At the Threshold: Supporting Individuals Considering and Pursuing Medical Assistance in Dying (MAiD)

Andrea Patenaude

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Dr. Peter Hall, PhD, RP, CCC. Capstone Instructor, Master of Counselling Faculty

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Abstract

The recent scholarship on MAiD in Canada highlights the need for MAiD-specific psychosocial support for recipients and their supporters, yet there is limited guidance for counsellors wishing to fill that need. This capstone project addresses the question of how counselling professionals can best support individuals who are considering and choosing to pursue MAiD in Canada. Based on a narrative integrative approach to reviewing the academic literature, this capstone sought to understand the nature and phenomenology of the suffering that leads people to consider MAiD, to characterize the experiential elements of choosing MAiD and to identify possible approaches for the treatment of existential suffering that could be drawn upon or modified in devising psychotherapeutic interventions for this population. This work uniquely highlights the ways that MAiD experiences are qualitatively different than other end of life trajectories and proposes a four-phase model of client needs based on where they are in the MAiD process as well as recommendations for counselling responses. Practical and theoretical considerations for relieving existential distress highlight important features of possible treatment approaches and ways that existing evidence-based manualized treatments of Dignity Therapy and Meaning Centred Psychotherapy might be modified to explicitly incorporate MAiD content into their programs. Ethical considerations related to maintenance of dignity and autonomy, the need to emphasize limits to confidentiality, special risks to consider in obtaining informed consent and issues of maleficence related to counsellor competence and training are identified. The work concludes with recommendations to guide practice and for future research.

Acknowledgements

This capstone marks the culmination of a long course of study that would not have been possible without the dedicated support, patience, sacrifice and good humour of my husband, Gerald. His care and tending have literally carried me though this program and I am forever grateful. I am also deeply thankful for the generous understanding of my two sons who always made sure I was ‘interruptible” before entering my workspace and were willing to play ping pong when I took a break! It also feels important to acknowledge the patience, love and tending provided to me by mom, Joan and my sister, Janine, who made sure I took breaks and provided a listening ear for my challenges. I also want to acknowledge the patience and support of many friends who I am looking forward to seeing much more often now that I am done!

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My sincere gratitude to Bridge C-14, particularly Lauren Clark and Chelsea Peddle, who took me on as an intern to share in their pioneering work. Their generous sharing of spirit and expertise allowed me to apply what I have been learning through my counselling education and research for this capstone into the realm of supporting individuals pursuing MAiD. Bridge C-14 is working hard to fill considerable gaps in this area, and their leadership in this field is inspiring. I am also thankful to those courageous souls I encountered through Bridge C-14 who chose MAiD and have been so generous to include us in their journeys.

Dedication

This work is dedicated in memory of two courageous and wise souls. First, I dedicate this work to my dad, Albert Henry Joseph Patenaude, who raised me to follow my curiosity and use my gifts with the confidence that I was wholly loved and supported. Also, I dedicate this to my late aunt Eleanor Wieler, who so generously shared her life wisdom and the privilege of walking with her in her last days.

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Chapter One: Overview of the Topic

Medical Assistance in Dying (MAiD) is a process that allows eligible individuals to obtain the help of a medical practitioner to end their life. Legally available to Canadians since 2016, over 60,000 individuals have accessed this option, and the rate of provisions has grown steadily every year (Health Canada, 2024). In 2023, MAiD accounted for 4.7% of all deaths in Canada, representing an increase of 16% over the previous year (Health Canada, 2024).

Behind each of these statistics is a broad range of subjective experiences that are not captured by the numbers. Every person who pursues MAiD provides a living example of the complex ways that ethical, moral, relational and existential challenges interface when living with degenerative and terminal illnesses. Having the ability to choose the timing and circumstances of one's own death inevitability requires us to confront the limitations of human experience including death, freedom, isolation and meaning. How individuals engage with this possibility for themselves and with their loved ones reflects their relationship with their own mortality in ways that cannot always be appropriately honoured through the institutional processes surrounding MAiD. As more people consider MAiD, there are indications that needs are outpacing systemic readiness in several jurisdictions, increasing the likelihood that counselling professionals will encounter clients who are pursuing MAiD or who have been touched by a MAiD death (Oczkowski et al., 2021).

Given counsellors' privileged positions as witnesses to the inner and social worlds of their clients, they are favourably situated to be of service to individuals considering MAiD. Research focused on individuals living with terminal or degenerative disease has repeatedly

found that psychological, social, spiritual and existential factors are more significant contributors to suffering than physical factors, positioning counsellors as obvious sources of support (Blake & Blake, 2023; Kresdenter & Chochinov, 2020; Rattner, 2022; Saracino et al., 2019). Clients with advanced disease require accurate information about end-of-life options, decision making support, psychotherapy, and couple and family counselling as they consider ways to address their suffering and to bring peace to their final days. While MAiD across Canada is usually delivered by specialized teams that may or may not include social workers or counsellors, they may not be ideally situated or resourced to generate an in depth, phenomenological knowledge of a client's situation within systemic time constraints (Pesut et al., 2023). Fully reasoned decisions around MAiD take time. The circumstances and thought processes that lead clients to request assistance in dying likely start well before MAiD programs are contacted, and once clients have been deemed eligible or not, moving forward with the outcome places unique demands on the client and their support system. This indicates a role for counsellors beyond the scope of only the MAiD assessment and delivery process.

There is growing recognition that enhanced psychosocial and spiritual supports are necessary for individuals involved in MAiD, yet no specific interventions have been proposed for this population (Frolic et al., 2020; Henry et al., 2023). The scholarship on interventions to alleviate non-physical forms of suffering at end of life is considerable; however, the extent to which these meet the needs of individuals considering and choosing MAiD has not been addressed. The emerging literature reveals that the experiences of patients, caregivers, the bereaved and medical professionals involved in MAiD can be qualitatively different than other end of life experiences. As such, consideration of how counsellors might best support these clients is warranted. As an emerging clinician seeking to specialize in grief, loss and

end-of-life care, I am motivated to offer this capstone project on how counsellors can meet the unique needs of individuals considering and choosing MAiD. Ultimately, the aim is to enhance the level of psychosocial support available to individuals considering and choosing MAiD, offering them the best opportunity to make the most of their time.

Background on MAiD in Canada

In Canada, MAiD refers to two processes: physician-assisted suicide is when a patient orally self-administers a prescribed lethal medication; voluntary euthanasia is when a medical practitioner administers a lethal injection (Government of Canada, 2024). The legal framework for MAID in Canada is a complex interweaving of core provisions, established in federal legislation, operationalized through provincial and territorial healthcare legislation, policy and professional regulatory bodies (Buote et al., 2022). MAiD laws are established within the federal criminal code in the form of exemptions from prosecution for physicians and nurse practitioners who assist eligible individuals seeking voluntary euthanasia or assisted suicide (Government of Canada, 2024). Federal law also protects other practitioners such as social workers, psychologists, or psychiatrists from prosecution when they provide individuals with information about the lawful provision of MAiD (Government of Canada, 2024).

Eligibility

Eligibility criteria for accessing MAiD in Canada continue to evolve. The initial legislation, Bill C-14, restricted eligibility to individuals whose death was reasonably foreseeable because of a life-limiting medical condition (Buote et al., 2022). With the passing of Bill C-7 in 2021, eligibility expanded to include individuals with medical conditions whose death is not reasonably foreseeable (Buote et al., 2022). The legislation stipulates different safeguards to be in place depending on whether death is reasonably foreseeable or not. As such, individuals are

either designated to Track 1 when their disease is expected to lead to their death, or to Track 2 when their suffering is due to an illness that is not deemed terminal, for example, in the case of degenerative neurological conditions or other incurable diseases (Government of Canada, 2024). Currently in Canada, fewer than 5% of individuals accessing MAiD do so through Track 2 (Health Canada, 2024).

To be eligible for MAiD, individuals need to:

a) be at least 18 years old,

b) have the capacity to make decisions respecting their own health,

c) have a grievous and irremediable medical condition,

d) decide voluntarily and without undue pressure from others, and

e) give informed consent for MAID after having been told of all alternative means to reduce their suffering, including palliative care (Government of Canada, 2024).

Further elaboration on "grievous and irremediable" stipulates that individuals can access MAiD when they have a serious and incurable illness, disease, or disability, are in an advanced state of irreversible decline in capability and are experiencing intolerable suffering that cannot be relieved by means acceptable to the individual (Government of Canada, 2024).

Inclusion of MAiD for mental illness as a sole, underlying medical condition was initially scheduled for February 2024; however, legislators temporarily delayed that extension until March 17, 2027 to address concerns regarding system readiness, appropriate safeguarding and assessment (Government of Canda, 2024). Further eligibility extensions being considered by legislators include mature minors whose death is reasonably foreseeable, and advanced requests for individuals with incurable illnesses that will negatively affect capacity (Parliament of Canada, 2022).

Process

While the process to be deemed eligible is administered differently across jurisdictions, legislation stipulates that the written request for MAiD must be witnessed by an independent observer and that at least two assessments must be conducted by independent medical practitioners (Government of Canada, 2024). Assessors must ensure all criteria are met and that the individual is not subject to external pressure. In assessing the nature of the requesting individual's suffering, the law is clear that the determination of intolerability is a subjective evaluation on the part of the requester. Legally, MAiD assessors and providers must ensure clients are presented with alternative means of addressing their suffering before pursuing MAiD, including palliative care or access to counselling and mental health support, which the requester has the right to refuse. If the two assessors do not agree on eligibility or require additional expertise in making their determination, other experts can be consulted. For individuals applying for a Track 2 assessment, a key safeguard is the requirement that a minimum of 90 days must occur between the initial assessment and the day on which MAiD is provided, although exceptions can be made when there is a risk of capacity loss in the intervening period. Reporting on the timing of MAiD provisions suggests that individuals on Track 1 tend to receive MAiD soon after being deemed eligible, a median of 13 days in 2023 (Health Canada, 2024). For those on Track 2, the intervening period can be several months to over a year, although there is no data on the relative contribution of patient factors versus institutional procedural factors to longer intervals.

Once approved, the client can choose a date and location for the provision (Health Canada, 2024). Most provisions occur in private residences, hospitals and palliative care facilities; however, sometimes arrangements are made for MAiD to occur in other

community-based settings. On the day of the provision, final informed consent must be obtained unless a waiver of final consent has previously been signed to account for possible loss of capacity (Government of Canda, 2024). Loss of capacity to consent tends to be the most common reason for denial of eligibility. Not all MAiD requests result in a provision. Of the 19,660 requests for MAiD in 2023, 4.6% were denied due to ineligibility, and about 17.3% were either withdrawn or the individual died of other causes (Health Canada, 2024).

Mental Health Practitioners' Role in MAiD

While MAiD can only be legally provided by physicians and nurse practitioners, mental health professionals are increasingly recognized as vital in the process (Buote et al., 2022; Walker & Wong, 2018). In Canada, the legislative framework for MAiD contains several explicit and implicit references to certain roles for mental health practitioners in the MAiD process. First, psychologists, social workers and psychiatrists are explicitly mentioned as resources for individuals seeking information on the lawful provision of MAiD (Government of Canada, 2023). Second, when individuals whose death is not reasonably foreseeable are seeking MAiD (Track 2 applicants), assessors and providers must make sure the "person has been informed of the means available to relieve their suffering, including where appropriate, counselling services, mental health and disability support services and palliative care and has been offered consultations with relevant professionals who provide those services" (Criminal Code, 1985, s 3.1g). As such, counselling and mental health professionals are envisioned as resources for alleviating psychological suffering related to advanced illness and end of life. Third, while the legislation does not require mental health practitioners' involvement in eligibility assessment for MAiD, the involvement of psychologists as consultants to MAiD assessors in determining decisional capacity is clearly envisioned as it is addressed in guidelines

provided by regulating bodies of psychologists in some Canadian jurisdictions (Canadian Psychological Association, 2020; College of Alberta Psychologist, 2024; College of Health and Care Professionals of BC, 2017). Finally, as MAiD becomes more established and its expansion to individuals with mental illness as a sole underlying condition evolves, the role of mental health practitioners in MAiD is expected to expand. For example, mental health practitioners will necessarily be implicated in questions of irreversibility and treatability of mental illness, although exactly how that will be operationalized is in development (Buote et al., 2022). Despite these outlined possibilities, research shows that broader involvement of mental health practitioners with clients pursuing MAiD is hampered by ambiguity around roles, scope of practice, legal boundaries and lack of sufficient training in MAiD and end of life care (Buote et al., 2022; Walker & Wong, 2018).

The focus in this capstone project is primarily on the way counselling professionals (e.g. counsellors, psychotherapists and psychologists) can support individuals going through this process, rather than meeting legislated needs of the MAiD process itself. Counselling professionals possess a range of skills and expertise relevant to individuals considering their options and preparing for the future: exploration of values and beliefs, identification of alternatives, choosing and planning; knowledge of interventions and treatment options for various forms of psychological distress; skills in family counselling and bereavement support; the ability to consult and collaborate with other health care professionals to provide education and training in end-of-life care; conducting research to address critical research gaps; and policy development (Buote et al., 2022; CPA, 2020; Marina et al., 2021; Walker & Wong, 2018).

Regardless of the roles counselling professionals *could* play in the MAiD process, the law is clear that no professional is legally required to include MAiD in their practice. Indeed,

regulatory bodies for psychologists generally appear to support conscientious objection to MAiD (CAP, 2021; CPA, 2020). As such, it behooves mental health practitioners to reflect deeply on their personal values, moral stance and personal suitability to work with the MAiD population and to choose their level of involvement accordingly. Even so, as the population of MAiD recipients increases, it becomes increasingly likely that counsellors who are not explicitly involved in MAiD-related work will have clients who are considering, pursuing or otherwise affected by MAiD (Walker & Wong, 2018). As such, understanding the legal and ethical nuances of MAiD, the needs of individuals considering and choosing MAiD and their families, and means of treating psychological forms of suffering with this population will be essential for all mental health professionals (Koocher et al., 2023).

Purpose Statement

The purpose of this capstone project is to explore how counselling professionals can best support individuals who are considering and choosing to pursue MAiD in Canada. Based on the available literature, my focus is: a) to understand the nature and phenomenology of the suffering that leads people to consider MAiD; b) to uncover elements that may be considered singular to the MAiD experience relative to natural death; and c), to identify theoretical, practical and ethical considerations for counsellors working with individuals considering and choosing MAiD.

Research Question

The research question guiding this purposeful inquiry is: “What psychotherapeutic approaches and considerations can address the psychosocial needs of individuals considering and pursuing MAiD?”

Theoretical Framework

My overall framework is to use existential-humanistic theory to position my understanding of the nature of existential distress, one of the most common forms of suffering at end of life (Vehling & Kissane, 2018). Counselling approaches based on existential theories explicitly foster an individual's awareness of their own position and agency in the world. They assume that by overcoming existential distress, psychopathology may be reduced (Vos et al., 2015). Grounded in the rich tradition of European existential philosophers of the 19th century including Soren Kierkegaard, Friedrich Nietzsche, Martin Buber and Martin Heidegger, existential theory has developed into a variety of associated therapeutic approaches by practitioners such as Ludwig Binswanger, Rollo May, Viktor Frankl and Irvin Yalom, among others (Iacovou & Weixel-Dixon, 2015).

