

Disenfranchised Grief in Response to Supporting Loved Ones
Through Significant Substance Use Challenges

By

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Abstract

This research explores lived experiences of individuals supporting loved ones through significant substance use challenges. The data was gathered by one-on-one semi-structured qualitative life history interviews with six female participants. The excerpts from the interviews collate to form a semi-fictional narrative of interactions between workers in the field of substance use, a teacher-mentor relationship, and a flow of conversation within a facilitated group to investigate the narrative of the loved ones supporting someone through significant substance use challenges. The research highlights the themes of stigma and anticipatory loss in disenfranchised grief.

The research explores the concept of disenfranchised grief from primarily a first-responder's perspective who invites loved ones of those struggling with significant substance use challenges to share their experience. The auto-ethnographic approach highlights the elements of one's personal process of grieving the loss of one's expected sense of reality and trajectory of life. The research engages in exploring the interconnectedness of these emotional experiences of loss, alienation, and distress, to increase understanding of professionals who interact with the social networks of those with significant substance use challenges.

Keywords: Disenfranchised Grief, Grief, Bereavement, Anticipatory Grief, Substance Use, Substance-Affected, Autoethnography, Complicated Grief, Ambiguous Loss.

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Dedication

To the clients and families, I have served since 2016 in the field of mental health and addictions.

You do not bring harmony within the duality of our existence by ignoring the negatives, avoiding the darkness, or by pretending it does not exist. You bring harmony by co-existing with acceptance -- I see you, I hear you...I acknowledge your existence the way I acknowledge mine. It is okay for you to exist along with the light. (An excerpt from my journal, 2019).

The BC Opioid Crisis –Cultural Relevance

As I pull my car into the garage I pause. I just don't want to make the call to Sherry to inform her of the terrible news. It feels like an eternity that I remain seated in my car and yet somehow, still not enough time. I just need a little longer. Finally, I say to myself, "Ok, you've got this," and taking a few breaths to gather the small amount of energy I have left from the end of my shift, I open the door.

I immediately plop down on the couch and dial Sherry's number. She is my closest friend, my comrade, my co-worker. I need to tell her what happened, so she doesn't come into work tomorrow morning unaware of what has happened. Even though it is late, a quarter past eleven, and as Millennials we rarely talk on the phone – this conversation is to be had over the phone. We made a pact to contact each other if a client could not be revived after an overdose on our shift. Being front-line workers who deal with death due to overdoses regularly, we are aware of how jarring each death feels, despite this being a regular occurrence. We need each other's support. We need to know someone understands this experience, even if it is just over the phone. So, Sherry will know that if I am calling her, it must be urgent.

She picks up on the first ring.

"Hey Sherry," I say softly.

She doesn't respond to my greeting but sighs and asks, "So, who was it?"

"It was Christine," I blurt out, "I am just so sorry." There just isn't a way to soften the news.

Sherry is silent for what feels like a long time. I can hear her take a deep breath in as she tries to let the news sink in. Having been on the other end of the line many times I imagine that she is trying to ground herself. I hold the phone quietly, knowing there is nothing more to say.

Sherry breaks the silence with, “Is this what it is going to be like?”

This is not the first time she has asked this question. I wait for her to finish her thought. I already know the words that will follow.

“Are we just going to wait for all of them to die?” she asks.

I am unsure if the question is rhetorical or not at this point. We both have been grieving one death after another for the last four years of working in the field. It has been four years since the province declared the opioid crisis as a public health emergency (City of Vancouver, 2020). The *Statistical Reports on Deaths in British Columbia* reported 667 deaths in 2016, 1226 deaths in 2017, 1334 deaths in 2018 and 833 deaths in 2019 due to fentanyl toxicity in illicit drugs (BC Government Coroner Services, 2020).

It just seems to go on and on.

More silence. I imagine that like me, it is dawning on her, that we have to go back tomorrow and deal with the aftermath—specifically, the loved ones of the deceased--but the rest of the work at the shelter will remain business as normal. There are 100s of other clients at the shelter we work at who will need our support and we don’t know if it may be one of their last days tomorrow. It is one thing to witness someone’s death, it is another thing to be breathing for them and compressing their chest only to find out, this time we couldn’t reverse their overdose. There is no answer to what it is going to be like; we can only take it day by day. With an audible sigh, I tell her that I should go, and I ask her if she is planning to go to bed anytime soon.

“Yeah,” she says wearily, “I’m so tired.”

“I know,” I say and with a sigh I tell her, “I love you, be good to yourself. And thank you for being there.”

“I love you too. I’m glad you called, thank you...for calling me and letting me know,” she says quietly, and with that, we end our call.

I hang up the phone and as I sit for a moment before starting my routine to wind down after work, I notice a piece of paper on the coffee table. I remember Sherry wrote this a few months ago in our group therapy session after a traumatic overdose. She did not want to hold on to it anymore she said at the time.

I breathe in as I pick up the neatly folded piece of paper. I did not read this letter when she handed it to me as I was still processing my own emotions at the time. Now feels like the right time to read what it says, as I look for words that may help substitute for another group therapy session with my team.

I open the letter and read,

At the front

They haunt me like ghosts,

The images in my mind.

Although, you are okay,

a piece of me is not..

The fear that this is the one

That might not

Be okay.

Am I okay?

I think so. I have to be.

In an instant, it is like NOTHING

Even

Happened.

Everything just goes back

To...normal.

I think I am okay,

I tell myself.”

“Yeah, that sounds about right,” I think.

Letting out a big breath, I shut my eyes for a second. For a second, it feels like everything around me has just disappeared. Like the capitalized nothing in Sherry’s poem, I try to find that nothing, that instant where nothing even happened. It is comforting to be in nothing just for a second. I fold the letter back up and put it back on the table.

As I climb into bed after answering a few emails and doing a quick wash of my hands and face I wonder if I will be able to sleep. I lay there feeling numb. I've noticed that my body always feels colder on nights when there has been an opioid-related death. My mind is racing with a collage of all the other times I have had to deal with clients' deaths. Superimposed are thoughts of my past struggle with substances and a sense of guilt for what I put my sister and the rest of my family through. Most people I know in this field of work either have dabbled in addiction or dealt with someone they knew with significant substance challenges, which often makes it easier to relate to the clients and be present for them. Sometimes the clients also mirror back some of our worst times, our worst nightmares.

I can't help but think about facing Christine's family members tomorrow. My mind is full of questions. Can I comprehend what Christine's family members really feel? Will I have the right words to say? Are there even any right words...other than how sorry I am for their loss? It is hard not to second guess myself and wonder if I am helping anyone as a first responder, or if I am just hurting myself? The losses hit so much harder than the wins in this field of work.

Suddenly an image of the mother to whom I spoke to a few months ago appears to me. Our team had failed to revive her son after an accidental overdose -- despite all our efforts. I have a clear image of her. Anne Marie looked so young to be the mother of a man in his twenties, and she seemed so kind. For some reason, I remember that she was wearing red. But it is the deep pain in her eyes that really haunts me and the conversation we had when she came by the shelter after her son's death remains vividly in my mind.

"Steven always talked about how supportive the staff at the shelter had been for him," she had said quietly, handing me two bags of clothes. "I think he would like his clothes to be here at the shelter," she added, her eyes brimming with tears.

It has been months since Steven's death and I still continue to relive that conversation with his mother. It is hard to articulate, but Anne Marie appeared so grounded, and yet at the same time she was obviously in excruciating emotional pain. Part of the heartache I am feeling is that I know she has another son at home who also struggles with significant challenges with substance use. Her calmness continues to make me wonder how many times she may have replayed this very scenario in her mind.

My racing mind then flips to other parents, and so many of the siblings, and spouses of my clients that I have met through work, but settles on a father who called the shelter recently. I cannot seem to get him out of my head. He hasn't been able to locate his daughter for days and keeps calling the shelter to ask if she is there. I hear the helplessness in his voice, unsure if his daughter is safe, or even if she is still alive. However, I cannot breach confidentiality, so I tell him as gently as I can, "It may be best to file a missing person police report." I can hear the helplessness between the long pause he takes before he hangs up the phone.

This collective grief is all around me: the silence, the hollow eyes, the patience, the impatience, the anger, and the tears of all the loved ones. Although the process of mourning is most commonly associated with sadness, the death of a loved one also evokes a wide range of other emotions, including what are considered to be negative emotions, such as anger, contempt, hostility, fear, and guilt (Bowlby, 1980; Bonanno et al., 1999, Neiyemar et al., 2011). I see it every day, all day. Having so many close encounters with death over the last four years of being a first responder means that the possibility of my clients' deaths never feels like a far-fetched idea. I know that I carry deep grief, but the element of surprise has slowly disappeared over the years.

There are days I feel selfish that my life has veered from the path my clients are taking. I now check in with my mother every few days because I know she worries--as my risky behaviour in my younger days has left its mark. She often says that all she asks is for a call or text just telling her that I am okay. I notice the relief in her voice just to know I am alive, every time I call. I am so much kinder to my family than I used to be.

Finding meaning in my grief has been a significant element of my bereavement process in both personal and professional arenas. It seems as if once I have a better understanding of a topic it does not feel as overwhelming anymore. This is why my academics play a crucial role in helping me ground emotionally.

I have spent more than a third of my existence learning about psychology, mental health, and addictions. I think one of the reasons I have been dedicated to this field is to have a better understanding of myself as a person. I have had my own struggles with emotional instability that I believed at the time could only be dealt with using substances. It has been an illuminating process to learn to manage my mental health and to explore my relationship with substances over the years. Mental health and addictions often go hand in hand (Crawford et al., 2003). The problem is, that addictions are often treated separately in our health care system (Canadian Mental Health Association, 2010, Canadian Center on Substance Use, 2013). These thoughts jumble around in my head after a stressful shift. My brain is exhausted, and I fall into an uneasy sleep at an unknown hour.

I awake still actively ruminating on how my colleagues and I share a feeling of frustration, thinking that we are being stunted by the current system of addressing addiction. It is hard not to feel exasperated by the minimal resources and barriers to client care sometimes. My

understanding is that viable systemic changes can be made through identifying and addressing the cracks within the system. This remains my motivation to work in the field.

Back at work my colleague and I attend four overdose calls, and lose one more client to an overdose; a 23-year-old named Jacob. Feeling defeated at the end of my shift, I head over to the staff room to gather my belongings. It's been a long day.

I find Sherry looking frustrated as she collects the dried up take-out containers spread across the room, the crumpled napkins, dishes with food stuck to them like glue. She pours out stale coffee into the sink. I know she is lingering longer than she needs to, so she can buy some time to process what happened with Jacob before going home to her husband and children. We exchange a quick glance.

Her sudden outburst catches me by surprise, "Do you think it was accidental?" she asks looking at me as she grabs more rotten food from the fridge and dumps it into the already overflowing garbage bag. Her frustration is not just about the filthy fridge.

I am a bit perplexed by her question though, and reply, "I can't possibly know."

She huffs and shakes her head. "He was going to a good university, he was clearly struggling, he said he didn't see the point in living. My god, he was only 23! I mean this is not just the overdose crisis. Maybe, fentanyl just gave him easy access to end it all," she says as she struggles to stuff the garbage down in the bulging garbage bag.

"It seems to me that people struggling with addictions are just left to die. You know what I mean?" she pauses and continues on without giving me a chance to slip in a word. "Is it on us? It isn't I know, because we did everything that we could...is it on him?"

I know she is frustrated from constantly feeling helpless, so I sit quietly waiting for her to continue.

She huffs again in frustration as she ties up the garbage bag, to get rid of the horrible stench, “People just keep falling through these cracks and it just seems like nobody cares.” She glares at me and says again, “You know what I mean?”

My chest feels so heavy. I know exactly what she means. Admitting that our system keeps failing our people just feels exhausting. “Yeah, sometimes it seems like addictions are treated like the unwanted step-brother who comes along with the mental health package,” I reply.

She reminds me of some recent research that supports what she is saying. In the field of addictions, stigma is not just derogatory comments made towards people who struggle with substance use, it is also systemic neglect (Amsalem et al., 2018).

“You may be onto something,” I say. “I came across a recent study that stigma against mental health rapidly increases when you have substance abuse too,” (John Hopkins HUB, 2014), I say in an effort to help Sherry find some validation to her visible frustration.

She appears to be interested so I continue. “Over decades of research, stigma has been found to contribute to be the main reason for discrimination and to contribute to the abuse of human rights (World Health Organization, 2014)”, I add.

“It is stigma!” she says emphatically. “And it’s exhausting,” she sighs. “You know what it is like, most of our clients refuse to get medical assistance at the hospital because of how poorly they say they are treated at the hospitals. It’s just so infuriating,” she adds as she collapses onto the sagging, stained sofa.

I see that she is overwhelmed after a stressful day, and I know this is a longer conversation than I have the time for right now, as I have to get to class. I try to put a positive spin to an inherently stressful day, by saying, “We reversed three out of four overdoses, which is

something, right?” As the words slip out of my mouth I realize I may have opened another can of worms.

She sinks into her seat, “Yeah, close calls...we brought them back *today*.” Her emphasis on ‘today,’ implies there will be another day we might not be able to bring them back. I know I’m rushing her but I have to go, so I get up and hug her goodbye and tell her to take care of herself.

“Let’s meet outside of work soon when we both have a day off,” I say as I leave the room, feeling guilty for abandoning her.

Terminology

I am half upset at Sherry for holding me up, and a half at the fact that I still need to be in class and have an assignment due tomorrow, even after we lost a client at work. There is simply no time to pause and truly feel the losses. A part of me is also afraid to pause, afraid that if I pause to truly feel the losses I may not be able to pull myself back up. So maybe, I am just distressed at having to witness the fallout of the fentanyl crisis day in and out and not so mad at Sherry. I am definitely upset that I am now late for my Psychology of Grief and Loss class.

I sneak into the classroom as quietly as possible. As I try to settle in, my mind is still wandering. Everyone in the classroom seems to be hooked into the lecture. I try to listen as Lisa introduces the class to the notion of Disenfranchised Grief (Doka, 1989). The term seems like a mouthful to say and it is a new concept for me. “Social norms govern appropriate ways of behaving, thinking, and feeling in a particular situation (Harris & Winokuer, 2016) and it affects how people process grief as well,” she says. My mind still fans out between the clients we revived, the client who died, and my conversation with Sherry. I keep trying to bring my focus back to Lisa. At the same time, I’m also feeling anxious because I know I have to hand in my thesis proposal soon. I pull myself back to the classroom.

“The concept of social norms permeates into the realm of grief, deciding what is appropriate regarding the intensity, duration, acceptance, and the importance of the loss the bereaved may experience” (Harris & Winokuer, 2016, p. 48), she goes on, reading from the textbook.

“Who has the time to think about social norms when one is grieving,” I think to myself. But then I remember how my response to grief and trauma has shifted over the years working in the field of mental health and addictions. I remember bawling my eyes in the parking lot at work,

with my supervisor standing beside me as I broke down after the second overdose I responded to that resulted in death. The first was a week before the second one. I may have been in shock possibly after the first one because all I could think about was that I have an assignment due the next day and proceeded to the library to work on it. The second client who could not be revived broke through that shock and solidified the reality of this work for me. I thought I was never going to stop crying. I have felt the same way, the same intensity of emotions for every client I have lost or have gotten close to losing to an overdose.

However, in this field of work, where death is prevalent, I cannot afford to emotionally break down every time someone dies. This is how the social norms come into play for what is considered an acceptable emotional response. The social culture changes you, it subtly asks you to adapt. Although I have stopped emotionally unravelling every time a client dies, it should not imply that it doesn't hurt just as much as it did the first time or the second time.

The clients revived after an overdose leave a different sense of loss than losing a client to an overdose. A narrow escape, uncertainty about their well-being after. I rarely see overdoses as these life-changing milestones for my clients. Most clients I encounter at the shelter, who are using substances seem habituated to walking on the edge of life and death. So do the front line workers, that is, we get used to watching clients walk this thin line between life and death. "How dreadful it is, to not know, to continue to live in uncertainty," I think to myself.

Lisa describes this grief as a 'living loss' that is non-finite. A non-finite living loss demands the individual to repeatedly adjust and accommodate to the loss because their loved one is still alive, still dealing with the changing circumstances of their lives (Harris & Winokuer, 2016).

Lisa's lecture is beginning to pull me into the class and listen.

The term 'non-finite' rings true for what I had been witnessing at the shelter, there are no fixed end dates to the losses occurring, whether that is the loss of hope, watching clients' capacity decompensate day by day due to significant substance use challenges.

What Lisa is saying is resonating with my experience. Even though I had a long day at work and school, finding new terminology to define grief experiences has me hooked with the rest of the class.

Lisa reads from the textbook, "Disenfranchised grief is defined as a grief process that is not recognized or validated socially (Harris & Winokuer, 2016). Doka (2002) notes several different ways in Principles and Practice of Grief Counseling (Harris & Winokuer, 2016), by which the grieving individual is disenfranchised and thus excluded from social support," she further adds, as she pulls out a dry-erase marker to write on the board to break down the elements of disenfranchised grief:

- The relationship that was lost was not considered valid, socially acceptable or important.
- The loss itself is not recognized or viewed as significant.
- The grieving individual is exempted from rituals that might give meaning to the loss or is not seen as capable of grieving for the loss.
- Some aspects of the death or loss are stigmatizing, embarrassing, or unacceptable, (p. 49).

A million connections are occurring in my brain as I read what she has written. I am amazed that what I have witnessed and experienced is known in the field of grief and bereavement, and that there are words to describe and identify it. It seems that my grief has not been recognized or validated by society. Even I haven't fully recognized my grief or at least

categorized it as grief. But now I see that there is language to describe it. I feel excited because I'm pretty sure others must feel the same way, especially family members or friends who are supporting someone who is struggling with substance use.

As I become fully present in class listening to Lisa, the bell rings and the class is over. My mind is not quite ready to let go of the lecture. I make my way to the library to sit down and read more about disenfranchised grief.

I reflect on what I have been noticing in the field of mental health and addictions and it seems that supporting a loved one who is struggling with substance use challenges can be quite an emotional roller coaster, but I have yet to see grief support for their families and loved ones in my field of work. While I often speak to family members and friends of substance users who call the shelter, suggesting grief support for families has not been part of our protocol.

I flip through the textbook, scanning the pages, inhaling everything that has been written about disenfranchised grief, and pause when I read this line: "non-finite loss is often not well understood; the experience may go unrecognized or unacknowledged by others. Support systems may tire of attempting to provide a shoulder to lean on" (Harris & Winokuer, 2016, p.111).

As I read ahead I find that Rando (1986) initially used the concept of anticipatory mourning to refer to the grieving process that individuals go through when their loved one is expecting to die due to a terminal illness, describing how loved ones may begin preparing for someone's death even when the actual death may be weeks or months or even years in the future. He also described this grief as a "...phenomenon encompassing the process of mourning, coping, interaction, planning, psychosocial reorganization" arising out of the awareness of impending loss or losses" (Rando, 1986, p. 24). I try to apply this to what I witness and wonder if the loved

ones may begin to anticipate a final loss as with every oscillation that occurs between recovery and relapse with the person with substance use disorder.

The concept of anticipatory mourning seems to be filling the gap in my understanding and this grief terminology is helping me find a sense of common language to describe what both Sherry and I have been not only experiencing ourselves and but have been witnessing in others.

I want to better understand this, but I think I need someone to bounce ideas around with me, which might help me gather my thoughts and ground my understanding of these concepts, as the implication of the theory is taking me off in all directions in mind.

Building the Plan

I text Sherry to ask if it is okay to call her.

She texts back asking, “Who is it this time?”

I reply, “No! Nobody is dead! Just learned some fascinating info—too much to text.”

She replies immediately with “LOL, give me 30 minutes. I’ll call you.” But she gets back in 20 minutes. I pick up quickly, excited to have this conversation with her. “What is going on?” she asks. I can hear that she is curious about why I would call.

“I just learned some really interesting language my Grief and Loss class. I think you’ll also find it interesting,” I say.

“Well I am glad nobody is dead,” she says sounding half-relieved and confused.

Chuckling I say, “Oh no, of course, you thought someone had died. Strangely that’s what I want to talk to you about. Are you free to grab a coffee and go for a walk by the ocean?”

“Yeah, let’s do it! Meet me at 5?” she responds sounding relieved.

I pick up coffee for both of us on my drive over. I see her sitting on a boulder by the ocean. It is a beautiful hot day and I’m so glad to see her. Our shiftwork and my school schedule make it almost impossible to meet outside of work.

I pass her the coffee and ask her how she’s been doing since our last shift together.

“Oh, you know, I am okay,” she responds somberly.

No, I do not know if she is okay, but I also am unsure what being okay really looks like right now. I smile encouragingly and settle in beside her.

“How are you doing?” she asks.

“I am okay too,” I say the words as if they have no meaning.

She takes a sip of her coffee. “What is it that you wanted to talk about so eagerly?” she asks.

I smile and begin to give her the gist of what I learned in class with Lisa. I explain to her how disenfranchised grief refers to a type of grief that people experience but cannot openly express because of social stigma. Due to the stigma, people may be denied support and an appropriate outlet to process their losses, interrupting their bereavement process (Harris & Winokuer, 2016).

She looks at me with curiosity but is clearly confused, “Well grief is a personal process. How can you be “denied” the right to grieve, if you know what I mean?”

