

Medical Assistance in Dying and its Impact on
Clergy Who Have Accompanied Patients Through the Procedure

by April E Hart

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Certificate of Ethical Acceptability for Research Involving Humans

This is to certify that the Research Ethics Board has examined the research proposal:

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and concludes that in all respects the proposed project meets appropriate standards of ethical acceptability and is in accordance with the Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans (TCPS 2) and Atlantic School of Theology's relevant policies.

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Dated this 3rd day of April, 2019 at Halifax, Nova Scotia.

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Abstract

“Medical Assistance in Dying and its Impact on
Clergy Who Have Accompanied Patients Through the Procedure”

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This Phenomenological Research study examines data revealed through the lens of clergy who have accompanied patients through Medical Assistance in Dying (MAiD) procedures. Through a series of one on one interviews, this study seeks to reveal the physical, mental, emotional, and spiritual impacts of said participation on those interviewed. Six clergy were interviewed – four of whom serve full-time in congregational ministry, one of whom serves full-time as an ecumenical hospital chaplain, and one of whom serves both in congregational ministry as well as in hospital and hospice chaplaincy. Though there were some differences revealed between the experiences of congregational-based clergy and those of hospital or hospice-based clergy, five main themes were revealed. First is that to be invited to walk with someone on their journey toward MAiD is an incredible *honour and privilege*. Second, critical to the clergy persons experience with a given patient were the primary reasons the patient had chosen MAiD; particularly, when it appeared a patient were choosing MAiD to *alleviate existential suffering*, the participants found the situation more difficult and questioned their roles in the procedure. Third, a great deal of *silence and secrecy* surrounds MAiD, so open dialogue on the subject is rare in our churches and the people who choose MAiD often do so in secrecy from their community, friends, and even family. Fourth, clergy tend to feel alone in their experiences, unable to debrief properly with a *trusted confidante*. Fifth, participants felt called to *advocacy work* on the subject of MAiD. The phenomenon of MAiD is so new, and the subject is so complicated, that this study only reveals the tip of the iceberg in terms of the wisdom that clergy can bring to discussions on the subject and to our evolving relationship with the procedure.

Introduction

More than three decades later I can still recall quite vividly my first experience of death. It was my paternal grandmother, dead at the age of 53, when I was just six years old. She and my grandfather lived next door to us, across a small field that became a vegetable garden every Spring. She had lost her battle with cancer, and so a couple of days after her death my dad and I walked across that garden field to her home, where she was being waked. I remember sitting on the kitchen counter next to the sink, while my dad chatted with his dad and his siblings, and I could see something unfamiliar jutting out around the corner of the wall, in the otherwise very familiar living room of my grandparents' home. After a while my dad lifted me down to the floor, took my hand, and walked me into the living room to see my grandmother, laid in a casket, as she was being waked in her home, according to local tradition at the time. I was aware that everyone grew silent as my dad walked me toward the place where my grandmother lay. I was aware of their eyes on me as I observed her there. I was aware I had been invited into this experience while my brother and sister stayed at home, deemed to young to participate.

I would not say I have an unusual interest in death, but rather a healthy interest. From the age of six on, I attended many wakes and many funerals, both for close family and for the family of friends and neighbours. Doing so represented an important value in my family, as did sitting vigil at bedside when a loved one was dying, or making a casserole for a bereaved neighbour after they had experienced the death of a loved one. That value is one in which I am well steeped, and it is likely why the work of helping

people navigate death – their own or that of a loved one – is one of my greatest passions in ministry and likely at the root of how I wound up doing this research.

About two years ago I enrolled in a Clinical Pastoral Education (CPE) unit with the Nova Scotia Health Authority. For eight months I worked two days each week as a student chaplain on the Stroke and Neurology unit at the Halifax Infirmary. Part of the CPE program included weekly didactics on various topics relative to chaplaincy work. One of the weeks, the topic was Medical Assistance in Dying – commonly known by its acronym MAiD – and I will use the term MAiD frequently throughout this paper. During that didactic on MAiD the facilitator referenced a statistic that caught my attention. She said – and I am paraphrasing – that a recent study had shown that the maximum number of MAiD procedures in which a medical professional could healthily participate was about six per year, beyond which the physical, mental, emotional and spiritual impacts of participation become detrimental to the person’s well-being. Unfortunately, though I have heard it referenced elsewhere since, I have not been able to locate the source of that statistic or the study she was referring to, so I cannot speak to its reliability. However, it is not specifically the number six that was ultimately of interest to me, but rather just that notion that participation in MAiD would have a significant impact on those accompanying the patient through the procedure. What, I wondered, would be that impact?

Relevance of the Research Question

What you may have commonly heard called euthanasia or assisted suicide in the past, formally became Medical Assistance in Dying (MAiD) in this country on May 30, 2016 when the Canadian government passed Bill C-14, legislation that decriminalized medical assistance in dying for specific members of the population that qualified under this new exemption from the law. In order for the set of qualifications for MAiD to be met, a patient must undergo a thorough medical review that assesses both the nature of their physical illness and their state of mind in terms of their capacity to make an appropriate, informed decision on the matter.¹ For those deemed qualified for the procedure, two types of MAiD are available. The first involves, “the direct administering of a medication into a patient’s body by a medical professional,”² and the second is, “the provision of medication by a medical professional to an eligible person for purposes of enabling that person to cause their own death by self-administration.”³ Though there is a difference in procedure for the two methods, the results are the same in each case – that the provision of prescription medication along with the withdrawal of life-sustaining treatments causes the patients’ death for purposes of relieving suffering.

An understanding of life and death is central to the doctrine of most, if not all, of the worlds’ major faith traditions. Ideas about the sanctity of life and questions about the experience of – and the experience after – death are some of what human being wrestle with most on their journeys to understand their very purpose for living. It is not surprising then that the

¹ Nazila Isgandarova, “Physician-Assisted Suicide and Other Forms of Euthanasia in Islamic Spiritual Care,” *Journal of Pastoral Care & Counselling* 69, no. 4 (December 2015): 217.

² Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 142-143.

³ Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 143.

legalization of medical assistance in dying would be the source of great debate for the general public, and specifically for people of faith and the clergy that support them. As one of my participants named in their interview, MAiD is this idea, this procedure, this phenomenon about which nearly everyone has an opinion, to which nearly everyone has some reasonably strong emotional response, but of which very few of us have any first-hand experience. Among those with that first-hand experience are many clergy, however, because formalized MAiD is so new, there is little to no research out there on this subject of just how participation in the experience might impact those clergy persons who accompany patients up to and through the procedure.

Shortly before MAiD was legalized in Canada I attended The 2016 Hayes Symposium titled “Living Through Death: Dying, Death, and Bereavement” at the Atlantic School of Theology. The event sparked significant debate among clergy representing various faith traditions about not only the appropriateness of this legislation, but also about the role and responsibility of clergy with regard to MAiD, including how they might respond to a member of their faith community if asked to accompany them through a MAiD procedure. The discussions were heated – not just between folks, but within individuals. For many clergy, MAiD causes some very important values to rub up against one another, and as such the choice to participate is significant and carries many potential consequences. However, despite MAiD being legal in other countries for several years, there is no research available that speaks directly to the experience of clergy who have accompanied congregants in MAiD procedures.

Methodology

This phenomenological research study is an examination of data revealed through the lens of clergy who have accompanied patients through Medical Assistance in Dying (MAiD) procedures. Through a series of interviews, this study seeks to reveal the physical, mental, emotional, and spiritual impacts of said participation on those interviewed. I have chosen phenomenology as my research method for this study because it focuses on the individual experiences of those being interviewed, teasing out specifically “what” they experienced and “how” they experienced it.

I conducted six interviews. Those interviewed included clergy from across Canada. Participants were identified through numerous sources; an ad was posted in a private Facebook group for clergy from the United Church of Canada, and an email was sent out to all clergy I know personally through the Atlantic School of Theology and otherwise, with encouragement for recipients to share the ad with their own clergy contacts. Several clergy identified themselves as willing to participate and others received a specific invitation to participate after having been identified by a friend or colleague as someone who might be qualified to participate.

Upon indicating a willingness to participate, a time and place for the interview was arranged, and participants were informed they would be asked to sign a letter of informed consent before beginning, guaranteeing their freedom to withdraw from the study at any time. Before the interview began, I shared with each participant the background for the study, answering any questions they had. Then they were asked to sign the consent form and informed that should they become distressed in any way during the interview, they could stop immediately and be provided with a referral to a helping professional.

Participants were also informed that should they choose to withdraw from the study at any point the recording of their interview and any transcripts thereof would be deleted.

Interviews were set-up with six participants. Interviews took place over a two-week period, five of which were conducted by telephone or video messaging, and one of which was conducted in person.

End-of-life care can be an intense and difficult experience for anyone involved, and because this research asks participants to reflect-on and relive experiences that may be accompanied by intense emotion, sensitivity to this reality was top-of-mind throughout the interviews, in processing the data, and during the presentation of the research. Should I, as a researcher, have discerned that pastoral intervention might have been helpful to a participant, I was prepared to offer to them the name of a skilled pastoral care provider with whom they could follow-up.

The intention is that this study might benefit clergy, faith communities, and persons considering choosing MAiD. Learning about the impact of participation in such procedures could be an important factor in a patients' choice to pursue MAiD, or in the expectations of clergy as it relates to frequency of participation in such procedures and/or appropriate care required for managing the effects of this work.

Data Analysis & Themes

Over a two month period I interviewed six clergy, four of whom work in congregational ministry, one in hospital chaplaincy, and one who works both in a congregation and a hospital/hospice context. In the following report I will almost exclusively refer to these clergy as my participants, but I will also occasionally use the terms clergy or pastor. And, though it is not typically how clergy would refer to someone with whom they are in a pastoral relationship, for purposes of clarity throughout this report, I will refer to the person intending to have MAiD as the “patient”. What follows is entirely the product of those six interviews.

What the research has highlighted quite clearly is that this subject is complicated. One of my participants even began his interview with those exact two words, “It’s complicated!” In fact, every one of my participants used that phrase at least once – and in most cases several times – as they described their experiences with MAiD. It seems that for every insight into their experience that one or all of my participants named, a competing, contradictory, or down-right opposite insight is also true.

An Honour & Privilege

This first theme is one that permeated every interview I conducted and was top-of-mind for my participants. All of my participants agreed that first and foremost, the invitation to accompany someone on their journey toward MAiD is a profound honour and privilege. One of my participants said, “It certainly is, and has always been, for me, a privilege and an honour to be able to accompany folks during that part of their journey. And it certainly has been filled with moments of great sorrow, but more than sorrow, certainly lots of great joy and privilege. It has enhanced, for me, the experience of the

Holy, and of course every time I encounter something that sacred and Holy it impacts my being.”

Another said, “I felt in some ways it was affirming for me that she wanted me to be a part of that conversation, part of that journey, that they were not only willing, but desired for me to be on that journey with them. I guess it gave me personal affirmation that I was doing the best I could for them in this obviously trying time.” Another said, “I had a sense of it being an honour, because there were very few people whom she had invited to be part of the inner circle.” And yet another participant said, “It was probably the greatest gift of ministry that I have ever had. I fell completely in love with her as we spent a couple of hours together every week for about six or eight months as she was dying.”

This sense of honour and privilege was abundant for my participants; to be invited into these most vulnerable moments of someone’s life, to be present to the most intimate of conversations, is a deeply humbling experience. One of my participants described it as, “one of the most powerfully spiritual experiences [of her life].”

But this feeling of honour and privilege was not necessarily an absolute for my participants. Several of them talked about how they imagined they had been rather lucky in terms of the cases they had been asked to be part of. They talked about how, to some degree, age and circumstance mattered. One participant described how in the two cases of MAiD in which she had taken part, one of the patients was 88 and the other was 101, and both felt they had been blessed with good, long lives; she admitted she might feel differently about the whole thing were the patient a very young person. It is not to say that to accompany a young person on a journey toward MAiD wouldn’t be an honour,

but rather that that sense of honour and privilege might not have been their most forward response to the experience. And age was not the only factor that my participants felt might change their experience. While one of my participants said, “The amazing thing about accompanying someone who’s made the decision for medical assistance in dying is that they are really open – or at least the people that I’ve worked with have been really open – to really reflecting on their spirituality. And the conversations with their families have been deep and honest, and I’ve been fortunate enough to be invited to be part of those.”

