The pandemic and the delivery of palliative care and MAiD: What was the impact?

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Abstract
COVID-19 changed healthcare forever. But behind the headlines and news coverage of the emergency rooms and intensive care units, another quieter battle raged on. Within the field of palliative care, the ill and vulnerable were suffering greater distress and their clinicians were struggling to provide care.

Introduction
COVID-19 impacted everything. It might be said that the pandemic affected all aspects of life, from how countries dealt with each other all the way to how individuals coped with the restrictions created by public health measures. There has been significant impact financially, economically, socially, emotionally, and psychologically on society, organizations, groups, families, and individuals. It could be argued that the greatest blow was within healthcare. There isn’t a person who isn’t aware of the desperation that permeated intensive care units and hospital wards across the nation. But within the field of palliative care, the war for good patient care, which is rarely in the spotlight, waged silently onwards. The provision of Medical Assistance in Dying (MAiD), frequently provided to patients who were obtaining palliative care, was impacted as well. The attention of the nation was focused on the patients who contracted COVID-19 and died, not on the thousands who were already dying of another illness and whose quality of life and death were severely affected.

What is palliative care?
To gain a better understanding of the effect of COVID-19 on the provision of palliative care, it is important to understand what palliative care is (and isn’t). Palliative care is the active care of patients who have an incurable illness or condition that will eventually take their life. It focuses on the management of symptoms to improve the quality, and sometimes the quantity, of life. It encompasses the physical, the emotional, the psycho-social aspects of the patient and those they consider to be their supports. Nurses and physicians provide the backbone of nursing and medical care, while social workers, occupational therapists, counsellors, clergy, trained volunteers, family, and friends provide other, crucial supports. Assistance is provided in a multitude of settings: home, acute care, long-term care, personal care homes, and shelters. Patients are at the centre. They determine what is important for them and, with the advice of the care providers, determine where, how, and when they will receive attention.

Palliative care clinicians may be involved from the time of diagnosis, assisting the patient to fully understand their prognosis and make decisions about treatment. They may be active throughout the entire course of the patient’s illness, supporting the patient with the symptoms that arise from the treatments and the disease itself. When the condition is considered to be at a stage where it is no longer treatable, palliative care focuses on addressing symptoms and enhancing the patient’s quality of life. At the end of life, palliative care clinicians provide care that eases the discomfort of dying, supports the loved ones and sometimes, provides a special designated place (palliative care unit or hospice) for the last days and hours. Some palliative care clinicians provide assessment and MAiD.

MAiD is a process whereby a patient determines that they wish to have a physician or nurse practitioner assist them to die at a predetermined time and place. There are strict criteria as to how this can occur and who can avail of this service. In some places, palliative care clinicians are involved in the assessment of patients and the provision of the service. In other places in Canada, there is a deep divide and MAiD is entirely separate. Regardless, the patients who opt for MAiD usually have some level of palliative care provided and are often known to the palliative care service.

Impact of COVID-19
The effect of the pandemic on palliative care and MAiD can be examined through two lenses: the patient’s and the care provider’s. While both suffered, the types of suffering were distinct and the influence different. Clinicians faced barriers to do their jobs effectively, suffered from post-traumatic stress, and some have left the field of palliative care altogether. However, clinicians lived to continue their lives and work. The dying dies only once. Clinicians who have been emotionally and psychologically damaged by providing substandard care have the chance to move forward, heal, and gain some satisfaction from new cases and a future within the field. Sadly, this is not so for the patients, nor for those they loved.

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At the heart of caring for the dying is the relationship between the clinician and the patient. This, more so in palliative care than any other field of medicine, is the crucial raison d’être. Clinicians give of themselves; they connect emotionally on a deep level with many of the people they come in contact with. Facing one’s mortality is heavy work. The fear, the longing for another chance, another month, and another treatment, is sad and penetrating. The decision to die using MAiD is a serious one and the clinicians who provide this service, feel this intensely. Clinicians use a multitude of skills to deal with this; active listening, silence, verbal support, non-verbal communication, and touch, to name a few. Of all of these, touch was the most affected by COVID-19. Nurses and doctors had physical barriers as well as physical distance that prevented touching patients. Hugs were forbidden. Gloves prevented the most human of skin-to-skin contact. Masks hid the smiles and tears of silent communication. Patients often couldn’t fully see our expressions. The lack of touch impacted our patients deeply as well. It is a basic human need to have physical touch and there are few times in life when it is as imperative as during times of suffering.

