

Exploring school administrators' perceptions of death education in public schools

by

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

MASTER OF NURSING

College of Nursing

Rady Faculty of Health Sciences

University of Manitoba

Winnipeg

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### Abstract

**Background:** Talking about death can positively impact health outcomes yet, death remains taboo. As a public health approach to palliative care, death education is one way to normalize conversations about death, dying, caregiving for those with life-limiting illness, and loss. Currently, these themes are not considered as part of the health curriculum in Manitoba. To find novel ways to bring death, dying, caregiving, and grieving into our daily discourse and to increase our death literacy, it is essential to consider upstream interventions for all ages. Death education is one such approach. To date, the current landscape of death education in the Manitoba public school system and administrators' perceptions of introducing and integrating this into the curriculum are unexplored.

**Method:** An exploratory, descriptive qualitative design was used. Semi-structured interviews were used to elicit experiences with death education and perceptions of formal inclusion in the curriculum from public school principals (n=7). Interviews were transcribed verbatim and content coding was used for analysis in conjunction with reflexive journals.

**Results:** The study revealed conversations about death and grief do occur in schools, while caregiving, life-limiting illness, and dying are left out of the discussion. Schools respond as best they can with limited resources and without guidance. There is an appetite to including death education in the classroom. Administrators saw potential barriers to doing so but also noted supportive measures and specific strategies that would assist in integrating these themes.

**Conclusion:** The knowledge gained from this study highlights the need to proactively address death, dying, caregiving, and loss in the school system. It also addresses the gap in the empirical literature regarding the current landscape and school administrators' perspectives on including death education in the curriculum.

## Acknowledgements

I would like to extend my deepest gratitude to the following individuals:

My husband and children for their love and support, even in the darkest hours. I could not have done this without them.

My family and friends who rooted for me, offered suggestions and support, and listened to me ramble on about my passion for normalizing death.

To my graduate student peers who took this journey with me. Your friendship and support meant everything.

Jamie Penner, my thesis advisor, for always being in my corner. She grounded me when I was running too fast, but also pushed me when I was moving too slow. Her guidance, wisdom, and mentorship proved to be invaluable.

Dr. Genevieve Thompson, my thesis advisor, for her encouragement, patience, and insight. She showed me what my sandbox is and to take a chance on my passions.

Dr. Lynn Scruby, my internal committee member for her guidance, support, and mentorship through this process, but also through my journey as a community nursing instructor.

Dr. Charlotte Enns, my external committee member, for her support and enthusiasm about this project and for adding insight with thoughtful feedback and questions.

The principals who took time out of their busy schedules during a worldwide pandemic to share, with open hearts, their wisdom, insight, and experiences about an often difficult to talk about topic. This project would not have been possible without them.

I would also like to acknowledge the following sources of funding support:

Mona McLeod Award (2020)

Dr. S. J. Winkler Memorial Award (2020)

Irene Nordwich Foundation Award (2020)

Graduate Nursing Students Association Scholarship (2021)

Foundation of Registered Nurses of Manitoba Inc. Graduate Award (2021)

College of Nursing Endowment Fund, Graduate Student Research Grant (2021)

## **Dedication**

This thesis is dedicated to school communities.

Thank you for sharing in the responsibility of both raising and loving our children for just a short time and for giving them the knowledge and skills to be contributing citizens and lovely humans.

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## **Chapter 1 - Background**

The purpose of this introductory chapter is to establish the foundation of this research study. This section will include the statement of the problem and discuss the significance of the research. This chapter will also describe the research questions that were used to guide the study and define relevant research concepts.

### **Statement of the Problem**

Everyone who lives, will die. Despite this universal truth, we exist in a culture characterized by death denial (Robert & Tradii, 2019). In our current climate, death has never been so visible to today's youth, with the pandemic's daily death tolls being reported by public health officials and news services. The bombardment of COVID-19 media coverage is regularly witnessed by children (Rapa et al., 2020). Children have and will continue to experience loss and grief because of COVID-19 (Fitzgerald et al., 2021). Collectively, grief is occurring worldwide, however children may be at greater risk for mental health impacts (Albuquerque & Santos, 2021). While the tragic consequences of the pandemic envelop school-aged children, it also provides an opportunity to engage school communities in conversations about death and dying (Smilie, 2021). It is important to note that resiliency, an essential component of maturation and a critical life skill, is built through dealing with loss (Fitzgerald et al., 2021). Death, made obvious in the context of COVID-19 amongst other current events, is ready for discussion, yet we are still not engaging in open conversations.

Demographic changes associated with increasing populations, increasing numbers of people living longer, increasing rates of dependency on others with age, and a reduction in younger populations able to care for those approaching end of life have had significant social impacts on our world, including isolation and loneliness in those who are aging and approaching



death (Verne, 2022). Moreover, these sociodemographic changes have also come with a decrease in knowledge, traditions, and practices associated with death, dying, and bereavement. The *Lancet* Commission on the Value of Death formulates a compelling justification for “rebalancing” the societal relationship with death and dying (Sallnow et al., 2022). They argue that dying in today’s world has changed so significantly from the ways in which we experienced death in the past that other options, such as those that fall outside of health care, are unknown to most. In fact, Sallnow et al. (2022) envision a “utopia” where stories and discussions about death, dying, and grieving become commonplace: recognized, shared, discussed, and addressed by all.

Discomfort discussing death and dying leaves many who are living with serious illness unprepared to make informed decisions about possible treatments and end-of-life care. There is ample evidence demonstrating that earlier conversations about death, dying, and patient goals contribute to increased quality of life (Detering et al., 2010; Pautex et al., 2008; Schichtel et al., 2020; Wright et al., 2008) and less distress (Chan & Pang, 2010; Cornally et al., 2015; Detering et al., 2010; Fan et al., 2019; Pautex et al., 2008) for patients and family members. Yet less than 20% of Canadians have engaged in discussions to outline the details of their healthcare wishes (Advanced Care Planning Canada, 2019).

Palliative care is a whole-person approach to care aimed at improving the quality of life (QOL) for those who are living with a life-threatening illness and their families (World Health Organization, 2020). This philosophy of care embraces dying as a normal part of life. A key feature of a palliative approach to care is engaging in discussions around goals of care, which help individuals with a life-threatening illness understand the serious nature of their illness, while helping healthcare providers understand the patient’s values and care objectives. These

discussions provide the basis for treatment decisions and ensure the individual is well-supported to live well throughout their illness and have the death they want in the end.

Conversations about death, dying, and goals of care can lead to increased acceptance of patient disease trajectories (Wright et al., 2008), less aggressive treatments with a greater focus on symptom management (Cornally et al., 2015; Wright et al., 2008), reduced hospital admissions (Caplan et al., 2006; Cornally et al., 2015; Molloy et al., 2000; Zagrocki et al., 2014) and greater patient satisfaction with end-of-life care (Detering et al., 2010; Schichtel et al., 2020). Despite recent shifts in thinking towards integrating a palliative approach to care and goals of care discussions earlier in a person's illness trajectory, in practice this approach to care and these conversations are still happening too little, and too late. A potential strategy to moving the conversation upstream and to normalize death, is through a public health approach.

A public health approach to care is aimed at empowering communities and individuals to improve their health through illness prevention, health promotion, and the provision of information to support informed decision-making (Government of Canada, 2022). Public health and community health nurses are leaders in this area, working with communities to support and further this important mandate (Canadian Public Health Association, 2010). Just as in other aspects of public health where a good outcome requires informed decision making, to ensure a good death requires that Canadians – patients, families, and healthcare providers – are readily engaging in conversations about death and dying and have the information and knowledge to have these informed discussions. As such, palliative and public health approaches are not mutually exclusive. In fact, Grindrod (2022) argues that while different in form and function, their integration would be beneficial.

A public health approach to palliative care (PHAPC) focusses on the prevention of suffering, early interventions to promote QOL, and harm reduction, within the context of death, dying, bereavement, and caregiving (Public Health Palliative Care International, n.d.). Nurses are well positioned to use their knowledge and skills to further the mission of a public health approach to palliative care in all settings and throughout the illness trajectory.

Public education is a key strategy within a PHAPC (Kellehear, 1999b, 2015b, 2016; Mills & Mills, 2016; Public Health Palliative Care International, n.d.; Sirianni, 2020; Tompkins, 2018) and death education, in particular, is an important intervention that can normalize loss and grief, promote understanding of the dying process and available care options, and reduce the fear, ignorance, and stigma that surround death, dying, caregiving, and grieving (Kellehear, 2015b). Increased knowledge leads to informed decision-making, better informed care policies, and practice, and environmental and behavioural changes that can positively impact the ways in which we live and die. In this way, death education can be viewed as an important step in changing current behaviors, attitudes, and policies, like other health-promoting and harm reduction campaigns, such as safe-sex education, seatbelts, bike helmets, and tobacco cessation (Kellehear, 2015b).

Knowledge can be shared within the formal institutions that are designed to do so. Using the existing school system to begin a conversation about death and dying puts a PHAPC into practice. Schools are ideal locations for the teaching of health-promoting behaviours as current habits and routines are not yet developed (Pender, 1987). Furthermore, permanent habits are more likely if established in childhood or adolescence. There has been an increase in health promotion activities worldwide, including within school settings (Murdaugh et al., 2019). In

Manitoba, over 210,000 children and adolescents attend school (Government of Manitoba, 2020) and over 16,000 teachers educate these students (The Manitoba Teachers' Society, n.d.).

