

September 10, 2017

Ontario Community of Practice for Death Midwifery Gathering

Attendees/attendance (_): Judith, Shirley, Shannon, Raven, Diane + note-taker (Logan)

Theme: Helping Facilitate Family Dialogue

Welcome: Lighting of the candle and a poem to start us off.

- *Raven says:* Words are not my forte. It's a body thing for me. I guess I would invite in clarity and openheartedness. I hope all the work done today is done with ease and grace.

Opening Circle

Judith begins by discussing mindful presence. A Henry Chatsworth poem is used to aid the opening circle.

"Under a spreading. . .each burning deed and thought"

Judith talks about finding the subject for today and picking themes. She mentions how Suzy promised to send the results of the surveys to Judith soon, but there were not enough surveys filled out to pick more themes. Afterwards, she dives right into mentioning that we need to grasp that people within families die. That there needs to be a death midwifery community, and that it is so important to build one. When [they] tried to remove the title Death Midwives, and failed. Some of our titles scare people off, but it is important.

Judith says that we are the first community practice of Canada, we've been growing for five years. "I am interested in helping the seeding of community practice." I was talking with a colleague in Houston and she was saying "people are going to call themselves midwives without the proper training and it scares me." Judith goes on to say: We need to choose each other and have specific roles for each. The Church down the road has an event on the 14 of September to discuss death, hosted by Linda. Linda has built a career to help people understand and discuss death. She is teaching people about the process and creating community education. This is not skilling up, this is about deepening your presence in the practice. For community practice to work, those we support should be among us. They would be able to shape our insight through their lived experience. Any community practice co-create knowledge. A principal of learning alongside people because it will ground you. We still haven't had that and it is because we don't have enough death midwifery practice going on. But I think it will happen.

"I'm here both as a practitioner, a recipient and an attendee. This makes perfect sense, and it is well put. Sometimes with the people I've seen, all they want after a death is to move on. It takes a rare person to commit to a movement."

“Once it grows, like in Toronto alone, there’s 1100 people apart of the community. Those people their lives shifted. We just need to serve more people for them to see the importance”

“Because it’s such a new thing in so many ways, there is a place for skilling up. Would there be a place for this group to offer that?”

“Suzy has that job, and hence why we had a survey! But a response of only six people responded and that’s not enough. We need more surveys. We need a Facebook for GloriousDeaths. Because if it was a Facebook page, we can create more of a following and have more engagement”

“On the first night of community practice, five years ago, we launched GloriousDeaths. Now we should move onto Facebook very soon. IF anyone give us trouble for the trade mark of death midwifery, we can call ourselves death carers. So, all in all, we need more exposure, post about courses and spread the word around.”

“I am very interested in the word cure (in French). This word is important because: people are planning their deaths. People are curating deaths lately. Something about that stood out to me, how even it sounds like “curing”. There’s something there”

“I use the word navigation because to me it’s not about being in charge, it’s about being in the moment and knowing what to do as it goes; navigation. The original doula means servant of someone else, I never liked that. I’m not going to call myself a Doula yet. Like a canoe, there on the journey and your navigating the waters”

“Doula is within a little scope. Based on capability, experience, and stories. People are each taken up by defining the scope. Doula to me is probably the least limited scope. It’s been said before, navigating education. In our community, it’s about walking with them and standing alongside them. Every person who calls you, you go into the imagination. In that first encounter, you set out what you can do and they set out their needs.”

“It is a big thing. Bringing this to society. We must be patient. Society pushes death under the rug. This is only me second or third meeting and I’m still learning.”

“In terms of presence, we talked about free workshops but I do not believe in that. For me I need a long time to prepare solid content. But anyway, I just want to understand how we can build a bigger community in the community of practice. How are we intentionally creating community in our community practice? For instance, I want to have a party called ‘a day in the death’, something we used to do, but I have visions for doing more community work.”

“I’d just like to back-track to skilling-up. There probably is a lot of people out there interested they just do not know about it. I want this space to remain the way as is and not just be an educational space.”