“Yeah, I get what you mean, it really comes down to the societal norms, for what is considered acceptable and what isn’t,” I say.

She curiously asks, “So like if you were having an affair that no one knew about and you broke up, or the person died. You wouldn’t be able to openly grieve because you were doing something wrong?”

“Yeah! Sort of like that,” I nod. “The disenfranchisement part is linked to social norms (Harris & Winokuer, 2016) since society dictates rules for how to act, dress, speak and operate in the world, society also imposes rules around grief that can be subtle or explicit,” I pause to let her take it in. I add, “and linked to social norms is stigma.”

“Oh, I see, so in relationships where there is an aspect that is stigmatized there is more of a likelihood of disenfranchisement in their grief process?” She is beginning to connect the dots.

“Yeah exactly, when someone dies due to drinking or driving, or of an accidental overdose, and so on,” I continue enthusiastically.

Tilting her head, she says, “That makes sense, if a death is stigmatized, their loved ones, or even people who work with them like us, may not get the typical support for their grief process.”

I hasten my words, as we are on the same page now. “Yeah exactly. But what I’m most curious about is the part about anticipatory grief. The way Lisa explained it is that there can be grief that happens even before a death or before a major loss even occurs. There are losses that happen which makes a person anticipate a loved one’s death and sometimes anticipate withering of one’s relationship as a by-product when a loved one’s health is deteriorating (Holley & Mast, 2009). What makes it relevant to our work is that it implies that people may begin to build ways to cope and adapt while they anticipate and begin to get ready for the worst possible outcome (Rando, 2000).”

Sherry leans in, “That’s fascinating, but also it sounds so obvious! I can imagine how family members of our clients would have to change their behaviours around someone who is battling with substance use challenges.”

“Yeah, and our clients are always at risk of death,” I say to reinforce her understanding.

“That’s right! Of course,” she says. She puts her coffee aside, “It just makes so much sense. I sometimes feel like I am waiting for the worst...the worst in our case being someone dying.” She takes a pause before adding, “I always kind of dismissed my feelings as just my personal level of anxiety.”

I take a breath before responding, “Right, it’s sometimes easier to call it anxiety than to acknowledge it as an appropriate response to what we notice at work. It can’t be just unwarranted anxiety though when we see death so closely, so many times. We feel anxious because the death of a client is a real possibility... all the time.”

She drops her shoulders almost with a sense of relief, “It is. It also means I’m not crazy for always thinking the worst. It’s ...well, it’s adaptive really. I’m preparing myself for a realistic possibility. It’s a calculated likelihood in the arena of drug use.”

“Yeah, a calculated possibility would be a good term to describe it. And maybe it’s conditioned response because we know this has happened so many times before, so we begin to expect it,” I say.

“This is giving me a lot to think about,” Sherry says with a sigh. “We sometimes take this constant fear of someone we care about dying as just a way of living, but it’s always there in the background... just lurking.”

I don’t say anything for a moment. I’m just going through how I process this constant trauma, grief, and loss in my head.

Breaking the silence somewhat hesitatingly, she says, “I think this grief may permeate into my personal life too. I always have felt good about my ability to compartmentalize, but when I think about it now, it seems like a lot of my compartments carry anticipated grief.”

I get the feeling that she is carrying a sense of shame for letting these boundaries be a bit enmeshed instead of completely compartmentalized, I let her carry on and nod as she speaks.

“I know I worry about my partner, as it hurts to see him struggle with substances. Often it feels like he is choosing to use drugs over our relationship. It’s been at the core of most of our arguments.” Sherry takes a breath in and quickly blurts out, “I know it isn’t all so cut and dry.”

I can’t tell if she is defending her narrative or worried that I might disagree with her. I remain silent as she continues.

“We can talk about boundaries, and we can talk about recovery, but I think at the end of the day I am afraid of one day getting the phone call, not about a client, but about my partner.

More than that, I've lost hope that our relationship can ever look the way that I once dreamed about."

I don't want to interrupt her stream of consciousness. I know she has been navigating the ups and downs of her partner's struggle with substances for years now, and this is not the first time she's been in a relationship like this. I've known that she worries about her partner, but this is the first time that she has vocalized her fear of him dying, and it's a big admission. We sit in silence for a few seconds to let her words sink in.

I maintain eye contact hoping to relay that I understand how incredibly difficult this was to say. "After your last boyfriend dying from an overdose and the work we do. You're not paranoid. You have a reason to worry. As you said earlier, it is a calculated possibility, the chances... of him dying," I pause, trying to really imagine her reality, and then gently add, "That must be hard to constantly revisit."

"Do you think other people feel this way too?" she asks, answering her own question in the same breath, "I mean how can they not? Especially with the number of overdoses that occur, this can't be just our bias as front-line workers in the field. I know that in 2018 alone, 1300 people died from fentanyl poisoning (BC Government Coroner Services, 2020)."

I remember. Sherry and I refer to 2018 as our *banner year*, meaning the worst year to be working as a first responder in BC. "Yeah, and what about all the people we revive daily, we hardly hear about that on the news," I say.

We can both remember the time before overdose prevention sites (OPS) were approved in our province. OPSs are a health service that provides supervised injection and immediate overdose response (Wallace et al., 2019) as a harm-reduction measure for illicit substance users. In 2016 in BC, OPSs were operational within weeks of sanctioning in major cities across BC. In

the first year of operation over 20 OPSs were established with approximately 550,000 visits, 2500 non-fatal overdoses, and no overdose deaths recorded at OPSs, at least in British Columbia (BCCDC, 2018).

We sit silently for a while. After that last class, with my thesis proposal looming, I've been mulling over an idea. Sherry knows me well enough to know that something is on my mind.

“So, should we be doing something?” she asks.

I quickly drop the bomb. “I want to write my thesis about this...I just don't know how yet.”

Since the idea first occurred to me I have been catching myself drifting into uncertainty I wonder if my idea is completely absurd, since I wasn't one of those students who had been dreaming about getting into graduate school for as long as they can remember. Every time I graduated from school whether that was high school or university, I swore I was never going back. However, working in the field of mental health and addictions continued to push me further to obtain better knowledge and training so I can better support my community. I was avoiding school like the plague back in high school, and despite this avoidance, I've somehow spent the entirety of adulthood in post-secondary education.

My role as a first responder during the opioid-crisis showed the stark reality of what a privilege it was to receive the mental health support at the time I needed it the most. The lack of accessibility of mental health support for my clients and their families during the opioid crisis gave me the push I needed to enrol in to school to become a counsellor.

Sherry pulls me back to our conversation, “That sounds great! What a great thesis topic!”

Her enthusiasm helps me feel validated that at least one person other than me thinks this might be a decent topic.

I stare at my coffee mug quietly, “I don’t know how or where to start...” I say slowly.

“Well I wonder if we could hear from more people and what their experience has been like, with both of our experience in the field and your schooling, maybe we can arrange for a conversation that would allow others to speak about their experience.” She is obviously excited about the idea.

But she is making it sound so simple. “You’re right,” I say hesitantly, “I’d just love to share what I’ve been learning. Having the language to describe what you are feeling is so liberating.”

“And,” she adds breathlessly, “it might help us both to know if it’s just us who have noticed this or if others feel this way too.”

I laugh, “But do you think people would come to a group like this? I mean, just so I can test some theories?”

“Well no, not just for testing theories, but if disenfranchised grief applies to our clientele, I think people may come forth to at least just talk about their experience, and maybe in the process they might find a way to validate their experience, just as we’re finding this new concept confirming our experience. This is something that both you and I know doesn’t get talked about enough because of the stigma against addictions (John Hopkins HUB, 2014; Link, 2001; Matthews et al., 2017; Olenuik, 2013),” she says with an encouraging smile.

“You know, from my readings for school, I know that it is widely accepted in the literature that any time people experience separation from someone or something that’s important to their life, they experience grief (Neimeyer et al., 2011). And this can include anger, sadness, guilt, desperation, loneliness, hopelessness, and numbness (Doka, 1989; Van Der Wal, 1989; Harris & Winokuer, 2016). So, I know the idea has to be worth exploring with loved ones

of substance users. We see the grief that they experience at work...and within our personal environment as well. But, I'm still feeling unsure," I sigh.

Sherry holds silence as she can tell that I am flooded with ideas and emotions. She finally asks, "What are you unsure about?"

"I'm not sure that I know enough. Maybe I should learn more about this topic before inviting people into such an inherently vulnerable conversation, but at the same time I feel excited. I really do love the idea," I say. Gazing out onto the water, I pause before adding, "I know I want to hear more on this and if I have learned one thing from school, it's that there is value in people talking about their experiences."

She looks at me while stating the obvious. "We break the stigma by talking about what is not talked about in the community. If you are up for it, I think we should organize a group session to hear others out. It won't be that difficult to do since we still have the community project funding for a room and snacks, we just need to find a suitable room and some willing participants."

We had been working in the field for long enough to notice how stigma entrenched within our community affects people not just individually but also systemically (Link, 2001). We also had been focused on our clients individually for years, without really providing space for their families or loved ones. I recall the 17th century John Donne's quote, "No man is an island. No one is self-sufficient; everyone relies on others" (Donne et al., 1938). In other words, all of us are interconnected, and unless we address the whole system we can't hope to prevent overdoses and their aftermath.

I take a big gulp of my coffee now that it has cooled a bit, while trying to wrap my head around how to implement this project.

“The more we talk, the more I’m thinking that it is the perfect thesis topic. It’s a question that’s important to me. I think it could be extremely beneficial to learn more about how grief is experienced and disenfranchised for people who are helping support substance users. It would also have a practical purpose, that it could help counsellors and other mental health workers, and even for loved ones to better support substance users and each other,” I say, as we spontaneously leave our sheltered spot and head closer towards the ocean. I can feel my attention shifting away from Sherry.

Sherry, picking up on my energy, says, “What are you thinking?”

I find a large log and sit back down next to it, now a bit closer to the water. “It just seems so overwhelming,” I say, glancing at her quickly. But rather than continuing the conversation I continue to sip my coffee in silence. Sherry, sensing my need for some space leans back into the log, obviously enjoying the ocean breeze on her face.

Finally, I break the silence and confide in her, “I’m afraid that hearing others speak might trigger my own emotions if I’m not grounded enough...I just have this sense of my own grief that feels, uh, well unsettled.”

Sherry takes a breath and nods.

I sigh and look at her, “I also just don’t know where or how to start. I don’t want the voices of those talking about their grief to be on a piece of paper as numerical values that are not descriptive of peoples’ experiences. Somehow, I just don’t think that by saying 10 out of 20 people expressed the need to hide their emotions won’t capture the vulnerability that they feel. That would just seem like such a cold approach. You know what I mean?”

Sherry nods, “I get it, these stories people might share with us would be extremely intimate. And another thing I was just thinking about would be that if you were to use our

findings from the group for your thesis research there would be tons of formalities involved with that process too?”

“Yeah exactly. Research is still pretty new to me. I’ve read lots of journal articles, but I haven’t done research myself. I’ve looked at some examples of traditional theses and I just don’t think that anything I’ve seen would be able to capture the emotional elements of the stories.”

“Why don’t you ask Lisa for her opinion. Maybe she has some ideas of how to approach it,” Sherry suggests. “If you want to go ahead, I would be honoured to be part it, in whatever way you want me to help,” she adds.

With that, my anxiety seems to dissipate. I am so grateful that I have such a great colleague and friend with whom to talk. After spending another hour or so chilling by the water, talking about random things before saying our goodbyes. I head home to write an email to Lisa asking for an appointment.

Meeting with Lisa - Literature Review

I am lucky enough to get in to see Lisa the next day. I knock on her office, a knot forming in my stomach, which indicates a familiar feeling of insecurity before making any decision.

She smiles readily, as she opens the door and greets me with a warm hello, “Hey, come on in.”

The knot begins to unravel with her welcoming presence. I admire her knowledge about the topic of grief, as this has been the focus of her career for years now; this also makes it a bit intimidating to bring up the idea of my research with her.

Not knowing how to start, I just take a deep breath and jump in, “Hey, it’s good to see you. Your last class really stood out for me...the stuff about disenfranchised grief.”

Her response calms me immediately, “Oh good! Please take a seat and tell me what struck you?”

I realize I just spilled out my first thoughts, but since they are out now I continue, “I guess everything. I can’t stop thinking about the ways grief doesn’t get recognized in our culture or responded to appropriately (Doka 1989, Corr 2002, Harris & Winokuer, 2016). I’ve been troubled at work, both for colleagues and myself, and for other people who support our clients, like the ones at the shelter I work at. I hadn’t heard of the term anticipatory grief until your class—you know--for those who haven’t died yet, or for disenfranchised grief where there’s stigma. I really think that both these concepts apply to first responders and also to other people who have a relationship with those who use substances. I mean, the people who had hopes and dreams connected to them, dreams that have not and most likely won’t come true (Rando, 2000).”

She seems to be following so I keep going, “Since the last lecture, I’ve been researching the idea of disenfranchised grief and I came across a study by Knight and Gitterman (2019) that

states that ambiguous grief results from a non-death loss. The reactions of loved ones faced with these situations rarely have been understood as a form of grief (Harris & Winokuer, 2016). The lack of recognition of ambiguous loss means that it is more likely to be disenfranchised (Knight & Gitterman, 2019).”

Perhaps, I am in a heightened state because every gesture or word that comes out of her mouth feels like a conscious attempt to settle my energy down. I really want her to say that she thinks this is a valid idea to research.

But I needn't have worried. Her smile grows bigger and she says, “So you see that the grief of loss is not always about death, but can also be about the loss of dreams, or finances, or a sense of security too.” She softens her tone and becomes more serious, “This must be pervasive in your line of work,” she says gently.

I feel calmer and sink more deeply into the comfy maroon lounger. With a deep breath and feeling the shame of the words that I am about to say, which could sound abrasive, I just say them aloud, “Yeah, sometimes it feels like I'm just waiting for people to die. I'm not meaning to be harsh, it's just that the tension of the expectation is so tiring.”

I am dreading having to make eye contact because I don't want to see pity or judgement in her eyes for what I just said. This is a regular occurrence, a regular experience, and by saying it out loud I am speaking my truth, but I hear the way it sounds, and it doesn't sound so gentle to say.

Lisa gives me a second to see if I want to add more to my statement. I don't want to say more until I hear her response to this first, it seems like I am constantly gauging other peoples' openness and willingness to have any conversation about my struggles at work.

Lisa leans in, “I am guessing it’s not only the feeling of waiting for death that’s difficult, but also how you regulate your emotions so that you can continue to show up for your clients day after day. It must be so challenging to watch them and their social networks struggle,” she says.

She gets it! “Yeah, that’s exactly it.”

Lisa nods her head. She looks into my eyes softly, the perceived shame of my words does not feel as heavy knowing she’s understood and is willing to have this conversation.

“I want to explore this idea more with people who are supporting someone with substance use challenges. I found this brochure for health care providers that refers to families of Alzheimer’s patients,” I say, pausing to dig it out of my bag.

“This line here about adaptation,” and I read it to her, “Family caregivers must continually adapt to new events or changes that occur at various stages of the disease and as part of their caregiving role,” (Alzheimer Society of Canada, n.d.).

“I think this applies to my clients’ families as well,” I add. “I see families that must need to constantly adapt to changes and build personal strengths and resilience when their loved ones are struggling with substance use. I know it’s hard when there is so much ambiguity... the uncertainty of how things may play out, and of course the ultimate possibility--death.”

Coming even closer, she explains, “That’s an important distinction about the anticipatory grief and the sense of displacement someone might experience. It’s not that the bereavement process of a person’s death has moved ahead before their death, but anticipatory grief is a process of the losses that occur while a loved one is still alive, it is just a less distinct set of losses than say when someone dies of a heart attack. It’s also different from preparing for death as one would with a diagnosis of a terminal illness (Rando, 2000).”

It's a relief to hear that the connection I'm making between family members of those diagnosed with Alzheimer's and loved ones of substance users may experience a similar sense of displacement along with helplessness. It's also a relief to hear that Lisa not only understands what I am talking about but is widening this conversation with me, so I feel comfortable telling her about mine and Sherry's idea.

"I want to co-facilitate a group to hear more about the experience of people who are supporting someone with substance use challenges. I would love to hear what you think we might need to know about facilitating a group like this," I say feeling vulnerable and eager to hear her response.

She looks at me with that warm smiles of hers, "What is it that you already know about the concept of disenfranchised grief from your experience and research?"

"Well, I know there's an element of shame and stigma that is still prevalent in our culture when talking about addictions (Link & Phelan, 2001). Supporting a loved one who is struggling with substance use can be quite an emotional roller coaster. Family and friends may feel a sense of chronic despair and ongoing dread, from what I have noticed and experienced," I say.

She nods her head in approval, "Go on."

"I've had some difficulty locating much on my client group in the literature, but I did come across an American study that, while not written about substance use, explores disenfranchised grief among family members of death row inmates who are incarcerated (Jones & Beck, 2006)."

She seems intrigued, and tilting her head to left asks, "How do you see that study relating to loved ones of those struggling with substance use?"

"It's the implied moral failure of the families..." I say.

She looks at me with curiosity, “I think I see the connection but maybe you can tell me what you think it is.”

There is a lot on my mind so I try to explain, “Well, there’s a connection between how we view family members of those struggling with substance use in our community and family members of inmates on death row due to the stigma both populations experience in the community. The researchers interviewed 26 family members asking questions about their relationship with the accused, changes in their family structure since incarceration, and their interactions with the criminal justice system, the media, their community and about their physical and mental health (Jones and Beck, 2006).”

“Can I just read you something?” I ask. Seeing her nod I pull out the article and read slowly to empathize how profound this is, “Often the offender is made to look so evil that it is difficult to imagine the existence of loved ones, and if loved ones are acknowledged then they are also viewed as questionable by extension” (Jones & Beck, 2006, p. 292).

It's hard to say these words. It just seems so wrong. I look up at her and I can see that she is with me.

“Go on,” she says, “This is interesting. I might have heard of this.”

“So, what the authors are saying is that the bereavement process was cut short or altered because the community considered the deceased to be evil, and the death itself was deemed unworthy of recognition. Not only does the community fail to acknowledge the execution as a loss to the inmate’s family members, but it actively marginalizes the family members’ bereavement process, making their mourning prolonged and difficult to alleviate (Jones & Beck, 2006; Joy, 2014)” I add.

Lisa shakes her head. I can see that she shares my sense of disappointment in our societal response, a response that is far too common when deaths are stigmatized.

“They go on to say that the family members showed patterns of social isolation due to stigma and their feelings of having been criminalized. There was intensified conflict between family members because of different grieving styles, as well as a sense of diminished self-esteem, shame, guilt, and chronic states of despair (Jones & Beck, 2006).”

I look to Lisa to see if I have gone on too long, but she is leaning forward, looking like she is really with me.

“I see the connection you are making. Loved ones of substance users may be similarly socially isolated as the drug use may be perceived by others as a self-inflicted fate,” Lisa says, as she shifts in her chair.

“Exactly.” Now I am doing well, so I continue, “I came across another study about the disenfranchisement of grief for families who have lost someone due to a critical substance use injury. You know, like an overdose. The grief response followed similar patterns of social isolation for the family (Gray, 2010). Their research suggests that the grief of those supporting their loved ones through substance use disorder may be invalidated due to being considered in some way complicit in the infliction (Gray, 2010).”

Lisa nods, “Oh right, now I know why this sounds familiar. It was mentioned in another study. The authors explored a similar notion, as they looked at drug or alcohol-related death and they found similar patterns to the death row inmates study (Valentine et al., 2016). The family and friends reported isolation, feeling the need to protect their reputation due to social stigma, feelings of humiliation, and even self-blame (Valentine et al., 2016),” she says.

“And you know what else? The lack of sympathy shown to those bereaved following so-called self-inflicted deaths, is also reflected in the way such deaths are reported in the media (Valentine et.al, 2016, p.287),” she adds.

“The way deaths are reported in media regarding fentanyl poisoning has very quickly turned people from human beings to a statistic,” I say.

“What exactly it is that you’ve noticed?” she asks prompting me to clarify.

“Well, maybe it’s a bias from working within the field, where there may be a level of desensitization to the number of overdoses we see or hear about daily. We’ve lost thousands of people over the years due to overdoses and lately, it feels like people are just becoming another number to add to the statistic,” I lower my gaze.

“Hmm, and they’re not just numbers to add to the statistics.” She locks eyes with me and continues, “They are people, loved ones, people with full-fledged lives, people with connections who grieve their loss after their death...and as you’re saying, maybe even while they are alive.”

Shrugging my shoulders “It sure does seem that way,” I say disappointingly.

I quickly jump to my next thought, “In another study in 2015 (Piazza-Bonin et al.), the researchers said that stigma inevitably finds the griever in violation of social expectations, and their experience becomes delegitimized, unrecognized, or unsupported by the social systems around them,” I say.

“Yes!” Lisa says and continues, “Addiction is framed as an issue of moral failure instead of a socio-political systemic failure (Kupfer, 2018), so it is often framed as a disorder of choice. So then, society begins to link addiction with a lack of morals (Kupfer, 2018).”

I can see that Lisa is completely engaged and enjoying this conversation as much as I am. I try to reconnect the dots to get back to my point and say, “Similar to the inmates on death row

(Jones & Beck, 2006) and the families' who were isolated after their loved ones were killed violently in gang-related homicide (Piazza-Bonin et al, 2015), the responsibility of moral failure often falls upon family and loved ones."

