Redrawing Palliative Care:
Therapeutic Architecture for the Body, Mind and Spirit

By

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“More and more sickness and dying was placed outside the family circle and in the hospital, and life was increasingly seen as something that should be happy. For anything so much related to suffering, decay, sorrow and mourning there was no longer a place in society.” ¹

Abstract

In the past five decades, hospice palliative care revolutionized the way we understand sickness and dying. The movement began as a critique to traditional healthcare practices and facilities that strictly focused on treating diseases, resulting in a neglect for the human experience, which also plays a major factor in overall health and well-being. A palliative approach to care focuses on meeting the patient’s and their family’s full range of needs -physical, psychological, social and spiritual- at all stages of a chronic progressive illness. Rather than focusing on death, it facilitates the optimization of life for patients living with terminal disease, allowing them to live to the fullest.

This thesis is a response to the demands for therapeutic architecture in view of a growing seniors population and climbing disease rate to support those in a unique stage of life. It seeks to examine the poetics and complexities involved in an architectural design proposition for a palliative care home in the city of Ottawa. Through exploring the philosophy of palliative care and its architectural manifestations, this thesis explores the architectural possibilities inherent in an understanding of care that provides hope and comfort in times of grief while embracing the opportunity to experience life to its fullest.
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Palliative Care

The term 'palliate' stems from Latin roots *palliare* and *pallium* meaning to cloak and to conceal. The *pallium* was an ancient cloak like garb worn by the Greeks. The term was adapted into English as a figurative cloak of protection. In medical terms, it means to lessen the intensity of a disease through the management of pain and symptoms.²

A palliative approach to care focuses on meeting a person's and their family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in their own care – and strives to give individuals and families a greater sense of control. Although it is an important aspect of end of life care, it is less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness, or the process of aging.³ Research published in The New England Journal of Medicine revealed that patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis not only were happier, more mobile and in less pain as the end neared, but

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they also lived nearly three months longer.\textsuperscript{4}

**Hospice**

The term hospice is used to describe a coordinated program that provides around the clock palliative care to terminally ill patients and supportive services to patients, families and significant others in a home like setting.\textsuperscript{5} While the term is used interchangeably with palliative care, it commonly refers to the place that offers end of life palliative care.

**Respite Care**

Respite is a temporary period of relief, or rest for primary caregivers.\textsuperscript{6} Through leaving a loved one with special care needs in the temporary care of another party provides caregiver with temporary relief from the physical and emotional demands involved in caring for them, providing time to attend to other responsibilities.\textsuperscript{7} It is crucial for caregivers to maintain a healthy physical and mental state in order to provide quality care for their loved ones during the course of their illness.


\textsuperscript{7} Respite care in Canada (Ottawa: Canadian Healthcare Association, 2012).
“Engaging in the full range of experience—living and dying, love and loss—is what we get to do. Being human doesn’t happen despite suffering. It happens within it. When we approach suffering together, when we choose not to hide from it, our lives don’t diminish, they expand.”

- Dr. Lucy Kalanithi

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Introduction

In our society today, sickness and dying—often medicalized, controlled and isolated—comes without tenderness, comfort, or serenity. Current healthcare facilities are focused on treating diseases and in this process, neglect the human experience, which also contributes to overall health. WHO defines health as not only the absence of diseases, but also a state of complete physical, mental and social well-being. Especially for individuals with a terminal illness that is not responsive to curative treatment, the control of pain, symptoms, psychological, social and spiritual needs become paramount. Palliative care comes in as a holistic approach to care that focuses on improving a person’s quality of life despite living with life limiting illness through addressing the needs of one’s mind, body and spirit. With rising demands for an approach that strives to steer away from conventional healthcare practices, there is a need for an alternative place that supports such programs. Thus, this thesis explores therapeutic architecture that supports palliative care, which takes care of the body, mind and spirit.

It is important to note that medical assistance in dying has recently become an available end of life option in Ontario. Oftentimes the motivation to pursue...

such decision comes from the desire to end pain and suffering. While palliative care offers the support and method to manage symptoms and side effects allowing patients to retain a high quality of life, WHO statistics have revealed that 86% of the world’s population who need palliative care do not receive it and 83% lack access to pain relief.\textsuperscript{11} The barriers include a lack of public awareness of how palliative care can help, cultural and social beliefs about pain and dying, insufficient skills and capacities of health care providers and over restrictive regulations for opioid pain relief.\textsuperscript{12} Although incremental steps have been taken to integrate palliative care into national health policies, there is still a long way to go for an improved, optimal access. While governments can revise laws and processes to improve access to pain relief and medical practices can include palliative care in their training to provide services in primary healthcare centres and homes, architects can also play a significant role. As society builds what it values, giving patients a place in the community would also give them a voice to raise awareness and to break the taboo surrounding sickness, death and dying. This is not to say that medical assistance in dying is not a valid option, but no one should be forced to consider this option because of a lack of access to palliative care.

\textsuperscript{12} Ibid.
The first part of this thesis outlines the issues and gaps in conventional healthcare practices and its impact on patients with terminal illness. Looking closely at current practices and underlying issues provides an insight into the specific needs for palliative care in the city of Ottawa. In a society that upholds growth and progress, the sick and dying are often isolated and hidden away without a place in the community. This is for the most part driven by fear, which often leads to denial and gets in the way of people making the appropriate care plans for themselves or their loved ones. While the preferred place for people to receive care and spend their final days is at home, studies have shown that most people end up in the hospital, which is the least ideal place to be during sickness. The issue associated with these common places of care are that they are oftentimes not designed to accommodate care practices for people at this stage of life. While most hospitals are designed to eliminate diseases instead of the well-being of patients, the home is not equipped with amenities to provide an optimal level of care. Also, receiving care at home places the burden on family members who often do not have experience, or knowledge to take care of their loved ones. With technological advances in medicine, life expectancy is prolonged as one can live for an increasing amount of time with an illness. It has been revealed that patients requiring palliative care demand the most time from care givers compared to other aspects of healthcare, as such, family members and
healthcare providers need to be properly taken care of to avoid burnout. This need gave rise to the hospice as a building typology designed for patients and their family who require palliative care.