The Reasons Matter

While one said the above, there was also a deep sense among my participants that the experience might be very different with a patient who was unable, unwilling, or uninterested in doing that spiritual work and having those deep conversations as part of their decision to undergo MAiD. One of my participants told me a story about a case in which he had accompanied someone up to the point of MAiD, but just before the procedure took place, the patient died “naturally.” He reflected, “In that particular case I was concerned about the motive. It’s kind of a funny thing. The request was adequate. The person had no hope of recovery. And they died before the procedure could be done so you knew there was no hope because end-of-life was right there. So in all the textbook ways it was okay, but what burned at me a little bit was knowing the individual and that they were concerned about burdening family, and things like that. There’s no rule that can help with something so subjective, there’s no safeguard that can deal with that. And would a safeguard even be proper? Everything they said technically and objectively was going to happen. Death was going to come very quickly and she was in a lot of pain. But

if they were to understand her reasons for wanting to pass away, or her specific reason for wanting MAiD: to unburden family from having to come stay at the hospital and be away from their jobs, does it cloud it? You know what I mean? It made it more challenging.”

Later in the interview the participant returned to this story, adding, “I really was concerned the patient was worrying more about others than they were themselves. All the things they said were accurate but I felt that by being present perhaps I was in some way condoning their rationale for choosing MAiD. And I don’t think I was. They had all the objective reasons for it, but their subjective comments left me feeling like I was being complicit in something that I didn’t know should be happening in the way that it was. It’s a complicated feeling, I’ll say that.”

Another participant said, “I’ve experienced MAiD when it is done very well and seemed quite appropriate, when the person has been in excruciating and unremitting physical pain and suffering. And yet they have also repaired their life and been filled with gratitude and been very much good to go.” This participant would continue with a profound and explicit explanation of what was perhaps the primary concern or objection to MAiD revealed in this study; other participants eluded to the same concern but none expressed it quite so plainly. The participant said, “I’ve seen MAiD carried out prematurely to end the person’s existential suffering by ending their life instead of addressing their distress. I’ve seen it used as a medical procedure to treat a spiritual condition.” And he continued, “The vast, vast majority of requests for MAiD come because of existential issues, not because of physical suffering. And the system is so young, and the psychosocial spiritual resources are so thin on the ground that it is rare for an adequate assessment of spiritual and psychological things to be done. He notes that,

“There’s no in-depth assessment. There’s no in-depth unpacking of the existential distress that is driving the choice for MAiD.” The participant went on to explain, “It all boils down, usually, to 4 things: the patient who sees no purpose in their suffering, fears the anticipated future suffering as they die, the burden of sorrow upon their family and their desire to protect them from that, and a very utilitarian view of: What am I good for now? Nothing. I can’t work. I can’t play the role in my family. I’m not going to gain any pleasure or enjoyment from my life.” The participant wrapped up this thought, adding, “While not hedonistic, those four reasons do not constitute a deep dive into one’s self-awareness and place in this world. [The conversation the patient needs to have to unpack this stuff] would take months of counselling sessions, and [in a hospital setting] you have ten days, at best.”

It is complicated. It is an incredible honour and blessing to be invited to journey with someone through such an experience. Unless of course you find yourself questioning the integrity of the decision and the process and wrestling with your part in all of it. And finding trusted peers with whom you can do that wrestling is incredibly difficult, because there is still so much silence and stigma surrounding MAiD.

Silence & Secrecy

My participants told me that they accompanied folks through MAiD in secrecy from their congregations, their church councils, their family and friends, and in some cases even the patients’ own friends and family. And that secrecy meant my participants often found themselves in some challenging circumstances.

One participant described how she had been accompanying a member of her congregation toward MAiD for several months, and had been doing so without anyone else in the congregation knowing, only to find herself at the patient's home on the day of the procedure, face to face with a nurse, who was one of her parishioners, in fact, the co-chair of the church council. Neither knew the other was involved until that moment. And they never spoke about it after.

Another story describing unusual, awkward, and potentially shocking secrecy is this one, shared by another participant: "I guess it was complicated, too, because she only told one of her children up-front, and so part of my process, at her request, was that after she had passed away, I had to phone the other children, and get them over to the house, and read them a card she left me to read to them, [letting them know that she had died, and how]. Yeah, her sons were really mad, so it went into a lot of pastoral care."

Silence & Secrecy...& Isolation

The elements of silence and secrecy do not just complicate the interpersonal relationships of those involved or close to experiences of MAiD, but also mark the individual experiences of clergy, causing them, in many cases, to find themselves quite isolated by their experiences. One participant had this to say about her experience of isolation: "The first time, the woman who died didn't want the community of faith to know that she had died with MAiD. So that became a little difficult because the only person I could process my experience with was my husband. And also these are people I'd known and loved for a long time so I was emotional. It was difficult because I wasn't able to talk openly about it."

This challenge of feeling isolated in their experience and unable to talk about it was almost universal among my participants. One participant said, “So there’s all kinds of emotion that happens. Two years after I had journeyed with this woman I did a CPE unit and processed this a lot, because I hadn’t really talked about it otherwise. That was two years later and I was still processing so no doubt there was some deeper mental stuff that continued to work within.”

Another participant described how on one occasion, after the procedure had been completed, the medical staff all went off together to debrief their experience, while she was left alone. She said, “I definitely realised in that moment that this is a one man show. There’s nobody looking out for us. And I don’t mean that in a bitchy, whiny way. I mean that I learned in that experience that I have got to take care of myself. It’s not coming from anywhere else. And she continued, “And don’t get me wrong, I wouldn’t have chosen to go debrief [with them]. I wouldn’t have chosen that but it was just very stark in that moment – that for every system but ours there’s support systems in place to manage some of the personal stuff. But we don’t have that, so it really influenced me in understanding how important it is to take care of myself.” In considering the energy it required of her to participate in the event, this participant noted, “I took five working days off after that and anyone that even thought they were going to be able to begin to talk to me about that, well, I would just look at them.” The processing of her experience that the participant had done to that point allowed her to acknowledge the feelings of deep affection she had developed for the patient during their journey together. “I loved her. You know, we don’t talk about that in ministry very much. We talk about boundaries. Think about your most intimate pastoral relationship with someone and then multiply it

by 10. You can't [experience] that without falling in love, and I think that's what God asks of us." And further describing the intensity of her experience the participant said, "[After the death] you grieving hard because you helped make it happen. You walked into it with her. It's a completely different thing than walking through death with someone who hasn't chosen MAiD. It's completely different."