Falling back into her chair Lisa asks, "What part of that research interests you the most?"

There are just so much about this research that interests me but I try to pin my thoughts down, "Well it seems like the idea of the moral failure of an individual or the family tends to emerge from the idea rooted in the stigma that implies that the person using substances possibly began using substances because the family didn't have what it takes to raise healthy kids. From there, a line gets swiftly drawn between 'us and them' and society ends up treating families and loved ones of those struggling with substance use like they are dirty or worthless and not worthy of compassion in some way...not that the families of death row inmates deserve to be stigmatized either. Our society responds with such disdain to the loss of human lives outside disease or accidents it seems."

I know I've gone on a bit, but it just seems so unfair, and I am so tired of it all. I feel my shoulders drop as I lean back into the chair.

Lisa exhales, "You might be interested in the research by Livingston in 2010, the study explored disenfranchised grief to understand the experiences of adult children of Nazi perpetrators, who grew up with cultural norms of grieving alone or in silence. Both they and the culture around them seemed to feel that they didn't warrant empathy," (Livingston, 2010).

"I can't possibly imagine the stigma they experienced," I say.

"Yeah, it is quite the research," she says. She further adds, "The author (Livingston, 2010) points out that these families' grief was unduly complicated. What I found interesting was

that conversations between Holocaust survivors and descendants of Nazis gave opportunities for mourning to both groups.”

My eyes grow wider, “Wow, I can only imagine how difficult it would be to have these conversations, but what an opportunity for just letting it out.”

I pause for a second trying to articulate. “I find it unsettling because, without some process around bereavement, the stigma and complicated grief affects generations of people.”

Lisa says, looking directly at me, “What is most bothersome for you about this stigma?”

I take a deep breath, “It seems as if we are dehumanizing individuals and their loved ones, this stigma prevents them from sharing their experience with others or from seeking help while they are grieving; a time where they probably need the most support (Oleniuk et al., 2013).”

The knot in my stomach begins to travel to my chest, “People are shamed into submission to be complicit with what our culture dictates is okay to share and encourages them to hide everything else. I don’t want to be in hiding, I don’t want my emotions to be in hiding and I don’t want that for other people either,” I say with more passion than I expected.

With obvious frustration in my voice, I add, “The amount of social support available is also a key factor influencing grief, and studies have shown folks with adequate community support will have an easier time of resolving their grief (Romanoff & Terenzio, 1998, Neimeyer et.al., 2011, Harris & Winokuer, 2016, Wolfe, 2018) than those with little or no social support. I mean those who are forced to carry the burden of grief alone.”

We sit in silence for a moment and then Lisa shows her support by saying, “I really like your idea. What do you think it is that you need to facilitate a group such as you’re describing?” she asks with a smile.

“I love being in this counselling program,” I think to myself. Rather than telling me what I should know, Lisa has a way of bringing out my inner knowing. “I guess it’s important that I ensure that the people participating in the group feel safe. I would want to create an environment that is...I don’t know, friendly, supportive, where they wouldn’t feel judged. Like I feel when I’m talking to you, or maybe with a friend or trusted colleague,” I say.

Lisa nods, “It sounds like you want to humanize the interaction.”

I nod.

“I see,” she says thoughtfully. “Because there is a stigma around substance use, it might not be an easy conversation because of cultural conditioning. By making it safe, they might feel like they could risk talking about what they are truly feeling.”

I nod my head in agreement knowing that while I cannot expect to just banish the stigma that is engrained in our culture with a magic wand, I can hopefully create a non-judgmental environment to talk about these experiences in a way that may begin to dismantle some of the stigma.

Lisa adds, “Yes, it’s important to be aware of how sensitive this topic is. What else do you think you need to be prepared for going into this group?”

From my last three years of counsellor’s training, and especially from my group processes class, I know the answer to that. “I would have to monitor the emotional temperature of the room while at the same time being mindful of my own feelings (Barcelona & Rockey, 2010), to make sure that the emotions related to my past don’t creep in and I am grounded and actively present with the participants in the group. If I am being triggered by my emotions, then I have to be able to manage my emotions so has not to override or take the focus off the

participants. And I would have to make sure that the participants can express themselves without going beyond their own comfort level.”

“Yes, I would suggest you focus on the participants while still being mindful of your own internal responses-thoughts, sensations, emotions. Of course, it’s important to realize that it’s okay for the participants to feel a bit overwhelmed or take some time on their own for reflection. You could let them know that they can come and go as they need to, and this could help them to manage difficult or overwhelming emotions... you know, so they wouldn’t have to feel like they were stuck in a conversation that was too heavy for them.”

“Right,” I say.

“Sometimes having an opening and a closing ritual can help solidify a sense of a contained space for these conversations to flow and end appropriately as well (Rasmussen & Hansen, 2018, Jebreel et al., 2018),” she adds.

“That sounds perfect. I have some other ideas too. I thought I might keep a grounding exercise ready if I sense that people are feeling distressed (Grecucci et al., 2015). I also want to give people space in case they want to withdraw into themselves at times, while still monitoring them and asking if it feels okay to be in the room. I also want to assure them that I wouldn’t expect them to talk about something so important without the possibility of their emotions rising. You know, that tears, anger, sadness, and anything else they feel would be perfectly natural and welcome. I’ll ensure that there are tissues in reach if a participant feels the need to reach for it.”

I continue, “I like what you did in your workshop, for instance, where you kept checking in with the group to see if we needed a break or to go in a different direction. It just provides more autonomy to the participants and it seemed to work really well in your workshop.”

“As a facilitator, I also want to be open to adapting to the needs of specific people and even changing the agenda for the day if needed” (Yalom & Leszcz, 2015),” I add.

She smiles, “Sounds like you have somewhat of a plan going.”

Methodology

Now that Lisa is on board with me co-facilitating the group, I am unsure how to tell her that I want to use the findings from the group for my thesis. I have never done a formal research project, although I have taken research methods courses through my undergraduate and graduate degree. I have a certain idea of what I want this research to look like, but I haven't got a map for navigating the process. I'm just not sure where to begin. I sit in silence feeling nervous and once again, a bit vulnerable. I may be nervous because I don't want to sound dumb, especially in front of Lisa.

Lisa waits patiently while I collect my thoughts. Then I continue, "So I think my research question is, *how do people who support those with significant substance use challenges experience disenfranchised grief?*"

Lisa's eyes light up as if this is what she's been waiting to hear, "This is a wonderful idea and a valuable research topic, what's the hesitation about?" she asks.

"When I think about this topic, the disenfranchisement of grief and inviting others in a space to talk about their grief, it just doesn't feel sufficient to quantify it or to objectively speak to it, when nothing about this is objective, I don't feel like I would be doing justice to the narrative of others or my own experience through traditional research." Feeling unsure of how she might respond, I continue, "It just seems wrong to quantify experience, and well...you know, people's heartfelt experiences to be reduced to just numbers. Do you know what I mean? It's just hard to find words for what I'm trying to say," I look at her not knowing how she can possibly make sense of what I am saying.

Lisa smiles, "There is a type of research called an auto-ethnography. It is a way of doing research in the field of psychology that recognizes that research is not objective, and in fact

celebrates the researcher's bias by acknowledging that it plays a critical role in how the research is presented (Gorichanaz, 2017)."

I'm shocked and pleasantly surprised at how immediate her response is to my query, "I would love to learn more about this" I say, eager to hear more.

"Research has longstanding reliance on masculine archetypes that situate the researcher with an objective neutral viewpoint (Adam et al., 2015)," she says, but then explains further, "Autoethnography is a qualitative means of research that emphasizes accounts of storytelling. It recognizes that human experience is rarely objective. Each experience takes place in the broader context of cultural understanding and implications and is too complex for quantitative research."

I am listening intently.

She adds, "I suggest you look up Carolyn Ellis (Ellis, 1999; Adam et al., 2015). She does a wonderful job of explaining the method."

I find that there is value in acknowledging that our experiences are not separate from others, especially and definitely not neutral or objective. What stands out the most for me, as I hear Lisa speak, is that an autoethnographic process is the recognition that the researcher is not completely separate from the research. My interest in this topic comes from my past struggles with substance use and understanding the impact it had on my loved ones. It leads me to my work in the field of mental health and addictions and motivated me to support my street family and their loved ones. It also helped me to know what to offer some friends through their challenges with substance use. Furthermore, my personal experience will undoubtedly affect my understanding of anticipatory grief, and disenfranchised grief and how it relates to stigma, which will hopefully make me more caring and more effective in the response I give to the people who I serve. And I hope it is allowed to have an impact on how I present my research.

Auto-ethnography has my interest. “Does this change anything in terms of what I need to know to run my group?” I ask.

“It adds a few elements for sure,” she speaks with a certain level of emphasis, “You would require the approval from the IRB (Institutional Review Board) (Appendix A; Appendix B; Appendix E) to get your research approved and I would be happy to supervise.”

“Oh wow, that would be wonderful,” I say. “But it sounds a bit daunting. What do I need to get approval from the board?”

She notices the visible shift in my mood before she states, “I know that there is a perception that the IRB process is intimidating, and I’ll explain in a minute. But first, I want you to really get that the IRB is there to help your process and not to thwart it. Believe me, when you begin your research you want to know you have covered all the issues from an ethical standpoint. You need them because they have the experience to make sure that you don’t do anything that would put your participants, or you for that matter, at risk. You would feel terrible if you caused the participants harm in any way, right?”

“Oh yes, that would be awful,” I say, “It just seems so overwhelming.”

“It’s not really that complicated. By filling out the forms you do a lot of the thinking upfront so that when you’re ready to begin you’ve laid out the step-by-step process that you will use.”

“I guess that doesn’t sound so bad,” I think to myself.

Still listening to her intently as she speaks, “The forms ask you to describe how you will protect the identity of your participants (see Appendix A).”

“They want to ensure there is an informed-consent form (see Appendix B) for participating in the study that lays out the confidentiality and any risks involved with participation, right? (Creswell & Creswell, 2018),” I ask.

“Yes of course, as well as that their participation is voluntary and since you will be writing about your process along with the experience of others, it is crucial you protect their identity by using pseudonyms for their names and eliminating any identifiable information such as their place of work, location, and case specifics that could be traced back to either you or them.

She talks with a certain seriousness about the implication of working with human-subjects for this research. Lisa continues, “The ethics of an autoethnography also requires that the researcher protects the identity of the participants by disguising names, providing anonymity to identifiable markers that the participant may share (Adams et al., 2015, Fabian, 2008).”

“That makes sense and something I am interested in learning more about,” I nod along.

Lisa adds, “Even though the research itself is not objective at all, you still have to maintain the role of the facilitator and not the role of the researcher while facilitating the group since talking about this sensitive topic can bring up uncomfortable and potentially overwhelming emotions for the participants. This is an ethical requirement--that you put their needs first. You only have the one session with them, so you’ll have to provide resources so that they can get follow up help if necessary.”

I knew I had more work to do before I began this project. I tell Lisa, “I am looking forward to reading more about this process.”

“Let me know what you think about autoethnography after you get a chance to do a bit of your own research. If you have questions, shoot me an email and I’d be happy to chat,” she smiles generously.

I feel lighter after laying my thoughts out to Lisa and so happy to have met with enthusiasm as well as to have been given some concrete guidance. I drop by the library on my way home to try to find the books Lisa had suggested. I find *Autoethnography; Understanding Qualitative Research* (Adam et al., 2015) at the local library. I sign it out and make my way home.

Autoethnography! What is it? Lisa's description of an autoethnographic approach made it sound appealing yet confusing at the same time. I am intrigued by its focus on human experience and according to Lisa, it's accessibility to readers outside of academia. I have a vested interest in my work being read, hopefully by my colleagues, or others who may come across loved ones of substance users, so that their experiences can be heard and acknowledged.

I also like the sounds of an Institutional Review Board approval that ensures that my research process is sound. In our research methods class, it was made really clear that good research starts with a question, followed by choosing a method that will best answer the question (Teherani et al., 2015). The autoethnographic approach seems to be the most suitable for this project since each experience takes place in the broader context of cultural understanding and implications (Adam et al., 2015).

Lisa validated what I had thought -- that the nuances of experience cannot be captured in a quantitatively oriented study (Adam et al., 2015). An autoethnography is a type of qualitative research that falls under phenomenology and lends itself to a contextually constructed understanding of the details of an experience that cannot be garnered in any other way (Pitard, 2017; Ellis & Adams, 2014). By exploring anecdotal and personal experience it allows the researcher to connect this experience with her own self-reflection and to the wider cultural, political, and social meanings and understanding (Ellis, 2004; Marécha, 2010). What I particularly like about phenomenology is that it focuses on the commonality of a lived experience within a particular group. The fundamental goal of the approach is to arrive at a description of the nature of a particular phenomenon (Creswell, 2013).

It is so liberating to find a method of research that adapts to suit the expression of human experience. As I read further I see that phenomenology is described as the "philosophy of

experience” (Armstrong, n.d). I like this because the whole basis is that the ultimate source of all meaning is lived experience (Liamputtong, 2019).

I read on, “All philosophical systems, scientific theories, or aesthetic judgments have the status of abstractions from the ebb and flow of the lived world. The task of the philosopher, according to phenomenology, is to describe the structures of experience, and in particular, consciousness, the imagination, relations with other persons, and the situatedness of the human subject in society and history” (Armstrong, n.d).

This is what I want to do!

It feels like I’ve found a whole new way to think about research. With roots in philosophy, psychology and education, the phenomenological approach attempts to extract the purest, untainted data (Maxwell, 2013). An autoethnographic approach is clearly the most appropriate way to honour those who are willing to share their intimate experiences with me. And it has the added bonus of allowing me to integrate the value of my own experience. This is a way for me to make the study participants and their experiences so much more than a cluster of numbers. But it also means that I am not just allowed, but required to bring my own thoughts, experiences, lived experiences, education, and self-reflection (Ellis, 2004).

I pick up the book that I checked out from the library to find a simple way deconstructing what an autoethnography means. I read that autoethnography implements the self (auto), culture (ethno) and writing (graphy) (Adams et al., 2015). The process requires the researcher to look within, at identity, feelings, and experiences and connect them to the external world, such as relationships, communities, and culture (Adams et al., 2015).

Chang (2008) warns autoethnographers of pitfalls that they should avoid in doing autoethnography:

- (1) excessive focus on self in isolation from others;
- (2) overemphasis on narration rather than analysis and cultural interpretation;
- (3) exclusive reliance on personal memory and recalling as a data source;
- (4) negligence of ethical standards regarding others in self-narratives; and
- (5) inappropriate application of the label autoethnography (p. 54).

So, it's becoming more clear to me, how to go about this kind of research.

Autoethnography is a form of writing where the author uses methodological writing to explore anecdotal and personal experiences and connect this to wider cultural, political, and social meanings and understanding while using self-reflection (Ellis, 2004, Fabian, 2008).

I feel reassured as I begin to understand that an autoethnographic process not only humanizes the participants but also the researcher. This is because it recognizes that human experiences are unique and complex. However, the art of storytelling provides space for the readers to take what may be relatable. Adams et al., (2015) states "autoethnography focuses on human intentions, motivations, emotions and actions (about particular lives) rather than generating demographic information and general descriptions of interaction" (p. 21).

What a relief it is to find that there is a type of research that endorses the humanity of one's experience over the efforts to statistically trying to pinpoint and reduce the expansive nature of one's experience.

A major goal of the autoethnographic method then is to produce meaningful, accessible, and evocative research grounded in personal experience (Ellis and Adams, 2014). I appreciate the idea that as a researcher I can bring legitimacy to an ancient way of telling stories using narrative inquiry in the development of human knowledge (Pagnucci, 2004, as cited in DeLeon, 2010).

The more I read about autoethnography, the more it rings true that although no experience is the same as others, by diving into the essence of the experiences of loved ones of substance users I may be able to find commonalities among these experiences. It just seems so obvious that as a researcher my interest in this topic will of course be intertwined with the experiences of the participants. To honour that shared experience, to honour their vulnerability in sharing their experience, it makes so much sense to acknowledge what my psyche has to offer in the research. Since “autoethnographers study culture, they often focus on the collective relational practices, common values and beliefs and shared experience of a group of people with the purpose of better understanding the group and themselves” (Adams et al., 2015, p.50), this makes it the perfect fit for how I want to approach this research.

As I’m thinking this through a pop-up notification on my laptop catches my eye. It’s an email from my supervisor Lisa, suggesting that I attend an online training module on research that involves human subjects as part of the approval process from the Institutional Review Board.

“The first of many steps to get this research approved,” I think to myself. Eager to get going I click on the training link that Lisa provided.

I find that the guidelines for ethical practice with human subjects are outlined by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1978). The guidelines cover the need for respect for participants in the study with appropriate consent and autonomy to withdraw consent when needed. They require that the research and researcher must aim to minimize any possible harm that may be caused due to their research. Furthermore, the researcher must work to ensure a fair distribution of research benefits and burdens (Adam et al., 2015; National Commission for the Protection of Human Subjects of

Biomedical and Behavioural Research, 1978). These guidelines are comforting to read as this aligns with my personal values of treating others with dignity and operate from standards that allow for autonomy or freedom of choice for others.

It sounds simple enough to do. I complete the training module the next day and respond back to Lisa, “Done!”

Lisa responds back, “I am glad you’ve completed the training. For the next part of your IRB process approval process, I really need you to think about how you plan on maximizing the benefits and minimizing the risks and what steps you will take to proceed in an ethical manner. I’m attaching the IRB forms along with this email that will provide you with a step-by-step process for what is expected to get approval from IRB (see Appendix A).”

I can’t help but wonder if the IRB human subject training was the easy part and the complexity of this project is yet to be tackled.

After exchanging a few emails back and forth with Lisa over the weeks, to discuss the ethical review protocol from the IRB (See Appendix A), we finalize the questions for the research. I like the idea of using semi-structured life history interviews (Jupp, 2009), as it will allow me to document this particular aspect of the participants' experience as it has developed over their lifetime (Olive, 2014). This also makes sense because supporting someone with substance use is not a matter of one incident or one moment in time, it is an experience that is often ongoing and for instance, for children of substance users, it may even be a lifelong process. Instead of running statistics on a rigid survey, a flow of a conversation will help provide a more integrated and cohesive picture of the participants' experience of supporting their loved one with substance use challenges over a period of time.

A portion of developing the questions for the IRB approval includes a trauma-informed philosophy (Substance Abuse and Mental Health Services, 2014). This is to ensure that the researcher minimizes the risk (Adams et al., 2015) to the participants when posing the questions for discussion. Yet it still allows flexibility as to how a participant might choose to respond. In how they may choose to respond to the posed questions.

As a researcher, I can see that my ethical responsibility is also bound by parameters that ensure that I select enough participants to make my research reliable but also feasible to implement. After talking to my supervisor and connecting with IRB, I am aiming to include at least 5-6 participants for my research, as this is a common and suggested number for autoethnographic studies as it is small enough to provide depth but large enough to have some variation in circumstances and experiences (Creswell & Creswell, 2018).

After perusing the ethical review protocol Lisa emails me saying that we are ready to submit the informed consent to the IRB, and the poster I will be using to invite participants to

take part in my research (see Appendix A, Appendix B, Appendix C, Appendix D). These forms ensure that the language I use to invite the participants is ethical, how I recruit the participants is at an arm's length distance, so participants are not obliged to participate in my research against their voluntary choice. As a researcher, I am beginning to get used to the review process, knowing that there is a community of researchers glaring at my work with a keen eye, ensuring it is up to proper standards of research and ethics.

This diligent multi-review process ensures that ethical integrity of this research is placed at the forefront to honour not just my role as a researcher but to also commemorate the shared experience of the participants in a responsible manner.

Feeling relieved to have submitted my final forms to the IRB; I fall asleep, peacefully for the first time in a long time.

Getting the Word Out -- Recruitment

I wake up to an email from Lisa informing me that the IRB has given me the approval for the research (see Appendix E). I email Lisa back right away, thanking her for the help during this process and text Sherry to share the good news, “We got the approval!”

Sherry texts back, “Congratulations! This is so exciting! I can’t wait to get started on this with you. When should we date for the group?”

Sherry and I set the time for our group for January 10th, 2020. We post the IRB approved invitation posters (see Appendix, C; Appendix, D) on our social media pages to begin the recruitment process. This feels like a massive step from hearing a lecture that resonated with me to identifying a research question and creating structure around the research to implement it.

We both know that we want to do this and now we have the green light. After posting the invitations, I feel a wave of fear. “What if nobody responds?” I think to myself, I wonder if Sherry is thinking the same thing, but I’m too involved in my own process and managing my own insecurity to ask her. I turn my off my phone and other electronic devices to prevent myself from checking constantly if somebody replied to the invitation or not.

When I turn my phone back on in the evening I see a text from Sherry that reads, “Did you see the number of people reaching out, and multiple email notifications?” There is an exhilarating response of 12 people within a few hours of posting the invitation.

I respond back to Sherry, “No! Sorry my phone was off. We’ve got to amend the post and shut down recruitment, this is a lot more participants than we were expecting!”

“Yeah who would’ve thought, eh?” She replies back.

Sherry’s response confirms that she shared my doubts. We amend the post to shut down recruitment for the study.