Already in place is the Healthy Schools initiative, which aims to promote the physical, emotional, and social health and well-being of students and concentrates on nutrition, mental health, physical activity, safety and injury prevention, sexual health, and substance abuse (Government of Manitoba, n.d.-b). This initiative acknowledges the unique role schools have in conveying impactful guidance to students and school communities. These topics are health-promoting and important to discuss from an early age, but death, dying, grieving, and caregiving are noticeably missing. In order to bring these themes into the classroom, it is important to know if the school system is ready for such an introduction. And, if they are ready, where would we start?

### **Significance of the Study**

Finding novel ways to allow death and dying to become part of our daily discourse can greatly impact the health and well-being of our society. Sallnow et al. (2022) argue that death literacy is necessary for all. The current education system is an uncharted territory with respect to death education. Public health approaches to palliative care, which includes creating space to discuss death, dying, and bereavement with the goal of changing perceptions and attitudes can start with those who dedicate their time to health education. Nurses are in the profession of caring and educating patients throughout the lifespan. This includes during times of acute illness but also as a part of health promotion, harm reduction, and public health education. The study of death is multidisciplinary in nature. This is because death is not a medical issue, but a social one, with some medical aspects (Abel & Kellehear, 2016). In fact, those approaching death will spend only 5% of their time with doctors or nurses with the remaining time being spent within their

own social circles (Kellehear, 2022). Nurses, as educators, are well positioned to use their knowledge and skills to further the mission and vision of a public health approach to palliative care in non-traditional settings. To shape those social circles, the 95% need to be prepared to care for and be with the dying. This study is a first step to normalizing death, dying, caregiving, and bereavement, perhaps trying to reclaim these actions as social ones rather than medical events. By describing the current landscape and perceptions around death education in the school curriculum, we can know where we are and where we need to go. Using a health-promotion and prevention approach to palliative care can provide information to the public before reactive healthcare is necessary. Formal and informal education can assist individuals in developing the knowledge required to make informed decisions about their health at all stages, including when faced with a life-limiting illness or as they age and approach death. We can engage populations in leaning into death and dying, rather than looking away and perhaps create a better experience for all of us.

### **Theoretical Framework**

Well-designed research is strengthened by acknowledging the framework that provided the conceptual rationale for the study (Polit & Beck, 2017). This framework allows the researcher to understand how and why people behave in certain ways, and how they will impact or be impacted by other influences. This study was guided by Social Cognitive Theory (SCT).

In essence, SCT seeks to explain how humans learn given their personal characteristics, behaviour patterns, and the environments in which they live (Bastable, 2008). The relationships between these three factors are reciprocal in nature, and people both shape and are shaped by environments and behaviours that surround them (Bandura, 1986). Furthermore, SCT attests that most human behaviours are learned through observational modelling. Additionally, Bandura

(2001b) suggests that agency is at the centre of being human and allows for individuals to develop and adapt with change. This is because humans have the capacity to organize, plan, act, reflect and regulate their actions and behaviours. Furthermore, agency requires the belief that desired results are possible and that undesirable results can be avoided by one's own actions, a concept known as self-efficacy. Self-efficacy is the basis for one's motivation and behaviour, especially when undergoing individual change (Bandura, 1998). Because adhering to and mastering healthy habits require perceived self-efficacy (Bandura, 1986), health-promotion research needs a basic understanding of SCT.

Consistent with a public health approach, Bandura (1986) saw limited impacts of the reactive, disease-oriented biomedical approach to health and felt that a broader, preventative approach where individuals assume some responsibility for their own health and well-being through knowledge and control over their habits and environments was warranted. The idea for this research study emerged from observations around the nature of our current environments. We are so rarely in settings where death is discussed freely and the social reluctance to have these conversations is still prevalent. Understanding SCT and the relationships between environments, thinking, and behaviours, it is clear that to create change, one of these factors would need to be influenced and manipulated. Education could certainly change thinking, changed thinking could create new behaviours, new modelled behaviours could change environments, and so on. Understanding the environment within the public-school setting and behaviours of those within the system could help explain both the resistance to death education and illuminate potential areas for change.

### **Purpose of the Study and Research Questions**

The purpose of this qualitative research study was to describe the current landscape of death education in the Manitoba school system and to explore school administrators' perceptions of introducing and integrating death education in the standard public-school curriculum. This study was guided by the following research questions:

1. Are the topics of death, dying, grieving and caregiving currently being discussed in the classroom? If so, when?
2. How are these topics being discussed? Is there a formal curriculum to do so?
3. What training and guidance are given to teachers to address these topics?
4. What are administrators' perceptions of whether death education should be included in the curriculum?
5. What do school administrators and teachers need to feel confident in teaching these subjects?

### **Assumptions**

Creswell (2013) encourages researchers to understand the personal beliefs and assumptions that inform their research and to incorporate these into written work. The following assumptions underpin this study:

1. School administrators want what is best for their students, staff, and school communities.
2. Experiences surrounding death, dying, caregiving, and loss are contextual and differ from person to person.
3. Participants will be honest in discussing their experiences and perceptions.
4. Talking about death and concepts surrounding death is hard.

In addition to these assumptions, there are personal beliefs and values held by the researcher related to death, dying, caregiving, and loss. The researcher feels that death is an important, valuable, and necessary topic to discuss. Having experience working with chronically ill patients, those near or at end of life, and their families, the researcher has witnessed the struggle of closed or non-existent communication, not addressing final wishes, the fear of death, futile medical treatments, and avoiding death altogether. As a result, patients often did not choose their preferred place of death, families did not have a chance to say goodbye to loved ones, and they experienced complicated grief. By waiting too late into the illness trajectory to address what is important to them, individuals living with serious illness often are unable to live their good life until the end, which can lead them to also not having a 'good death'. These beliefs contributed to the conceptualization of this research study.

### **Definitions of Terms**

To proceed with the research, it was important to clarify the language being used. This section outlines a number of key terms and how they are defined for use in this study.

#### **Palliative Care**

Palliative care is a person-centered approach to care that focusses on improving QOL for those with life-limiting illness (World Health Organization, 2020). There is overwhelming consensus that holistic palliative care seeks to prevent, identify, assess, and treat the physical, spiritual, emotional, and social issues that arise over the course of a severe illness in order to support patients to live fully until death and families and caregivers during the illness trajectory and into bereavement (Radbruch et al., 2020).



## **Public Health**

Public health is a structured approach to keep societies healthy (Porr et al., 2020). Concerned with population level health, public health focusses on reducing illness and improving health for all (Kellehear & Sallnow, 2012). Through health promotion strategies, this enables individuals take control to improve their health, which is further complimented by collaboration across all sectors (World Health Organization, 1986). In this way, health and well-being are not the sole responsibility of the provider; health services are just one resource for individuals to access as necessary.

### **A Public Health Approach to Palliative Care**

First suggested by Kellehear (1999b), the junction between public health and palliative care approaches was first labelled “health-promoting palliative care” (p. 76). Borrowing from a public health approach, PHAPC utilizes the concepts of early intervention, harm reduction, and prevention and focusses these strategies on issues related to death, dying, bereavement, and caregiving (Public Health Palliative Care International, n.d.) with a further emphasis on building assets to strengthen and reorientate health and social services and fostering community capacity in order to ensure the public assumes some responsibility for their own health and well-being when living with a chronic progressive illness (Kellehear, 2016). Kellehear (2013) emphasizes those living with life-limiting illness and their caregivers face their own unique quality of life issues: depression, anxiety, isolation, spiritual distress, financial stress, and others. Furthermore, these concerns are frequently under-addressed and would benefit from these same public health approaches.

**Death Education**

Broadly defined, death education is simply teaching and learning related to any topic associated with death (Corr & Corr, 2003). This can include a variety of topics ranging from death rates, causes, attitudes, experiences, funeral and memorial rituals, legal issues, suicide, religious or spiritual views, and bereavement. Death education can be seen as a way of contemplating themes related to death and dying with the objective of increasing awareness of these topics (Testoni, Palazzo, et al., 2020). Because the purpose of this study is to look at death education as a way of increasing comfort with death as a natural part of life and facilitating conversations about death and dying, all of these topics are relevant. Like most health-related education, this can be done in both formal and informal ways. For the purposes of this study, death education is considered the curriculum that takes place in a formal school setting.

**School Administrators**

The concept of school administrators may differ depending on the type of school and the region in which school operates. For the purposes of this study, a school administrator is considered to be a principal or vice-principal in a school. According to the Council of School Leaders of the Manitoba Teachers' Society (2019) a principal or vice-principal is responsible for carrying out activities as outlined and defined by The Public Schools Act, including the implementation of school board policies, the daily operations of the school, the administration and spending of allocated funds, the assessment and promotion of students, the supervision and evaluation of teachers and other school staff, and acts as a liaison between and consults with the school board and the parent community.

### **Summary**

In this introductory chapter, the statement of the problem and the significance of the study were presented. This chapter also discussed the research questions that guided the research and introduced relevant definitions required to understand the study overall. In the next chapter, a review of the literature will be presented.

**Chapter 2 – Literature Review**

To gain a broader view of the problem, this chapter will provide a review of the literature and identify any knowledge gaps that currently exist. Specifically, this section will discuss the importance of having conversations about death and dying and how death denial contributes towards the social reluctance of confronting death and dying. This chapter will also provide discussion of how compassionate communities, as part of a PHAPC, can better support these important and necessary conversations. Furthermore, as a PHAPC intervention, death education will be examined, including its goals and benefits, barriers to inclusion, and potential fit for students. A brief history of a similar taboo topic, sexual education in schools, will also be examined.

Death education in the school system is abstract and a combination of multiple concepts. Working with a health sciences librarian, a robust search strategy was created based on four concepts shown in Table 1.