The secrecy and the stigma around MAiD can cause clergy to feel isolated and disable them from doing the important work of processing their own experiences around MAiD, and in some cases, my participants suggested, that stigma and secrecy probably prevented some patients from asking their pastor to accompany them – or at least stalled them in doing so. Several participants named that the patients they walked with often approach them first with timid questions meant to test the water, to see what their pastor thought about MAiD, before revealing their interest in the procedure. One participant told me, "The one person was very hesitant to talk to me about it in the beginning. She was afraid that I might have some concerns about her wanting this way of dying."

It was clear to my participants that if a patient summoned up the courage to ask their pastor to accompany them on their journey toward MAiD, it was because for that patient, having the companionship and blessing of someone representing their faith was critical to the comfort and confidence they would have in their decision to undergo MAiD. One participant said, "So for my lady, she had pancreatic cancer and was hanging on well beyond when she wanted to, but what was really important to her was that God not be mad at her, and that she wasn't disappointing Christ."

Questions of faith and lived theology remain close to the surface for the participants, not only in their lives, but poignantly in those of their patients. Another

participant said, “When I'm explicitly wanted there, I am there representing the church, representing the embodiment of their faith in some way. I don't mean to put myself up above common people but to them I think I represented something. Their wishing and desiring for me to be part it acknowledged that they wanted to be good in their faith and they didn't want to be seen to be contrary or doing something that was opposed to their faith. And I think they really wanted to know that they were accepted and loved as they are, with the choices they were making, in the eyes of not just their church or their faith but also in the eyes of their church family...and my being present affirmed that for them.

Participants wrestled with who they were, as God's representatives within the MAiD event. As one participant observed, “You know, lots of people still think very much of that idea of clergy being an emissary to God, right? I mean, that's not a contemporary theology, but it is still true for many people in our churches. So, when they believe we are the only emissary to God that they have – that their only way of speaking directly to God is through us – then for us to be present transforms the experience for them, and makes it something not to fear.”

So there is stigma, secrecy, silence, still, all around the subject of MAiD. And yet every participant I interviewed spoke passionately about the need for advocacy around MAiD. They did not all agree on what they felt they needed to advocate for, but they all spoke to feeling compelled to speak out, given their experiences.

A Call to Advocacy

One participant, who lives in Ontario, said to me, “The other piece for me is around advocacy. Where I live hospitals are run by either the catholic public health or public health non-religious and the catholic health boards are having a huge debate about

whether or not they will allow this procedure to happen in their hospitals, and they've started that debate by saying that conversations about MAiD can't happen in their healthcare facilities." She went on to describe the very practical challenges these policies caused, "So the doctors are having to have conversations with patients about the option for MAiD in parking lots because they aren't allowed to have those conversations in the hospital building. The families have to bring the patient – who most often is in chronic pain or palliative care – out of the building – sometimes across the street – so they can have this conversation. And that just drives me batty. So I've had a few conversations around that advocacy piece." And she continued, clarifying, "[I agree] that the doctors should have the right to say they'll never do the procedure, but the system has to allow for the conversation, and for the patients to have access to the procedure."

On the subject of advocacy another participant said, "Does MAiD go far enough? I think that it needs to be opened up. Particularly I find it difficult that the patient has to be lucid and able to give consent – again – on the day of the procedure. There are instances where people reach the day of the MAiD procedure and their disease has been so debilitating that they're no longer able to really give a response and so the procedure is cancelled. And I think that is more damaging for families than going ahead with the procedure. Because then they have to not only watch their loved one die in a different sort of way – quite often being hopped up on drugs because the pain is so difficult that it can't be managed any other way – but also continuing in the knowledge that their loved one made this decision and now it's been denied. How can that be peaceful?"

And still, on the theme of advocacy, another participant said this, "I'm among those few that can be there, in the trenches, and I'm grateful that I can be. And that gives

me even more opportunity to speak up.” He continued, describing why he felt particularly qualified to do so, “I’m learning – as I have from every patient – more and more about the hardest moment of life and how people engage with it. I’m witnessing the most noble qualities of the soul, as well as how fear and lack of purpose can drive us to our end.” And then he explained why he felt compelled to speak out, saying, “ We live in a culture that has the highest rates of suicide of anywhere in the world. Depression, mental illness – the highest anywhere in the world. And with that comes death anxiety. So of course MAiD has developed here and I see it as the tip of the iceberg. And it calls me to participate in the conversation and not shrink back.” For this participant, translating his experience with MAiD into advocacy on the subject was something he saw as a critical part of his life’s work. He said, “I know that if I reach the end of my life and I haven’t spoken about this, I will regret it. But if I reach the end of my life and I can say, ‘Well, I spoke up and I tried,’ then that’ll be a peace in myself. And when I speak up, I think it’s important for it to be said, ‘I’m wrestling with this and I invite you to wrestle alongside me.’”

Wisdom

I set out last September to determine, through this research, what impact participation in MAiD has on clergy. What I learned is that we are just in the very beginning stages of figuring out how this phenomenon will play out for any of the people involved. The clergy I spoke with are pioneers in this work that they are doing, and as such they are literally figuring out how to do it as they go, trying to unpack and process their experiences along the way, and in that unpacking there are so many little nuggets of wisdom already emerging. So, to close, I want to share with you three quotes from my

participants that speak volumes to my original question about the impact that participation in MAiD has on clergy.