The existential-humanistic theory of psychology posits that much of human suffering arises from our own unique confrontation with four givens of human experience: death, freedom, isolation and meaninglessness (Yalom, 1980; Vos et al., 2014). All humans face the ultimate limitation of death, yet they have the freedom and capacity to choose how they encounter this and other limitations in life. While existential thinkers vary on the extent to which they consider meaninglessness to be inherent in the Universe, there is recognition that humans have a fundamental drive for meaning and purpose in their lives as well as the freedom to choose their own attitude towards their life and their suffering (Yalom, 1980; Bailey, 2022). Furthermore, while humans enter and leave this world alone, their experiencing of the world is fundamentally a relational experience (Yalom, 1980).

Between birth and death, human beings operate from one of two states of being (Mietkiewicz, 2020; Santa Maria, 2023). In the state of *forgetfulness of being*, humans engage

superficially with the world, consumed with trivial pursuits to distract us from the anxiety that comes from more profound reflections on the nature of existence. Inevitably, events such as the death of a loved one, a diagnosis, job loss, or a divorce, strip us of our false security and force us into a state Heidegger called *mindfulness of being*. In this state, individuals are drawn into a more reflective, questioning stance (Mietkiewicz, 2020; Santa Maria, 2023). The ability to face and engage with the struggle inherent in such boundary situations, rather than to avoid or deny, is what gives rise to the potential for healing and growth (Mietkiewicz, 2020). While all humans operate within the context of these givens, it is the phenomenological flow of subjective experience that is the essence of being, and hence the focus of therapeutic work (Vos et al., 2015).

While existential concerns can underlie human problems at any stage in life, in the context of end of life, existential distress engenders a distinct domain of concerns that might occur along other forms of distress or may be present even when physical pain is well-managed, social support is available and there are no other mental disorders present (Philipp et al., 2021). Expressions of existential distress in individuals with life-limiting conditions can take the forms of death anxiety, loss of dignity, demoralization, grief and regret, loneliness and a sense of loss of social significance, desire for hastened death, hopelessness, and fears of recurrence (Grossman et al., 2018; Philipp et al., 2021; Rosenfeld et al., 2014; Vehling & Kissane, 2018).

While the the ability to choose one's timeline for death adds a dimension of choice in terms of confronting existential suffering present at end of life, it is also important to recognize that engagement with existential themes is likely highly influenced by identity factors and cultural contexts including race, gender, socio-economic status (SES), ability and religion. Existential theory's origins in 19th century's Western philosophical traditions are

steeped in dualistic thinking and an emphasis on the individual that may not resonate with cultural worldviews that espouse more wholistic, relational or collectivist perspectives. Consideration of these influences will be incorporated throughout this capstone.

Methodology

My engagement with the literature followed a traditional narrative and integrative approach, drawing on a variety of academic disciplines and diverse research methods including qualitative, quantitative, and theoretical studies (Efrat & Ravid, 2019). The aim of this type of review is to consult a wide spectrum of literature on the topic and to synthesize it into a coherent account that highlights key themes, issues and complexities (Efron & Ravid, 2019). Given the limited psychological literature directly pertaining to counselling practice with the population of individuals considering and choosing MAiD, I also consulted journals in the fields of medical ethics, social work and palliative care to survey the state of knowledge on MAiD that may be relevant to counselling practice.

The initial literature search was conducted in the City University Library and Google Scholar search engines. The CityU databases searched included PSYCINFO, PSYCHARTICLES, PSYCBOOKS, and the Mental Health and Social Care Collection. Search terms used included combinations of the following: MAiD, euthanasia, death, dying, counselling, psychotherapy, existential distress, death anxiety, end-of-life care, palliative, cancer, desire for hastened death, culture and dying, meaning, meaning-centred psychotherapy, dignity, hopelessness, existential therapies, anticipatory grief, and Terror Management Theory. Peer-reviewed qualitative, quantitative and theoretical studies published in the last 10 years were all included. The titles and abstracts from the studies that appeared in search results were scanned, and those that were deemed useful in informing the primary research question were selected.

Among the quantitative studies, systemic reviews, randomized control studies and meta-analyses were prioritized. Among the qualitative studies, preference was given to studies in which the research subjects were pursuing MAiD in Canada; however, these were limited and so studies centering on caregivers or healthcare professionals were selectively included if they captured new and relevant perspectives or opposing viewpoints. Studies that did not appear to address the research question, or did so only peripherally, were excluded. All selected studies were read and notable thematic information and identified research gaps and recommendations were extracted from each study within topically related groupings. A further level of literature search was employed: the "Literature Cited" portions of highly relevant articles were searched for additional relevant studies or opposing viewpoints.

Finally, it is acknowledged that while my choice to use an integrative narrative methodology to guide this literature review supported a higher-level understanding of the main themes and methodologies guiding research in this area, there were limitations to this approach. For example, the lack of formal rigor, susceptibility to bias in study selection and challenges to replicability of a narrative integrative approach may have introduced more bias in my representation of the findings than had I chosen another method such as a systemic review or scoping review. As such, I attempted to minimize selection bias by seeking out discrepant findings or opposing viewpoints during my review.

While this section detailed the process I used to conduct my literature review, further information on how I engaged with the content of selected studies related to the research question and my chosen theoretical orientation is provided in Chapter 2.

Contribution to the Field

This project seeks to reduce obscurity around the role of counselling professionals in providing psychotherapeutic support to individuals considering MAiD, thereby contributing to enhanced availability and quality of care for this population and their families. Given limited extant training for counselling professionals whose clients may be touched by MAiD, this project might stimulate counsellors to reflect on their readiness and willingness for this work from an informed stance and provide a resource for enhancing counsellor preparedness and competence. Regardless of the regulating body to which a counselling professional might belong, competence is always a key factor in ethical practice in terms of minimizing the risk of harm to clients. While this project does not proport to replace comprehensive training, in the absence of such programs, it provides counsellors with a distilled survey of the literature to inform the parameters within which practice with this population might operate. This capstone can support counsellors in identifying when consultation or supervision is best sought. This work also highlights a number of important gaps in the research and policy arenas that may stimulate further work to improve knowledge and training resources for counsellors in providing quality care to MAiD clients.

In addition to providing a comprehensive resource that distills current literature, this capstone project builds upon the existing scholarship to provide original contributions to the literature. For example, two original contributions of this capstone include: a) highlighting the ways that MAiD experiences are qualitatively different than other end of life trajectories; and b) offering an original process-based model that identifies potential shifts in client needs according to where they are in their MAiD process as well as appropriate counselling responses.

It is important to emphasize that this project is not intended to address any role that mental health practitioners could play in formal assessment of clients for eligibility for MAiD under current or future criteria. Rather, this capstone emphasizes the role that counsellors can

play with respect to assisting clients with decision making around pursuing MAiD, assessing and treating emotional and relational issues related to engagement with the MAiD process, planning and preparing for end-of life, or re-engagement with living in cases where clients are deemed ineligible for MAiD. It is hoped that in considering client experiences and relevant psychotherapeutic approaches aside from the mainstream focus on the ethically complex domain of MAiD eligibility assessment, this project can address the reticence that some counselling professionals outside of medical and MAiD coordination teams might feel towards engaging with this population.

Reflexivity and Positionality Statement

I am approaching this research topic as an individual who has actively engaged in the topic of death and dying since the age of six years old when I discovered my own mortality through a storybook about pet death. This early discovery fostered a lifelong relationship with my own mortality that moved from early terror, to a growing curiosity that fueled spiritual explorations, to a strong sense of purpose as I felt called to witness others develop their own relationship to death and, ultimately, life. In this journey, I identify as subscribing to an ethic of death positivity, in which death is viewed as a non-medical, natural process which should be personal, de-institutionalized, and infused with recognition of its psychosocial and emotional dimensions (Incorvaia, 2022). This view informs my belief that how individuals engage with death reflects how they engage with life and drives my entry into the counselling profession with a view to specialize in loss, grief and end-of-life. Having worked as a hospice volunteer, I have gained an appreciation of some of the familial, ethical and systemic complexities that can emerge in navigating end of life and bereavement, and the value to the client of being witnessed in these experiences. To the extent that I will be able to pursue this aspiration as a counsellor, supporting

individuals in exploring how they want to engage with end-of-life aligns with my personal values of compassion, autonomy, dignity, and social justice. In stating my bias upfront, the ethic of autonomy calls me to respect where each person is at and is headed in their own journey without undue influence.

This capstone project is the culmination of several intersecting personal perspectives I have gained on the topic of MAiD. The unfolding story of MAiD in Canada is one I have followed closely since my father died one month before it became legal in June 2016. Having lived with an irremediable, degenerative condition for over a decade, my father had hoped to see it legalized in time to access it. Unfortunately, his rather undignified hospital death left me with a personal perspective of what MAiD has the potential to mitigate for those who choose it. More recently, I supported my aunt as she sought MAiD. I observed both the potential for institutional trauma around this process, and the profound offer of comfort and meaning available through MAiD when the right supports are in place. Finally, one of my internship sites for my Master of Counselling is with Bridge C-14, a national non-profit organization that provides support to individuals pursuing MAiD and their families. I hope this capstone project can inform and be informed by their work in highlighting gaps in the end-of-life care literature and systems.

MAiD is a complex topic. I am aware that my own positionality as a White, heterosexual, middle-class, educated, Canadian woman of European decent has also equipped me with privileges, beliefs and a worldview that may not be reflected in the ongoing discourse on MAiD in Canada and may bias my engagement with the literature. Even in my selection of existential-humanistic framework as a grounding theory, it is important that I remain mindful of its roots in Western philosophical traditions. I must remain open to recognizing that the relationship with mortality and primacy of autonomy at end of life within that framework may not align with

diverse worldviews. As a researcher and aspiring clinician, it behooves me to align myself with the ethical imperatives guiding research and clinical practice. With continual self-reflection, supervision, consultation, peer feedback and support, I hope to offer a meaningful contribution to the literature on providing psycho-social support to individuals considering and pursuing MAiD in Canada.

Brief Roadmap

The first chapter of this capstone project has provided an overview of the topic by outlining background information on MAiD in Canada, describing the roles of counselling professionals and articulating the purpose, theoretical orientation and personal positioning guiding this project. In the second chapter, I take a traditional narrative and integrative approach in reviewing the theoretical and empirical (qualitative and quantitative) literature on end of life care. I examine the nature of the suffering that leads individuals to choose MAiD, highlight unique aspects of MAiD experiences relative to natural death, and examine select interventions for treating existential suffering at end of life that can inform approaches to supporting individuals touched by MAiD. This leads into Chapter 3 in which I synthesize the information in terms of theoretical, practical and ethical considerations for counsellors working with individuals, both during the decision-making processes of choosing MAiD and after eligibility assessments have been conducted.

Definition of Terms

Death Anxiety: Death anxiety refers to the worry, fear and psychological stress that people experience in response to situations that elicit awareness of one's own mortality. Regarded as a normal human experience, it underpins the development and maintenance of many psychological issues and can increase in intensity in response to life-threatening situations (Eren et al., 2023).

Desire for Hastened Death (DHD): A construct from the palliative literature defined as the wish for a quicker death than would occur naturally arising in the context of suffering in individuals with a life-limiting medical illness or a degenerative disease (Rosenfeld et al., 2014).

Dignity: The inherent value that each individual possesses by virtue of being human, deeming each person worthy of respect, fairness and compassion regardless of their circumstances (Chochinov et al., 2002; Borges et al., 2024).

Dignity Therapy: A brief, individualized narrative psychotherapeutic intervention that involves guiding clients through a narrative life review process to reduce existential suffering and promote dignity, meaning and hope at end of life (Chochinov et al., 2002; Bluck, et al. 2020).

Existential Suffering: Existential suffering can be conceptualized as a distinct, painful psychological state that arises from situations that challenge fundamental assumptions about existence and force the realization that life has lost meaning (Gaignard et al., 2023; Vehling & Kissane, 2018).

MAiD: Medical Assistance in Dying (MAiD) is a legalized process that allows eligible individuals to obtain the help of a medical practitioner to end their life. In Canada, this can involve either euthanasia, in which the medical practitioner administers a lethal substance, or assisted suicide in which a patient self-administers a lethal substance in the presence of a medical practitioner.

Mental Health Practitioners: Professionals from various disciplinary backgrounds with a specialization in mental health including psychiatrists, psychologists, psychotherapists, social workers and counsellors.

Track 1: A category of procedural safeguard applicable for individuals requesting MAiD whose death is reasonably foreseeable because of a life-limiting medical condition. (Government of Canada, 2024). This category contains the vast majority of MAiD requests and provisions i.e. >95% (Health Canada, 2024).

Track 2: A category of procedural safeguard applicable to individuals requesting MAiD whose death is **not** reasonably foreseeable (Government of Canada, 2024). Fewer than 5% of MAiD provisions that occurred in 2023 were in this category (Health Canada, 2024).

Chapter Two: Literature Review

Approach to Inquiry

For this literature review, I took a traditional narrative and integrative approach to addressing the research question: "What psychotherapeutic approaches and considerations can address the psychosocial needs of individuals considering and pursuing MAiD?" As elaborated on in Chapter 1, existential theory is the theoretical framework I chose to guide my selection of relevant studies and topics. Existential-humanistic theory posits that much of human suffering arises from our own unique confrontation with concepts that psychotherapist Irvin Yalom identified as the four givens of human experience: death, freedom, isolation and meaninglessness (Yalom, 1980). With this framework in mind, I was guided to consider how MAiD shapes our engagement with the inevitability of death and the deaths of others, the essential freedom and responsibility that people have to shape their experiences, the unavoidable loneliness and isolation that people experience and the human need to find meaning in a life that is inherently meaningless. When investigating potential therapeutic approaches for working with populations considering MAiD, I selected those informed by existential concepts. Additionally, when selecting research studies to elaborate on, I looked primarily for outcome variables in the existential domain such as existential distress, death anxiety, dignity, meaninglessness, hopelessness and the desire for hastened death.

The Status of MAiD Research

MAiD legislation emphasizes that individuals define for themselves when suffering is intolerable; what individuals are willing to endure to alleviate suffering naturally implicates a phenomenological stance that honours subjective experience. We must understand the lived experiences of individuals who initiate MAiD because this understanding informs the nature and

effectiveness of our systemic and human responses to relieving suffering in those with intolerable suffering.

While the scholarship on MAiD in the psychological literature has steadily grown over the last decade, it is dominated by the perspectives of medical practitioners, caregivers and bereaved family members. The voices of those who are considering and choosing to pursue MAiD in Canada and elsewhere continue to be sparse. Where they are captured, demographic variables are commonly excluded, omitting valuable contextual information. Overall, my research detected a paucity of quantitative studies and only limited qualitative research focused on individuals who have chosen to pursue MAiD, particularly in Canada. In a 2023 scoping review of worldwide qualitative studies on what constitutes a "good" assisted death, only two of the 19 included articles interviewed individuals who were seeking this option rather that their physicians or bereaved family members (Martin et al., 2023). Another systematic review of quantitative studies, including a subset of nine studies with individuals seeking MAiD, found that poor social connectedness is not a clear risk factor for requesting MAiD (Cocoran et al., 2024). The only qualitative study found that included Canadians pursuing MAiD was a descriptive study with 23 clients recruited through a single clinic in Vancouver in the first year after MAiD became legal (Nuhn, 2018). Nuhn (2018) provides a first glimpse into the reasons people pursue MAiD and some of their preferences; however, the study was geographically and demographically limited. Nuhn (2018) did not include individuals seeking MAiD whose death was not reasonably foreseeable because eligibility for that condition only came into being in 2021. As such, there remains a need for more current, demographically and geographically diverse research on individuals pursuing MAiD in Canada.