**Table 1**

*Concept Terms for Literature Search Strategy*

Concept 1: Death	Concept 2: Education	Concept 3: School system	Concept 4: Administrators
death		school*	principal*
grief	educat*	K-12	"vice-principal*"administrator*
grieving	teach*	classroom*	superintend*
"end of life"	curricul*		
death[mesh]			

attitude to death[mesh]	"experiential learning"		
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Literature was searched, retrieved, and reviewed from CINAHL, PubMed, PsychINFO, Scopus, ERIC, and Sociological Abstract databases. Because of the dearth of information on both death denial and death education in the last five years, relevant literature was included, regardless of publication date. In addition, reference lists of articles were hand-searched and relevant citations retrieved.

**Importance of Having Conversations About Death and Dying**

Talking about death is important. From a health care perspective, as part of a patient and family centered approach to care, understanding the needs, wants, and wishes of individuals provides health care teams with instructions for how this individual wants to be treated for the remainder of their life. One way this can be done is through a formal process called advanced care planning. An advanced care plan (ACP) puts into writing the personal health care plans an individual would want if they became unable to speak for themselves and may include appointing a substitute decision maker and potential treatments the individual may or may not want (Advanced Care Planning Canada, 2020). Contrary to common belief, for those with advanced cancer and their families, talking about end-of-life was not associated with negative mental health outcomes such as feeling depressed or worried (Wright et al., 2008). Formal ACP has led to greater rates of documented EOL preferences, including place of death, earlier referral to palliative specialists, and improved communication (Jimenez et al., 2018).

In fact, having these discussions allowed these patients to understand the nature of their illnesses, accept symptom relief over curative measures, and complete ‘do not resuscitate’ orders which were associated with an increased quality of life. There is further evidence that formal ACP improves both quality of life (DeCoursey et al., 2019; Schichtel et al., 2020) and end-of-life outcomes (Detering et al., 2010; Dixon et al., 2018). Talking about death can allow for better support for those who become isolated: individuals living with life-limiting illness, their caregivers, and the bereaved by normalizing dying and reducing the fear and ignorance that seem to be ever-present (Kellehear, 2015a, 2016).

Patterson and Hazelwood (2022) suggest that having the knowledge, skills, attitudes, and behaviours to prepare for, cope with, and support others through death, dying, caregiving, and bereavement is important. This ‘end of life literacy’ influences individual experiences of death and dying. Additionally, having these conversations contributes broadly to raising awareness and changing attitudes about death, dying, and grief while having the potential to grow social networks and build support for each other in times of need.

While there is some willingness to have these conversations, interest in having a discussion does not always translate into any form of action (Smyth, 2017). The benefit to open communication about death is evident, yet there continues to be avoidance in doing so (Omilion-Hodges et al., 2019). There are many reasons why individuals do not engage in conversations, fear and denial being two of the biggest reasons (Kortes-Miller, 2018). For health care professionals, avoidance and fear of diminishing hope for families is another reason (Sallnow et al., 2022; Volandes, 2015). Furthermore, amongst health care providers, there is a lack of understanding of how to engage in these conversations. In fact, many nurses report inadequate preparation and confidence to engage in discussions about palliation and end of life (Brazil et al.,

2012; Ersek et al., 2000; Moir et al., 2015; Powazki et al., 2013). Sallnow et al. (2022) also suggests that the culture of fixing those with illness at any cost is still prevalent in modern hospital settings. There is a need to see discussions about death as necessary and to ensure that health care professionals see engaging in conversations as a responsibility.

Do we avoid death? Maybe, but Kellehear (2007) suggests that death is addressed, rather than avoided, through individual planning and preparation in an effort to maintain continuity, transfer status or power to survivors, create hope, provide support and offer consolation to those who remain. While these behaviours have deep historical roots, this is seen today through estate planning, creation of trusts, and pre-purchased cemetery plots. Indeed, many people feel the need to get their “affairs in order”. These “affairs”, however, are more about what happens after we die rather than facing death itself or how we want to die. In some ways, preparations and planning are a good first step towards addressing death and dying, but there is still avoidance of the topic until the later stages of life. One thing is certain, death remains an uncomfortable topic.

### **Death Denial**

Our aversion to death stems from our unconscious belief that our own death is inconceivable (Kübler-Ross, 1969). The fear of death is, in many ways, a survival mechanism (Becker, 1973; Kübler-Ross, 1969). Humans simply do not want their life to end and wish to remain forever. There are numerous examples within narrative literature that speak to the human search for immortality – the fountain of youth, the resurrection of the dead, and epic legacy projects (Sallnow et al., 2022). Gawande (2014) suggests that the search for medical mortality is a failing experiment. While Kellehear (1984) does not believe, from a sociological perspective, we deny death completely, he does propose that it is human nature to establish order and control around it. It is the human awareness of death that creates a series of anticipatory responses that

can be either negative or positive in nature (Kellehear, 2007). The positive or acceptable responses include learning about, preparing for, and planning for death, while the negative or defensive responses include the need to predict, protect and defend against death, and ascertain risk factors for a possible death. The various responses to and our overall discomfort with death have been debated throughout history (Corr, 2014; Kellehear, 1984; Zimmermann & Rodin, 2004). Some literature speaks of, at the very least, an acceptance of death, albeit through a begrudging awareness brought forth through media, poetry, and the funeral business (Corr, 2014). Death denial is often described by the individual and collective ways in which we involve (or do not involve) death in our lives, mainly through avoidance of discussing the topic (Kortes-Miller, 2018; Kübler-Ross, 1969; Tucker, 2009; Volandes, 2015; Zimmermann & Rodin, 2004), the medicalization of death (Rosenberg et al., 2016; Zimmermann & Rodin, 2004), and the societal and behavioural practices we engage in (Kellehear, 1984; Zimmermann & Rodin, 2004).

### **Avoiding Conversations**

Talking about death remains taboo and difficult for many (Abbey et al., 2020; Kellehear & O'Connor, 2008; Kortes-Miller, 2018; Lakasing, 2014; Mannix, 2018; Nyatanga, 2018b; Remedios, 2020). Even amongst health care staff, death is an often-avoided topic (Litzelman et al., 2016; Österlind et al., 2011; Salisbury, 2019; Towsley et al., 2015; Tucker, 2009; Volandes, 2015; Zimmermann & Rodin, 2004). Practitioners will find other activities to occupy their time, rather than address this topic with patients and families (Litzelman et al., 2016; Österlind et al., 2011). For health care providers, barriers to talking about death include time constraints (Alftberg et al., 2018; de Vleminck et al., 2014; Fulmer et al., 2018; Sharp et al., 2018), lack of communication skills or training (Aslakson et al., 2012; Fulmer et al., 2018; Moir et al., 2015), and fear of failing the patient (Tucker, 2009). In the classroom, educators avoid talking about



death, because they fear students might ask complicated questions that they cannot answer (Stylianou & Zembylas, 2021). Teachers see the topic of death as a societal taboo, which then transfers into the education system where there are no formal procedures in dealing with death nor any training for educators (Rodríguez Herrero et al., 2020). And yet, for children, having honest and open conversations about death helps them cope better with death as a child, but it also helps them cope better with the death of the loved one as adults (Martinčeková et al., 2020). In fact, adult participants in this recent study wished they had more information about death and greater understanding of both how to grieve and that it was acceptable to do so.

### **Medicalization of Death**

Before the modern era and the advent of hospitals, people died where they lived. Death was a social event; acknowledged, inevitable, and observed by community members. The rise of industrialization and urban development shifted dying from those smaller communities into cities, where death was ‘managed’ by professionals (Field, 1994; Kellehear, 2007; Rosenberg et al., 2016). This change was part of a social shift in values of the middle class, which had previously been seen only amongst nobility (Kellehear, 2007). To ward off death, those with money could turn to professionals to have more done to prevent illness, suffering, and even death. Currently, dying at home is an uncommon practice, with over 60% of death occurring in hospital settings (Statistics Canada, 2021). Within these medicalized settings, health care professionals use technological advancements to prolong life and ward off death (Hetzler III & Dugdale, 2018; Illich, 1976; Kellehear, 2020; Kortés-Miller, 2018; Kübler-Ross, 1969; Smeenk et al., 2017; Tucker, 2009; Zimmermann & Rodin, 2004) often seeing death as a failure. By medicalizing death, we have failed at relational care, misused our resources, and increased suffering for those at end of life (Sallnow et al., 2022).

### **Social and Behavioural Practices**

There are various ways that we avoid or deny death in our actions. Euphemisms are a good example of this. The language that is used to discuss death and dying is often ambiguous and confusing (Corr, 2014; Kortess-Miller, 2018; Nyatanga, 2010; Robert & Tradii, 2019; Rodenbach et al., 2016; Sutherland, 2019; Wass, 2004) and typically stems from our temperament to soften messaging. This can be seen in phrases referring to the deceased as having 'gone to a better place' or 'sleeping'. This type of language can cause children, who still think in concrete ways, to misunderstand and misinterpret these statements in literal ways (Schonfeld, 1993).

Another practice that speaks to our avoidance of death, is the separation of the dying from the rest of the community. This can be seen by moving those near death into a more private space and away from informal caregivers, such as to a hospital setting (Corr, 2014; Kortess-Miller, 2018; Nyatanga, 2010; Talwar, 2011; Tucker, 2009; Zimmermann & Rodin, 2004). Indeed, death and dying are hidden away and treated like a temporary problem (Kellehear, 2020). Sallnow et al. (2022) suggest that individuals no longer have opportunities to see the dying or even a dead body with the dependence placed on health care systems. They further suggest that "death is not so much denied but invisible" (Sallnow et al., 2022, p. 9)

Regardless of the language and definitions used to describe attitudes towards death, our relationship with death and dying continues to be complicated and would benefit from a transformation. Indeed, an unbalanced relationship has transpired across the world, in a multitude of settings and cultures (Sallnow et al., 2022). Using a PHAPC has the potential to create a welcomed change.