Through personal experience with palliative care and working with over one thousand patients, palliative doctor Brian J. Miller identified five things that matter most for individuals with life limiting disease facing the final stages of their illness—comfort, feeling unburdened, unburdening to those they love, existential peace and a sense of wonderment and spirituality. Although sickness and death are inevitable and we can’t solve for it, we can design towards it. The five goals prompted three design cues that can be incorporated in therapeutic architecture to support palliative care—teasing the unnecessary suffering out of the system, tending to the senses and setting our sight on well-being. With these goals and design prompts established, strategies and process have been developed. This section first looks at the philosophical undertaking of palliation as a theoretical cloak to conceal the unpleasant experience. The top four terminal illnesses in the city of Ottawa and their associated symptoms have been identified and through this process, four patients with specific needs are established as primary users. The design will be explored through their perspectives. Then sensory

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14 Ibid.
design will be explored as a way to tease unnecessary suffering out of current systems. Sensory design addresses not only physical and psychological needs, but also spiritual needs of both care givers and care receivers. Art addresses spiritual needs as a powerful tool for the search for wholeness, healing life’s wounds and making peace with the world. Art has the capability to reawaken the senses often ignored during long illnesses and is a vehicle for self-expression thus a significant tool for transformation during advanced stages of illness. Nature on the other hand incorporates both art and sensory experiences to provide spaces conducive to healing. Using these theories and strategies, the design strives to create not only spaces and programs for the users but most importantly, the synthesis of these ideas in creating a sense of place.

The Site of this thesis is in Orleans, eastern Ottawa. Responding to the rising demand for additional residential palliative care options in the city. The location houses an existing long-term care home with a palliative daycare centre that opened in 2017. By extending daycare services and expanding the premise to an around the clock residential palliative care home, the proposal aligns with the city’s goal to provide services for the French speaking community and to increase the number of beds devoted to palliative hospice care using resources that are readily available.

The design proposition presents a speculative purpose-built palliative care home that synthesizes various facets of the care approach with a site that is conducive to a feasible built option. The palliative care home presented as a built form represents society’s evolving attitude and acceptance of caring for the sick and dying. By providing patients and families with a purpose-built place where they can receive optimal care and feel a sense of serenity and belonging, it stands as an empowering message that they are valued. It also embraces palliative care’s integral view of sickness and dying as a natural part of life. Ultimately, the goal of this thesis is to reclaim suffering and the end of life as a human experience instead of primarily a medical one.
01. Issues

Fear

WHO has revealed that globally, only about 14% of people who need palliative care receive it.\textsuperscript{16} In Canada, studies have shown that 16-30% of patients receive it.\textsuperscript{17} While the major reason is due to lack of knowledge and training amongst healthcare professionals, cultural and social barriers such as beliefs about death and dying seem to be the underlying causes that have led to a lack of access. With technological advancement that followed the second World War, medicalization of sickness and dying has driven us towards a death denying society. It seems that as more cures are discovered, the more death is feared as an option. While patients and their families fear the unknown of what comes after life, medical professionals fear suffering and dying as the failure of their medical practice. Medicine is built on science. Science is rational and objective, which enables predictability and control. As such, life and death often seem to be under control.\textsuperscript{18} This control however is often in the hands of medical professionals instead of the patients themselves. Our society has become used to seeing human beings as stable and autonomous individuals, but when people grow ill and deteriorate, we do not know how to respond. The Western culture seems

\textsuperscript{17} Canadian Institute for Health Information, Health Care Use at the End of Life in Western Canada, Ottawa: CIHI.
to be unable to reconcile with death and its inevitability. This attitude often prevents patients and families from focusing on positive, meaningful things. This interferes with empowering them with the best options for quality of life. For instance, denial about impending death and avoidance of having such discussions will undermine care planning and in turn cause unnecessary suffering for patients and place excessive burden on families. The practice of palliative care offers a shift away from this mindset - while sickness and dying are inevitable, life cannot exist without death - death defines life. Palliative care aims to give control and empowerment to patients allowing them to choose to continue living with hopes for the best possible life before death. It replaces passive negativity with proactive optimism about what could be achieved.

Jacques Choron in "Death and Western Thought" (1963) discussed several philosophical views of death, he pointed out that what we fear is not pain, as death is seen as a refuge from pain. What is feared is the loss of an individual.\(^{19}\) Fear is an emotion that has a specific known object and one can position themselves towards fear.\(^{20}\) Courage is a virtue that can be developed by being exposed to the object one fears. Thus, knowledge about the fear becomes the first step in overcoming it.\(^{21}\)

The fear of death has been studied by psychologists


\(^{21}\) Ibid.
for decades and a look into the scales used would give us a sense of what is at stake. The Collett-Lester Fear of Death Scale is used to evaluate two key dimensions involving death that both have two sides, the first being the state of death and the process of dying, the second concerns one's own death versus the death of others. This reveals the complexity of the underlying fear surrounding death as an experience that not only affects one self but has great impact on everyone around. The way we witness other people's life and death greatly impact our personal view and attitude towards it as the memory will stay with us for the rest of our lives.

Palliative care for people living with life threatening illness usually takes place in the hospital, hospice or at home. Studies have shown that most people with advanced illness prefer to receive care at home while the least desired place to be is the hospital. However, over 70% of terminally ill patients end up spending their final moments, or even days in a hospital bed. While home is a familiar setting and provides physical and emotional comfort, it is often not equipped to provide a desirable level of care for people with advanced illness. Unless they have the means to employ a full-time home nurse, family members become the primary caregivers with occasional support from visiting nurses and visits to the hospital. A 2010 study conducted in Toronto

revealed that the cost of home based palliative care averages $25,000 per month (Figure 2). This number takes into consideration the cost absorbed by the patient and family in lost wages, leisure time and other out of pocket expenses which amounted to $18,200.\textsuperscript{24} The high cost associated with a home-based care option renders it not feasible for low income families, or retired individuals who simply do not have the means. Oftentimes, family lack the knowledge and training to provide specialized care for their loved ones and when situations arise, they end up spending countless hours in the emergency room.