There are a small number of studies originating from outside of Canada that use individuals who have chosen MAiD as their research subjects; however, design limitations narrow the generalizability of the findings. Most studies about end of life tend to focus on cancer populations, precluding the ability to generalize findings to individuals with other diseases. Furthermore, participant recruitment is almost always voluntary, leading to selection biases that impact the generalizability of the findings. Perhaps due to the challenges of recruiting large numbers of participants in the last few weeks of life for quantitative studies, there appears to be a greater reliance on qualitative research designs, highlighting possible tensions in the literature. Some lines of research on MAiD reveal a misalignment between quantitative versus qualitative approaches. Wibisono et al. (2022) reports that quantitative studies provide no strong evidence of an association between engagement in MAiD and negative mental health outcomes in medical practitioners, yet qualitative studies with this population consistently identify moral and related distress to be common (Gaignard et al., 2023; Pesut et al., 2021). This discrepancy highlights the importance of consulting multiple modes of inquiry when seeking to comprehensively examine a phenomenon such as the needs of individuals seeking MAiD. It further highlights where ethical tensions might lie and where there might be benefit to greater scholarly engagement with different perspectives.

Given the paucity of data that centres on the experiences of individuals choosing MAiD, I had to consult the literature on end-of-life care and living with advanced disease more generally. I also reviewed studies focused on family members, caregivers, medical professionals and the bereaved, as well as research from other countries where MAiD is legal. My goal was to extrapolate the particular needs and experiences of individuals considering and pursuing MAiD in Canada.

The methodological challenges around whose experiences are the focus of MAiD research raises another critical question: to what extent are MAiD decisions influenced by socio-cultural factors that may not be captured in the current research? Understanding these contextual dimensions is essential for counsellors who must navigate diverse client perspectives and experiences. The following section explores some of the ways that limitations in MAiD research with diverse populations might narrow our understanding of attitudes and practices around MAiD.

Culture & MAiD

Notable gaps in the MAiD literature involve consideration of the role of race, culture, diverse gender and sexual identities or socioeconomic status on MAiD attitudes and experiences. Understanding the role of such factors on engagement with MAiD is critical as culture shapes how individuals make meaning out of illness, suffering, death and dying (Dorji et al., 2022; Northcott & Wilson, 2021; Spitentatter & Schnell, 2023). In Western industrialized countries, cultural attitudes towards death and dying are characterized by denial, reluctance to speak about death, reliance on medicalization, professionalization of death care practices, and segregation of the sick into care facilities and hospices (Dorji et al., 2020; Incorvaia, 2024; Northcott & Wilson, 2021). In Canada, the impact of these cultural influences is evident in a lack of willingness to engage in contemplation of or preparation for one's own mortality, evident in low rates of advance care planning and continued application of medical treatments beyond the point of curative value (Northcott & Wilson, 2021).

Religion is a factor identified in views and attitudes towards MAiD overall, though its role in actual pursuit of MAiD is less clear. While official religious doctrine usually considers MAiD morally wrong, personal stances appear to vary. In a poll of over 3500 Canadians, Dying

with Dignity Canada reported that 79% of Canadians who identify as having a non- Christian religious affiliation (e.g., Jewish, Hindu, Muslim or Buddhist) support MAiD, only somewhat lower than the overall 86% support rate (Ipsos, 2020). A study of Buddhist-Canadians found that despite doctrinal understanding that suffering is a normal aspect of life and that MAiD is regarded as killing, individuals vary in the ways they prioritize these teachings against the equally emphasized value of compassion towards relieving the suffering of others (Dorji et al, 2019). The extent to which religiously informed attitudes predict actual behaviour with respect to choosing MAiD does not appear to have been widely investigated; however, religions likely provide frameworks in which individuals reach meaningful understandings of MAiD at a personal level.

In addition to the myriad ways that culture can shape views of MAiD, concerns about the impact of the availability of MAiD on individuals with systemic vulnerabilities (e.g., minoritized groups, disability status, low SES) are a large part of the ethical discourse on MAiD. Concerns raised include systemic injustices and differential access to support that can drive requests for MAiD when needs are not met and affect equitable access to MAiD. Ficella & Sanders (2016) show culture-based disparities in patient experiences of the health care system overall, especially with respect to race and ethnicity. Comeau et al., (2023) also outline disparities for those with diverse sexual and gender identities, underscoring the importance of ensuring that demographic and diversity variables are included in research results and reporting on MAiD. To date, the inclusion of socio-demographic identity factors is limited in both academic research and government reporting.

In one of the few quantitative studies looking at the impact of socio-demographic factors influencing those accessing MAiD, Downar et al. (2020) reported that those accessing MAiD

tended to be younger, of higher SES, less likely to reside in an institution and were more likely to be married than decedents in the overall population. This pattern was consistent with findings from other countries where assistance in dying is legal, indicating that these services tend to be more likely to be accessed by individuals with higher SES (Downar et al., 2020). Nonetheless, this study from Ontario also found that those who requested MAiD tended to have already been recipients of palliative care, suggesting that lack of access to palliative care is not a driving factor, at least for individuals whose death is reasonably foreseeable (i.e. Track 1 applicants) (Downar et al., 2020). Conversely, another quantitative study based in London, Ontario found that MAiD assessments were more often requested by individuals living in lower income areas; however, SES was not found to affect rates of positive eligibility determinations or completed MAiD provisions (Tran et al., 2022). Taken together, these studies suggest that a regional lens may be necessary when examining and proposing studies that investigate equitable access to MAiD.

While Health Canada consistently reports on age, geography and gender of MAiD recipients in annual reporting, they only began reporting on racial, ethnic, cultural, socioeconomic and disability variables in their most recent annual report. Voluntary reporting by MAiD requesters, inconsistencies in MAiD assessors' approaches to data collection and delays in jurisdictional reporting have imposed limitations on data quality and consistency. However, some high-level trends have been identified. Based on the roughly two-thirds of MAiD recipients in Canada who shared their identity factors in 2023, the vast majority identify as White (95.8%). Individuals identifying as East Asian were the second most common group (1.8%), whereas only 80 individuals identified as Indigenous. These findings highlight the question of why there appears to be less engagement with MAiD among diverse groups. Whether this discrepancy is a

matter of accessibility, privilege and system factors versus incompatible worldviews and value systems could be a fruitful topic for further study. Regardless, this discrepancy in engagement with MAiD among racial and cultural lines raises the possibility that my choice to apply an existential framework to this inquiry risks obscuring insights into this phenomenon.

Based on preliminary analyses, Health Canada (2024) found that at a high level, people who receive MAiD do not disproportionately come from lower-income or disadvantaged communities; however, a higher proportion of Track 2 recipients tended to be characterized as experiencing residential instability. Further, while women tend to access MAiD slightly less often than men, women receiving MAiD are more likely to live in lower income neighborhoods. Finally, mirroring the regional perspective of Downar et al. (2020), Health Canada (2024) found that access to palliative care does not appear to drive requests. While preliminary, these findings call attention to areas for further investigation.

Overall, there continues to be a need for broader and more consistent inclusion of socio-demographic and cultural variables in MAiD research and government reporting. The narrow range of studies reporting demographic and cultural variables limits the ability to understand the role of identity factors, not only in terms of access and vulnerability protections, but also in terms of the particular beliefs and worldviews that inform individual experiences of MAiD. From a counselling practice perspective, this underscores the value of a person-centred approach emphasizing curiosity and avoidance of assumption-making when working with individuals and families considering and choosing MAiD.

The Context of Choosing MAiD

The Nature of Suffering

It is necessary to understand the nature of suffering in advanced illness to optimize therapeutic support. While discourse on the philosophical and theological bases of suffering has long been a human endeavor, advances in modern health care have brought these issues to the forefront of practical consideration. Questions regarding the nature and function of suffering, who gets to decide when suffering exists or is intolerable and what is a moral response to suffering form the basis of clinical guidelines and debates that undergird approaches to alleviating suffering (Pesut et al., 2021).

In the palliative care research, a clinical conceptualization of suffering appears in the concept of "total pain", describing suffering as not only a subjective physical experience but also containing a combination of social, psychological, emotional, existential and spiritual dimensions (Rattner, 2022). The ways these dimensions interact can be complex. For example, fear of future physical suffering could be considered a non-physical form of suffering. One study out of Oregon investigated the reasons healthy individuals thought they would access MAiD in future compared to the reasons given by those actually pursuing it (Blake & Blake, 2023). Blake and Blake (2023) found that among healthy individuals, fear of uncontrollable physical pain was the top reason why they might consider MAiD in future, whereas this was significantly less of a factor than non-physical forms of suffering among individuals who were pursuing MAiD.

Government reporting on the nature of suffering of MAiD recipients in Canada reveals that while inadequate pain control was cited by about 55% of recipients in 2023, it was raised notably less often than other factors (Health Canada, 2024). Rather, the top three most frequently cited reasons given by MAiD requesters are the loss of ability to engage in meaningful activities

(95%), loss of ability to perform activities of daily living (87%) and loss of dignity (65%) (Health Canada, 2024). These significant losses were also accompanied by existential and emotional distress for about 38% of MAiD requesters and perceived burdensomeness on family members in 45% of requesters (Health Canada, 2024). Though making up only about 5% of MAiD recipients, Track 2 individuals (whose deaths are not reasonably foreseeable) were significantly more likely than Track 1 individuals (whose death was foreseeable) to cite loneliness or isolation as a factor in their request (47% for Track 2 and 21% for Track 1); Track 2 individuals were also significantly less likely to cite loss of independence as a factor (39.1% for Track 2 and 52.8% for Track 1). Both these differences may be a function of the additional finding that Track 2 recipients are more likely to have been dealing with chronic or degenerative illnesses over a longer period of time than Track 1 recipients. Track 2 recipients may have had more time to adapt to reduced levels of independence but also may have dealt with shifts in relational dynamics common with advanced illness over a prolonged period. Further research is required to substantiate this hypothesis. Regardless, these findings reveal that themes of loss, identity and worry constitute the primary sources of MAiD recipients' non-physical suffering.

Gaignard et al. (2023) and Rattner (2022) show that medical and palliative providers are much more adept at addressing physical pain and often feel helpless or incompetent when confronted with non-physical forms of suffering. While physical and non-physical forms of suffering often occur together, physical forms of suffering are more likely to be well-treated whereas psychological, existential and spiritual needs are often less consistently incorporated into care (Gaignard et al., 2023; Teo et al., 2019). This focus on the physical can be counter productive. For example, inadequate or inappropriate treatment of depressive or anxiety

symptoms can exacerbate physical symptoms (Lerman et al., 2015). This point highlights an essential role for mental health and spiritual care practitioners in wholistic care.

The process of dying is widely recognized as occurring in a social context, yet individuals often struggle to express their non-physical suffering to their caregivers, loved ones and healthcare providers (Beuthin et al., 2021; Northcott & Wilson, 2021; Santa Maria, 2024). For many clients, their non-physical suffering remains unshared due to clinical emphases on physical forms of suffering, communication barriers and complex relational dynamics (Rattner, 2022; Walker & Wong, 2018). In the first grounded theory study ever published, Glaser and Strauss (1965) observed death and dying scenarios in six hospitals over six years and identified four phases in the process of awareness of dying that are still relevant today (Andrews and Nathaniel, 2015; Walker & Wong, 2018). Phase 1, called *closed awareness,* refers to a phase when the patient is unaware that they are dying, and medical staff act in ways that conceal the true nature of their condition. In the second phase, *suspected awareness*, patients become increasingly suspicious that medical practitioners believe them to be dying even though they are being treated as merely ill. The third phase, *mutual pretense,* occurs when all parties know the patient is dying, but pretend otherwise. For example, in families in which a focus on hope for survival precludes dialectical positions of acceptance, or acknowledgement of fears, clients may not feel able to openly share their concerns or thoughts with those around them to maintain normalcy, hope for those they love or to reduce the burden on their caregivers (Santa-Maria, 2024; Walker & Wong, 2018). The final phase of *open awareness*, when everyone is free to acknowledge reality, often only arises as physical decline becomes obvious.

The first three phases of the process of becoming aware of death involve some form of social collusion to deny the reality, and during this period there can be a strong sense of

emotional isolation that exacerbates the patient's suffering. Walker & Wong (2018) argue that having MAiD as an option is a greater prompt towards the *open awareness* phase for the patient, facilitating movement towards what they propose should be an additional phase of *meaningful integration and acceptance* of impending death. Regardless of the implication of MAiD on awareness of dying, the understanding that non-physical suffering at the end of life often goes unshared speaks to clients' need for safe outlets to share their suffering, fears and concerns in a way that does not further burden family, caregivers and other loved ones.

Understanding Intolerability

In the context of the suffering that leads to choosing MAiD, the notion of tolerability becomes defining and personal. A growing understanding is emerging from the psychological literature regarding personal limits of tolerability, underlining the importance of context rather than pure symptomology. A recent scoping review of studies on suffering leading to MAiD requests characterizes suffering as not only the accumulation of symptoms in various domains, but also the result of person-context interactions, driven by an individual's beliefs, values, social roles, relationships and prior life experiences (Henry et al., 2023). This is supported by a Dutch grounded theory study by Dees et al. (2011) which found participants characterized their suffering as intolerable in the context of identity characteristics, life histories and existential motivations, revolving around a point of hopelessness. Patients emphasized that loss of what made life worth living with no hope of restoration tipped the scales towards an evaluation of their suffering as unbearable (Dees et al., 2011). Individuals evaluate their life as meaningful and worth living based on the particular contexts in which that meaning is experienced and expressed, reflecting the individual-contextual interaction piece. Notably, unbearability was not related to physical symptoms nor to the continuousness of suffering, as most individuals noted

fluctuations in the intensity of their suffering (Dees et al., 2011). Only patients identified as having clinical levels of depression reported being in a continuous state of suffering (Dees et al., 2011). Indeed, individuals experiencing clinical levels of depression have been found to be four times more likely to express a desire towards hastened death (Kredentser & Chechinov, 2020).

This points to the challenge in the assessment and treatment of suffering in the face of advanced illness of distinguishing normal emotional responses to the limitations inherent in these conditions from clinically significant symptoms (Kredentser & Chechinov, 2020). For example, hopelessness and depression are often considered mental health issues characterized by distorted thinking patterns and pessimistic views of the future. In particular, hopelessness can impact quality of life independent of depression and has been linked more closely to suicidal ideation and behaviour than depression (Rosenfeld et al., 2006). Given the inevitability of death and the degeneration associated with advanced illness, hopelessness and depression may rather be viewed as existential or spiritual concerns rather than mental health concerns (Smith et al., 2015). When these symptoms are present, mental health practitioners are trained to screen for suicide risk and have an ethical and legal obligation to carry out risk assessment, harm reduction planning and hospitalization for more imminent cases (Walker & Wong, 2018). In a Swiss study, Gaignard et al. (2023) identified that while most medical providers of assisted death viewed referral to mental health clinicians as important in addressing primarily existential suffering, others were reluctant to refer for evaluation due to possible pathologization of legitimate responses to the inherent limitations of serious illness.

The prospect of forced hospitalization for suicidality for patients expressing a wish for hastened death or expressing interest in MAiD presents an ethical dilemma. While greater levels of hopelessness and depression are found to be associated with a desire for hastened death and

interest in MAiD (discussed in the next section), how they contribute longitudinally to the actual pursuit of MAiD is less clear (Kredentser & Chochinov, 2020; Smith et al., 2015). As such, further education and clinical guidance to support discernment of suicidality from a request for hastened death is necessary to guide mental health practitioners to provide appropriate responses to individuals considering MAiD. For example, impulsivity and impairments in decision-making play crucial roles in the move from suicidal ideation to action (Gvion et al., 2015), whereas MAiD is associated with a reasoned evaluation and consideration of decision-making capacity. The absence of such guidance is one reason why mental health practitioners outside of palliative and hospice settings may be reluctant to venture into supporting individuals pursuing MAiD.