First, I will share with you a response from one of my participants to the question, “How has participation in MAiD procedures affected you in your work?” He said this, “Going through this MAiD process has opened up my eyes to the fact that everything we see and hear is very superficial until our convictions, our faith, our ethics, our sense of justice are tested. I don't think we can really know what someone else ultimately believes, in much the way we can't know ourselves until those times of trial, those times of being in the desert, and so when I look upon people in my congregation, and family and friends, I don't assume as much as I may have before. Many of us can say we have no fear of dying, for example, and we hear that a lot, and I think it's true that people believe that. But it's when we're faced with it that we take that conviction to another level. And so having gone through this experience I don't just presume [what I think I know is true]; I think that we need to wait until the time of trial comes and then be there – be compassionate and allow folks to come out with a different view or even a different understanding of their faith altogether.”

And in response to that same question another participant said, “Like most things in our profession, MAiD complicates our work and it simplifies our work. Theologically it's a very complicated concept and so for me there's a lot that surrounds the decision to participate – you know – faithfully. There's an awful lot of people trying to decide if a single person has the right, or the mental capacity. There's so many people deciding if someone's allowed to do this. And so anytime you participate in something like that you're making Christological decisions. So, I think it helps me understand how powerful

my job is and how powerless it is. And that's when I'm happiest in this job – when both of those things are true at once.”

And a little story that highlights the complexity of the clergy's role in MAiD, alongside the opportunity it offers for really thoughtful and beautiful ministry: One of my participants spoke throughout her interview about her experience walking through MAiD with a woman whose daughter could not whole-heartedly support her mother's decision to have medical assistance in dying. Mom and daughter were very close, and both were women of deep faith, and the daughter expressed her difficulty by saying, “My faith makes it impossible for me to condone this by my presence, and yet my faith also makes it impossible for me to abandon my mother on this part of her journey.” And so my participant arranged with the hospital to have a space made available adjacent to where the procedure would take place. And the patient – the mom – was set up in one room, along with some close friends, and the medical team, and the daughter was set-up in the room next door, and so while the preparation and procedure took place in one room, right next door, the daughter sat vigil for her mom, and prayed. And my participant went back and forth between the two rooms, throughout the morning, updating the daughter on what was happening, and bringing words of love from the daughter to her mom.

And my participant said this about that experience, “So I had this daughter who was a woman of deep faith. She disagreed that the procedure should be available, and yet she honoured her mom's decision with grace. And I tried to offer her grace in return, acknowledging how hard this was for her. And so on the day of the procedure there I was walking back and forth between those two rooms: the room where the daughter was sitting, in prayer, trying to be respectful of her mom, and say goodbye properly, and the room where this strong woman who'd made this decision was, and I felt that in my very

presence [in each of these rooms and in the walking back and forth] that I got to physically embody something that I spiritually believed in. And so for me the word that came to my mind over and over that day was sacrament – it was the making visible and physical of something invisible.”

Implications for Ministry

This project intended to explore the experiences of clergy who had accompanied patients through medical assistance in dying, for purposes of determining how participation in such an experience would impact the clergy person mentally, emotionally, and spiritually. Scripture tells us, “Naked I came from my mother’s womb, and naked I will return. The Lord gave and the Lord has taken away.” (Job 1: 21) Beliefs about the sanctity of life, and particularly beliefs about how life should end and who has the right to take life are of deep importance to people of faith, and even to secular society. Providing spiritual care at the end of life is a rich but often draining experience at the best of times. It is not unreasonable, then, to imagine that accompanying someone through an end-of-life experience via MAiD might be particularly challenging, forcing the clergy person to reconsider his or her most basic understanding of life at the same time as they are forced to reconsider their understanding of their call to service and care for the person desiring both your care and MAiD.

What was made obvious in the research is that the church has a great deal of work to do if it is to meet the needs of clergy as they relate to MAiD. There need to be safe spaces made available to discuss and debate one’s theology as it relates to the subject. Support systems need to be made available so that clergy are not forced to hold the weight of their experiences of MAiD on their own. Guides need to be created that help clergy and lay people consider the questions crucial to discernment on this subject; these guides need to include Biblical interpretation and cultural context for understanding the issue in contemporary society. Work needs doing to familiarize clergy with the medical procedure itself, so they know what to expect when entering the room for the procedure, both for their own preparatotion and for purposes of helping to prepare the patient and

their family and friends. To that end, information needs to be provided so that clergy have a basic understanding of the patients' rights with regard to the time immediately around the procedure; this includes practical information like how long the procedure will take, whether or not the room can be decorated, if the patient can have music playing or loved ones present, etc. Sample liturgies for the occasion would be helpful. Lists of local clergy willing to accompany patients in the case that an individual felt they needed to say no to the invitation, so that a referral could be made.

What was obvious from the study is that this issue is top-of-mind for many clergy, right now. There is a hunger and a curiosity for information on this subject. There is a clear sense that it is a critical issue for ministry personnel in the 21st century.

This issue is not going away and it is not going to get less complicated as future legislation looks at expanding the availability of MAiD beyond its current boundaries for who qualifies for the procedure. In a death denying and increasingly secular culture, clergy and churches will have to be increasingly prepared to navigate this issue with grace and courage. Clergy are already out there trying to do this work on their own, without supports; the church needs to act quickly to catch up not only for the sake of meeting an obvious obligation to its clergy by doing so, but also so that it can take a leadership role in these discussions as they continue to unfold, for no individual or body is better suited to helping the country discern their way to the future with this phenomenon than are clergy and the church.

Dedication

Finally, I want to offer a dedication of this piece of work that you have just read. I began this project purely as a researcher, but while doing this research I was asked by a friend to accompany her husband and their family as he sought out Medical Assistance in Dying. I hesitated a bit because I worried that doing so might make it difficult to be objective with this research. In the end I went with my heart, which was to walk with this family on this journey. And just like my participants described, being part of that experience was very much an honour and a privilege. And ultimately I do not think that having that experience unfairly skewed how I interpreted my data, but rather it did perhaps help illumine the material, and make it even richer. And so, I want to dedicate this project today to my friend Alan Murray, with great thanks for allowing me to be part of his journey.

