right into that project and a lot of people, lot of people helped, but it was constant raising money, cause we were non-profit. And had wonderful nurses, and — and dear, dear patients. And a photographer in — at Hartford Community College was commissioned to do an AIDS project — a photography project — at the Corcoran Gallery in Washington [D.C.], and he chose us. And the images that he captured were just incredible. So, and that toured the country, and I went with him to Portugal for a big expo— it was — it was just

again, wonderful. But along came the anti-retrovirals and we needed that, and so my, my patient load dropped, Hershey Medical Center wasn't referring as much, York Hospital — you know, because the patients were getting better. Which, you know, is what we wanted. You know, so at some point. It had been about three months that I didn't have any patients, and the board said, you know we can't keep funding this, I mean you know, there has to be work for the nurses and there has to be money coming in for donations and all. And we probably need to close. So, I was pretty upset with that. You know how much energy and love you put into that kind of project, and the medical director said one of your options would be to turn this into a respite house for cancer patients. I said, "Well that's a possibility, but then you have to get Medicare approved," and the strings were awful, just awful. And I said, "No, we're gonna close," because it was meant for AIDS patients. And there were a lot of respite programs and in hospitals for — for cancer patients. And it was like this is what it was intended for, and — and I guess we're gonna have to do that. Which was a very mixed feelings, you can imagine. And, but I scooted our little patients off and they — they were starting to get better, and the drugs were working and that's of course what we wanted. So we had in five years 95 deaths. One was a little five years old with us. And then his mother came to die in the same room he had died about a year later. We had a lot of spiritual activity. There were a lot of little spirits moving through that house, and it just made it a really special project and — and something that I will always be very proud of.

JO: I wanna back up just a bit. I loved your story it was wonderful. Whenever you were talking about before the hospice, the movie and *60 Minutes* and all those sort-of intense media attention on your work — what impact did that have on your personal relationships, on your relationship with your family?

JC: Well it attracted a lot of women. That was great. And actually I was in a relationship then which was — was pretty good. And then — and I would take that partner on you know, we have a speaking engagement in Tulsa [Oklahoma]. "Gee that's a funny city to go to, but let's go." And now we have a speaking engagement in Washington, so that was sort-of a really neat little power thing that we had going. I had a lot of lectures. We made a lot of money. We sold my books, and so that was — that was pretty good then, pretty good.

JO: Did being a lesbian ever affect, like, your publicity was there negative publicity about you or did they now generally know?

JC: No, actually wasn't. I never had anything. And I think it's because — I mean, people knew I was gay when I was on stage I dressed that way, and had hopefully the mannerisms that I want to have. And I was at Tulane [University, Louisiana] speaking. And this beautiful, old university setting with the — the risers of the, you know, the whole auditorium went up and these big steps and your looking down on the stage, and I was greeting people afterwards and taking questions, and someone slipped me a little note and I opened it and said, "You will find bars that you want in Regent Street." [laughing] So, that was a little hoot. I think it was because the story of all my patients and all those nurses that were just flocking to hear them and how to help their patients. I think that was more the focus, yeah.

JO: Well, well that's good. Some — I mentioned to your prior to the interview that a lot of people in the other interviews talked about your hospice and one of them mentioned to me that

hospice atmosphere in yours unique. That is was really peaceful and calm and it felt like a good place as opposed to a place where people were just there to die.

JC: Right.

JO: How did you create that environment? Did you have — was it just part of — just because your personality spilling over or was a specific plan to make it a nice place?