Intentions Towards Dying

One important concept that appears clear from the literature on end-of-life care is that an individual's expression of a wish to die does not always signal an intention to pursue MAiD (Borges et al., 2024; Ohnsorge et al., 2014; Rodriguez-Prat et al., 2024). Rather, manifestations of a wish to die can be characterized along a spectrum defined by the degree to which cognitions of dying are associated with action (Ohnsorge et al., 2014; Rodriguez-Prat et al., 2024). At one end, the wish to die can reflect acceptance or anticipation of the natural end of one's life, while on the other it might arise as a response to intense, unbearable suffering that can lead to plans to hasten death through such actions as voluntary stopping of eating and drinking, refusal of life-sustaining treatment, suicide or requests for euthanasia (Li et al., 2021; Rodriguez-Prat et al., 2024).

While definitions of a "wish for hastened death" vary in the literature, inherent in all studies is the notion that this desire is a reaction to suffering (Borges et al., 2024; Ohnsorge et al., 2014; Rodriguez-Prat et al., 2024). The wish for hastened death can arise from a range of factors

related to challenges in the existential domain (loss of identity, dignity, autonomy and meaning), physical domain (exhaustion, loss of function, pain etc.), social domain (dependency, self-burden on others) or psychological domain (hopelessness, depression, demoralization) (Borges et al., 2024; Ohnsorge et al. 2014; Rodriguez-Prat et al., 2024). In the context of advanced physical disease, expressions of a wish to die may emerge occasionally in up to 55% of individuals or more persistently in a desire for hastened death in 4 to 11% of individuals (Belar et al., 2024; Li et al., 2021).

For clinicians to understand what is being communicated when an individual expresses a wish to die, they must be aware of the reasons, meanings and functions of this expression. Qualitative studies have variously characterized the wish for hastened death to convey several meanings such as a sense of letting go, a need to exert control or a way to escape intolerable despair and suffering (Belar et al., 2024; Borges et al., 2024; Saracino et al., 2019). The wish for hastened death may also serve different functions, such as a coping mechanism against anticipated suffering and loss of control or as communication to caregivers of unmet needs (Belar et al., 2024; Borges et al, 2024; Saracino et al., 2019). As such, mental health practitioners working with patients with advanced disease must be aware of the possible meanings and functions of expressions of a wish to hasten death. This emphasizes the need for wholistic, person-centred care in addressing such expressions to help individuals tease out what is driving this desire and other options for relieving their suffering that exist and are acceptable to clients.

While longitudinal studies of the desire for hastened death are few, existing studies show that the persistence and intensity of the desire for hastened death can vary temporally, even in the last weeks of life, based on transitional moments in disease progression, evolving self-understanding or other personal factors (Belar et al., 2024; Li et al., 2021; Ohnsorge et al, 2019;

Rosenfeld et al., 2014). Subjective experiences of decline trajectories and symptom burden associated with specific conditions can evoke characteristic motivations initiating the wish to hasten death (Ohnsorge et al, 2019). For example, individuals with neurological conditions are most likely to consider hastened death when breathing challenges present, when dependency increases or when feeding tubes need to be introduced (Ohnsorge et al, 2019). For frail and elderly individuals, the move to care facilities, loss of social relationships and declining capabilities in day-to-day functioning tend to be associated with desire for hastened death (Ohnsorge et al, 2019).

Beyond disease specific elements, factors that have been shown to reliably predict a desire for hastened death include hopelessness, depression, meaninglessness, and spiritual wellbeing (Li et al., 2021; Rodriguez-Pratt, 2024; Saracino et al., 2019). Interestingly, demographic characteristics including age, gender, education and religiosity have not been found to be consistently associated with this phenomenon (Rosenfeld et al., 2014). Less reliably, other factors associated with an expression of a wish for hastened death include pain, high disease burden, low self-esteem, attachment insecurity, being unmarried, being younger in age and having a history of psychiatric illness (Li et al., 2021). For example, individuals with an avoidant attachment style may employ strategies to defend against attachment needs such as self-reliance, control, autonomy and aversion to dependence on others, factors that have been shown to be associated with requesting MAiD (Oldham et al., 2011; Smith et al., 2015). Presenting concerns of self-esteem, spiritual well-being, a perception of meaninglessness, and attachment security are known to respond to forms of psychotherapy, and as such may be targets for treatment in situations of advanced illness.

Clearly, the wish for hastened death is a complex and multifactorial phenomenon that may or may not lead to a request for MAiD, and may be treatable should treatment be a client's goal. Research dedicated to uncovering the socio-cultural contexts and personal factors that influence the longitudinal development of a request for MAiD remains under-developed (Li et al., 2021). Yet, for clinicians working with individuals considering MAiD, awareness and understanding of the different intentions, functions and motivations of clients' expression of desire to hasten death become ethically relevant. Understanding an individuals' consideration of MAiD in terms of their worldview and values about dignity, autonomy, the value of life and the meaning of suffering is critical for supporting individuals in the decision-making process, treating non-physical suffering that might arise at any point in the process and to ensure due diligence and fulfilment of ethical obligations surrounding suicidality. At the very least, knowledge gained in exploring clients' experiences and moral understanding of MAiD may serve as a foundation for interventions, allowing clients to experience their last days as meaningful.

MAiD as Palliation of Suffering

Issues of autonomy and dignity become central features in advanced illness as individuals are confronted with loss of independence and control. MAiD can represent one way to maintain control over uncertainties such as actual or anticipated functional loss, institutionalization, symptom burden and the process of dying. Whether or not a person chooses to pursue MAiD, sometimes simply having the option to end one's life on one's own terms can relieve suffering. Individuals going through the steps of the process and being deemed eligible to access provision are shown to experience an increase in their wellbeing and wish to live longer, a phenomenon first described as the *Oregon phenomenon* (Lee, 2010 in Ricou and Wainwright, 2019). Having

the option of MAiD in one's back pocket can reduce uncertainty and restore some degree of predictability and even pragmatism. Choosing MAiD becomes an act to reclaim dignity and autonomy when the progressive assaults of illness on the body and personhood reaches individually determined thresholds of tolerability.

MAiD-specific Experiences: Implications for Counselling Practice

While the end-of-life journey associated with terminal and degenerative illness can vary widely, the emergent qualitative literature is revealing experiences singular to the MAiD process relative to natural death. Accounts of individuals choosing MAiD and those of their family members, caregivers and medical practitioners discuss experiences such as the ability to choose dates and timelines, the need to share and defend one's choice, and institutional barriers to accessing the right to die. Pesut et al. (2021) reveals that much as MAiD can palliate various forms of suffering, "the process itself can result in different and quite distinctive forms of suffering" (p.5). Many of these distinct experiences with MAiD can be articulated in terms of the existential constructs of death, freedom, isolation, and meaninglessness. For example, taking the opportunity to choose the endpoint of one's life necessarily precludes denial of death in the chooser, yet that base level of acceptance might not be met by others, creating tensions in the relational sphere. Alternatively, MAiD can arise as a source of meaning that can transform a narrative of suffering into one of liberation and transcendence. Counsellors can play a critical role in helping clients to identify and name the distinctiveness of these experiences and to articulate a coherent understanding of them. The following section elaborates on these distinctive features of the MAiD experience as a basis for the development of assessment and intervention approaches in counselling individuals considering and choosing MAiD (explored further in Chapter 3).

An Empowered Choice

Perhaps most obviously, the ability to choose MAiD is often presented as one that can empower individuals to die on their own terms, exercising freedom in the face of existential limitations. A known timeline can allow individuals to tend to the practicalities of dying, to complete unfinished business and to be more deliberately reflective about their life and legacy. As illness slowly strips individuals of bodily control, they can maintain agency by dying in a way that is true to their authentic self (Santa Maria, 2023). In determining one's time of death, individuals can exercise autonomy and control over aspects of the dying process that have been shown to be associated with a good death (Martin, 2023). For example, a qualitative study by Martin (2023) identified that choreography of the event, incorporation of ceremony and ritual, the ability to be conscious up until death, the ability to ensure the presence of important others, and peacefulness were all features of a good death that MAiD can support.

One consideration is that the notion of "a good death" has been criticized as a construct of the privileged. Systemic discrimination and inequities in access to medical care for marginalized groups render the notion of a "good death" unrealistic for many groups. Furthermore, while MAiD may be seen as introducing an element of power and personal autonomy to end of life for some, it is important to consider that the degree to which MAiD might be experienced as empowering may vary along socioeconomic, racial and religion lines (Suntai, et al., 2022). For example, within some cultural contexts or value systems, MAiD might be seen as "giving up" and empowerment might be more likely by mobilizing all lines of treatment defense as fully as possible (Suntai, et al., 2022). Alternatively, the notion of personal autonomy as articulated within humanistic- existential perspectives may not align with more collectivist cultural views or religious notions that submission to the will of a greater power is

more important than personal autonomy (Suntai, et al., 2022). Overall, while MAiD can address the need for autonomy in the face of the inevitability of death, counsellors should not make assumptions about where sources of empowerment may lie for their clients.

MAiD as Acceptance

One perspective that appears to be de-emphasized in the literature is the possibility that the choice of MAiD signals acceptance of the limitations inherent in embodied existence (Santa Maria, 2023, Walker & Wong, 2018). Dying is considered by some authors to be a developmental process, and in alignment with life stage developmental theories, may subsume various phases and tasks (Emanuel et al., 2007; Lo, 2018). The medical privileges and normative death denying tendencies of Western culture have created an implicit assumption that death "should" only come after a long life and engagement with all the developmental tasks in various phases of life. This view reinforces the shock and sense of unfairness when illness and the prospect of one's own death comes "too soon". When confronted with the prospect of dying, people are forced into questions of generativity that are typically associated with later life phases. As such, the prospect of an "early" death necessarily casts individuals into a developmental phase in which final tasks in the practical, relational and personal realms become the focus (Emanuel et al., 2007). Individuals' capacities to navigate these tasks and come to a place of acceptance vary and can be obstructed by lack of death awareness or inadequate symptom control (Emmanuel et al, 2007; Walker & Wong, 2018). In this context, Walker & Wong (2018) stress that the choice to pursue MAiD signals a willingness to not just passively accept death but to actively "grapple with the mystery of death and what it means to stand at the threshold between living and dying" (p. 378).

Contrary to the suffering-based perspective inherent in the literature, one phenomenological study identified the wish for hastened death as emerging out of a "state of transience" from turning away to moving towards the finiteness of life and accompanying feelings of demoralization, hopelessness and grief (Belar et al., 2024, p.1). This state elicits efforts to reconnect with one's core self as the various masks that protect self-perceptions fall away (Belar et al., 2024). In this process, choosing MAiD may not merely be a symptom of demoralization and suffering, but might instead reflect a transition in one's self-concept towards greater acceptance of mortality, or in existential terms, mortality salience (Belair et al., 2024; Santa Maria, 2023). Choosing MAiD opens the possibility for transcendent experiences that are only possible when fully confronting death while also fully engaging with life (Martin et al., 2023). Additional quantitative studies comparing levels of mortality salience between individuals choosing MAiD, individuals dying a natural death and individuals in the general population might lend further credence to these postulations.

Relational Dynamics

While birth and death are solitary experiences, humans are relational beings who experience life in a social context. The process of dying is heavily influenced by interpersonal dynamics, previous exposure to death and dying, religious and cultural views, communication and the quality of social support (Santa Maria, 2023). Beyond this, MAiD can add additional layers of complexity to the experience of dying, particularly when family members disagree or are not supportive of an individual's choice. For family members, a loved one's choice of MAiD can be viewed in ways that complicate the relational field around dying. Some family members might view the choice as depriving them of maximal time with their loved one. Others might struggle with the view that MAiD is akin to suicide. They may fear being exposed to

disenfranchisement and stigma during bereavement. In the context of religious teachings deeming suicide as a sin, family may experience moral distress at the prospect of being permanently separated from their loved one in the afterlife (Serota et al., 2024). Awareness of such impacts on family members and loved ones can sometimes amplify the psychological and existential suffering that MAiD aims to relieve (Pesut et al., 2021). Gamondi et al. (2019) demonstrate the highly integrated role family dynamics play in the process of MAiD, identifying the need to include MAiD-specific systemic supports for family members before, during and after the provision.

Impacts on Bereavement

In cases where family and friends are supportive of a MAiD decision, it may offer friends and family the possibility of a more easeful bereavement experience (Andreissen et al., 2020). The scholarship on loss and grief indicates that the quality of the dying experience can impact bereavement such that more difficult endings tend to be associated with greater chance of more complicated bereavement (Srinivasan, 2019). With MAiD, family members and caregivers have time to seek closure, to participate in planning and facilitating the death day, and to prepare themselves emotionally for bereavement (Beuthin et al., 2022; Srinivasan, 2019). As the individual remains awake up until the moment of lethal drug administration, interaction until the final moment is possible, circumventing guilt that is often associated when family members are not present in the room. A systematic review by Andreiessen et al. (2020) found little evidence of increased risk of adverse grief or mental health outcomes in MAiD bereavement, although other qualitative research identifies factors such as secrecy, fear of stigma, disagreement with the choice of MAiD and lack of targeted bereavement supports that may contribute to more complex MAiD bereavement experiences (Beuthin et al.,2022; Yan et al. 2023).

The Burden of Decision Making

The weight of decision-making involved in the MAiD process can be relentless. The emotional labour involved in deciding whether or not to seek MAiD often involves complex calculus of continually balancing pros and cons of the present condition in the context of an unknown trajectory (Pesut et al., 2021). Understanding where one's line of intolerability lands and consideration of the impact of one's decision on others may require these clients to hold dialectal positions. This process can be particularly difficult in the case of Track 2 clients whose illness may be progressive and chronic but not deemed "terminal". Over the course of the 20th century, the leading causes of death transitioned from acute to chronic and medical advances have allowed death to be postponed. As such, much of dying now occurs in the context of chronic illnesses that are not deemed terminal (Bern-Klug, 2004). Individuals living with chronic illness often find themselves in a state of ambiguous dying; only upon a determination of eligibility to pursue MAiD can ambiguity be removed and the work of preparing to die begin. Once one is deemed eligible for MAiD, determining when one is "ready," choosing a date, and orchestrating the day of the provision can involve heavy contemplation, planning and many difficult conversations.

Handling Disclosure

Additional emotional labour can occur around managing disclosure of the decision to pursue MAiD. By the time an individual has made the choice, they have already reached a certain degree of acceptance of death and a possible sense of relief for the end of their suffering. Yet, for those hearing about the decision for the first time, there can be shock, disbelief, reluctance to accept an upcoming loss or even resistance (Boven et al., 2023). Concerns around stigma can emerge with numerous studies reporting experiences of patients and/or family

members being judged or having to endure unsolicited opinions or vocal opposition which can effectively alienate people from social support (Crumley et al., 2023; Singer et al., 2023). Only 55% of Canadian families who have experienced a MAiD death feel able to speak openly about MAiD as the manner of death, particularly those involved in religious communities (Ditchfield, 2018, as cited in VanKessel, 2024). Maintaining secrecy around the choice to pursue MAiD can protect loved ones from stigma and judgement yet can also impose considerable psychological burden and logistical challenges (Crumley et al., 2023). While a recent quantitative study in the US has shown that concerns of direct stigma towards family members of individual choosing MAiD are generally unfounded, experiences of alienation, judgment and stigma nonetheless emerge in qualitative studies of MAiD experiences, representing a topic that may emerge in the counselling space with individuals touched by MAiD (Crumley et al., 2023).

