

The Impact of the Mainstreaming of Hospice Palliative Care  
on a Small Community Hospice Program in Central Ontario from 1988-2017

by

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B.A. (Psychology), McMaster University, 1998

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### **Abstract**

The hospice social movement, which emerged as a new social movement based on the ideals of providing a more humane and natural approach towards death, illness, and grief, led to the creation of community-based hospice programs across Canada. This single case study explored the factors that influenced the life course of a small, community-based hospice (Hospice Orillia) from its beginning in 1987 to 2017. A preliminary timeline was created through a review of secondary data sources which identified milestones, events and individuals who were in leadership roles in the organization. This information was then used to recruit nine key informants who participated in semi-structured interviews. Through thematic analysis, the interviews identified that the organization's geographic location, its relationship to the formal health care system, its ability to access funding, and issues regarding advocacy and awareness all played key roles in how it developed over the years, leading to its eventual decline.

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## **Introduction**

Illness, dying and grief are universal human experiences. However, the impact that these experiences have on individuals, families and community members is shaped by numerous contextual factors including time, place and culture. We are not immune to this phenomenon in Canada. In the mid-twentieth century, death for most Canadians occurred in a hospital setting, apart from their friends and family members, often having experienced pain while dying. The community-based hospice movement emerged as an alternative to the bio-medical, technologically-dominant approach of caring for the terminally ill. Hospice Orillia was established as part of this movement, providing a grassroots, community-based program for the dying, their caregivers and the grieving. This thesis is a single case study that explores the key factors that have contributed to Hospice Orillia's life course. By examining this particular case, lessons can be extrapolated about the unique challenges faced by Hospice Orillia specifically, and the community-based hospice movement in general.

### **Chapter One: A Look Back at the Development of Hospice Care**

Historical accounts of hospice credit their inspiration to medieval European waystations, often associated with monasteries, which were dedicated to “the physical and spiritual care of the sick and the dying, and the Christian burial of the dead” (Ley, 1994, p.31). In Canada, the modern day, community-based hospice movement emerged across the country as a response to the poor treatment of the terminally ill by a biomedically-oriented, technologically driven health care system. In the 1970s and 1980s, hospice societies were established by community members, around a kitchen table or church basement, who desired to provide an alternative way of caring for the dying and of providing support for their caregivers, friends and families (HAO, 2009).

However, the development of palliative care as a medical specialty has impacted the development of community hospice programs. The routinization and medicalization of death and dying has created a fundamental shift away from the original values and ideals upon which the first community-based hospices were founded (Rosenberg, 2011). A core concept underpinning the hospice movement was the idea of a “good death,” as opposed to the institutionalized, unattended and painful death many experienced (Floriani & Schramm, 2012). As well, the original ideals of the hospice movement included a primary focus on diffusing power relationships between patient and professional (consistent with a feminist ethic of care) and an emphasis on helping to facilitate death in the home (rather than in an institution).

As palliative care has gained increased funding and acceptance within both the medical community and the Ontario provincial government, the emphasis has simultaneously shifted towards creating residential hospice facilities – alternative places of care for the dying. This been driven by a number of factors, including the lower costs of providing end-of-life care in a stand-alone hospice facility vs. the cost of stay in an acute care facility (Sussman, Seow, Bainbridge, 2011; Tanuseputro et al., 2015). As Brown (2003) argues, the implementation of hospice services have been largely driven by neoliberal “fiscal austerity measures in order to reduce public expenditures,” given that “the end of a person’s life is one of the costliest for the health-care system” (p.76).

The emphasis on hospice as a place of (medical) care rather than a philosophy or counter-institutional alternative way to care for the dying has created a tension within the hospice movement itself. Increasingly, community-based hospices (which are often located in smaller, rural communities) must compete financially and strategically with residential hospices which are often established in larger, urban centres. Subsequently, many community-based hospice

programs in Ontario are struggling to prove their legitimacy, their relevance, and ultimately to survive. However, it must be acknowledged that, as an alternative hypothesis, the struggles experienced by community-based hospices may simply be the natural (d)evolution of the hospice social movement's life-course.

### **Death and Dying in Canada**

Prior to the mid-20th Century, death, dying, illness and grief were part of the social fabric of Canadian society. According to Katherine Arnup (2013):

Most people...died at home, cared for by family members and friends. Death was frequently a community event, with extended family, friends and neighbours attending to the dying person and then participating in rituals of visiting the family as the body lay at rest (p.6).

Following WWI, an influx of technological and medical advances, including gains achieved through public health innovations, the public's increasingly positive perception of hospitals, and changes in women's role (as women moved increasingly into the paid workforce) meant that dying moved into the hospital setting, as did birth (Smith & Nickel, 1999). However, this shift came at a cost. Death moved into the shadows, and became an unspoken and unattended affair. People were no longer confronted with mortality as part of the fabric of life.

In the 1970s, French historian Phillip Aries chronicled the evolutionary changes in the social construction of death and dying. Aries wrote of the sense of immortality and invincibility inherent in the modern age in his article *The Reversal of Death: Changes in attitudes toward death in western society* (1974). There he commented, "In our world where everyone acts as though medicine is the answer to everything-where even though Caesar must die one day, there is absolutely no reason for oneself to die" (p.542).

Author, professor and sociologist Alan Kellehear, in his book *The End of Death in Late Modernity* (2007), argues that Aries "documented the shift in personal power from dying person

to doctor as the understanding about the ‘facts’ of death made their transformation from religiously inspired social imagery to mere physical & cellular” (p.72). This references the loss of agency and control an individual has in a biomedically-oriented culture to influence and ascribe meaning to their own death. Rather than being viewed as a sacred, mysterious transition, or an opportunity for reconciliation and reflection with loved ones, death and dying were/are seen "both as a failure and as a taboo" (McCann, 2013, p.290). The technological achievements of medical science "transformed the experience of dying from a part of normal life to a highly technological event" (Rosenberg, 2011, p.15). This led to an increased level of death anxiety in the Canadian public:

With the advent of modern medical technology and the more common usage of artificial measures to prolong life, many people today are more fearful of the process of dying than of death itself (Carstairs, 1995, p.1).

What had once been a communal event, with friends and family members attending at the bedside to offer comfort, was now the domain of medical professionals: especially physicians, nurses and medical technicians (Mills, Rosenberg & McInerney, 2014). The aforementioned cultural shift, with its emphasis on curing, resulted in medical professionals who were adept at disease management, yet were ill-equipped to care for those for whom no cure was possible. This led to people being left alone, neglected and dying in cold, sterile hospital rooms apart from the familiarity of home and loved ones (Abel, 1986).

### **The Origins of Hospice**

The modern hospice movement originally emerged as a counter-hegemonic discourse to the biomedical perspective that influenced the health care delivery system in the Western world during the post-war period (Rosenberg, 2011). Dorothy Ley, an early advocate of the hospice movement in Ontario, said:

Hospice, in the twentieth century, began as a revolt against medical attitudes and practices and the rigid institutional bureaucracy that reduced dying people to the state of a disease in a bed (Ley & VanBrommel, 1994, p.50).

By the late 1960s', Dr. Cicely Saunders in Great Britain, and Elizabeth Kübler-Ross in the US, helped define the inappropriate treatment of the dying as a social problem (Smith & Nickel, 1999). In the UK in 1967, Saunders developed St. Christopher's Hospice, a home for the dying, that embodied the principles of being with the terminally ill and managing their "total pain" (Clark, 1998). Meanwhile, in 1969, Kübler-Ross' seminal book *On Death and Dying* was released, based upon her research findings from interviewing over 500 terminally ill individuals. Her work revealed that individuals were often mistreated and neglected in the hospital setting, as health care providers were ill-equipped to care for those for whom "nothing could be done" (Kübler-Ross, 1979). Kübler-Ross challenged the dominant discourse around end-of-life, reminding the general public that dying was a part of the life course of every human being. She also emphasized that the dying had a role to play in the life of a community, with significant gifts to offer others, and actively promoted the concept of dying at home.

Heavily influenced particularly by Kübler-Ross, the community-based hospice movement in North America emerged in time of increased collective action in society. During the 1960s and 1970s, there was mounting discontentment with the Western capitalist system's impact on the "life-world" (Habermas, 1981, p.33). As Jürgen Habermas (1981) explains, there was a growing discourse around problems regarding "quality of life, equality, individual self-realization, participation and human rights" (p.33). This set the stage for the emergence of new social movements such as the civil rights movement, the women's movement, and the peace movement which offered alternative discourses and pragmatic responses to societal issues. As Siebold (1992) explains:

The hospice movement developed in an environment that favored collective action...the hospice movement was among these collective activities, and its cause, to ameliorate the plight of the dying, was consistent with increased efforts to improve conditions for all members of society (p.28-29).

According to Abel (1986), the hospice movement in North America also coincided with the rise of counter-institutions, such as food co-operatives and alternative schools, which sought alternatives to dominant, patriarchal, mainstream (and oppressively bureaucratic) cultural systems (Cox, 1994). While food co-operatives addressed the relationship between consumers and businesses, and alternative schools tackled the area of education, community-based hospices were established to provide an alternative way of caring for the dying and supporting their caregivers, seeking to remove them from the confines of institutionalism (Syme & Bruce, 2009).

### **Hospice vs. Palliative Care**

Meanwhile, also moved by the work of Kübler-Ross, Dr. Balfour Mount, an oncologist at Royal Victoria Hospital in Montreal, Quebec, conducted similar research at his own institution. When the results mirrored those of Kübler-Ross, he travelled to the UK to spend time with Saunders at St. Christopher's Hospice in order to learn from her. Upon his return, Dr. Mount established a hospital-based "palliative care" wing/program at Royal Victoria Hospital (Mount, 1976, 1978). Mount argued that the hospital was an appropriate place to care for the terminally ill, not only as they had access to medical technologies and trained staff, but also because "It enable[d] the hospital that cares for patients in all other phases of life to meet its responsibility to them when they are dying" (Wilson, Ajemian & Mount, 1978, p.7). As Stolberg (2017) argues, "the idea was that by creating these structures within a general hospital with a curative mandate, palliative medical care would be established at the very heart of health care" (p.181).

This launched the formal beginning of the "palliative care movement" in North America, and introduced the term embraced by the international medical community, including the World

Health Organization (WHO). By 1987 the Royal College of Physicians and General Practitioners in the UK recognized palliative care as a medical specialty (Clark, 2007), and in 1989 the WHO had developed a definition for palliative care. The current definition reads:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2018).

It is important to note that while both the palliative care and hospice movements began in an attempt to improve the end-of-life experience, palliative care began within the health care system and was aimed at pain and symptom management provided by professionals. This differed significantly from the goal of hospice:

Hospice societies were founded and were, by definition and composition, outside of the sphere of standard medical care. Hospice societies were community-based, voluntary, grassroots organizations brought about by impassioned leadership from an individual or group within a community.

They came into being at the same time as palliative care was struggling to be accepted in healthcare. This leads us to suggest that hospice societies provided what was not available or acceptable in mainstream healthcare and filled a perceived gap in care for terminally ill members of the community (Syme & Bruce, 2009, p.20).

The founders of community-based hospices were moved by a belief, as Byock et al. (2001) states, that:

The experiences of serious illness, dying, caregiving, grieving, and death cannot be completely understood within a medical framework alone. These events are personal, but also fundamentally communal. Every community responds to its members who are living through these difficult experiences in ways that at once reflect and shape community life (p.759-760).

Hospices were created to provide the community a different way of being with and caring for the dying, their friends/families and the grieving. However, this approach was not without its opponents. As Stolberg (2017) explains:

For many hospice initiatives, medical care provided by doctors was not the main priority from the outset, and critics were concerned that dying patients might receive inadequate symptom control and, in particular, insufficient pain medication (p.179).

Whereas palliative care focused on the professional, multi-disciplinary team's ability to provide clinical care in a hospital (or health care) setting, hospices were created to focus on the non-medical, informal, psycho-social aspects of the dying's (and their informal caregiver's) well-being. Kellehear (2007) argues that palliative care is often viewed as a "medico-nursing set of services place the emphasis on physical care, simultaneously de-emphasizing psychological, social and spiritual care" (p.77). Kellehear explains that palliative care often focuses on: the individual, interpersonal domain; health services research; the control of physiological symptoms; and the clarification of professional issues/ethics, while simultaneously dismissing community development, political criticism and social research. Kellehear goes so far as to say that "palliative care has also been interpreted as the provision of good pain relief and the provision of an on-call chaplain" (p.78).

More recently, Kellehear (2016) argues that "our academic and obsessions about affluent dying are also narrowly focused at point-of-professional-contact with the dying" (p.3). Palliative care has been influenced by the neoliberal agenda for health which is based on the three core tenets: (a) the necessity of free market (in which we work and consume); (b) individualism; and (c) the pursuit of narrow self-interest rather than mutual or communal interest, with the assumption that the pursuit of these tenets will lead to social good (McGregor, 2001). Rosenberg (2011), in his article *Whose business is dying?* offers a critique of palliative care, stating that it:

Continues to exhibit many of the paternalistic practices of mainstream health care that its forbearers were resisting. These practices, while well intentioned and often effective, find their origins in a sense of 'ownership' of the business of dying. But the clinical expertise of palliative care practitioners in the business of dying does not equate with ownership (p.16).

Rosenberg gives specific reference to the conceptualization of the “good death,” which, he argues, “has largely been measured by nurses’ perceptions of patients’ and families’ acceptance of the death and the degree of peace with which it was met ” (p.18). He also discusses how dying people are placed in the role of “user” or “consumer” of palliative care services, and that the level and nature of their involvement in the social management of their own dying is often at the discretion of health professionals (p.18). Even Rosenberg’s reference to dying as a business is a nod to the pervasiveness of neoliberalism and the market mentality in western culture.

Therefore, hospice and palliative care, while both striving to bring about change for the dying and their families, have many points of divergence. Since its inception, proponents of the hospice movement have expressed concern regarding its (the movement’s) ability to maintain the integrity of its values and ideals as time progressed. Community-based hospices originally aimed to keep the dying connected to their own communities. Ideally, this meant being able to stay out of institutions and being cared for at home.

### **Community-Based Hospice as a Social Movement**

To understand the community-based hospice movement’s development over the years, it is necessary to provide an overview of new social movements in general. While defining a social movement can seem like an elusive endeavor, many scholars have provided sound starting points. Goodwin & Jasper (2015) define social movements as “conscious, concerted, and sustained efforts by ordinary people to change some aspect of their society by using extra-institutional means (p.3). Sidney Tarrow, in his book *Power in Movement* (1994), defines movements as “collective challenges by people with common purposes and solidarity in sustained interaction with elites, opponents and authorities” (p.4). As well, Christiansen (2009), prefacing his essay on the development and processes of social movements, argues that social

movements are organized, informal, engaged in goal—oriented, extra-institutional conflict (usually aimed at influencing policy/cultural change) (p.2).

Hence, social movements are deliberate, organized attempts towards change, usually involving conflict with the dominant group or culture. This involves engaging in strategic planning, as Siebold (1992) explains:

A social cause does not emerge and then simply attract people to it; rather, participants become interested in a social issue, and as they form groups to discuss it they also shape the definition of the problem and the strategies aimed at resolving it (p.84)

### **Components of Social Movements**

Throughout the years, social movement theories have constantly evolved to reflect the changing nature of social movements themselves. For instance, the new social movements which emerged in the 1960s focused on issues related to personal identity, individual rights, lifestyle and culture, rather than focusing on political issues, as previous social movements had done (Melucci, 1980). Social movement theorists have also noted that the "key actors in these [new social] movements [were] different as well, as they [were] more likely to come from the "new middle class" rather than from the lower classes" as had those involved in labour movements (Stolberg, 2017).

Many new social movements were reactions to dominant cultural hegemonic discourses. Gramsci stressed the crucial role of the ideological superstructure (schools, churches, the media, families, etc.) in manufacturing the consent of ordinary people in their own oppression (Robinson & Garratt, 2008). Hence, these movements sought to create counter-hegemonic ideologies to frame and counter-institutional strategies to address social issues.

Theorists have identified key components of new social movements, including: the importance of cultural frames/ideology (Tarrow, 1994; Melucci, 1980; Siebold, 1992); and the

power of collective action (which includes social networks (Tarrow, 1994), social capital, and civic engagement (Putman, 1995)). Moreover, social movements have a predictable life course (Blumer, 1995), which ultimately leads to their decline, either through success, organizational failure, co-optation, repression, or establishment within mainstream society (Christiansen, 2009).

### ***Cultural Frames/Ideology***

In order to gain the attention and commitment of participants for a new social movement, the movement must provide a way of seeing a social problem that resonates with potential recruits' personal beliefs and experiences. This process is called "framing" by social movement theorists (Goodwin & Jasper, 2015; Snow & Benford, 2000). As Goodwin & Jasper (2015) explain:

Frames are simplifying devices that help us understand and organize the complexities of the world; they are the filtering lenses, so to speak, through which we make sense of this world (p.55).

Snow & Benford (2000) suggest that there three different types of frames: *diagnostic* (identifying a problem that needs to be addressed); *prognostic* (identifying ways that a social problem can be remedied) and *motivational* (appealing to potential participants on the basis of emotion).

### ***Stages of a Social Movement's Development***

As the term 'movement' connotes, social movements are dynamic entities. Christiansen (2009) provides a framework for understanding the four stages of a social movement's lifecycle, originally based on the work of social theorist Herbert Blumer (1995). While Blumer described the four stages as social ferment, popular excitement, formalization and institutionalization, Christiansen claims scholars have "refined and renamed these stages, but the underlying themes

have remained relatively constant” (2009, p.2). The stages, he explains, are now known as emergence, coalescence, bureaucratization (or routinization) and decline.

### ***Collective Action***

According to Tarrow (1994), the power inherent in social movements exists in the quality of social relationships and in social networking. He argues that:

Although it is individuals who decide whether or not to take up collective action, it is in their face-to-face groups, their social networks and their institutions that collective action is most often activated and sustained (p.21)

However, power is never neutral. It “can be exercised to create or destroy, and creativity or destruction can be either salutary or negative in its effects and consequences” (Swigonski & Raheim, 2011, p.16). Tarrow (1994) in his work *Power in Movement*, argues that for movements, their “major external resources are the social networks in which collective action occurs along with the cultural and ideological symbols that frame [them]” (p.17). The power that exists in social connection has been explained at length through the work of Robert Putnam. In his article *Bowling Alone*, Putnam (1995) explains that social capital “refers to features of social organization such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit” (p.225). Furthermore, he argues that social capital is essential in movements:

Networks of civic engagement foster sturdy norms of generalized reciprocity and encourage the emergence of social trust. Such networks facilitate coordination and communication, amplify reputations, and thus allow dilemmas of collective action to be resolved (p.225).

However, Putnam concedes that while social capital and collective action can generate positive outcomes, their results can also be negative.

In terms of how social capital operates, Lewis, DiGiacomo, Lockett, Davidson & Currow (2013) identify three types: *bonding social capital*, which is “used to characterize the densely

connected relationships of family and close friends, connections between people holding the same or similar values” (p.95); *bridging social capital*, “which refers to “weaker” ties or relations of mutuality with individuals and groups across boundaries” (p.95); and *linking social capital*, as “the capacity for relations and networks to cut across power gradients to connect with the representatives of formal institutions in respectful and trusting relations” (p.95).

### **Community-Based Hospice as a New Social Movement**

The importance of ‘linking social capital’ was essential to the hospice movement’s success and underlying philosophy in its early days. While exploring the work of Cicely Saunders in the decade prior to the opening of St. Christopher’s, Clark (1998) argues that it was Saunders’ ability to develop social networks, along with her strong sense of personal calling/mission and her commitment to professional development that moved the “St. Christopher’s Project”, and hence the hospice movement forward (p.46).

Syme & Bruce (2009) claim that in the context of the hospice movement, “hegemony refers to the dominant ideology and practices of medical care by clinicians within a model of biomedicine.” And that “as a movement, hospice both augments and simultaneously opposes mainstream curative medicine as the prevailing hegemony” (p.20). According to Abel (1986), the values which undergirded the hospice social movement were:

to minimize the amount of control, bureaucracy, authority, institutionalization and regimentation which was found in the delivery of modern medical care; to bridge the gap between expert and non-expert; to make relationships central to the care experience; to empower and support the terminally ill and their families by facilitating their ability to experience life, dying and grief with as few impositions as possible; and to normalize death as a natural part of life (p.74).

As Rosenberg (2011) argues, it was a movement led by community members to reclaim dying and to return the focus of care to the patient and the family.

## **Comparisons and Contrasts in Hospice Care: Community-based hospice versus medical specialization**

Regardless of its growth, proponents of the hospice movement have expressed concern regarding the direction of its evolution. Max Weber's theory of the routinization of charisma (1952) has often been applied to the hospice movement. The routinization of charisma suggests that movements (specifically religious movements in Weber's work,) "alternate between charisma and routinization through bureaucracy" (James & Field, 1992, p.1365). Charisma is a creative, disruptive element (in part an individual personality) that produces innovation in response to 'inhumane' experience (p.1365). However, charismatic leadership only succeeds as long as the group is small. As James & Field explain:

When exposed to everyday demands, charismatic movements inevitably become confronted with the need to create an administrative machine; the acquisition of funds; and the problems of successions-and so the process of routinization begins (p.1365).

Routinization refers to the "giving way to powers of tradition or of rational socialization...of all those powers that lessen the importance of individual action" (Floriani & Schram, 2012, p.297).

In particular, concerns about the routinization of hospice have been raised by (among others):

James & Field (1992) and Clark (1994) in the U.K; by McNamara, Waddell & Colvin (1994) in Australia; Floriani & Schramm (2012) in Brazil; and by Syme & Bruce in Canada (2009).