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Appendix A: Letter of Informed Consent

I acknowledge that I have been given a description of the research project, “Medical Assistance in Dying and its Impact on Clergy Who Have Accompanied Patients Through the Procedure.” I am aware that my participation is strictly voluntary, and that I can end my participation in the project at any point in the process.

I am aware that my participation is confidential. An audio recording of the interview will be made, and field notes may be taken. This recording along with the transcript of the interview and all field notes will be destroyed following the completion of the research project. My name and any other personal identifiers will be changed in order to maintain confidentiality. This consent form will be stored separately from the research data in order to maintain confidentiality.

The Research Ethics Board of the Atlantic School of Theology have approved this project. Any ethical concerns about this project may be taken to this Research Ethics Board.

By signing below, I am consenting to participate in this research study.

Name

Date

Appendix B: Literature Review

The practice of taking one's own life has been historically frowned upon – and one might argue misunderstood – in our culture, regardless of the impetus behind the act. Those who completed suicide were often labelled selfish or cowardly, and the moral judgement placed upon them was so significant that the act was deemed illegal under the criminal code; I has only been 50 years since suicide attempted suicide was decriminalized in Canada, and this step – taken in 1972 – is seen by many as the first toward the legalization of physician assisted suicide for terminally ill patients.⁴

Commonly called euthanasia or assisted suicide, in 2016 the Canadian government passed legislation that decriminalized medical assistance in dying – formally, in this country, MAiD – for specific members of the population that qualified under the new exemption from the law. In order for the stringent set of qualifications for MAiD to be met, the patient must undergo a thorough medical review that assesses both the nature of their physical illness and their state of mind in terms of their capacity to make an appropriate, informed decision on the matter.⁵ For those deemed qualified for the procedure, two types of MAiD are available. The first involves, “the direct administering of a medication...by a medical professional that causes their death,”⁶ and the second, “the provision of medication by a medical profession for the purposes of enabling an eligible

⁴ Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 143.

⁵ Nazila Isgandarova, “Physician-Assisted Suicide and Other Forms of Euthanasia in Islamic Spiritual Care,” *Journal of Pastoral Care & Counselling* 69, no. 4 (December 2015): 217.

⁶ Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 142-143.

person to cause their own death by self-administration.”⁷ For some, the distinction between these two procedures is significant, such that the first procedure described above may be called “active” MAiD and the second circumstance described as “passive” MAiD.⁸ Although the results are the same in each case – that the provision of prescription medication along with the withdrawal of life-sustaining treatments causes the patients’ death for purposes of relieving suffering – participation in the act may be interpreted very differently as in the case of passive MAiD the physician simply removes the barrier to death for a patient, whereas with active MAiD the physician actually initiates the process that directly takes the patients’ life.⁹ While there is plenty of research available that defines the various terms and types of MAiD there is little said about the response of accompanying persons to the two types in terms of a preference to one or the other based on ethics, morality, or theology.

Woodland acknowledges that though the social and moral consequences of MAiD are significant, the reality of its legalization means that clergy are inevitably going to face the invitation, opportunity, or obligation to walk alongside a patient who pursues and ultimately chooses MAiD, helping the individual and their family to wade through the wide range of emotions and potential spiritual distress that will inevitably be part of the journey and the decision-making process.¹⁰ Whether the clergy person agrees with the patients’ decision or not, Woodland argues that they have a responsibility to understand

⁷ Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 143.

⁸ Nazila Isgandarova, “Physician-Assisted Suicide and Other Forms of Euthanasia in Islamic Spiritual Care,” *Journal of Pastoral Care & Counselling* 69, no. 4 (December 2015): 217.

⁹ Nazila Isgandarova, “Physician-Assisted Suicide and Other Forms of Euthanasia in Islamic Spiritual Care,” *Journal of Pastoral Care & Counselling* 69, no. 4 (December 2015): 217.

¹⁰ Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 143.

the context in which they will be ministering – including familiarity with MAiD terminology and procedures – and to show respect for the law and the patients’ right to engage in this lawful procedure.¹¹ Having said that, Woodland also acknowledges that in her vast research on the subject, it is abundantly clear that those pastors and healthcare providers that directly encounter MAiD find it both emotionally and spiritually disturbing, and the cause of a complicated web of emotions.¹² What Woodland does not comment on is how clergy might address said emotional and spiritual disturbance; she seems to suggest that the clergy responsibility to the patient always comes first. There is no discussion that I could find about the importance of clergy self-care or the possibility of emotional or spiritual burnout for clergy directly involved with MAiD procedures.

Other researchers acknowledge more readily the challenge for clergy whose work brings them face to face with MAiD. The clergy persons moral principles form the foundation for organizing their thoughts on end-of-life process. Primary to these principles for many clergy is a belief in the sanctity of life as a gift given to us by God and ultimately ended by God as well. Lay this belief alongside one that there is value in preserving the natural course of life and in accompanying one another through the process; that a good death is inherently part of a good life. And of course these two beliefs must exist alongside a commitment to caring for the suffering in one’s community – listening without judgement, offering empathy, genuinely desiring to understand the person’s thoughts and feelings, and accompanying them through the most difficult of life’s decisions in a way that genuinely cares for the whole person. The clergy persons

¹¹ Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 143.

¹² Gloria J. Woodland, “Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying,” *Direction* 47, no. 2 (Fall 2018): 145.

job is not easy in these situations, and yet research shows that clergy consistently prioritize pastoral care for the patient over whatever suffering they might endure as a result of conflicting moral beliefs on death and dying.¹³ What is difficult to locate is research depicting the results of this choice to prioritize pastoral care for others even when the choices of the other violate one's own values. Does that make the environment more stressful? Is sincere engagement with the patient more difficult? How does the clergy person process and reconcile these clashes between their beliefs and the patients' choices? Lack of answers to these questions highlights a significant gap in the research.