JC: I was taught death and dying by British and Scottish physicians who were very very Christian. All of them had been medical missionaries in Africa, and that came from them. I'm not Christian, but the attention to detail is what was taught over and over. So that you actually asked the patient, "Do you want ice in your drink or not?" That kind of feeling is that the patient feels he's being heard to the tiniest little detail, and he might not come right out and say that, but he's talking about other things and then he'll slip out, "and you know my dad hates me. Yeah I'll have some rice pudding." "Wait a second, I just heard ya say, 'and your dad hates you.' Let's talk about that for a minute." So — it was a beautiful old house and actually a black physician had lived there, and I'm not sure if he had his office there, I don't think he had his office, but he — it was his home. And if you had three beds or less you did not have to declare yourself as a personal care home, so that's why I limited that. The — the wall paper — sometimes the kids from, well the students from Bradley Academy would show me wall paper pieces that they wanted to put up and I would say, "No, and if you look that looks like eyes and AIDS patients get dementia, and I can't have him lying in bed looking up and being terrified of these eyes. So we're gonna change the wall paper." We're gonna use cotton sheets because these patients perspire profusely, and the cotton absorbs that and we can change that and have it washed daily. We're gonna use down comforters because these patients get chilled very badly and are — have tremors and shake, so that's what we're gonna do. We're gonna have a tone in this hospice of love and acceptance and peace. And it's going to — it's not going to be clinical. I never had an oxygen tank at that hospice. If patients were getting short of breath, I gave them small doses of morphine, hand and foot massages, and a small fan blowing air which gave a sensation of — of air and calming. We didn't have an elevator. We carried our patients up those stairs as our brother. We had a cook so that patients who didn't — "We'll you have to eat at 8 o'clock, cause that's when the cook's cooking." No, they could get something at 8 o'clock at night. "I think I can eat some scrambled eggs, is there any?" "Yep." Here we go. Some other things for detail. [thinking] Televisions were turned off during the dying phase and the nurse would just sit at the bedside, so that the patient was never alone, and turn this into a very spiritual event. We had numerous Hispanic patients whom I loved, and people would come from their church on Sunday with guitars and they'd sing and it was just very enthusiastic and and the patient wasn't near death yet, and so it was his home now. And I went in one Monday morning and the nurse complained that they had eaten us out of house and home. All his friends were there and his family. And I said, "Then, here's a check. Go to the supermarket and replenish it. That's his family and friends and we're gonna feed them too." So there will always be enough. So it was that kind of a tone. When we were doing the wall paper and scraping linoleum and doing all that, there was a little kitty outside who had been terrified by some kids and she ran up a tree and I rescued her and she was the house cat so sometimes patients might enjoy having the kitty on their bed purring and that's very therapeutic. At Christmas we'd decorated to the hilt, cause

that's what patients loved and wanted and knew it was there last Christmas, you know. We had a patient who enjoyed eating clay from Georgia and his mother would send that to him, and so we certainly — Pica is it's a—

JO: Mmm hmm.

JC: So he on his death bed still had some clay that he was chewing. One day we had a patient die and her crazy boyfriend wouldn't let us in the room. And Jack the photographer for the Corcoran project stayed there with us in case he harmed us. And it took hours to talk him out of it and and for me to say, "the —the mortician is here with the hearse and I need you to help me carry Judy's body down." So that he had to open the door and come out, and "Let's take some pictures of you with Judy, and this is the final time, and we'll make sure you get some copies of that, that's special for you. And let's get a lock of Judy's hair and give it to you." So that it took a lot of calming him down. He was very anxious and upset. He wasn't sure she was dead, but she was. So it was always keeping it gentle and soft and and accepting. We had a real sweet young woman who came to the door — very ill and emaciated and said, "Can I come here and die?" and I said, "Yes you can." Well — "I'm going back and get my stuff." I said, "Okay. I'm gonna" — worried we wouldn't see her again, she was pretty ill, came with the little grocery bag of her clothes — and there was a gang in that area. The Crips. And they wrote on the side of the building their sign and their ya know. And one of the guys was sitting front steps and I said to him, "You know what this place is?" "Oh yeah, word's out, the word's out." I said, "Good, listen. I need you guys to protect us from other gangs in town. Can I count on you to do that?" "Oh, yeah. Yep. We'll be watching you day and night — take care of you." Well there was never an ounce of problem and there I'm running around with morphine and never an ounce. So I think they saw what the project was that many of our patients were waifs, one little guy I got out of a box behind the library. So the word went out, you know, that Joy's good, you make sure that place is okay and that gave them a sense of being part of the AIDS epidemic too. We handed out condoms all the time, we — you know we were this huge education — was always speaking to rotary and Lions Club and I'd never leave without a check though. And remind them, "We are our brother's keeper and we make no judgment on this I see you're sittin' there smoking cigarettes. We'll you're gonna get lung cancer, should I not treat you?" You know, so I sort of shamed them into it, which was pretty good cause York's old German and so they came around and it was a wonderful project, yeah.