Hospitals have been and continue to be designed as efficient buildings that house efficient professionals who treat the sick in cost-efficient ways.\textsuperscript{25} The idea of

\textsuperscript{24} "Palliative Care at the End of Life - HQOntario," 17, accessed January 18, 2018.
a warm and welcoming healing space has changed over the years as medical technology advanced and instead of being human centered, it became a disease centered practice. The modern hospital has become increasingly institutionalized and dedicates a majority of its space to large machines and equipment. It has evolved into a place that people avoid whenever possible as it has become in our common experience overly sterile, isolating, and associated with negative sensory experience. Historian Alain Corbin in his book "The Foul and the Fragrant" described the hospital as a place of discipline in which somatic control changed the behavioural patterns of patients and stripped them of comfort, individuality and autonomy. As medical technologies advanced, so too did the necessity for efficient and sterile practices within the hospital. Rules and regulations for both staff and patients over time did not only influence medical procedures, but also the design of healthcare environments. For instance, patients are discouraged to wear their own clothes, or bring in their personal belonging as an attempt to improve hygiene. As patients are dressed in the same way and removed from family and familiar surroundings, their identity is replaced by the disease that separates and classifies them. The sick and vulnerable are isolated in the name of infection control and hospital interiors are designed to have little, or no tactile quality for the same reason, while domestic interiors reflect comfort and individuality of

the occupant, hospitals reflect the hygiene and efficient practices of the institution.\textsuperscript{27} Additionally, nursing practices relies heavily on observation techniques, which led to standardized lighting levels to facilitate clinical examination rather than rest, comfort, or view.\textsuperscript{28} This has direct impact not only on patient’s privacy but it has a negative effect on their health and well-being. Further, hospital planning rarely address the issues of dying as it is not in the core business of the institution for healing. However, it is suggested in terminal cases that a separate space should be considered for dying patients, considering that other patients might be discouraged by the somberness of the circumstances.\textsuperscript{29} From the hospital’s point of view, terminally ill patients have ceased to become primary users of the facility, the needs of the dying are superseded by the needs of the living.

As a response to the over institutionalization of medical care in existing healthcare facilities, a new building typology in the form of the hospice emerged. Hospices reject the machine for healing that results from pure rationalism. Hospice care is about assuring every individual the right to receive care and complete their lives with dignity, in a supportive setting.\textsuperscript{30} The word hospice stems from the Latin word hospitum meaning

\textsuperscript{28} Ibid, 17.
\textsuperscript{29} Charles Butler and Addison Erdman, Hospital Planning (New York, NY: Dodge, 1946), 154.
\textsuperscript{30} Stephen Verderber and Ben J. Refuerzo, Innovations in hospice architecture (Abingdon, Oxon: Taylor and Francis, 2006), 5.
guesthouse. It was a place of shelter for sick and weary travelers returning from pilgrimage and other lengthy journeys. The rise of the Modern Hospice Movement led by nurse, social worker and physician Cicely Saunders in the 1960’s saw the completion of the world’s first purpose-built hospice St. Christopher’s. The new building typology helped shape the philosophy of hospice care by presenting a shift away from the mega-hospital model which was embraced by the industrialised world at that time. Since then, later buildings have made strong attempt to connect this care model with homeliness. To this day, the hospice continues to be a changing building typology as it evolves in parallel with new research, practices and holistic attitudes to terminal illness. The contemporary hospice building provides for far more than just a place to die. It can be seen as part home, part garden, part hospital, part hotel, part community centre, part school and part office.

The words ‘hospital’ and ‘hospice’ share the same etymology with hospitality. ‘Hospes’ and ‘hospit-’ meaning to host, highlight the friendly relationship between hosts and guests. It is in this tight-knit relationship between caregiver and care receivers that

33 Ibid, 34.
healing happens. However, the size and complexity of most hospital buildings and management systems stop them from being able to focus on a close relationship between caregivers and patients, undermining the opportunity for such supportive healing. For instance, policies such as visiting hours and infection control tend to separate patients from their family and friends, who play a huge role in reducing anxiety and stress for patients. Recognizing the important role of family and friends, palliative care emerged as an alternative to the isolation of institutionalized models of care to include a multidisciplinary team of doctors, nurses, therapists, social workers, spiritual leaders and volunteers who would encourage families and friends to take part in the caregiving process. The scale of the need for palliative care cannot be met by professionals alone.

Care receiver is often the centre of attention in healthcare design, however, in such a demanding and high stress line of work, the well-being of care givers cannot be understated. In fact, it is crucial for health care providers to attend to their own self-care needs if they are to provide support for others. Self care is not only necessary to prevent stress and burnout, but it is essential to ensure that caregivers do not further burden the patient with their own needs. Thus, the emotional and psychological integrity of care providers must be addressed in the design so that the boundary can be maintained and the vulnerable do not feel imposed on.

Care Giver & Care Receiver
Canadian aged ≥15 provided care to a family member or friend.

Fig.3. Statscan 2012 Social survey on care giving and care receiving.
This ensures a provision of care that does not exalt the care giver, but instead respects and honors the dignity and individuality of those facing a life limiting illness.35 A Statscan social survey revealed that 28% of Canadians over 15 provided care to a family member or friend (Figure 3).

Palliative care presents an interesting position in which family plays the role of caregiver and care receiver at the same time throughout the process of grief. This presents a unique design opportunity for architecture that supports palliative care to address this need which is often neglected in current healthcare institutions. However, the experience of illness and impending death of a loved one have far greater impact on family members as the memory would stay with them for the rest of their lives. While proper palliative care is recommended to begin upon diagnosis, it doesn’t end once the illness ends since bereavement care for the family is also part of the holistic care model. The city of Ottawa has identified that there is an overwhelming need to boost bereavement programs on top of other services.36

Additionally, respite care comes in as an important program for family member care givers. Certain

35 Sandra L. Bertman, Grief and the healing arts: creativity as therapy (Amityville, NY: Baywood, 1999), 43.
healthcare spaces like hospices and long-term care homes in Ottawa have identified the need for respite care programs and have incorporated a number of beds to provide such services for people in the community. However, the numbers are far and few despite a rising demand. The proposal of this thesis will see the incorporation of additional respite care beds and services in the city of Ottawa.