In deciding how to disclose their choice of MAiD and to whom, clients may benefit from exploring with counsellors how to balance their own needs and the needs of their families, friends and community members. Clients who feel a strong responsibility for protecting or managing the reactions of others may benefit from working on establishing clear boundaries or designation of a spokesperson. Clearly exploring one's own moral reasoning and rationale regarding their choice with a counselling profession may help clients prepare for difficult conversations. Counsellors may be called upon to assist in preparing clients by rehearsing difficult conversations, composing disclosure communications or the facilitation of family conversations around the decision. Having counsellors as a resource in the task of informing others may help to ease some of the additional emotional burden of managing exposure to other people's reactions.

Institutional Suffering

Institutionalized suffering can occur when individuals have negative experiences with the healthcare system. By the time an individual is considering MAiD, they have likely had interactions with the health care system that may have already compromised their trust, particularly if they belong to marginalized groups. For individuals seeking MAiD on Track 2 who suffer from prolonged chronic health conditions, experiences of frustration with ineffective treatments and lack of validation within the medical system are unfortunately common, and the process of being found eligible for MAiD can be viewed as acknowledgement and legitimization for their suffering (Fruhstorfer et al., 2024). Sometimes psychosocial support is offered through palliative care, however, these patients often do not qualify for palliative care under many jurisdictional regimes (Frustorfer et al., 2024).

Pathway ambiguity is a term that describes lack of clarity and misinformation in navigating coordination of MAiD, and has been found to be common in some health authorities and institutions (Close et al., 2023). Lack of timely referrals or misinformation by healthcare practitioners can add to the burden. For example, when individuals seeking information about MAiD are told by their medical practitioner that they are not suffering enough, this not only disregards the legal requirement that suffering is what the client says it is, but it invalidates the patients' experience. Instances of poor communication with MAiD coordination teams or lack of resources delaying expected timelines around such a sensitive process can compound difficulties.

Institutional objection of MAiD by hospitals, hospices or residential care facilities on religious grounds continues to hinder access to MAiD in several jurisdictions (Close et al., 2023). A recent qualitative study documented negative emotional and psychological impacts to patients, families and health practitioners when patients are forced to transfer to facilities that

permit MAiD onsite (Close et al., 2023). In addition to forced transfers, other less visible forms of institutional objection can include lack of transparency, refusal to sign forms or insert IVs or delaying referrals. For individuals who are already experiencing significant suffering, power dynamics that impede access to care can exacerbate suffering. This can be a particular issue in rural areas where switching care facilities involves extensive travel.

The Risk of Ineligibility

In cases where individuals seeking MAiD are deemed ineligible, new forms of suffering can arise. Under the auspices of a law that recognizes a patient's right to define what they view as intolerable suffering, being deemed ineligible can represent a form of institutional betrayal and infringement on one's agency (Isenberg-Grzeda et al., 2020; Pesut et al., 2021). This risk appears to be much higher for individuals pursuing MAiD under Track 2 in Canada. Whereas Track 2 provisions in Canada (i.e., death not reasonably foreseeable) comprise less than 5% of MAiD recipients, they represent 27% of requests that are deemed ineligible, pointing to the complexity involved in assessing those cases (Health Canada, 2024). When a request has been found to be ineligible, the work of re-engaging with life can represent a significant challenge for individuals and clinicians alike. The period immediately following a determination of ineligibility for MAiD has been found to bring about a heightened safety risk (Isenberg-Grzeda et al. 2020). Some researchers have suggested that MAiD requesters are commonly characterized by values of high independence, self-reliance, control and autonomy (Isenberg-Grzeda et al. 2020). Those motivated primarily by fear of dependence and loss of autonomy are hypothesized to be less likely to opt for other palliative options as they do not address fear of losing independence (Isenberg-Grzeda et al. 2020). As such, safety planning and additional supports

such as psychiatric care in these cases have been recommended; however, the potential for ethical dilemmas for mental health practitioners abound.

Overall, despite considerable gaps in the MAiD literature, the existing and emergent research features several elements that may be considered particular to MAiD experiences that mental health practitioners need to be aware of. While some of these elements point to the need for more systemic support (e.g. addressing institutional gaps in care) or practical support (e.g. logistical supports for the day of provision), many offer a way of engaging with underlying existential themes around death, meaning, isolation, freedom. As such, it seems reasonable to suggest that mental health clinicians can further support clients considering and pursuing MAiD by incorporating awareness of these elements into possible psychotherapeutic approaches to dealing with existential suffering.

Selected Approaches to Treating Existential Suffering

Given the significant contribution of existential concerns to the suffering that leads to MAiD and the finding that such concerns often go undertreated, it stands to reason that counsellors supporting MAiD clients can benefit from an understanding of approaches and interventions for treating existential distress. Though defined in a variety of ways, existential suffering can be conceptualized as a distinct, painful psychological state that arises from situations that challenge fundamental assumptions about existence and force the realization that life has lost meaning (Gaignard et al., 2023; Vehling & Kissane, 2018). Studies that investigate non-pharmacological interventions to treat existential suffering operationalize it using a range of constructs including death anxiety, meaninglessness, hopelessness, dignity related distress, spiritual distress, demoralization, and desire for hastened death (Gaignard et al., 2023; Vehling & Kissane, 2018). While palliative care and psychological literature point to a range of non-

pharmacological approaches for treating psychological suffering at end of life, in the interest of preserving a manageable scope of inquiry, I will here examine select and well-researched approaches grounded in existential theory.

Existential Therapies

While existential theory has given rise to a range of different therapeutic approaches for addressing existential suffering, research is limited primarily due to reticence among many existential practitioners to rely on positivist, reductionist quantitative research methods (van Deurzen & Adams, 2016; Vos et al., 2015). Such methods are seen as contradictory to the phenomenological emphasis necessary for capturing the nuances of individual experience. As such, the literature on existential-based therapies tends to describe a range of unstandardized interventions with poorly operationalized metrics (Vos et al., 2015). One meta-analysis investigating outcomes of existential therapies on positive outlook, self-efficacy and psychopathology detected very few studies of sufficient quality to inform the study (Vos et al., 2015). Among the included studies, the strongest level of support emerged for structured meaning-focused therapy which generated moderate effect sizes on self-efficacy, psychopathology and physical well-being, relative to supportive-expressive therapy, experiential-existential or cognitive-existential therapies (Vos et al., 2015). Oddly, outcomes of constructs salient to existential theory (e.g. meaning, death anxiety, hopelessness etc.) were not investigated.

While the research base on the effectiveness of existential approaches is limited, the body of work on Terror Management Theory (TMT) offers more concrete evidence to inform development of treatment approaches for relieving existential distress. Grounded in social, existential, and evolutionary psychology, TMT posits that humans' awareness of our own

mortality uniquely primes us with a terror of death from which we protect ourselves by activating two types of psychological defenses: proximal and distal (Perry et al., 2022; Pyszczynski et al., 2015; Willis et al., 2023). Proximal defenses are activated in response to reminders of death and involve attempts to banish mortality salient thoughts from awareness through strategies such as denial of vulnerability, thought suppression, threat avoidance, distraction or health promotion (Perry et al. 2022; Pyszczynski et al., 2015; Willis et al., 2023). From a TMT lens, proximal defenses could be considered to underlie some of the communication and relational challenges identified in delivering wholistic psychosocial and physical support to those with advanced disease (Svet et al., 2023).

Distal defenses operate at a deeper level to prevent the inherent meaninglessness and groundlessness of death from entering conscious awareness (Pyszczynski et al., 2015; Svet et al., 2023). Though not always logically connected to death, distal anxiety-buffering strategies include the pursuit of meaning in one's worldview, boosting self-esteem by adherence to one's worldview, and seeking security in personal relationships (Sven et al, 2023). Distal defenses enable people to achieve a sense of immortality and view themselves as valuable contributors in a meaningful universe (Pyszczynski et al., 2015).

There is a vast research base supporting the main tenets of TMT in relation to everyday behaviours and symptom severity in mental illness; however, TMT has been less consistently researched in populations with chronic and life-limiting illness for whom death is far more salient (Burke et al., 2010; Menzies et al. 2019; Svet et al., 2023). In a recent and relevant study, Willis et al. (2023) found strong support for TMT in which cancer patients with a greater number of strong distal defences (e.g. attachment security, high self-esteem, meaning in life etc.) had significantly less death anxiety than those with no or only one strong

distal defense. A recent systemic review of studies applying TMT to populations with advanced illness included only six studies, precluding the ability to assess bias and sensitivity. Nonetheless this study pointed to the utility of further research in understanding how belief systems and defences might be leveraged to provide wholistic care to individuals with advanced illness (Svet et al., 2023). Building on Svet et al.'s (2023) recommendation for further study of TMT with populations with advanced disease, there could be some value in a comparative study of relative reliance on distal and proximal mechanisms in those who have and who have not chosen MAiD.

Based on the empirical support for TMT overall, addressing existential suffering in individuals considering and choosing MAiD might involve simultaneously promoting healthier proximal mechanisms such as acceptance and reappraisal while also boosting distal mechanisms such as self-esteem, meaning making, spiritual strength and family supports (Perry et al. 2022; Svet et al., 2023). Indeed, two well-established and empirically validated interventions that have been developed specifically for individuals at end of life take advantage of these findings: Meaning-Centred Psychotherapy and Dignity Therapy

Meaning-Centred Psychotherapy

Meaning-Centred Psychotherapy is a manualized intervention that leverages the well-established influence that a strong sense of meaning has been shown to have on increased quality of life and spiritual well-being and decreased psychological distress at the end of life (Breitbart et al., 2015; Rosenfeld et al., 2018; Steger et al., 2006; Vehling & Philipp 2017; Zhang et al., 2019). Developed by Breitbart et al. (2002), Meaning Centred Psychotherapy is based on the works of Viktor Frankl, a psychiatrist who survived the Holocaust and went on to develop logotherapy, a form of existential therapy. Frankl argued that within a meaningless universe,

humans are driven by a will towards finding meaning and purpose in their lives and that the only true freedom humans possess is the attitude they apply towards their circumstances (Frankl, 1962). Meaning-Centred Psychotherapy focuses on fostering clients' understanding of sources of meaning in their lives, promoting a supportive context for exploration of challenges and emotions related to their experiences of illness, and enabling the creation and maintenance of a sense of meaning despite challenging circumstances.

Though initially developed as a group-based intervention for clients with advanced cancer, it has since been adapted into an individual format to accommodate limitations that declining health and mobility pose to group attendance (Breitbart et al, 2018). Delivered in 7 or 8 2-hour sessions for the individual and group formats respectively, the therapy incorporates psychoeducation, discussion and experiential exercises. The first session (or two for the group format) is devoted to participants getting to know one another and sharing stories of illness. The second session primarily takes a didactic approach to learning about existential concepts and general sources of meaning. Each week thereafter focuses on a different source of meaning such as illness, creative sources of meaning, attitudinal sources of meaning, experiential sources, and relational sources. Homework in the form of bibliotherapeutic readings, including parts of Viktor Frankl's *Man's Search for Meaning* (Frankl, 1965) and reflection prompts are assigned between sessions.

Randomized control trials have demonstrated Meaning-Centred Therapy to be more effective than general supportive therapy for improving advanced cancer patients' quality of life and reducing their depression, hopelessness, and desire for hastened death (Breitbart et al., 2012 2015, 2018; Rosenfeld et al., 2018). Furthermore, Rosenfeld et al. (2018) identified patients' sense of meaning as the mechanism of change behind positive therapeutic outcomes in

participants. In their study, meaning was found to be both an intermediary outcome as well as a mediator of other beneficial changes for participants (Rosenfeld et al., 2018).

Dignity Therapy

Dignity therapy is an individualized, narrative-based intervention designed to relieve psychological and existential suffering by enhancing an individual's sense of dignity, meaning and legacy through storytelling (Chochinov et al., 2002; Iani et al., 2020). Though developed for clients in palliative care, this approach has been adapted for use with individuals with chronic disease and the elderly. Dignity Therapy is theoretically grounded in an empirical model of dignity developed by Canadian psychiatrist Max Henry Chochinov (2002) that conceptualizes dignity based on experiences and emotions in three thematic categories. In the first category, illness mediated concerns capture preoccupation with loss of independence and growing symptom distress. The second category encompasses the repertoire of dignity conserving perspectives and practices that patients might employ to cope with advanced disease and approach death, including focusing on legacy, role preservation, hopefulness, autonomy seeking, acceptance, resilience, living in the moment, maintaining normalcy or seeking spiritual comfort. Third, the social dignity category articulates elements of changing relational dynamics that can threaten a client's sense of dignity, including loss of privacy, social support, caregiver attitudes, burdensomeness, and concern for the ones who will be left behind (Chochinov et al., 2002). Research that demonstrates a positive relationship between dignity and quality of life at end of life, and a negative relationship with depression, death anxiety and hopelessness, provide empirical support for the relationship of dignity to existential and psychological suffering (Donato et al., 2016).

The therapy arising from the Dignity Therapy model is itself relatively simple. A brief intervention that can be delivered in two sessions, it is based on a 10-question protocol intended to elicit client memories, life lessons, values roles, and the legacy the client wishes to leave behind (Kresdenter & Chochinov, 2020). In the first session, a trained clinician conducts a semi-structured interview with the client who has been provided with the questions in advance to give them an opportunity to reflect. The session is recorded and following the interview the client's responses are transcribed, compiled and lightly edited to develop a generativity or legacy document that can be shared with family and friends, allowing the client's voice to be carried into the future. As a therapeutic process, Dignity Therapy places less emphasis on interpretation, insight and working through, and greater emphasis on meaning-enhancing processes. While Dignity Therapy is not explicitly identified as a meaning-based therapy, meaning-making has nonetheless been identified as one of the central processes of change supporting the effectiveness of the therapy, particularly with individuals experiencing higher levels of existential suffering and spiritual distress (Bluck, 2022). This approach allows individuals to engage the opportunity to reframe life challenges, to find benefits in hardship, and to articulate the spiritual significance of life events. In sharing the generativity document, clients can foster better understanding and closeness with family members and communicate their wishes for them.

Numerous research studies have evaluated the effectiveness of Dignity Therapy worldwide, including several randomized control trials and at least two systemic reviews (Donato et al., 2016; Kresdenter & Chochinov, 2020; Saracino et al. 2019). Overall, Dignity Therapy has been shown to provide high and moderate support for enhancing dignity, meaning, and purpose in individuals with terminal illness, and has overwhelmingly high levels of acceptance by participants and their family members (Saracino et al., 2019). While some studies

show Dignity Therapy to be related to significant improvements in depression and anxiety in patients with high initial levels of both, its impact on actually reducing variables of existential distress in individuals with low or very high levels of depression and anxiety is less conclusive and warrants further study (Donato et al., 2016; Iani, 2020; Kresdenter & Chochinov, 2020).

Evaluating Interventions

While there are numerous approaches to treating non-physical suffering in individuals with advanced chronic and terminal disease, I have chosen to focus on psychotherapeutic approaches with a strong basis in existential theory for alleviation of existential distress, a pervasive and undertreated form of suffering at end of life. In considering how these types of therapies perform relative to others, four recent systematic reviews and/or meta-analyses were found that examined varied interventions for treating existential distress in relation to advanced cancer (Grossman et al., 2018), chronic illness (Eren et al., 2023) and mental disorders (Menzies er al., 2018; Vos et al., 2015). These reviews included studies on diverse procedures including exposure therapy, logotherapy, death education, cognitive and behavioral therapies, legacy therapies and spirituality-based care, as well as more specific manualized therapies such as Meaning Centred Group Psychotherapy (Breitbart et al., 2002) and Dignity Therapy (Chochinov, 2002).