In the Canadian context, Syme and Bruce (2009) question if the trade-offs made to secure funding, namely: performance agreements and accreditation; shifting power dynamics (from grassroots clinicians and volunteers to professionals within mainstream palliative care); and the development of partnerships between hospice societies (or community hospice programs) and mainstream health care services in the development of clinical pathways have triggered the routinization or bureaucratization of community-based hospices. Emily K. Abel explores this

from a North American perspective in her article *The Hospice Movement: Institutionalizing innovation* (1986), and Cathy Siebold does the same in her book *Hospice as a Social Movement: Easing death's pains* (1992). Abel (1986) argues that, despite the founders' desire to "start afresh, unencumbered by the practices, traditions, and regulations of the traditional health care system" (p.77) the hospice movement faced challenges as they were forced to rely on mainstream institutions for resources (funding, personnel, political acceptance) which "compelled them to modify their practices and goals," leading to routinization (p.71). Siebold (1992), on the other hand, attributes the routinization (and the key challenges) of the hospice movement to its ambiguity of purpose, the contradictory nature of the movement's philosophy, and its relationship with mainstream health care.

Siebold argues that the major participants in the movement had mixed allegiances and motives for participating in the movement. She writes: "the lack of a clear values statement and the differing beliefs of core members resulted in a blurring of the movement's mission as leaders attempted to implement their ideas" (p.82). This challenge exists in Canada to this day, as the term 'hospice' is used interchangeably to refer not only to a community-based social movement embodied by volunteer-led programs, but also to a health-care facility, a philosophy of care, a hospital-based program, community-based palliative care teams and, in the U.S., to a welfare program (Brown 2003).

Kellehear (2005), in his book *Compassionate Cities*, discussed the 'mainstreaming of hospice' arguing that community hospice volunteers, in their work with individuals and in their fundraising, "underline and support the professional clinical care rather than serving as equal partners in that direct care" (p.8), and that hospice is now more reflective of "psycho-social

palliative care” (p.7) than the original goals of the hospice movement which involved cultural change and a revolutionary approach to care.

At the same time, there has also been expressed concerns raised about the medicalization of palliative care. In the 1970s, Ivan Illich (2013) introduced the concept of medicalization, in which “everyday life events become defined as medical issues and therefore come under the gaze of healthcare professionals within a medical model” (Bruce & Syme, 2009, p.22). Rosenberg (2011), among others, challenges the application of a disease-management model being applied to death, dying and grief. He argues that do so ultimately pathologizes what are fundamentally normal, life course events.

Since 2010, there have been many reports in support of increasing access to and the quality of HPC both nationally and provincially. However, the emphasis of the care (and of the funding) is often biased towards medical interventions in pain and symptom management and increased professional supports (ultimately with the desire to divert people from accessing costly acute care services), rather than addressing the other facets of ‘total’ pain that are experienced with a life-limiting illness. Yet many scholars have argued (and continue to argue) against the medicalization of death and dying, most notably: Phillip Aries (1974); Elizabeth Kübler-Ross (1975); and Allan Kellehear (1995, 1999, 2007, 2013, 2016). All of them insist that death and dying belong to, and should happen within, the context of the community.

### **Evolution of Hospice and Palliative Care in Canada**

With both the community-based hospice movement and the palliative care movement in Canada being in their fifth decade of existence, their evolutions have been inevitable. The Canadian Palliative Care Association (CPCA) was established in 1991 to be a national advocacy voice for palliative care. On October 21, 2001, the CPCA changed its name:

the [largely medically-based] membership of the then Canadian Palliative Care Association (CPCA) overwhelmingly supported a motion from the Board of Directors to update the logo of the association and change the name of the association to the Canadian Hospice Palliative Care Association (CHPCA). Due to the fluidity of the English language, "hospice care" and "palliative care" are no longer recognized as separate entities. The term that is now widely accepted in Canada is "hospice palliative care" ("History", 2018).

The term "hospice palliative care" was coined to recognize the convergence of hospice and palliative care into one movement that has the same principles and norms of practice ("History", 2018). However, Syme & Bruce (2009) state that the process of merging the terms was aimed at unifying the multi-disciplinary, professional, end-of-life team:

the consultative process used by the CHPCA to obtain national consensus on the values and principles underpinning hospice palliative care was another effort to identify what unites *hospice palliative care professionals* (p.22, emphasis mine).

Specifically, this change in terminology, as well as the definitions/norms created by the CHPCA, dismissed the counter-cultural, anti-institutional, anti-bureaucratic nature of the volunteer-driven, community-based hospice movement. According to CHPCA:

Hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved (2001).

While extremely broad, the new definition bonded together the two terms. Williams et.al (2010), conducted a study to trace the evolution of Hospice Palliative Care across Canada, through a case study of seven provinces, including Ontario. The study found that hospice palliative care (HPC) continued to be at the margins of the health care system, that the development of HPC had "encountered structural inheritances that have both sped up progress as well as slowed it down," and that the progress of HPC in the Country was due, in large part, to circumventions, initiatives and interventions to shift the system (including hospices) (p.7,8).

DeMiglio, Dykeman, Williams, & Kelley (2012), use the data from Williams et al. (2010) regarding the evolution of HPC in the province of Ontario, to trace the evolution of palliative

care in this particular province. Chronologically, they define three distinct periods: the 1980's (beginning), the 1990's (increased government involvement), and 2000+ (stakeholders working together). They also acknowledge that funding, advocacy and geography (specifically the emphasis upon urban centres vs. rural locations) were key forces impacting how palliative care has been developed across the province.

Syme & Bruce (2009) examine the evolving nature of hospice palliative care in Canada and ask important questions about “the factors that unite us and divide us as palliative caregivers” (p19). These authors also question “whether the life cycle of hospice as a social movement is coming to an end” ..... “whether the new characterization of HPC adequately attends to old and new ideals of EOL care”, ...and “how does a community-based voluntary service fit into the picture of rapidly expanding mainstream palliative care?” (p.20).

### **Community-based Hospice Programs in Ontario**

Most hospices in Ontario originated as community-based volunteer programs. These programs typically involved providing carefully selected and trained volunteers who would go into a dying person's own home to assist with: practical tasks; to provide companionship, emotional, and spiritual support; and to provide respite for family caregivers (Claxton-Oldfield, 2014). While research has been conducted in regarding community-based hospice programs, researchers have often centred their studies around the role of the visiting hospice volunteer (Claxton-Oldfield & Jones, 2012; Claxton-Oldfield, 2015) and less on hospices' organizational components.

For instance, studies have also been conducted regarding perceived enablers and barriers of referrals to community-based hospice programs (Claxton-Oldfield & Marrison-Shaw, 2014), concluding in recommendations to improve the education and promotion of hospice volunteer

services. A focused ethnography study by McKee, Kelley, Guirguis-Younger, MacLean & Nadin (2010) of community members in rural Northern Ontario found hospice visiting volunteers serve as a bridge, possessing a “third culture of care” to connect the person (patient) to their community, and the person (patient) to the health care system. Their findings suggest that “hospice volunteers are the linchpin in the system of formal and informal care that make it possible for people to die at home”, and that they “bring a non-medical, person-centered culture of caring” to individuals and their family (p.109).

While some information has been sought regarding the role hospice volunteers play in bridging social capital with the community and the health care system, the bulk of research has been done at the individual level of service delivery to the patient. No attention has been given to the larger role that hospice societies sought to have at the onset of their development, in terms of mediating a culture shift through the hospice movement. Also, while research been conducted to trace the evolution of hospice palliative care policy and system development at both a national level and a provincial level, there is no information on how individual community-based hospice programs have similarly evolved.

## **Chapter Two: Research Questions and Method**

### **Research Question**

While Hospice Orillia recently celebrated its thirtieth anniversary as an organization, questions have been raised about its future role in the Orillia community. As “the roots of the present lie deep in the past” (Lewis, May 4, 2017), reflection on how the community-based hospice originated and its life course offers insight into its present situation, and may provide suggestions for the organization in the future. The purpose of this study was to investigate the evolution Hospice Orillia as a grassroots, community-based hospice program which emerged from the hospice movement during a time of social and political change. The primary research question was:

What factors have influenced the evolution of a small community hospice program in Central Ontario from 1988 to 2017?

### **Methods**

This section outlines the rationale and detail of the research design and methodological approaches taken in the study. Also, key ontological and epistemological assumptions which influenced the approach will be defined.

It is imperative to recognize that the main researcher was an employee of Hospice Orillia for four years, and in a shared role with Hospice Orillia and the North Simcoe Muskoka Hospice Palliative Care Network for three years, working as a front-line social worker with people within the Orillia community and North Simcoe Muskoka region. The researcher lived in Orillia during this time, and as such she held insider knowledge which required her to engage in bracketing, an iterative, reflexive process whereby the research process itself involved “trying to understand the

effects of [her] experiences rather than engaging in futile attempts to eliminate them“(Ahern, 1999, p.408).

Ahern (1999) describes bracketing as:

The means by which researchers endeavor not to allow their assumptions to shape the data collection process and the persistent effort not to impose their own understanding and constructions on the data (p.407).

This process is in keeping with feminist research and a constructivist perspective, as reflexive research involves the realization that “researchers are part of the social world that they study (Ahern, 1999, p.408). The research topic and case itself were chosen in a desire to give voice to the experiences of those who had been involved in Hospice Orillia throughout its life span. To this end, it was important to engage in reflexive research, so that the data and the analysis centered the participants’ stories.

Field notes (including pre and post interview memos), journaling and external consultations were strategies used to facilitate maintaining an open stance to other ways of interpretation and to other perspectives of research data (Tufford & Newman, 2010). While the researcher’s insider knowledge/position may have created a tension requiring an awareness of biases and assumptions, it also facilitated the research occurring with cultural context, from a position of genuine interest in the research topic and from perspective that follow certain lines of reasoning with greater understanding (Tufford & Newman, 2010).

### ***Research study design***

As the purpose of the study was to examine how key factors played a role in the life course of a community hospice organization, a qualitative case study design was selected. Qualitative research differs from quantitative research in that it focuses on “describ(ing) and

explain(ing)...experiences, behaviours, interactions and social contexts without the use of statistical procedures or quantification (Fossey et al., 2002, p.717).

Qualitative research emphasizes understanding the meaning or knowledge that is constructed by people. According to Yazan (2015), “what really intrigues qualitative researchers is the way people make sense of their world and their experiences in this world” (p.6). This desire is rooted in a philosophical commitment to constructivism. As Baxter and Jack (2008) argue, “one of the advantages of this approach is the close collaboration between the researcher and the participant, while enabling participants to tell their own stories” (p.545). Foremost in qualitative research is the desire to privilege lay knowledge and lived experience (Fossey et al., 2002). According to Merriam (1998), “the key philosophical assumption upon which all types of qualitative research are based is the view that reality is constructed by individuals interacting with their social worlds” (p.6).

### ***Case study methodology***

In keeping with a constructivist paradigm, a case study methodology was most appropriate for this particular study as the goal was to gain an in-depth understanding of a single case in its real-world context (Yin, 2014). Qualitative case studies are based on two elements: using multiple methods/sources of data and focusing on one (or more) examples of phenomena which are part of a broader category (Lune & Berg, 2017). In this instance, the aim was to obtain insight into community-based hospice movement by examining the life course of a single organization, Hospice Orillia.

By using a case study methodology, the research process provided both a holistic description/explanation of the phenomenon, and it revealed various “nuances, patterns and more latent elements that other research approaches might overlook” (Lune & Berg, 2017, p.161). In

particular, the case study methodology was ideal both for doing an in-depth study of a bounded system (Merriam & Tisdell, 2018) and for tracing events over time (Yin 2014). Applying an intrinsic, holistic case study design provided the opportunity to explore Hospice Orillia as a specific case, fulfilling the intent of the study: to provide insight for the Orillia community and members of the organization's past to help inform its future planning (Baxter & Jack 2008). As is common with this particular approach, theoretical propositions, which are usually outlined at the outset of most case study research, were not identified as doing so would have interfered with the inductive and exploratory nature of this endeavour (Baxter & Jack 2008; Yin 2014).

### ***Defining the case***

The case explored in this study was Hospice Orillia, a small, community-based, charitable hospice program which emerged from the efforts and ideals of the modern-day community hospice social movement.

### ***Case context***

Hospice Orillia has been in existence since the late 1980's and was still operating at the time of this study. The organization was formed in 1989 by those who lived and worked in Orillia. The founding members were influenced by the work of Cicely Saunders, Elizabeth Kübler-Ross and June Callwood, to change the experience of those who were dying, caregiving and grieving in the community.

Hospice Orillia's service area includes approximately 80,000 residents not only of the City of Orillia itself, but also the outlying municipalities of Ramara, Severn Township, part of Oro-Medonte, and the Chippewas of Rama First Nation. Orillia is a popular destination in the summer and fall months for cottagers. However, in the winter, the weather can be harsh and unpredictable due to lake effect and its northern location.

Although Orillia is within close distance of both Barrie and Toronto, it shares many characteristics with rural and remote communities, including the homogeneity of the population (94% of the population speaks French/English, 10% of population were/are immigrants (primarily from Central/Southern European countries) and over 98% are Canadian citizens (Statistics Canada, 2016)). It has a local hospital which provides acute care services and is the centre for the Regional Kidney Program and the Neo-natal Intensive Care Unit. The majority of primary care physicians in the city belong to the Couchiching Family Health Team (FHT), which offers services (including counselling, chronic disease management, etc.) to residents in the area who have a family doctor associated with the FHT.

According to the 2016 Census, the average household income in Orillia is significantly lower than the average for Simcoe County (\$38,722 to \$44,949) and the rate of seniors living in the area is higher than the County average (Statistics Canada, 2016). While hospice services are available and accessed by all ages, the inherent trajectory of chronic illness, aging and dying suggests the population within the Orillia area could have a substantial need for hospice services, especially as they are offered free of cost, unlike many other supports.

These demographic details provide an important context for this study, as throughout, Orillia is often compared (both by interview participants and in other data) to its neighbouring urban centre, Barrie. The residents of Barrie are, on average, younger and more affluent than most residents of Orillia (the average age in Barrie is 39.6 and the average annual household income is \$91,293 (barrie.ca)). Currently at a city population of 141,434, (and a total metro population of 197,059) Barrie has experienced immense growth in the past decade, as it is within commutable distance to Toronto, provides more affordable housing options, and has many amenities found within a larger city (barrie.ca).

### ***Case study framework***

The research methodologies used by Williams et al. (2010) to capture the evolution of hospice palliative care on a national scale were adopted to explore the evolution of the Hospice Orillia hospice social movement on a mezzo, or organizational, level. As in the study by Williams et al. (2010), this project occurred in two phases. Phase I involved a review of relevant secondary data, to provide a historical context for the study and to identify key informants. Phase II involved interviewing key informants and applying thematic analysis to ascertain commonalities between and within the informants' interviews. This was deemed relevant, as drawing from numerous data sources is a hallmark of case study research.

Due to the nature of this study, often the data collection and data analysis occurred simultaneously (Yazan, 2015). Prior to any research being conducted, I received approval from the University of Victoria's Human Ethic Review Board (*Appendix F*).

### ***Data collection***

The data collection process included two distinct components: secondary analysis of documents and interviews with key informants.

## Chapter Three: Research

### Phase 1 - Initial Document Analysis & Timeline Creation

The study began by negotiating access to various documents that would provide historical and contextual background to the informants' interviews. A ProQuest search of local and major newspapers using the search terms "hospice" and "palliative care" from 1987 to 2017 was conducted. Media releases from the Ministry of Health were also reviewed to track increases to funding for community-based hospices (including Hospice Orillia) as were other government and non-government reports and legislation related to Hospice Palliative Care in Ontario and Canada. Permission was sought and received from the North Simcoe Muskoka Hospice Palliative Care Network (NSMHPCN) to review historical documents for Hospice Orillia (*Appendix C, D*). These organizational documents/records included:

- Letters Patent
- Hospice Orillia By-Laws
- Hospice Orillia Annual Reports (from 1989-2016)
- Hospice Orillia Formal correspondence, meeting minutes

Using data compiled from the document review, a timeline was created of relevant reports, external events, and potential key organizational milestones related to the development and evolution of both the hospice movement in Ontario and Hospice Orillia. The detailed timeline (*Appendix G*) was used as a reference point to facilitate conversations with research participants in Phase Two of the study.

## Summary of Phase I Findings

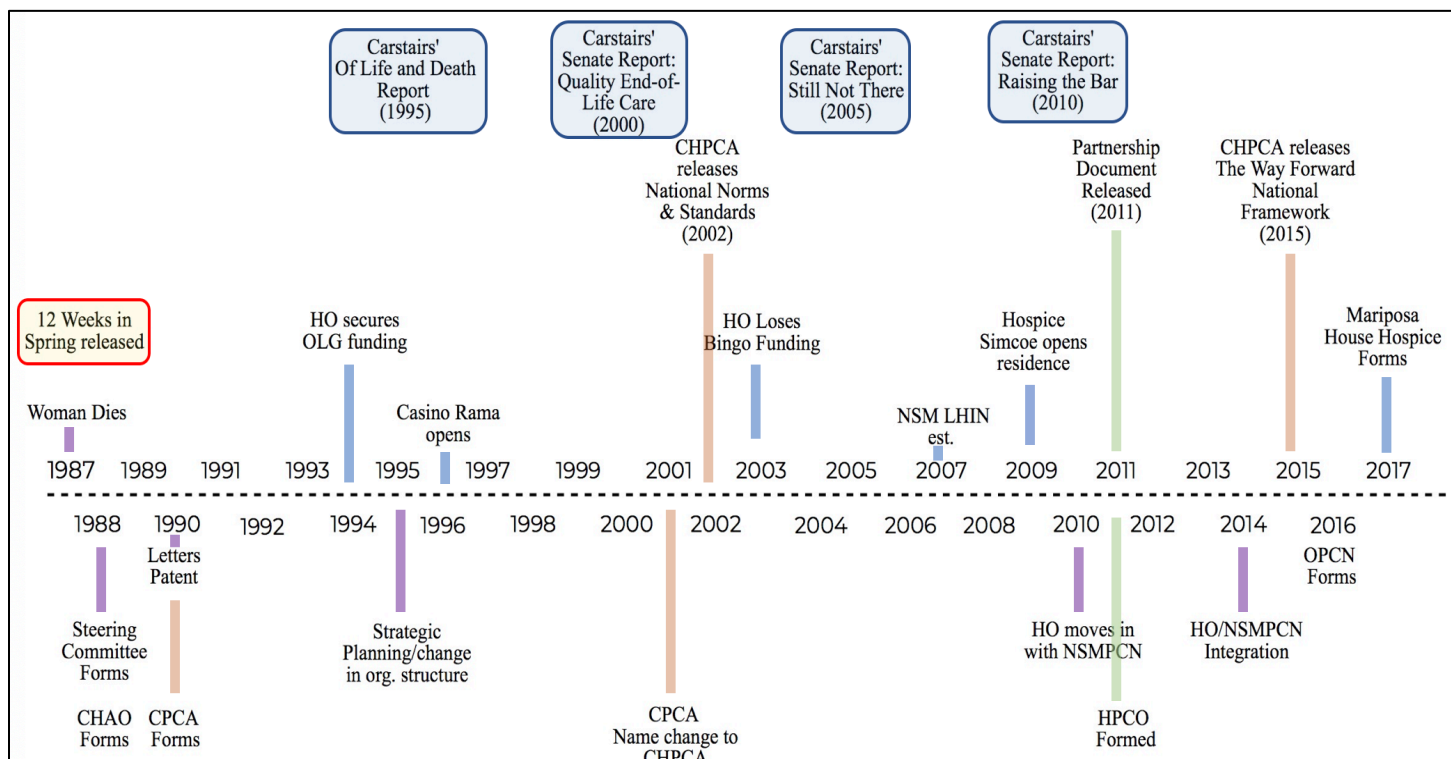


Figure 1: Summary of Key Events Identified Through Secondary Data Review

## Relevant Reports

During Hospice Orillia's life-course, there were a number of government reports, aimed both at a national level and on a provincial level, which influenced both the direction of (and the velocity of change for) hospice and palliative care in Ontario. The following is a summary of the key documents found in the literature review.

### *National Reports*

In response to the growing concern regarding the quality of End-of-Life care in Canada, Senator Sharon Carstairs tabled the landmark report *Of Life and Death* in 1995. This was the first of four reports, followed by: *Quality End-of-Life Care: The right of every Canadian* (2000); *Still Not There: Quality end-of-life care* (2005); and *Raising the Bar: A roadmap for the future of*

*palliative care in Canada* (2010). These reports highlighted recommendations to all levels of government to devote attention and funding to the development of palliative care across the country. More specifically, the authoring committee sought a national framework for palliative care to be created, implemented and evaluated on an annual basis. This national framework was to involve dedicated funds to palliative care research, increased pain and symptom education for health care providers, increased supports for informal caregivers, and the development of an integrated palliative care system across all disciplines and sites of care (Carstairs, 2000; 2005; 2010).

Concurrently, Health Care reform was happening across Canada, influenced heavily by the report *Building on Values: The future of health care in Canada* (2002) (commonly known as the Romanow Report). A key recommendation in the report was the need to make home care an essential service, including increased palliative home care services and support for informal caregivers. This reinforced Senator Carstairs' recommendation that hospice palliative care services to be accessible to all Canadians. In response to Senator Carstairs' further recommendations for a consistent plan and strategy to be implemented nationally, the CHPCA developed Norms and Practices for hospice palliative care (2002) and a national framework for hospice palliative care (*The Way Forward*, 2015).

### ***Provincial Reports***

At a provincial level, the Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) was formed in 2010 “to bring together organizations, universities and research institutions working at a provincial level in the hospice palliative care field” (hpcoco.ca). This group worked with the MOHLTC to identify priorities and to strategize on how to improve the hospice palliative care delivery system in Ontario. In 2011 the QHPCCO and LHINs released *Advancing*

*High-Quality, High Value Palliative Care in Ontario: A declaration of partnership and commitment to action* (hereinafter referred to as *The Partnership Document*). This paper identified six key priorities that to guide the work of HPC in the province:

- Broadened access timeliness of access to hospice palliative care
- Strengthening caregiver supports
- Strengthen service capacity and human capital in all care settings
- Improve integration and continuity across care settings providing hospice palliative care (including the home)
- Strengthen accountability and introduce mechanisms for shared accountability
- Build public awareness... engage the public conversation

While this document (and the others previously mentioned) provided a wealth of direction, many recommendations and even some strategies, this document did not hold any authority. Introduced as a ten-year plan, accountability measures were identified or enforced, and access to funding was not tied to adopting or implementing the recommendations. By 2016, it was evident that the province was not going to meet its identified goals and targets without heightened accountability structures in place.