Over three in ten Canadians suffer from a chronic illness, while four in ten have a sufferer in their immediate family. Meanwhile seniors make up the fastest-growing age group and are projected to make up 23-25% of the population by 2036, nearly doubling in number.\[37\] While there is almost unanimous support for palliative care in Canada, currently only 16-30% of Canadian entering the final stage of advanced illness have access to, or receive palliative care.\[38\] In fact, a study conducted comparing the death of cancer patients across seven developed countries revealed that Canada has the highest proportion of people with cancer dying in acute hospital settings.\[39\] It seems that there are fewer opportunities to keep patients out of hospital in Canada compared to other countries like the United States, UK, Netherlands, Belgium, Germany and Norway. However,

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38 Ibid.
the lower rates of hospital admissions, length of stay and deaths in hospital in the other countries suggest that end-of-life care can progress to reflect patient preferences and goals.  

With a population close to one million, Ottawa should have 70 beds dedicated to palliative hospice care. This estimate allows for population growth and increasing mortality as population ages, but as of 2017, the city only had 19 beds (Figure 4). The provincial government only began providing funding for hospices in 2006. Although government funding has increased since


then to cover 60% of the cost, the funding model for residential hospice care still relies heavily on charitable donations (Figure 5). However, Liberal Senator Sharon Carstairs who founded the Canadian Virtual Hospice has revealed that providing palliative care at a hospital, or long-term care facility is the most expensive form of delivery.42 This is where autonomous care homes like the hospice comes in to help reduce the burden on hospital’s emergency rooms and acute care. It would be a cost-effective model for an aging population as compared to a hospital bed, which costs two to three times more to operate than a hospice bed (Figure 6).43

**Existing Services in Ottawa**

Hospice Care Ottawa is a community based charitable organization that provides palliative and end of life care in the city. Currently, Ottawa has two residential hospices and one daycare palliative centre run by the organization. One being the May Court Hospice located in central Ottawa and Hein House at Ruddy Shenkman in Kanata. The hospices house nine beds and ten beds respectively. A ten-bed hospice model is estimated to free up $1.5 million healthcare spending annually in the province.44 Shifting the budget to hospice beds would also free up beds in the hospital for other priorities. The 2016 Ontario budget increased funding to support up to twenty new hospices in the province, which reveals

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43 Ibid.
44 Ibid.
the pressing demand, support and recognition of the care approach. Hospice Care Ottawa has revealed long term plans to expand services with the primary goals to reach out to Francophone and to open more residential hospices throughout the city to provide appropriate care closer to home.

Residential hospice care provides 24 hour specialized palliative nursing care in a home like setting. Community hospice daycare provides a supportive environment and respite for caregivers, various therapies and bereavement care. Hospice Care Ottawa has over 65 full-time health care providers and more than 1000 volunteers. Individuals who need palliative services and bereavement support can self refer to the daycare centres, but referrals for residential palliative care must come from a health care provider.

A look into the two existing residential hospice models in the city provides a better understanding of what is currently available. From this observation, gaps that need to be filled will be identified to better inform future design decisions.
May Court Hospice

Location: 114 Cameron Ave, Ottawa

The May Court Hospice is located on the bank of the Rideau River and houses nine residential hospice beds providing services since 1999. The property is owned by May Court Club, which is a charitable organization whose purpose is to provide service through volunteer activities and monetary grants to the Ottawa Community. Originally a women’s convalescent home in the 1910’s, the premise was rented to Ottawa Hospice Care at no cost to continue May Court Club’s mandate to service the community.

May Court is located in a residential neighborhood and provides a serene environment for its guests through exposing interior spaces to nature. Almost every room in the building has visual connections with the outdoors through openings to interior courtyards and greenery that envelopes the home (Figure 9- 11). There are several pockets of gathering space to accommodate multiple family gatherings at a time.
As it was built in the 1910’s, the May Court Hospice has a dated aesthetic with finishing material that makes the space seem dark despite many openings to the outdoors, therefore the spaces rely heavily on artificial lighting as shown in the bedroom (Figure 11). Particularly the long dark hallway, although providing direct and convenient access, sparks memories of a hospital corridor (Figure 8). There also seems to be a lack of handrails, and supportive elements for accessibility and self care.
Hein House

Location:
110 McCurdy Drive,
Kanata

Architect:
Vincent P Colizza
Architect Incorporated

The Ruddy-Shenkman is a full-service hospice located in Kanata, Ottawa West that completed the addition of ten residential hospice beds plus two respite beds in its recent expansion. The Hein House residential wing opened in September 2017.51 (Figure 12)

Like May Court, the spaces throughout the Hein House receive plenty of sunlight and every room has views to the outdoors. The use of natural materials in its structure and finishes give the space a warm home-like ambiance (Figure 13). Wood as a building material has been banned from hospitals and clinics for over fifty years and by incorporating wood and stone in this space brings back the color and texture of the life that is often missing from large healthcare institutions. Future palliative care facilities will see an increase in respite care rooms as the demand for it expands.