As the day of the event draws near three people write to say they will not be attending. I wonder how many more may drop out. One of the prospective participants messages me saying, “I’m sorry, this still feels too raw for me to be able to talk about, I won’t be able to make it.”

I respond back, “I am happy you reached out. I understand this is a sensitive topic. I’m pleased to see that you are honouring the space you are in. It is completely okay with me for you to listen to your feelings and stay home. Please take care of yourself.”

I suspect more people will drop out before the day of the group.

The Day of the Event

Sherry and I both arrive at the location of the group session an hour and a half early. We set up the chairs around the room in a circle with a flipchart outside of the circle. We lay the snacks and coffee out for the attendees and waited for them to arrive. Sherry signs her consent form that outlines the boundaries of confidentiality and guidelines for her voluntary participation in the study (See Appendix B). We put some adhesive name tags and pens by the front for the participants to write their names on. Both Sherry and I grab a tag and write our names on and stick the tags on our shirts.

I look at Sherry, “How are you doing?”

She exhales, “I’m more nervous than I thought I was going to be. It also feels like such an honour to facilitate and be part of a conversation that is not often had. How are you doing?”

I smile, “I’m glad we’re doing this. You do know that if it ever begins to feel uncomfortable you can withdraw consent at any given time, even after the group is over.”

She nods back affirming she is aware. “I appreciate you saying this. But I’m sure I want to do this. I’m glad this is happening,” she says.

The other participants begin to trickle in shortly. A couple of women walk in at the same time. They look a bit nervous and do not make much eye contact with each other. I assume they must have just met outside, in the parking lot.

One of the women is dressed in a casual grey blazer and cuffed up blue jeans. She takes the initiative to ask, “Is this the group for loved ones of those struggling with addiction?”

Sherry smiles, “Yeah come on in, you’re in the right place! I am Sherry,” she extends her hand forward to shake the woman’s hand.

The woman in the blazer replies, “Hey, nice to meet ya! I’m Jessica.”

The woman beside Jessica gives a quick wave to both Sherry and me, “I’m Claire.”

A few other participants begin to arrive. We welcome them in and encourage them to grab snacks and coffee or water before they settle in, and we show them to the table where they can write their names on their nametags.

As the time approaches and there don’t seem to be any new arrivals, the casual conversation dies down. We explain that we want to address the papers that we’re handing out, so we can go over them together, just to be sure that the participants understand what they’re agreeing to before they sign. There are few questions or reservations and the forms are filled in fairly quickly. I check with Sherry and we both agree that we have given everyone a fair chance to withdraw and that they all understand the form and what their signature means. I sense that there is an eagerness to talk and yet at the same time, some nervousness too.

We set up some general guidelines for the group. “Thank you for taking the time out of your schedules to join us here today. It is really important to both Sherry and I that we work together to create a safe and respectful dialogue with one another today. So, I hope we can agree to take turns speaking without interrupting each other (Yalom & Leszc, 2015). I also just want to reiterate that you only need to share what you feel comfortable talking about.”

Sherry with a gentle smile adds, “Being silent is also okay too.”

I smile back at Sherry and then to those in the room.

Sherry continues, “We also want to remind you that you have agreed to keep our discussion confidential (Appendix B). If at any point, you need some space to step outside that’s fine, either Sherry or I will check on you within a few minutes. You are also free to withdraw consent at any time, but please let us know before leaving so we don’t worry about you. We want, more than anything, to make this experience okay for you (Appendix B).”

Everybody seems pretty receptive as evidenced by some nods around the circle. We give the participants a second to see if there are any questions that arise.

From there, Sherry and I take turns talking.

I take the lead again, “Both Sherry and I have been working in the field for a little over 4 years at the homeless shelter where we support those struggling with substance use challenges in a professional setting. Both of us have also been supporting people with substance use challenges in our personal life,” I say.

I tell the group a bit about my experience with the intent of setting the stage for the conversation with purposeful self-disclosure that explains my interest in the study (Yalom & Leszcz, 2015). It is important to model active listening, attentiveness, firm identity, and role within the circle, so I choose my words carefully, to tell them enough to give myself credibility, but not so much as to overwhelm them (Substance Abuse and Mental Health Services, 2005).

“Learning about mental health and addictions along with learning about the gaps in our system of care for all those who are affected by substances is a core focus of my academic and personal growth over the years...” I pause, “and I am hoping to learn from you today, since you are the ones on the frontline of support for your loved ones,” I add.

I look around the room as I speak and make eye contact with each participant. This helps to acknowledge their presence and to deliberately connect with each of them (Yalom & Leszcz, 2015; Gostečnik et al., 2018). I look towards Sherry to see if she wants to add anything to what I just said.

Sherry smiles and says, “There is no strict agenda today...but we do have a few ideas to help get the conversation moving,” she says as she points to the flipchart that has a few conversation prompts printed on it.

I notice the participants begin to shift a little in their chairs. As I look around I can see that I am not the only one feeling a bit anxious.

“But before we do that,” I say, “I like to begin and end groups with something that helps me to really bring my attention to this place, to this time,” I pause and continue, “And also, I get nervous at the beginning of a group and it helps me to calm down,” I say with a laugh. I see that others relate as they softly smile.

I lift the black and golden Tibetan singing bowl in the palm of my hand, passing it to Sherry as I speak, “I’m going to ask Sherry to ring the bell, and then I’m hoping that we can just sit quietly for about a minute. If this isn’t your thing don’t worry, you can think of anything you like. Would that be okay?”

Everyone indicates in some way that it is okay. “After the moment of silence, I thought we might then introduce ourselves, does that sound okay for everybody?”

The participants nod in approval.

Sherry holds the Tibetan bowl in her palm and hits the bowl gently with the mallet, encircling the bowl for about a minute, filling the room with a soothing ringing sound. She lets go of the mallet from the bowl and waits for the echo of the sound to end before she speaks, “Welcome everybody,” she says.

The First Prompt

The first prompt on the flipchart reads, *“Introductions and Who is it that you are supporting or have supported with significant substance use challenges?”*

The room is silent. I look around the room and initiate the dialogue again.

“Since I already introduced myself a little bit already, I’ll keep it short, I have been supporting friends who use substances.” I pause and take a deep breath and continue, “I’ve lost some friends to overdoses over the years, and I’ve been working in the community for a little over four years now supporting clients with substance use challenges. Currently, I’m supporting a close friend through her struggles with alcohol and opiates. It’s been difficult worrying about her over the years,” I breathe out feeling the weight of my words leaving my body, recognizing how difficult this conversation feels, even for me. Although it is hard to say these words, as a facilitator it is my role to set the tone by modelling the kind introduction that I’m looking for. So, I push myself to be the first to be open and vulnerable, understanding that it takes time for things to warm up in a group (Substance Abuse and Mental Health Services, 2005; Yalom & Leszc, 2015). I’m not asking participants to do anything that I am not willing to do myself.

I receive some nods from the participants, but one holds eye contact, indicating that she would like to go next. Rolling her shoulders back, leaning forward and crossing her arms in her lap, she says hesitantly, “I’m Emma, and I have had to support two generations of family members caught up in substance use or addictions. My grandmother was into opiates when she was alive, and my father struggles with both alcohol and opiates.”

She releases a big breath out, like she just let go of a rock sitting on her chest. I nod along as she speaks, to relay that I’m listening intently. I hope I’m also conveying that I cannot know, how difficult her experience has been. I notice other participants nodding their heads as well.

Sherry speaks up in response, “Parents are tough ones. Thank you for sharing that.”

It seems appropriate that Sherry replies to Emma as I am aware Sherry has had experience supporting her father as well.

Claire and I share a look from across the room, as we know that we can feel so vulnerable when talking about our loved ones.

I look around the room and ask, “Would anyone like to volunteer to go next?”

Claire raises her hand and smiles to indicate she is willing to go next, “I’m Claire...and I have been supporting my mum for a bit over a decade at this point, with mental health and addiction. It started as a pretty problematic addiction that turned into very apparent mental health issues. I was only a child, so I had to bear the brunt of it for a long time. The work of supporting her has now gone over to my family,” she pauses and looks around the room, exhales and adds hurriedly, “but yeah, it has been absolutely exhausting.”

I share soft eye contact with Claire.

“I hear you. Sometimes words are just not enough to describe how tiring things can feel. Thank you for sharing that Claire,” I say.

She gives me a nod, “Yeah,” she says quietly.

The woman sitting next to Emma jumps in, she appears to be in her early 20s. She has short curly hair with a hint of blue and green faded dye, and pointing to the nametag on her chest says, “I’m Elizabeth. I can go next.”

I can see that there is a shift occurring, in that participants are looking visibly more comfortable, maybe finding a sense of camaraderie in hearing the first few people speak.

Elizabeth's eyes lay low as she gets ready to share, looking down at the ground as if she doesn't want to see or be seen. "I don't usually talk about my sister. Part of our family values is to sweep everything under the carpet, so it's been difficult to talk about it."

She peeks a glance at me but quickly looks down again, "I was kind of brought up to keep quiet," she says gently. This time, when she looks up she circles the room with her eyes before adding, "This group came at just the right time as I've been challenging some of my conditioning and realizing that avoiding things may not be working so well for me," she pauses as if gathering her courage. "My sister struggled with her mental health from a very young age."

This seems like a big admission and it takes her a couple of seconds before she can continue, "She has done every substance under the sun...right now she is active... um... in addiction, heroin... having gone off methadone probably three months ago... so that's been difficult."

I nod while maintaining eye contact. My heart goes out to her. I see that everyone in the group seems to have empathy for her as well, for which I'm grateful. When someone takes a chance in showing their vulnerability it's so important that they get a positive social response (Bonnano & Papa, 2003).

With the exception of one woman in her forties, all the participants who have spoken at this point are in their twenties yet seemingly wise beyond their years.

Elizabeth cues that she has finished her introduction as she looks down to her feet silent.

Working as a first responder, I am aware of how scary it is to witness others using substances when they are known to be mostly laced with fentanyl. I understand the worry of the possibility of a terminal dose just around the corner, I feel for her. "A relapse can especially be so scary right now, with fentanyl on the streets... thank you for sharing this with us," I say.

Elizabeth swiftly nods, “Yeah that’s the scariest part because you don’t know what you are getting anymore when you buy drugs these days.”

I shake my head sideways to convey my concern and the helplessness that comes along with knowing how dangerous the drugs feel right now. In the short silence that follows it seems like we are all feeling the impact of her words.

The honest admission of this fear in the room opens space for more authentic dialogue.

Sherry looks around the room. I think she is getting ready to share a bit of her story, “I too have a sibling who uses--my older brother but we don’t talk much anymore,” she says looking down and then back up to make eye contact with Elizabeth. “My father and his girlfriend and my step-brother who is too far gone,” she shakes her head reflecting on her words. “It is a chaotic world sometimes, especially supporting my dad was much more difficult when I was younger as he battled with addiction for most of my childhood,” she says with the slightest curve of at the corner of her mouth.

She continues, “As a kid, you don’t understand that your dad isn’t well, he was always just in and out. I think it has left me not understanding relationships and it is hard to share with others because more often than not...they don’t get it.”

She once again circles the conversation back to end on a lighter note, by saying, “I’m learning to let go of my expectations, well maybe it’s more accurate to say, my hopes, and to set boundaries with him, so his using doesn’t become detrimental to my health.”

Even though I have known this about her, I listen to her and I can’t help but wonder about how difficult it would be as a child to be put in a position where you have to be the parent to the adult in the household (Li Ping Chee et al., 2014). Did she ever have a chance to be a kid, and by that I’m thinking--carefree, relaxed, not worried? As one of my closest friends, I know

she hasn't caught a break in the longest time and I sense her exhaustion. At the same time, I'm impressed with the wide capacity she holds for caring for others.

Sherry releases her shoulders, which have been hunched up around her ears, and slowly looks around the room.

I see a few nods.

"Moving to the present time, I am currently supporting my partner who I've been with for the last five years. He struggles with using cocaine, cannabis and alcohol...off and on." She pauses to regain her breath, "...and I should say that I've dated people in the past who were using substances as well."

I look at Sherry and nod in approval for sharing a piece of her history that I knew was difficult especially within this group. It makes me wonder if the stigma of dating or being married to someone who uses substances adds another layer of stigma as others may perceive it as one's own choice. A common perception I think, since, while we are born into a family, we actively choose our partners. I notice several others who nod in encouragement as if to say, your story is safe with us.

Added to choosing a partner with substance issues, I think one issue that makes it difficult to admit to having that partner die or be injured, is that society views it as a "self-inflicted fate" (Gray, 2010). So, the grief of the people who love a person who struggles with substance use becomes invalidated because they are seen as complicit in the infliction (Gray, 2010).

"That was hard to say," she says and lands with a smile.

I glance at her. As the other group facilitator, I know that she wants to ensure that she maintains her composure. It's hard to know exactly the right amount to share.

“Wow, I didn’t realize how much I’m surrounded by substance users until I said this piece. Thank the lord for my therapist,” she says, with a wry laugh.

I see a few others give a knowing chuckle.

“Yeah, it’s interesting how common substance use is, yet the stigma makes it seem like such a taboo topic sometimes.” I nod in agreement and thank Sherry for sharing.

I battle with exposing myself to the group, not just because of shame, although that’s a big part, but also because I want to reveal only what’s necessary to model the willingness to be vulnerable (Edwards & Murdock, 1994). I can see the effect on the group as Sherry speaks and I know that what she has said is just the right amount to give her, not only credibility as a group member but as a facilitator too (Lu & Jiang, 2013).

I notice that the petite woman with dark wavy hair wearing a bright orange hoodie sitting next to Emma is looking down in her lap and fidgeting with her fingers. She looks up with her nervous almond eyes, “Can I go next?” It is just easier to go now than to wait. I also really don’t want to go last.”

I smile at her and look around the room to notice their response. The other participants seem approving of her to go next. “Of course, go ahead!”

She stops fidgeting with her fingers and says, “I’m Jessica and I’m currently supporting my sister. It’s not her; it’s her partner. He has a serious drinking problem...”

There’s silence. I’m not sure if she is waiting to say more or if she’s done, but she carries on.

“I’ve dated a person who was using substances too. I had a partner who was using substances...he died a few years ago...at that time I too was using many substances,” she stops and exhales loudly. “After my ex died, I began drinking more and using other substances

thinking it would help me cope. Looking back, I can see that I was young, and our relationship was complicated... his death was so complex and...well, it was just so traumatic.” She stops and thinks for a moment. “We began dating when I was 17 and he died when I was 22,” her voice softening, “I don’t use substances anymore.” She glances down and begins to fidget again.

I share a look with Sherry because I know she’s lost her partner too. I can see that she is acutely tuned in to what Jessica has to say.

Jessica continues, “I’m really glad I don’t have a problematic relationship with substances anymore, but it still just sucks.”

I feel as if there is a rock tied to my ankle pulling me down into the ocean as I listen to Jessica, just thinking about the shame I carry for having also used substances. “Jessica it takes a lot to challenge a relationship with substances...especially when it is tied with grief. I’m happy for you to not be dealing with that anymore,” I say.

This internalization of stigma acts as a major barrier for people to seek help and even more so if they have mental health issues (Pearl et al., 2017). In my experience, it is a big step to even begin to admit our problematic relationship with substances to ourselves sometimes. I can see she has spent some time reflecting on her experiences thus far.

Jessica looks around the room, and I watch her take in the deep compassion on the faces of the other participants. “We were both young, and at the time I didn’t know how to help another person who was facing their inner demons. So, I started using too. I just didn’t know how to get through.”

The regret in her voice is clear. She obviously cared about him and wanted to help, but just didn’t know how. She exhales and puts a smile on her face and adds, “Because I’ve gone through supporting someone with substance use challenges, I am trying to help my sister help her

partner...but it's difficult because I've seen the worst possible scenario. I'm always worried. I'm protective of her, worried for her, and worried for her partner," she exhales.

"Thank you for sharing that Jessica, it can be so difficult to watch someone you care about being in a similar situation as you've been in, because you can feel that experience so deeply. I'm so sorry about your ex...I am sorry for your loss," I say trying to empathize.

I see tears roll down Jessica's eyes. We all sit quietly while she wipes her tears on her sleeve and says, "Nobody has said that before."

I lean in.

"Nobody has said I am sorry that he died, before because our relationship was complex...so thank you," she says. She reaches down to grab a sip of her water blows her nose.

I nod at her to let her know that her tears are more than okay. I'm glad that Sherry shared what she did because it may have allowed Jessica to tell her story.

The woman who appears to be in her mid-40s to 50s had been sitting quietly with minimal non-verbal interactions in the group. Her presence is soft and gentle, as she sits listening quietly to all those present in the room. Sitting beside the window she has been observant but a bit constricted in her body language. She allows her arms to uncross from in front of her chest as she speaks, "My name is Jamie," she says, in a voice not as soft and gentle as I was expecting. "And...uh, the father of my children and, well, I mean I married him, so my husband...well he always just so weird," she says quickly, the words just tumbling out. "I didn't ever quite get what was going on with him. He was just such an oddball, he showed all of them Asperger traits or maybe narcissism...but oh, he wasn't stupid... he was manipulative!" She exclaims with some force to her voice. "I wasn't even sure that I should marry him, but that was the Catholic thing to do because I was pregnant. My family never believed me when I told them he was a bit off. If

you left your husband...you were done,” she says with a shake of her head, “There was no support for back then.”

It seems to me that she is trying to pinpoint a reason for her choices. Gathering steam, she speaks boldly with a residue of lingering anger in her voice.

“So, I stayed with him for 20 something years, my brother had died of cancer, my parents had dementia...everyone just took their piece of me...like it was okay,” Jamie pauses suddenly to notice others in the room.

I speak softly without meaning to disturb her train of thought and say, “It wasn’t okay” nodding in encouragement, in the hopes she will continue.

But after her outburst, it appears that she isn’t sure if expressing her resentment is okay. She retreats a bit and proceeds more timidly again, shyly looking around the room to see if she still has support from the group. Seeing the compassion, she charges through powerfully without a pause, like she had been just waiting to get this off her chest.

She takes a minute and continues, “I knew he was drinking socially when I married him but then, he just went crazy. He was so stupid, like a baby. He would buy booze for our daughter, who went wild too. He would spend all of our money; cashed in our RSP to put it on his hairdresser and told them about a dot com company like he just did stupid shit like that.”

I sit there listening, even though I’m not sure what she means by putting it on his hairdresser, but it is apparent, she’s frustrated and has been waiting to let this out.

The mood in the room begins to change. Anger is also a part of the grief process but maybe not be as acceptable to express among women as tears are (Cox et al., 2003; Thomas, 1993). The face of grief can be infused with anger and frustration; an experience many others may share because of a perceived loyalty or idea of what the actual relationship should have been

(Rees et al., 2017). I see heads nodding around the circle. Jamie may be providing a voice for a fraction of the experience with frustration and anger that the others in the room may have also experienced.

I acknowledge the feelings by saying, “That does sound frustrating and infuriating. It sounds like his actions also compromised the safety of your daughter, and that must have been scary as well,” while others in the room concurrently nod.

I notice a few participants with tight lips, as if this is a frustration they have felt themselves. It is seemingly apparent that there is more to be said about this experience of frustration.

The conversation is already beginning to feel intimate as we finish our introductions. I look around the room and suddenly become aware that not all the people who have signed up are here. I half expect another participant to join us. Maybe, having these five and Sherry and I is just the right amount for the circle. I can see now that the twelve participants that I was expecting to join the group would be too many. I like the intimacy that comes from having just a few people in our circle. In my experience with facilitating groups a small group can allow deeper meaning to be found (Puskar et al., 2012), and for the purpose of a phenomenological study, Creswell and Creswell (2018) recommend 5 – 25, while Morse (1994) suggests at least six participants. The number of participants in this group is ideal, I realize, not just for collecting data for the study, but for the well-being and function of the group.

The Second Prompt

I thank everybody for the introductions and note that we all seem ready to move ahead. But I want to check to make sure that I'm not missing something. "Does it feel okay to move on to the next prompt?"

Claire is the first to respond, "Yeah, that seems okay to me."

Other participants echo a similar response.

The room begins to feel warmer, not in a soothing way, but in a fired-up, ready-to-get going way. I notice Emma, Claire, Elizabeth, Jessica, and Jamie beginning to make eye contact with one another, and I interpret it as them beginning to form a bond of trust (Schlesinger, 1978; Gostečnik et al., 2018).

Sherry takes over, glancing at the flip chart and directing the participant's attention to the next prompt that states, "*What has been the most difficult part about supporting your loved one through substance use challenges?*"

Elizabeth begins to play with her curly locks and looks up to the ceiling. Jamie shakes her head right to left, as if to say, there's just too much to say, where do I even begin? Emma sips from her water bottle and exchanges looks with other participants, all of whom seem to also be wondering who will start the conversation.

Claire crunches up her face and then widens her eyes as she takes a deep breath as if she were about to jump into cold water. She makes the decision and goes for it, "Well I resonated with the term 'disenfranchised grief' (Doka, 1989) on the Facebook invitation post, and I thought it was neat that you put the definition on the poster too (See Appendix A) because it was pretty interesting how you explained it (Appendix, C). It sure got me thinking. It's really hard for people to understand the loss when the person is still living...the term and the definition

resonated with my experience with my mother.” She speaks stoically with emphasis on her words pronouncing each syllable carefully.