In 2016, Parliamentary Assistant John Fraser, released the *Palliative and End-of-Life Care Provincial Roundtable Report* (March 2016) for the Minister of Health and Long-Term Care. This report, which provided feedback gleaned from province-wide consultations with community members and stakeholders (Fraser, 2016), was influential in determining the allocation of an increased 75 million dollars in funding for hospice palliative care in Ontario (MOHLTC, 2016).

This money would go towards developing a comprehensive Provincial Palliative and End-of-Life Care strategy which would include:

- Supporting up to 20 new hospices across Ontario and increasing the funding for existing facilities
- Increasing supports for caregivers that will help families and loved ones support palliative patients at home and in the community

- Promoting advance care planning so that families and health care providers understand patients' wishes for end-of-life care
- Establishing the Ontario Palliative Care Network, a new body to advance patient-centred care and develop provincial standards to strengthen services (MOHLTC, 2016).

The new strategy would support the implementation of both *Patients First: Action Plan for Health Care* (2015) and the government's three-year plan outlined in *Patients First: Ontario's Roadmap to Strengthen Home and Community Care* (2015), the MOHLTC's blueprint to create a more accessible, integrated, patient-centered health care system (Hoskins, 2015).

### **Major External (Provincial) Events**

Largely due to the advocacy efforts happening on a national level, various organizations and initiatives were created to move both hospice and palliative care forward in Ontario.

Specifically, non-Government Organizations (NGOs) in support of advocating for both hospice and palliative care in Ontario were established, and specific strategies (which involved funding to hospices) were introduced by the Ontario Ministry of Health and Long-Term Care. These external elements contributed to the overall context in which Hospice Orillia operated.

#### ***Creation of the Community Hospice Association of Ontario (CHAO)***

In 1989, the Community Hospice Association of Ontario (CHAO) was founded as a forum to provide support for local, grassroots hospice organizations and to engage them in the Hospice movement on a provincial scale (HAO, 2001). Hospice Orillia joined CHAO in 1990 (HO, 1990), which provided them with guidance regarding developing Board and governance skills as well as standards of practice for visiting hospice programs (HAO, 2001). However, in 1994, due to funding challenges of their own, CHAO restructured, limiting the amount of support they were able to provide local hospices (Hospice Orillia, 1995).

In the early 2000's, the renamed Hospice Association of Ontario released a number of tools to help visiting hospice programs become more standardized and efficient (Hospice

Association of Ontario, 2001). For example, they released: a “Target and Indicators” tool, allowing hospices to monitor their ability to meet objectives; a standardized training program for volunteers; and Client Service Standards (HAO, 2001). While the influence of HAO seems to have also been a major factor in the formalization and bureaucratization of Hospice Orillia, it also provided an opportunity, through its annual conference, for the local hospice to connect with the larger hospice movement. This was noted in the organization’s 2000 Annual Report:

The board sponsorship of 8 volunteers to the HAO conference was very much appreciated by those who attended. The comments expressed by the volunteers indicated that they felt a part of the larger organization and enjoyed the opportunity to meet other Hospice visiting volunteers (Hospice Orillia, 2000).

This connection afforded Hospice Orillia the ability to be aware of potential issues and challenges affecting the ability to move the hospice movement forward not only on a local level, but provincially and nationally.

#### ***Growing relationship with the Ministry of Health and Long-Term Care (MOHLTC)***

The first amount of government funding was granted to visiting hospice programs in Ontario in 1992 through the Ministry of Health (MOH) as it directed funds provincially to palliative care initiatives, including volunteer support and education (DeMiglio, Dykeman, Williams, & Kelley, 2012, p.113). Hospice Orillia submitted a joint application for Ministry of Health funding with Hospice Simcoe and Hospice Collingwood (Hospices of Simcoe County, 1994). The amount, while small, marked the beginning of a formal relationship between the health care system and the community hospice (HO, 1994). However, this only accounted for a small amount of overall costs. The bulk of costs associated with hospice programs were shouldered by the community.

### *End of Life Strategy (2005)*

In October 2005, the Ministry of Health and Long-Term Care (MOHLTC) announced an \$115.5 Million Dollar End of Life Strategy for Ontario (MOHLTC, 2005). The funding was allocated to Community Care Access Centres (CCAC<sup>1</sup>) and hospices with the goal of improving community-based care. Part of this announcement was a commitment to providing operational funds for residential hospices by 2008. While the financial impact of this announcement may not have been significant, the commitment to investing in more residential hospices influenced the mission and direction of the regional hospices in general, and Hospice Orillia specifically. In 2008, the End-of-Life Strategy funding came to an end, without this hope being realized in many communities (including in Orillia). However, Hospice Simcoe (in Barrie) received a large donation from the MOHLTC to help establish a 10 bed hospice. According to an article in the local paper:

The province recently contributed more than \$2.8 million to support the \$5-million project. The \$5 million will include all construction fees, soft costs, and furnishings, and will allow the first year of operational funding. The ministry of health and long-term care will fund half of the annual operating costs with a promised \$583,000 a year, while remaining expenses will be covered by the United Way of Greater Simcoe County and fundraising (Nicholl, 2008).

### *Development of the LHINs*

In 2006 the Local Health System Integration Act was passed by the Ontario provincial legislature (MOHLTC, n.d.), leading to the creation of 14 Local Health Integration Networks (LHINs) across Ontario (MOHLTC, 2004). The LHINs replaced District Health Units as the planning and funding bodies for Health Care at the local level. Through the creation of the Multi-Service Accountability Agreement (M-SAA) with the LHIN (Hospice Orillia, 2008), Hospice

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<sup>1</sup> Community Care Access Centres (CCACs) were organizations designated to coordinate and provide health care support (ie./personal care workers, nursing, occupational therapists, social workers) in the community.

Orillia established a secure partial funding source. However, they were still responsible for raising a large portion of their operational costs through community fundraising efforts.

### ***Aging at Home Strategy (2007)***

Due in part to Senator Carstairs' recommendations, as well as those in the Kirby Report (2002) and the Romanow Report (2002), the Ontario Provincial Government began investing in community-based care. This was also due to concerns regarding the encroaching "silver tsunami", the aging cohort of those born between 1946 to 1965 affectionately known as the "Baby Boomers" (Krotki & Henripin, 2018). The *Aging at Home Strategy* redirected funding from the hospitals into the community sector. Although hospice programs did not receive additional funding through this strategy, this re-allocation of funds resulted in budget and program cuts at the local hospital. The hospital emphasized its mandate as an acute-care facility and cut its palliative care program.

### ***Integration of HAO with OPCA***

In 2011, The Hospice Association of Ontario (HAO) integrated with the Ontario Palliative Care Association (OPCA). The integration of the two provincial organizations was promoted as "a significant achievement for hospice palliative care in Ontario, unifying the sector's voice to strengthen hospice palliative care for the people of Ontario" (HPCO, 2011). Until this merger, OPCA and HAO had worked separately in promoting hospice palliative care, often duplicating efforts and advocating for systemic change in an uncoordinated way (Williams et al., 2010, p.115).

### ***The Creation of OPCN***

In March 2016, the MOHLTC announced the creation of the Ontario Palliative Care Network (OPCN) (MOHLTC, 2016). According to their website, OPCN is:

...a partnership of community stakeholders, health service providers and health systems planners who are developing a coordinated and standardized approach for delivering hospice palliative care services in Ontario (OPCN, 2018).

In order to make this provincial plan feasible at a regional and local level, the OPCN created 14 Regional Palliative Care Networks (RPCNs). Each RPCN was to be locally governed, but “accountable to the Local Health Integration Network CEO and Cancer Care Ontario Regional Vice-President” (OPCN, 2018). The role of the RPCN was to be the regional advisor on high-quality hospice palliative care and to help inform decision making in the region (OPCN, 2018). The NSM RPCN was created in March 2016 (OPCN) and in 2017 it announced that plans were underway to integrate the existing clinical services of NSMHPCN into the LHIN Home and Community Care program (formerly the CCAC).

### **Organizational Milestones**

While external (national and provincial) events influenced the historical context in which Hospice Orillia developed, a review of secondary data revealed significant organizational milestones. This section provides an overview of the key events and turning points that occurred locally in hospice and palliative care in Orillia, and organizationally, for Hospice Orillia throughout the years.

#### ***Establishing the program***

Hospice Orillia was incorporated as an organization on August 29, 1989 (Hospice Orillia Letters Patent, 1989) and gained charitable status on June 13, 1990 (Canadian Revenue Agency, 1990) in large part due to the efforts of five women who comprised a steering committee.

Membership of the organization was open, granted to community members on a \$5 per-fee basis (Hospice Orillia, 1990). In 1991, Hospice Orillia obtained an office space and hired a part-time office coordinator to assist in administrative tasks (Hospice Orillia, 1991). All other aspects of the organization, from conducting in-home assessments to matching volunteers to fundraising were handled by community volunteers.

### ***Community/physician engagement***

Part of the initial mission of Hospice Orillia was to provide education and resources to the general public about hospice and palliative care (HAO, 2001). Community education events were held, bringing in speakers such as Dr. Dorothy Ley and Dr. Balfour Mount to explain what this approach to care meant for individuals and their families (HO, 1992; Sidhu, 1990). These events helped to raise awareness of hospice services as well as provide an opportunity for the medical community to “facilitate improved medical care to terminally ill patients” (HAO, 2001). Education events did not, however, necessarily create a wave of acceptance within the local medical community. Fortunately, there were a few physicians within the community who championed the work and vision of Hospice Orillia in the early days (I1,2; HO, 1990, 1991, 1992, 1993, 1994). Their support helped to move the program forward and forged connections within the mainstream health care system.

### ***Raising funds***

Obtaining external funding for the community visiting program was difficult at first (HO, 1994). Membership fees provided a small source of income, as did fundraising events such as car washes and yard sales (HO, 1990, 1991, 1992, 1993b, 1994). As the policies and by-laws were developed, a Trillium Grant was secured in 1991, providing \$66.2 thousand in seed money for the organization over five years (HO, 1993a). With a charitable number secured, the organization

began receiving direct donations. The fundraising committee provided a quarterly newsletter to communicate with its members, donors and the community at large (HO, 1991, 1992, 1993b, 1994).

In 1994, the Fundraising Committee pursued and secured two sources of funding through the Ontario Lottery and Gaming Association (OLG): a weekly Charity Bingo night and a license to sell “break-open” lottery tickets at a convenience store location (HO, 1994). With these two new external sources of funding, the OLG and the MOH, the Head of the Fundraising Committee made the following recommendation in the 1995 Annual Report:

I certainly have one suggestion for our organization, and that is to continue doing one or two things very well and be successful at it, rather than many small events that don't reap the benefits of the toll (HO, 1995).

The “toll” referred to was the time and energy required to run events which did not raise a fraction of the amount of money the other external funding sources were bringing in. With the urgency to raise funds alleviated, the amount of donations and fundraising dollars (from internally organized events) accrued decreased slightly the following year (HO, 1996). However, this was of little concern, as the organization was flourishing financially.

### ***1995 Strategic plan and organizational restructuring***

In 1995 Hospice Orillia, as an organization, created a strategic plan, identifying a new mission statement, vision statement and philosophy of care (HO, 1995). With their increased funding they created new staff positions, including an Executive Director role, and moved into a more spacious office facility, increasing their overhead costs (HO, 1995). At this time they also moved from an organizational model of a steering committee and a collective, open membership to a Carver Model governance board (who now fully comprised the membership) and staff-led programs.

### *2010 - Sharing resources with NSMPCN*

In early 2010, the North Simcoe Muskoka Palliative Care Network (NSMPCN) approached Hospice Orillia's Board with a proposal to share physical office space (Hospice Orillia, 2010a). At the time, NSMPCN's CEO was also the part-time Executive Director for Hospice Simcoe, the hospice in Barrie which was in the process of establishing a residential facility. One of the Local Health Integration Network (LHIN)<sup>2</sup>'s stipulations of the shared physical space with NSMPCN was a shared leadership model between Hospice Orillia and NSMPCN (Stokreef, 2010). A letter from the HO Board Chair to the NSMPCN leadership from January 14, 2010, stated concerns regarding this model:

The Network [NSMPCN] is an umbrella organization whose members are hospice palliative care service providers (including our own organization) and Hospice Orillia is a community-based organization whose members are individuals from within our community. We see this as a key difference that impacts the mandate of each organization, and these differences must be acknowledged. While many of the concerns raised by our Board might be addressed by development of a strict governance model, our board did not feel this work was a current priority given what is already on our table. Basically, our Board felt that the coming year requires 100% focus on our current Strategic Plan....

...Hospice Orillia is still interested in pursuing the possibility of co-location between our two organizations, but we understand that the LHIN is not supportive of this initiative without a merging of ED positions (Stokreef, 2010).

At Hospice Orillia Board meetings, concerns were raised about plans being made at a regional level regarding future of Hospice Orillia which were not being shared with the organization:

We felt there may be some benefit in discussing with (HS Executive Director) and Hospice Simcoe Chair, the plans for Palliative Care in Simcoe County. The general sense is there is an agenda which is in place but not completely understood by our Board (HO, 2010b).

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<sup>2</sup> Local Health Integration Networks (LHIN) are the regional planning and funding bodies for the Ministry of Health and Long-Term Care in Ontario. There are 14 across the province. Hospice Orillia is located in the North Simcoe Muskoka LHIN (NSM LHIN).

Despite these concerns (due to circumstances explained in detail in Phase II of the research findings), Hospice Orillia and NSMPCN did move into a shared location and initiated a shared staff model later in 2010. In 2014, Hospice Orillia formally and fully integrated with NSMPCN, dissolving its separate legal organizational status and becoming a division of NSMPCN instead.

### *Residential Hospice Committee*

In 2013, the local hospital announced significant budget cuts which meant the elimination of nine ALC (Alternate Level of Care) beds (Kehoe, 2013). These beds were designated as resources for individuals who did not require acute care but who were unable to be discharged home (often individuals at end-of-life), and subsequently this change significantly impacted the ‘palliative care program’ at the hospital. Without an answer or alternative place to care for individuals at end-of-life, the hospital and health care professionals, mainly hospital administration and physicians, began to increase pressure on the LHIN and Hospice Orillia to provide residential hospice beds for the community (Matys, 2014; Winson-Sarvis, 2014).

A Residential Hospice Committee, which included Hospice Orillia board members and leadership as well as local physicians, was established and a plan was presented to the LHIN. A co-location model was proposed (Phillips, 2014; Matys, 2014), whereby the wing of another facility (ie./LTC facility, retirement home) would be renovated and made into a space for a residential hospice program, reducing overhead maintenance and facility operational costs (Matys, 2016).

A feasibility study was then initiated to determine whether or not there was sufficient community support to move forward with the project (Inspire, 2016). The feasibility report cited a number of concerns, including the potential fundraising competition in the community, donor fatigue, and the lack of awareness/understanding of what hospice palliative care could offer

(Inspire, 2016). However, while conducting interviews with potential stakeholders, the researchers identified another major issue:

There was a small group of individuals who were quite passionate and vocal about this being the wrong model, citing that a stand-alone option would be less costly and preferable. Through further discussion, it appears that this group is actively working towards establishing a stand-alone hospice; counter to the efforts of Hospice Orillia. While this group claims they have a lot of support behind their plan – for example they mentioned that the physician community supports them – [name of research group] did not speak to any individual outside of the four in the group that advocated for or were aware of this plan (p.10).

The recommendations of the report included the need to either bring alongside the group of community leaders who were looking at a stand-alone model or to revisit and reimagine another model for the residential hospice. Without consensus, it was deemed imprudent to move forward.

In 2016, the North Simcoe Muskoka Local Health Integration Network (NSM LHIN) received funding for an additional ten residential hospice beds in the region, including five beds designated for the Orillia area (Phillips, 2016). As the LHIN did not specify the funding was designated for Hospice Orillia to develop the residential program, the other group of community leaders, led by two physicians, decided to move forward in September 2017 and create a new entity, Mariposa House Hospice (Phillips, 2016; Matys, 2017). Stating partnerships with entities such as the local hospital, the family health team and a local builder, the group anticipated an opening for April 2018 (Matys, 2017).

Mariposa House Hospice (MHH) was not interested in vying with Hospice Orillia for community-based programming (i.e./visiting volunteer program and bereavement services) but solely to provide end-of-life care to individuals during their final two weeks of life (Matys, 2017). With MHH aggressively focused on their vision (Shahid, 2017), Hospice Orillia leadership decided to support MHH's campaign for the beds, as the MOHLTC's December 2018

funding deadline meant if the beds were not operational by that time, the community would lose the available funding and it would go to another municipality (Shahid, 2017).

It is currently unknown what the fate of Hospice Orillia will be in the future, as its community-based programs are nested in NSMHPCN. Questions remain regarding the fate of Hospice Orillia once the NSMHPCN Nurses are integrated into the LHIN, the service planning component of NSMPCN is re-designated to the RPCN, and Mariposa House Hospice opens its residential facility to the Orillia community.

## Chapter Four – Analysis & Findings

### Phase II Findings – Themes emerging from participant interviews

The second phase of the research process involved interviewing key informants involved with the leadership of Hospice Orillia over a significant number of years or through points of transition. To identify potential data sources, purposive sampling was used. Merriam & Tisdell (2018) explain that:

Purposeful sampling is based on the assumption that the investigator wants to discover, understand, and gain insight and therefore must select a sample from which the most can be learned (p.97).

Through a review of the documents in Phase One the names of potential key informants/interviewees were noted as potential participants for Phase Two. These key informants were expected to have the ability to provide the “greatest possible insight into [the] topic” (Eckerberg, 2002, p.93) due to their level of involvement with Hospice Orillia at a leadership and decision-making level. Eleven individuals were invited to participate in the study via phone, email and social media. Nine individuals agreed to participate in an interview.

Interview times were arranged through phone and email, with the participants deciding the location, time and day of the interview. Upon initial contact a letter outlining the purpose and aims of the study (*Appendix Bb*), a consent form (*Appendix Ba*) and a preliminary draft of Hospice Orillia’s timeline (*Appendix G*) were provided to the interviewee.

#### *Interviews*

This study utilized a semi-structured interview process. This method was ideal for the study, in that it centered on eliciting “participants’ views of their lives, as portraying in their stories, and so to gain access to their experiences, feelings and social worlds” (Fossey et al., 2002. p.727). Semi-structured interviews facilitate the exploration of specific topics using an

interview guide that contains a “list of questions and prompts designed to guide the interview in a focused, yet flexible and conversational, manner (p.727).

The interview guide used (*Appendix A*) contained general questions to guide the conversation. In keeping with a semi-structured format, the questions were used during the interviewing process to focus the interview on the relevant topic, but also to allowed enough flexibility in the interview for the interviewee to tell their story and to introduce themes and details that were important to them (Yin, 2014).

Nine participants were interviewed, with the interviews ranged from 43 minutes to 100 minutes in length. The interviews took place in private residences, private office spaces and semi-private public spaces (including the local library and a coffee shop), as chosen by each participant. Each interview was digitally recorded and transcribed verbatim manually. Interview transcripts and notes from interviews were provided to participants for member checking, and they were encouraged to provide further input, corrections and feedback regarding the material in order to increase credibility of the data (Baxter & Jack, 2008; Merriam & Tisdell 2018).

### *Data Analysis*

As in most qualitative research, data collection and analysis occurred concurrently (Baxter & Jack, 2008). Data analysis can be understood as:

the process of making sense out of the data...[which] involves consolidating, reducing, and interpreting what people have said and what the research has seen and read – it is the process of making meaning (Yazan, 2015, p.18)

A substantial amount of time was spent with the data, as thematic analysis is “not a linear process of simply moving from one phase to the next. Instead, it is more recursive process, where movement is back and forth as needed, throughout the phases” (p.11).

Clarke & Braun's (2006) outline of thematic analysis was used and their strategy followed to analyze the interview data. Thematic analysis, according to Clarke & Braun (2006) is "a method for identifying, analyzing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail" (p.4). They further explain that "thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data" (p.3).

#### *Data Analysis of Interview Transcripts*

The six phase method outlined by Clarke & Braun (2006) was used to analyze the interview transcripts. This involved: becoming familiar with the data (including transcribing the interviews); generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report itself. Paper copies of the data were kept in a locked filing cabinet, and the CAQADAS system NVivo was employed to help organize digital copies of interview transcripts, notes and data items.

After the interviews were transcribed, time was spent immersed in the data set. As Clarke & Braun indicate, "Immersion usually involves 'repeated reading' of the data, and reading the data in an active way - searching for meanings, patterns and so on" (p.87). Field notes were made prior to and following the interviews and also served as a source of data. Phillippi and Lauderdale (2018) argue that maintaining field notes throughout the data collection process is essential to conducting rigorous qualitative data, in that the process:

prompts researcher(s) to closely observe environment and interactions; supplement(s) language-focused data; document sights, smells, sounds of physical environment and researcher impressions shortly after they occur; encourage(s) researcher reflection and identification of bias; facilitate(s) preliminary coding and iterative study design; increase(s) rigor and trustworthiness; and provide(s) essential context to inform data analysis (p.382).

In order to maintain participant confidentiality, identifying information was omitted from the notes.

They signed the consent form and provided me with a copy of it. I then set up the digital recorder (or at least I thought I had) and began the interview. After the first few minutes, I checked to see if the recorder was taping (it wasn't,) so we re-started the interview.

Things that I noticed – The participant was very diplomatic and cautious about stating any opinion too strongly or taking sides when areas of conflict were addressed. Also, while the emphasis of the interview was on Hospice Orillia, very little was said about the volunteers or the programs of Hospice Orillia itself – much more was stated about hospice palliative care in general, or the work of the Palliative Care Network. The participant did not mention any names (except for the names of the physician champion who they credited with their involvement with HPC.)