Although the Hein House is a purpose-built hospice, there are certain aspects of it that are reminiscent of

hospital spaces. For instance, the long straight hallway lined with patient rooms and mechanical beds that seem very institutional (Figure 14). The spaces seem to lack a sense of warmth and intimacy that comes with a home. The skylights and large windows in the space provide adequate sunlight into the space, but there needs to be moderation especially for patients who may have sensitivity to light, or those who need to rest during the day (Figure 15).
The crux of palliative care is to manage the symptoms that come with illnesses and the side effects that follow treatments so that one can live as fully and actively as possible. Firstly, to recognise the specific needs of the audience, the top ten terminal diseases in Ottawa have been identified (Figure 16). By narrowing down to the top four illnesses, which make up more than half of the data group, specific symptoms and side effects have been analyzed (Figure 17). These would become design cues for the new palliative care home and be presented as four personas navigating and interacting with proposed spaces. While this list depicts the physical and psychological needs to be addressed for specific illnesses, social and spiritual demands of patients and care givers also need to be addressed.
Fig. 16. Leading Causes of Death in Ottawa
Fig. 17a. Symptoms & side effects associated with top four illnesses:

**IHD**
- Anxiety & depression
- Stress
- Extreme fatigue
- Shortness of breath
- Difficulty falling asleep

**Dementia**
- Changes in mood & behaviour
- Confusion in similar environment
- Difficulties with everyday tasks
- Difficulty with words & numbers
- Memory loss

**Lung Cancer**
- Infection & bleeding
- Shortness of breath
- Skin reaction
- Fatigue
- Gastrointestinal issues

**Cerebrovascular**
- Decline in motor skills
- Short term memory problems
- Post-stroke depression
- Difficulty processing language
- Impulsiveness
Fig. 17b. Caregiver’s physical and psychological demands
Peter Zumthor in his book ‘Thinking Architecture’ expressed that the experience of space is sensuous. To experience architecture in a concrete way means to touch, hear, smell and see it. As such, Architectural design has the power to enhance human experience and lifestyle through the senses as there is an intimate relationship between our emotions and the things around us. As a primary healthcare facility, the hospital is known to be a place that assaults user’s sensory experience with its sterile environment, bright lights, strong smell of disinfectants, constant noise from machines and busy staff. To design an alternative care environment conducive to psychological and spiritual health, one must steer away from the hospital experience therefore each sensory attribute of the design deserves utmost attention and care. By speaking directly to a person’s senses, it makes them feel connected, shifting the focus to the person rather than their disease.

Sensory attributes of a building work together to have compounding effects on the occupant’s health through physiology. Figure 18 illustrates this relationship between sensory input of a building and how it poses positive, or negative effects on its occupants. Sensory design when incorporated in the built environment unites function with form in such a way that occupants

53 Ibid, 85.
Sensory design presents an advantage to link these together, by using stimuli to evoke a range of human processes within building occupants.55

Oftentimes comfort is confused with the absence of sensation and delight is neglected.56 With increasing technological accuracy, the spaces we inhabit are controlled to a narrow range of light, temperature, smell, sound, texture and color. These environments are engineered to be favourably for the average person. Particularly for patients who have endured long illness and treatment whose bodies have gone through changes that may have altered the way they perceive

their surroundings, the standards for an average person simply do not apply. For instance, cancer patients going through chemotherapy may have sensitivity to smell and light that falls within the average standards. While we are designing for a broad range of users who have diverse and changing demands, sensory attributes of a given space must have the flexibility to evolve with their changing needs.

As patients become frustrated and limited in the ability to live life freely, their identity is threatened. Spirituality is an existential construct that includes all the ways in which a person constructs meaning and organizes their sense of self around a personal set of beliefs, values and relationships. Sometimes it is understood as transcendence, or inspiration and may include involvement in a community of faith and practice. It is the search for wholeness, meaning and purpose in one’s life. It is something everyone experiences regardless of religious background and beliefs. Spiritual needs typically address questions such as why does one suffer? What or who beyond myself do I believe is important in my life? Such existential questions arise inevitably at some point in life especially when one, or someone close, are sick or in crisis. This is where spiritual care comes in to help care receivers and care givers find meaning and purpose in the things they value to bring hope in times of suffering and loss. Spiritual care tends to receive the
least focus in the realm of healthcare compared to care for the body and mind. However, the psychological and spiritual aspects of coping with suffering and impending death are intertwined. How people cope emotionally is affected by their spiritual belief system and the capacity for spiritual growth is affected by psychological health.\textsuperscript{57}

In his book ‘Art of Living, Art of Dying’, Dr. Carlo Leget\textsuperscript{58} presented an ancient \textit{ars moriendi} (art of dying) model that can be seen as an \textit{ars vivendi} - an art of living. It views preparing for suffering and death as a way of life since what is worth living for is discovered best in the light of one’s mortality.\textsuperscript{59} From this model, a spiritual framework was developed to help patients and care givers discuss what it means to suffer and what is needed to complete life in a meaningful way. The contemporary framework is open to a variety of spiritual beliefs, both religious and non-religious. This model can be used in palliative care by integrating the spiritual dimension into physical and psychosocial care. The model stemmed from the belief that in the face of sickness and suffering, one is confronted with hopelessness, pain, fear, guilt and pride. Being absorbed in such negativity prevents a person from living to their full potential and could lead to poor mental and physical health. The \textit{ars moriendi} model presents five big themes that aim to guide a person through spiritual transformation in a process.

\begin{itemize}
\item \textsuperscript{57} Stephen R. Connor, Hospice: Practice, Pitfalls, and Promise (Washington: Taylor & Francis, 1998), 45.
\item \textsuperscript{58} Carlo Leget, PhD. Head of Care Ethics Department at the Univerisity of Humanistic Studies in Utrecht, Netherlands.
\item \textsuperscript{59} Carlo Leget, Art of living, Art of dying: spiritual care for a good death (London: Jessica Kingsley Publishers, 2017), 38.
\end{itemize}
of openness and surrendering. The five dimensions are presented in the form of a pentagonal diagram coined as the *ars moriendi* diamond (Figure 19).

**Faith**: Do not clasp to what the eyes can see or measure, trust that there is much more between heaven and earth that fits in your head.

**Hope**: do not fixate on what went wrong in the past, or on the feeling of guilt. Be mild towards yourself and have faith that you will be looked on with love.

**Love**: do not cling on to what you have gathered in your life. It aggravates the pain of dying. Let go and focus on where you are expected.

**Patience**: resist the restrictions of being identical with
your pain and suffering. You are more and bigger than your pain. Have faith that the pain will end.

**Humility**: do not fight to preserve your achievements, your decorum, your pride. There is nothing more to prove. Do not pretend to be bigger than you are.