“This work has to be collective. It all started with not knowing who was interested. And midwives met one another through their constant meetings. I am looking to create a collective. There has got to be an ease among death midwives. I need a community because it will make more sense, knowing to refer people to the correct carers. We are trying to expose people to the moral ethical conduct of this practice. Saying to people this is what I’m going to charge and therefore I charge this much for it. We need high quality, educated carers.”

“In my work place, I am the first psycho-spiritual care person they have hired and I am creating a care program. They have replaced a lot of staff because they were not regulated and I feel the tension. All I’m saying is I want to bridge that regulation to community practice to further legitimize it. And there really is money in doing this, in institutionalized. On Thursday, I’m going to the community practice meeting and while I’m there I am going to meet with Barb, who has connections with people who are more serious.”

“I have not done enough work in this. I have worked 25 years in another field and death with 150 families, this however, I have only helped 12 people.”

“I need to make money off this because it is costing me so much money. I don’t even want to see myself as an entrepreneur, I just want to provide a service and grow with it. It is a livelihood in a sense that I am living with this as my vehicle of practice (calling) but I cannot make a living off it right now unless things change.”

“My friend practicing in this field is extremely career minded and never does things like this. Things where we reflect, meet, discuss and create themes to follow. So, when we get paid, it becomes harder to create a collective and it becomes easier to become a bit corporate. [laughter]”

“We are not going to put up with dying in an alienated context. We will take charge of our deaths. This is a beautiful thing. I am actually working with a lawyer in BC that wants to make it so people in BC with mental health issues can be allowed to die if they want.”

“This was our sign of the times conversation. That is when you come together and it’s the conversation people have been burning to have because it has been getting in the way of their practice.”

Opening Exercise

When I first started FSF, I started with eight families and help them speak about what matters. I met with these families regularly, and we talked about what matters. It takes ages to get people to talk, and only in the last hour is it extremely juicy! In the beginning, there is a lot of warming-up and only in the last hour do people really share the deep stuff. I look to see if they invite me into their story because people will take your offer of support but then they own that story and you play this walking alongside them. What matters is that they make a claim.”

“Why are you doing it? It’s to help families remain resilient. So, I presume that they are already resilient. My biggest fear is that it is going to blow us apart. I have had people say stuff like ‘my life will blow up if this person dies’ because that is their way of coping with it. We want to help them make sure that is not the case. I am fearlessly committed to helping you explore what needs to be done to make sure that there is no blowing-up. The resilience helps with that. Your major task is to get people to willfully say what is on their mind. I need to make sure I never overstep, and I need to know journey for that person. How deep or wide they are willing to go. Then when you’re in safely, you just check when they broaden it. People they give you a scope and they always constrain it. If it’s going well and people are abiding by the safety stuff, then they are willing to choose the broader scope (in terms of content). There is also tone, because tone can kill everything.”

“We have to constantly deal with stuck-ness. People are always stuck. And I am currently working on understand what stuck-ness means and why It happens. It is the main reason why people do not express well enough.”

Sharings in ROUND 1

“I just say, you got to test me. You know what of the presumptions I make is that people need to test your capacity of spaciousness. When I say I’m fearless, I mean I am spacious. I feel within myself that I will not be running. I will not be leaving the conversation. I will help you figure out the limitations and direction of this journey. This is why the “Do No Harm” exists because: If you do not feel this spaciousness, then please do not offer it to others. If you don’t feel capable, then you are not. I’ll take a huge example of masturbation, people did not know how to talk about it and kept referring to others. Not enough openness to discuss this big issue.”

“I want to make a side note on sexuality and dying/eroticism and death. There is a lot of stuff in this field. Sex matter in terms of death, we will make it a theme for some other time.”

“I think that we are all addicted to this work in some way. And the question here is what exactly are you addicted to? For me, I am addicted to the clarity, helping people be clear. By addiction I mean something that keeps bring you back repeatedly. For instance, some midwives say everything goes on hold for seven days while they work on someone’s death. They are so addicted to help them.”

“How do we invite them without telling them what it is all about? They are willing to go there, in fact people make decisions about their treatment. I always say to my clients, I tell them you just made a life changing decisions, how are you going to inform your family? Families are sometimes not in the loop and left freaking out about decisions they did not know were being made. So, I guess for me its two things, its opening up and talking about topics no one imagines to talk about, but it is also about bringing families together. We need families to come together.”