*Figure 2 Example of Field Note*

She was far more forth-coming in our conversation than I had expected. I was surprised by many of her answers, as she didn't hold back from confirming some of the details that I suspected may have been the case, but couldn't verify. Her knowledge of the LHIN, the NSMHPCN and the other community players was very helpful. She reiterated to me at the end of the interview that she didn't have anything to hide, because at the end of the day she was more concerned about outcomes than anything else - the ability to provide hospice palliative care services to people in Orillia.

*Figure 3: Extract from Field Note*

Upon completing the interview transcriptions, coding of the transcripts began. According to Saldana (2009):

a code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data (p.3).

Using the generated codes, a thematic map was created. Themes were identified, as were relationships between the themes and different levels of themes. The coded data extracts were collated according to related potential themes and kept in separate computer files accordingly.

Following this initial search for themes, the collated data for each theme was again reviewed identify patterns in the data. The entire data set was then re-read to ensure that the

thematic map reflected the aim of the research study. Following this review, a “double coding” process was employed whereby “a set of data are coded, and then after a period of time the researcher returns and codes the same data set and compares the results (Baxter & Jack, 2008, p.556). Clarke & Braun (2006) explain that “the need for re-coding from the data set is to be expected, as coding is an ongoing organic process” (p.91).

Once this process was completed, theme names were refined and a final thematic map was created (Figure 4, p.43). The documents and archives identified in the first phase of the research were re-examined and key information from these materials integrated into the thematic map. As Baxter & Jack (2008) note:

In case study, data from these multiple sources are then converged in the analysis process rather than handled individually. Each data source is one piece of the “puzzle,” with each piece contributing to the researcher’s understanding of the whole phenomenon. This convergence adds strength to the findings as the various strands of data are braided together to promote a greater understanding of the case (p.554).

Converging the data facilitated triangulation, in order to enhance the reliability and validity of the study itself. The results of this analysis are outlined in the following section.

### ***Phase II Findings - Themes emerging from participant interviews***

#### **Introduction**

Though analyzing the interview data, it was clear that there were two distinct parts to the information shared by the participants: the factors/events that contributed to the emergence of Hospice Orillia as an organization, and the factors/events that contributed to the development of the organization throughout the years.

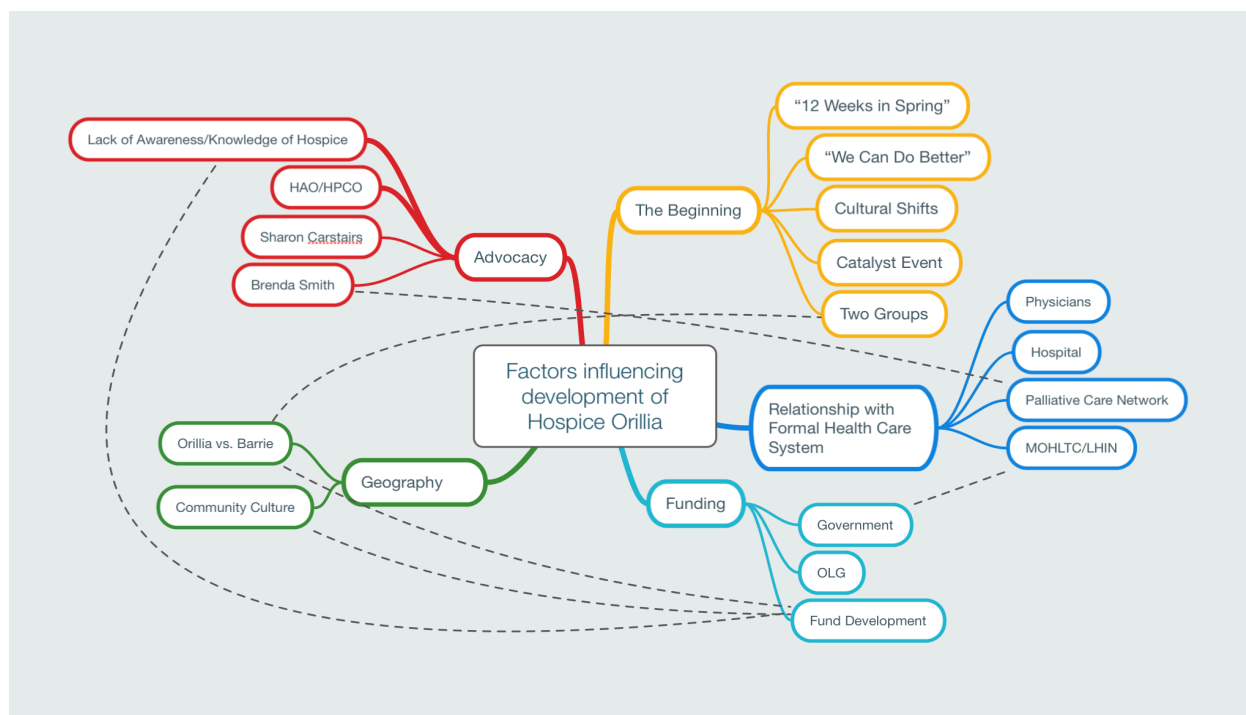


Figure 4: Thematic Map Identifying Final Themes from Participant Interviews

### ***Part I – The Beginning of the Hospice Orillia Social Movement***

This section describes the key motivators and barriers identified by interview participants to the creation of Hospice Orillia. Specifically these were: the change in location of death; the need to improve the quality of care for individuals who were terminally ill (and their caregivers); the influence of June Callwood’s *Twelve Weeks in Spring* (1986); and the gathering and collaboration of movement participants.

#### ***Change in location of death – from home to hospital***

Many of the early members and participants in the formation of Hospice Orillia identified that they were drawn to “do something” about the way in which dying individuals were cared for. In the mid-20th century, the location of both birth and death had shifted from home to hospital (Arnup, 2013). As some participants noted, this was due to a shift in the culture of communities and families post World War II:

*I think what happened is the demographics started to change. People had to work - they no longer had an opportunity to stay home to look after their loved ones that were dying. So you didn't have that home-based voluntary support to be able to... deliver, or allow people to stay home and die now. People were going to hospital. And both spouses having to work, and there was nobody staying at home with children - there was no-one staying at home looking after the elderly, and so there was this underground movement about how are we going to look after these people for whom we have looked after our whole lives, right? What are we going to do? And so that started a little bit of rumbling here and there. (I3:372-392)*

Also, while people often wanted to stay at home as long as possible and die at home, that was difficult to do with the amount of support that was offered (I4). Prior to the creation of the Community Care Access Centres (CCACs) in 1995, there was a lack in the amount of care offered from government agencies (I3). While some families/individuals could afford private nursing care (I2), government subsidized care was only offered during business hours (8 am to 5 pm) without any after-hour support (I4):

*I worked for the VON so visiting people in their homes and could see that need in the home - visiting people on their own turf, and I think that as time went on, I could see that there was more the need. People who needed support; people who were so unwell and maybe towards their end of life...I think family support, families that the whole load was on the one individual or maybe more than one...They needed that extra support, that extra help (I2:51-68).*

Rising concerns by visiting community nurses of having to leave families at home, struggling without the necessary supports they needed to cope with caring for a loved one, lead to creating solutions to help provide more support to allow people to die in the location of their choice:

*We knew that if we wanted people to be able to stay at home they needed more help than they were getting. My motivation to get involved was because palliative patients wanted to be at home, it was the only way that we were going to be able to help keep them at home was if we if gave them some support in the evening and at that point, CCAC - or "home care" they we called then, weren't funding evening care. So - let's get the volunteers in there. We'll support the volunteers (I4:349-374).*

***“We need to do better”***

Some were motivated by the need to “do better” in caring for those who were terminally ill or dying. People spoke of the need to provide care for people even when there was no chance at curing them of their illness:

*Pain was an issue for many people, we needed to make that better and better understood - we needed goals for people, it wasn't just 'oh well, they're dying - leave them be' - No. We needed to get in there and find out what their needs were, what they wanted out of the rest of their life, be it what it is...How do we make that happen? (I5:260-265).*

However, since hospitals were now the primary place of death, dying, which had once been the purview of the community, was foreign and shrouded in mystery. Death had become even more frightening than before, as many did not have the opportunity to spend time with the dying or to engage with a dying person. As one participant explained:

*We used to think, generally speaking, of course, that you could catch cancer. You know that, right? Years ago - you could catch cancer? Years and years ago, “I’ve got cancer.” I’ve had patients come into the hospital and they stand at the end the bed, but away - not touching the bed. -- With hands, usually elderly ladies, with hands like this (crosses arms across stomach) - “You can come closer and hold their hand, if you’d like” - “Oh, I’m fine” - Yeah. Oh yeah. I saw that in the hospital. It was just that, what we tend to stay away from, or fear. Thank goodness that has all changed. But yeah, I saw that in the hospital, a number of times, just that “Can I come in the room?” “Oh, yeah, of course, yes - please come in.” We saw that quite often - it was this fear ...that they might catch something. There was a lot of teaching had to be done” (I1:480-508).*

***Twelve Weeks in Spring – Another way is possible***

While front-line caregivers experienced the challenges of caring for and witnessed the suffering of the dying, another approach was being explored by advocates such as Dr. Elizabeth Kübler-Ross and Cicely Saunders. However, it was Toronto journalist/social advocate June Callwood’s book, *Twelve Weeks in Spring* (1986), that inspired many of the early proponents of Hospice Orillia to believe that another way might be possible:

*Twelve Weeks in Spring had just been written, and so... people were starting to talk about the movement itself. And Kübler-Ross's book was on the bestseller list. At that point so people were starting to become - and we now know that Kubler-Ross's book is -passe- - But at that point it was considered sort of "the book". It was groundbreaking at the time - so there was that general interest, and I think people wanted a better way (I8:317-329).*

In *Twelve Weeks in Spring*, Callwood recounts the story of Margaret, a single woman in her 60's who was diagnosed with cancer and wanted to die at home. Although Margaret did not have any immediate family members, her friends, acquaintances and colleagues from different facets of her life worked together to coordinate a schedule and to provide support to her. This allowed her to stay at home during her final days, surrounded by her community, overlooking her blooming gardens, as was her wish. This story provided a stark contrast to the institutionalized, isolated death many witnessed happening in hospitals and institutions at the time.

#### ***Catalyst event – Creating a team***

It was the terminal cancer diagnosis of a local Orillia woman, a young nurse and mother, which provided the opportunity for many in the original 'group' to put this new-found approach into action (I8). The woman requested she be supported by her friends and family, that they spend time with her while she was still living, rather than just attend her funeral when she died (I8). Her best friend agreed to facilitate her request, and developed a roster of thirty friends to sit vigil with her while she was in the hospital (I8; I4). After her death, some members of her 'team' decided if they could support this woman so well, perhaps there might be a way to offer other people in the community a similar type of care (I8).

#### ***Beginning – Two groups***

Shortly after the local woman died, the people coordinating her team of friends and family members began thinking about starting a local hospice program. At the same time, there was another group of individuals who were interested in starting a hospital visiting program:

*After she died, [her friend] phoned and said that it had worked really, really well – would I be interested in being part of a group that met to help form a hospice? ... At the same time, or very shortly there afterwards, I got a call from my old friend [who] said, ‘hey! We’re thinking of starting a hospice – and she knew about my interest in hospice, and would I be interested in sitting on a committee for that?’ – So I went to that meeting and I said – “There are two groups trying to form a hospice – why can’t we bring both of them together?” And so we did. And that first meeting was held at [name’s] house. [Name] has the most amazing dining room table...(I8:53-64).*

While the merging of the two groups lead to the creation of a joint entity, initially one of the groups had been in discussions with the leadership of a more established hospice program in Barrie, the urban centre of Simcoe Region:

*My initial conversations were with Hospice Simcoe. We used to meet regularly with [the Board Chair] at that time of Hospice Simcoe. And they had a vision that we wouldn’t, that ...hospices throughout the region wouldn’t have to get incorporated because they could be the umbrella. That was their vision. That’s why they call themselves Hospice Simcoe. So they could cover the county, there could be smaller ones that would be very community-based and funded community-wise, anyway. But [Name] told us how to get from A to B. Because initially, it was just going to be a hospital initiative or program (I4:217-261).*

There was resistance from some of the group members about this model. As one participant said, “at the time that Hospice started...it was very clear; Orillia had to have its own.”(I4:995).

Regardless of this tension, the group moved forward to develop a strategy:

*We got together and said “Okay, what can we do together... ‘cause there’s no point in us trying to do this from two different perspectives?” And with [Hospital Administrator] and the hospital giving us a little – some support, in terms of a place to meet we came together and had to learn about how...we would develop an organization right off the bat. Because here we were, like five women saying we’ve got to fix this - how are we going to get any money, and what are we going to – what would fundraising look li-e - and we started right away to work on a Trillium Grant - which we eventually got, but it took us a long time to even develop the background that you need for something like that- (I3:92-135).*

As they organized and became more strategic, the evolution of Hospice Orillia as a community hospice program began to take shape. Initially, the five founding members formed a steering committee, with sub-committees facilitating the tasks of promotion, education, fundraising and

coordinating the visiting volunteer program (Hospice Orillia, 1993a). During this season, there was a heightened sense of purpose and energy:

*We all had the passion. That was the exciting thing about it; we had no money, we had no way of getting money originally, no place to meet. We used to say that we carried our hospice office in the trunks of our cars. We all had totes in the backs of – in – our trunks, and so we would arrive at meetings with our tote... (I8:107-112).*

During this time, everything was volunteer-driven, building on the skills and talents of community members:

*What people don't really understand is how long that initial stage takes. To form your policies and your procedures and become incorporated and all the nitty-gritty stuff that needs to be done. And we were very lucky, because um, [NAME] for instance, loves policies. I'm not a policy person. I slugged through it because I knew it had to be done, but [NAME] loves it – that's one of her fortes – (I8:91-97).*

Slowly, the organization began to evolve in its structure and role in the community.

## ***Part II – Factors in Hospice Orillia's ongoing development***

The second part of the findings highlights the barriers experienced throughout the years by Hospice Orillia as a community-based hospice. Through their interviews, participants identified that funding, Hospice Orillia's geographic location, the efforts of hospice palliative care advocates and relationships with the formal health care system were key factors in the organization's development.

### ***Funding***

How Hospice Orillia obtained funding to support its services was seen by participants to play a major role in the organization's life course. While in the beginning funds were raised through small events (such as car washes) and a one-time three year Trillium Grant, three ongoing streams were named: Government funding through Ontario Ministry of Health (eventually the Ministry of Health and Long-Term Care); revenue from Ontario Lottery and Gambling Association (OLG); and fundraising efforts within the community.

***Ministry of Health and Long-Term Care (MOHLTC)***

Hospice Orillia first obtained financial support from the government in 1992, as money was given to educational initiatives, including visiting hospice volunteer training programs (I3). This began a formal relationship with the Ministry of Health, the overseeing health care body in Ontario. With this partnership came a heightened fiscal accountability (and structure):

*I guess when you're a grassroots -kinda - thing, you - kinda think that we're a nice, - we can do everything together, just everybody working together to do things - and then they bring in these tax forms and everything else gets all so structured, and you think 'Oh golly - we've lost that community kind of thing and become a business almost" - tax forms - but the government, you had to account for everything (I1:2585-2591).*

However, the amount initially received was quite small (approximately \$3,000) (I1), and the paperwork required for the funding was extensive and time consuming:

*I always remember the fellow - Bill Fountain, his name was, the gentleman, very supportive of the hospice movement but the forms that we had to fill out for government funding, were pages and pages and pages long. And, we had to do them quite often during the year. And justify the pennies. I have no problem with that, that's just the right way - but for the small amount that we got, it was very difficult to go through all that. And, and trying to find other sources of income and get the government to give us a little bit more (I1:563-571) .*

As time progressed, the MOHLTC continued to provide funding for Hospice Orillia, however, the amount provided only covered a portion of the organization's costs. It was necessary to find other sources of financial support.

***Ontario Lottery and Gaming Association***

In 1994, Hospice Orillia began a partnership with the Orillia Charity Bingo, hosting weekly events. These, along with revenue generated from Nevada "break-open" tickets sold at a local convenience store, brought in a substantial amount of money for the organization (I9, I1, I5). However, this funding source was threatened on two occasions: when Casino Rama, a large

entertainment/casino/hotel facility opened in 1996 (I1), and when the City of Orillia passed a non-smoking by-law in 2003:

*We lost Bingo...because they made it non-smoking. and a good majority of the Bingo people smoke. And so that - so it's non-smoking and so they'd go out to the Casino, they'd go somewhere else - that was a, that was a difficult loss... (I9:391-397).*

According to Participant #1:

*We lost significant income...So our revenue started to drop dramatically. I can't honestly give you an exact figure after all these years, but it was significant. And we had to look for other ways of increasing money – funding (I1:510, 542-545).*

Before the Charity Bingo closed, it had provided Hospice Orillia with more funds than the MOHLTC (I5). The local Legion tried to revive the Charity Bingo a few years later, and while it did provide some consistent income to Hospice Orillia, it was not as lucrative or successful as the previous one had been (I9). This left the organization to re-engage in community fundraising, which they had not aggressively pursued since they started with the Bingo nights eight years earlier.

#### ***Community fundraising/fund development***

While the early days of Hospice Orillia involved volunteers hosting and engaging in small community fundraisers (such as car washes and garage sales), after the loss of Bingo, Hospice Orillia had to develop new ways of raising awareness and funds (I1). They hosted their first of many galas, or special events (I1, I2, I7, I9):

*We did put on a, a dance, dinner and dance, and people, artists donated paintings. We had an auction [NAME], the girl that you see on tv,--that..she was the auctioneer - that was wonderful - volunteered her time, the paintings were donated. We had a wonderful dinner that was provided by the chefs in town. And after all was said and done, after all the food and everything else, I think we made about five thousand dollars. It was to us, a wonderful success, but a lot of work (I1:618-626).*

Meanwhile, attempts were also made to find other income sources:

*I researched other hospices to find out what other hospices were doing for funding - how do you create money? How do you establish with what you're doing - a lot of it was - for many it was corporations getting them on their Board, so it was - and working with the hospitals, which we were already doing (I5:434-438).*

A direct mail campaign was conducted to try to generate new individual donors and corporate sponsors, with lackluster results:

*I - put numerous letters out to various organizations and corporations to try and get individual funding - probably 50 or so - um, I did a bunch of research and tried to get 'buy-in' letters, if you know anything about fundraising, that's a huge - endeavour, and - y'know, one I took on - um, trying to find funds to secure funds when we lost the Bingo... unfortunately, a lot of that fell through - it didn't happen - um, the letters went out - and very little response - I did manage to get maybe \$20,000 - but that was about all, and it was a one-time funding. So it wasn't ongoing funding - (I5:415-491, 447-449).*

With little success to show for traditional fund development methods, they returned to hosting special events in the community (I9). However, concerns were raised about the purpose or efficiency of this strategy:

*The events were held because they were fun - and people liked to have them - but I don't know if the direct costs were ever actually looked at when it came to - because we didn't ...we kept people's names, but it was for the purpose of sort of the next event, rather than ... developing a donor base (I7:288-292).*

With a small staff and the amount of internal time, energy and resources necessary to make the events happen, it was questioned whether the fundraisers were actually generating funds or depleting resources from the organization's ability to provide hospice services to the community (I7).

Many interview participants noted that Hospice Orillia has struggled financially throughout its lifespan (I1, I2, I3, I5, I7, I9), and that this lack of financial stability has been a major factor in the organization's development. Although there has been ongoing revenue generated from MOHLTC (which has increased over the years), the OLG (Bingo & Nevada) and

community donors/fundraising, this has also necessitated fiscal accountability to all of these entities, as well as recognizing them as stakeholders in the organization.

### ***Relationship with the formal health care system***

Although Hospice Orillia did not seek to provide any medical services or supports to individuals and their families, in order for them to be accessed, it was necessary to build relationships with the formal health care system, specifically with physicians, the local hospital, the MOHLTC and the regional palliative care network.

#### ***Physicians***

Interview participants indicated that local physicians have had a mixed response to the presence of hospice care in Orillia since its inception. Participants described physicians as any of the following: champions of hospice (I6); supportive/ambivalent (I1); or barriers/gatekeepers to people accessing support (I1, I2, I3).