The centre of the *ars moriendi* diamond is an inner space that represents openness and the acceptance that is needed to achieve the five spiritual dimensions. It is a metaphor for a state of mind in which one can experience different thoughts, emotions and impulses without identifying, or being influenced by them.60 This state of mind is especially important for both care givers and care receivers. Each discipline has its unique way of framing reality, but as palliative care is an interdisciplinary approach, working within it requires a flexible mind. Leget proposes that there are six paths through which one can reach the inner space: humour, the body, emotions, virtues, spiritual traditions and silence.61 This affirms that the body, mind and spirit are deeply intertwined, one cannot address spirituality without addressing the physical and psychological aspects.

Meaning must be discovered, not imposed. Art illuminates the human condition both in process and in product. In the process of creating, artists often act out their needs and expose their personal life histories. The products produced by artists, in turn, reach out to others, helping them to understand and participate in the reality of the artist. It promotes feelings of universality, expands empathy and helps others with understanding emotions. Most importantly, it displays a shared reality that has the capability to comfort and provide hope for others— an affirmation that they are not alone in the suffering and someone has experienced and overcome the hardship. Thus, art is a powerful tool in palliative care as it addresses a person's emotional, physical and spiritual needs, it addresses what is possible rather than what is lost and brings beauty, joy and expression in times of suffering. Art has the power to reawaken the senses often ignored during long illnesses.

Art comes in as a vehicle for self-expression and a significant tool for transformation during sickness and times of suffering. It is proven to be an effective, non-verbal form of expression that assists patients, families and staff to understand the whole of their lives. It serves as a language that provides a sense of control and choice at a time when life does not seem to be offering any other choices. Art therapy is an essential part of hospice palliative care through two motivations— the desire to

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62 Sandra L. Bertman, Grief and the healing arts: creativity as therapy (Amityville, NY: Baywood, 1999), 289.
63 Ibid, 139.
summarize one’s life experiences and to make gifts for loved ones. This in turn provides the opportunity for the patient to become a participating member of the community and to reclaim their power. As healing occurs in the relationship between care giver and care receiver, art becomes not only a tool of communication, but also an activity that both parties can participate in together. It creates an emotionally neutral situation in which new conversations are initiated and both care giver and care receiver can explore meaning together. Art is also capable of building community among people, which is important for those suffering from an illness who feel like they no longer have a place in society. Being immersed in artwork not only enhances a patient’s experience, but it has also proven to greatly reduce stress and anxiety.

Palliative care is not only an approach to care but a philosophy. Concealing the unpleasant experiences in life allows a person to focus on the things that truly matter. It serves as a reminder that suffering and loss are an integral part of life and our time on earth is finite. One can approach suffering with different attitudes—run away, hide from it, or surrender to it. The palliative approach does not intend to conceal suffering to allow

64 Sandra L. Bertman, Grief and the healing arts: creativity as therapy (Amityville, NY: Baywood, 1999), 140.
65 Ibid., 142.
the person to run away, or hide from the fact, but instead encourages the acknowledgement, embrace and celebration of a natural phase in life.

The idea of an embrace and celebration of life’s wounds is exemplified in The Mending Project by Lee Ming Wei at the Venice Biennale (Figure 20). The installation invites participants to bring in a damaged textile article that needs repair and while the artist does the mending, they engage in an intimate conversation with the participant. What sets this apart as a work of art and not simply tailoring is that it takes on an emotional value as participants bring in personal items of clothing and the artist uses different colored threads on the damaged item to not only mend the damage but to commemorate the repair. The act of mending is not done to hide the damage but to celebrate the repair and exchange happened meanwhile. This turns the act of palliating, or concealing into a form of art. It also illustrates the relationship between care giver and care receiver in palliative care where the exchange among families, friends, healthcare providers and volunteers are highlighted and celebrated. Within this context emotional and spiritual healing takes place.

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68 Ibid.
Fig. 20a. (Top) The Mending Project by Lee Ming Wei.

20b. (Bottom) Commemorating the repair by turning the damage into art.
The Role of Nature

“Where does this depth of feeling that we all associate with landscapes come from? I think there are special moments when we, as human beings, truly realize that we belong to living nature, that we come from it and that we will return to it, experiencing landscapes seems to encourage transcendental thoughts of this kind.” – Peter Zumthor

The relationship between nature and the management of the patient’s pain is a critical facet of palliative care, the environment and setting of the place of care has a significant impact on the quality of care in this respect. The founder of modern nursing Florence Nightingale in her pioneering work during the Crimean War discovered the powerful healing properties of nature, especially sunlight and fresh air as healing agents. Environmental psychologists Stephen and Rachael Kaplan also pointed out that nature is a stress-relieving modality considering that the pressures of a hyper-accelerated culture forces humans into prolonged periods of directed attention. While this requires considerable effort and concentration, it can

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71 Florence Nightingale (1820-1910) was a social reformer, statistician and founder of modern nursing.
be physically and mentally exhausting.\textsuperscript{73} Interaction with nature in turn satisfies a person’s need for a restorative experience, which requires a temporary escape from routine demands on the attention.\textsuperscript{74} As such, nature received great emphasis in healthcare design through the incorporation of therapeutic gardens and sun terraces.

Being immersed in nature is a full sensory experience that engages the body, mind and spirit in a therapeutic way. The garden is a source of interest as there is no repetition in nature, everything constantly changes in the organic world. It is therefore seen as the antithesis of the indoors where everything is routinized—time, schedules, unvarying colors, walls and corridors found in most conventional healthcare spaces.

On top of physical symptoms and side effects of treatments, terminally ill patients experiencing stress, anxiety, restlessness and difficulty falling asleep can benefit from the relaxed and calming qualities of nature. Further, as Peter Zumthor suggests in Thinking Architecture, nature evokes transcendental thoughts and provides an unrestricted space and background for reflections, which is critical for the spiritual journey of discovery. Nature as a therapeutic agent that supports the care for the body, mind and spirit will be an integral element in the design of a palliative care home.

\textsuperscript{73} Stephen Verderber and Ben J. Refuerzo, Innovations in hospice architecture (Abingdon, Oxon: Taylor and Francis, 2006), 37.
\textsuperscript{74} Ibid.
The illustration above gathers the design prompts identified in research which will inform all design decisions.