“Talking about the notion of fighting, treating death as a form of war, that people have to fight. That shapes their narrative. But looking at death like its war and you are a warrior fighting give it a negative connotation. But if that’s how they look at it, then this is their narrative you work with.” (This section has been summed up due to distractions)

Talking about family resilience, and helping families talking about what matters

‘So, I go through a lot of this in my work and I still don’t do this with my own family. I had the opportunity to get a client and a daughter talking (some other family members too). So, I was feeling out what the boundaries of that conversation were. The daughter was able to hear the mothers wishes and the realities, and I was able to help the mother understand the realities of her daughter. I had three meetings with her before she died, which was short. But as far as I got with this woman is meeting with her family. But at least one of the things about this work place situation is because there are boundaries that already exists. Consent of a client is a first thing (to even seen). So, with that family, I did not get that involved. Being a doctor and meeting families, phew, it is always difficulty. SO many people think doctors do not know how to talk about this stuff, but in my opinion, younger doctors are getting better at it. There is a saying where people take three times to hear something before they understand it and I have seen this with people getting diagnosed.”

“For institutional work, boundaries are automatically built in this. There is not a lot of room for ego, it’s about transferring accountability. This week is my first meeting with a family, the family speaks English but the client does not. Working in Scarborough is hard because I only speak English. I want to get the basic gist of this client’s needs and with the use of an interpreter. To try to understand this man’s life. Some of his family think he’s depressed, but he is sad and I want to source this out within the limited time I get with them. So, languages and cultural customs change stuff, there are so many words that do not get used because they Are simply not a part of their culture. Even the word depression does not exist in some cultures at all. Navigating that is tough, and you do not want to push people out of their boundaries”

“I have seen hard conversations facilitated whereas I knew I couldn’t, it was not my place. So again, transferring of accountability, in a way its knowing your limits as a friend or a practioner (institutional professional). I have been told to get out of the room so many times. Going deeper, you just need to let people know you and listen, to me it is an art. It truly is an Art.”

“Talking about issues like this (death, planning death, not being afraid of it) is seen as a white-culture custom. People of color or from cultures elsewhere are not sensitive enough to take this conversation seriously. So, what matters is based on their beliefs and what is important to them”

“I really loved the expression of spaciousness. I do not think I go into new thing as spaciousness, right away. I work there. I get myself there, it is not like a new situation confronts me and I am open right away. It’s just who I am. And yet, my addiction is about being present. If I can be present with people, I love that. I love the opportunity to be there

in a situation with people. But they come together, its just being spacious is not my response. So does that mean I should never say yes? I went to see a new client, and her daughter was the one who bought me in. The daughter is much younger, a doctor and her native heritage is very important part of who she was and how she was. She purchased sacred tobacco and such to the meeting, and it was lovely. Eventually the dad and sister joined the meeting, and we talked about what I can do for them. When I thought it was the end of the conversation, they all started talking about things they never ever mentioned before. The woman said something and the daughter said 'I did not know you thought this way?!' and this big conversation broke out and it was healthy. I said nothing but I could not believe, stuff that was never mentioned was finally talked about it. It taught me to be patient in these situations, to be spacious."

"another experience that happened a couple of times: the daughter got her mom. I was bought in to be a companion and to do a few chores and shop/cook. They knew my background, and knew I could do that part. Really lovely lady who said to me how nice it was to have me there and because she got to direct my life. No one is telling her what to do or how to talk. So I followed her lead in anything she wants. But the daughter would say to me "my mom is very easily polite and she will do what you want her to, and it is not necessarily what she wants" but what was odd to me is that the mother led everything and I sat back. And so when the daughter said that to me, I found it very interesting because this clearly meant there was misunderstandings between the daughter and her mother. The daughter started to say, my mother does not need spiritual care, and that is not what I was doing at all. And in the end, I stopped seeing her before she died and I was sad because I really liked her. But I guess the point is, those are the things I have dealt with. The mother/daughter relationship is so interesting and you need to be very careful how to navigate that."

"I don't think I am ever going to fully change my personality, but I do really get that people react to spaciousness. If I can control my reactions, it will help the situation, allow them to talk and navigate what matters most. Also, being aware of peoples triggers and getting them under control."