The early success of Hospice Orillia was attributed to the physician champions that promoted hospice services through conversations in medical rounds (I3). As one participant said, “we needed a physician’s voice to get to the physicians” (I3:602). These doctors would attend multi-disciplinary rounds (I2), make referrals (I1) and even advocated for hospice services to be provided within the hospital (I6). One of the biggest challenges was getting the physicians “on board”:

*One of the biggies was getting doctors on board. Back at that time well, we didn’t have the so-called Palliative Care Physicians early on... So, it was partly trying to educate the doctors as to what we could provide... and let them know that, I mean, anybody can make a referral to us, to hospice. So the docs, or anybody – a referral could come from anywhere (I2:223-232).*

This challenge was attributed to physicians’ level of comfort with death and dying:

*In all fairness to the doctors, I, I had a doctor once tell me that, like, he had a five-minute course in palliative care when he was in medical school. He said “they didn’t even call it that - they just spoke about dying (I1:857-860).*

Other participants questioned whether physicians’ either didn’t know about hospice, didn’t understand what value it could offer the patient and family, or were potentially threatened by the hospice philosophy of comfort, team-based care vs. traditional, curative medicine:

*A couple of them were not too receptive - maybe they did not understand the full concept of hospice. I don’t know. Maybe they didn’t - maybe I don’t know if they felt- threatened? In a way? (I2:232-237).*

*I don’t know what their understanding would’ve been – but, I mean, pain and symptom control – and making the journey a little bit easier when you’re passing on...and I think part of that part of that was also coming to terms with the DNR...I think because it hadn’t really been addressed at that point in time – it was like, you do whatever you can to keep this person alive (I2:313-328).*

Participants spoke of the importance of hospice in providing an individual with control over the services and care they receive:

*What is critical to me, that I think is the very best thing about hospice, is, is you don’t need a doctor’s permission to go in, you don’t need particular clinical orders, if anybody thinks that you could use a hospice, and the person agrees, anybody can call...and refer. The person has to agree before goes in or an assessment is made, but anybody can call, and then we’re there until the person says “we don’t need you anymore” so - you don’t have a certain criteria that you have to meet or else we’re doing a discharge, you - we’re there. And we’re there after the person dies - (I4:487-496).*

*The value-add is that they’re patient-directed, right? So the patient gets to choose what it is that they want in a hospice environment, right? It’s not a service that’s required - it’s not a service - that someone else can say ‘you need this and therefore you must get it’ - it’s not like saying ‘your thyroid’s wacky and you need bloodwork - go there’ - right? It’s for the patient to choose - what is valuable to them that supports their life goal. Whatever that is. So that’s the difference - and that’s the value-add of hospice in the middle of a service continuum, right? (I3:1854-1862)*

The concept of physicians feeling the need to be in control of the patient’s journey (whether real or perceived) was spoken of by many participants (I1, I2, I3, I4). In Orillia, this role of ownership was heightened as family doctors provided “womb-to-tomb” care:

*We have one of the few communities, I think, in Ontario where the family doctors in the community...provide[d] the full spectrum of care - they [did] house calls, and they... provide[d] palliative care. In a lot of the bigger centres, and even in some of the small communities they [didn't] do that. It's just not sustainable but somehow we manage[d] to attract people...willing to provide that service so, and as time had gone by, I think they were becoming more comfortable with providing that service (I6:238-246).*

Family physicians were designated as the Most Responsible Physician (MPR) in an individual's journey through the health care system in Orillia (I6). In terms of hospice services, this created a challenge, as physicians were often looked to by their patients to provide information about resources and supports:

*People believe physicians are - they still believe physicians are god-like, 'right? And so if the physicians can't speak well about it, then the patients aren't even going to understand - or their families aren't going to understand. 'Cause \_they - y'know or if they haven't had exposure with it in some way...(I3:1131-1136).*

As well it was noted that although people were dying in the hospital, this was not an issue for physicians until the hospital's budgetary constraints put pressure on them to keep people home or in a different location:

*The physicians - up until this time - were not getting a lot of flak for people dying in hospital. Hospital budgets, we've got -y'know, occupancy was somewhere around 80% - you were funded for 100% - people could stay in hospital, they got good care, no one was really raising a ruckus. And then all that changed. So when the financial picture changed, and hospitals...were saying "y'know, we not only think this is the wrong place - we can't afford to have them here - 'cause we're not making any money - 'cause they're a different category of funding", then there started to be push back on the doctors. It wasn't until we [had] the physician's voice (I3:396-410).*

Funding also impacted delivery of care provided by the physicians, it changed to a per capita model, limiting the amount of time physicians were able to spend with their patients (I3).

However, changes were also made to remunerate them for driving distances to patients' homes and doing house calls (I6). Also, family health teams were created in Ontario. As Participant #3 explained:

*They needed a team - So the family health teams' funding model was an improvement on that... then they had money to hire a social worker, and another nurse, and do some palliative care - However that's now causing fragmentation in our system. Because each family health team is creating their own strategies around dealing with palliative care - (13:943-954).*

In Orillia, this palliative care team was led by family physicians and reported to them, often with duplication of existing palliative care services. For Hospice Orillia, this meant an increased number of professionals in the home, often overwhelming the family and minimizing their willingness to access hospice services, regardless of how they might benefit from them (16).

### ***Relationship with the Local Hospital***

While Hospice Orillia has had a tenuous relationship with Orillia physicians, their relationship with the local hospital has been equally precarious. As previously mentioned, in the beginning of Hospice Orillia's existence, volunteers functioned solely within the hospital, and eventually were able to follow people back and forth from the community to the hospital (18). This was a major success for Hospice Orillia, "*because you became very close to the people that you worked with. Um - and just to be able to follow them home and follow them - because people do go in and out of hospital*" (18:1208-1209). After a time, Hospice volunteers were no longer permitted to visit people in the hospital as volunteers (allowing them to visit after hours, etc.) but only as visitors (11).

During this time, two physicians championed for a space in the hospital for individuals at end of life:

*We liaised with the hospital powers that be, on the second floor, which was a medical floor, there were two rooms that were eventually, supposedly set aside for - for - palliative care patients. And actually Hospice Orillia decorated those rooms. And there was also, a quiet room, a sitting room, where the docs could meet with the family... Hospice decorated that room (12:272-277).*

*Somewhere in there, we um, we um furnished - the hospital gave us a room and a sitting room. Right? And somewhere in there were raised money to furnish that - and so we had a little hospice unit in the hospital. Right? It was fabulous - right? (I3:275-279).*

This provided a much needed space and support to families:

*There was some people who were - saw the need - for this type of the thing in the hospital, like places where the families could go - 'cause otherwise, they'd only allow you two to a room, and the families were getting very stressed out, because they wouldn't - they couldn't all go in the room at the time (I1:1608-1612).*

This area was also maintained by professionals with palliative care training and hospice volunteers (I1, I5). However, it was a challenge to advocate for it to be used for end-of-life support:

*Seniors, a lot of them stayed in hospital - And not necessarily in palliative care beds. Which was always my challenge when we had empty beds with surgical or medical patients in them - and we had a palliative care patient on another floor - why weren't they down in the palliative care unit where we had somewhat trained staff - to be able to manage that? (I5:560-569)*

Hospice staff often had to advocate for the area to be used for individuals at end of life, rather than for other purposes. Eventually this area was reclaimed by the hospital for another use, due to budgetary constraints and the reallocation of hospital resources (I3,I6,I7). This left some volunteers from Hospice Orillia, who had advocated and fundraised for that space, to be hurt and confused by the transaction, finding solace in the thought that if they were taking away the makeshift space, perhaps it would be replaced by a separate residential hospice facility (I7), as many of the deaths in the Orillia area were still happening in the hospital, and not in the community (I6).

In the meantime, the hospital established its own visiting volunteer program through its spiritual care department:

*The hospital had its own volunteer coordinating program, we tried to integrate - again change is hard - and we had a hard time getting the two groups to work closely together - we made some, some headway, ah, we did introduce the courses and people from the*

*hospital were taking it, but we couldn't get our volunteers to have more presence in the hospital. We had some, but not as much as we would've liked (I6:266-274).*

Participants attributed the challenges experienced in having Hospice Orillia volunteers in the hospital to concerns regarding the maintaining of confidentiality, liability and bureaucracy (I1):

*..it's hard within a hospital system - there's a lot of red tape to go through, there's a lot of committees you go through, and to get things passed you have to ask so many different levels before you get permission to do things - part of it is for protection (I6:285-288).*

However, at one point, shortly after the loss of the separate space, Hospice Orillia was offered an office space at the hospital:

*We looked and looked a couple of times at the space they wanted to give us, and it just wouldn't have been appropriate - it was too small - and even if we could've segregated a spot off for [name] to talk to clients, it wouldn't have been private enough. Y'know, it wouldn't have been a good deal. And we couldn't ever be guaranteed any of the teaching rooms for any of the events that we wanted to put on because if they wanted it - then - you're out, too bad - no matter what you've planned, so - it was unfortunate (I9:362-368).*

Despite attempting to provide services to individuals and families at and through the hospital Hospice Orillia had never been able to establish a solid partnership with the organization.

### ***Ministry of Health and Long-Term Care***

As previously mentioned, Hospice Orillia began receiving funding from the Ontario Ministry of Health and Long-Term Care (MOHLTC) in 1992. Despite having to complete extensive reports to receive Ministry funding (I1, I5), it wasn't until 2003 when the Ontario MOHLTC began to focus on hospice palliative care and end-of-life issues (I5).

In 2004, the newly appointed Ontario Liberal Government announced that it would be supporting the creation of residential hospices across Ontario, including six in North Simcoe Muskoka as part of an effort to improve end-of-life care in Ontario (I5):

*When [Dalton] McGuinty [Liberal Premier Leader] was in, first we get a promise that we're going to have - we're going to be number six on the list to get a residential hospice - dream of dreams - like that's just - y'know? (I9:128-130)*

The challenge, however, was that the government's plan was for a different model than what was needed/would be appropriate for Orillia:

*At that time, we were looking at a 10 bed hospice because that's the only thing the government would [support], which was a downfall for us because we only see when we put information out there five beds is probably all we could afford to go with, and probably met the need in Orillia (I5:85-88).*

Despite the odds, the leadership of Hospice Orillia investigated what would be required to establish a residential hospice in the city:

*We had travelled - I went with [NAME] and a couple of other people and we went to other hospices - we went to see palliative care physicians in Toronto, like - we really did our research. That cost us time and money - we got prepared and went to meetings with Brenda Smith - she was a wonderful leader and a mentor - she was just superb. And we all would go to these meetings and I was ...Then all of a sudden - oh no - we're not going to do that anymore. So how many did they get? Two or three? Out of six? (I9:131-141).*

The change in MOHLTC agenda coincided with the creation of the Local Health Integration Networks (LHIN), fourteen entities which would replace the District Health Councils across the province (I5,I7). As one interview participant noted, when the North Simcoe Muskoka Local Health Integration Network was established, it “*changed the focus on how everything worked*” (I5:78-79). Intended to be a regional body to help allocate healthcare resources, (I9), while the LHINs were establishing themselves, there was concurrently a renewed sense of pressure from advocates and the MOHLTC to address health care needs:

*These LHINs that are now expected to provide good care - hopefully, that was the point - and then they realized okay we have Baby Boomers that are demanding good palliative care - without realizing that it all depends on where you live as to what kind of death you're going to have. So I think that was a huge piece of 'Okay, there's inequity - what are we going to do about it?' (I7:311-312).*

With the implementation of the LHIN came unexpected changes for Hospice Orillia, which had essentially operated with very little influence from the government to this point:

*Then the LHINs came in and everything became more about the business. And I totally understood, the need to keep all of the hospices reporting in the same*

*manner - because we were all doing our own bookkeeping systems and everybody was sending numbers, and where do we get those from and they needed it to be the same. But then they brought in a bookkeeping system with account numbers that were this long - for a three-woman office - I mean, that's meant for a hospital (I9:90-96).*

The demands placed on the small hospice program exceeded what they had anticipated and what they were capable to deliver:

*Then I'm struggling to get money in and the LHIN is saying "do this, do this, do that"- and making me spend money on more stuff that just wasn't necessary - it just wasn't necessary! That accounting program - that they brought in for instance. And I was not the only - ours was not the only office that really struggled with that ... you'd have to get somebody to come in and try to teach you again how to do this because the seminar we went to, it didn't work - (I9:416-426).*

*...it was totally, totally stressful for small offices to be able to send half - more than half of their staff out to things when we were needed where we were (I9:160-162).*

Throughout the beginning years of the LHIN, it was unclear what their mandate and vision was (I7, I9). This added stress to an already fragile situation for the hospice:

*Standards were shifting, the expectations were shifting, the funding was shifting. And just by the nature of the changes within the developments of the LHINs and they were continually changing - like initially, the first - I know that they're still changing - but the first few years - it was difficult to understand what it was that they were trying to do because it seemed to keep changing. And the reports were a challenge to do! (I7:323-328).*

In the end, the implementation of the LHIN resulted in a culture shift, not just for Hospice Orillia, but for many other organizations as well:

*With the funding from the LHIN and the reporting, I mean - we really needed to raise the bar in many of the organizations. Not that we weren't doing good work - but it was a shift in the culture from very grassroots orientation -'cause -- that's how many hospices of course started that way, around a kitchen table - ah, to all of a sudden we need to be professional and we need to measure and we need to, y'know, report - so I think, y'know - that was - y'know, a challenge for many small organizations (I7:163-176).*

However, recognizing that their new standards and requirements may require some adjustments, the LHIN did their part to encourage small organizations to amalgamate and merge where possible:

*The LHIN I think was just really encouraging all the small organizations whether it was Alzheimer's or Hospices or whomever to look at partnerships - whatever that might look like - to save costs and deliver good service. They also recognized that all these small organizations were all competing for board members, they were all trying to fundraise they were all going after the same staff (I7:163-176).*

As the LHIN did provide base funding to Hospice Orillia in order to support their services (I6), the increased emphasis on partnerships and accountability meant that the organization had to make decisions regarding its operations and structure moving forward. However, while the pressure and expectations of the LHIN were clearly felt, the MOHLTC was not the only stakeholder in Hospice Orillia as an organization.

### ***Palliative Care Network***

Regionally, palliative care (as in clinically based pain and symptom management) gained momentum through the Pain and Symptom Management program offered through Hospice Simcoe and the Palliative Care Nurse Consultant, who was employed through Georgian Bay General Hospital (I3; I5). Together, this was the beginning of what would eventually become the North Simcoe Muskoka Palliative Care Network (NSMPCN). According to one participant, the purpose of NSMPCN was to:

*Improve care overall - based on ah, clinical standards. Which were supposed to be being developed by Palliative Care Ontario [the advocacy body for palliative care in Ontario], who couldn't agree on the definition and so it developed locally however it did (I3:721-723).*

Originally, Hospice Orillia had very little to do with NSMPCN, due in part because of its relationship with Hospice Simcoe:

*Palliative care network was run out of Barrie at that point - under Hospice Simcoe - Hospice Simcoe was seen as the hub, we were just a branch. We didn't want to amalgamate to become a part of that - was the Orillia theme (I5:608-610).*

When, in time, NSMPCN separated from Hospice Simcoe and became its own entity, Hospice Orillia, along with the other hospices, were quite detached from NSMPCN:

*The little grassroots hospices said, "oh, well - we'll be members, but - we don't want you to tell us what to do". Wherein, ... I think our vision wasn't broad enough, and I think we didn't go for local support soon enough in order to have some influence over the hospices. But the hospices weren't getting any money from government. So, it wouldn't have mattered what anybody had said anyways. "We're doing our fundraising, we're doing our own thing, we are looking after our people and thank you very much" It's really nice of [Pain and Symptom Management Nurse Consultant] to come in and tell us about pain management and symptom control - we want our volunteers to know that, we're not delivering that service so it doesn't matter." And so there was that disconnect between really good work and the broader vision, and lack of authority of the Network. Even when the LHINs came in in 2006 (I3:648-668).*

It was clear that while NSMPCN and the hospices were involved in providing care for the dying and their families, their mandates and approaches were different. However, NSMPCN, a non-profit organization, was fully funded by the MOHLTC (eventually the LHIN).

In 2010, Hospice Orillia experienced a critical event due to funding shortfalls, organizational restructuring and some community backlash. At this point in time, the LHIN approached the part-time CEO of the Network (who was also acting as the part-time ED of Hospice Simcoe) to help lead Hospice Orillia for a day a week on secondment. They agreed to do so, with the stipulation that Hospice Orillia move its operations to the NSMPCN office location (which was also located in Orillia at that time) (I4). This new model, with shared staff and a shared location, marked a substantial shift but provided financial stability for the organization (I3). At the time, this seemed to be a positive arrangement:

*certainly as we were going through our downward spiral um, y'know, we had the conversation about whether the organization could remain independent or whether it was in the best interest to, ah, partner with them and they were very gracious and very supportive - right? They could've said 'no, get lost!' but they didn't (I7:853-857).*

It was also felt that this was a positive move strategically for Hospice as an organization, as NSMPCN was more politically aware of what was happening in hospice palliative care provincially at the time:

*I mean the Board was, y'know, I think tuned in regarding what they would like hospice palliative care to be in the community? But I think the Network had a better grasp of the reality of all the moving parts that were involved (I7:870-872).*

Soon after this informal merger happened, the LHIN approached NSMPCN to initiate a regional “Hospice Alliance,” an attempt to “convince all the hospices to come together under one board,” with NSMPCN being the umbrella organization (I3). However, this idea was not well received by the hospices:

*We were still in those organizations, turf infancy not the system picture, just the local support - and [the local hospices] really felt they'd lose their voice - somewhere along the line their money would go - and that someone else would tell them what to do - and they didn't want any of that. So it was set up to fail (I3:1590-1594).*

*Some people were uncomfortable with that and I think the big reason for that was loss of identity. Uh - each community felt that what they had was really sacred - they had kinda grown it, and organized it, and it suited their needs and, also there was a feeling that if we amalgamate some of that may get lost - you lose power, by losing power, then you can't make decisions, and decisions that are made by your body that's not made up of local people may not be the best for each of the areas, so there was I think a combination of loss - loss of decision-making and loss of identity. So, the other hospices were not too keen to amalgamate - (I6:105-131).*

While Hospice Orillia shared resources with NSMPCN, they were still governed by a local board of community members. The concept of formal integration with NSMPCN was received with mixed feelings:

*There was some division among board members there was those who wanted to leave Hospice Orillia [as] a local, grassroots run organization where we're looking at the needs of the community focusing on things like fundraising or having, uh, uh, volunteers that either helped with whatever capacity that they could. The leadership that was there at the time specially the Executive Director had a broader vision and her vision was to look at becoming more systematic and more organized and really looking at seeing if we*

*could achieve more, rather than just sticking with the grassroots and what - what we had done so far. ...*(I6:105-131).

Originally, Hospice Orillia and NSMPCN were “*two separate entities and weren't - were never intended to be together*” (I3:612-613). However, in 2014, they formally integrated, resulting in a name change for NSMPCN (to North Simcoe Muskoka Hospice Palliative Care Network or NSMHPCN) and Hospice Orillia retaining its name as a program of NSMHPCN (I6). While the other hospices refused to integrate at that time, it was the thought of the NSMHPCN that they would continue to approach them with the eventual goal of complete regional amalgamation (I6).

However, NSMHPCN experienced a huge organizational shift in 2016 with the MOHLTC announced the creation of the Ontario Palliative Care Network (OPCN), a partnership between the LHINs and Cancer Care Ontario (a provincial body involved with evidence-based research and high-quality care). Suddenly, NSMHPCN, as an organization funded by, but separate from the LHIN, no longer had jurisdiction over palliative care in the region, as that responsibility was handed over to the regional branch of the OPCN (I3). With that shift, the future of NSMHPCN became unknown, with possible consequences for Hospice Orillia:

*Yeah. So how are, how are you going to separate that? That's a challenging piece. In front of Hospice Orillia now. It's so entwined with the Network. Like (sighs) ... tricky* (I4:1003-1008).

Relationships with the health care system have been a natural and necessary part of Hospice Orillia's developmental history. However, as one participant stated, “*the medical sector is huge and expensive and - y'know, they're their own little planet, right?*” (I7:351-353). While originally hoping to work alongside with the formal healthcare system and provide core hospice services, the eventual need for resources brought with it the cultural constraints inherent in the system itself.

### *Awareness and Advocacy*

According to Interview Participants, throughout Hospice Orillia's life course, there has been confusion as to what the terms "hospice" and "palliative care" mean. This has impacted its development and evolution with respect to its relationships internally and externally, especially related to gathering community support and how it has been impacted by advocacy efforts and organizations.

### *Lack of Awareness/Understanding of Hospice*

A significant challenge for all involved in promoting better end-of-life care was a cultural aversion to discussing death:

*That's a funny thing too. People didn't used to like to talk about dying. Like, that was, that was a subject that nobody wanted to talk about. And I would go to say in the original starting days, the early stages of the hospice, it was getting over that fear of people let's not look at that - although it's a part of life, let's not look at that. We don't want to talk about dying. We - we - even the terminology - you talk about language - "the passing over"- (I1:1203-1210; I9)*

This reluctance, or death-denial, meant much of the focus in the early days was just starting the conversation about dying with the general public and health care community (I1, I2, I3, I9).

Participants noted that challenge was only the beginning, as the terms "palliative" and "hospice" were confusing and unknown to people. As one participant said:

*I think there wasn't a great understanding of - the word palliative and, and that's where I think ah, some of the docs, uh, were not into that - "well - wh..what does that \*\*mean\*\*?" (I2:297-299).*

However, this confusion also existed amongst supporters of hospice and palliative care themselves:

*We couldn't agree – what's hospice, what's palliative care – what does end of life mean? And we spent all these years right up 'til now, trying to talk in the same way, in the same language (I3:176-179).*

While the Canadian Hospice Palliative Care Association merged the two terms into “hospice palliative care” in 2002 believing that they held the same principles and goals, interview participants still made a distinction between the two:

*What year did they start to put those two together? We started to put it together at the Network [NSMPCN]. Because previous to that, they were separate, right? It was clinical; It was hospice. And I think that probably with the residential piece is when it really started to be sewn that the two were, the two needed to be together. And palliative care is best delivered out of that model. Um, yeah, so probably 2008/9 in there is really when they got sewn together (I4:509-527).*

While the inability to clearly articulate these terms has meant disagreement and conflict for the health care system and service providers, it has also led to a sense of confusion within the general public. As one participant said:

*So right now the bottom has been us, little service providers, but the public isn't with us, right? Y'know, for the few people that have, that have had - few people comparative to the province as a whole - The few who've had and seen excellent service - and understand what it means - or could say this is hospice and that's palliative care - well, hospice is part of palliative care - but they wouldn't understand that continuum. We barely understand that continuum - (I3:1074-1085).*

The lack of understanding of specifically community-based hospice and the services it offered was identified as a major challenge in the organization's development:

*People just didn't know. They really didn't know. Hadn't heard of it. What is it? You mean you're not going to do anything for my mom or dad? No, that's not what we're saying, we're going to be with them - right to the end, and support them that way (I1:449-453).*

*I can remember doing a tag day a long time ago - and people kept saying 'the hospital?' So I think even now people don't understand what hospice is... And if they've never had to use it, or have known someone who's used it - they don't understand the need for it (I8:571-578)*

Interview participants spoke of the need to spend time engaging with health care providers and the general public to education and raise awareness of hospice:

*Education - or the lack of knowledge that the service was available - and so we did a lot of public speaking different organizations, the Lion's Club, church groups, umm - it was*

*the educational part of it. And, um - once we got in to there - it was, like, maintaining that knowledge base (I1:1611-1615).*

Although some participants attributed the lack of awareness to the lack of a communication strategy (I3), others spoke of writing newspaper articles (I9), having signs on buses (I1), and doing regular presentations with physicians and community members (I1, I2, I9). An awareness and understanding of how hospice could be of benefit and its services could be accessed was vital to the organization, not only in promoting its services, but also in garnering both financial and community support:

*I know that the part of the struggle in getting going is funding....and getting people on board that recognize the need, and the doctors - and the financial requisite of starting a hospice...I think that's hard to get people on board unless they already have some understanding ... (I2:559-574).*

Hospice Orillia was not alone in this challenge, as other community-based hospice programs experienced similar issues.