A meta-analysis by Grossman et al. (2018) included only nine well-designed studies that showed small to medium overall effect sizes on measure of existential distress ($g = 0.449$) (Menzies et al, 2018). The meta-analysis by Menzies et al. (2018) included 15 randomized controlled trials in clinical and non-clinical populations and similarly found small to medium effect sizes ($g = 0.45$). While Menzies et al. (2018) found that psychological therapies outperformed more general death education approaches in relieving measures of existential

distress, this was largely accounted for by multiple studies included that showed strong effects of cognitive behavioural therapies, which are not considered in this capstone (Menzies et al. 2018). Other therapies tended to only be represented by one or two studies. Menzies et al. (2018) also reported that studies that screened their participants for high death anxiety found significantly greater effects, as did interventions that involved weekly sessions over several weeks rather than longer, but less frequent treatment sessions.

Overall, meta-analyses of the effectiveness of a range of psychotherapeutic interventions for different measures of existential distress have been mixed due to several, usually methodological challenges. Future research should ensure adequate randomization, compare active interventions to psychoeducation, provide clear and well-validated measures of the existential constructs being used and focus on maximizing sample sizes. Another issue that reviewing authors have proposed that impedes clarity of results is failure to control for other confounding factors known to be associated with death anxiety, such as attachment security, severity of symptoms and gender. Furthermore, the literature on existential distress in health care, while not prolific, is clearly biased towards populations of cancer patients, limiting its applicability to managing existential distress in participants challenged by other diseases.

Essential Findings

Overall, the information examined in Chapter 2 has brought forth essential concepts relevant to the role of mental health practitioners in understanding the psychosocial needs of individuals considering and choosing MAiD. The discussion has also outlined treatment approaches used in end-of-life contexts that may be relevant for these clients. The first part of this chapter examined forms of psychological, existential, and social suffering that commonly occur when living with severe and terminal illnesses, but that often go underacknowledged. This

highlighted the basic need for individuals engaged with the limitations imposed by advanced illness to have their experiences of existential distress, meaninglessness, depression, hopelessness, loneliness, loss of dignity and bodily autonomy witnessed and treated regardless of their decision to pursue MAiD. While the option to choose MAiD may be seen to offer a degree of palliation to some of these forms of suffering, the complexity of identifying when personal limits of tolerability have been met uncovered client needs for decisional supports, psychoeducation and access to timely referrals when a desire for hastened death is expressed, reasoned through and deemed actionable.

This chapter also extrapolated from the literature the unique aspects of experiences of MAiD relative to natural death, pointing to other considerations. MAiD can create a possibility for meeting basic human needs of empowerment, autonomy, dignity and may be an expression of a developmental need for acceptance of death. Given unique relational stressors and impacts on people who are left behind, support in navigating systems, family relationships and cultural contexts may emerge as central depending on the unique context of each client. The Chapter uncovered that MAiD experiences also create the possibility for new forms of suffering such as institutional trauma, social stigma, the burden of disclosure, and being deemed ineligible for MAiD, each of which may need to be named, acknowledged and processed. It became clear that the nature of some of these burdens may be carried more heavily by individuals on Track 2 than those on Track 1, highlighting the need for tailored approaches that will be explored in Chapter 3. Assessment of these needs and considerations in addressing them will be examined in greater detail in Chapter 3.

Finally, this chapter explored critical elements of interventions designed to support non-MAiD populations at end of life as a basis for exploring how they may be applied to those

considering and pursuing MAiD. Evidence from meta-analyses and systemic reviews of the efficacy and effectiveness of common psychotherapeutic interventions from various modalities for treating existential distress at end of life is not straightforward given several challenges and deficits in the research. There appears to be theoretical rationale for drawing on existential therapies to support MAiD clients, and empirical findings from the body of work on Terror Management Theory indicate that existential suffering in individuals considering and choosing MAiD might involve simultaneously promoting acceptance and reappraisal, boosting self-esteem, meaning making, spiritual strength and family supports. The strongest empirical support among existential therapies examined appears to exist for manualized therapies focused on meaning and dignity. The next chapter will further explore how these therapies might be modified to treat MAiD populations. Overall, the findings in this literature review provide a solid foundation on which to develop a more targeted account of the psychosocial needs of individuals considering and pursuing MAiD. Chapter 3 explores practical, theoretical, and ethical considerations and recommendations for clinicians who work with this population.

Chapter 3: Providing Psychosocial Support to Individuals Considering and Pursuing MAiD

It is both a key developmental endeavor and an ethical imperative for counselling professionals to consider the application of empirical research findings to clinical practice. Thus far, this capstone project has taken a traditional narrative approach to reviewing and integrating the qualitative and quantitative literature on MAiD and end of life care. It has addressed practical questions regarding the psychosocial treatment needs of individuals considering and choosing MAiD and identified elements of potential therapeutic approaches for addressing them. While my review uncovered limited targeted guidance for counselling professionals looking to work with this population, the findings nonetheless offer helpful insights that I will integrate with my own observations from my internship placement at Bridge C-14, a national, non-profit organization for supporting individuals affected by MAiD. Chapter 3 highlights important theoretical, practical and ethical implications for counsellors working with individuals choosing MAiD. I then summarize my recommendations for future research and clinician development in working with this population. This chapter concludes with personal reflections on the implications of my learnings to my practice aspirations.

Psychosocial Support Needs

While I could locate no formal published studies or tools for assessing the psychosocial needs of individuals considering and choosing MAiD, the broader literature on end-of-life care I reviewed was helpful for extrapolating needs arising from the various forms of suffering inherent in advanced illness, and the personal and contextual factors that may contribute to them. Careful examination of qualitative studies centering the perspectives of those engaged with MAiD, alongside the broader literature on end-of-life care, also revealed distinctive elements of MAiD

experiences relative to other trajectories of dying that can inform needs assessments. Furthermore, Clark and Peddle (2024) of Bridge C-14 have disseminated a helpful MAiD Psychosocial Needs Assessment Template which, although not yet published offers a useful starting point to support practitioners working with this population.

Overall, recognition of the wholistic nature of suffering arising not only from physical but also from psychological, emotional, existential and social pain highlights the range of domains counsellors must consider. As physical bodies make their limitations known, themes of loss, fear and anxiety, low mood, hopelessness, burdensomeness, social isolation, meaning and dignity related concerns can arise and interact with individual personalities, histories, identities and relational contexts to create unique assemblages of needs. This underscores the importance of a person-centred approach in sensitively and ethically addressing the various subjective manifestations of individuals' engagement with advanced illness.

MAiD Process-based Needs

An emergent consideration arising from this literature review is that the nature of the psychosocial needs of individuals considering and choosing MAiD is shaped by where they are in the MAiD process. Based on the literature and my internship experience with Bridge C-14, I propose four MAiD process-based phases to guide consideration of client needs and interventions. While various types of interventions such as psycho-education, decision-making support, bearing witness, relationship support, spiritual care, meaning making or referrals can occur at any point in the process, to a large degree, MAiD legalities and regional procedural variations shape the characteristic needs at various points in a client's journey. Table 1 contains a representation of this proposed four-phase model of process-based needs and potential counselling responses.

Table 1

MAiD Four-Phase Model of Process-based Needs and Counselling Responses

Phase	Key Needs	Counselling Responses
1) Decisional Support	Comprehensive information on treatment and end of life options	- Identify options and client preferences - Engagement with care teams
	MAiD pathway information	- Provide information about the lawful provision of MAiD - Psychoeducation on desire for hastened death - Referral to local MAiD coordination teams
	Emotional support*	- Basic counselling skills such as active listening, reflection, validation, non-judgement - Assess situational and baseline levels of symptoms - Modality consistent interventions
	Coping*	- Psychoeducation on self-regulation techniques, mindfulness, distraction, self-care
	Values-based decisional support*	- Solution- focused or Acceptance and Commitment Therapy approaches - Non-coercive problem solving
	Honouring losses*	- Assessment of grief symptoms and distinguish from depressive symptoms - Psychoeducation on anticipatory grieving - Naming and normalizing grief responses
	Engagement with social supports*	- Couple or family counselling - Group therapy or peer support groups
	Existential concerns*	- Meaning based therapies, support client autonomy, restoration of dignity and hope, life review
2) Eligibility Assessment	Navigating institutional uncertainties	- Possible advocacy needed - Engagement with care teams

Table 1 (continued)

3) Confirmed Eligibility	Life Review /Legacy	- Dignity Therapy, Meaning-based Therapy, art therapy, journalling, letter writing, creative projects
	Disclosure Management	- Facilitation of family and couple counselling or meetings - Rehearsing difficult conversations - Exploration of client of needs versus others' needs and boundaries
	Establish personal readiness to choose a date	- Explore coping and resilience in face of changing suffering - Consider unfinished business, relationship repair - Consider what values and meaning MAiD addresses for client
	Planning the Day	- Visualization, planning and clarifying client's vision - Other resources such as spiritual care or death doulas
4) Confirmed Ineligibility	Safety	- Safety risk assessment and enhanced informed consent
	Acknowledge forms of institutional or systemic trauma*	- Name and acknowledge forms of discrimination within the system - Engage in advocacy

Note. This table contains some of the key clinical psychosocial needs identified for individuals considering and choosing MAiD outlined in this capstone project, and possible counselling responses to them. The * indicates items that occur in multiple phases.

Decisional Support Phase: Individuals with advanced illness are often working to integrate their internal experience with the changing external realities of their illness. Living with the reality of continued decline, treatment uncertainty, ambiguous dying, or approaching death necessarily involves constant recalibration of one's capacity to tolerate what is present and what is coming in relation to the range of options available to that person and their own unique context. In accordance with the research demonstrating the various meanings and functions of an expression of a wish for hastened death, skillful navigation of such expressions to uncover unmet needs may point to referrals needed to expand the support team or possible targets for psychotherapy (Borges et al., 2024; Ohnsorge et al., 2014; Rodriguez-Prat et al., 2024). At a practical level, individuals grappling with advanced illness require easily accessible and comprehensive information about decision points and their options. Counselling professionals should assess a client's understanding of their options and choices; concerns about navigating these options and preparedness for end of life can point to issues to address in counselling or other referrals or resources required.

While it is illegal to advise or coerce someone into choosing MAiD, due to the relative recency of MAiD legalization in Canada, not all clients will be aware of it. Evidence also suggests that this option is not always presented in a timely fashion to patients in medical settings (Close et al., 2023). However, in the context of a conversation about end of life wishes or an expression of hastened death there may be a need for counselling professionals to provide information about all possibilities surrounding the desire to die including how it can fluctuate over time, how it may signal other unmet needs and that MAiD exists as a legal option for eligible individuals. Though it is beyond a counsellor's scope of practice to provide medical advice, having basic knowledge of end-of-life resources and access points, including information

about the process and lawful provision of MAiD can help to mitigate the "pathway ambiguity" identified as a source of frustration for those navigating end of life (Close et al., 2023). Care on the part of the practitioner to not imply eligibility for MAiD prior to the completion of such an assessment by MAiD assessors is critical for maintaining ethical standards of preserving autonomy and avoiding harm to the client.

Regardless of a client's medical pathway, gentle broaching and exploration of a clients' views of and relationship with their illness, suffering and mortality within the context of a therapeutic relationship can help clients to clarify their own choices and decision points whether MAiD is chosen or not. From a therapeutic perspective, achieving a balance between acknowledgement of the limitations and suffering present while also cultivating a client's ability to cope and adapt to these limitations and reengage meaningfully with what life they do have may help them to align their choices with their own values and inner guidance.

Eligibility Assessment Phase: Once a client has decided that MAiD may be an option for them, they must make a request to the regional MAiD coordinating office and the eligibility assessment process is triggered. In this phase, emotional support in navigating institutional uncertainties or managing communication and disclosure of one's choice to others may take centre stage. Different procedural safeguard for those pursuing MAiD under Track 1 (death reasonably foreseeable) and Track 2 (death not reasonably foreseeable) mean that that this phase often lasts several weeks and months longer for those on Track 2 versus those on Track 1. In general, Track 2 assessments tend to involve more complexity and there is greater uncertainty in a desired outcome of eligibility. For individuals seeking MAiD on Track 2 who suffer from prolonged chronic health conditions, the process of being found eligible for MAiD may at once hold the potential for legitimizing their suffering, and it may also activate feelings of systemic

distrust for those who have endured institutional trauma within the medical system (Fruhstorfer et al., 2024). Individuals who have experienced systemic discrimination within the medical system due to marginalized identities may need to have those experiences validated, to name the particular form of injustice experienced, and possibly to have support in advocating for their needs within those systems.

Regardless of the extent and quality of a client's relationships, being at the brink of a choice to end one's own life is a significant threshold that may create a sense of isolation. Research reviewed in this capstone accentuated the pervasiveness of denial, secrecy, relationship pressures and social isolation that often emerges around diagnoses and advancing diseases (Glaser & Strauss, 1965; Rattner, 2022; Walker & Wong, 2018). This can be further compounded by the possibility of stigma and risk of social judgement around a decision to pursue MAiD (Crumley et al., 2023; Singer et al., 2023). For those who are feeling isolated, connecting with other individuals in a similar predicament may partially mitigate this disconnection, pointing to the possible benefit of peer supports or group counselling.

Confirmed Eligibility Phase: After being deemed eligible, individuals may move into a more reflective space considering legacy and meaning, addressing remaining tasks of dying and unfinished business, choosing a MAiD date, and planning what that day should look like. The question of how individuals will know when to set a date becomes salient, particularly for Track 2 individuals for whom the non-foreseeability of death renders the question more open-ended. With no known guidance framework for this type of decision, further research on definitions of personal readiness with individuals in this phase is warranted. Based on my research and personal experience working with individuals facing this decision, a preliminary framework might include four main elements. First, individual evaluation of personal levels of tolerance for

the suffering they endure requires looking closely at where declining function meets the ability to not just endure but to adapt to the change. For example, as the ability to engage in certain meaningful activities shifts, other elements such as a greater appreciation for moment-to-moment pleasures may offset some of the suffering and provide a new source of resilience to changing conditions. As this can be a moving target, it is important that other factors be considered. A second consideration in personal readiness might be in identifying any unfinished business including things people still want to accomplish or relationships that need repair or closure. A third factor in this exploration could be in developing an individual's conception of what they are moving towards in choosing MAiD, rather than what they are moving away from. For example, this could involve uncovering how choosing MAiD might align with certain values and meanings or an opportunity to explore spiritual beliefs. Finally, for some there just may be an innate sense of knowing that it is time. A well-designed qualitative research study could be helpful in substantiating or revising this preliminary framework and offer some guideposts for individuals who struggle with the decision. Regardless of the existence of a framework to guide such decisions, it becomes an intensely personal decision that calls, at minimum, for an open and unbiased listener. Further referrals and informational needs may arise around coordinating the provision date, including where MAiD is to occur, who will be present, how it will unfold, how the body will be transported and disposed, and planning of ritual or ceremony that incorporates elements of the person's life and legacy. Depending on a counsellor's scope of competency, this phase may require referral to other specialists such as spiritual carers or death doulas.

Confirmed Ineligibility Phase: For individuals who are deemed not eligible to receive MAiD, the limited current research suggests that a period of heightened safety risk and more intensive support may be required; however, the nature of the required support is presently an

important gap in literature. For counselling professionals, work with such individuals may involve addressing emotional reactions to such a decision, supporting re-engagement with living and monitoring for heightened safety risk for which consequent safety planning may be warranted; however, counselling professionals would benefit from development of best practices in this domain. Continuing to regularly check in and stay current with the client's intentions towards dying would be necessary to gauge risk. In the event a client who has been deemed ineligible for MAiD discloses a well-reasoned plan to end their life, the question of harm to the client can become a grey area and highly context dependent. In the absence of concrete guidance, counselling professionals would benefit from leaning into the ethical decision-making frameworks of their professional organizations for managing ethical dilemmas that may arise. There may be a further need to adjust informed consent processes to highlight counsellors' professional obligations in these cases.