"I don't have a whole lot of experience. Although I have volunteered as a family care volunteer, the job description never included what matters. My experience sitting on a bedside is that there is no discussion of what matters either. The two experiences I had independently, one I doubled up with Nelly close to the end of relationship with a woman but she needed a vacation so I took over for six weeks. We had a couple of deep conversations, but none with her family. I remember thinking that my role was to listen, and to ask questions for clarification. I started to feel that maybe I was not the director, and I was just the ear she could talk at to help herself figure herself out. I'm not sure I was a big role, because I just listened but just before her death, she discussed some of those deep things with her husband."

"My brother and my mother do not get along, so I have always kind of had to be the project manager of their relationship, and our relationship with our mother. I do not know how to have conversations that matter with my family. My oldest brother never wants to talk about it. My older brother, that never talks to her, became the go-to-guy for my mother's caring

system. And this did not make sense to us because I was more of a communicator with my mom, I understood her needs and it would make more sense for both of us to be the go-to-guys for this. As far as clients and families I don't know, I never really had the opportunity to have meaningful conversations. I have a feeling I can bring spaciousness, listening ears and the right questions. One of my strongest attributes is asking questions. That and keeping in mind spaciousness, this might help with conversations with families."

"The poem that you read at the beginning, but my immediate reaction and the first word that came to me was wholeness and arrival. This to me seems very relevant to talking about what matters."

"Being the new kid on the block, I have no experience. I have had a hospice client (volunteer visitor for hospice, and I have had three visits). I feel a little like I am underqualified to be here, and I really appreciate the sharing. A few things have scared me. Sometimes, I will go to this insecure place where I am, convinced I can never offer something important. I get passionate about things and this gives me the impression that I might start directing, and it makes me realize it is important to identify this because this is not my agenda, but the agenda of others. With my family, I left a copy of the exit planner on my father's laptop and talked to them briefly about it. They knew nothing about it. I need to get my head around the important pieces so to see where my family is too. I wanted to help them plan so there is no surprises and nastiness. I look forward to these conversations with family. With some trepidations, no questions, but I still look forward to it.

Sharings in ROUND 2 ***Focusing on resilience***

"It is interesting to me that there were two things coming and people mentioned them. The idea that stuff that matters. People decide to play big whenever, and you cannot have an agenda where you do not want to play big. You have to go with the flow. Partly, being present is saying thanks for saying/signaling, that you want to talk about it. I do make a shift that we are not going to talk about something intense. I am trying to wake up the conversation, and I engage with others to see if they have anything on their minds. People are much more willing to talk during a good condition. Earlier someone talked about almost leaving when a conversation became really important, and then deciding to sit back and listen to enjoy the moment. Create a space where they can revel in their dysfunctionality."

"So, the fact is and all of us said the same thing: I want to be chosen when the time comes. This will train me for even my own family, when my time comes. There are times when my brother was at risk because of illness. We have had to talk about intense things and I saw for the first time this new side where I am put into the loop and allowed to speak. Families do not know if they are bold enough to do it. After you leave a dance card for a topic, they start trying not to talk about it but end up talking about it for two weeks. Then the families realize they actually do need my help."

"I am here to serve you, so name the subject and I will follow. I do not know where your wounds are or how this conversation will end. I enter into a conversation with "let's see, it's your subject, not mine." A cleric reflects on speech then reacts."

"I do not like the word client, and we have chosen 21 years ago and be bold about the people we serve. Client for me just stabs me, and I teach at the college to use the word client. For me it seems counterproductive and like it sends the message that there is a difference between me and you. It unveils unconscious power. This is somebody death we are dealing with and it is not personal if on their death bed they are known as clients. Using labels on people always, when there is more than just that. It just reiterates power difference. I do not like the differentiation."

"When I was younger, I became a camp counsellor and remember how I felt so powerful. It created a divide between me and the rest of the campers. I guess I wanted the power, but this is something I do not appreciate now." (summed up)

"I totally agree that the word 'client' is a word I am thrilled with. I even do not like the word patient. We prefer to use for instant resident as opposed to patient in our hospice. When I was working with Nelly and I would email Michelle, I was a lot more comfortable using resident as opposed to patient, it felt more personal. I remember I cringed once after using the word patient. SO in the same way, the word client makes me really uncomfortable. In a dark situation like this, what are you going to refer to them as? I would love to come up with a label which would be best."