### ***Advocacy***

To help address the challenges faced by community-based hospices, the Community Hospice Association of Ontario (CHAO) was founded in 1989. As one participant said:

*You'll see here that, um, Hospice Association is founded in um, of Ontario was founded in 1989 - so, not unlike all little communities across the province, every grassroots little group was starting to do things and in a way that was unique to their community.... And so as this hospice association was being founded, we were being invited to participate and - there was no cost for membership - we were just trying to get together and at least have, ah - the same conversation - Well, we couldn't ever decide on a definition - (I3:144-170).*

One of the difficulties was the uniqueness of each hospice represented, and how they emerged :

*Locally vs. provincially - even across our LHIN - not just Hospice Orillia, but each of the Hospice organizations are in a different spot. Their evolution has been different - based on who started it - right? And what the push was, and what happened, right? And so, if you said "what's your story" to each of the hospices, it would be, it would be like ah, - chapters in a book that all looked different. And - and all of them are really important*

*and all of them are really valuable to help us understand what - what next, right? And I think that people are in various stages of evolution and there isn't the local leadership (I3: 1175-1184)*

Recognizing this, CHAO provided support to the hospices in terms of governance policies (I1) and guidelines, and held an annual conference for its members to attend (I1, I9). It also provided some momentum in advocating for funding and a political voice:

*So when the Hospice Association of Ontario was formed, it was really all of the EDs coming together of all of these little grassroots saying, "okay, what can we do together?" "Is there any way of getting any money - 'cause none of us have any money?" (Laughs) - right? ...And how do we get the political - how do we get attention of the politicians..." (I3:431-443).*

Meanwhile, the Ontario Palliative Care Network (OPCA), whose membership consisted of medical professionals, was created to promote palliative medicine in a similar way (I5).

In the late 1990's/early 2000's, after releasing her report *Of Life and Death* (1995) Senator Sharon Carstairs began visiting organizations and individuals involved with providing end-of-life care to find out what was happening across the Canada (I7). Having heard her speak at an HAO conference, one participant spoke of her highly, saying "*she kinda said it the way it should be said*" (I1:415). Another said:

*It was just the political pressure of people realizing that there was such inequity – y'know, the challenge of, that - y'know -we had Senator Carstairs doing her thing back in the late '90s – she came to [Hospice Name] – I remember talking to her over lunch and - y'know -we're talking about what we were doing and why – and what our plans were and that – but just -y'know - there's always that tension between the medical model, right – you're actively dying – versus hospice can be there – (I7:332-339).*

In her subsequent reports to Senate on the state of end-of-life care in Canada, (*Quality End-of-Life Care: The right of every Canadian* (2000); *Still Not There* (2005); and *Raising the Bar* (2010)) Carstairs would continue to make recommendations for accessible, equitable end-of-life care for everyone.

As the roundtable meetings were happening across the country, Brenda Smith, the Executive Director of the NSMPCN, ensured that the local hospices were represented at those table and championed having residential hospices built in each of the communities across the region (I4, I9). She was an inspiration to many who were involved in both hospice and palliative care in the area:

*She was the focus and the drive behind a lot of this. And anybody who jumped on board like I did with her to, y'know – to go to meetings with Sharon Carstairs, to go to the government level – invite government to come in and have these negotiations with – and just listen to the stories – hear the people – get the education out there – it was, I mean, what a change – what an opportunity! (I5:658-662).*

However, Brenda's influence on the regional hospice palliative care community was cut short when she was diagnosed with terminal cancer:

*That I remember with her, it was all about getting the residences in all of the different communities - just having the residences there - and she was so compassionate and yet so firm and so - she was driven. She was a big loss - when she died. It was a huge loss. I remember we were at a meeting - and I think it might have been in Huntsville, but I'm not positive - we were all sitting around the table waiting for Brenda to come - or to - she was going to - Yeah, yeah - we were going to all sit around the table and talk to Brenda - and that was the day she phoned us and broke the news. It was like "what do we do" - you know what? I think we all felt the same - Like "Oh my God - now we're lost" because, y'know, she was such a huge - she pushed and she was so passionate and yet she was kind and loving and gentle - y'know? She had everything (I9:305-332).*

Brenda died in 2008, and the role was subsequently filled by another individual who did not have the same level of influence or charisma that she had possessed.

Throughout the participant interviews ran a theme of lack of awareness of hospice (both its philosophy and its services). There was a lack of conceptual clarity both within the movement itself and in the larger field of end-of-life care. Therefore, the advocacy efforts of the community-based hospices were often muted by the needs of the larger medically-based palliative care community. In 2011, HAO and OPCN, the two provincial advocacy bodies

merged, creating Hospice Palliative Care Ontario. This raised concerns from community-based hospices:

*At that point um, that was when the two organizations at the provincial level were coming together - So there was a lot of confusion and tension and um - I think there was concern among the grassroots hospices that they were sort of going to get left behind in the dust (I7:993-1001).*

Due to the merging of the two organizations, the annual conference, which had been the opportunity for hospices to network, access education, and gain solidarity, became inaccessible:

*We talked about - y'know, the changes at the LHIN and the changes at the provincial level with hospice palliative care and the two organizations in kind of coming together, and y'know, I remember discussions about when they held the first joint conference - and the cost of going to the conference. Like, all of a sudden it became, like out of reach, right? For smaller organizations – (I7:841-847).*

Quite literally, small, community-based hospices lost a seat at the table as the provincial conference sought to attract a different audience.

### ***Geographic Location***

Geographic location as a key factor in Hospice Orillia's development was another theme emerging from the interviews. More specifically, participants spoke about how there were specific challenges to providing hospice services in the Orillia area, including; the demographics and geography; a lack of awareness of hospice services, and the relationship between Orillia and Barrie, the larger, urban regional centre to the south.

### ***Orillia - Area & Culture***

As Hospice Orillia began as a community-driven initiative (I6), the unique features of the community of Orillia itself had an impact on the life course of the organization. Participants spoke positively of the culture of caring in Orillia. As one participant said, "*Orillia's very community-based, community-centered. so people in general do look after each other from a*

*community perspective...*”(I6:229-231). While one participant noted that the populace included an “*overabundance of people who just want to help*” (I3:1238), another said:

*This is an interesting community because we have those that have significant incomes or significant livelihoods. Or - have a strong social connection, have a faith community or whatever - So they have a very stable, privileged life. And for many of them, y'know, volunteers are some of those folks, that they want to give back and they want to care. But they want to care and support those that are like them (I7:410-415).*

This dynamic was noted as being a challenge for Hospice Orillia:

*Yeah, I, I think that ah, there's probably a dichotomy there - with ah, people that didn't make that much money - and then there were the higher ones that were a little higher up in the ladder. So, I don't know - I think maybe Orillia had a, a segment of people that were not as well off. Um - and maybe - maybe those were more the people we got referrals from, too (PAUSE) (I2:796-801).*

Demographically speaking, participants identified that poverty, unemployment, and issues that emerge from those conditions, were prevalent in the city (I1, I2, I3, I6, I7, I8, I9):

*Orillia has challenges with housing - transportation - mental health - family violence. And certainly - y'know, poverty of poverty. Just within the County, we rank #1 on a lot of things about poverty (I7:408-410).*

However, one of the participants said:

*The annual wage interval in Orillia is much lower than in Simcoe County. Having said that - we also have a higher level of retirees. So my salary level is lower because I'm a retiree... with the demographics, although we have a higher percentage of seniors, who are at that end where they are retired, their income is less - but they need less (I8:876-879, 911-913).*

Transportation (or lack thereof) was also identified as a challenge, as the area served by Hospice included many remote locations:

*We had a very large geographical area to attend - and that, that was a little bit of a problem too - - of finding volunteers that could service: Brechin area, Lagoon City type of thing - you really wanted to keep people out there (I1:1752-1756).*

Participants also noted that the harsh winter weather also made accessing services difficult for people:

*Orillia is, just - it goes back to winter, I think, a big part of it. Winters, getting around is hard for, for patients, especially if they're not well. Getting services to them may be difficult; geographically we're spread out so there is a concentration, in central Orillia but there really close surrounding communities that, that are hard to access and when we do (laughs) when I was doing a lot of home-care, my husband used to say "why is it that every patient you go to see, - decides when they're ill or when they're old to live out in the, in a farm or somewhere really far when the resources aren't accessible to them?" in some ways it's spread out - that makes it, that makes it tough, I think. we don't have, we do have public transportation, it's not the best, so if you don't have a car it can be challenging to, to get to places to get the help that you need, (pause) there is, there is a fair bit of poverty, so that could be also a factor in it as well, but ....but that's, that's, those are the major things (I6:352-368; I1, 15).*

Therefore, while Hospice Orillia had a high level of need for hospice services (I6), those accessing the services were not necessarily those who would be able to support (financially or socially) the organization. As well, the high level of poverty and other social issues in the city made fundraising difficult, as there were many causes, organizations and campaigns fighting for the same dollars:

*Right now? Politically? The City's got some very serious issues to look at. In the next couple of years we've got Building Hope [homeless shelter], Hospice, Green Haven [women's shelter], and the Hospital. Building Hope is asking for \$500,000. That's a 1% tax increase in your taxes. If they all want the same amount, they're not going to get it, because that's 4% on our taxes - we can't afford that (I8:856-860).*

As well, due to the size of Orillia, the lack of larger businesses and local supporters, fundraising was a challenge, as resources were scarce (I5). However, participants noted that this was, in part, due to the culture of Orillia, describing it as:

*A little closed. And I, I gather from years ago - like, '60s and that - they didn't want big business and stuff to come up here and things because that was going to stay in Barrie and this was going to be a nice little country community - which it, even when I did come up here, I loved it - I loved it (I9:636-639, I1).*

This resistance to change was also applied to Hospice Orillia, by some participants:

*One of Orillia's faults is that they've stayed unique to their community way too long - - rather than following some, um - being more open to looking at standards across the province and being part of a bigger picture (I3:148-149; I5).\_*

However, another participant came to Orillia's defense, saying that, as a community, it was merely being "*very protective of itself*" (I1:1732), especially in relation to its neighbour, Barrie.

### ***Barrie vs. Orillia***

Throughout the interviewing process, almost every participant commented on an underlying tension between the City of Barrie and the City of Orillia (I1, I2, I3, I4, I5, I7, I8).

One participant said, "*Barrie and Orillia have this thing -And I can't explain the thing - other than the thing is there. And it's still there, to some degree. I mean, I don't get it. I don't get it*" (I5:482-488). Another said:

*This is the Orillia/Barrie split, no matter what. If you talk about Orillia hospital and RVH, you could have the same conversation, just - change the subject it's exactly the same, right? There's this competition - Barrie's better. Or Barrie thinks they're better. And Orillia's not so good. We're not so big, we don't have the same infrastructure, we're not so good - and Barrie - um - will just steamroll to get what they want - right?*  
(I3:1709-1715)

While participants explained that the tension went beyond healthcare and impacted other areas as well, such as education (I5) and business (I8), it was experienced by the leadership of Hospice Orillia:

*Well, Barrie was the big sister. Barrie was the big area - the regional area, um - I sometimes went to different palliative care meetings and sometimes felt like the little fish in the pond, and like, - and "Gee, does anybody ca -? - can I say something?" - and they would listen - I mean, it was an open discussion - but there were some real heavyweights in those meetings. Heavyweights from Community Care Access, heavyweights from the hospitals, and this is not to put that down as a term, but people with a lot of connections and power within the system. That could - The movers and shakers if I could say it that way - were kind of there (I1:1737-1746).*

As previously mentioned, the hospice in Barrie, Hospice Simcoe's original vision was to be a regional organization with smaller, community-based branches in the smaller communities (I4).

Throughout the years, this idea was revisited with the hospices:

*There was talk - about Hospice Simcoe amalgamating with everybody - and all the other hospices were all anxious about that because they didn't want a takeover - so, y'know, and yet - and I get that. I get that. Because we are unique. I guess the way I felt about it probably back then and probably still today - no, still do today - is, as long as you don't lose the identity of who you are or your needs of your community - if that were to happen? (I5:523-529).*

Instead of amalgamation, however, Hospice Simcoe pursued building a residential hospice facility:

*In Barrie, they had a different level of funding, they were five years ahead of us - about five years head of us - and so they had matured enough to be able to think about "okay then how do we get some beds". 'Cause - -they were doing a visiting program, but they weren't - I don't think they were following the people to hospital (I3:463-466).*

This created more tension with the smaller hospices, including Hospice Orillia:

*There was, Hospice Simcoe were looking to have a residential - resident hospice. And there was a lot of focus and concentration - if I sound, like, a little bit of jealousy, that there was Collingwood, and ourselves, and Midland with the hospices and Hospice Simcoe that concentration of money (coughs) Excuse me - was going to Hospice Simcoe (I1:618-623).*

However, one participant said:

*There was the political will in Barrie, amongst the physician group to say "we need some beds" - and so they started looking for ways to get funding to do some beds... it wasn't - it wasn't a tension of they got it and we didn't, they were ready and we weren't, right? And so, and they were the first beds in - in the LHIN, in the County, right? (I3:470-479).*

In establishing the residential beds in Barrie, it was understood that one bed would be allocated for individuals from other areas in the region (I5, I1). Once the residential facility was open and operating, this introduced a new dynamic between Hospice Orillia and Hospice Simcoe, as they began pursuing the same fundraising dollars from the Orillia community:

*Hospice Simcoe was in full fundraising mode - and they had the people and the resources to do it. And, y'know, they're a building. It's bricks and mortar which is a lot easier than - y'know, we can't put a sandwich board and a volunteer to walk around 'I visit people!' (I7:202-205)*

*We'd be visiting somebody in their home they'd be transferred to Hospice Simcoe - and Hospice Simcoe would get the donation. I mean they'd be in Hospice Simcoe for two days and die and we'd been visiting them for 18 months. Right? (I7:225-228).*

While the original hope was that many hospice beds would be established across the region, this did not happen as planned. Hospice Orillia (and healthcare providers) were dependent on Hospice Simcoe for providing this particular service, requiring friends and families to travel to Barrie to visit their dying loved ones (I1, I4, I5). As one participant said, this diminished the view of what Hospice Orillia was able to offer people:

*That, because it's a smaller organization, and because it doesn't have residential beds, that what we're providing is not up to the standard of what [Hospice Simcoe is] providing (I3:1702-1705).*

The uniqueness of Orillia's geographic location, its demographics, culture and relationship to its regional urban centre all had a substantial impact on its ability to develop and maintain resources (and sustainability) throughout its lifespan.

## Chapter Five: Summary and Conclusion

### Lessons Learned from Hospice Orillia About Hospice as a Social Movement

The aim of this study was to explore what factors contributed to the evolution of Hospice Orillia from its early days, when it emerged from the hospice social movement, until the present. Interestingly, Hospice Orillia's life-course, as an organization which emerged from the hospice movement, followed Christiansen's (2009) four-stages of social movement development: emergence, coalescence, bureaucratization and decline. Furthermore, within each stage, there emerged both internal factors and external factors which impacted the direction (and well-being) of the organization. This is in keeping with Tarrow's (1994) argument that the power required to control and sustain collective action has both an internal and external dimension. In this section, I will discuss what factors were involved in Hospice Orillia's development, and how they worked together to bring the organization to its present.

#### *Internal Factors*

As previously mentioned, Tarrow (1994) argues that social movements' power comes from the combination of their cultural or interpretive frames and their ability to utilize social capital. While the hospice movement was able to clearly articulate a *motivational frame* (the concept of a "good death" vs. a painful, isolated, institutionalized death) it was far less successful in achieving agreed upon *prognostic* and *diagnostic frames* (Snow & Benford, 2000). For Hospice Orillia, this was apparent from the very inception of the program, as, for example, some founding members saw the program addressing the need for caregiver respite in the home and others wished to have a hospital visiting volunteer program. Siebold (1992) identified this issue, the ambiguity in purpose and definition of the hospice movement, as being a complicating factor in its ability to maintain and gain ground. While there were, as previously discussed, some key goals and ideas, there were (and still are), myriad interpretations of the hospice philosophy and

manifestations of the hospice model of care that have been introduced globally throughout time.

As Tarrow (1994) states, this is, in part, positive, in that:

A good part of the power of movements comes from the fact that they activate people over whom they have no control. This power is a virtue because it allows movements to mount collective actions without possessing the resources that would be necessary to internalize a support base.

For Hospice Orillia, this allowed the founders the freedom to define hospice care as they saw fit, and to introduce creative solutions for community-specific problems rather than having to adapt a prescribed model. However, internally, this meant that, from the outset, there were differing visions and goals about how hospice should be organized and developed in Orillia. This ultimately set the stage for internal factionalism and conflict (Christensen, 2009).

In the beginning, Hospice Orillia provided residents of the City who were concerned about how the terminally ill were being cared for with a venue through which they could act upon their discontent. Tehan (1985) explains:

Whenever a movement is attempting to carve out its niche, the individuals leading that movement see themselves as missionaries. Hospice was no exception. The early leaders had high enthusiasm, a sense of mission, innovation, dedication, and the belief that they could demonstrate what care for the terminally ill should really be (p. 10).

The founders of Hospice Orillia possessed passion, drive and determination to make their dream of having a local hospice program a reality. The collective organizational model, with an open membership and volunteers responsible for executing tasks, provided a high level of ownership for those involved and meant that Hospice, through its large membership, had access to many social networks. While they did not have much money and few resources, they mobilized volunteers to do the work (Abel, 1986, p.75). This often resulted in creating strong allies and supporters in the community who broke down some of the barriers inhibiting their progress (i.e./hospital administrators, physician champions) and who were able to provide resources for

the program. Abel (1986) argues that “the absence of remuneration enhanced dedication and commitment. Because they reaped no extrinsic rewards, their work truly could be considered a labor of love” (p.75). Hence, while they lacked financial resources, the organization was building strong *bridging* and *linking social capital*.

However, Hospice Orillia, like many other hospices, discovered that they could not continue to operate on the amount that they raised from small fundraisers, grants and donations (Abel,1986). While the funding from the OLG and the MOHLTC already introduced a level of fiscal monitoring and bureaucracy, when the high level of revenue was generated through Bingo, the subsequent shift resulted in a hierarchical organizational structure reflective of the dominant, patriarchal, institutional model that hospice originally opposed. Christiansen (2009) argues that this often happens in the life-course of an organization, as:

it is difficult for members to sustain the emotional excitement necessary and because its continued mobilization becomes too demanding for participants. Formalization often means that paid staff can fill in when highly enthusiastic volunteers are not available (p.3).

Centralizing power and authority to the Board, the organization ultimately diminished its social capital. According to Judith Levy:

Hospice growth and survival depends on its members’ success in convincing other individuals and institutions to provide such resources as money, legal entitlements, and public support for its activities (as cited in Abel, 1986, p.78).

When the responsibility for an organization’s survival moves from the many to the few, this potential is severely limited. While the reasons for altering the organizational structure remains unclear, Floriani & Schramm (2011) argue that:

One cannot disregard that routinization was part of a strategy deemed necessary, and consciously desired, to confer social legitimization on the hospice movement, with all the possible consequences of this organizational process (p.302).

However, this major shift represented the first incident (not the last) where the membership of Hospice dropped in number. Tarrow (1994) argues that this is the flip side of not having control of the direction of a movement: "...the autonomy of their supporters also disperses the movement's power, encourages factionalism and leaves it open to defection, competition and repression" (p.23). Factionalism, according to Christiansen (2009) is:

One of the ways in which social movements fail. It is marked by increasing internal strife within social movements between groups who have differing ideas about how the movement should function or what goals it should have (6).

Smith and Nickel (1999) explain how the hospice movement is especially prone to this phenomenon:

The hospice movement was shaped by conflicting beliefs among its leaders and by the limited political power of its key advocates – nurses, ministers, and survivors...this constituency lacked the political power necessary to implement its ideals, and it had limited access to the financial resources that would have allowed for independence (p.58).

Therefore, it is easy to see how volunteers, once committed and engaged with the work, may defect when there is a philosophical or tangible shift in the organization's identity or operations. With the new OLG funding, the organization also increased its infrastructure, expanding its staff, which required more expensive overhead costs to be added to the budget line.

When the OLG funding stream diminished, the organization found itself in survival mode, operating with a diminished support base, a community who did not understand or value the services offered by the organization, and an infrastructure built upon a short period of financial security. While Hospice Orillia had believed itself to be moving towards growth, it had been thrust into scarcity mode. Tehan (1985) writes how this shift is common in hospices, and often leads to a change in administrative focus:

Increasingly, the visionary is being replaced by a professional health care manager with administrative, fiscal management, and fundraising skills. There is more emphasis on survival and less on the individual's commitment to the hospice concept (p.13).

As the missional focus waned, the organization became more of a service-delivery organization and less concerned with promotion, education and advocacy for hospice and palliative care.

When the MOHLTC provided more funding to Hospice Orillia, this led to a higher level of bureaucratization and fiscal monitoring, and ultimately, routinization. Abel (1986) notes that:

Hospices have confronted the same problem as other counter-institutions: reliance on established order for resources, personnel, and acceptance has undermined their ability to offer true alternatives (p.81).

However, as Hospice Orillia became more and more bureaucratized, the decisions made at the Board level led to several incidents of division, factionalism, and defection of its volunteers. In each instance, this led not only to a diffusion of the power (and integrity) of the hospice movement in Orillia, but also to a loss of social capital, and in some cases, led to the creation of some damaging and hostile counter groups (Tarrow, 1994).