### **A Public Health Approach to Palliative Care**

First suggested by Kellehear (1999b), the junction between the public health and palliative care was first labelled “health-promoting palliative care” (p. 76). Borrowing from a public health approach, PHAPC utilizes the concepts of early intervention, harm reduction, and prevention on issues related to death, dying, bereavement, and caregiving (Public Health Palliative Care International, n.d.). Kellehear (2013) emphasizes those living with life-limiting illness and their caregivers face their own unique quality of life issues: depression, anxiety, isolation, spiritual distress, financial stress, and others. Furthermore, these concerns are frequently under addressed and would benefit from those public health approaches. A PHAPC is advanced through education, community engagement and development, and collaboration and partnerships with key stakeholders.

#### **Education**

Public health education, at a societal level, is a key component of a PHAPC (Bollig et al., 2019; Kellehear, 1999b, 2015b, 2016; Mills & Mills, 2016; Public Health Palliative Care International, n.d.; Sirianni, 2020; Tompkins, 2018). As a formal process, Kellehear (2015b) suggests death education is of great importance to public health because it can normalize loss, promote understanding, reduce fear, ignorance, and stigma, and further research. As part of public health education, sharing experiences about death and dying, can assist with changing societal attitudes towards death, dying, and bereavement. These outcomes can lead to better-informed palliative care policies and practice and more open discussions about death and dying. The general public will benefit greatly from increased end of life literacy, made possible through public health education in a variety of formats (Patterson & Hazelwood, 2022).

## **Community Engagement and Development**

Traditional palliative care delivery does not focus on community development (Kellehear, 2013). While public health approaches to palliative care vary in practice, it is important to note that formal and informal partnerships are necessary (Rosenberg et al., 2016). This means engaging community social supports for those living with life-limiting illness and their caregivers (Kellehear, 1999b, 2016; Kellehear & Sallnow, 2012; Sirianni, 2020; Tompkins, 2018). Engagement in end-of-life care exists along a spectrum of community involvement, from passive information sharing provided by local organizations to more active empowerment, where communities assume full control and development of all care activities (Sallnow & Paul, 2015). Community development becomes a process of shared learning and assessment, in which communities actively contribute to identifying and addressing end-of-life care needs (Kellehear, 2015a). Public health approaches need to build this community capacity for end-of-life needs, including finding ways to enhance having difficult discussions, providing support and physical care, and changing the cultural norms surrounding needing help (Grindrod & Rumbold, 2018).

## **Collaboration and Partnerships**

A PHAPC assumes that the public shares the responsibility for their individual health care, which includes palliative care (Abel, 2018; Kellehear, 2015a, 2016; Nyatanga, 2018a; Pallium Canada, 2020a; Tompkins, 2018). Specialized clinical services are an essential and necessary part of the care required for those nearing the end of life, but are not enough (Abel et al., 2018; Grindrod & Rumbold, 2018; Kellehear, 1999b, 2015a, 2016; Rosenberg et al., 2016; Tompkins, 2018). Formal care is important, but informal caregivers have the required knowledge needed to “share the journey” (p. 1) with someone who is dying (Rosenberg et al., 2016). Collaboration between formal and informal caregivers is necessary. There is a larger need for palliative care

specialists, generalists, social systems, and communities to work together to enhance palliative care delivery (Abel et al., 2018, 2022; Kellehear, 1999b, 2016; Rosenberg et al., 2016; Sirianni, 2020; Tompkins, 2018). Partnering with a variety of community members such as schools, spiritual centres, workplaces, mass media, and businesses to provide social, spiritual, and practical supports could decrease the burden on those who provide direct palliative care services and create additional availability for them to focus on more complex clinical cases (Kellehear, 2013).

### **Compassionate Communities**

As part of a PHAPC, compassionate communities (CC) recognize that illness, death, and bereavement occur within the “orbits of its institutions and regular activities” (Kellehear, 2015a). While typically palliative care is delivered by formal health services (Grindrod & Rumbold, 2018; Kellehear, 2013), our interactions with these services, are intermittent at best (Kellehear, 2015a). Rather, it is within our social circles: with family, friends, co-workers, and others, that we spend our time living, dying, caregiving, and grieving. CC aim to create broad, robust systems of supports to assist these smaller inner circles of caregivers and patients (Abel, 2018). These communities try to bridge the gap between the reality and the practice of death, dying, and bereavement while attempting to positively alter the ways in which care is considered, especially from a social needs perspective (Conway, 2012). Those with life-limiting illness and their caregivers experience social marginalisation and alienation (Kellehear, 2016; Nyatanga, 2018a). The care of those approaching end of life is not exclusively the role of medical professionals (Kellehear, 2015a, 2020), since death a social issue (Abel & Kellehear, 2016; Kortes-Miller, 2018). CC aim to use health promotion, education, and community development as an upstream approach to palliative care, rather than clinical, bedside, end-of-life care (Kellehear, 2013). This

idea of moving death and dying away from highly medicalized institutions and placing it back into the community, allows for our social circles to acknowledge what was previously hidden away, ensuring that death and dying are a topic at the forefront. Open discussion and experience-sharing on topics related to death and dying provide for better understanding, increased knowledge, and changed attitudes which then lead to greater supports and less isolation for those approaching end-of-life and their caregivers (Kellehear, 2013).

### *The Compassionate City Charter*

The compassionate city charter provides specific direction for local government and community leaders to enhance end-of-life needs through social change (Kellehear, 2015a). The charter outlines how civic institutions: schools, workplaces, trade unions, place of worship, hospices and nursing homes, museums and art galleries, media, homeless institutions, and prisons can contribute to supporting, facilitating, and commemorating care for others during life-limiting illness, frailty, disability, dementia, grieving, and bereavement. There are a variety of ways in which this can be done: policy changes, guidance documents, development of programs, exhibitions, memorial parades, awareness campaigns, and transparent goals and objectives that are continually audited and updated. Furthermore, the charter serves as a tool to assist communities in providing education, promoting social advancements related to death, dying, and loss, activating social groups to participate in promoting well-being at end of life, forming partnerships for end-of-life care, and stimulating change. Each community will consider how to best use the charter to organize applicable and impactful actions that will support citizens to participate in end-of-life care (Abel, 2018). The charter proposes clear strategies to move death and dying away from being a medical experience and to enable people to think about death and grieving in different ways (Kellehear, 2015a).

Currently, Pallium Canada advocates for the CC model to be implemented in communities across Canada (Tompkins, 2018). Pallium Canada is a national, non-profit organization whose mandate is to improve palliative care throughout the country through engaging communities and improving health care practice (Pallium Canada, 2020a). There are 20 communities across Canada that have implemented this approach, but none exist within Manitoba (Tompkins, 2018).

### **Death Education**

Public education is a key component of a CC and a PHAPC (Kellehear, 1999b, 2015b; Mills & Mills, 2016; Public Health Palliative Care International, n.d.; Sirianni, 2020; Tompkins, 2018). This includes death education in schools (Hartley, 2012; Martins Pereira et al., 2018; Rumbold, 2012), formal palliative care education for health care workers (Downing et al., 2012; Tompkins, 2018), and public awareness efforts (Conway, 2012; Kellehear, 2015b).

Interest in death education inclusion in the school system has waned over the years. Most of the available research on the topic is decades old, as death education was popular in the late 1970's and early 1980's (Durlak & Riesenber, 1991; Smilie, 2021). At that time, death education was found in a variety of locations, with a wide reach: children in preschool to high school settings, in colleges, for health care professionals, for adults with general interest, and for those who provide counselling and therapy (Wass, 1980). Although initially, there was much excitement and interest in including death education in both elementary and high schools, the integration of this controversial subject became diffused within the curriculum, where the responsibility of teaching it could be avoided (Smilie, 2021). And with time, formal death education brought controversy, expanded to include other forms of loss, and struggled to find its place within the school curriculum (Stevenson, 2004). Furthermore, those involved with death

education have retired or moved on and the language has been broadened and, perhaps, softened to focus on loss, grief, and crisis, rather than death. The world has changed significantly over the last 40 years, but one thing has remained constant: death is still inevitable. Currently, death education is not offered to most Canadian students (Tompkins, 2018). In fact, death is considered an “educational taboo” (Galende, 2015).

### **Goals of Death Education**

The goal of death education is to normalize death and loss as part of life (Hymovitz, 1979; Kellehear, 2015b, 2020; Kennedy et al., 2020; Talwar, 2011), reduce fear and anxiety (Kellehear, 2015b; Kellehear & O’Connor, 2008; Kurlychek, 1977; Talwar, 2011), decrease ignorance (Kellehear, 1999a, 2015b; Penny, 2018), equip learners with coping skills to better handle future encounters with death and loss (Kurlychek, 1977; Lee et al., 2014; Noonan et al., 2016; Talwar, 2011), and demystify the frequently suppressed concept by providing knowledge about the subject (Doka, 2015; Stylianou & Zembylas, 2018; Testoni, Ronconi, et al., 2020). There are negative consequences to not acknowledging life-limiting illness, death and dying, caregiving, and grieving as universal; mainly disenfranchisement, isolation, and poorer health outcomes (Kellehear, 2020; Kennedy et al., 2020).