Richmond points out that popular discussion around MAiD frames the procedure first and foremost as an incredible gift of compassion for those who are ill and living with – or facing – unbearable suffering.¹⁴ The research coming out of places like Holland, the Netherlands and Oregon state, USA – all places where MAiD has been legal for more than a decade – indicate that very few patients ask for MAiD because of unbearable pain, but rather for fear of lost independence, dignity, or quality of life and the risk of being a burden to one's family.¹⁵ Richmond's argument is that though the public is being sold an image of MAiD that makes it look like the one and only compassionate response we can offer to folks facing unbearable physical pain and distress, the reality of the reasons most people indicate for wanting MAiD indicate a spiritual crisis rather than a physical one. To this end, he insists we must recognize the relevance of spirituality for those who are

¹³ Karen Mason, Esther Kim, W. Blake Martin and Rashad J. Gober, "The Moral Deliberations of 15 Clergy on Suicide and Assisted Death: A Qualitative Study," *Pastoral Psychology* 66, no. 3 (June 2017): 339.

¹⁴ David Richmond, "How Should Christians Respond to Proposals to Legalise Euthanasia and Assisted Suicide," *Stimulus* 21, no. 1 (April 2014): 21.

¹⁵ David Richmond, "How Should Christians Respond to Proposals to Legalise Euthanasia and Assisted Suicide," *Stimulus* 21, no. 1 (April 2014): 23.

facing end-of-life and prioritize meeting their spiritual needs alongside meeting their physical needs.¹⁶ There appears to be two schools of thought on this subject – one that argues clergy participation in MAiD is a required part of their job as pastoral care providers and thus personal feelings should be set aside in order to best care for the patient, and a second that argues that because of their moral or religious convictions clergy should abstain from involvement in MAiD altogether. What is missing seems to be some discussion about how to come to healthy decisions, considering cases individually, rather than just drawing a line in the sand that one either must or must not participate, regardless of the circumstances.

A study of the attitudes of clergy and lawyers toward euthanasia raises an interesting point not mentioned elsewhere in the research. The authors point out that both legal and ethical guidelines governing the way we approach end-of-life matters are becoming increasingly complicated as medical technology continues to develop, enabling what may seem like positive life-saving or life-improving procedures to lengthen life temporarily, but ultimately create more complicated circumstances later. This both indicates that end-of-life decisions are becoming increasingly difficult, and that as we live longer, having survived various illness previously in life, the need for assistance in death is likely to increase.¹⁷

Overall, the literature on this subject is surprisingly sparse, given how long MAiD procedures have been legally available in some parts of the world. In particular, I was

¹⁶ David Richmond, “How Should Christians Respond to Proposals to Legalise Euthanasia and Assisted Suicide,” *Stimulus* 21, no. 1 (April 2014): 28.

¹⁷ Caroline E. Preston and John Horton, “Attitudes among Clergy and Lawyers toward Euthanasia,” *The Journal of Pastoral Care* 26, no. 2 (June 1972): 108.

able to find only a single article that even considered the implications for clergy who participate in MAiD, beyond the most basic consideration of the competing values between one's morals around the sanctity of life and the desire to provide end-of-life care.

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Appendix C: Theological Framework

The reality of the decriminalization of Medical Assistance in Dying (MAiD) in Canada is that eventually we will each face the procedure on a personal level as either we or a loved one considers the option for our/themselves. Because Christians may struggle with conflicting values around the sanctity of life vs. a desire to walk with someone on their journey through illness and toward death, it is important that we consider the theological implications of MAiD for all those involved, including the patient, the patient's family, the medical team, and the pastoral care provider.

On the presence of God

A primary consideration for us as Christians is our call to be Christ-like – a call that inescapably asks us to practice deep compassion. In Luke's gospel Jesus encounters folks on the road to Emmaus and recognizes their confuses and distress. His pastoral response is to listen carefully to their most heartfelt thoughts and feelings, honouring their sense of loss with his deepest attention. As we endeavour to walk with folk experiencing similar feelings of disillusionment and fear of the unknown, we are called to follow Jesus' example – offering a non-anxious presence, listening deeply, and perhaps helping to guide them into new awareness of the presence of Christ that accompanies us always. This example of Jesus' care reminds us that pastoral care takes place in the midst of suffering, and likewise God is present to us and active in the midst of our trouble, not

apart from it. As Christians we need always to remember that God *is*; God *is* and so God's presence is constant and not contingent on the situation or circumstances.¹⁸

Resmer affirms the importance of getting clear about how we understand God to be at work in the face of suffering. God is not concerned with power and success and control as we understand them, nor is God most concerned with helping us avoid difficulty or removing us from it when it arises. God is most concerned with being present to us in the places we least expect but most need God's presence.¹⁹

On Suffering

Lee argues that the problem of suffering and pain is one that most confuses and challenges people of faith in contemporary culture.²⁰ For many Christians, our embedded theology tells us that our struggles are a means of being tested or a means of being exercised by God into closer relationship with God. These are easy beliefs to live with in the comfort and safety of our Sunday school classrooms where they are taught, but much less understandable in the places of real life. We eventually encounter suffering that just feels wrong: good people who do not seem to deserve to suffer as brutally nor as long as their illness has them do, children living with debilitating illness, and innocent people murdered in gruesome circumstances. Do these people endure their suffering so God might shape their characters? If so, how could we not argue this God is abusive? Is that a God we love or a God we fear? And for how long will we remain faithful to this God?

¹⁸ Gloria J. Woodland, "Ministry amid Competing Values: Pastoral Care and Medical Assistance in Dying," *Direction* 47, no. 2 (Fall 2018): 149.

¹⁹ Adele Stiles Resmer, "Physician-Assisted Suicide: What Is the Pastoral Task?" *Word & World* 16, no. 1 (Winter 1996): 35.

²⁰ HyoJu Lee, "Pastoral Theology in Response to the Problem of Suffering and Pain," *한국기독교신학논총* 109 (2018): 265.