JO: You mentioned some of your patients — there families being there. Was it common that there was family and friends around?

JC: Yes, we encouraged that. And we had actually a family bed — beautiful bedroom on the third floor. Big poster bed and soft pillows and — and in case family who were waiting for the death watch or came from Hershey or Lancaster County could stay overnight. So we encouraged that. And they got breakfast in bed too and yeah.

JO: What were the biggest challenges in running the hospice?

JC: Money.

JO: Money.

JC: We were non-profit. I got that status within six months, which was pretty fast. And again it's old German here and, "You know those people brought this on themselves, so why should I give you three thousand dollar from out church?" "Well because you're a church, that's why." So, it was hot for a while then it would ebb and then ebb and flow, you know, come and go. Sometime it was very bad about the forth year, and the word would get out and I'd have to have a press conference and say, "We're gonna have to close the hospice I don't have money to pay my nurses." Of course my nurses had all said, "We don't want paid. We love our job." "No, you get paid. This is a — your professional." You know, and then the money would come in, and that would last for three of four months. I think it took about three thousand a month and of course I took a very very small salary and and that was fairly good. It's tough to maintain that as a non-profit. And patents who had social security/disability would give us their check, and then we'd take some of that money and give it back to them, but that seemed reasonable that you're gonna get exquisite care and dignity like you've never had in your life. "And that nurse that stayed here all night with you, she didn't get paid so —" "Oh yeah, okay, here's my check. Don't even give me any — I don't need no cigarettes." You know, so.

JO: You mentioned that you weren't Christian, but you have mentioned spirituality —

JC: Oh yeah —

JO: being very important to you. Can you elaborate on that?

JC: Sure. Well, I was raised Christian, you know, and this what good looks little girls do and it was a matter of time. [laughing] so, you know, just being exposed to other people and reading and just sorting out that probably Christ was great as Mohamed and and Buddha and all the other guys, you know, but it was too — it wasn't because I was gay that — that the church — that wasn't my problem it was just the overall feeling of restriction, judgementalness, hypocrisy — all of that, so I was in church as an adult, and I remember — a Lutheran Church — and I remember the minister at the — at the — with his back he was giving the final prayer, saying, "Dear Lord, move the hearts of your people." And I thought, "Wait a second, I don't think God's supposed to be moving the hearts. I think we're supposed to be moving our hearts." You know, and if God could move the hearts we wouldn't have had the Holocaust, or Japanese internment— you know. So I don't think it works that way. I think we're to find — I think there's a piece of the creator in each of us, and we can chose love or fear. And when acting fearfully, that's when were not kind and feeling guilty and feeling grief and all of those things. Anything that's not love I think is not real. I think love is the only reality. But we have these other things that come from being human. But the answer's there. And if we choose love, we get — I think we all have had it a least I've had one or two of them where you just knew this was how it was supposed to be. That was the answer. So, we did have a sweet Hispanic priest at the hospice, and — cause many of the patients were Catholic and we always had a service at the end of the year for all the patients who died, and so that was a religious service and it was Christian, but I had a priest, a Catholic, and a rabbi. A priest — I had the whole gang there to cover, you know. And certainly patients would ask for clergy and communion and we would just love to have whatever they needed for their peaceful death, their own death, you have to die your own death. I can care for

you and love you, but you have to find your own peace, and I'm not sure all of our patients did, but they certainly had — were loved and had dignity.

JO: Can you talk about some of the other fundraising efforts that you did? Were organizations like SCAAN [South Central AIDS Assistance Network], I've heard a lot of talk about — were they affiliated with the work you did or was it a very separate thing?