### ***External Factors***

Tarrow (1994) provides a context for understanding the external factors that have impacted Hospice Orillia's development over the years:

Movements are affected by the fact that the same political opportunities that have created them, and which diffuse their influence, also produce others – either complementary, competing or hostile. Particularly if collective action succeeds, these opportunities produce broader movement cycles which spread from movement activists to ordinary interest groups and citizens and, inevitably, bring in the state. As a result of this dynamic of movement diffusion and creation movements succeed or fail as the result of forces outside of their control (p.24).

The internal factors influencing the direction of both Hospice Orillia and the community-based hospice movement were closely related to the development of social capital and cultural or interpretative framing. As well, despite wishing to provide a counter-hegemonic alternative for

the dying, the role and influence of western, neoliberal culture on the development of Hospice Orillia (and the community-based hospice movement) over the years cannot be overstated.

As indicated in the research findings, an important part of Hospice Orillia's work was establishing connections with other organizations and stakeholders. However, factionalism, defection, competition and repression, pose just as much of a risk to inter-organizational collaboration as they do to internal organizational dynamics. From the beginning, social networking was an essential component for proponents of Hospice Orillia to create strategic allies in the community (including the hospital) and within the hospice movement.

Again, while the *motivational frame* of a "good death" offered by the hospice movement was widely accepted (and even, it could be argued, exploited by the government and health care system as a rationale for budget cuts and resource re-allocation), the *diagnostic frames* offered by community-based hospice programs (the concept of total pain, the importance of a social model of dying) were not as clear or well-received as palliative care's frame of mitigating physical pain and symptoms in a health care institution under the supervision of a physician. Also, the community-based hospice movement's diagnostic and pragmatic frames were often incompatible with the beliefs and goals of those external entities they needed to collaborate with for their very survival.

For example, physician champions were necessary to promote hospice services among their colleagues, as the medical community was "initially...skeptical of the hospice movement and wary of associating with it" (Abel, 1986, p.76). Despite the philosophical differences between the two groups, Hospice Orillia acknowledged that "all hospices must strive to gain acceptance from the medical community because they depend on hospital discharge planners and private physicians for referral" (Abel, 1986, p. 78). As well, hospice volunteers are an essential

piece of bridging the community to the formal health care team, and a goal was to, ultimately, have them recognized as integral, equal members of a terminal individual's care team. That being said, the quest for the egalitarian, multi-disciplinary palliative care team has never been realized in Orillia. As stated by Floriani & Schramm (2011), this may be evidence of the medicalization of palliative care, in that "one of the consequences of medicalization is that the interdisciplinary approach is questioned, to the extent that the view of palliative care is determined by medical know-how" (p.301). As in many other places, professional members of the care team still do not refer to hospice visiting volunteer programs, as they are unsure of the volunteer's role and the benefit to the patient (Claxton-Oldfield & Marrison-Shaw, 2014).

While the services Hospice Orillia volunteers provide have never been fully embraced by the Orillia physicians, there has been an increased understanding and appreciation of palliative care among them, due in part to the funding which has been allocated for this service. As Abel (1986) notes:

Although hospice leaders pointed to the glaring deficiencies of hospital care for the dying and called for a radical reordering of medical priorities, they failed to examine the economic and social forces responsible for the problems they deplored. Believing that social change follows automatically from a change in personal beliefs, they placed their faith in infusing traditional health care institutions with a new set of values. But the technological and curative focus of modern medicine stems not simply from the ideas and attitudes of individual providers but also from financial incentives built in the structure of the health care system (p.83).

Certainly, as the government has increased its support for hospice palliative care and palliative medicine has become embraced by more of the mainstream health care system, there has been a cultural shift by the physicians in reclaiming control over their patients' dying process (Rosenberg, 2011). It has only been through an appeal to neoliberal, economic, utilitarian values of providing hospice and palliative care (it saves money and it can generate funding) that the government and mainstream health care system has accepted hospice palliative care.

The work of advocates such as Sen. Sharon Carstairs, John Fraser and many others has been instrumental in moving Hospice Palliative Care forward in policy and in practice. However, again, while there is agreement regarding the need to improve end-of-life care, the work of advocates has often promoted alternative *diagnostic* and *prognostic frames* than those which would align with community-based hospices. For instance, the emphasis for much of the advocacy work has been a *diagnostic frame* of health care providers are ill-equipped to provide pain and symptom management therefore the *prognostic framing* of how to resolve the issue of a bad death is to provide more education to health care providers. Similarly, there is a similar *diagnostic framing* of caregivers' "burning out" while providing for a loved one. Therefore, the *prognostic frame* to resolve this is to create residential hospice facilities where people can be cared for (which also serves the purpose of minimizing public health care costs by redirecting care to partially funded, community-based organizations supported by a largely volunteer workforce). It's a win-win for a neoliberal, biomedical (patriarchal) system, and for those who benefit most from it in terms of power and financial gain.

For Hospice Orillia, government funding and stakeholder partnerships has led to standardization practices and accreditation processes, based on the hospice palliative care core values as stated by the Canadian Hospice Palliative Care Association. While the community-based hospice movement desired to provide a counter-institutional alternative for the dying, the mere fact that Hospice Orillia established itself as an organization in a neoliberal, market-based economy throws it into the position of having to compete for funding, to be fiscally accountable and essentially to operate as an efficient, productive business.

Syme and Bruce (2009) question the wisdom of this, in that:

while overall agreement about core values may be present; however, claims to homogeneity and uniformity run the risk of ignoring different priorities, professional cultures, and disciplinary-specific worldviews (p.22).

Both Tehan (1985) and Abel (1986) identify that accreditation processes moved hospices further into bureaucratization. Tehan (1985) argues that “developing standards of care was essential to gain credibility with government and private payers” (p.11), while Abel (1986), on the other hand, states that even without accreditation, the day-to-day operations and funding needs of hospices would have required “more formalized and sophisticated management structures” (p.80). For Hospice Orillia, as government funding for hospice programs increased, so did the level of required reporting and accountability measures to the health care system and to the government of Canada (due to their charitable status).

Tarrow (1994) warns of this challenge for social movements, saying:

Although social movements almost always conceive of themselves as outside of and opposed to institutions, collective action inserts them into complex policy networks, and, thus, within the reach of the state (p.25).

This tension is clearly evident for not only the hospice movement but for Hospice Orillia as an organization. A further challenge for the organization is that it receives funding from not only the health care system, but also from the community through fundraising and through private donations. In order to fulfill its mandate of bridging the community to the patient to the health care system, it is required to dance between all of these worlds: networking, negotiating, communicating and demonstrating accountability to each.

One of the greatest challenges for Hospice Orillia, and for the community-based hospice movement in general, lies in its inability to generate support for the *prognostic frames* it promotes (including death in the home, community involvement in care, and allowing a natural death) within the general public and among potential supporters. In contrast, while ardent community-hospice loyalists often resist the institutionalization of care, for many community

members and external supports, the *prognostic framing* of a stand-alone residential hospice building is a much easier “sell”. Subsequently, Hospice Orillia has often had difficulty articulating its mission and vision for the organization, walking a tension between what the community wants and what is actually feasible given economic and logistical constraints.

Maintaining this balance of accountability to community, to the health care system and to the people served by Hospice Orillia has been further complicated by its (Hospice Orillia’s) integration into the North Simcoe Muskoka Hospice Palliative Care Network, which up to the moment of integration was solely focused on promoting palliative pain and symptom management education. By sharing a location, equipment, staff and Board members with a regional non-profit that was fully funded by the Ministry of Health and Long-Term Care, Hospice Orillia strengthened its bond to, and enmeshed itself within, the formal health care system (complete with its own neoliberal agenda of streamlining, budget cuts and restructuring).

Floriani & Schramm (2011) generously state that:

The integration between the hospice movement and healthcare systems has been partly an attempt within the movement itself to become aligned with the biomedical model, and partly the healthcare systems themselves displaying an increasing acknowledgement of the major contribution this movement provides for end-of-life care (p.297).

While Hospice Orillia’s amalgamation into NSMHPCN was a matter of the organization (HO)’s survival rather than a purposeful marriage of hospice services and palliative care, this merger made the organization more vulnerable to the culture and pressures of the mainstream health care system (including its neoliberal proclivities). While integration seems ideal from an economic perspective (and even by some HPC advocates) this has diffused and diluted some of the ideals of hospice care as being community-based, responsive, and focused on the social, relational and spiritual needs of the terminally ill.

However, while the mode of Hospice Orillia's decline is unknown, it is unfair to say that it failed in its mission as a manifestation of the hospice movement. While its history has been marked with internal and external factionalism, increased routinization and scarcity, when members have defected, they have often redirected their passion in caring for the terminally ill and bereaved by creating new programs (such as the hospital's visiting volunteers, the FHT's palliative team, and Mariposa House Hospice). Therefore, according to Tarrow (1994)'s theory, the collective action the original founders of Hospice Orillia were a part of has been successful. While resources which potentially could have been combined have been diffused, and the general hospice philosophy has not exactly been embodied (de-medicalization of care; commitment to compassion, team, community) the situation for the dying, their caregivers and the bereaved has definitely improved from what it was thirty years ago.

### **Conclusion**

The objective of this study was to explore the factors which contributed to the development of Hospice Orillia, a grassroots, community-based volunteer organization which emerged from the hospice movement in the late 1980's, through a multi-stage, single-case intrinsic qualitative case study. The first phase of the study involved developing an organizational timeline through a review of grey literature, which was used in the second phase of the study to prompt semi-structured interviews with nine individuals involved in leadership with Hospice Orillia throughout its life-course. The research reflected that Hospice Orillia had developed in a manner consistent with the Christiansen (2009)'s four stages of a social movement's development: Emergence, coalescence, bureaucratization and decline. The challenges to the community-based hospice movement's ability to provide a counter-cultural alternative for the dying in a neoliberal, bio-medically centric climate has been highlighted

through this study. Furthermore, this study has also demonstrated the impact of neoliberalism on the non-profit sector, specifically for community-based hospices in rural (or small) communities. Hospice Orillia's geographic location (being a small, rural centre in comparison to its regional neighbor, Barrie), its relationship to the formal health care system (including the local hospital, physicians and the MOHLTC), its ability to access funding, and issues regarding advocacy and awareness all played key roles in how it developed over the years.

As an initiative rooted in the hospice movement, Hospice Orillia experienced the power of social capital which is inherent in a movement's collective action both internally and externally. While the organization began with a sense of mission, collective action and shared purpose, its lack of defined (and clearly retained) cultural frames set the stage for factionalism, competition for resources with others (largely due to the impact of a neoliberalism on the non-profit sector) and routinization through its life-course. Regardless of whether the internal factors or external factors influencing the organizations' development lead to its decline, the outcome was the same. Hospice Orillia, except for a brief period of time, existed in survival mode, working hard to sustain itself financially. This impeded its ability to move forward and to develop the potential social capital necessary to move the vision of community-based hospice forward in a way that would change the culture around death, dying, illness and grief in Orillia.

While this research was initially conducted for both Hospice Orillia and the community of Orillia, the findings of this case study may be transferable to community-based hospice programs. This cannot be completely known unless similar research is conducted on those organizations. Regardless, the hope is that it will provide clarity about what the community-based hospice social movement sought to achieve for the dying and their community and

reinforce the importance of providing social, spiritual or practical support (either formally or informally) through community to those who are experiencing illness, grieving, loss, and death.

The community-based hospice movement in Canada has long lost its counter-cultural, rebellious nature. As it evolved, it integrated into the mainstream healthcare system as part of the field known as hospice palliative care. Consequently, it has also been exposed to the neoliberal agenda of the health care system. While the values and philosophy of hospice have been diffused and diluted through this process, this has also facilitated the provision of better (although still profession-centric) care for the dying and their families, and has increased the prominence of hospice palliative care in popular discourse. Stakeholders may argue that the decline of the hospice movement has occurred through mainstreaming with the healthcare system, or that it has been successful in achieving its goals, or that it has failed in achieving its ultimate goal of changing the culture of healthcare. All three are true. However, as we face an unprecedented amount of chronic disease, illness, death and grief in an aging Canadian society, it is more important than ever to be diligent in identifying existing gaps and barriers for individuals and their caregivers being healthy in the face of death. If we seek to provide a more equitable, accessible and holistic person-in-community experience for them, it is imperative that we reflect on where we have been so that we can move forward in a more informed way, learning from lessons in the past.

### **Epilogue – Personal Reflection**

I was employed with a small community hospice program for seven years. Before working professionally in hospice, I had been involved in supporting two of my friends as they lived with, and eventually died from, cancer. These experiences shaped my understanding of death, illness, and grief as happening in the context of shared, mutual relationships; a position consistent with feminist ethics of care. A feminist ethic of care is described by Joan Tronto as “a relational ethic” that situates morality not “in universal, abstract principles but in the daily experiences and moral problems of real people in their everyday lives” (Tronto, 1987, p. 654, 648). She further explains that:

“an ‘ethic of care’ is...a set of moral sensibilities, issues, and practices that arise from taking seriously the fact that care is a central aspect of human existence...a species-specific activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web” (Tronto, 1993, p. 103).

While working in hospice palliative care, I embraced the way in which the hospice philosophy challenged the dominant, Western medical model and promoted death as being a natural life course event. However, rapid changes happened at the provincial and regional level to facilitate the anticipated high demands of an aging cohort of Baby Boomers. These changes, which involved access to funding, partnerships, and new provincial oversight bodies, had a significant impact on Hospice Orillia’s (and other small, rural community hospice programs’) organizational health. While hospice programs with residential facilities (often located in urban centres) were able to provide a full spectrum of services, those without struggled in this political context (and some were forced to dissolve). As someone who was raised, lived, and worked in a small town, the impact on hospice care in rural settings was distressing to witness. So much so that I was led to ask “how did this happen?” and “what could be done to offset this?”

As a feminist researcher, I believe that “knowledge production is an important site in the struggle for social justice” (Moosa-Mitha, 2015, p.79). Epistemologically, I believe that knowledge is subjective and inductive, meaning that truth is “multiple and contextualized within subjective and specific lived experiences” (p.79). From a feminist perspective, Joan Scott (1999) explains that “experience is shaped by one’s particular context – by specific circumstances, conditions, values and relations of power” and that “experience is discursively constructed by dominant ideological structures” (as cited in Hesse-Biber, 2012, p.9). In this research project, I sought to understand how the leaders of Hospice Orillia understood their work and the context it was shaped by. It was important for me to centre their stories and perspectives in this study.

Sauer & Wöhl (2011) argue that “feminist perspectives can reveal (the) contradictions of women’s everyday practices, show the gaps and broken pieces that neoliberal restructuring leaves behind, politicize and change them” (p.125). Therefore, as Lawson (2007) states, “care ethics suggests different ways of theorizing politics” (p.3), a politics informed by something other than neoliberalism. Moosa-Mitha (2015) explains that “feminists are social constructionists and regard mainstream knowledge to be the purview of privileged men who construct particular views about women that are then accepted as natural” (p.79). While a discussion of gender, in particular, was beyond the scope of this study, this is important for me to state, as modern medicine is rooted in positivist, Enlightenment thought that privileges rationality, reason, objectivity, and impartiality (Strega, 2015).

According to McCann (2013), “dominant western culture...tends to be composed of monotheistic religion, whiteness, socioeconomic power, and rational scientism” (p.289). While the mainstream healthcare system is increasingly driven by financial efficiency and quantifiable quality improvement plans, death and dying are experiences that ultimately involve spiritual,

social and emotional components that are not measurable or time-bound. And, while hospice palliative care as a discipline states that there is room for different disciplines and epistemologies at the table, the reality is that some voices are more loudly heard.

As a feminist researcher, it was imperative to be reflexive throughout the process and aware of how my own location and biases could affect the research outcomes (Hesse-Biber, 2012). As Lawson (2007) indicates, a care ethics approach to research design requires taking seriously the research study is “for others” and to build connection and responsibility as key values in research. Strega (2015) adds that:

The standards and needs of the community in which the research is being conducted or from which participants are being recruited are crucial to evaluation. Our work must, therefore, be reconstructive as well as deconstructive (p.145).

My hope is that this research study is not just seen as a critique, but rather that it illuminates some of the differences between community-based hospices (and what they desired to achieve) vs. the mainstream hospice palliative care system. My hope is that this study will highlight how significant the impact of funding decisions, social networks and geographic factors can be from a health equity perspective. For those involved with hospice palliative care, I believe that this case study stresses how important a clear, consistent understanding of and message about what these terms, these concepts, are. Had there not been as much ambiguity of purpose and disagreement amongst hospice supporters, perhaps the power inherent in the community’s social networks would have been more creative (rather than destructive), and there may have been more community resistance against the mainstream health care system’s influence over hospice care in Orillia.

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## Appendices

### APPENDIX A: Research Questions/Interview Guide

#### Research Questions to Guide Semi-Structured Interviews with Key Informants

- a) Could you tell me something about your involvement with Hospice Orillia/Hospice Palliative Care in Ontario over the years?
- b) There have been various twists and turn throughout Hospice Orillia's/HPC in Ontario's lifespan. What is your understanding of what has driven/contributed to those twists and turns?
- c) What was hospice care like during your period of involvement? How did we organize hospice care?
- d) When do you think that Hospice Orillia/HPC in Ontario did good work? When do you think that we struggled off course or had some challenges?
- e) Could you tell me about Hospice Palliative Care in general and Hospice Orillia specifically?

## APPENDIX B: Letter to Interview

### Participants

Monday, July 10, 2017

Dear \_\_\_\_\_ ,

I am currently enrolled in the Master of Social Work program through the University of Victoria. A requirement of the program is the completion of a research thesis into an area of social work. The topic I have chosen for this project is a case study exploration of the factors that have influenced the development of Hospice Orillia from 1988 to the present.

I am writing to request your participation in the research study. You have been identified as a potential participant because of your knowledge either of the evolution of Hospice Palliative Care in Ontario or your knowledge of Hospice Orillia as an organization.

Please note that your participation in this research study is completely voluntary. If you have any questions about this study, please feel free to connect either with me by email at [apritzke@uvic.ca](mailto:apritzke@uvic.ca) or (705) 238-1371 or with my supervisor, Dr. Patricia MacKenzie at (250) 472-4698 or [patmack@uvic.ca](mailto:patmack@uvic.ca). You may withdraw your participation at any time, by identifying so in writing to either my supervisor or myself.

Your participation would involve three components:

- 1) Review and input regarding the development of a timeline of key events and changes in Hospice Palliative Care's/Hospice Orillia's lifespan.
- 2) A semi-structured telephone, Skype or in-person interview (approx. length of time = 1 hour) to discuss four key questions (see attached). The interview will be digitally recorded (audio) with hand written notes taken concurrently. *If the interview is being conducted via Skype, the recording will be in video format.* If there are topics/time periods/questions that you are not willing/able to discuss, please identify them beforehand, and they will not be addressed. As much identifying information as possible will be removed from the data, understanding that this is difficult to insure given the nature of the research.
- 3) A physical review of your interview transcript.

My hope is that this research study will be a gift to both Hospice Orillia and the City of Orillia. I hope that by placing the organization's evolution - including its challenges and its successes - in a historical context that involves consideration of societal, political and environmental influencing factors, we will gain clarity about Hospice Orillia's mission, its values and ultimately its vision for the future.

My hope is that, by looking back at what has brought the organization to this point, we will be able to move forward in a more informed, intentional way. The founding members of Hospice Orillia saw a pressing need for hospice support in the community, and thanks to their commitment and vision, Orillia has had hospice services for the past thirty years. My hope is that this research will help prepare us for supporting the ill, dying, grieving and caregiving in the Orillia area for the *next* thirty years.

Thank you so much for your consideration,

Sincerely,

Amy Pritzker, BA/BSW, RSW

## APPENDIX C: Participant Consent Form



**University  
of Victoria**

Participant Consent Form

### **Raging Against the Dying of the Light:**

*The impact of the mainstreaming of Hospice Palliative Care on a small community hospice program in Central Ontario from 1988-2017*

You are invited to participate in a study entitled ***Raging Against the Dying of the Light: The impact of the mainstreaming of Hospice Palliative Care on a small community hospice program in Central Ontario from 1988-2017*** that is being conducted by Amy Pritzker.

Amy Pritzker is a Graduate Student in the School of Social Work at the University of Victoria and you may contact her if you have further questions by email at [apritzke@uvic.ca](mailto:apritzke@uvic.ca) or by telephone at.....

As a Graduate student, I am required to conduct research as part of the requirements for a degree in Master of Social Work. It is being conducted under the supervision of Dr. Patricia MacKenzie. You may contact my supervisor at - or by email at [patmack@uvic.ca](mailto:patmack@uvic.ca).

### **Purpose and Objectives**

*The purpose of the study is to explore the evolution of a small community hospice program in Central Ontario from 1988 to 2017 through a qualitative case study analysis.*

**Research question:** *What factors have influenced the evolution of a small community hospice program in Central Ontario from 1988 to 2017?*

### **Importance of this Research**

Research of this type is important because it will a) investigate the evolution of a grassroots organization during a time of social and political change and b) it will examine the values and factors underscoring the provision of care for the ill, dying and their caregivers in a small rural community. As healthcare needs increase in Canada, research of this kind provides insight into how external factors impact the direction and quality of service development for care recipients.

### **Participants Selection**

You are being asked to participate in this study because they you have been identified as a key informant and/or knowledge broker about either Hospice Palliative care in Ontario or Hospice Orillia as an organization. You have been selected based on being mentioned in secondary data (ie./Hospice Orillia board meeting minutes, Hospice Orillia organizational correspondence) and/or key reports. Your participation will help verify key dates, provide insight into the context of the historical data, and will help fill in gaps in knowledge.

### **What is involved**

If you consent to voluntarily participate in this research, your participation will include reviewing a timeline of the evolution of Hospice Orillia prior to a one-time, one-hour interview (either in-person or by telephone) to provide context for the evolution of Hospice Palliative Care/Hospice Orillia during your period of involvement. Your interview will be digitally recorded, written notes will be taken, and a transcription will be made. You will be provided with a copy of the transcript of your interview for you to check before it is analyzed. The full participation commitment will be approximately 2 hours.