**Preliminary Design Explorations**

The following vignettes offer preliminary design explorations of ideas that are based on research of the nature and quality of palliative care, art and sensory design. They also serve as an exploration for possible programs, private and public spaces that are needed by different users.
A canopy at the entrance provides a sheltered procession in and out of the home, which becomes important in different weather conditions. Especially during the winter seasons, it eliminates the need for snow removal and the chances of bringing dirt and snow to the indoors. The canopy becomes an artistic design opportunity. The glass canopy interacts with sunlight and colors to bring life into the threshold creating a warm and welcoming atmosphere. It transmutes the idea of collective art work, like quilting, and the idea of mending into glass work design.
The bedroom space is configured as a private space with access to sunlight and nature. The level of light should be adjustable and controllable by the resident. The bedroom should allow for personalization based on the desires of each guest, and should also have enough room for family and friends to feel welcome to spend time there.
Large scale murals as community project by local artists, family and volunteers present an opportunity for creative exchange and as a replacement of the rigid way-finding system that characterizes large healthcare institutions.

A curved hallway hides destination from our immediate view thus heightens our other senses like hearing and smell.
Quiet space for care givers to temporarily withdraw themselves from stressful and emotional situations that arise. In this space, the connection with the outdoors and possible use of a reflective pool creates a calming atmosphere for quiet reflection.
The kitchen is an important space in a hospice. It serves as a gathering space for families and friends and is a place for daily exchange. Although some of the residents may not be able to eat, the smell of cooking and baked goods evokes the memories and joys of everyday life. An open kitchen that accommodates several families at a time offers the flexibility of a private and communal experience at the same time.
Connection to nature is an essential aspect in palliative architecture as it provides a full sensory experience. Besides providing a breath of fresh air and sunlight, the sounds of birds and wind have therapeutic effects. The smell of certain plants and herbs also provides health benefits and helps to relax the mind and body.
03. Site

879 Hiawatha Park Rd, Orleans

Currently, there are two residential hospices servicing the city of Ottawa. May Court is located in central Ottawa while Ruddy-Shenkman services the Ottawa west neighborhood in Kanata. The proposed site for architectural design exploration is in Eastern Ottawa in the neighborhood of Orleans (Figure 28). Adjacent to a palliative daycare centre and nursing home, the proposal will see a new expansion to the existing daycare facility already provided on site to include in-patient beds and associated programs.
Site History

Prior to its presence as a continuing care home, the site was home to a convent for The Sisters of Charity. The religious order was founded by Élisabeth Bruyère whose mission was to serve the sick and needy in the community. The nuns also played an immense role in the development of Orleans. With ownership of land throughout the city, they employed a lot of people in their farming areas. However, a tragic event occurred which changed the fate of the site and its operations. In mid May 1956, a fighter jet crashed into the convent, which caused a huge explosion that destroyed the building and took 15 lives including 11 nuns (Figure 29). Investigations after the crash came back inconclusive and it remains a mystery to this day as to why, or how an aircraft on a routine mission from the Uplands home base managed to strike the only building in a rural area.

It was an important tragic event that happened in the community to be remembered. A new building went up on the site in 1965 and was used as a hospice for a brief period. Currently, it is a long-term care home run by Bruyère Continuing Care. The design proposition of this thesis reintroduces a hospice palliative care home to the site, remembering the nuns who made significant contributions to the development of the city and to carry on The Sisters of Charity’s legacy to service people in the community who are in need.


**Site Analysis**

Access to staff and resources is crucial to the success of the hospice therefore its proximity to a long-term care home and the Montfort Hospital will provide convenient access to readily available resources.

The following site study offers an analysis into the proposed site in Orleans. Looking closely at the site surroundings will inform the design strategies in the proposition.

Figure 30. The site is located right along the edge of the Ottawa River.
Figure 31. The site is surrounded by greenery and parks, the location offers a serene environment where visitors and residents have access to nature—a powerful healing agent.

Figure 32. The site is conveniently accessed by public transit and cars.
Figure 33. The site is located in a quiet residential area composed of single detached houses and town homes.

Figure 34. The site is unobstructed by tall structures allowing access to sunlight throughout the day.
Figure 35. The site receives wind predominantly coming from south-west which informs the placement of entrances.

Figure 36. This is a quiet site where potential noise from nearby school and commercial area is blocked by a forest. Yet the site is exposed to the sound of flowing water from the Ottawa River. Sound of water has proven to be therapeutic and reduces stress and anxiety.
Figure 37 presents a site study that looks into the surrounding environment with scenic views of nature and the surrounding neighborhood.
04. Design Proposition

While the design of the palliative care home responds to symptoms, side effects and several design prompts identified earlier, the most important consideration is to give all users a sense of space, time and freedom for intimate human moments. The goal is to create a safe place for patients and families to freely express their emotions and individuality during difficult times.

Figure 38 identifies a list of programs and user groups that would interact with each space. Here, users are categorized into three groups based on the amount of time they would spend at the palliative care home. Residential hospice care is catered to patients in their final stages of illness who have needs that cannot be taken care of at home or in a long term care home. Typically the patients would spend up to 3 to 4 months at the palliative care home.78

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Fig. 38 List of programs and user groups

Respite care in Ontario offers up to 60 days of residential services for patients who are receiving home-care when their caregiver is unable to provide care due to issues such as health problems or being out of town for an extended amount of time.79

Daycare services include therapy sessions, support group meetings and grief and bereavement care for families and friends.

Site Strategies

Programs are grouped into clusters, separated into different pavilions and arranged from public to private.

Residents experiencing fatigue are encouraged to take short naps throughout the day. Separating private areas from public areas will ensure a quiet environment for rest.

In a demanding line of work, caregivers often need to have personal space and time away for emotional and mental well-being to avoid burnout.
By locating building away from urban sites, roads and pollution, being surrounded by trees and water enable occupants to breathe in clean and non-polluted air. This layout encourages occupants to be outdoors as often as possible as engaging with nature has proven health benefits.