### **Outcomes of Death Education**

There are several positive outcomes from death education, including addressing death anxiety, developing empathy, and feeling comfortable interacting with those near death or grieving death (Wass, 2004). Participation in formal death education has been found to reduce death anxiety (Moore, 1989; Testoni et al., 2019; Testoni, Palazzo, et al., 2020; Testoni, Ronconi, et al., 2020; Wallace et al., 2019), enhance spirituality (Testoni, Ronconi, et al., 2020), increase understanding of concepts surrounding death (Edgar & Howard-Hamilton, 1994;



Schonfeld & Kappelman, 1990), improve empathy (Testoni, Palazzo, et al., 2020) and positively influence death attitudes (Durlak & Riesenber, 1991; Testoni et al., 2019; Tieman et al., 2018; Wallace et al., 2019; Wong, 2009). Furthermore, death education can provide a safe and supportive place to reflect on the themes of death, loss, and grief (Bollig et al., 2019; Hetzel et al., 1991; Testoni et al., 2019; Testoni, Palazzo, et al., 2020; Testoni, Ronconi, et al., 2020; Tieman et al., 2018). Caring for each other during times of crisis and loss is an underlying assumption of the CC model (Abel, 2018; Abel et al., 2018; Abel & Kellehear, 2016; Kellehear, 2013, 2015a; Nyatanga, 2018a; Tompkins, 2018) and these topics can be introduced and reinforced through death education.

### **Talking About Death with Children**

Children are interested in and comfortable with talking about death, but do not necessarily have accurate facts (Canine & Dates, 1993). Understanding death requires an awareness of the following: death is universal, inevitable, irreversible, and is caused by the end of organ function (Gutiérrez et al., 2020; Harris, 2011; Slaughter, 2005; Speece & Sandor, 1992). Furthermore, the understanding of death also includes the knowledge of one's own mortality and the unpredictability of dying (Slaughter, 2005). This argument suggests, however, that death is biological only (Menendez et al., 2020). Younger children seem to grasp the concept of biological death between the ages of 6 - 10 (Kortes-Miller, 2018; Mahon, 2011; Menendez et al., 2020; Slaughter, 2005; Speece & Sandor, 1992), but as they age, a cultural, religious, or spiritual understanding of death begins to emerge (Gutiérrez et al., 2020; Harris, 2011; Menendez et al., 2020). And while younger children may not fully understand the concept of death, they can still be impacted by it, feeling sadness, grief, and loss (Kortes-Miller, 2018).

Children encounter death, either personally through the death of a family member or via the media (Galende, 2015; Kortés-Miller, 2018; Talwar, 2011). In fact, death is readily available through popular cinema programming targeted towards children (Cox et al., 2004; Graham et al., 2018; Tenzek & Nickels, 2019). Death education needs to be embedded into the curriculum as a counterbalance to the glorification of death in media (Wass, 2004). Since exposure to death cannot be avoided, it is also appropriate for children to have the ability to discuss their feelings, ask questions, and be prepared for future encounters that will ultimately arise. Hymovitz (1979) suggests that schools have a “moral responsibility” to address death and dying in age-appropriate, learner-appropriate ways. While younger children can be able to talk about death, their developmental readiness and biological understanding needs to be assessed in order for discussions to be successful (Slaughter, 2005). For adolescents, while they have begun to think more abstractly, there is still much variability in understanding, when it comes to the concepts of grief, loss, and death (Hetzl et al., 1991). Furthermore, adolescence is a period for acquiring life skills, which includes dealing with loss.

A recent study corroborates that when faced with communicating the impending death of a loved one from COVID-19, there have been obstacles to sharing information with children, mainly withholding information in order to protect them or misunderstanding the seriousness of the situation (Rapa et al., 2021). These children were left unprepared. Furthermore, when faced with preparing adolescents for death of a significant adult, families reported that internet resources were often targeted towards younger children, and they struggled to find the right words to do so, often relying on euphemisms. These individuals wished they had help from health care professionals to deliver such a message. Clearly there is a need for tools to assist children with death and dying.

### **Barriers to Classroom Inclusion**

Death education is typically seen as an uncomfortable topic (Friesen et al., 2020; Glass, 1990; Kellehear, 2015b; Kurlychek, 1977; Talwar, 2011; Thompson et al., 1985). It is often left out of the classroom due to teacher inexperience or lack of confidence (Engarhos et al., 2013; Stylianou & Zembylas, 2021), lack of adequate time to insert into the curriculum (Talwar, 2011), and a lack of preparedness or knowledge to address these themes in the classroom (Case et al., 2020; Engarhos et al., 2013; Kellehear & O'Connor, 2008; Smilie, 2021; Stylianou & Zembylas, 2018; Talwar, 2011). Death education, which shares characteristics with sexual education in that it is an uncomfortable topic, must be inserted covertly into the school curriculum (Smilie, 2021). There is also the issue of parental consent. Like sex-ed, death education is something that seems to require permission (Friesen et al., 2020). There may also be concerns around children's religious and cultural beliefs (Stylianou & Zembylas, 2018; Talwar, 2011) or the belief that children are too young to understand (Mahon, 2011).

### **A Brief History of Sexual Education**

Several topics have been considered taboo in our recent history, one of which is sexual health. There was a time when conversations about sexual activity were not being had and sexual health promotion was not taught to children and adolescents at home or at school. By providing a brief history about the trajectory of sexual health education, parallels can be drawn to death education.

A shift occurred in the beginning of the twentieth century, generated by demographic, cultural, and economic changes connected to big city immigration (Tupper, 2014). These changes resulted in increased anxiety surrounding prostitution, promiscuity, and venereal disease. Sexually transmitted infections (STIs), known then as venereal diseases, became

especially problematic for Canada during World War I (Carstairs et al., 2018). At this time, volunteer organizations interested in public health and the elimination of these diseases commenced operations, although their educational messaging was based on the moral standards of the time and promoted abstinence before marriage, often shaming women for violations of these values (Carstairs et al., 2018). Meanwhile, young women, were discarding the traditional feminine expectations that had been placed on them and were engaging in what were typically seen as male vices (Tupper, 2014).

Although there were early signs of interest in, at the very least, talking about sexual health, there were still no formal sex education programs in Canada until the 1960's (Marsman & Herold, 1986). As knowledge about STIs, their transmission, and their treatment emerged, advances in sexual education curriculums continued to develop (Tupper, 2014). Further changes in attitudes towards sexual activity allowed for the resurgence of school sexual education programs (Tupper, 2014). By the 1970's sex education was offered in many Canadian school settings, although they may have been insufficient in their content, with early goals focussing on sexuality through a negative lens which included suppressing sexual thoughts and habits and highlighting the negative outcomes that arise from sexual activity, such as unwanted pregnancy and disease (Herold, 1984). This may be attributed to the longstanding fear amongst adults that learning about the positive aspects of sexual health could encourage and promote a youth's curiosity to engage in sexual activities (Tupper, 2014). This fear, of course, was not substantiated as comprehensive sexual education is not associated with increased risk of sexual activity (Kohler et al., 2008). While the message was, and in some places still is, that individuals abstain from sexual activity until marriage, the reality is a large majority of people are engaging in pre-marital sex (Finer, 2007).

With any activity comes risks and consequences thus education about reducing the risks of sexual activity, mainly prevention of unwanted pregnancies and STIs, became necessary. Comprehensive sexual education is associated with increased use of contraceptives amongst males (Jaramillo et al., 2017) and during first intercourse (Cheedalla et al., 2020; Coyle et al., 2021). In school settings, sexual health education increases both knowledge and positive attitudes towards sexuality (Sommart & Sota, 2013). While this topic is still sensitive to many, the fact remains that sexual health education programs are being created and adapted worldwide to supply youth with knowledge and resources to shape their sexual health behaviours and attitudes. At the very least, this conversation is happening and being normalized in a school setting.

Currently, the World Health Organization asserts that the provision of sexual and reproductive education is essential everywhere (World Health Organization, 2021). Today, sexual health education uses unbiased language to equip individuals and broader groups with information to aid in the creation of competencies that improve sexual health, promote positive outcomes, and avoid negative outcomes (Public Health Agency of Canada, 2008). Additionally, this education considers individual diversity, including age, orientation, and religion. Furthermore, within Canada, comprehensive sexual health education should be accessible to everyone. While it might not be perfect, the topic itself is no longer the taboo it once was. The conversation has started and continues to develop and be adapted in school communities worldwide.

### **Current Status of Death Education**

Unlike its counterpart, sexual health education, death education is not typically included in the school curriculums of developed countries (Friesen et al., 2020; Kennedy et al., 2017;

Martins Pereira et al., 2018; Smilie, 2021). In Manitoba, death education is not formally included in public schools. Certainly, the topic of death surfaces naturally when talking about current or historical events, but it does not seem to be overtly embedded into the curriculum in ways to normalize death as part of the life span.

While there is some evidence of death education research taking place with students worldwide, as part of a public health approach, these are few in number or decades old (Bailis & Kennedy, 1977; Moore, 1989; Mueller, 1976; Schonfeld & Kappelman, 1990). There is an interest and willingness from teachers to discuss death as part of their teaching practice (Galende, 2015; Kennedy et al., 2020; Rodríguez Herrero et al., 2020; Stylianou & Zembylas, 2021), yet this has not yet translated into any form of proactive learning in the classroom. To ensure that teachers are equipped with the strategies and tools to facilitate this process, they need strong support from their administration and the broader system. There are no studies found that consider the opinions of school administrators. This gap suggests that prior to the potential inclusion of death education in the curriculum, the perspectives of those individuals who manage schools need to be explored.

### **Summary**

Having conversations about death and dying is vitally important to humankind. The earlier these conversations happen, the better the outcomes can be for both the dying, those who care for those with life-limiting illness, and the bereaved. This is no easy task as we continue to be uncomfortable acknowledging and talking about death. This can be compared to the integration of sexual health education in the school system. A once taboo topic is now commonplace and addressed with youth, albeit not always perfectly. Because of this, it is essential that, using a PHAPC, we find opportunities to normalize death and have these

conversations. One such way of doing this is through death education in the school system.