For some, this understanding of God is acceptable. For others this God behaves in a way that is incongruent to most of the rest of what we have been taught is “good.” At that realization one either stops believing or begins to reconsider their theology, applying what they have been taught about God to what they have experienced about God, and reshaping or replacing much of that embedded theology with what Lee calls “deliberative” theology – theology we develop out of our deliberations about faith and life as we experience them for ourselves.²¹ Encounters with circumstances that may lead to MAiD are precisely the kind of life events that cause us to question our embedded theologies and discern new ones. A considerable opportunity and responsibility exists for clergy in these spaces; as spiritual guides we can recognize those occasions when a person’s embedded theologies may bump up against life circumstances that may lead to disillusionment and help folks span that gap through exploration of their faith, rather than see them abandon their faith instead.²²

Underwood points out that as clergy we must approach issues of pain and suffering carefully, giving voice to both a theology of the cross and a theology of the resurrection. Focusing too much on the cross and suffering may needlessly pressure a patient to hide their true feelings behind a veneer of stoicism and inhibit the person’s ability to feel hopeful. Ignoring pain and suffering in favour of a focus on resurrection, however, may steer the patient away from confronting the very real possibility of death, any meaning that might be gleaned from the suffering, and could even leave the patient

²¹ HyoJu Lee, “Pastoral Theology in Response to the Problem of Suffering and Pain,” *한국기독교신학논총* 109 (2018): 269.

²² HyoJu Lee, “Pastoral Theology in Response to the Problem of Suffering and Pain,” *한국기독교신학논총* 109 (2018): 269.

feeling inappropriately optimistic.²³ Lewis, who suffered considerably through treatment for cancer agrees with the importance of holding both of the theology of the cross and that of the resurrection alongside one another. He writes that, “the complex, multiple meaning of the story [of salvation] will only emerge as we hold in tension what the cross says on its own, what the resurrection says on its own, and what each of them says when interpreted in the light of the other.”²⁴

Resmer explains the theology of the cross as follows. Since as Christians we believe Jesus to be the incarnation of God, it follows then that it is God, Godself who is ultimately put to death on the cross. In that experience God is intimately exposed to the pain, hopelessness, and mortality that are inevitably part of every Christian’s life as humans. God does not seek to save us from all such experiences or even to deny the very real challenge of these experiences, but rather God seeks to accompany us through them. Understanding God’s participation in our lives like this invites us to be more thoughtful about our own experiences of suffering and hopelessness; we consider these things and discover God is with us throughout. Besides assuring us that we are never alone in our struggles, the belief that God is with us always allows us to be more hopeful in the face of our own challenges. This hope is not one that our experience will miraculously change to a positive one, or that our pain will somehow be less, but rather it is hope in the promise that a new day will surely come.²⁵

²³ Ralph L. Underwood, “Hope in the Face of Chronic Pain and Mortality,” *Pastoral Psychology* 58, no. 5-6 (December 2009): 657.

²⁴ Alan E. Lewis, *Between the Cross and Resurrection: A Theology of Holy Saturday* (Grand Rapids: Eerdmans, 2003), 33.

²⁵ Adele Stiles Resmer, “Physician-Assisted Suicide: What Is the Pastoral Task?” *Word & World* 16, no. 1 (Winter 1996): 36.

On Spiritual Pain

Cicely Saunders – founder of the hospice movement in 1967 – was a medical professional who recognized that, “not all pain has a physical source,” but rather “total pain” always includes a spiritual dimension.²⁶ She identified an inability to find meaning in life, a sense of injustice in the circumstance faced by the patient, and a feeling of being forgotten by God as the primary sources for spiritual distress and the pain that accompanies it. Although this pain cannot be treated with pharmaceuticals, Saunders believed it still required acknowledgement and management – both often best achieved in the practice of spiritual or religious ritual.²⁷

On Death

The Christian church touts a fundamental understanding of death as a new beginning, based on a belief that in our very creation God intended our life in a physical body to be temporary – part of an ultimate journey to eternity in a new life with the Divine. Though we were created for eternal life, the very intention of our birth was corrupted by original sin, and thus we now face suffering and death as part of our experience of life on earth. While death may seem mysterious and frightening to our mortal selves, the expectation of the faithful is that we trust God whole-heartedly and view death as an ultimate destination for peace, perhaps even going so far as to long for the day when we die to this world and go on to eternity with Christ.²⁸ Jesus’ death on the

²⁶ Tara Flanagan Tracy, “Hospice Care and a Theology for Patients at the End of Life,” *Dialog* 53, no. 3 (Fall 2014): 262.

²⁷ Tara Flanagan Tracy, “Hospice Care and a Theology for Patients at the End of Life,” *Dialog* 53, no. 3 (Fall 2014): 262.

²⁸ “What the Church says about death,” accessed 20 November 2019, <https://www.artofdyingwell.org/what-is-dying-well/a-good-catholic-death/church-says-death/>.

cross tells us that death of our mortal selves can be conquered in favour of an eternal life to which our spirits rise and dwell forever. Our task as Christians is to prepare for death by praying, confessing our sins, and being love in the world.²⁹ “I am the resurrection and the life. Those who believe in me, even though they die, will live, and everyone who lives and believes in me will never die.” (John 11: 25-26)

Shutte agrees that one of our great challenges with death is its mystery, and he says this has been a challenge to society throughout history. There is plenty of evidence showing that people have always wrestled with death’s uncertainty, viewing it as a question needing answering or a problem needing solving. All societies – regardless of culture or religion – have created and used ritual as a means of trying to understand and cope with death.³⁰ Our view of what happens at the time of death really depends on how we view our humanity. If one understands a human being to be primarily the collection of cells that makes up our bodies, then death is that time when these particles cease to be able to function together in a coherent fashion, and one would logically desire to put off the occasion of death as long as possible. Christians, however, understand human beings to be made in the image of God. We are not only body, but also spirit. We are not God, but the spirit of God dwells within us, and is eternal. And so for Christians, death is merely the time when the body separates from the spirit. The body, which is mortal, is destroyed, and the spirit, which is of God, lives on for eternity.³¹

²⁹ “What the Church says about death,” accessed 20 November 2019, <https://www.artofdyingwell.org/what-is-dying-well/a-good-catholic-death/church-says-death/>.

³⁰ Augustine Shutte, “Euthenasia and the Theology of Death,” *Journal of Theology for Southern Africa* 102 (November 1998): 62.

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Appendix D: Interview Questions

What is it like to accompany someone through the MAID experience?

How do you understand your role as a clergy person accompanying someone through MAID?

How has participation in MAID procedures affected you in your work?

Has participation in MAID affected your faith?

How has your understanding of MAID changed because of your participation in these procedures?

How has your participation in MAID affected you physically, mentally, and emotionally?

Is there anything else that you would like to add?