"Is there a way that we can help them get to what matters before we are about to leave? And If there is, I would love to hear it. Referring back to this idea of being present even when you are about to leave, it just makes me wonder, what if I have other things to do? How can I find a way to get the conversation flowing in the beginning and not in the very end."

"I want to circle back to this notion of culture getting into talking bout what matters. I do not think that all cultures are against talking about death, some even embrace it. But what I am saying is if there is a family that does not like talking about something like this does not want to talk about it, then we should distance ourselves."

"I have had to un-brainwash myself from using the word patient. I have also had to refrain from using the word consumer. I do not even like using the word the dying. But what do we call ourselves in the therapeutic relationship? I hate that."

"Letting the people you're with set the agendas. There's a big thing in the official chaplin world (??) going into things with an empty mind, no agenda. Beginners mind. So anyway, I hide my emotions and fears and that's what July was. It was a death and dying experience for me. I read into a new level of tomb, and I came out. The veil is a little more thin and I want to find language that is less harsh."

“A good friend of mine is about to die from cancer and she has prepared us so very well. I just want to talk about resilience and spaciousness. Sometimes just being there it can feel very impersonal and it opens things up and relationships change.”

“My husband left me for someone 20 years ago and I tried to discreetly state that I forgive them for that. After that, there was silence and awkwardness because I think here in Ontario people do not talk about that. The point is, I just wanted to open up and say I was over it. And even through the awkwardness, it got the couple talking eventually. Sometimes people die without these conversations happening.”

“I think that your presence creates a safety when families are able to open up about some intense stuff around you. I think you are mutual ground, and that you allow conversations to happen just by being there.”

“I have never ever liked the word patient. I use first name because I prefer to do that. Thank you for reminding that it is considered an imbalance in a way. I shamefully admit that my self-esteem is low, and when I have a client, I feel a sense of importance because I am giving someone something they need. So, in that sense, what do I use to refer to someone I am working with.”

“I want to go back to round one. I remember thinking a lot when I was considering this week’s topic. I had just come from visiting my family and my sister was talking about how she thinks she’s not brave. So, I’m thinking about that and I’m taking a course where it’s come up a lot. I do not think anybody does confidence easily. So, one of these things that keeps coming up is that we either avoid conflict or shoot towards it. But this is because we are not taught to deal with the situations. Our culture did not teach us to resolve conflicts. In our patriarchal culture, there is the ‘in-charge’ mentality of no we are not going there, or you will all listen to my say of it. And this is so like families and family dynamics. Interesting enough, when you do not feel safe, you can either shut down or come off strong. So, this is where my thought process went when I was thinking about family dynamics. Just being aware of the dynamics of the family. The ruler decides where a conversation goes and being a third party in a situation like this is tough. You have no idea how to control a situation where there is one person ruling and everyone else going with them”

“What matters is the tip of the ice-berg. We are helping people to practice that, because there is so much material to get to and there is not enough time. You set the conversation because it helps them understand immensely. Do not start on a conclusion or presumption, because you will get screwed up for it.”

“This business of avoiding important conversations. It is important because I have seen that women and men have different stances. It seems the woman is doing a lot of the talking even though you would mostly believe that it is the man making the decisions. Most men say they feel their wife has the last call on family life.”

Sharings in ROUND 3

“When you lead the conversation, they are left with fireworks in their consciousness. When things are spoken, it’s hard to control words that have been spoken. When people do not revisit a topic, they may be healing from speaking it once. Speaking of abuse and all those things, they exact their price on a person. It isn’t easy to do it and once it’s said the reality changes. Some people say something and go back in for many months because they are healing from story-ing their life.”

“The truth of saying stuff at death is hard. A lot of intense and deep things get said around death beds. When people first start talking about trauma, they try to hide. I have seen this with families, where one big issues come out and they disappear for three years.”