There is little current information about death education inclusion in schools and no information about the perspectives of administrators in integrating this. This thesis attempts to address this gap.

### **Chapter 3 – Methods**

This chapter addresses the methods that were utilized to conduct this research. This includes discussion of a) methodology, b) setting, c) sample characteristics, d) sampling procedures and recruitment, e) data collection methods, and f) data analysis. Methodological rigor and ethical considerations are also discussed.

#### **Methodology**

To describe the current landscape surrounding death education in public schools and explore education administrators' perspectives of introducing and integrating this into the standard curriculum, a qualitative study design was used. Morse and Field (1995) recommend that researchers select a methodology based on the description of the problem and what is known about the topic. Qualitative methodologies are holistic, flexible, and collect data in naturalistic settings (Polit & Beck, 2017). Qualitative designs are especially useful when describing a phenomenon in which little is known and researchers will use the data to describe what is occurring, to find patterns, and will consider relationships between the concepts (Morse & Field, 1995). As discussed in chapter 2, there is a paucity of knowledge about death education in public schools. Because of this, and the fact that the study aimed to uncover administrator perspectives about integrating death education into the standard curriculum, a qualitative approach is appropriate.

Specifically, this study used an exploratory, descriptive design. Descriptive designs are used when the goal is to discover the “who, what, and where” of a phenomenon and report the details of the findings as close to the facts as possible, in an attempt to accurately represent the words of the participants (Sandelowski, 2000). Qualitative description is frequently used when researchers look to describe and summarize a phenomenon with little interpretation (Kim et al.,



2017). This is not to say that interpretation is absent, but rather researcher interpretation remains closer to the data. When there is so little known, it is useful to describe a phenomenon as factually as possible. This methodology provides a thorough summary of the topic in the everyday language of the individuals experiencing it (Sandelowski, 2010). Qualitative description is also suitable for reporting straight, simple answers that come from asking straight questions (Sandelowski, 2000).

### **Study Setting**

This study was conducted in the Province of Manitoba through the Pembina Trails School Division (PTSD). At present, Manitoba is broken into 38 separate school divisions: six within the city of Winnipeg, with the remaining divisions residing outside of the province's major urban centre (Manitoba School Boards Association, 2021). Divisions have differing opinions on in-class discussion around topical current events. For example, one division, outside the city of Winnipeg, recently requested teachers not engage in discussion around the topics of immunizations and minor consent with students (Macintosh, 2021b). In fact, the introduction of a newly drafted and controversial bill, known as the Education Modernization Act (*Bill 64: The Education Modernization Act*, 2020), suggests that "sensitive topics" will require policies on how to be handled within schools (Macintosh, 2021a). Each division has different policies and visions on how to best educate children for tomorrow.

Pembina Trails, promotes itself as innovative and a division that engages learners through creativity and technology (Pembina Trails School Division, n.d.). Furthermore, their objectives include promoting community and ensuring students care for each other, within their school communities and beyond. The PTSD resides in the city of Winnipeg and includes 36 schools comprised of 17 at the elementary (early-years) level, six at the middle-years level, six that are

mixed early/middle years, and 7 secondary (senior-years) schools (Pembina Trails School Division, 2022b). These schools are home to almost 16, 000 students, 37.4% in early years, 38.2% in middle years, and 24.4% in senior years (Pembina Trails School Division, 2022a).

### **Sample Characteristics**

To address the objectives of this study, the sample sought those individuals who have experience with the public school system and can provide rich insight into the current landscape of death education and its integration into the standard curriculum. For inclusion in this study, participants were required to be:

1. 18 years of age or older;
2. Able to speak and read English;
3. Currently employed in or recently retired from (in the last five years) an administrator role of either principal or vice principal at a public school at any level in the province of Manitoba.
4. Had been in an administrator role for at least two years
5. Had access to a computer or hand-held device in order to complete the online interview.

### **Sampling Procedures and Recruitment**

Unlike quantitative research, which aims to accurately reflect a population through a representative sample, qualitative research seeks to uncover meaning from those who have experienced a certain phenomenon using non-probability approaches (Polit & Beck, 2017). This study used purposive sampling to recruit those individuals who can provide the greatest insights into the research question (Patton, 2015; Polit & Beck, 2017); in this instance, principals and vice principals who work in the public school system.

As previously discussed in chapter 1, principals and vice principals are responsible for the daily operations of the school in which they work, implementing school board policies, and the financial administration of school funds (Council of School Leaders of the Manitoba Teachers' Society, 2019). Furthermore, they act as a liaison between school boards, teachers, staff, and communities. Principals and vice-principals also hold a valid teaching license and have typically spent time in the classroom educating students. Considering their position within the public-school structure, principals and vice-principals are well-positioned to understand the unique needs and challenges of curriculum changes from the school division, classroom, and community levels. They are also familiar with teaching methods in the classroom and what teachers might require to be best supported when engaging with new or additional material. Their perspectives were of greatest benefit to the study.

Since children as young as six are able to understand the concept of death (Kortes-Miller, 2018; Mahon, 2011; Menendez et al., 2020; Slaughter, 2005; Speece & Sandor, 1992) and this understanding continues to grow into middle and later adolescence from a cultural, religious or spiritual perspective (Gutiérrez et al., 2020; Harris, 2011; Menendez et al., 2020), death education has a place at all levels of education; in elementary, middle, and secondary schools. Therefore, understanding the perspectives of principals and vice principals at different education levels were of great importance to the study. It was important to note if death education is currently taking place, how it might be taught to children at different ages and stages within the existing curriculum, and who is teaching these concepts.

### **Sample Size**

When it comes to qualitative sample sizes, there are few fixed rules (Patton, 2015). In qualitative research, sample sizes are not typically determined in advance and are guided by data

saturation (Morse & Field, 1995; Polit & Beck, 2017; Sandelowski, 1995). Seven participants took part in this study.

### **Recruitment**

Ethics approval was obtained from the University of Manitoba Research Ethics Board (REB1) prior to starting recruitment for the study. Once this approval was received, access approval was sought from various school divisions in Manitoba. Emails seeking access to principals and vice-principals (Appendix A) within multiple divisions were sent. Access approval was sought from Winnipeg School Division (WSD1), Garden Valley, Interlake, Frontier, Hanover, Sunrise, Louis Riel, and Pembina Trails School divisions. Only Pembina Trails and Frontier school divisions provided access approval. Upon receiving approval from these school division's superintendents, email invitations to participate in this study (Appendix B) were sent to principals and vice-principals within the division by the superintendent. Multiple attempts to gain access to administrative personnel in WSD1 were unsuccessful. The remaining divisions all respectfully declined participating in the study, owing to already strained staff from two years of pandemic-related issues. Reminder emails to each individual school in both the Pembina Trails and Frontier school divisions were sent out approximately two weeks later. Only administrators from the Pembina Trails division volunteered to participate.

In addition to email invitations, recruitment posters were posted on my personal Twitter, Instagram, and Facebook accounts to reach a broader network of potential participants (Appendix C). These posters did not elicit additional participants. Email invitations and posters provided the study purpose, aim, and procedures, as well as the researcher's contact information for participation. Potential participants responded to emails by contacting the researcher, where they were screened for eligibility and briefly informed about the study. Any questions

participants asked were answered at that time. The researcher also determined how each administrator heard about the study. A recruitment tracking log was kept on a password protected secured server through the University of Manitoba (MS One Drive) and was accessible to the researcher and advisors only. Once eligibility was established, participants were assigned a unique participant identification (ID) number.

In addition to the described recruitment process, snowball sampling was used, by asking participants to suggest other potential informants who meet the inclusion criteria (Polit & Beck, 2017). Participants are the most knowledgeable about others in a similar situation and are in the best position to share with others. The researcher sent an email after each interview thanking administrators for their participation and asking them to forward the recruitment poster to anyone else they knew who might be eligible. Unfortunately, no additional administrators were recruited using this method.

### **Data Collection Methods**

Data collection methods included, semi-structured interviews, a demographic questionnaire, field notes, and researcher reflexive journaling. These methods are described in more detail below.

#### **Semi-Structured Interviews**

After obtaining consent from participants, semi-structured interviews were used to elicit participant information while allowing for a more conversational tone and providing space for participants to illustrate their perspectives and stories in their own words (Morse & Field, 1995; Polit & Beck, 2017). Interviews with participants were conducted one-on-one by the researcher. A prepared topic guide with open-ended questions (Appendix D) was used to extract data related to each of the research questions. This interview guide included prompts to encourage the

participant to provide more details to gather rich information about the inclusion of death education into the public-school curriculum (Guest et al., 2013; Polit & Beck, 2017; Saldana, 2011). This strategy is consistent with a qualitative descriptive methodology (Sandelowski, 2000).

Conducting interviews in person and having face-to-face contact allows for observations to be noted by the researcher and can help establish a comfortable rapport and establish trust (Polit & Beck, 2017). In addition, being face-to-face allows the interviewer to probe deeper and clarify answers to questions (Guest et al., 2013). Due to the Covid-19 pandemic and keeping this study aligned with public health orders, in-person interviews were not permitted during data collection. All interviews were conducted using a licensed version of Zoom, an internet-based videoconferencing technology. Participants chose the time and their preferred location of the video-call, which assisted in establishing a trusting relationship between the researcher and participant (Morse & Field, 1995). Zoom was not used to record interviews, but rather an external digital audio recorder captured the dialogue and was placed near the computer audio speaker. This was done in order to have recordings transcribed for analysis. Using a recorder allows for greater accuracy than taking hand-written notes, and the recorder was small enough to not be seen as a barrier to communication (Guest et al., 2013). By not also recording video, participants could be more natural, without worrying about their image being captured as well.