“Could you tell me a bit more about what resonated with you, Claire?” I ask.

Claire, I am finding out, can be very articulate. “When you’ve lost someone to addiction or when you have lost someone to mental health it is an incredibly strange feeling because if someone dies, you’ve lost them. They’re gone. It’s concrete. There’s no ambiguity. If you are losing someone to addictions, you lose pieces of them, and sometimes they are there, but sometimes they’re not.”

Her face softens and so does her voice. Looking around the room she elongates her exhale, “This inconsistency...you feel close and loving, and then it hurts so much to have to try to disconnect... again and again. Especially when I was younger, I was just so confused. So for instance, if I tried to talk to my friends, or even to adults, and said that I was having problems with my mum, people would be like... everyone has problems with their mom.”

She pauses letting her shoulders drop in utter frustration, “Yeah everyone has problems with their mum, when your mom worries about the boy you’re texting...but those weren’t my problems and people didn’t understand how I was missing her...even though she was here...she was alive... yet somehow not really here.”

Everybody in the room seems engrossed with what she is saying.

She maintains steady eye contact with the others in the room. She rolls her shoulders back, as she sits with an air of self-assurance in her chair. She releases a breath to add, “But when that relationship has been so damaged, or you just feel so mistrusting of what is happening, on a visceral level ... I mean the person can be there but they’re just triggering you and that’s

incredibly confusing for your body-- to be looking at your mother, feeling that she is your mother, but then also at the same time feeling viscerally unsafe.”

She glances down briefly as if to gather her thoughts, “Um... and those are conflicting emotions and it’s so hard to articulate. It is difficult for people to understand and sometimes it feels like it can be just reduced or dismissed and it...it...” she seems to have lost the thread here, and takes a moment to breathe before continuing, “And, people think that it’s as simple as that. Like, my mom’s improved...she’s doing significantly better than she was this entire decade, thank God. But there are still decades worth of damage that needs to be repaired, and that’s incredibly hard to work through, and quite painful. Recovery is very slow...healing just doesn’t happen quickly.”

Claire pauses and looks around the room before she continues, “She’s kind of coming back into her healthy self, which I am *grateful* for, but for a very long time I was grieving a person that was alive.”

I notice how she emphasizes on the word *grateful* and wonder if she is worried that her own experience will be obscured or minimized in some way, by her mother’s recovery, as if that could make up for all that she has been through. We make eye contact and I say, “Right, just because she’s getting better, doesn’t mean that your experiences can now just be forgotten. It’s so much more complicated than that.”

We all sit in tune with Claire as she continues to speak, “She blamed me for being a traitor when I was 14 because I told my auntie that she had been drinking every day. She shamed me when I moved away from her when I was 19. But I had to protect myself! I was made to feel very, very, very badly about myself...and I carried so much guilt for so long, and then so much frustration and anger towards my family for putting that on me. It felt like they were trying to

force this relationship down my throat, even though I had expressed time and time again that I needed space...but we've come a long way since then. No, I guess I can say that we're not there anymore."

Even though I haven't had this same experience, I can relate to the part where she was trying to put an experience behind her that had dominated so many aspects of her wellbeing, and how it may even be disorienting to suddenly be out of the immediate situation. And yet, that situation has still, shaped significant aspects of your identity. Ironically, in some way, even with physical distance, it's always right there.

Claire sighs, "I sometimes felt that if I were to tell people my mom has cancer...that would be better accepted than to say my mum had an addiction and relapsed." She looks around the room and shrugs her shoulders as if to say, what can I do?

I take a sip of my water before speaking, "Claire, that's a lot to navigate, the loss of someone who is still present is quite different than death or loss from or illness or say, an accident. I think that not many people have the capacity, or maybe not capacity, but experience to understand it."

"You touch on something really important here. I came across a term called 'anticipatory grief' at school. It's a type of loss, or a sense of mourning that occurs when death becomes part of the new expected reality along with the extreme concern for the loved ones' well-being (Harris & Winokuer, 2016; Rando, 2000). It has many of the same symptoms that a person experiences after the death of a loved one, such as, depression-like symptoms and adjusting to an unforeseen reality. However, it doesn't mean that the post-death grief process has just moved upstream or that the grief after that loved one's death will last a shorter amount of time by any means (Shiel Jr., 2018). This is its own unique type of grief."

I pause for a moment before adding, “Your feelings about your mom make a lot of sense, anticipatory grief includes many losses, such as the changing roles within a family dynamic, or loss of dreams, or hope even the dream of what life or your relationship could have been (Rando, 2000). The loss is not necessarily of the person dying...”

I pause and exhale to pace myself and add, “...but everything else that has shifted or been lost along the way” (Rando, 2000).

Claire jumps in, “Oh I like those words... *anticipatory, grief, mourning.*”

Jamie pitches in, “Huh, I guess the loss of an “expected reality” speaks to me. The most difficult part for me was that he ultimately chose to drink over me. That was just so hard to believe. That he would do that, I mean. How could he?” She shakes her head, as a big tear rolls down her cheek, “It was just so lame, but he was lying and stuff too. It's just weird. I just could not... I had no respect. I just couldn't...”

Her heart sounds broken, her voice struggling to find the words to explain her experience and then her tone of voice changes from visible anger to a subtler sombreness.

“I don't think anything or anyone has ever validated my experience and it...” Jamie stutters, “and, and I'm part of it too. I have to learn how to validate it for myself. I mean my feelings were justified! They were real! I wasn't making it up!” she asserts herself.

The frustration returns in her voice.

“My family was all about mortal sin. When I spoke to my family about him, they wouldn't believe how bad it was, they would just tell me to stay with him anyway. Even while I had social workers coming in and out of my house! I was so ashamed. Holy shit. Like you know, *who* gets their kid taken away? Like how that can happen?”

It seems as though Jamie is revisiting the experience and I'm pretty sure that she must have dissociated while the experiences were taking place. I cannot really grasp the reality of what she is saying. To help Jamie to settle herself, I try to see if she can remember anyone who was a positive or comforting force.

“Was there anyone who heard you at the time, Jamie?” I ask.

She looks at me confused, “I didn't want anybody to know, I just did not. Yeah, I pulled away. Like in those times when he was really failing, I pulled away. I used to play squash...but yeah, I just pulled away from all that stuff.”

She looks at me like I should know that she could not have possibly trusted anyone to listen.

She adds, “Eventually, I had no time to do anything social. And then, when we did go to a gathering he would get so drunk. But it's not like he was loud. He was... a quiet drunk, but then he would pass out. But it's just, you know...embarrassing. He would come and pick me up at work and he was, like so loaded it was ridiculous. When he showed up at my work drunk and he'd, he looked so...he had been living in his car for like three days... and it was just so humiliating.”

I lean in to show empathy for Jamie's experience and to let her know I'm listening.

Jamie revisits the frustration that her ex-husband caused for her, “I had no respect for him. He was always doing stupid things...like going to a gas station, filling up and driving away.”

I try to validate Jamie's experience, “That sounds extremely frustrating...and yes embarrassing...and people's judgements can play such a critical role in how we process our stories too...” I say shaking my head in dismay.

Jamie is quiet after letting out some of her frustration.

Sherry jumps in, “Other people’s response can really affect how we ourselves make sense of our experiences. I wish that you had gotten a different response--one that validated that you were speaking the truth, that the whole thing was infuriating. And I wish that someone in your world had been able to show you some compassion in a way that you could take it in.”

Emma rolls her eyes, “In an ideal world it would be nice, yet here we are,” she says with a playful smirk.

Jessica adds, “It’s embarrassing to even tell other people that your partner is using, and there’s so much more that comes along with it.”

She sounds frustrated. I take this moment to validate that embarrassment is conditioned by social responses. “You’re absolutely correct, the responses we get from our social circles can really affect what we choose to share or not, and then of course what we tell ourselves about our experiences,” I say.

I see some nods around the room so I continue, “There’ve been studies that suggest that the process of grief is at times understood as what they call a transactional response within one’s sub-system occurring at an intrapersonal and interpersonal level (Corr, 2002), I know it sounds like just a bunch of words but let me explain.”

Claire seems intrigued and asks, “I’m assuming the transactional response means the interactions we have within our socio-cultural context, right? But what’s the difference between intrapersonal and interpersonal?”

“Yeah, that’s exactly what it means. Our social interactions can have a significant influence on our adaptation to a critical life event (Bowlby, 1980; Lazarus, 1991, Bonnano, 2001),” I add to clarify.

“We integrate these social interactions in two ways...Intrapersonally and interpersonally,” I see some confused looks in the room.

I slow down my words. “Intra-personally means we may navigate our loss through internal processes of making meaning of our grief and the inter-personal process occurs between the griever and their social network. These responses set expectations and boundaries for the person grieving for what is considered an appropriate amount of support (Corr, 2002),” I say.

I take a moment before adding, “With the added layer of shame, since our culture conditions us to not speak about our experiences due to the embarrassment it may cause, we may begin to believe moving through the world alone is what we ought to do.”

Sherry tries to simplify the conversation, “Inevitably, for some people, the expression of their experience or needs may go against social expectations and may not fit the box of what is commonly expected.” She looks around the room to see if what she is saying is resonating with others and continues, “...so that your experience becomes delegitimized, unrecognized, or unsupported by the social systems around you,” (Piazza-Bonin et al., 2015).

I see Elizabeth beginning to nod along now.

I add, “It doesn’t surprise me at all that you wanted to withdraw. It seems to me like that was the correct response at the time, and even rather smart of you. You had correctly assessed that you were not going to get any support. You were wise to just try and survive until you could find someone who would offer support. And you did just that, and... you got yourself here.”

Jamie nods, “Maybe it was smart, but there was also nothing else I could have done, it was the only option I had, people often think we pick and choose,” she says looking defeated. “I don’t think many realize that *choice* is a matter of privilege that many don’t have, especially when you’re trying to hold on to the last bit of your dignity, save face in front of your family, or

protect your children,” she pauses for a second and continues, “or maybe you’re right, I knew there was no point talking about this to anyone really, it is hard to tell now,” she exhales.

“It is apparent that social norms dictate what behaviours are accepted and expected by the community, which plays such a critical role in how grief becomes disenfranchised (Harris & Winokuer, 2016),” I think to myself.

I notice Elizabeth seems to be soaking in the information as she stares at the flipchart before offering, “Stigma by itself probably brings up a whole bunch of different types of losses that we would not foresee coming.” She looks around and continues, “as Claire said, sometimes it feels like it would be easier to tell people that so and so has a disease, or has something physically wrong with them, instead of an addiction because without a doubt people would respond with more compassion, instead of passing judgement.”

I nod along in response.

Jessica looks up, “Yeah, well I think most people around me were relieved when my ex-boyfriend died. They had such a hard time understanding why I was even sad...because he was just a junkie with anger issues, you know what I mean?”

The ice in the room is broken now. The participants are starting to communicate without needing prompts. It’s a conversation close to their hearts too, and it shows.

Elizabeth sighs and says directly to Jessica, “Yeah that’s terrible, it’s crazy how stigma can play such a big role that we forget that it is still people who are dying, you know?”

I shake my head in disappointment at the grief response Jessica received, in agreeing with Elizabeth’s statement. “I think you’re right, Elizabeth. We’re well aware in our community about the sense of shame or self-stigmatization that is often identified by those who use substances (Matthews, Dwyer, & Snoek, 2017), but we rarely talk about it in a systemic context, and how

this sense of internalized shame permeates into people who use substance and ripples out into their families and loved ones.”

Sherry, in agreement with our exchange, nods and says, “It is hard not to internalize the stigma because of the criticism, negative connotations and stereotypes associated with addictions, (Matthews et al., 2017) so we may begin to believe that we shouldn’t ask for help, or that we are not supposed to, or that we don’t deserve to have any type of support. And we certainly have a legitimate fear that we won’t get it.”

“Yeah, people don’t get it, unless they have been through it or seen it,” Jamie adds.

“It seems crucial to cultivate more awareness for what people are going through. This is not something hidden from society anymore. I mean, we hear it on the news every day, the number of people struggling because of the opioid crisis,” I say.

Jamie leans forward in her chair to add, “That’s a lot of families that are actively struggling then.” It’s a heavy realization for all of us to imagine how many families may be currently dealing with loss without real support. Jamie takes a big breath, and silence descends upon the room.

She’s right. I know from my readings that according to the last Canadian Alcohol and Drug Use Monitoring Survey in 2012, it was estimated that 21.6% of Canada’s population met the criteria for a substance use disorder. That’s close to 8 million people suffering from addiction in Canada alone (Addiction Centre, 2019). It a big number to think about when you consider that all of them have families or networks of some kind.

Emma brings the discussion back to the prompt by saying, “Well the most difficult part for me is the familial obligation. You’re supposed to love your parents, right? You know, it’s inherent in us and I do love my dad...but I continuously have to cut him off. He’s gone to

treatment six or seven times at this point. I don't expect anything from him anymore. Nothing has been successful, he's still active in his addiction, and like you guys, I was brought up to just pretend it wasn't happening."

She sighs and continues, "One thing that I've finally learned is that you can't expect others to heal the way you would like them to, you have to keep your agenda aside. But that's easier said than done."

I take a breath, as I too know what it is like to get that sense of hope every time a loved one decides to go to rehab. You begin to set your bar lower and lower with every failed attempt, but it's like an asymptote which is a fraction that depletes over time, and in this case, the fraction is the amount of hope that diminishes with each relapse, leaving nothing left to hold onto.

The other participants also look like they know exactly what she's talking about.

"I guess the stigma does get to you too," Emma huffs in frustration, "I'm tainted by association if I share my family history with someone. They assume I must be an addict too or unhinged in some way--a loose cannon." She pauses and continues, "They expect you to be messed up too. Brian disappointed me throughout my childhood, because time doesn't exist, especially for opiate addicts. I was always concerned for my safety, I finally left home when I was 14."

I take a second to connect that she is calling her father by his first name now.

She exhales, "There are a lot of people in my life who would never know how bad my dad's addiction is, because I don't think they can handle it. They can't get past their own expectation that parents are always caregivers. They can just ignore the idea that sometimes children *have* to become caregivers for their addicted parents. Which means that you're

constantly accommodating other people's emotions, instead of attending to your own sense of loss, or even your own need for support."

We nod synchronically before Emma continues, "There've been so many losses along the line. It would be useless to keep count. He's still abusive, we usually go off and on for months before talking. I'll get curious you know, I'll go back to check up on him, and that will last three or four months until I feel like my head is going to explode. And then I realize that I am becoming angry again because it doesn't just consume you while you are having the conversation, his hurtful words stay with me for weeks. I'm left having to find ways to heal from his words over and over again."

"My stepmom left him when I was eight after he put her head through the wall while he was drunk. So, I had to start cooking, and cleaning and you know... getting him into bed after cleaning his puke off his clothes and everything around him. That was just how life was until I was 14 when I moved out." Emma continues, "My grandmother, his mom was a mean woman. She once stabbed him with a fork, and tied him up outside, like an animal," she shakes her head.

Emma reflects on her words, "So, pretty severe...pretty severe abuse during his childhood. I tried to keep that in mind ...but you're trying to kind of disassociate your love for someone because of what they've put you through once...once you get older."

I notice that Emma oscillates between humanizing her father's experience for the group to ensure he is not demonized because he was abusive, and addicted. The emphasis in her voice asserts a demand for compassion for her dad. The dad for whom she says she has lost all hope.

"That sounds like a lot for both you and your dad," I say looking towards Emma.

"It's so complicated when you love someone, and you have compassion for them, while at the same time being enraged and frustrated," I add.

Emma exhales, “Yeah.”

We’ve all patiently listened to Emma’s story and I feel a sense of honour to be part of a group who have such a capacity to hold space for each other’s experience.

Emma continues, “My dad's addiction was already really bad by the time he was 17. I mean, he was always a heavy drinker, but when he was 17 he was cliff diving and broke his back, then due to overprescribing of his medications, he became addicted to painkillers pretty quickly. She takes a big breath in and adds, “I’ve watched my dad deteriorate and I think his brain might be churning too much, he can’t recall things that have happened anymore.”

I see the tug of war between the dichotomies of her experience with her father, as she oscillates between calling him by his name, and addressing him as her *dad*.

“It must be tough watching him deteriorate,” I say without really expecting a response.

“It is,” she says.

Elizabeth gazes up to meet Emma’s line of vision, “It is the helplessness that gets to me too.”

“Go on,” Emma says offering the stage to Elizabeth to speak.

Elizabeth continues, “For me, it’s been such a chaotic dynamic from the time we were little...the self-harm and um, seeing my sister’s relationship with men has been a really hard one for me to swallow, because she is selling sexual services for money, and that’s her primary source of income right now. I think I’ve gotten used to being in crisis situations with her, the overdoses, and dropping everything at a whim, to attend to her.”

“Then there were my parents, who also kind of brushed me off, because my sister was always in crisis, and I guess they were too. I wanted to be included in the process. I’m not sure if

they were trying to protect me, or if they were just occupied with her,” she pauses for a moment to catch her breath.

I nod to relay to her that I’m still listening. “So, you felt like you were left out, but also that you were neglected,” I say.

“Yeah for sure,” she continues, “They did me a disservice by not including me because of course, I wasn’t oblivious that my sister had just overdosed. I mean she did it at the house. Did they think that I could maintain my innocence or something? It felt like we were different from other families, you know when you see them being all lovey-dovey and close and that sort of stuff. We simply didn’t have that.”

She shakes her head. “In our case, it was like you have to drop everything and kind of attend to the crisis she was in and try to get the support that she needed... not being included in part of her treatment process was difficult when I was younger. She was hospitalized at a mental health facility when she was 13, and she would come home on passes and I guess everyone, the hospital workers, my parents, would always tell me things were just fine, when I knew they weren’t,” she sighs. “It’s only recently that my parents have let their guards down a bit.”

“Oh wow,” I say. “So really, by saying that everything was fine, it shut down the conversation. It must have left you feeling a bit crazy—like, your senses were telling you that there was a serious problem but everyone around you was saying it was fine,” I interject.

“For sure,” she says, and then adds. “Now I guess feeling utterly helpless is the most difficult. She’s been struggling for as long as I can remember, dating back to her elementary school. If multiple visits with mental health professionals and social workers couldn’t help her to figure it out, what am I supposed to do?” She pauses for a second as she wrestles through her brain trying to create a map of the most crucial elements about her concerns about her sister.

She continues, “Every bit of it has been difficult, it’s been a difficult relationship with a chaotic dynamic, like from her being 12 years old and hanging out with 20 years old guys and everything from, her drug use and the people that she chooses to associate with and the way that she has treated my parents, to the way that she’s treated me.”

Elizabeth speaks calmly despite her sense of frustration with her current reality, “Both my parents work in healthcare, and she’s so privileged to have access to all these different services and supports and, like knowledge and that sort of stuff. At the end of the day, a lot of it boils down to, that things aren't firing properly in her brain and she’s hurt, and she just can't... you know, everything is so chaotic you know, and scary in her head, and she’s just looking for ways to fix it and make it feel less shitty all the time.”

Elizabeth glances down, “There is literally nothing I can do about it, except for being present and to show up when she needs me.”

Acceptance and surrender are not always blissful, I think to myself, as I watch her curate a dialogue that so efficiently reflects the fine line she walks between helping her sister and stepping away.

She shakes her head disapprovingly, “Like right now, she’s living in her car with a boyfriend and there’s another guy involved who is, like really scary and is threatening her life, and she's on bail and was stealing fentanyl pills. Well, the list just goes on and on, and on and on. So, it's, um, ...you just kind of ... there's nothing I can do and I accept that, but there's just, so many things you want to be able to help her with.”

“It sounds excruciating. Like an endless tug of war between wanting to help and wanting to protect yourself from the overwhelming and conflicting feelings that her behaviour arouses in you,” I say.

That utter helplessness of moving through the motions of the possibilities etched into the unknown possibilities. It's clear that it wasn't unusual for those sitting in this room to stand still amidst the chaos-- a learned skill, a conditioned response, to hold steady, and respond as needed.

"I guess a lot of it has been difficult, I'm just starting to acknowledge this. As I began to notice that I may not have been dealing with as well as I thought I was, I notice myself drinking more often and that doesn't feel good, but it's on my radar of awareness now...like I said this group kind of came at a good time, it's allowing me to reflect," she smiles.

Steady and grounded, she looks at Sherry as if to pass the baton to her.

"Thank you for sharing such a difficult situation with your sister. It really strikes me how much you have been carrying on your own, and for such a long, long time," she says. "I can relate to a lot of it." Sherry takes a moment before speaking as she gathers her thoughts, "But the most difficult part for me, has been not knowing, and I know we can't possibly know, but it has been extremely difficult," she exhales.

She gathers her thoughts to continue, "I feel like I am always expecting the worst and the worst doesn't feel like a far-off possibility. I worry all the time about my partner. I just effortlessly assume his death as the most immediate possibility. That's just where my mind goes."

I glance around the room and I notice that the group is feeling some affinity with what Sherry is saying.

"Whether it's that he's having a bad month, a bad week, or a bad day, or accidentally receives a bad batch of drugs, I know the possibility is right around the corner, and I don't want that to be my reality, and I don't want to have to make peace with that possibility. As Jessica and Claire said, it would be easier to tell people that he died of cancer or that a bus hit him instead of

him dying of an overdose. I don't think people would show the compassion that he deserves or that I do," Sherry sighs, as if it's just more than she can take.