JC: You know who was here then Bernie Earhart, and he had — I forget the name of his group — but they did a lot, and they would give money to us as well as money for their own, they did a lot of home care things and buying patients food at home and that — well one was a letter to Princess Diana. And I said to her, “You'll love coming here. I know you go to New York frequently and that AIDS is your project, and we're right on where some of your relatives are named Duke, King, Queen, Princess Street. And we would love to have — it would be a thousand dollars a plate and we would have it at a huge thing.” Well you know, it was my best grammar and English, it was beautiful and I sent it to — where was she? At Kensington Palace I guess. Well little did I know, cause I'm working my buns off, I'm not reading the *National Enquirer* where she's off with so and so sucking her toes on the Rivera, I don't know all this is going on — I think — so we didn't hear for months and finally a check for a check for £ 500 came with a letter from her secretary saying, you know, the — who was she? The Duchess of — no she was Princess Diana, but was it York? No, Fergie [Sarah Ferguson] was York. But anyway and so we had a lot of publicity about that, and then some money would come in cause people thought, “Well if Princess Diana...” We did that one, we had a beautiful quilt made and raffled that off. That made a lot of money for — but see stuff would only hold us for about three months, then we'd have to get the next thing. The Winebraum (sp. ???) Jeweler was big then and David Hancock was this wonderful flaming queen that we all loved and he would wear furs and jewels and all and he made — he got all the jewelers in town to contribute a gem and then they made that necklace and we raffled that and that made about 10 thousand [dollars] for us. But you know, I could walk in anywhere — I'd walk in York Hospital and say, “Hi, I'm here again, I need hepatitis injections for my nurses.” “All right bring them over Friday, they'll get that.” I could walk in Osteopathic Hospital and say, “I need a crib, we're getting a five year old little boy coming.” “Okay, there's a crib out — load up.” So there was that sense in our community that even though we were taking the brunt of it financially, they respected the humanitarian effort.

JO: What have you been doing since the hospice closed? I'm mean it's been a very long time now. Are you still in this line of work? I know you write and other things, but —

JC: I do write. I had a column in the nursing journal for 30 years. Which I really loved doing and then they — they started changing my words, and said, “Wait a second, that isn't how I mean to describe that patient, and I'm not doing this anymore unless I get to do my own words.” “Well, okay.” So they let me do that for a while. I just wore out with that, I mean it was 30 years of and you get some letters from people, like Dear Abby, but I had to create the column every month, you know. And nursing changed. Well, I went — lost my job, and got hired as a consultant, isn't that what we do? We do consulting — to a home care hospice in Maryland and that was very nice. I liked that, and they gave me a job 'cause I was really grieving and they were thrilled to have me, which was very nice. But I think some of the nurses were threatened, you know, “This

is really my patient, I don't need Joy." Plus I really loved hospitals, those little small hospitals. So I got a job at a small hospital in — in Haverty Grace in Maryland on the river there, it was just sweat. Worked there for a while, then they built another hospital in Bellaire, Maryland and that was your big brass and glass and "We're gonna be big," and actually Palliative Care started coming in and this was around 2008 and 9 — "Palliative Care's coming and we want a Palliative Care team." Well I was so threatened, [laughing] you know, I'm jumping on the table at the meetings, "You have me. You don't need a team. The worst thing to do is emulate a team, where you have 5 or 7 people go in and have bureaucratic exhaustion to this poor patient." "Now the chaplain will be in in about an hour. I'm the social worker, and then after me will be the pharmacist..." I said, "I know how to do my patients. I know when it's time to call the chaplain because the patient told me she wants a chaplain. I know when to change from morphine to dilaudid because I have been trained in pain management. I'm doing this. You don't need this." Well, they weren't gonna hear it. And my partner at the time says, "You know, they don't, they don't want — it's been two years of screaming and shouting and frustration." And I said, "I think, I think I'm done." So it was very difficult to retire. And give up that wonderful career, plus I actually knew what was right and what was best. And had a wonderful reputation with patients and families and the docs, it was, it was real good. But, people who didn't know diddly about Palliative Care would come in now with their little badge and it was very frustrating, 'cause they didn't know what they were doing, and it was all this outcome measurement. "You don't need to measure whether she's nauseated or not. I got a Compazine order and she's not nauseated, so we don't need to write all this stuff down. Look at your patient, is she vomiting? Well, no. That's how you tell. That's your outcome." So, but it was all this justification of funds and the whole thing went fluey and, and I said, "I can't be part of this, this isn't —" I was such a purist with the hospice philosophy. So, I retired. I had a little private practice for a while. I didn't seem to be needed in that. No hospice program in the area took me on their board, 'cause they were afraid what I'd, you know. I kept writing some, and then you know it took me about a year to sort of settle and switch from the professional to enjoying my horse and my miniature donkey and playing with the chickens and mowing and doing the garden. [excuse me] And I said you know, this is fine. I've done it and I'm proud of it and and I love to read and I'm fine, you know. People — sometimes someone will call and say, "My grandma's really bad, can you come..." "Sure, you bet." Or, "My dad's in a lot of pain. Remember he used to farm with —" "Yeah, okay, I'll be right over to your dad," You know, and call that hospice and say, "He doesn't have any liquid morphine. When was the last time your nurse was here?" So, there's still some of that input. But it's good. I'm good.