### **Field Notes**

Detailed observations were collected and written down after each interview. These observations, known as field notes, can add depth and context that are not captured by the interview alone (Morse & Field, 1995). Field notes described what was happening during the interview, including the setting, impressions of the interaction, and any non-verbal

communication. These were completed immediately following each interview which ensured details were not forgotten (Polit & Beck, 2017). Furthermore, field notes were not collected during interviews in order to not distract from the moment. These field notes were kept on a password secured network and only accessible to the research team. Field notes were referred to as necessary during the analysis phase.

### **Demographic Data**

Demographic data was collected to determine the characteristics of the sample. Participants were asked to provide information related to age, gender, education level, number of years in current role, number of years spent teaching, and any formal training or education related to death, dying, or grief. A demographic survey was sent to participants by email prior to the start of their interview (Appendix E). They were asked to complete this and return to the researcher along with their completed consent form. These completed forms were put into a spreadsheet for further analysis and saved to a password protected secured server, accessible only to the research team. The researcher also kept track of the school level that each participant was currently working in to assist with the analysis.

### **Reflective Journals**

Reflexivity in qualitative research is the practice of critical self-reflection to watch for researcher bias (Polit & Beck, 2017). It allows the researcher to make note of and analyze personal values and how those might influence data collection and analysis. By reflecting on these values and how they have the potential to bring judgement into data collection, credibility is added to the research (Jootun et al., 2009). After each interview, time was spent reflecting on each discussion and thoughts were captured in reflexive journals. Journals were written weekly during the data collection phase and as needed during the analysis phase. A total of eight

reflexive journals were completed during the study. By journaling throughout the data collection phase, greater insight was gained into the student researcher's personal thoughts on death education and its inclusion in the curriculum, which allowed for deeper understanding into the participants views. This process made the student researcher more mindful as they engaged with administrators during interviews. These journals were used throughout the data analysis as a reminder of each interview and to consider the thoughts that arose initially during the process. Journals were used to consider thoughtful questions with the intent of discussing them later with the student researcher's advisors. This led to the triangulation of data through the reflexive journals, the transcripts, and discussion with advisors, who verified these thoughts and offered alternative perspectives.

Journals were done electronically through a word processing program and saved to a password protected secure server through the University of Manitoba and only accessible to the research team. By keeping these accessible, they could be referred to during the analysis phase. It was important to think about how personal views may or may not align with those of the participants in the study.

### **Data Analysis**

Through semi-structured interviews, principals shared their experiences with death education, recounting stories in which death was discussed in the school and expressing their opinions and perceptions around integrating death education into the standard curriculum. These interviews were transcribed, verbatim, to ensure the participant's words are being captured (Polit & Beck, 2017). A transcription service was used to transcribe the audio recorded interviews. This service, called Transcript Heroes, provided a signed University of Manitoba Research



Ethics Board (REB1) approved confidentiality agreement prior to receiving the audio files through a secure upload.

Data analysis was iterative and began right after the first interview transcript was returned from the transcript service. Upon receipt, the transcripts were verified against the audio recording. This provided another opportunity to experience the interview, while being less of a participant and more of a passive listener. Doing this also ensured accuracy; that the correct words of participants were used and the nuance of spacing was captured. Sometimes, there were long pauses or breaks in the conversation and these were not always captured by the transcription service. Because talking about death and dying can be difficult and take time and emotional space, it was important these breaks were captured in the written transcripts to ensure the full tone was captured. Once I was confident that the transcripts were identical to the recordings, they were saved and used for analysis. Each interview was read through multiple times before formal analysis started.

### **Coding**

Consistent with descriptive qualitative studies, content analysis was used to analyse the data (Sandelowski, 2000). After an initial and subsequent readings of the data, transcripts were broken into smaller fragments, and codes assigned to segments of text (Polit & Beck, 2017). Qualitative coding is inductive, and data driven, generated from the data itself (Hsieh & Shannon, 2005; Sandelowski, 2000). Using the comments function in Microsoft Word, I was able to highlight especially salient quotes and make comments in the margins that then became raw codes. I read through each interview more purposefully looking for sections of text where participants provided answers to each of the research questions. Always keeping the research questions in mind, sections of text were coded throughout each interview. These raw codes and

quotes from each of the seven interviews were then transferred into a spreadsheet, using different worksheet tabs for each research question, for further manipulation. These raw codes became a starting point for data analysis. Any salient quotes attached to the raw codes were transferred to the appropriate lines in each spreadsheet. From here, the data could be sorted in different ways to look for similarities and group these like-codes together using the functions within the spreadsheet software.

Codes are used to find patterns and organize the information for additional analysis (Saldana, 2011). Codes can be clustered together and developed into categories (Polit & Beck, 2017). The raw codes were sorted and manipulated in the spread sheet to find those that were conceptually similar. The results of this process allowed for a summary of these newly formed formal codes into categories that were uncovered through this data analysis process with minimal interpretation (Sandelowski, 2000).

During this process, some codes that were attached to one research question, were moved to a different question where they had a better fit. In addition, all of the verified interviews were open during this process so the participants written words could be reviewed to ensure the coding captured what was truly being said. Journals were read and reread during this time as a reminder of the initial thoughts that arose. This iterative process of returning to the interviews and reflexive journals and moving the codes around to ensure the best fit allowed codes to be clustered in ways that helped to tell the story and answer each of the research questions. While descriptive studies aim to report findings that are closer to the data, this does not mean the data is free from interpretation (Sandelowski, 2010). Data does stand alone; it requires the researcher to interpret it in some way. By grouping data into similar categories, the research questions could be answered in a simple way.

### **Maintaining Trustworthiness**

Within qualitative research, integrity and quality are important issues (Polit & Beck, 2017). Furthermore, the concepts of validity and rigor found in quantitative research are not used to describe the integrity efforts used in qualitative research. Instead, trustworthiness is the term used to describe the reliability and validity of qualitative research. Typically, this consists of credibility, dependability, confirmability, and transferability (Guba, 1981) although authenticity has also been added (Polit & Beck, 2017).

Credibility refers to the truthfulness of the data or how believable it is (Polit & Beck, 2017). Credibility was maintained through triangulation, using two (or more) data sources, in this case through interviews, field notes, and reflective journals (Arksey & Knight, 2011). The reflective journals were maintained in order to keep records and build confidence in the data (Polit & Beck, 2017). Using the journals to prompt questions to ask the student researcher's advisors also assisted in the triangulation of the data, so these discussions could be had with them.

Dependability indicates how reliable the data is over time and is also necessary in establishing credibility (Polit & Beck, 2017). To ensure that subsequent studies could repeat the results, an audit trail was established and maintained including detailed notes and original documentation (Guba, 1981). All records related to the study, along with detailed notes have been stored on a password protected secure server through the University of Manitoba. The research team are the only individuals who have access to all this information for confidentiality purposes, but it is readily accessible should the need arise.

Confirmability represents objectivity, that two or more independent individuals, would agree on the accuracy, applicability, or meaning behind the data (Polit & Beck, 2017). This can

be achieved through triangulation and an audit trail but also through a confirmability audit (Guba, 1981). Data review sessions were completed throughout the study, including after analysis, with the student researcher and their advisors. Using Microsoft teams and conversations through the comment and track changes function in Microsoft Word, accuracy and the plausibility of the codes, categories, and summaries that came from the data were confirmed. Working closely with expert advisors, as a novice researcher, was important to ensure the data remained objective. Any changes were noted, and previous versions of the data were saved and can be easily referred to.

Transferability considers the likelihood that findings could apply to other groups or settings (Polit & Beck, 2017). Typically, this is avoided in qualitative research because researchers in the naturalist domain believe that data is always bound to the context it was gathered in, however, collecting thick descriptive data can assist with assessing if data can apply in other contexts (Guba, 1981). The data that was collected prodded deep into the perceptions of the participants and the results were information-rich, which may suggest these findings could apply to other schools with similar characteristics in other divisions.

Finally, authenticity is achieved when participant's experiences are true in tone and readers can feel their genuineness. This has been achieved by choosing and using accurate quotes from those interviewed to present in the findings section and ensuring all reported data is close to the words of participants.

### **Ethical Considerations**

A number of potential risks and benefits were contemplated by the researcher prior to engaging in the study. This risk/benefit analysis outlines the potential benefits and risks of participating in the proposed study. This type of analysis is necessary in research and aims to

ensure risks are minimal and communicated with participants (Polit & Beck, 2017). In qualitative research, risks may not be known at the beginning and risk assessments continue throughout the duration of the study. These risks and benefits are outlined to participants in the consent form (Appendix F), that each participant will need to complete prior to enrolling in the study.

### **Potential Benefits**

Identified benefits to participants included increased insight into their attitudes towards death, dying and grief and participant satisfaction from being able to provide information that can help normalize death and dying within society. Participants were also able to discuss any personal experiences about death education, which they may not have been able to do previously. The interview provided an opportunity for the participant to share perspectives on the current death education landscape and share suggestions or ideas for inclusion in the curriculum for the purpose of creating change. Furthermore, since this study uses a nursing lens to collect data from those working in education, this collaboration between educators and nurses can add to the advancement of interprofessional relationships across sectors.

### **Potential Risks**

Identified risks included the potential for physical discomfort associated with sitting in the virtual interview for a period of time, psychological discomfort related to the topic of death and dying, loss of time for participating, and monetary costs associated with participating that might include lost time from work or childcare expenses required to participate.

In order to mitigate the financial costs associated with participation, a stipend, in the form of a \$25 coffee gift card, was provided to participants. By conducting interviews via

teleconference, time for participating was reduced as each participant was able to quickly join from wherever they chose to join from.