People living close to trees and green spaces are less likely to be inactive, or dependent on anti-depressants.
Occupants experiencing fatigue and shortness of breath are encouraged to engage in light physical activity. A winding path with varying scenery creates interest and encourages occupants to take walks.

A winding path or hallway will slow down patients experiencing impulsiveness moving too quickly through space without the ability to think ahead.

Different spaces will not only have view but also access to the outdoors. Being exposed to nature will make occupants feel connected and relaxed.
Site Plan

Each pavilion is designed around a centre that draws occupants together and is represented by an element while the spaces along the perimeter is for personal time and solitude. The decagon plans correspond to the number of rooms and residents at the palliative care home, providing spaces for each family while the pentagonal plans reflect the ideas of the ars moriendi diamond of five spiritual dimensions.
Legend
1. Lounge/ Common Room
2. Kitchen
3. Bedrooms
4. Nurse Station/ Office
5. Meditation Room
6. Parking Lot

Site Boundary

Covered Walkway

Enclosed Covered Walkway

Existing Buildings
Fig.45 Site Plan Model
Bedroom

There are 10 bedrooms at this palliative care home. Each bedroom is an individual suite with its own bathroom and space for visitors and family to stay. Each room also has direct access to the outdoors, where patient’s bed can be wheeled outside during warmer seasons. The large angled windows in the bedrooms provide visual access to the outdoors at all times and take into consideration that patients laying in bed would also be able to look out to the trees and sky. However, depending on the stage of illness, some patients prefer to be in the dark. For instance, cancer patients who have received treatment may develop skin sensitivity to sunlight, they are advised to avoid direct contact with the sun. In this scenario, an electro-chromic window provides moderation and flexibility in how much light the room receives within the control of the occupant. While avoiding window blinds and drapery, the tinted windows still offer visual connections to the outdoors while the occupant is sheltered from strong sunlight.

The inhabitable walls in the bedroom not only provide storage space for equipments and belongings but also create a buffer to block out possible noise coming in from the circulation space. Meanwhile, the deep window sills offer additional seating for family and friends to visit and spend the day.
Figure 48. Bedroom Configuration 1 showcases a pet-friendly premise and use of storage space.

Figure 49. Bedroom Configuration for dementia patient.
Figure 50. Bedroom Configuration 3 for patient with heart disease.

Figure 51. Tinted bedroom windows controlled by occupants allow for naps throughout the day.
The kitchen and dining space is not modeled after a traditional dining room. The space allows for casual and impromptu meals throughout the day catering to different needs of residents and visitors. The kitchen consists of 5 stations that have the flexibility to open and close to accommodate an intimate gathering or larger groups through a roller shutter partition. Each station can also be opened up to the patio for an outdoor dining experience and an opportunity to interact with other residents.
Meditation Room

The meditation pavilion provides a quiet space for reflection and temporary withdrawal from stress. This space is particularly important for caregivers and staff. The pavilion has 6 private rooms on the perimeter for solitary meditation or prayer. The private rooms provide a spiritually neutral space for people with different background to meditate, pray and find solace through their individual beliefs. Each room has access to natural light and looks out to the garden through large windows. The centre of the pavilion consist of seating area around a water feature that reflect movement and sound qualities throughout the space as it sits directly below a skylight. The calming qualities of water is reflected and echoed through the undulating geometry and material of the roof to provide a tranquil environment for solitary reflection and rest.
Fig. 54 Meditation Room Section

Fig. 55 Meditation Room Plan

Individual meditation room

Water feature
The lounge serves as a living room for the palliative care home and is a space for social gathering. It is located near therapy and counselling rooms accessed by patients receiving hospice care, respite care and daycare. It also serves as a waiting area for meetings and pick up as it looks out to the main entrance. The lounge is centered around a fireplace very much like a home with several seating stations to accommodate both small and large groups.
Fig. 56 Lounge Section

Fig. 57 Lounge Plan

- Lounge
- Waiting area
- Reception
- Group therapy rooms
The circulation space is a continuous journey that connects all of the pavilions together through a seamless transition from the outdoors to indoors. The beginning of the path is marked by an extended coloured glass canopy at the entrance. The stained glass canopy reflects light onto the path and becomes a permanent art installation that create a welcoming and delightful threshold for the care home. The intertwining relationship of art and nature provides an interesting journey that encourages residents and visitors to engage in light walks which is helpful for symptoms such as shortness of breath and fatigue. The partly enclosed walkway create opportunities for moments of pause-pockets of seating for social interaction and rest.
05. Conclusion

A recent news article has revealed that many physicians in Canada have knowledge deficiencies that can impair them from helping patients manage pain that comes with major illness. Doctors are also not well versed to engage in end of life conversations, which means that patient’s goals and wishes often remain unclear and they do not receive optimal care in a desired setting. With a recently passed bill for doctors assisted suicide in Ontario, issues surrounding sickness and dying have never been more important or the need to resolve them more pressing. Proper palliative care provides an opportunity for patients to live well right through to the end by managing symptoms and side effects, allowing them to recalibrate their hopes and goals. However, it is ironic that in an attempt to provide terminally ill patients with more choices near the end of life, the option to live is undermined by a lack of access to palliative care.

This thesis is about creating a place that supports the value of living well to the end. The goal was to define a new typology for a palliative care home that embodies an environment conducive to providing support and care for those facing terminal illness and nearing the end of life. It is about providing a place for a marginalized group of people to live freely, with the support they

need to live with dignity.

By exploring how architecture can provide physical, psychological and spiritual comfort for the terminally ill and caregivers, they are presented with a choice at a time when life seems to be out of their control. The palliative care home at times becomes a humble background for the expression of intense human emotions surrounding an important stage of life. It is also a powerful place for transformation, changing the perspective of fear towards death built up over the past hundreds of years. The architecture of palliative care must provide a sense of inspiration, wonderment and spirituality that goes beyond physical comfort. I hope that through the discussions generated from this study, there will be a shift in perspective about the fear and taboo surrounding sickness and end of life. Ending the silence about death will diminish its terrors and shift the focus on improving the quality of life for patients and their loved ones.
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