I notice the others agreeing with what Sherry is saying--the uncertainty of what the drugs might be laced with, the uncertainty of what might happen next, is a familiar experience in this room.

She continues, "I know I've been grieving for him, for our relationship, and yet it's confusing because he's isn't dead, he's...but in a way I'm always worried that he could die at any moment. It's not the same as someone in the last stage of a terminal illness, because in that case, you know that someone is dying, and you can prepare. I guess the way things are, I'm always on edge, I'm preparing anyway, and I am grieving anyways, even though he is still here."

She keeps her gaze lowered when she speaks. It's clear that Sherry can't bear to look at anyone as she says this. Maybe the compassion that people feel will just make it all too real.

She brushes the hair from her face as she adds, "I asked him to see the same counsellor that I went to when I was at university. He came home and said that the counsellor thinks his first relationship is to his substances and not to me, and he said he didn't want it to be like that. Even though I knew it all along, it was true and hearing him say it hurt." She stares into space for a minute before adding, "I don't share much about us with others."

"I think that's understandable, Sherry. It's hard to believe that other people won't share the same judgments about you that you have of yourself. It's hard for us to understand, so why would other people be any different. And when you feel vulnerable already, it's just not worth the risk," I say as gently as I can.

Sherry lets out a long breath, to collect herself, "Yes, whenever I do say something people just tell me that I should leave but believe me, I know that! I know it's a toxic situation.

But then he cleans up his act, and I'm just as shattered by his relapse as I was the last time, or maybe even more than the last time."

As I listen to Sherry I find myself reflecting on the values I grew up with, values much like everyone else in the room. I knew I was not to speak to others about our perceived shortcomings, pain, grief, or trauma. My family struggled with communication, honesty, and family secrets, and of course, we all made mistakes that surfaced eventually. We still don't talk about mental health along with a million other things, but we do love each other regardless. Somehow, I was taught that despite our flaws or shortcomings, we always deserve to be loved.

My thoughts are interrupted when Sherry continues, "It's not so easy to leave him, and I don't want to leave him, I want us to be better, I want *him* to get better. How can I abandon him?" She adds, "But, it's not easy to stay either, because my life is so wrapped up in what he's doing, or what my dad is doing, sometimes I just want to shut down and run away from the world, you know what I mean?"

I knew what she meant, but I don't need to vocalize it, so I just nod.

"I guess that there's no way of really knowing that we ever will be better, or that he will be better. And that's difficult," Sherry stretches her arms as if to move the energy through her body and nodding to me conveys she is finished speaking.

I thank Sherry for sharing, and she smiles back and takes a sip of her water, looking up just in time to catch Jessica looking at her, "I don't think people understand what it is like dating someone with substance use issues unless they have been there, people hardly know the right thing to say to sound supportive," she says.

I nod in agreement.

Jessica continues, “The most difficult part for me...was not knowing how to help my ex at the time, but I’m trying to learn more. I see my sister going down the same path with her boyfriend. Not knowing how that might end, is the hardest thing now. I’ve witnessed the worst-case scenario. I would never wish that upon someone else, I think it is hard knowing that the world isn’t kind to you after you lose someone either. They’re not kind while you are with someone who uses substances and they’re not exactly best grief supporters after they die either. It’s hard to find relief anywhere, to be honest,” she says, as she shakes her head with disappointment.

Elizabeth raises her hand to speak, “I know we’re not in the same boat, but I know what it’s like to be worried for a loved one...it’s not easy,” she says trying to validate Jessica’s experience.

I take a deep breath. “It’s terrible that people hardly know how to respond when others are hurting.” I look down, “I wish it wasn’t so,” I sigh. “Grief can be complicated in so many ways...I don’t think everyone has a clear understanding of this.”

I notice that the participants are beginning to seem a bit weighed down. It seems like some movement may help in easing some of the emotions that may be coming up. “We’ve shared some heavy stuff today, and I want to check in to ask if anyone would want to take a break, stretch out, get some fresh air?” I ask.

“Yes!” exclaims Claire.

“Sounds like its break time. Why don’t we all reconvene in about 15 or 20 minutes before we start the final piece of our session?” I ask.

The group collectively consents.

The Third Prompt

I notice that there is a comfortable sense of camaraderie among the participants as their chitchat is punctuated with laughter in the room as they reconvene with their snacks and drinks. The last prompt was designed to lead into some appreciation for everyone's contribution and to provide a sense of closure for the group (Yalom & Leszcz, 2015).

I smile and look around the room. "Thank you all for returning! Are we ready to begin again?"

I see an approving shrug and some nods around the room. I read the last prompt for the day, from the flip chart:

"Has there been anyone who responded positively when you reached out for support and what did they do that was helpful? Or if you have not experienced any positive exchanges when you asked for support, how would you have preferred people to respond to you?"

I interpret the silence that follows to mean that it's difficult to recall support received. It might be easier then, for them to think of what response might have helped. But I'm not sure, maybe it's just hard to think at this point. So, I wait patiently to see.

Claire is the first to speak up, "It's just that if you haven't been through this, it's kind of foreign, and others clearly feel uncomfortable. And then they're kind of overly sympathetic and instead of them being supportive of you, they feel sorry for you, or they just don't know what to say or do, and you end up sort of, trying to take care of *them*."

Emma nods in agreement and adds, "Some people just stop talking to you and it's not just because they think you are damaged, but because their bubble is broken. The world is not great, you know? And they become sad when they look at you, so that makes both of us feel uncomfortable."

“So, it’s like you’re constantly expected to accommodate other people's emotions, based on how they respond to you (Bonnano, 2001; Corr, 2002),” I reflect.

“Yeah, I think so,” Claire replies, adding, “I’ve found the most help from doing yoga, and I’ve also done psychedelic-assisted therapy, which I found to be insightful and powerful. That’s been where I’ve found the most letting go and acceptance. I’ve talked to a few counsellors on occasion, but talking hasn’t been all that helpful for me.”

Elizabeth agrees, “I’ve rarely found counsellors or professionals helpful,” and she continues, “I’ve been talking to an older co-worker, though. He’s someone who has been around the block and he noticed how I pour myself into work. Then one day he asked me if I was okay and I shared a little bit about my sister with him. There was just no shock value when I spoke to him, and that conversation really helped,” she says with a sense of relief, before continuing, “I’ve been able to use him as a source of support a lot. Especially when my life is going sideways with my sister,” she lets out a deep breath, and says, “I find counsellors were always trying to pin me down with a diagnosis when I was younger, because my sister was diagnosed with so many labels. It’s like they were making an assumption that there must be something wrong with me too,” she sighs.

If there were moments that one could pinpoint when and how stigma begins to become internalized, this was the moment that Elizabeth was describing. These thoughts do not seem foreign to me, I too had met some mental health professionals who I thought were pathologizing me instead of being helpful, and I didn’t like it. I realize how lucky it was for me to have connected with the right counsellor early on.

Sherry shifts the tone, when she says, “I’ve found counsellors helpful for my substance use. And also, people in the recovery community. I didn’t always have the support of the

counsellors though. Often, it feels like people feel the need to say something, but the wrong things come out...if others could just sit there and listen they could be so much more helpful.”

Emma looks at Sherry nodding clearly in agreement.

Sherry continues, “People who have the ability to just hear my experience without changing their perception of me after hearing my story—that has the most impact, in my opinion.”

The conversation is moving quickly as Jamie adds, “I would’ve preferred if people believed me.”

I look back at Jamie and I tell her, “Oh Jamie,” I say, “I hope you know that I believe you,” not knowing if she had gotten that she has been heard... I mean truly heard. I don’t know if she truly trusts me or anyone else in the group since it is apparent that she has been starved for validation of her experience.

Jamie lowers her gaze. “That’s a hard one...even though you say you believe me, it doesn’t quite sink in.” Jamie continues, “It’s been three years since I left the father of my children...” she looks back up to say, “I met a medicine man who told me that I shine brightly. He says that I have good light and that I am meant to be here on this earth, and that it’s no accident that I am here. He says, I was called. I’ve been connecting back with my traditional roots and that’s been so healing.”

I smile and nod. It is a relief to hear that she has found a connection somewhere.

Claire lets out an intrigued “huh,” as if Jamie’s comment about connecting with her roots has brought forth a realization for her. “Connecting with your roots is so important,” she says to Jamie, and then continues, “I have lots of strong women in my life who tried to take on a

motherly role, I'm fortunate to have them in my life, but nothing can ever, ever even begin to replace the connection that you have with your biological mother."

"Yeah despite the strong connections, there is something unique about the longing for that connection with your mother," I say.

"I've always been a fiercely independent person," Claire continues, "I didn't appreciate when people would be too intrusive or invasive, but the relationships that I've found the most supportive are when I've had a strong connection to begin with, so I could turn to them when *I* felt the need, and not just when they wanted to offer support. It needed to be on my terms, not on their terms."

Sherry reflects on Claire's comment, "Claire, I agree. It's so crucial to have people around you that you can turn to. I find it hard to share my day with others, even in the professional realm, and I often end up feeling alone. I don't talk about work when I go home, to not trigger my partner or to be a downer. A silent presence goes a long way, the person who has been most supportive for me at work has been the one who just listened instead of trying to tell me how to feel."

Jessica nods while looking towards Sherry, "I've found that being able to speak to someone who understands is so difficult, my therapist has been helpful, my sister I can talk to her now, but before I couldn't. Not while my ex was still alive. I didn't talk to anyone...and it wasn't helpful when I tried, and then there just wasn't anyone."

She continues, "People often say 'oh you should talk to someone' but who is there to talk to? There aren't many people who get it, or understand or know how to respond in a way that is at all soothing."

Sherry validates what Jessica by saying, “It’s tough to find people who genuinely create a judgement-free environment and are truly willing to listen.”

I respond to Sherry, “...a non-judgmental open space can speak volumes eh?” Sherry smiles and nods.

Emma pipes in, “Counsellors have been a big part of my life, I first saw one when I was 13 and I remember being in a group talking about body awareness to manage my temper better by externalizing it, and that was helpful. I had an explosive temper as a kid. I still have a temper, but I’m able to manage it better now. I’ve seen counsellors through most of my adult life. But the indigenous community has been a very big source of healing for me as a white kid who grew up on the reserve. When you are taken in by someone that is not like you and they love you and they accept you, you feel a great deal of appreciation. I learned from my community that I could call upon the elders or others who have crossed over.”

Emma’s smile grows bigger as she shares more, “Spiritual ceremonies that we did were like out of body experiences, or that’s what they were trying to do, although it never actually happened for me. Your body is supposed to be replaced by elders that you call on, and they’re supposed to help you deal with what you are going through. During the spirit-ceremonies, you know, you call on your community too, to help and it creates a shield between you and the trauma.”

Emma closes her eyes while reminiscing, “Those teachings, well I carried them with me for the rest of my life” she says, and she takes a deep breath in.

“I am so glad the cultural learnings have helped you carry forward Emma.”

Emma nods, “There are not many places that allow for integration of these experiences. I am glad the spiritual aspect of my upbringing helped anchor some of my experiences.”

The circle is quietening. I look at each participant, noticing their body language. It's been a long day of sharing stories in a way that many may have not experienced before. Agreeing with Emma and reflecting on the minimal spaces for acknowledgement of one's grief I add, "It does seem like grief becomes disenfranchised in so many ways, whether it's social isolation, or the stigma that makes it shameful to speak about our experiences." I say shaking my head.

Sherry's thoughts seem to be merging with mine when she says, "Yeah this is a significant experience for supporting loved ones through addictions. I am still learning about disenfranchised grief, this is a new concept to me. I am still trying to understand what it really means in my life, and how and where else it may be showing up."

I listen to Sherry and I see others being receptive to what Sherry just said. She continues, "There are so many subtle ways our experiences can feel like they are being dismissed by others, and that becomes internalized so that even we dismiss it by thinking that if we were just stronger or had been wise enough or together enough to make a different decision...or whatever we tell ourselves. Or we may just not even feel like that our experience is worth sharing because of the response we expect to get."

Elizabeth adds, "Yeah absolutely, it's taken me a while to come to terms with talking about it."

"Yeah Elizabeth, that's true for so many of us. We had to work towards accepting that we can break the silence and speak up," I say.

Jessica pitches in, "It's also just such a personal experience, it's intimate, our needs might be different from each other but what is common is that talking about our grief has been uncomfortable and shameful. I'm glad we are beginning to open up though."

“Yeah, it really does speak to the level of disenfranchisement that comes along with the stigma that is associated with substance use. It almost sounds like it’s the society that tries to hover and manage people’s response to their grief instead of allowing a natural process to occur, in all its authenticity,” I say.

I notice others agreeing, but there is a sense of fatigue too. I’m feeling it too. It’s been a long day, and I think it’s time to wrap this up.

I look around the room and let out a big breath. I know these conversations will be keeping me up at night for some time. I ask if there is anything else anybody wants to add.

Claire speaks up, “I just want to say that I’m grateful that we’re having this conversation here. It’s hard to find people who know how to respond appropriately. So, thank you.” Others echo a similar response.

I thank the participants for coming forward and sharing these intimate parts of their life. I ask if this seems like an okay place to end and receive a response of approval from all. They shift in their chairs, stretching their arms and legs. I take the cue they are ready to get moving.

I ask if anyone would like to take a turn at the singing bowl to end our ceremony.

Jamie raises her hand, “Could I have a go?”

I smile at Jamie as I pass her the singing bowl. She takes a deep breath and begins to ring the bowl harmoniously. She lets go of the mallet and breathes out.

The participants slowly begin to make their way out. Although they leave silently, I can hear them talking softly to each other as they retreat down the hall.

Sherry sticks around to help pack up. I leave the group feeling grateful to have initiated such an important and satisfying conversation.

Piecing it Together

The next day I meet for coffee with Lisa to talk about the group. I approach her office less wound up than the last time I was in there, feeling pretty excited that I pulled it off. But there are still things I want to talk about.

I tap on her door, which is slightly ajar, and she rises from her desk to greet me with a huge smile, “How are you? How did it go?”

I smile back at her and take a seat, “It went well, better than I expected.”

Lisa smiles back, “Yeah, how come?”

“I’m not going to lie, I was a little nervous about sitting down with people to talk about this sensitive topic, but it went pretty smoothly. I had quite a few people drop out which is something I did expect...but I lucked out with the participants who came, and I realized that a small group was probably better than a bigger one anyway,” I say.

“Yeah, okay,” she says and then asks, “So, how are you doing now?”

“I’m doing okay. It was a lot of information, a lot of heartfelt conversation...only those who self-identified as women showed up, which I find interesting.”

Lisa asks, “Did you have people from any other gender reach out to you?”

“I had one gender-queer trans femme person contact me, but they never got back and absolutely no males.”

Lisa raises her eyebrow, “What do you think that’s about?”

“Well, it could be that whole thing about grieving styles between men and women. Researchers say that gender doesn’t determine grieving style (Harris & Winokuer, 2016), but that social conditioning certainly does seem to influence it (Harris et al., 2011).” I say.

Lisa nods in agreement, and we don't speak for a moment. "You seem a bit quiet," she observes.

"I guess I'm still processing the conversation, but I'm glad that at least people showed up to the group!" I laugh.

Lisa smiles with anticipation, "What was it like?"

"Well it was good, it was intense but good. I am still wrapping my head around all the conversations that took place," I say. I continue, "One thing I've been thinking about is that the people who showed up for the discussion had done some level of inner work or they would have been too raw or defended to be so open. It was clear that the participants who showed up for the group have engaged in some sort of process of working through their grief."

"Hmm does that affect your findings?" Lisa asks.

"In a way it does," I say.

"This leaves the group of people out who have not yet begun to process their sense of loss as well as the trauma that comes with facing the terror of watching a loved one decompensate in front of ones' own eyes. I wonder how their needs and experiences may differ from that of the participants who made it to the group. While it was insightful to hear them talk with self-awareness around their process, it leaves me wondering how people might have responded to the prompts if they hadn't participated in some kind of reflective process previously. I'm also curious to know if it's possible for younger people to articulate their thoughts in the same way that adults could because, all of the participants really could have used help at a much younger age."

Yes, I see what you mean, says Lisa. "But I'm still curious about how the conversation went in the group. What did you learn?" she asks pulling me back to the present.

“The conversation went well I believe...shared themes of disenfranchised grief and diverse stories about how the marginalization of grief plays out. Of course, stigma plays a critical role in the process of marginalization (Doka, 1989; Corr, 2002; Livingston, 2010; Harris et al., 2011).” I continue, “While there was a wide range of social responses that people received, all lead to a similar sense of disenfranchisement. It supports the widely held notion in academia that stigma distorts the transactional grief response and process of bereavement (Bonnano, 1999; Doka 2002, Jones & Beck, 2006),” I say with a sigh.

“When I think about it from a social functional perspective, we are aware that social responses affect our psycho-social wellbeing and ability to cope with a loss (Hudson et al., 2011) I was thinking about the research from Bonnano & Papa (2003) who say that increasing positive social responses to grief may help mitigate the negative symptoms of complicated grief (Bonanno & Papa, 2003). It was evident that most people in the group did not receive positive social responses when they reached out to people for support.” I pause to collect my racing thoughts.

Lisa nods her head as a gesture for me to continue talking.

“What’s weighing heavily is that I’m still trying to comprehend the vastness of this experience,” I add.

Lisa looks at me curiously. I know she’s waiting for me to elaborate, so I try to gather my thoughts. “We came together to talk about how supporters’ grief becomes disenfranchised through being stigmatized. The idea sounds so one dimensional now, after having these conversations that are still echoing in my mind. There are just so many different elements to their losses.”

I look down, “I’m still trying to wrap my head around everything else that the participants lost or continue to lose in this process of supporting their loved one.”

Lisa puts her coffee beside her as she looks at me, “Go on,” she says.

“If it makes sense, what I’m trying to say is that the loss of their loved one may be the explicit loss, but there are other many implicit losses that a person may also be grieving. It felt like the conversation in the circle was just the tip of the iceberg,” I say.

Lisa takes a moment to pour a cup of coffee from a carafe on the table and taking a sip she still manages to listen attentively.

“There’re just too many losses along the way,” I sigh.

“I mean, for some, there’s the loss of the connection with their loved one, and if they were young, then the loss of childhood as our society expects it to be, where parents take care of children and protect them from worry, harm and responsibility. For others, it’s the loss of an experience of a healthy relationship. The focus on the substance user dictates much of what else is going on in a person’s life due to the level of care and resources that person may require—not just from time to time, but for a prolonged period. And being in a relationship with a substance user separates them from their social group because of stigma—that is they can’t talk about what’s going on because they’re perceived to be either contaminated or culpable.”

“The caregivers may feel quite burnt out then,” she says.

“I mean how can they not? And it’s so different than a terminal diagnosis or a progressive neurocognitive disease like dementia. And the worry and grief can go on indefinitely. They keep having hope that it will get better and it may get better, but they always have the fear that the person will relapse and may even die. These challenges can almost be like anticipating a terminal

illness, in that there is so much of the unknown, coupled with the helplessness to impact the situation, ” I say.

“There’s a study about caregivers of dementia patients, who exhibited symptoms like apathy, anxiety, and depression-like symptoms when facing agitation and irritability (Hiyoshi-Taniguchi et al., 2018), and I wonder if the participants in your group shared any similar experiences?” Lisa asks.

“The symptoms are similar, but the experience is quite different because there’s a social perception that addiction is a disorder of choice (Kupfer, 2018), ” I say trying to clarify. “It’s a prominent discourse in our society and it’s deeply internalized. It’s hard not to feel a sense of resentment when the person you love or care about is “choosing” to use substances over you. Whereas in other cognitive disorders, even when the caregivers experience burnout or resentment due to the level of care required (Holley & Mast, 2009) there is a sense of helplessness to make things better; and the understanding that the terminal diagnosis isn’t the person’s fault,” I say.

I realize I’m saying a lot but there’s just so much that I’ve been thinking about. “There wasn’t a single person in the group who felt like they could share their experience with others without first assessing the kind of response they might get. I don’t think that people whose loved ones are diagnosed with terminal illnesses share the same experience, because they know they can expect a compassionate emotional response. These participants reported being silenced by the judgements of those around them.”

Lisa nods, and says, “This is where stigma plays in, eh?”

“Yeah it does, it appears that the level of care and support is negatively affected for caregivers of substance users,” I say.

“It’s unsettling...that people who are in fact grieving can be further isolated if they reach out for support, (Jones & Beck, 2006; Gray, 2010; Valentine et.al, 2016)” I add.

Lisa leans in and reflects back to me, “It’s unsettling because we know these loved ones are in the most need of support...support for a lifetime of uncertainty, fear, anger, disappointment, betrayal...well, everything that goes with loving someone who is using substances.” I nod to express my agreement with her comment. “It seems there may have been some benefit to exploring this idea after all,” she says.

I knew Lisa brought this up to lift my mood, but this experience felt like it had become more than just research for my thesis. “There were elements of anticipatory grief (Rando, 2000, Harris et al., 2011),” I say.

“It seemed like each relationship that was presented in the group had its own challenges, you know? It was interesting how different elements of grief came up in different relationships. A part of our social conditioning is that we have certain expectations from a relationship. For instance, we don’t expect the same things from a sibling as we would from our mother.”