### **Benefits**

The potential benefits of your participation in this research include:

- The ability to add your voice/perspective to the historical development of Hospice Palliative Care or Hospice Orillia
- Providing a historical context for the evolution of Hospice Palliative Care in Ontario and in Orillia in order help facilitate future planning
- Investigating the impact of high-level policy and funding changes on front-line service delivery and organizational structures.

### **Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be used only if you give written permission.

### **Anonymity**

You may choose whether or not you are named/credited in the research as a participant. Should you wish to remain anonymous, your anonymity will be protected in the research results. However, we recognize that a potential benefit of participating in the research will be to have your contribution to the work of Hospice Palliative Care/your perspective to the history of Hospice Palliative Care acknowledged and will name/credit participants for according to their wishes. Participants' identity will not be disclosed in the corpus data unless the participant has indicated in writing that they wish to be identified/credited in this body of research.

### **Confidentiality**

Your confidentiality and the confidentiality of the data will be protected by electronic data being stored in an encrypted manner, and hard (paper) copies of documentation being kept in a locked, secure, private location.

### **Limits to Confidentiality**

Due to the context of the study and the size of the participant population (individuals involved with Hospice Palliative Care in Ontario or Hospice Orillia as an organization) there is a possibility that identity may be inferred. Therefore, confidentiality cannot be fully guaranteed by the researcher.

***Participants' identities will not be disclosed throughout the research process. However, since this is a small field of practice, participants may know each other. Raw data collected by interview will not be disclosed to other participants.***

### **Dissemination of Results**

It is anticipated that the results of this study will be shared with others through the direct dissemination to research participants; through a thesis; and as a written copy for Hospice Orillia as an organization and the City of Orillia for their archives.

**Disposal of Data**

Data from this study will be disposed of upon completion of thesis. Raw data from Interviews will be erased, and paper copies will be shredded. However, corpus data will be made available through transcription as an appendix to the thesis.

**Contacts**

Individuals that may be contacted regarding this study include the Researcher, Amy Pritzker, and her supervisor, Dr. Patricia MacKenzie. Their contact information can be found on the first page of this document.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
----------------------------	------------------	-------------

WAIVING CONFIDENTIALITY *PLEASE SELECT STATEMENT only if you consent:*

I consent to be identified by name / credited in the results of the study: \_\_\_\_\_ (Participant to provide initials)

I consent to have my responses attributed to me by name in the results: \_\_\_\_\_ (Participant to provide initials)

***Please make two copies of this signed consent. Please send one signed copy to:***

***Please keep one signed copy for your records.***

**APPENDIX D: Request for Permission from NSMHPCN**

Monday, June 26, 2017

North Simcoe Muskoka Hospice Palliative Care Network  
169 Front Street South  
Orillia, ON L3V 4S8

Dear NSMHPCN Board of Directors,

As you may be aware, I am currently enrolled in the Master of Social Work program through the University of Victoria. A requirement of the program is the completion of a research thesis into an area of social work. The topic I have chosen for this project is a case study exploration of the factors that have influenced the development of Hospice Orillia from 1988 to the present.

I am writing to inquire your permission for two components of this research:

- 1) First of all, I am asking permission to review files including: board minutes, past records and other documents pertaining specifically to Hospice Orillia.
- 2) Secondly, I would like permission to recruit interview participants (i.e./former administrators, provincial Hospice Palliative Care advocates, former board members, founding members) to the study using Hospice Orillia letterhead. Being able to use the organization's letterhead will add validity to the study and also confirm that this research is being conducted with the organization's knowledge/permission.

My hope is that this research study will be a gift to both Hospice Orillia and the City of Orillia. I hope that by placing the organization's evolution - including its challenges and its successes - in a historical context that involves consideration of societal, political and environmental influencing factors, we will gain clarity about Hospice Orillia's mission, its values and ultimately its vision for the future.

My hope is that, by looking back at what has brought the organization to this point, we will be able to move forward in a more informed, intentional way. The founding members of Hospice Orillia saw a pressing need for hospice support in the community, and thanks to their commitment and vision, Orillia has had hospice services for the past thirty years. My hope is that this research will help prepare us for supporting the ill, dying, grieving and caregiving in our area for the *next* thirty years.

Sincerely,

Amy Pritzker, BA/BSW, RSW

**APPENDIX E: Letter of Permission from NSMHPCN**

**North Simcoe Muskoka  
Hospice Palliative Care Network**  
169 Front Street South, Orillia, ON, L3V 4S8  
PH: 705-325-0505 FX: 705-325-7328  
www.nsmhpcn.ca



June 26, 2017

Dear Amy,

This letter serves as confirmation that the Board of Directors of the NSMHPCN has approved your thesis request as presented. I have included the motion from the Board minutes below for your reference.

**"Motion: Approve Amy Pritzker's Thesis request as presented**

Moved by: Deborah Duncan-Randal

Seconded by: Nancy Roxborough"

If you require anything further please do not hesitate to let me know.

Sincerely,

## APPENDIX F: Certificate of Approval University of Victoria




Office of Research Services | Human Research Ethics Board  
 Administrative Services Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada  
 T 250-472-4545 | F 250-721-8960 | [uvic.ca/research](http://uvic.ca/research) | [ethics@uvic.ca](mailto:ethics@uvic.ca)

### Certificate of Approval

PRINCIPAL INVESTIGATOR: <b>Amy Pritzker</b>	<b>ETHICS PROTOCOL NUMBER: 17-273</b> Minimal Risk Review - Delegated
UVic STATUS: <b>Master's Student</b>	ORIGINAL APPROVAL DATE: 04-Aug-17
UVic DEPARTMENT: <b>SOCW</b>	APPROVED ON: 04-Aug-17
SUPERVISOR: <b>Dr. Patricia MacKenzie</b>	APPROVAL EXPIRY DATE: 03-Aug-18
PROJECT TITLE: <b>Raging Against the Dying of the Light: The impact of the mainstreaming of Hospice Palliative Care on a small community hospice</b>	
RESEARCH TEAM MEMBER: None	
DECLARED PROJECT FUNDING: None	
<b>CONDITIONS OF APPROVAL</b>	
<p>This Certificate of Approval is valid for the above term provided there is no change in the protocol.</p> <p><b>Modifications</b> To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.</p> <p><b>Renewals</b> Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.</p> <p><b>Project Closures</b> When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.</p>	
<b>Certification</b>	
<p>This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.</p>	

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**APPENDIX G: Timeline of Hospice Orillia History**

	<b>Staff/Board Comp</b>	<b>Milestones</b>	<b>Major Events (External)</b>	<b>Relevant Reports</b>
1987	2 different grps, one OSMH based, one community based meet		<ul style="list-style-type: none"> <li>• AIDS (Casey House campaign)</li> <li>• 12 weeks in Spring (Callwood, 1986)</li> </ul>	
1988				
1989	Board Chair: Lois Fenton Secretary: Deborah Duncan	Letters Patent/By-Laws	<ul style="list-style-type: none"> <li>• Hospice Association of Ontario (HAO) is founded</li> </ul>	
1990	Board Chair: Lois Fenton Treasurer: Deborah Duncan	Hospice Orillia becomes a registered charity		
1991	Board Chair: Dr. Carol Strickland Treasurer: Deborah Duncan			
1992	Board Chair: Dr. Carol Strickland Treasurer: Deborah Duncan		<ul style="list-style-type: none"> <li>• MOH provides \$4.8 million in funding for 4 educational initiatives: <ul style="list-style-type: none"> <li>○ Education for MDs</li> <li>○ Interdisciplinary Edu.</li> <li>○ Visiting Hospice Programs</li> <li>○ Regional P&amp;S Mgmt teams</li> </ul> </li> </ul>	
1993	Board Chair: Cate Root Treasurer: Deborah Duncan	<ul style="list-style-type: none"> <li>• Hired ED: Cheryl L. MacDonnell</li> <li>•</li> </ul>		

1994	Board Chair: Nancy Harris Treasurer: Deborah Duncan	<ul style="list-style-type: none"> <li>• Trillium Funding ends</li> <li>• Charity Bingo &amp; Nevada secured</li> <li>• Hired Office Coordiinator:</li> </ul>	<ul style="list-style-type: none"> <li>• Bill 173 – LTC Act</li> <li>• Home Care and Community Services Act (1994)</li> </ul>	
1995	Board Chair: Anna Zwicker Treasurer: Karen Uren Staffing: ED, Office Administrator, Case Coordinator &PT secretary	<ul style="list-style-type: none"> <li>• Bingo provides an average income of \$1174.00 each week (\$62,070)</li> <li>• Strat Planning</li> <li>• Caregiver Network Project</li> </ul>	<ul style="list-style-type: none"> <li>• Hospice Simcoe sponsors P&amp;S management team</li> <li>• Eleanor Watt, Simcoe Palliative Care Coordinator</li> <li>• HAO restructures due to budgetary constraints</li> <li>• Community Care Access Centres (CCACs) created</li> <li>• Cancer Care Ontario created (implemented 1997)</li> </ul>	<ul style="list-style-type: none"> <li>• Senate Report: “<i>Of Life and Death</i>”</li> </ul>
1996	Board Chair: John Millward Treasurer: Karen Uren ED: Cheryl MacDonnell Service Coordinators: Joan Ambrose & Cheryl MacDonnell Office Assistant: Pam Tuvey Secretary: Rhonda Sheppard Case Coordinator: Donna Kumagai	<ul style="list-style-type: none"> <li>• Cate Root designs/develops VV training program</li> <li>• Regional Meetings with Hospice Huronia, Hospice Simcoe &amp; Hospice Collingwood</li> <li>• Cheryl MacDonnell retires</li> </ul>	<ul style="list-style-type: none"> <li>• Casino Rama opens</li> <li>• Ontario gov’t cuts civil service positions by %15</li> <li>• Health Care Consent Act (1996)</li> </ul>	
1997	Notes missing ED: Joan Ambrose	Notes Missing	<ul style="list-style-type: none"> <li>• RVH (Barrie) opens at Georgian Drive location</li> </ul>	
1998	Board Chair: Cameron Bigelow	<ul style="list-style-type: none"> <li>• Adopted Carver governance model for board</li> </ul>		

	Treasurer: Karen Uren ED: Joan Ambrose	<ul style="list-style-type: none"> <li>Expanded service delivery into Palliative Care Unit @ OSMH</li> <li>Partnership with Trillium Manor</li> </ul>		
1999	Board Chair: Dannette Blue Treasurer: Karen Uren ED: Joan Ambrose	<ul style="list-style-type: none"> <li>Visioning Day/Open Space planning session</li> <li>Bereavement Task Force/Walking Group</li> <li>Family Room on Palliative Care Unit at OSMH</li> </ul>	<ul style="list-style-type: none"> <li>GSK “Living Lessons” Promotional Campaign</li> <li>New nursing agencies given contracts by CCAC</li> <li>CCAC Palliative Care Working Committee</li> </ul>	
2000	Board Chair: Harvey Watt ED: Joan Ambrose New service coordinator, Wendy Lee	<ul style="list-style-type: none"> <li>Aligns visiting hospice client standards to those outlined by HAO</li> <li>Adapted HAO visiting hospice training program</li> <li>Sent volunteers to HAO conference</li> <li>Goal to develop website</li> <li>Promotional materials in FH pre-planning pkgs</li> <li>Tree of Remembrance planting at Park</li> <li>Bereavement walks started</li> </ul>		Senate Report: <i>“Quality End-of-Life Care: The right of every Canadian”</i>
2001	Board Chair: Harvey Watt		<ul style="list-style-type: none"> <li>Creation of Orillia Grief Resource Network</li> <li>HAO releases “Target and Indicators Final Draft”</li> <li>Cancer Care Ontario (CCO) launches Palliative Care Integrate Project (PCIP) with partners in</li> </ul>	

		Southeastern Ontario – Common tools <ul style="list-style-type: none"> <li>• Secretariat on Palliative and End-of-Life Care formed &amp; led by Sen. Sharon Carstairs</li> </ul>	
2002	Board Chair: Harvey Watt/Phil Chevalier	<p>“Funding is also a concern especially now with a new government. Hospice Orillia must fund-raise 80% of their budget with our present MOH supports. Ongoing communication with our provincial hospice body HAO and the MOH is imperative during this time of change. There will be many and ongoing challenges.”</p> <p>“Concerns, however, linger in what appears to be an apparent breakdown in the delivery of palliative care services to patients entering the hospital and returning to the community, and for many who must go to other areas like Toronto for treatment and then return back to this community for services”</p>	<ul style="list-style-type: none"> <li>• Romanov Report: Commission on the Future of Health Care in Canada (2002)</li> <li>• CHPCA National Model to Guide HPC (2002)</li> </ul>
2003		Designated \$\$ for Palliative care to all provinces through the 2003 Canadian Federal Health Accord	
2004	Board Chair: Jeff Smith Joan Ambrose retired as ED,		<ul style="list-style-type: none"> <li>• CCO makes HPC priority for 1<sup>st</sup> time</li> </ul>

	Bonnie Jeremy successor		<ul style="list-style-type: none"> <li>• Personal Health Information Privacy Act (PHIPA),(2004)</li> </ul>	
2005	Board Chair: Bill Sheppard  ED: Bonnie Jeremy Bill Smith Heather Tuline-Alden	<ul style="list-style-type: none"> <li>• “In 2005 the MOH made a huge investment in EOL care. Our portion of the money brought us from \$25858 annually to \$46,358 – an increase of \$20500. This looks very rosy, but with the loss of bingo in Orillia, we are still severely under funded.”</li> </ul>	<ul style="list-style-type: none"> <li>• Creation of NSM EOL Network</li> <li>• Creation of 14 HPC Networks to coincide with CCACs</li> <li>• Creation of LHIN</li> <li>• MOHLTC EOL Strategy - \$115.5 million over 3 yrs for HPC</li> <li>• Orillia Chapter of Bereaved Families of Ontario (BFO) closes</li> </ul>	Senate Report: “ <i>Still Not There</i> ” Quality End-of-Life Care: a Progress Report
2006	Board Chair: Bill Sheppard  ED: Heather Tuline-Alden	<ul style="list-style-type: none"> <li>• Negotiations with LHIN/MOH</li> </ul>	<ul style="list-style-type: none"> <li>• Local Health System Integration Act (2006)</li> <li>• Creation of Simcoe County &amp; Parry Sound Palliative Care Network</li> </ul>	
2007	Board Chair: Bill Sheppard  ED: Heather Tuline-Alden	<ul style="list-style-type: none"> <li>• Trillium Grant - \$30000 over 2 years (until 2008) to fund Bereavement Support Program</li> <li>• Hired Program Asst.</li> <li>• End of palliative care team at OSMH</li> <li>• Residential Task Force – Goal to make Hospice Orillia residential by 2011</li> </ul>	<ul style="list-style-type: none"> <li>• Creation of North Simcoe Muskoka Palliative Care Network</li> <li>• Creation of 14 LHINs – Local Health Integration Networks across Ontario</li> <li>• MOHLTC – Aging at Home Strategy (\$1.1 billion over 4 years to assist LHINs in providing home care)</li> <li>• Dr. Mary Lou Kelley Model of “Developing Rural Community’s Capacity for Palliative Care”</li> </ul>	
2008	Board Chair: John Stokreef  ED:	<ul style="list-style-type: none"> <li>• Partnering with NSMPCN to offer</li> </ul>	<ul style="list-style-type: none"> <li>• e-Health Ontario is launched</li> <li>• Recession – “Great Financial Crisis”, loonie</li> </ul>	

	Heather Tuline-Alden Annalise Steneke	Fundamentals as training <ul style="list-style-type: none"> <li>• Orillia has new Palliative Care Physician</li> <li>• CCAC case managers are generalists – no longer palliative care specialists</li> </ul>	drops – period of fiscal restraint money was tight lead to board making decisions	
2009	Board Chair: John Stokreef  ED: Annalise Steneke (mat leave)  Acting ED: Frances Yarborough	<ul style="list-style-type: none"> <li>• Organizational Development (funded by Community Grant from Casino Rama);</li> <li>• Website – Launched Jan.2009</li> <li>• Strategic planning – started winter 2008, postponed until Annalise hired.</li> <li>• Revised Mission, Vision, Values</li> <li>• Accreditation.</li> <li>• For the next three years, we have identified five areas of specific focus including: <ul style="list-style-type: none"> <li>• 1) organizational development;</li> <li>• 2) outreach &amp; education;</li> <li>• 3) service development;</li> <li>• 4) fundraising and</li> <li>• 5) enhancement of partnerships.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Hospice Simcoe (Barrie) opens 10 residential hospice beds</li> <li>• RVH launches Phase 1 of capital campaign for new facilities – including Regional Cancer Centre</li> <li>• 1<sup>st</sup> joint conference between HAO and OPCA</li> </ul>	<ul style="list-style-type: none"> <li>• Provincial EOL Care Network Report: HPC System Design Framework Knowledge Synthesis Report</li> </ul>
2010	Board Chair: Dee Cox  ED: Frances Yarborough	<ul style="list-style-type: none"> <li>• Staff pares down to pt client care coordinator &amp; program assistant</li> </ul>	<ul style="list-style-type: none"> <li>• Concept of a “Hospice Alliance” suggested in LHIN 12</li> <li>• “Excellent Care for All Act” (2010)</li> </ul>	<ul style="list-style-type: none"> <li>• Report to Senate: “Raising the Bar: a Roadmap for the Future of</li> </ul>

	(Acting) – resigned Cate Root (Interim, shared ED with NSMPCN, HS)  Major Re-structuring	<ul style="list-style-type: none"> <li>Office moves to Memorial Avenue w/NSMPCN</li> <li>Controversy within volunteers</li> </ul>	<ul style="list-style-type: none"> <li>MOHLTC provides funding for Pain &amp; Symptom Management Consultants</li> </ul>	Palliative Care in Canada”
2011	Board Chair: Dee Cox  ED: Cate Root/Sandra Dunham		<ul style="list-style-type: none"> <li>HPCO formed (HAO &amp; OPCA combine)</li> <li>1<sup>st</sup> Baby Boomers turn 65</li> </ul>	<ul style="list-style-type: none"> <li>LHINs/QHPCCO release “The Declaration of Partnership &amp; Commitment to Action”</li> </ul>
2012	Board Chair: Dee Cox  ED: Sandra Dunham	<ul style="list-style-type: none"> <li>Obtains Seniors’ Grant for “Legacy Project”</li> </ul>	<ul style="list-style-type: none"> <li>Hospice Huntsville opens Hospice Algonquin Grace, 5 Bed residential Hospice</li> </ul>	<ul style="list-style-type: none"> <li>The Way Forward National Framework (CHPCA)</li> <li>Action Plan for Health Care: Better Patient Care through better value for \$\$</li> </ul>
2013	Board Chair: Dee Cox/Neda Rowhani-Seki  ED: Sandra Dunham	<ul style="list-style-type: none"> <li>Board Chair, Dee Cox dies</li> </ul>		
2014	Board Chair: Neda Rowhani-Seki  ED: Sandra Dunham	<ul style="list-style-type: none"> <li>Hospice Orillia integrates with NSMPCN; becomes a program of the North Simcoe Muskoka Hospice Palliative Care Network</li> </ul>	<ul style="list-style-type: none"> <li>Hospice Georgian Triangle opens Campbell House (Colliingwood) w/ 6 residential beds</li> <li>Patients First Legislation is introduced in Ontario</li> </ul>	

		<ul style="list-style-type: none"> <li>• Shared staff model with NSMHPCN</li> </ul>		
2015	<p>Board Chair: Lianne Raymond</p> <p>ED: Sandra Dunham</p>	<ul style="list-style-type: none"> <li>• Moves office into Orillia Common Roof with NSMHPCN</li> <li>• NSMHPCN pursues idea of residential hospice in Orillia – co-location model</li> <li>• Fund Development Lead is hired</li> </ul>	<ul style="list-style-type: none"> <li>• Trudeau Liberal majority government is elected</li> </ul>	<ul style="list-style-type: none"> <li>• Patients First: Action Plan for Health Care</li> <li>• Bringing Care Home: report of the Expert Group on Home &amp; Community Care (The Donner Report)</li> </ul>
2016	<p>Board Chair: Lianne Raymond</p> <p>ED: Sandra Dunham</p>	<ul style="list-style-type: none"> <li>• Fund Development</li> <li>• Feasibility Study is done with community re: residential hospice</li> </ul>	<ul style="list-style-type: none"> <li>• Ontario Palliative Care Network (OPCN) is introduced &amp; launched</li> <li>• Patients First Act: Bill 41</li> </ul>	<ul style="list-style-type: none"> <li>• Palliative and End-of-Life Care Provincial Roundtable Report (The Fraser Report) MOHLTC</li> </ul>
2017	<p>Board Chair: Bruce Bound</p> <p>ED: Sandra Dunham vacant</p>		<ul style="list-style-type: none"> <li>• Campbell House (Collingwood) opens 4 more beds</li> <li>• Mariposa House Hospice gains charitable status</li> </ul>	<ul style="list-style-type: none"> <li>• Thriving at Home: A Level of Care Framework to Improve the Quality and Consistency of Home and Community Care for Ontarians ~ Final Report of the Levels of Care Expert Panel</li> </ul>

**APPENDIX H : List of Acronyms Used**

CCAC – Community Care Access Centre

CCO – Cancer Care Ontario

(C)HAO – (Community) Hospice Association of Ontario

CHPCA – Canadian Hospice Palliative Care Association

HPC – Hospice Palliative Care

HPCO – Hospice Palliative Care Ontario

LHIN – Local Health Integration Network

MOH(LTC) – Ministry of Health (and Long-Term Care)

NSM – North Simcoe Muskoka

NSM(H)PCN – North Simcoe Muskoka (Hospice) Palliative Care Network

OPCN – Ontario Palliative Care Network

RPCN – Regional Palliative Care Network