Clinicians had to quickly pivot from the standard method of caring for patients. All of a sudden, in-person clinics were abandoned, and virtual care instituted. There was a major pressure to accelerate virtual care access often without formal training or assistance. The virtual platforms were challenging to use, especially with the multiple layers of cybersecurity that was required to keep patient information confidential. Some organizations used more than one platform. This required multiple installations on computers, technology support frustrations, several passwords and identification, multi-step login procedures, and challenges with remote access. Information technology professionals were inundated with demands from clinicians who couldn’t log on, couldn’t make the systems work, lost documentation, and all of whom had significant time pressures to ensure their patients were looked after quickly and well. Sometimes the platforms were abandoned, and new ones put in place. This created extra stress with clinicians who struggled with the initial process. Not all clinicians are tech savvy, but the world expected them to be, or to learn fast. The learning curve was steep and painful. Patients and families were also expected to have world expected them to be, or to learn fast. The learning curve was steep and painful. Patients and families were also expected to have

opioids, stimulants, and other potent, restricted medications, without ever fully examining the patient and having to do all interviews by phone (many patients didn’t have access to or familiarity with the technology required for video interviews), would not be supported by their provincial college or the Canadian Medical Protective Association. Again, new rules and modes of practice were set up quickly and the thorough evaluation of the risks and benefits often not completed.

While the assessment for MAiD can be done virtually if required, the actual procedure is in-person. There is the option for patients to be provided with a prescription for oral medications, although there are significant barriers to this. The vast majority of MAiD in Canada is completed through injection. This requires a clinician to insert two intravenous lines, bring the medication to the location of injection, obtain final consent, and inject the patient. Then the paperwork is completed, and in some provinces, a call is made to certify that MAiD has taken place. During the period of time when restrictions on home visiting, in-person assessment, and admission to hospital, patients who were interested in obtaining MAiD, found themselves limited or forestalled by the pandemic. MAiD providers are small in numbers, and many found the emotional toll of the pandemic restrictions and the barriers between themselves and their patients, traumatizing and exhausting. The already limited access was worsened by travel and admission restrictions. We do not have statistics on how many patients might have wanted MAiD but were unable to avail of it during the pandemic.

Isolation was huge loss for both patients, those who loved them and their care providers. Hospitals, long-term care facilities, and palliative care units were forced to institute severe restrictions on visitation. Many patients, who relied on carers to assist with the most basic of needs, were denied this. Clinical staff at the facility was forced to “police” these rules which often put them at odds or in direct conflict with distressed family members. Many families and friends considered felt their situation was an exception to the restrictions and the role as gatekeeper on the palliative care unit was tough, especially for nursing. In addition, the rules seemed always to be in flux. This was challenging and frustrating for patients and families to understand and follow. A patient may have been told he could have two family members visit on one day and the next there was something different because the organization was adapting to public health mandates.

The constantly changing “rules” were a large source of frustration and confusion to both providers and patients/families. Many people could not understand why the science was constantly changing and therefore the mandates about masking, physical distancing, visiting rules, and others was so fluid. Organizations had trouble keeping current, and the trickle-down effect of information through the organization wasn’t always straightforward and clear. Some facilities followed the rules zealously, others were relaxed. Families and patients were understandably confused and angry if a patient was transferred from a relaxed facility to a more stringent one. The staff, particularly the frontline nurses, were caught in the middle. All clinicians involved in palliative care and MAiD had challenges with both enforcing rules and dealing with the impact of those on themselves and their patients.
Some patients did not get admitted to the proper facility. There were restrictions in place such that some long-term care locations closed their doors to new admissions. Discharges home from acute care were delayed because there were constraints on home care provision and community health visitation. Many patients didn’t come to palliative care units or hospices because they feared that the visiting rules would preclude family and friends. Some patients died at home with suboptimal care specifically because of the visitation policy in facilities.

Home care services were often disrupted. Some agencies didn’t provide care because they couldn’t afford the extra costs of personal protective equipment or because the public transit didn’t run and therefore the home support workers couldn’t get to the patient. The government subsidies were an improvement in pay for some home support workers, and many left the occupation financially better for them not to work. This highlighted the substandard value placed on home care.