I elaborate on that thought, “The adult children of substance users made me wonder how the sense of safe attachment for a child may be affected when helping a parent with substance use challenges. Parolin & Simonelli (2016) also investigated how drug addiction can affect the quality of adult attachment style and found that parents with substance use challenges can have a detrimental effect on the co-construction of the attachment bond between the parent and the child. These attachment styles and patterns may then also be re-enacted in other adult relationships (Parolin & Simonelli, 2016).”

Lisa agrees, “Yeah absolutely. The parental bond really sets the foundation for those attachment styles and we often only think about the attachment bond between parents and

children (Bowlby, 1977), but a sense of safe attachment is crucial in other relationships as well and it can be damaged through other relationships too (Levy & Johnson, 2019).

“Yeah I’m definitely interested in learning more about the effect on attachment while supporting a loved one with significant substance use challenges, and how it may permeate into other relationships and one’s relationship with themselves,” I pause and continue, “As you know I kept my questions quite broad (Appendix A) to allow the participants to eliminate my own bias of anticipatory grief as well as that of stigma, but it did come up repeatedly in our dialogue. It was prevalent that most of those supporting someone with substance use challenges have adapted in various ways to support their loved ones, they all had the ‘typical grief symptomology’ before a loss,” I say, making air quotes around the phrase typical grief symptomology.

“What kind of symptoms did you notice?” she asks

“Well, alienation, withdrawal from the world, a lost sense of control, profound sorrow (Harris et.al, 2011, p. 356), but we can’t approach it the same way that say, palliative care with a terminal diagnosis is approached, because the grief often can’t be easily identified or seen, or even understood by the person or the people around them. It’s just ongoing, you know what I mean?”

Lisa exhales, “Yeah, I can see that there is so much uncertainty with substance use, and a distinct set of challenges when compared to other kinds of losses.”

“Yeah, for example, your terminally ill grandmother will not be stealing from you, lying to you, showing up to your work drunk or selling sexual services in a risky manner. It’s just a different set of challenges, which makes it difficult to continue to support someone through substance use. And it’s a no-win situation because if you separate from them you feel guilty and it’s exhausting.”

“In dementia cases, there are similar challenges, especially when dealing with grief but yes, it is still quite different, there is a loss of the person that was known and loves ones have to watch them deteriorate, (Sikes & Hall, 2017), but it’s still different because the stigma isn’t there,” she says.

I take a deep breath and continue, “When someone has dementia there are often supports for the family that are anchored by the medical system. We rarely see the same compassion towards families of substance users in my experience of working within the field.”

Lisa raises her eyebrow, “It would be so interesting to see if we focused on the quality of care and end of life care in the same way for substance users as we do for others with terminal illnesses.”

“Yeah, well I know we don’t,” I say sounding disgruntled.

“It’s a lot to process,” she says, validating what I am feeling.

We sit silently for a couple of seconds as I process my own meaning-making of hearing the dialogues in the group. I assume Lisa too is taking space to process what I’m telling her. There’s just so going on in my brain still.

Lisa opens the stage back up for me to help vocalize my process, “What else came up for you?” she asks.

“Well, I was struck by how culture can have such a crucial role in a person’s healing, whether through traditional spiritual means, or something as simple, as holding space,” I say. “From a family systems perspective (Bowen, 1978), it’s important we begin to provide grief support for families and loved ones of those using substances and respond to family structures as a whole instead of individualizing the treatment just to the person who is using substances.

There's a lingering effect of unresolved grief when family members don't get a chance to process their emotions, which can go beyond family to the users' whole social circle too."

Lisa understands my point, "I'd be curious about how a person's role in the family would shift because of a loved one struggling with substance use?"

"This did come up in the group. One participant mentioned the parentification of children, another of added pressure to keep it all together for a sibling, in order to ameliorate the stress, the parents were feeling, another mentioned the sense she had of being the only parent. All these roles have unique needs for support and I just hope that our system can do that one day," I say.

Lisa nods silently, taking it all in.

"Oh, and another thing is that the role of loved ones is further complicated by social rules that forbid complaining about their family members whether it's a spouse or a parent or a sibling. They just aren't allowed to talk about it. And it isn't just family either, it can be the community or a religious group too."

Lisa nods, "You make a good point, it is not generalizable what the person's needs would be in a given circumstance." She takes a second before gently cueing me to elaborate, "I'm curious about the aspect of generational trauma especially in relationships, especially with children of substance users," she adds.

"How exactly do you define relational trauma?" I ask.

Lisa explains, "It means exactly what it sounds like, it's the experience of repeated neglect, abuse, bullying, or other types of behaviour that causes lasting psychological harm (Mackay, 2017),"

“I guess then, that relational trauma was prevalent within the group. There was mistrust, loss of hope, a sense of obligation, avoidant or anxious attachment, but I would be hesitant to define what is traumatic for a particular person... I think they would have to define it as trauma for themselves,” I say hesitantly.

“I guess I should put it differently, it’s not to say they’re necessarily traumatized because of the experience, but some harm was done to their expectation of the relationship, hence the experience of the grief of someone who is still alive,” Lisa clarifies.

I quickly respond, “When we talk about trauma, it is hard not to think about mental illnesses that also stem from trauma, and how some carry more stigma than the others from what I’ve noticed.” I continue, “The term relational trauma is something I often hear in association with Borderline Personality Disorder (American Psychiatric Association, 2013), which as you know a highly stigmatized mental illness (Aviram et al., 2006). It also brings up another point; there’s room for further research on how the stigma of substance users may be intertwined with the stigma of certain mental illnesses and how that may further disenfranchise the grief of loved ones.”

Lisa nods. “So, what you’re saying is that stigma plays a crucial role in the type of support people receive or are even willing to ask for, and if we want these supports to be in place, we have to address the barriers that stigma creates. We need to know more about how stigma affects specific mental illness as well as specific relationship dynamics too.”

“Absolutely,” I say. “I noticed that intimate partners of those struggling with substance use presented concerns about not wanting to be judged as complicit in their partner’s challenges with substance use, and subsequently responsible for their own distress.”

I pause for a moment, and add, “I also noticed that socioeconomic status didn’t seem to play a significant role in for the participants.” I bring that up as I’ve noticed many people still hold the narrative that substance use is something that only affects poor people. “Economics may have played a role, but at least in this group, it wasn’t brought up as an issue.”

“It seems though in the mass media at least substance use is highly glamorized among the higher socioeconomic status (American Addiction Centers Treatment Facility, 2020) and demonized among lower socioeconomic status. Since the invitation posters for my research were posted on my social media pages, the people who responded to the invitation were part of my existing social network from work. Although I didn’t ask, from what I observed, the participants fall in the categories of the upper-middle class to lower middle class, some coming from professional families and some with minimal income while growing up, from what I know about them.”

Lisa looks intrigued. “I would be curious how one’s drug of choice further perpetuates stigma and affects the grief process. Since you are mentioning the role of socioeconomic status in your sample, I’m curious if families face a different type of stigma associated with the substance users if they are using high-end drugs like cocaine compared to substances marketed for street users,” she says.

“Yeah, I’d be curious about that too, since certain drugs are associated with SES (Pederson & VonSoest, 2017) as well as some drugs carrying more stigma than others (Palamar et al., 2012), there are too many unanswered questions still,” I sigh.

Lisa furrows her eyebrow a bit, “But you did gain some insight, right?” she asks. “I’d really like to hear about that part.”

The right side of her lip rises, as she says this into the slightest smile that seems encouraging, so I go on. “I guess I did find a few things that will help me in my future practice,” I say feeling assured.

Lisa smiles, and says, “Tell me more.”

“First, I learned how important it is to address the stigma that the substance-affected feel when they care about a substance user and how this stigma affects their grieving process. I mean, if you feel too ashamed to talk about it, or you repeatedly get responses that indicate that your experience is not understood, or worse, judged, you stop talking about it. As we know those with adequate community support will have an easier time resolving their grief than those with little or no social support who are forced to carry the burden of grief alone (Romanoff & Terenzio, 1998).”

“Having the space to speak about it can really begin to deconstruct the shame associated with the societal stigma. Livingston’s research (2010) states ongoing dialogues about one’s loss can provide an opportunity for support for groups of people who are experiencing disenfranchised grief,” she says confirming the implication.

I nod in approval and continue, “Yeah absolutely, I also learned that it’s crucial to understand the cultural sub-systems that our clients may be coming from, and norms that are particular to that sub-culture (Corr, 2002), whether that’s religious or spiritual sets of beliefs, inter-generational exposure to trauma, internalized shame and stigma, not to mention gender differences. There may even be value in deconstructing the narrative the bereaved may have formed about their own self-concept, struggles with power and social dynamics to deepen their understanding of grief. These conversations will also allow one’s grief to be truly seen and be re-enfranchised.”

Lisa understands what I am saying and adds, “It seems that the foundational stage for grief work with a client would be to first acknowledge the societal dismissal of their experience with loss, and validate the losses that they’ve experienced.”

“Yeah, so they can begin to find meaningful ways to mourn (Neiyemar et al., 2011) and process the losses that they’ve experienced and continue to experience,” I say.

I pause for a second to connect the common themes from the group and add, “The group participants shared an underlying yearning for others to understand their experience and they all spoke of people not quite getting it, so I wonder if group therapy could also assist with people in finding those who share similar experiences (Yalom & Leszc, 2015).

“That makes sense, group therapy has been found to help build relationships, and shed layers of internalized shame (Wolfe, 2018). I’d be curious about willingness to attend group sessions especially based on the gender differences that you noticed. I’d also be interested in how group therapy could be presented in a manner that deconstructs the stigma of attending a group related to substance use problems in the family,” she adds.

“That’s a good point group therapy may not seem so accessible for some due to the stigma both societal and internalized...but it may be an option for some and may provide an opportunity for deconstructing stigma as it did in the Livingston (2010) study,” I say.

I exhale, “It’s also important to remember that traditional talk therapy may not be suitable for all those who are grieving. One of the participants founds physical movement as a modality to process her grief and trauma, along with psychedelic-assisted therapy. There were also participants who spoke about the importance of connecting with spiritual practices as a means for integrating their experience. I think it’s crucial that as counsellors, we’re aware that talk therapy may not be a modality that works for all our clients, so we need to collaborate with other

therapeutic modalities in the community that can assist in grief work, such as meditation, yoga, and dance (Sausys, 2014; Whately, 2016), music therapy (Wlodarczyk, 2013) nature-based wilderness therapy (DeDeigo et al., 2017) and ...well there must be lots of others, so we can offer a range of resources.”

Lisa nods and smiles, “It can be quite humbling, as well part of our responsibility and ethical standard of practice for counsellors to recognize our limitations for helping specific clients (Canadian Counselling and Psychotherapy Association, 2015). This also aligns with the BCACC code of ethical conduct is that emphasizes that all interactions and decisions with and involving the client are made for the client’s best interest in mind (BC Association for Clinical Counsellors, 2017, Principle 2).”

“I agree, it’s futile to think that one type of approach can work for all clients,” I say stating the obvious. We both sit in silence for a moment.

I shift in my seat and pull my water bottle out of my backpack. We’ve been talking for some time. I take a sip of water as Lisa reaches for her cup coffee, which surely must be cold by now. “I can’t help but wonder about the weight of the caregiving aspect towards the loved ones,” I say, breaking the silence.

“It’s a lot of work to take care of someone with significant substance use challenges,” she nods.

“In an ideal world, I would like to see loved ones of substance users receive a similar level of care and support that loved ones receive with their family members in palliative care,” I sigh.

Even though I appreciate the time that Lisa offers me to talk this out, I realize we've been talking for a while, and my mind begins to wonder about piecing this research together for my thesis.

Lisa seems attentive still, so I add, "I was unable to dig further into how a person's disenfranchised grief may inhibit their quality of life beyond interpersonal relationships. The participants touched on social isolation, as a critical element; however, there is value in investigating how one's functionality may be affected within other areas such as finances, academics, ability to obtain and maintain housing and general well-being that comes from engagement in leisure activities and sports along with other lifestyle factors."

"You know in the world of counselling we say we're depositing seeds for our clients, seeds that one day might bloom but you might not be there to witness that. These interactions for many of the participants may have been like those seeds even though you couldn't counsel them...but hearing others have similar experience can be quite validating," she says as she leans forward into her chair.

She locks eyes with me to add, "In some ways, this small group may be a seed for you to further your interest in further research on this topic," she says.

"Providing a safe space for conversation and bearing witness can be profoundly healing for some," she adds. "Are you ready to write your thesis?" She asks

"I have some ideas," I say softly, feeling a bit unsure.

"For whatever it's worth, I believe, this is an important conversation to have and I'm more than happy to help with the process," she smiles. I find this assuring.

I respond with half a smile, feeling intimidated by the weight of the thesis.

"What was your initial hope for this project?" she asks.

“Well, my greatest hope was to find and provide a wider understanding of the experiences of loved ones supporting someone with substance use challenges. I hoped that hearing their conversation would provide an insight into how people manage their mental health while supporting others. With more understanding, we can then begin to create a system of care that assists loved ones to ...well become more functional, you know, better at coping and processing grief.”

I continue, “And I want to provide context to counsellors, so they understand the experiences of substance-affected clients, so they can see how important it is to support them. I also wanted to provide a platform for these unheard voices to be heard, because so often they are both shunned and silenced. Hopefully, I want to help humanize these experiences as well. I would hope that more research like this, with less time and funding restraints, may help increase mental health worker’s understanding of disenfranchised grief, so they can support those who are substance-affected in a more efficient manner.”

She smiles back, “That’s a reasonable hope. You’ve already accomplished a part of that goal by starting the conversation in the group.”

I thank Lisa for her support through this project, I also feel ready to leave the office, so I can stop imposing on her time. There are still plenty of things that I am wondering about and I am still hearing the echoes of the dialogues I shared with the participants.

I leave Lisa’s office, but I’m not ready to go home just yet. So, I decide to drive by the ocean, to the same spot where Sherry and I often meet. I get out of my car and sit by the rocks near the ocean. The breeze by the ocean feels comforting and the vastness of the experiences that I have been trying to comprehend seems to be mirrored by the ocean as the waves crash against

the rocks. The water constantly moving in and out in a soothing rhythm that seems peaceful. The sun is still warm, and the wind is cooling, and for a few seconds, I am just breathing.

I didn't expect this project or the interviews to be easy by any means; however, engaging in this dialogue with the participants was satisfying and informative, given how little I knew when I began. I have been frustrated with our community response towards people who use substances, so it felt natural to want to explore how stigma ripples out to family members of substance users.

In thinking about the interviews, I find I have a better understanding of the collective grief in our community. My motivation for this project may have been primarily due to my personal experiences and to possibly finding some resolution for my understanding of how my actions may have affected others around me. Substance use challenges are normalized within my community to such an extent that the people I know hardly blink an eye for the struggles they may be facing taking care of others and taking care of themselves in this process. Substance users surround me, and so too are the participants of my study. It blows my mind how something that happens so commonly can be so stigmatized in our society. So many people marginalized due to the stigma sits heavy with me. I let this heaviness flow with the waves of the ocean.

Listening to the stories of the participants for those hours has brought forth the complexity of the individual experience of loved ones that lay on top of the statistical perspective that the news headlines offer almost every day as they report the death rate due to fentanyl poisoning. In March 2020, 113 people died from an illicit drug overdose in the province of British Columbia— marking the first time B.C. has recorded more than 100 fatalities in a single month since last March (Victoria News, May 2020). I also realize the hours that I spent engaging

with the recording of the dialogue of the participants still do not capture the intricacy of their experiences. There is a lot more under the tip of this iceberg.

As I tune into the grief of my participants, those who dropped out of my study because this felt too raw for them to talk about, and many others who may or may not have the support system to acknowledge and navigate their grief work, my heart feels open to walk more gently, to speak more softly, and show up more kindness towards others.

I allow the wind to help me feel a bit lighter, the sound of the ocean to clear my thoughts. I notice the birds flying back towards their nests as the sun begins to set and I pick up my backpack. I too head for my car, so I can go home and rest. While I may not be able to help everyone, I can help myself, by trying to stay grounded and attending to my own care. I think Wendell Berry (1991) says it well in *Peace of Wild Things*:

*When despair for the world grows in me
and I wake in the night at the least sound
in fear of what my life and my children's lives may be,
I go and lie down where the wood drake
rests in his beauty on the water, and the great heron feeds.
I come into the peace of wild things
who do not tax their lives with forethought
of grief. I come into the presence of still water.
And I feel above me the day-blind stars
waiting with their light. For a time
I rest in the grace of the world, and am free (Berry & Curtan, 1991).*

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Appendix A: IRB Ethical Review Protocol



**Institutional
Review Board
Ethical Review
Protocol**

City University of Seattle Ethics Training completed on this date: October 1, 2019

1. **Title of Project:** Disenfranchised grief in response to supporting loved ones through significant substance use challenges

2. For Faculty Researcher(s)

Name: _____

Department/Division _____

Telephone _____

E-mail _____

3. For Student Researcher

Name: Shweta Pal

Faculty Supervisor: Andre Serzisko

Department/Division: Arts and Sciences Degree sought:

Master of Counselling Telephone: 1+250-885-2353

E-mail: palshweta@cityuniversity.edu

-
4. Project Coordinator: _____
5. Sponsor (if any): N/A

Fill in this protocol completely, including appropriate consent form(s) at the end. Incomplete protocols will be returned for resubmission.

- Research question(s):

How does disenfranchised grief present for those supporting someone with significant substance use challenges?
--

Basis for the question including supporting quote from research:

A study done by *John Hopkins Bloomberg School of Public Health* showed that general public was more likely to have negative attitudes towards those dealing with drug addictions than those who were only dealing with a mental illness (John Hopkins HUB, 2014). Stigma against people who use substance has been researched for over the decades (Buchman, Leece, & Orkin, 2017). This study would help illuminate how the ripple effect of stigma effects family members/loved ones of those struggling with substance use challenges. Furthermore, Knight and Gitterman (2019) state “ambiguous grief results from a non-death loss...The reactions of loved ones faced with these situations rarely have been understood as a form of grief. The lack of recognition of ambiguous loss means that it is more likely to be disenfranchised.”

Disenfranchised grief is defined as grief process that is not recognized or validated socially (Harris & Winokuer, 2016). When grief is not recognized it can mean that social support is then not seen as valid or necessary because the loss itself is not considered significant (Doka, 2002), he further notes several ways which the grieving individual is disenfranchised:

- “The relationship that was lost was not considered valid, socially acceptable or important.
- The grieving individual is exempted from rituals that might give meaning to the loss or is not seen as capable of grieving for the loss.
- Some aspects of the death or loss are stigmatizing, embarrassing, or unacceptable.”

In simple terms, disenfranchisement of grief is the deprivation of appropriate support when a person is experiencing grief. The stigma around addictions isolates individual from seeking support or sharing their stories with others. The anticipated social response from the community is often negative due to stigma associated with addictions.

Social norms govern appropriate ways of behaving, thinking, and feeling in a particular situation. The concept of social norms permeates into the realm of grief, deciding what is appropriate in regards to intensity, duration, acceptance, and the importance of the loss the bereaved may experience (Harris & Winokuer, 2016, p.48).

Personal Interest:

My work as a first responder for over three years with an overdose prevention site has prompted a curiosity into this thesis research. I noticed how family members are often in their process of supporting their loved ones as well as sometimes isolated from their social circles due to the stigma around addiction. Family and friends may sense chronic despair and a sense of ongoing dread. Harris and Winokuer (2016) describe this type of grief as living losses that are non-finite. A non-finite living loss demands the individual to repeatedly adjust and accommodate to the loss because their loved one is still alive. Harris and Winokuer (2016) further adds “nonfinite loss is often not well understood, the experience may go unrecognized or unacknowledged by others. Support systems may tire of attempting to provide a shoulder to lean on” (p.111). In my personal life I supported my ex boyfriend who passed away in 2013 due to an overdose. My sister is currently supporting her partner through alcoholism and i support her supporting him. I also have very close friends one of them who continues to relapse with cocaine, who has been to rehab has been on the verge of losing his job and others and it has been difficult watching him oscillate between his recovery and relapse for the last 5 years, with fentanyl poisoning other substances this has been a scary process for me. Through a professional space as a shelter worker, i support many clients in active addictions, having known them for over 3 years, the cycles of recovery and relapse becomes difficult to navigate at times. Part of my job is to liase with family members collaborating in recovery plans, passing along messages from family members and also notifying the family in the worst case scenario of death.

The basis for this question is to explore experiences of those supporting somebody through significant substance use and elaborate on their experience through my own lens of self-reflection and connect their stories and my own to the wider cultural, political, and social meanings and understandings.

I hope to explore experiences in particular, of the disenfranchised anticipatory grief of those supporting somebody through significant substance use. My intention is to connect my own observations of how stigma affects social networks in order to better help those who are in positions that attempt to support those with substance use disorders.

- Purpose of the study:

The purpose of the study is to explore the experiences of loved ones who are supporting someone through significant substance use challenges and explore how that grief might become disenfranchised due to social stigma.

- Methodology:

The primary source of data collection would be qualitative interviews conducted with either family members, partners or friends of those who are or have been engaged in substance misuse. I am aiming for 2-3 interviews with each interview taking approximately 90 minutes. I will utilize the participants' narratives to look for patterns in the grief process if any exists. This will provide me with the opportunity to analyze the data from a systemic lens with the hope to shed some light on existing cultural barriers that exist in providing appropriate support for the research population.