JO: Was there any patients that you had that sort of maybe changed you or changed how viewed hospice work or like — a patient who left an impact on you?

JC: Hmm, that's a good question. We had a gentleman named Barney, whose father's name was Bernie. And he was a redneck kind of guy — carpenter, and Bernie was very artistic, and Barney would come and slowly he'd stay there. I think he lived in New York State actually. And he would stay there for a week and he'd do the carpentry things or fix the furnace for us, you know. And just slowly started being very valuable to us and us to him, because he saw what we were doing for his son. I was in my office, Bernie and Barney were there pretty close to death and Barney came down and said, "Hey Joy can you come up quick?" "Sure." And I went in and

Bernie said, “Can you see them?” And I said, “No, I can’t, they’re here for you.” “Oh, Joy, you gotta see them, they’re huge. There’s three of them down there by the bed. Can’t you see them?” “No, they’re here for you dear.” “Well, they have colors like I never could paint.” And so that death was very, very spiritual. In that same room, there was another patient that — Sheila — who came to say, “Could I die here?” And one of our young men was out on the porch with his mother and she said, “Are younez cooking steam and rice down there?” And I said, “No.” “I can see it right there coming out...” Well it was his chakra coming out. He was in a chair dying, and his mother grabbed him and she said, “Oh, there it came back in.” She pulled him back in. So he didn’t die that day. But I sat out on the porch with her and talked and all of the sudden I saw her complete aura and it was — it was sort of jumbled up and it wasn’t smooth and relaxed. She was very anxious. So we had that. I think it’s the spiritual things. Boo Boo was the five year old and his spirit — those nurses would say, “Oh, he’s the bathroom with me Joy. He —” And they would just see him and, “He’s moved the angel that was by his mother’s bed.” You know [laughing], it was really— we had a lot of activity.

JO: Wow.

JC: I think what that did for me not being religious, but it just confirmed again that where love is there’s spirit and help and yeah. So they probably were the special ones.

JO: Throughout your life were you ever able to reconnect with daughters?

JC: My one daughter is a — is a psychotherapist now. She connected probably about 12 years after I left. My other daughter was younger, and she has nothing to do with me. She moved to Washington State. She called, was very vociferous on the phone, and I said, “I will not take this. I did the best I could. I had to survive, and when you’re ready to be respectful and us a decent conversation, I’m here. I love you and I’m here.” Years but —but my other daughter is in Lewistown and she’s just great and I have two grandchildren and my grandson has just transitioned to be a female. And, and he’s just beau — she’s just beautiful — and we just were together at Christmas, so — and she is the most brilliant person on the earth. She went to Becknell [University] and is now teaching at State College in Biophysics. So she’s just wonderful, and

JO: Wow.

JC: It’s just amazing isn’t it? What— and reincarnation has been a big part of my philosophy and it — I just know that this time around were all where we’re supposed to be and it’s okay and they’ll be many, many, many other times and it — it’s just — it’s just fine. It’s all fine.

JO: What are some of the struggles you see the LGBT community having? I mean, the AIDS crisis has sort of alleviated —

JC: It has.