“Who I know myself to be with this amount of truth out there. I found a way to be in it. As soon as I let out this piece of truth, that it changes my shape. It affects me. When big things are spoken, the relationship changes people change.”

“it seems to me that all this leads to one thing: timing is important. Conversations about death need to be discussed years before deaths come so that when the time comes, it’s been practiced and done. People aren’t unused to it.”

“I wonder if the conversation about death is an important step. To me, our conversations in general have to contain more truth in order for us to ever get there. It needs to be a system where people are more open and truthful in order for conversations of death are effective.”

“People need to realize that stories aren’t ‘either/or’, but they are ‘ands’, because this shows that everybody has a valid version to stories. To me, I want to know why you behaved a certain way during a time of death. The only way you can do this is if you validate and acknowledge every person’s story or version of their story.”

“Our childhood is so suppressed, we give up on giving it meaning. You’re either someone that remembers everything or nothing. And this is childhood.”

“Since we are changing, we change stories. We construct it and our identities. Assembling a new voice for me, I found myself pose conversations I never saw coming. My voice changing is a new level of identity that I have come to.”

“Serving without being servile. Serving through my own humanity and limits. I will do it out of my own will and not because I have to.”

“When someone sticks their head out and says something, and it is considered abuse. Then what if their life does not change? What if people do not change and open-up or talk about what matters. I just find it really hard, how do you navigate that? The truth-teller says it’s the truth but does not do anything about it. That’s it, they just tell a few people but nothing ever changes.”

“I do not have the language to say this in the way I want to. Some people attract abuse in my opinion. In a time of death, is it easier to accept that? I have an expectation that things are going to get fixed and if they don't, I am confused. When you are holding something that is not being resolved ever?”

“Thinking something will change is a presumption. Complicity is really a motivating drive. You will feel this way always as a death midwife. I get told secrets always and if some of the information could tare a family apart. When abuse is involved and we find out about it, we have a professional duty to say there are ways to act from this point onwards. We are not saviors or rescuers.”

“We cannot change the world. We do not have to stick around when people are not changing or not wanting to. IT is hard to be in this situation because if things are not changing, you need to worry about yourself and your mental health. It is like setting a self-care boundary.”

“in my personal experience, people need their time and cannot just change or act. I did not leave my marriage till I was fifty. I could have left way earlier but I prolonged it. People need their time.”

“In Quebec, I stayed with my mentor and she has a huge family that does not speak with her (except her brother). I went there specifically spend time with her and her brother. Her one sister (that she gets along with) was trained in Quebec but moved to Spain to practice medicine. When she had a son, at the age of six her son got severely injured and she came back to Quebec for the treatment. This story pained me, and she is writing a story about how she wants to help end her sons life and her life. To immerse in the mystery and tragedy of these folks who are brave enough to consider it.”

Closing Circle

Random statement in regards to these meetings: “What I like about this system, the three rounds, is that sometimes people can't have their say. If each one of us allotted time till you give up the talking piece, you are afraid to say everything. But with this system gives you three chances to say what's in your head.”

“I like that today's theme was not based around facilitating, but helping facilitate the process of talking about stuff that matters. It stresses on the idea of being there and sitting back while people discuss what is within their comforts.”

“Truth telling is a very important phrase to me right now. I have been reading a book that helps you understand what you have been through your whole life and how much it actually changes you.” (Mark Matousik)

“I am feeling a lot of gratitude for the circle and process. And how important the contemplation is, for my own growth as a person and somebody in this field. How do we do

this more of this? For insight, talking out loud so important to me. It really brings up so much importance. In the big picture, this contemplation really has value for my life.”

“I feel a lot of gratitude for the space and the sharing. I feel really full, it will take a lot of time for things to set. I care for the education bit and for instance I never want to say client again.”

“I look forward to developing more spaciousness and listening. Specially in relation to working with my newest friend who will be dying. Any kind of referrals, information and resources, she has done this before. I am not afraid for her, for once.”

“I am taken up by this question about where do the truth people go on the planes? I do know that you cannot call them back, they start growing in the earth. What is the purpose of those if they seem to go forward into the world? Do they start working on sculpting? I am fascinated by what it takes to get to the point of speaking the truth and what happens when the truth is spoken.”