To best answer the question I will opt for an auto-ethnography. According to Ellis, Adams, and Bochner (2011), an auto-ethnography is a way to do research and writing that allows the researcher to describe and systematically analyze personal experience in order to understand cultural experience. I will take measures to maintain the anonymity of the participants through my auto-ethnographic dialogue by eliminating identifiers like name of the participants and specific locations. I will be sharing my own reflections upon

the participants' narrative and connecting the two to make meaning of our cultural, social and political

These reflections will be based on my personal experience as defined in the section "basis of research".

My personal experience supporting my late partner, my friends as well as supporting my sister who

supports her boyfriend who is an alcoholic provides me with the insight on disenfranchisement of grief

when supporting an addict. As a front line worker at the homeless shelter, I also noticed other family

members who come and visit their loved ones often seeming isolated, not sharing with friends and family

that their loved one is living at an active substance use low barrier facility for food and shelter due to their

addictions.

Minimal Risk per governmental regulation is defined as research that “poses no more risk to the human participants than that encountered in ordinary daily life”.

Check this box if faculty supervisor or faculty researcher believes this research constitutes minimal risk according to the above definition. The IRB will make final determination regarding the level of risk.

6. Description of participants (include number, ages or age range, location, and special characteristics to include gender and ethnicity).

I will hope to recruit 5 - 6 participants for this research:
The participants must be over the age of 19 who live within Greater Victoria, BC.
They must have the capacity to comprehend and understand the questions asked during the interview.
The participants will self identify as experiencing disenfranchised grief (as per the research poster); this will re-assessed before the interview to ensure that the participant still fits the criteria

7. If research is conducted through an agency or institution, complete the CityU Organizational Consent form to include the names, contact information, and contact persons for any institutions or agencies. If outside institution's consent form is used and attached, researcher is responsible to assure that all provisions are in concert with CityU approved Research Participant Informed Consent form.

Attach to the Email you send with this form the completed organizational consent as “ ‘Student Name’

Attachment

A”.

N/A I am the sole researcher for this study.

8. **Recruitment Phase** (Do not include your process of acquiring informed consent): Describe how participants will be identified or recruited. Include in your answer the exact wording of all

notices, advertisement and/or scripts used to recruit participants. If the human participants include minors or vulnerable adults, include the script used to advise them of the study.

The participants will volunteer to participate in the research by responding the poster that the researcher will post on a facebook page that for which she is the sole administrator. The page is called The Good Vibes Project <https://www.facebook.com/goodvibesprojectvic/>

The posted will also be posted on my personal social media accounts i.e. instagram and facebook.

The researcher will also circulate an email through her work sent to all co-workers to keep the recruitment of the participation at arms length.

Given the possibility of knowing the participants due to our work relation. I would like to disclose that I do not hold a supervisory position at work. However, I recognize there may be an undue influence regardless, consideration to this influence has been spoken to in the informed consent that focuses on the voluntarily nature of one's participation has been in the informed consent process as well as explicitly stating that their participation will not impact our relationship negatively in the future.

The poster will read as follow: See Appendix C

Research Study:

Disenfranchised grief in response to supporting loved ones through significant substance use challenges

9. Informed Consent Phase (do not include recruitment information): Describe your informed consent process. Include in your answer the exact wording to be used in information letters, emails, telephone scripts to participants and parents/guardians, oral scripts and/or email scripts. Also please attach a copy of your consent form, which must be based off of the CityU template that can be downloaded from the IRB website.

I will set aside up to 15 minutes before the interview to inform the client of our consent. I will inform the participant of my role with City University as a Graduate student in the Master of Counseling Program and that this study is being done for a partial fulfillment of my degree. I will go over the purpose of the study and re-iterate that their participation is voluntary and they have the right to withdraw at any point without negative consequences. I will explain to them that everything that they share with me is confidential and all of the information they share with me will be saved on the data voice recorder and transferred onto an encrypted USB, all files will be password protected and used on a password protected laptop that will remain only accessible by me. I will store the paper copies of our informed consent appropriately in a locked cabinet for 5 years and all the data will be shredded and destroyed after that. I will inform them that their participation will be kept confidential.

See informed consent attached with the email.

10. What data collection tools will be used and how will they be administered? Include, as an attachment, an exact replica of data collection tools, e.g.: written questionnaires, interview questions, observation schedules and confirm the source and/or copyright permission for any collection tools from outside sources. Summarize the attachments here.

What has your experience been like supporting this person?
 What kind of responses do you get when you share details about your loved one?
 How have supporting your loved one impacted your interpersonal and other social connections?
 Have you ever felt hesitant about sharing your experience with others? Why?
 Who have you turned to for support regarding your loved one?
 Do you find your that your relationship with your peers tends to shift when your loved one is in crisis? If yes, how so?
 What has been difficult for you about supporting _____(insert name of the person)?
 In what ways do you find your grief is disenfranchised?

11. Will participants receive inducements or rewards? Give details.

N/A

12. How will the confidentiality of each participant be protected?

All data will be recorded on a data voice recorder, transfered to an encrypted USB for back up. All data will be stored on encrypted USB drive the laptop used for accessing the data will be password protected. Folders containing data will also be password protected.
 I will have the signed copies of consent forms secured in a sealed envelope and placed in locked filing cabinet.
 The confidentiality of participants will be maintained in my writing by eliminating identifiers like names of people and specific locations. The researcher will ensure to not share identifying information about the participants through any means of communication with others.

To further ensure the confidentiality of participants I am not publicly advertising my research at work or on facebook. The emails will be privately sent to prospects I currently know are supporting someone through significant substance use. Confidentiality as per the informed consent will be explained to the participants.

13. How and where will data be stored?

Encrypted USB drive, password protected laptop

- Electronic data

storage:

- Paper data Signed copies of consent forms secured in a sealed envelope and placed in locked storage: filing cabinet.

- Other data storage, e.g. audiotapes, Data voice record
videotapes:

14. City University of Seattle requires data to be securely for a period of 5 years then permanently destroyed:

- Permanent destruction methods for each data item: _____
Hard drives will be physically destroyed. Shredder for the permanent destruction of the raw data. Paper copies of signed consent will be put shredded in a paper shredder.

15. Describe any possible risk or distress and safeguards in place to address risk or distress including access to counseling, with attention to vulnerable populations who may be participating in this research.

The participant may experience psychological and/or emotional distress due to the sensitive matter of the research. As graduate student who is in the last stages of completing her Master's Degree and my work within the community with mental health has equipped me with tools to detect subtle signs of emotional distress. Some of these indicators include but are not limited to: Shallow breathing

Sudden change in eye contact
Sudden change in tone of voice
Contracted body language
Fidgeting

I am aware I cannot counsel a participant through distress during or after the interview, however, as an empathetic individual being aware of signs of distress can allow me to provide the participant with space and time in order to reduce harm. I will ensure emergency counselling service resources are made available to the participant on a handout. I will provide them with the contact information for the Vancouver Island Crisis Line : 1-888-494-3888 as well as crisis text service: 250-800-3806, I will also list our local low cost sliding scale counselling agency if they need extra support Citizen's Counselling: 250-384-9934.

I will keep water and Kleenex within the reach of the participant and they can reach for it as needed. I will incorporate a grounding exercise midway through the session if needed and ensure we do a grounding exercise at the end of the session. I will also make the aware that they can stop the interview at any point and have no obligation to finish after taking a break.

Script for the grounding exercise as follow:

Start by settling into a comfortable position and allow your eyes to close or keep them open with a softened gaze. Begin by taking several long slow deep breaths breathing in fully and exhaling fully. Breathe in through your nose and out through your nose or mouth. Allow your breath to find its own natural rhythm. Bring your full attention to noticing each in-breath as it enters your nostrils, travels down to your lungs and causes your belly to expand. And notice each out-breath as your belly contracts and air moves up through the lungs back up through the nostrils or mouth. Invite your full attention to flow with your breath. If it feels comfortable place your one hand on the belly as you notice the inhale and the other hand on your chest as you notice the exhale..

Notice how the inhale is different from the exhale. You may experience the air as cool as it enters your nose and warm as you exhale. As you turn more deeply inward, begin to let go of noises around you. If you are distracted by sounds in the room, simply notice them and then bring your intention back to your breath.

You might become distracted by pain or discomfort in the body or twitching or itching sensations that draw your attention away from the breath. You may also notice feelings arising, perhaps sadness or happiness, frustration or contentment. Acknowledge whatever comes up including thoughts or stories about your experience. Simply notice where your mind went without judging it, pushing it away, clinging to it or wishing it were different and simply refocus your mind and guide your attention back to your breath.

Breathe in and breathe out. Follow the air all the way in and all the way out. Mindfully be present moment by moment with your breath. If your mind wanders away from your breath, just notice without judging it – be it a thought, emotion, or sensation that hooks your attention and gently guide your awareness back to your breathing. As this practice comes to an end, slowly allow your attention to expand and notice your entire body and then beyond your body to the room you are in. When you're ready, open your eyes and come back to awake and alert.

I will inform the participant that they can take as much time as they need to answer a question and they have the freedom to not answer a question if they choose not to. Given the subject matter of the research, I plan to do a mid-way check in with the participant to ask how they are doing and if they are okay to proceed with the interview.

Participation in research may result in undesired changes in mood, thought processes and emotions such as experiencing low mood, feelings of stress, guilt and/or confusion and even re-traumatization. These changes may be transitory or recurring. To mitigate the risk I will equip the participant with the resources listed above.

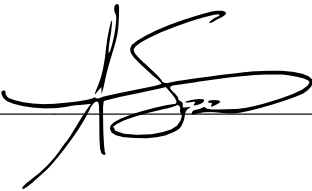
The risk of breaching confidentiality will be minimized as per the plan mentioned in the informed consent and addressed in Question 13. This plan will be discussed with the participant to affirm that what they share with me will remain confidential.

Submission of this form electronically signifies that the researcher takes responsibility for the accuracy of the contents of this submission and that student researcher's Supervisor approves of the submission, in an equivalent manner to an original signature.

Before signing, the research Supervisor/advisor is responsible for reviewing the scientific and scholarly validity of the proposed research study. As research supervisor/advisor confirm the following:

1. The research procedures are the least risky procedures that can be performed consistent with sound research design: Yes No Yes No
2. The research is likely to achieve its aims: Yes No
3. The proposed research is of sufficient importance to justify the risks entailed: Yes No
4. There are adequate resources to complete this study: Yes No

Name of Researcher: Shweta Pal



Research Supervisor/Advisor: _____

December 4, 2019

Date

: _____

Appendix B: Participant Informed-Consent**City University of Seattle**

School/Division of Arts and Sciences

CITYU RESEARCH PARTICIPANT INFORMED CONSENT

Autoethnography research

Autoethnography is a type of qualitative research where the person conducting the research serves as both the researcher, and as one of the human participants. In autoethnographic research, researchers seek to extend human knowledge by reflecting on their own autobiographical experiences, and extrapolating from them to inform our understanding of the world.

Title of Study: Disenfranchised grief in response to supporting loved ones with significant substance use challenges

Name and Title of Researcher(s): Shweta Pal (BSc. Psychology, Post-degree Diploma Mental Health and Addictions, M.C. Student)

For Student Researcher(s):

Faculty Supervisor: Andre Serzisko

Department: Division of Arts and Sciences

Telephone: +1250-885-2353

City U E-mail: palshweta@cityuniversity.edu

Program Coordinator (or Program Director): Andre Serzisko

Sponsor, if any:

Key Information about this Research Study

You are being invited to participate in a research study.

The researcher will explain this research study to you before you will be asked to participate in the study and before you sign this consent form.

- You do not have to participate in this research.
- It is your choice whether or not you want to participate in this research.
- Your participation is voluntary and you can decide not to participate or withdraw your participation at any time without penalty or negative consequences.
- You should talk to the researcher(s) about the study and ask them as many questions you need to help you make your decision.

This form contains important information that will help you decide whether to join the study. Take the time to carefully review this information.

You are eligible to participate in this study because you identify experiencing disenfranchised grief and have experience a loved one through significant substance use challenges.

You will be in this research study for approximately 45 minutes – 2 hours

About 5-6 individuals will participate in this study.

To make your decision, you must consider all the information below:

- The purpose of the research
- The procedures of the research. That is, what you will be asked to do and how much of your time will be required.
- The risks of participating in the research.
- The benefits of participating in the research and whether participation is worth the risk.

If you decide to join the study, you will be asked to sign this form before you can start study related activities.

Why is this research being done?

Purpose of Study:

The purpose of the study is to explore the experiences of loved ones who are supporting someone through significant substance use challenges and explore how that grief might become disenfranchised due to social stigma.

Research Participation.

You will be asked to participate in the following procedures:

I understand I am being asked to participate in this study in one or more of the following ways (initial options below that apply):

x- Respond to in-person and/or telephone Interview questions; Approximate time up to 2 hours

Answer written questionnaire(s); Approximate time _____

Participate in other data gathering activities, specifically, Approximate time _____

You may refuse to answer any question or any item in verbal interviews, written questionnaires or surveys, and, you can stop or withdraw from any audio or visual recording at any time without any penalty or negative consequences.

I understand that my participation involves:

Agreeing to have the history of my relationship with the researcher specific to the research question described as part of the research data analysis and included in the research thesis.

_____ Agreeing that you are NOT participating in this research out of an obligation to the researcher.

_____ Agreeing that you are participating in this research out of your own will.

_____ Agreeing that your choice to participate will not negatively impact your relationship to the researcher in the future.

_____ Agreeing to have my relationship (coworker, family, friend) with the researcher specific to the research question described as part of the research data analysis and included in the research thesis.

_____ The researcher having no relationship of power or authority with me.

_____ Voluntarily agreeing to participate in this research without feeling any obligation to the researcher.

_____ Understanding that my choice to participate or decline to participate will not negatively impact my relationship to the researcher in the future.

You are entitled to review the description of the researcher's relationship with you specific to the research question. You have the right to withdraw your consent for this description to be included in the researcher's thesis without any penalty or negative consequences.

Are there any risks, stress or discomforts that I will experience as a result of being a participant in this study?

Taking part in this research involves certain risks: This topic can be sensitive for some people you may find that discussing it reminds you of painful or stressful situations that may cause you psychological distress.

Will being a participant in this study benefit me in any way?

We cannot promise any benefits to you or others from your participation in this research however possible benefits to participating may include, the satisfaction of helping to learn more about the grief of people who are related or support those with significant substance use. It may be that the chance to talk about your experiences in a safe atmosphere will also be experienced positively.

Other possible benefits may include validation for your experience, a non-judgmental and confidential space for sharing experience. Some people who participate in studies such as these sometimes find that it is satisfying and meaningful to contribute to further learning that might benefit others in a similar situation

You will not receive any payment for participation in this study.

Confidentiality

I understand that participation is confidential to the limits of applicable privacy laws. No one except the faculty researcher or student researcher, his/her supervisor and Program Coordinator (or Program Director) will be allowed to view any information or data collected whether by questionnaire, interview and/or other means.

If the student researcher's cooperating classroom teacher will also have access to raw data, the following box will be initialed by the researcher.

I understand I have the right to review the researcher's thesis prior to submission to City University of Seattle for approval, and that I have the right to withdraw the description of my relationship with the researcher without any penalty or negative consequences.

Steps will be taken to protect your identity, however, information collected about you can never be 100% secure. Your relationship with the researcher and the description of your relationship with the researcher could mean that your identity can be disclosed. The results of this study will

be published as a thesis and potentially published in an academic book or journal, or presented at an academic conference.

All data (the questionnaires, audio/video tapes, typed records of the interview, interview notes, informed consent forms, computer discs, any backup of computer discs and any other storage devices) are kept locked and computer files will be encrypted and password protected by the researcher. The research data will be stored for five years (5 years). At the end of that time all data of whatever nature will be permanently destroyed. The published results of the study will contain data from which no individual participant can be identified.

Signatures

I have carefully reviewed and understand this consent form. I understand the description of the research protocol and consent process provided to me by the researcher. My signature on this form indicates that I understand to my satisfaction the information provided to me about my participation in this research project. My signature also indicates that I have been apprised of the potential risks involved in my participation. Lastly, my signature indicates that I agree to participate as a research subject.

My consent to participate does not waive my legal rights nor release the researchers, sponsors, and/or City University of Seattle from their legal and professional responsibilities with respect to this research. I understand I am free to withdraw from this research study at any time. I further understand that I may ask for clarification or new information throughout my participation at any time during this research.

I have been advised that I may request a copy of the final research study report. Should I request a copy, I understand that I will be asked to pay the costs of photocopy and mailing.

Participant's Name:

Please Print

Participant's Signature: _____ Date: _____

Researcher's Name:

Please Print

Researcher's Signature: _____ Date: _____

If I have any questions about this research, I have been advised to contact the researcher and/or his/her supervisor, as listed on page one of this consent form.

Should I have any concerns about the way I have been treated or think that I have been harmed as a research participant, I may contact the following individual(s):

Andre Serzisko,

Program Director, City University of Seattle in Canada

Address: 877 Goldstream Ave #305, Victoria, BC, V9B 2X8

Phone: 250-213-2353

This study has been reviewed and has been approved by the Institutional Review Board (IRB) of City University of Seattle. If you have questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the IRB at IRB@Cityu.edu.

Appendix C – Research Invitation Facebook Poster

Research Study:

Disenfranchised grief in response to supporting loved ones through significant substance use challenges

I am a Masters of Counselling student working on my research for my thesis that hopes to illuminate the experiences of loved ones who are supporting their loved one through significant substance use challenges. .

We often talk about stigma around addictions in our society but do not talk much about how this stigma impacts the family members/loved ones of those struggling with significant substance use challenges.

The focus of my study is to explore the experiences of loved ones who are supporting someone through significant substance use challenges and explore how that grief might become disenfranchised due to social stigma:

Research suggests we grieve the loss of the living when we are dealing with:

- ongoing uncertainty that causes emotional exhaustion,
- shattering of assumptions how the world should be and,
- experience a lack of validation of the significance of these losses (Harris & Winokuer, 2016)

Disenfranchised grief is defined as grief process that is:

- not recognized or validated socially
- minimized due to shame or stigma or even considered invalid.

Furthermore, the grieving individual may become isolated as certain aspects of the loss are considered embarrassing, or unacceptable.

If you relate to the experience mentioned above or know someone who may and would like to share more of your experience for this research please contact: palshweta@cityuniversity.edu

Appendix D: Research Email Invitation

Email Invitation:

Subject: Invitation to participate in a research project on “Disenfranchised grief in response to supporting someone through significant substance use challenges”

Dear Prospective Participant,

My name is Shweta Pal and I am a Master’s of Counselling Student at City University of Seattle University. I am working on a research project under the supervision of Professor Andre Serzisko.

I am writing to you today to invite you to participate in a study entitled “Disenfranchised grief in response to supporting someone through substance use challenges”

The purpose of the study is to explore the experiences of loved ones who are supporting someone through significant substance use and explore how that grief might become disenfranchised due to social stigma.

This study involves one 45 - 120 minute interview that will take place in a mutually convenient, safe location. With your consent, interviews will be audio-recorded on a data voice recorded and backed up on an encrypted USB drive. The recording will be stored for 5 years and then destroyed.

While research often has potential risks, such as revealing personal information and discussion of sensitive material that could cause distress, care will be taken to minimize these risks. This will be done by keeping all responses anonymous and allowing you to request that certain responses not be included in the final project.

Should you feel distress of any kind you will have the right to end your participation in the study at any time. If you choose to withdraw, all the information you have provided will be destroyed.

There may also be benefits to participating, such as the satisfaction of helping to learn more about the grief of people who are related or support those with significant substance use challenges. It may be that the chance to talk about your experiences in a safe atmosphere will also be experienced positively.

All research data, including audio-recordings will be encrypted. Research data will only be accessible by the researcher and the research supervisor by request.

The ethics protocol for this project was reviewed by the Institutional Research Board and City University of Seattle in Canada, which provided clearance to carry out the research.
(Clearance expires on: October 1,2020.)

If you have any concerns with the study, please contact Andre Serzisko, (aserzisko@cityu.edu) or

If you would like to participate in this research project, or have any questions, please contact me at 250-885-2353 or palshweta@cityuniversity.edu

Sincerely,
Shweta Pal

Appendix E: Institutional Review Board Certificate of Approval**Institutional Review Board
Certificate of Approval****IRB ID# Pal_Serzisko120419**

Principal Investigator (if faculty research):
Student Researcher: Shweta Pal
Faculty Advisor: Andre Serzisko
Department: DASC

Title: Disenfranchised grief in response to supporting loved ones through significant substance use challenges

Approved on: December 4, 2019

- Full Board Review
- Expedited Review (US)
- Delegated Review (Can)
- Exempt (US)

CERTIFICATION

City University of Seattle has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The Faculty Advisor Andre Serzisko and the student researcher Shweta Pal have the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original Ethical Review Protocol submitted for ethics review.

This **Certificate of Approval** is valid provided there is no change in experimental protocol, consent process, or documents. Any significant changes to your proposed method, or your consent and recruitment procedures are required to be reported to the Chair of the Institutional Review Board in advance of its implementation.



Brian Guthrie Ph D, RSW, RCSW
Chair, IRB City University of Seattle