Social Need Considerations

The studies reviewed in this capstone reveal that decision making and preparation for MAiD are complex and nuanced processes involving heavy emotional labour for the individual as well as their family, friends and care team at all phases of a MAiD journey. Depending on personal preferences and capacity as well as relationship dynamics, individuals may differentially prefer to explore the decision alongside important others or to the exclusion of others. Evaluation of a client's perception of isolation, the extent and quality of the client's social support system and the client's level of comfort in discussing emotion and end-of-life matters can help to identify whether MAiD specific group counselling, peer support or professional therapy may be beneficial to supplement informal networks of social support. Counsellors should further evaluate how family members have been responding to the client's

broaching of MAiD, the clients' preferences for family involvement in the provision, the client's experience of stigma and judgment, the involvement of children, complex family dynamics or disagreement with the choice to pursue MAiD. Counsellors might further explore with their clients whether family or couples counselling approaches may be beneficial.

Emotional Need Considerations

Regardless of the circumstances, humans have a deep need to have their emotional experiences witnessed and validated. Counsellors should assess for the range and variability of primary and secondary emotion arising from illness experiences and the possibility of impending death, and also specifically to MAiD as the mode of death and what it represents for a client. The prospect of considering MAiD for oneself can bring about guilt, relief, sadness, fear or moral distress which can be helpfully processed in accordance with a person's beliefs and worldview, history of observing the suffering of others, moral understanding, and social-relational context.

Although possibly a limitation imposed by my research strategy, my investigations suggest that experiences of grief related to advanced illness and end of life appear to be de-emphasized in the literature. In particular, the literature on grief related to MAiD tends to focus on the experiences of the bereaved, and less on the grief of the dying. Anticipatory grief has been conceptualized as "grieving a loss that is still to occur, to already feel it, prepare for it, and act upon it. Simultaneously, these losses that are expected to happen are folded into the experience of losses that occur in the present" (Lemos Dekker, 2023 in Worrell & Hemer, 2024). The experience of living with advanced illness and dying has a large component of grief for non-death losses of abilities that contribute to sense of self, the falling away of normalcy, changing social roles and mental capacities. For individuals facing end of life, grief for the future loss of everything one knows can weigh heavily. Once a date for MAiD is chosen, life becomes a

"parade of lasts" that requires a huge capacity for holding (Pesut et al., 2021). Counsellors can determine client needs around their grief experiences by assessing grief symptomology, normalizing styles of grieving and emotional expression, and evaluating the need for additional coping strategies and psychoeducation on grieving processes.

One related issue emerging from my review pertains to determining clinically relevant levels of emotional distress from what would be understood as normal reactions to advanced disease and impending death. Clinicians must avoid pathologizing natural responses to human experience, yet there remains a necessity to recognize when such states are severe and impairing (Eren & Kissane, 2018). In the realm of MAiD eligibility assessment, the presence of clinical levels of depression is important not in necessarily precluding MAiD as an option, but rather for preventing it from hindering sound decision making around a desire for hastened death. Aside from eligibility assessment, more severe levels of depressive symptoms may interfere with individuals undertaking the tasks of dying and optimizing the time they have left. Though beyond the scope of this capstone project, selection and employment of instruments designed to assess depression severity may help to identify when more targeted interventions are required. Further assessment to discern grief symptomology from depressive symptomology in clients with advanced illness expressing a desire for hastened death is a recommended topic for further study. It is suggested that targeted training of counsellors to assist in discernment of grief and depressive symptoms and ranges of variability would support counsellor confidence in working with this population.

Cultural Need Considerations

Despite the paucity of data on the influence of culture and various identities on MAiD experiences identified through my review, counsellors are nonetheless trained and ethically

required to assess the culturally relevant needs of all their clients regardless of presenting concerns. As such, counselling professionals should carefully inquire into how clients' cultural identities inform their perspectives on illness, dying and MAiD, the degree of respect they have felt for their identities within the health care system and during the MAiD process, and determining whether there are cultural practices clients would like to incorporate into their provision day.

Counsellors may uncover different needs for family involvement depending on whether individuals are from collectivist cultures or individualistic cultures. MAiD legalization and assessment processes are founded on values of respect for personal autonomy that recognize the ability to make independent and fully informed decisions. While this is seen as important to ensuring decision making is free from coercion, manipulation and abuse, such an emphasis on individualist conceptualization of autonomy can undercut important social values such as family harmony, filial piety and community and social responsibility that are cornerstones of decision-making in some cultures (Gomez-Virseda et al., 2019). As such, the concept of relational autonomy has emerged from medical literature to challenge the privilege of Western concepts of autonomy and to balance individual and collective needs in end-of-life decision making. Relational autonomy aims to maintain the essential aspect of autonomy, namely control over one's life, while at the same time, incorporate insights of social embeddedness (Gomez-Virseda et al., 2019). Further study of potential directions for operationalizing relational autonomy within MAiD processes may bring cultural alignment for some groups. At the very least, counsellors should assess the need for family interventions.

Spiritual & Existential Need Considerations

Confrontation with one's own morality inevitably brings about questions of spirituality. From a needs assessment perspective, the construct of spirituality can be divided into two aspects: a religious component, referring to one's faith and relationship to their conceptualization of the divine, and an existential component, referring to one's sense of meaning and purpose in life (Bauereiß et al., 2018). Counsellors can determine spiritual needs by inquiring about how clients' religious beliefs contribute to their understanding of the nature of suffering, death and MAiD, religious practices or ceremonies that might support clients, any connection they might have with religious and spiritual leaders and the degree of alignment of their decision to pursue MAiD with the teachings and beliefs they hold. Psychoeducation around the value of ritual at end of life, whether religious or secular, can help clients to bring intentionality into their final days, to integrate beliefs, legacy and moments and to integrate friends and family who are present at the provision. Depending on the needs identified, referrals to spiritual counsellors, chaplains or death doulas who might hold expertise in ritual and ceremonial practices at end of life may be provided. Even when clients do not have a strong religious or spiritual orientation, inquiry into existential questions of meaning and purpose, locus of control, identity, their reflections on the legacy they are leaving behind and the meaning they hold of MAiD can illuminate fruitful directions for spiritually aligned counselling.

Treatment Considerations

Practical Considerations

My literature review uncovered that working with populations with advanced illness and at end-of-life entails specific practical considerations that apply to those choosing MAiD. Individuals in these circumstances commonly struggle with declining physical health, frequent

"bad days," and other symptoms (e.g. physical exhaustion, cognitive fog etc.) that may interfere with optimal participation in therapy. Such clients may also be subject to limited medical and legal appointment availability, resulting in less control over their schedule. High attrition is frequently noted in longitudinal research studies and in therapy formats that require commitment to a certain number of sessions, highlighting the need for counselling approaches that emphasize flexibility and brevity (Breitbart et al., 2018; Samuels et al., 2021). Furthermore, interventions that involve weekly sessions appear to be most effective (Menzies et al., 2018).

Counsellor flexibility is required with respect to scheduling and cancellations, accommodation of client energy levels (e.g. shortened sessions, having more sessions in periods of relative wellness) and location of treatment (Saracino et al., 2019). Varker et al. (2019) show that telepsychology is as or more effective as in-person counselling for a range of mental health conditions and that one of the benefits is improved accessibility for populations with declining physical health and mobility. Yet, variations in mobility and technological competence may require the presence of a helper to facilitate the client's use of an online platform. Finally, counsellors must be willing to engage with families and treatment teams to facilitate integration of personal tasks with relational and practical tasks at end of life.

While group counselling targeting MAiD clients may offer an important means of addressing isolation and loneliness, careful consideration should be given to the objectives, the relative merits of closed versus open formats and group membership. Given the distinct process-based needs identified through this capstone, it would be practically and ethically prudent to separate group offerings for those considering MAiD from those who have been deemed eligible for MAiD. For those considering MAiD, foci may be on sharing experiences of living with advanced illness (e.g. grief, relational challenges etc.), reflection on values and priorities,

fostering connection and providing accurate information about the MAiD process. For those who have been approved, there may be a greater need for explorations around meaning making of life and death, legacy, navigating disclosure, planning for the MAiD date. While one does not necessarily need to be eligible for MAiD to explore meaning and one's relationship with mortality, mixing these two groups may introduce ethical complexities should a member in a closed group be deemed not eligible. Closed formats may facilitate more intimate connections among group members; however, some accommodation for frequent absences may be required, limiting the degree of group cohesion that can be achieved. As such, shorter workshop-based interventions focusing on specific topics of interest may be appropriate to address particular topics that emerged through this capstone as important to this population such as "How Will I Know When I am Ready?" "Telling Others About My Choice," "Sharing My Legacy" or "Planning My MAiD Day". Such approaches might be sufficient to address clients' needs for information and connection or they might be useful adjuncts to more individualized therapeutic support.

Theoretical Considerations

Based on my review, it is difficult to draw definitive conclusions about the potential effectiveness of various therapeutic approaches and interventions for working with individuals considering and choosing MAiD. Generally, evidence from meta-analyses and systemic reviews of the efficacy and effectiveness of common psychotherapeutic interventions for treating existential distress at end of life is not straightforward given several challenges, including but not limited to application to a narrow range of populations, lack of cohesive and consistent outcome measures, and failure to include important correlates.

Yet, examination of the approaches and evidence base of existential based therapies that are often used to treat existential distress with clients approaching end of life nonetheless provides helpful departure points for approaches to support individuals considering and choosing MAiD. One notable point relevant to the purposes of this inquiry is the suggestion by Grossman and colleagues (2018) that the interventions they evaluated as having measurable benefits on variables of existential distress did so because they comprehensively addressed, to varying degrees, a characteristic suite of domains. These include: a) maintaining and strengthening relationships; b) regaining a sense of control; c) sustaining a sense of continuity of self; d) decreasing a sense of burden to others; e) production of generativity documents or legacy projects; f) relief of fears about the dying process; and g) maintenance of hope. It is noted that several of these elements align with proximal and distal mechanisms for addressing death anxiety identified through empirical research on Terror Management Theory (Perry et al., 2022; Svet et al., 2023). To the extent that these elements can be captured in working with individuals considering and choosing MAiD, modifications to ensure inclusion of unique aspects of the MAiD experience may be helpful. Of course, selection of any type of intervention must include consideration of the client factors and the skill set and theoretical grounding of the clinician.

To the extent that benefits to quality of life, sense of meaning, dignity and resultant moderators arising from Meaning Centred Psychotherapy and Dignity Therapy might be applied to MAiD populations, adding explicit MAiD content to these manualized programs may help to tailor them to this end-of-life trajectory. Indeed, this approach has informed the development of MAiD programming by Bridge C-14, a national non-profit organization that provides

psychosocial support to those considering and choosing MAiD and their supporters (Clark & Peddle, 2023).

Dignity Therapy holds potential as a way for individuals choosing MAiD to communicate their experiences of suffering and rationale for choosing MAiD to family and friends. This may help to bolster circles of support and mitigate silence and isolation while also supporting loved ones' bereavement processes. The current Dignity Therapy interview protocol could be adapted for MAiD populations by incorporating specific questions about the client's choice to pursue MAiD such as: "How is your decision to pursue MAiD a reflection of your life and values?" or "What role has the option of MAiD played in your life and what meaning does it give you?" Such questions would explicitly invite the client to examine their choice within the embeddedness of their context.

Possible adaptations of Meaning Centred Psychotherapy might also involve explicit incorporation of discussions about MAiD as a source of meaning. The limited research reviewed that centred individuals choosing MAiD found that applicants often regard MAiD as an expression of their values of autonomy and control (Gamondi et al., 2019). While suffering and loss of meaning in the face of illness might drive requests for MAiD, the ability to exercise autonomy and choose an end consistent with values provides clients the opportunity to make their death meaningful and possibly even empowering. Clients might be encouraged to consider how attitudinal, creative, experiential and relational sources of meaning in their lives help to inform not only their choice of MAiD in the face of suffering, but also how those sources of meaning might support the way they approach the tasks of disclosing to family members, addressing stigma, or choosing rituals or elements of their MAiD day. Another consideration related to the possibility of adapting the manualized version of Meaning-Centred Psychotherapy

for MAiD clients is the relevance of Viktor Frankl's Man's Search for Meaning as the resource book for a group focused on MAiD (Frankl, 1962; Clark & Peddle, 2023). Feedback from participants in a pilot program called Meaning Based Group Psychotherapy for MAiD developed by Bridge C-14 uncovered that although participants valued exploration of existential concepts, Frankl's emphasis on survival could be read as a characterization of death as a failure to find meaning in overcoming adversity which may not be consistent with contemporary views underlying motivations for MAiD (Clark & Peddle, 2023). Furthermore, specific content in the book may not promote a sense of cultural safety for racialized and sexually and gender diverse clients (Clark & Peddle, 2023). Any adaptation of Meaning Centred Psychotherapy for MAiD clients might best choose a different foundational resource.

Overall, while there appears to be good rationale for adapting these manualized approaches to MAiD populations, further research is required to substantiate the nature and degree of potential beneficial outcomes to specific measures of existential distress. A further consideration is that the recommendations for adaptations of these therapies herein assume the choice to pursue MAiD has already been made and thus may best be applied to individuals whose eligibility has been confirmed through the MAiD eligibility assessment process.

A final consideration for application of both Dignity Therapy and Meaning Centred Psychotherapy is the challenge of applying manualized therapies to meet unique needs. While manualized therapies are conducive to conducting research necessary to establish evidence-based psychotherapies, there is little evidence that they are superior for obtaining clinical outcomes than non-manualized therapies (Truijens et al., 2019). Given the importance of personal and contextual factors in determining limits of tolerability, readiness for dying, and the necessity of

flexibility, strict adherence to manualized therapies may occlude existential theory's emphasis on phenomenology and challenge the maintenance of a person-centered treatment approach.

It is also important to recognize that not everyone will benefit from meaning centred therapies or existential approaches. Lo (2018, p.2657) proposed that "that the ability to cope with mortality is influenced by a person's developmental history, including their pattern of resiliencies and vulnerabilities in response to prior life challenges, and their life stage before the onset of illness." Researchers stressing the central role of grief and loss in the end-of-life experience argue that interventions that focus on facilitating meaning making and fostering personal growth may circumvent the need for approaches that simply acknowledge and hold space for patients' profound and varied losses, worries and fears (Rattner, 2022). Sometimes, the most appropriate and therapeutic response is simply bringing a deep compassionate presence and bearing witness to the clients' struggles without attempts to make meaning, reframe or other more "active" interventions. The ability for a counsellor to recognize when such an approach is needed is fundamental to competent person-centred care.