JO: ‘Casue it’s a disease that’s now you know, chronic as opposed to terminal a lot of times. So what else?

JC: The main problem with AIDS was that it was sexually transmitted and it was deadly. And our society does not do well with either of those things. So it did help, but I think AIDS is on the universe for us to choose love. So, probably, I think we've come a fairly long way of course with *Will and Grace* [a TV sitcom] and Ellen [Degeneres] and all of that. I think now, it's — it's children who are paving the way and — and not seeing the prejudice and — and not being taught that fear, and racist too, you know it's a huge thing. Sometimes gay people would liken their journey and their struggle with the civil rights movement. And I would say, "You know what? Actually, I'm not sure we have that." I've never really had a lot of trouble. People haven't wacked me on the head and if I wanted to I can sort of tone down my characteristics and still walk into a Chick-fil-A. If your black, you can't change that, you know. So it might — it's different. It's not worse or easier. It's different. And I think what's happened — my mother called me once after the *60 Minutes* piece and said, "You know, it's not my fault your like that." And I said, "I know it's not. I was born this way and I'm happy. So it's nobody's fault." And I think that's what's been changing. That we know in every society since man, there have been about 10% homosexuals in that society. And the Indians had a name for it, and they just let him dress in squaw's outfit or her be a warrior, you know there was no problem. It was religion that came along and said, "This is the abomination." That's where the problem started, so I'm not gonna have someone translate the Bible to make me live my life the he thinks the Bible says I should. I'm not gonna do — So I think it's — with — actually with gay marriage now you know, I think we've really jumped pretty quickly from where we were 100 years and the slower that went. We still have a lot of — lot of ways to go, with beating people and things like that, and that just tells you how fearful someone is, and — and that their rel— they hide behind their religion to do a lot of damage. Yeah.

JO: Have I missed anything? Is there something else I need to be asking you?

JC: I'm not sure this reincarnation that I didn't choose to be gay and then the good career and the advocacy for waifs wasn't part of that. Probably therapists would say, "Well, your compensating and overcompensating for being gay that's not acceptable but chose and area that would be acceptable and people would look up to you." I don't know and I don't care. But, I think we just need let people be themselves. And we're seeing that again with — with little transgendered kids. There was a pediatrician on the other day who said she had and 18 month girl say, "I a boy." And certainly that doesn't mean that we need to start gearing that child, but the flexibility. Here's a truck and here's a doll and here's a dress and here's some overalls — here's — here you be you, and I love you. Yeah. I think that's sorta where we're headed, so I'm — I'm pleased about that.

JO: Great. Do you — can you think of anybody else we need to be contacting that might have stories that are important to either HIV and AIDS activism or just LGBT community members.

JC: Oh its — I see. Too bad Bernie died, I just loved him. Bernie Earhart. You know I'm not — I'm not out there in the — with the professions — professional people now as much. I'd have to think about that and get back to you.

JO: Okay, that's fine you can get back to us. And if you have any material from your hospice days that we could have for the collection we would greatly appreciate it.

JC: Oh really?

JO: We —the Dickinson Archive would be ever grateful to have —

JC: I — I would be thrilled to donate a lot of stuff. Where is the office?

JO: The LGBT Center is in Harrisburg on 3rd Street [not quite yet said to Mallory who was running the camera] and — the —Dickinson is in Carlisle.

JC: Right.

JO: But usually stuff starts at the Center and then goes to Dickinson once they sort of catalog and photograph everything for the records.

JC: So, I could just take the stuff up to Harrisburg?

JO: Absolutely.

JC: Oh, I will get that ready in a week for you.

JO: Amazing.

JC: I have a lot of wonderful things. Some of the photos from Jack.

JO: That would be, that's perfect.

JC: You bet. I will give — I'm —that'd be — what a wonderful place for it to go.

JO: Exactly.

JC: It's now in the attic, you know, so sure.

JO: That's part of the purpose of this program is being able to sort of get the stuff in place where when somebody wants to look at it down the line they can have access to those things.

JC: Oh, great! Great.

JO: Perfect. Thank-you so much for time and talking with us today. It was great.

JC: Sure, my pleasure. Thank-you.