Some palliative care patients chose MAiD rather than come into a facility that had limitations on visiting. Those patients cited the suffering that would be created by dying alone was too great to bear and opted for an earlier death. The clinicians who provided MAiD were variable in their policing of COVID-19 “rules” regarding use of personal protective equipment and allowing visitors in the home; some patients had their loved ones with them for the procedure, others didn’t. It is impossible to know how many patients may have made this decision because of COVID-19.

Drug shortages continued to be a concern and appeared to worsen somewhat with the pandemic as drug manufacturers focused on COVID-19 treatments and vaccines. Clinicians had to scramble to find alternative treatments and at times, there were none.

Within the field of comfort care, the strength of the team is often gauged on the level of interpersonal interactions and supports. The heavy emotional toll that caring for those who are highly distressed because of a terminal illness and the suffering that is witnessed is best managed when it is shared with those who completely understand. However, most palliative care teams found themselves physically distanced from their teammates, at a time when togetherness was most crucial. Hospital or progressive care unit clinicians still managed to see and interact with their co-workers but those who provided outpatient care often worked from home, completely isolated from their peers. While a telephone conversation or a text is helpful in connecting, it doesn’t replace a hug, a shared coffee, or a team potluck lunch.

The mental health of clinicians became notably reduced. While the long-term impact is unknown, the immediate concerns have been significant. Some clinicians are burnt out, frustrated, and exhausted. Initially, those who stayed on the job, caring for the ill and dying were lauded. But as time passed and the general public’s frustration grew, the pedestal was knocked over and healthcare workers found themselves denigrated and on the receiving end of abuse. Family of patients, who may initially have been accommodating, were increasingly angry and demanding. Our ability to tolerate and respond kindly, lessened. It wasn’t only frontline emergency and intensive care unit personnel who suffered.

There is a significant concern that a higher percentage of patients than normal, will end up requiring palliative care service because of lack of timely diagnosis. Screening and investigations for many conditions were severely impacted. Already we are seeing patients who are highly distressed because their symptoms were not investigated, and their disease found late. How many of these patients remain to be seen and it will be important to assess the degree to which this has happened and the impact on patients and family, and subsequently on clinicians. This field of medicine is already limited and often stressed because of lack of skilled staff and woefully inadequate funding. How will we cope with increased numbers of referrals of patients who are additionally distressed by their inability to get diagnosed on time?

**Positive gains**

There were a few positive gains brought into the palliative care by COVID-19. Social media provided an opportunity for palliative care clinicians across the country to connect on a daily basis with each other, providing the forum for challenging case discussion, suggestions for dealing with drug shortages, and providing support and comradery. While using video or telephone isn’t optimal, it did allow more patients to be seen without the stress and financial cost of them traveling into a facility for a clinic appointment. Most clinicians increased the frequency of contacting their patients as they knew that families and patients were highly stressed by the pandemic as well as their illness, the lack of hospital supports and the uncertainty of care. Perhaps this created a stronger bond and was helpful. The importance of touch and non-verbal communication was reaffirmed as being essential to palliative care. The vital role of home making services, community health nurses and volunteers were highlighted. Sometimes it takes losing something to realize just how valuable and crucial it is.

**Future considerations**

COVID-19 isn’t over and the next pandemic is on the horizon. Pre-planning may help the healthcare system rise to meet the as yet undefined adversity ahead. Some suggestions arise from the lessons learned through the recent experience.

1. Palliative care needs to be recognized as a vital service.
2. Palliative care leaders need to be involved in pandemic planning.
3. Support to keep palliative patients at home and away from hospitals during pandemics needs stronger emphasis within the healthcare budget.
4. Virtual care is a key tool to link patients with palliative care providers. Efforts should be made to strengthen and improve this modality so that it can be quickly increased to meet demand.

COVID-19 is not the first pandemic and will not be our last. It was both a crisis for palliative care and an opportunity to learn. While the impact on families and healthcare providers will be...
long lasting and, in some cases, unable to assuage, the lessons we acquired regarding the crucial importance of non-verbal communication, the personal touch with our patients, and the tremendous value of support services cannot be understated. COVID-19 may have impacted everything in healthcare, but it did not and will not change the desire of all clinicians who practice palliative care and MAiD, to provide the best care while the patient is living, and the best death possible, to all our patients.

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