Limitations

One important limitation of this capstone project has been my narrow focus on two existentially based manualized approaches: Dignity Therapy and Meaning Centred Psychotherapy. In not taking a more systematic approach to reviewing psychotherapeutic interventions that also appear to have robust literature in some end-of-life populations, I precluded uncovering the value of other approaches that might also dovetail nicely with existential theory. For example, there appears to be a growing research base pointing to the utility of mindfulness-based approaches such as Acceptance and Commitment Therapy (ACT) and/or Mindfulness Based Cognitive Therapy (MBCT) related to living with chronic and

terminal illness that could also be explored. ACT is a form of cognitive behavioural therapy that aims to maximize an individual's potential for a meaningful life by teaching psychological skills that bolster the ability to allow and effectively cope with difficult thoughts and feelings, and take actions that are consistent with one's values (Harris, 2019). Based on a cursory glance at the literature on this modality, there appears to be good rationale for its application to MAiD populations. Emerging evidence is pointing to the effectiveness of ACT in improving quality of life and alleviating depression, fatigue as well as existentially related symptoms such as anxiety, distress and anticipatory grief among individuals with advanced progressive illness (Davis et al., 2017; Fang et al., 2021; Gibson-Watt et al., 2023). As such, this exploration is incomplete.

In addition to the ways my chosen existential framework narrowed the scope of potential treatment options I considered, it may have also narrowed the cultural perspectives I could fairly represent in this capstone and the applicability of my findings to clients with diverse worldviews. A further limitation in the findings of this capstone project is that the combination of my stated initial support for MAiD along with my narrative integrative approach is that there may have been some bias in my selection of articles for the literature review. To minimize selection bias as much as possible, I did seek out discrepant findings or opposing viewpoints in the literature. On one hand this approach allowed me to develop one of the key themes of this capstone that MAiD can be a source of suffering as much as an approach for the palliation of suffering; however, on the other hand, there may be ways that my personal biases affected my conclusions and recommendations. As such, careful consideration of ethics must inform any approach recommended in this this capstone.

Ethical considerations

In working with clients considering and choosing MAiD, adherence to professional ethical codes, standards and guidelines is essential for protecting both clients and practitioners, supporting quality of service to the public and guiding ethical decision-making. Currently practice guidelines for working with this population are inconsistently available across designations (e.g. psychologists, psychotherapists and counsellors) and jurisdictions within Canada. For psychologists, the Canadian Psychological Association has issued the *MAID Task Force Report & Practice Guidelines for Psychologists Involved in End-of-Life Decisions* (CPA, 2020) that touches on both assessment and psychological treatment aspects of MAiD. Some jurisdictional bodies offer guidelines which primarily touch on assessment considerations and the legalities around providing information on the legal provision of MAiD (CAP, 2024; College of Health Care Professionals of BC, 2017). Otherwise, the Canadian Counselling and Psychotherapy Association does not yet appear to have guidance relating to working with individuals considering or choosing MAiD. Regardless, the law and professional codes of practice and standards provide important frameworks for guiding counselling professionals working with this population and their families.

Dignity and Autonomy

Respect for dignity and autonomy of individuals is a foundational value for both counselling professionals and the legalization of MAiD. Recognition of individual self-determination in the choice of when and how to die is at the heart of MAiD legalization and counselling professionals are bound to respect their clients' rights to self-determination and personal liberty. This might mean that in cases where a practitioner's values are not consistent

with their client's decision on whether to pursue MAID, clinicians must avoid imposing their values on their clients.

While any healthcare professional can legally provide information, initiate and engage in discussion, and educate clients about MAiD, counsellors must not be seen to have the aim of inducing, persuading, or convincing the patient to request MAiD (Canadian Association of MAiD Assessors and Providers, 2022). In providing information, counselling professionals should make no statements regarding the potential eligibility of any client, as this could provide clients with a false sense of hope if they decide to pursue MAiD. Instead, referral should be provided to the regional body for MAiD assessment and provision. Any decision a client makes must be made voluntarily and free from any external pressure. To avoid the appearance of promoting or advocating for MAiD, counsellors should ensure such information is offered within the context of client questions or a conversation about end-of-life options. The use of neutral and non-directive language is recommended to avoid any expressions that might suggest a preference or influence a client's decision. Instead, counsellors should focus on providing balanced information and appropriate referrals that allow the client to weigh their options independently. For example, it seems more likely that a counsellor could be seen as unduly influencing a client if information on MAiD is provided in isolation from other information or referrals related to end-of-life including death and dying, palliative care and comfort care, community resources available, grief support, psychological interventions, or advance care planning. Furthermore, when providing information about MAiD and facilitating exploration of end-of-life concerns or expressions of a desire for hastened death, abiding by practice standards that stipulate accurate record keeping is especially prudent.

Confidentiality

One under researched area that emerged during the literature review is the potential for ethical dilemmas to arise when individuals have applied and been deemed ineligible to receive MAiD. The limited data currently available suggest that such individuals are at heightened risk of suicide. In such situations, careful navigation and revisitation with the client of the limits to confidentiality around imminent suicide, potential consultation with colleagues/employers and full consideration of the ethical decision-making frameworks outlined by professional bodies would be required.

Informed Consent

In addition to the full range of information given to clients undergoing counselling services, there may be specific risks for clients involved in group counselling with MAiD populations. Informed consent for closed groups of individuals who have been approved for MAiD should raise the possibility that members could choose their MAiD dates during the course of the program, representing an emotional risk to participants and counsellors alike, who may experience grief and lack of closure with the loss of a group member. Informed consent for online groups should include the possibility that other individuals outside the group may be present as helpers and these helpers should also be made to sign confidentiality agreements.

Competence

To avoid harm to clients, counselling professionals have an ethical obligation to practice within the limits of their competence. This requires obtaining adequate training in their areas of practice, seeking consultation when a client's issues are beyond their scope, and examining their own experiences, attitudes and beliefs for biases that might impact their work. My research has revealed that there are currently few training options for counsellors wishing to work with clients

involved in MAiD. The lack of training in MAiD for mental health practitioners in Canada is a recognized challenge in developing professional competency among mental health practitioners working with this population. Existing scholarship indicates that those working in larger, interdisciplinary team environments or who have some degree of end-of-life training generally feel better prepared to meet the needs of clients involved in MAiD, but that this does not replace MAiD-specific training (Buote et al., 2022; Bravo et al., 2023). For counsellors in general or private practice, the need to have access points and consultation resources available is crucial, yet counselling specialists in this area are few. At present, the most comprehensive MAiD training is a recently developed program for nurse practitioners and physicians through Canadian Association of MAiD Assessors and Providers; however, it is not targeted to mental health practitioners. Bridge C-14, a national non-profit organization dedicated to supporting MAiD recipients and their families, offers an annual conference for a range of practitioners, including mental health practitioners, health care professionals, death doulas and hospice workers.

Meaningful training to support a sense of confidence and competency in counselling professionals would ideally bridge basic counselling competencies such as active listening and communication, cultural competencies and professional ethics with subject matter education in palliative and end-of-life care, loss, grief and bereavement and specific MAiD content. MAiD content would need to provide an understanding of the overall process, as well as local iterations, references points and organizational supports. A strong emphasis on professional ethics with examination of case studies would further support professional development of counsellors looking to support this population. A key competency to include in such a training is the ability for self-care and self-reflection to buoy practitioners in maintaining professional integrity, offering responsive care and avoiding compassion fatigue. Gamino and Ritter (2012) highlight

the ethical imperative of *death competence*, defined as a specialized skillset in tolerating and managing clients' problems related to death, dying and bereavement. One of the core features of death competence is the ability to manage countertransference when confronted with clients concerns and experiences with death and dying. Conversations about death and existential challenges can be difficult and may activate counsellors' own death anxiety or identification with the client's loss of morale. In preparation for such work, counsellors are encouraging to explore what draws them to working with the dying and bereaved, how their own beliefs and experiences of loss and endings might affect their work, and what motivates their ongoing interest in the work.

As provinces and territories endeavor to operationalize federal MAiD provisions, the roles counselling professionals can play in this process are still somewhat ambiguous and ever evolving. As such, the value of a well-reasoned ethical decision-making process, professional consultation, and proper documentation all become clear. For counselling professionals open to including MAiD clients within their practice, continued self-reflection on values and biases, adherence to the ethical frameworks, following developments in the field, choosing relevant research topics and taking continued trainings on MAID *and* end-of-life care are measures that can be taken to help prepare them for that path.

Recommendations & Future Research

MAiD is still relatively new in Canada and while the research base is growing, much remains to be discovered. The various research and practice gaps raised in this capstone project represent opportunities for counsellors to embark on journeys of discovery with their clients and colleagues as trainers, consultants and researchers. Here I offer recommendations for future research and practice guidance generated from this exploration, categorized according to more

immediate recommendations to support counselling practice, methodological recommendations for future research and recommendations for future research topics that have the potential to inform theory and practice in the longer term.

Supporting Immediate Practice Concerns

- Professional organizations of counselling professionals should partner with MAiD trainers in other professions to support the development of and to deliver MAiD specific-training for counselling professionals who work with MAiD clients and their families outside of MAiD and medical coordination teams.
- Clark and Peddle's (2024) MAiD Psychosocial Needs Assessment Template offers a useful starting point to support practitioners working with this population; broader dissemination and validation work is recommended to help to expand its reach. Furthermore, given regional variations in access to programs and resources, consideration could be given to development of regional variations of this tool.
- Government and health care authorities should focus on the development of one-on-one psychological support for individuals considering Track 2 applications for MAiD. Although fewer in number than Track 1 applicants, Track 2 cases tend to be more complex, as evidenced by the disproportionate findings of ineligibility. As such, these individuals are more likely to be at risk of institutional trauma and have socioeconomic statuses that preclude access to professional counselling. Higher complexity may also limit the ability of any group programs to address needs in this group. Whereas Track 1 individuals are more likely to access services through palliative care routes, these services are generally not available to Track 1 applicants signaling a gap that needs to be addressed.

- Knowledgeable professionals in the realm of MAiD should consider research and work towards development of a framework to support personal definitions of readiness for when to receive MAiD, particularly for those on Track 2 when death is not reasonably foreseeable.
- Given the prevalence of grief in the face of the cumulative losses of advanced illness, consideration should be given to further development of tools for discerning grief symptomology from clinical levels of depression can support appropriate treatment.
- Development of guidelines for practitioners for ethical "gray areas" such as broaching MAiD and risk assessment with those expressing a wish for hastened death in the context of advanced illness or mental health co-morbidities would likely help to address perceived professional risks preventing counsellors outside of health care teams from engaging with this population.

Methodological Considerations for Future Research

- Identified research gaps on the role of race, culture, diverse gender and sexuality identities, ability or socioeconomic status on MAiD attitudes, access and experiences underscore the need for a greater focus on diverse populations in future research. At a basic level this requires ensuring that demographic and diversity variables are included in all research and government reporting on MAiD; greater intentionality in diversifying the study populations is essential.
- Drawing on the included systematic reviews of approaches to treating existential distress, future research should ensure adequate randomization, compare active interventions to psychoeducation, provide clear and well-validated measures of the existential constructs being used and focus on maximizing sample sizes. Analyses on how to streamline the

large number of outcome variables that are captured under the umbrella of existential distress would be beneficial for clarifying what the more important variables are to target in treatment planning. Finally, there should be a greater focus on controlling for other factors that are known to be associated with death anxiety and existential distress such as attachment security, severity of symptoms and gender.

Future Research Topics

- More outcome research with strong methodological approaches on the impact of various counselling approaches and interventions on those pursuing MAiD would help to develop the evidence base for various therapies. In particular, to inform the extent to which known benefits of Dignity Therapy and Meaning Centred Psychotherapy might be enjoyed by individuals choosing MAiD, research trials on adapted formats of these therapies with this population are warranted. Such research might consider whether engagement in meaning-centred therapy for eligible individuals is more likely to promote a greater engagement in life and/or delay of a provision date, or alternatively, whether these approaches are more likely to provide greater peace in choosing one's date sooner.
- Further research on counsellors' beliefs, attitudes, knowledge, education and experience with death and dying and MAiD, along with barriers to working with this population, can help to illuminate strategies for increasing the pool of counselling professionals beyond healthcare teams available to support individuals.
- Further research into the factors that influence longitudinal development of a wish for hastened death to a request for MAiD could help to illuminate more specific points of intervention for alleviating the suffering that leads to MAiD.

- Building on Svet et al.'s (2023) recommendation for further study of TMT with populations with advanced disease, further study of the relative value of distal and proximal mechanisms in those choosing and not choosing MAiD may offer more targeted approaches for treating non-physical forms of suffering.
- Further qualitative studies on the experiences of Canadians from various jurisdictions and identity groups pursuing MAiD are necessary. For instance, the link between culturally informed attitudes and actual behaviours with regards to choosing MAiD would help to provide a more meaningful understanding of the choice at a personal level.
- Finally, at a philosophical and broader-culture level, there is a need for further theoretical and qualitative research that considers the role of MAiD in either reflecting or facilitating acceptance of death and transcendent experiences of mortality salience. Such explorations can help to broaden the conversation around death and dying beyond the current focus on suffering to one that normalizes the desire to move towards death as more than a pathological response.

Conclusion

This capstone project aimed to address the question of how counselling professionals can best support individuals who are considering and choosing to pursue MAiD in Canada. This investigation first explored the extant literature to understand the nature and phenomenology of the suffering that leads people to consider MAiD, uncovered elements that may be considered singular to the MAiD experience relative to natural death, and identified approaches for the treatment of existential suffering that could be drawn upon or modified in devising psychotherapeutic approaches for supporting this population. The findings from the literature review were then integrated to develop an account of the needs counsellors must consider and

assess for in working with individuals considering and pursuing MAiD, depending on where clients are in the MAiD process. Practical and theoretical considerations for relieving existential distress highlighted both important features of possible treatment approaches as well as ways that existing evidence-based manualized treatments of Dignity Therapy and Meaning Centred Psychotherapy might be modified to explicitly incorporate MAiD content into their programs. Ethical considerations related to maintenance of dignity and autonomy, the need to emphasize limits to confidentiality, special risks to consider in obtaining informed consent and issues of maleficence related to counsellor competence and training were identified. Recommendations to guide practice and for future research that were identified throughout this work were summarized at the end.

Overall, this capstone project has proven to be a personally and professionally meaningful investigation. Having previous academic experience primarily with quantitative research methods, this capstone provided me the opportunity to appreciate the value of qualitative research in informing the range of possible themes that can be discovered. While quantitative research has an important place in informing ethical application of approaches and interventions, it is the qualitative research that I found most helpful as an emerging clinician to gain a sense of some of the range of perspectives that may emerge in the counselling space.

In considering how the findings might inform my practice with MAiD clients, I am inclined to consider the words of existential therapist Irvin Yalom that “therapy should not be theory driven, but relationship driven.” (2009, p. 8). While one can spend a lot of time considering the risks and benefits of particular approaches this should not detract from the understanding that the therapy endeavor is by and large an experience in relationality. Research shows that the contribution of specific modalities to therapeutic outcomes is limited relative to

that of the quality of the therapeutic alliance and client factors (Steenbarger et al. 2017). While the existential lens I have taken here has much to offer in terms of helpful philosophical departure points for exploration with clients, my therapeutic approach will be best supported by my ability to tune into the client, meet them where they are at, and build a therapeutic alliance. A person's choices with respect to MAiD cannot be understood or judged in isolation from their life, and the myriad factors that intersect with it including their age, type of illness, social context, culture, religion and experiences with the medical community and other systems. When individuals are considering or have chosen MAiD, my ability to hold that space for them will be bolstered by having accurate information about MAiD, a reasonably degree of death competence and a willingness to examine my biases.

This capstone has allowed me to take a very personal curiosity and to consider this topic as a professional. Given that the impetus for this capstone project emerged years ago in my early discovery of my own mortality, I recognize that my findings of the relationship between death anxiety and sense of meaning have personal relevance. My own terror about death and dying has become a motivating force for exploring how others encounter their own mortality; to be with clients in that place is a profound honour and privilege. This research allowed me to explore this topic in a personally, theoretically and empirically supported way that fuels my commitment to self-reflective practice and ongoing learning.

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