The topics being explored in this study focus on death education, death, and dying. Conversations with participants had the potential to bring up feelings that were distressing. When this occurred in the interview, we paused and allowed the participant to take their time prior to continuing. I acknowledged their feelings and thanked them for sharing authentically with me. To further mitigate this psychological discomfort, additional resources, which included links to the Canadian Virtual Hospice and Manitoba Health crisis and non-crisis contacts, were sent at the end of the session through a via follow-up email to participants.

### **Chapter Summary**

This chapter discussed the methods that were used to conduct this research study, the methodology of the study, the sample, data collection, and data analysis. Trustworthiness, and how it was established, and ethics were also considered. The next chapter presents an overview of the research findings.

## **Chapter 4 - Findings**

In this chapter, the findings of the study are reported. The characteristics of the sample are described, followed by the qualitative findings that relate to the research questions.

The purpose of this study was to describe the current landscape of death education in the Manitoba school system and to explore school administrators' perceptions of introducing and integrating death education in the standard public-school curriculum. Specifically, the study aimed to answer the following research questions:

1. Are the topics of death, dying, grieving and caregiving currently being discussed in the classroom? If so, when?
2. How are these topics being discussed? Is there a formal curriculum to do so?
3. What training and guidance are given to teachers to address these topics?
4. What are administrators' perceptions of whether death education should be included in the curriculum?
5. What do school administrators and teachers need to feel confident in teaching these subjects?

Qualitative data was gathered in the form of virtual face-to-face interviews, using Zoom web-conferencing software from April 19 through May 13, 2022. Pembina Trails School Division, who provided access to principals, has a population of 35 principals and 26 vice-principals for a total administrative population of n=61. Seven administrators agreed to participate in interviews, for a response rate of 11%.

### **Sample Characteristics**

School administrators who participated in this study ranged in age from 49-62 years. They all held the role of school principal; no vice-principals participated in the study, although

many participants spoke of previous roles as either a vice principal prior to becoming a principal, in a different school level (i.e., elementary, middle, or high school), or in a school with a smaller student population. One of the seven participants identified as male, six were female. Five participants held administrative roles in elementary schools, and two in middle schools. No administrators in high school settings took part. The length of time that the administrators had spent in their current role ranged from 2-16 years. Four participants had a master's level degree, one had a post-graduate degree, one had a post-baccalaureate, and one had an undergraduate degree. All participants had spent more than five years in a teaching role, with the majority having been in the classroom for over 11 years. A summary of participant demographics can be found in Table 2.



**Table 2***Participant Demographic Data*

Characteristic	n	%
<b>Gender</b>		
Female	6	86%
Male	1	14%
<b>Highest Level of Education</b>		
Undergraduate Degree	1	14%
Master's Degree	4	57%
Post-Graduate Degree	1	14%
Other	1	14%
<b>Years in Current Role</b>		
0-5 years	3	43%
6-10 years	1	14%
11-15 years	2	29%
> 15 years	1	14%
<b>Years Spent in Teaching Role</b>		
6-10 years	2	29%
11-15 years	2	29%
>15 years	3	43%
<b>School Setting</b>		
Elementary School	5	71%
Middle School	2	29%

Secondary School	0	0%
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### **The Current Landscape**

This section describes, from the administrator’s perspectives and experiences, how death and grieving are addressed at school. This includes death in schools and the response from schools at the various levels. Caregiving and the process of dying as part of the lifecycle, although defined as part of death education and asked about during the interview, were not overtly addressed. In fact, dying and death were almost used in interchangeable ways to refer to end of life rather than thinking about dying as part of a life-limiting illness.

#### **Death in Schools**

Administrators shared that deaths do occur within the school community and may include the death of a student, a staff member, a classroom pet, or a family member of a student. These deaths are often viewed as traumatic: a suicide, a terminal illness, or an unexpected death. In addition, death is often part of discussions related to current events such as residential schools, COVID-19, or international warfare. Deaths occur within the school community almost annually: “...there has always been, every year, some sort of significant death in the last decade...” (P06, line 26-27) and “...it almost seems [at] every level...” (P05, line 84-85).

The administrators in this study reported that because deaths occur in schools and within the world surrounding children, the topics of death and grief are talked about in their schools, but almost always in reactive ways. Principals shared that death surfaces “not in any kind of specific, strategized way, it’s more as it comes up. It’s not really being proactive about it, it’s being reactive.” (P04, line 55-56). These discussions arise, as one principal shared, “because we teach humans, and death and dying is a part of being human...” (P01, line 20-21).

Interestingly, although death education was defined by the researcher prior to beginning each interview as death, dying, caregiving, and grief, when asked about these topics as part of the first research question, caregiving was typically not considered in the discussion. In fact, one principal overtly stated that while many of those topics arose, “not so much caregiving” (P03, line 25). Other participants did not speak to caregiving in their responses. Even dying was spoken of as a fixed moment and used interchangeably with death, rather than thinking about chronic life-limiting illness and the trajectory of aging and dying as a process. In fact, few participants spoke of aging as part of the life cycle. One administrator spoke of “trying to make the positives of growing old...weaving it [the concept of aging] so that we’re celebrating life” (P05, line 267-270) possibly through inviting older adults to share their life stories and growing older with students.

### **Response to Death in Schools**

As these topics arose in their schools, they have needed to find ways to address these topics. Participants in this study believed that kids are curious and open to sharing and they ask questions and discuss death in unscripted ways. “Inevitably, there are questions from kids like, well, how come there’s people that die at 2 [years old] ...” (P04, line 42-44). Moreover, administrators shared that younger children often share news in a matter-of-fact way: “Being in the elementary level, the kids just say it.” (P05, 140-141).

Administrators in this study overwhelmingly agreed that there is no guidance provided on how to address death and grief: no formal training, no curriculum provided, and no guidelines for schools. “There isn’t a map that tells us what to do, you know?” (P05, line 46-47). If a death occurs within the school community and is seen as traumatic, the division may provide guidance in the form of an emergency/crisis response. This was seen in one school with an accidental

drowning. Formal support was provided by school clinicians (social workers and psychologists) who provide resources, online links, communication scripts, and grief support. When emergency type support is needed, one participant felt “it’s often, it almost seems, like it’s taken away from the classroom teacher because it’s not their area of expertise.” (P04, line 28-29).

When death is not considered accidental or traumatic, there is no collective instruction for schools. In these cases, with the lack of formal crisis responses, organic and individualized responses within schools were reported by the participants. Administrators shared that schools tend to offer support for those who are grieving in the immediate moment and in the long-term through bereavement support. This can be seen in their schools through honoring the deceased, effective communication with the classroom and school communities, and resources to support students.

### ***Honouring the Deceased***

Some of the ways in which participants’ schools honour students, staff, or school community members is through tree planting, memorial displays, fundraising campaigns, and participating in post-death rituals such as funerals and fellowship. At one school:

For all the students who were this child’s classmates, at a point when the family felt that they could manage it and were OK with it, we had a planting of a tree out on our school yard, and we had some bubbles, and the kids shared on purple paper, because it was her favourite colour, purple, they shared messages of kind of what they remember about her and how much they cared for her. (P03, line 63-67)

Another principal shared that a small memorial was done in the classroom, where classmates and the parents of the deceased student could share in remembering the child who had died:

And then we had we had a little something, I wish I could remember the details more clearly. But we did have something at school for the kindergarten class. It was just a little sort of “come and go” for the parents just to come and talk. (P01, line 108-111)

Through the stories shared by the administrators in this study, there appeared to be no consistency around when schools honour those who have died. It appears these decisions are left up to the discretion of the individual school. Principals spoke of students, staff members, siblings of current students, and even a student who “was supposed to come [to school] but his illness kept him at home” (P03, line 105-106) who had all died and were honoured in some way.

According to the participants in this study, fellowship is important when the death relates to a school community member. One participant shared that gathering to grieve collectively was missing during the height of the pandemic. When things normalized slightly, the staff gathered to honour another employee who died earlier in the year. They used this opportunity “just to sit and talk and share stories and cry, and all of those things. And normalize that we – everybody’s sad.” (P06, line 306-307). Some participants shared that school staff would also attend funerals of other staff or students who had died to support families and participate in grieving the loss together. Administrators also spoke of sharing details of bereavement events with the broader community as part of this fellowship. One administrator spoke of a scenario where an “entire class attended the funeral” (P01, line 173) of a former classmate who had died.

### ***Effective School Community and Classroom Communication***

Administrators in this study believed that open, transparent communication with both students and families was an important factor when addressing death and grief. This was done in their schools through holding school assemblies, informing families of specific initiatives in response to a death, and using clear and honest language. Schools would let families know “this

[a death] has happened and it's sad, and here are the things that we've talked about. And here are the things that you can do as a parent to support your child." (P06, line 171-174). This messaging is important because "communication is key" (P06, line 170). According to administrators, schools make decisions about who to communicate with and what to communicate, ensuring that "if it becomes something that the family or the student want to process with their class community, then it becomes something that the class as a whole will undertake in a very sensitive and child developmentally appropriate way." (P03, line 174-177). These decisions on communication are made at the discretion of the principal, in collaboration with teachers and those directly impacted (i.e. family members of the deceased). One principal shared that after the death of a student, "we [the school] debated how public are we going to make this?" (P01, line 84-85). Another participant shared the amount of consideration that goes into these decisions and the importance of being:

Sensitive to the family, to the kids coming in the door, and the effect it [the death] did have – it did have an effect on some of the family members in the community who had lost children at times in their lives too (P05, line 43-45)

### ***Resources***

Administrators shared that books are often used as resources for students, especially in the younger years. One principal spoke of using literature to address difficult or sensitive themes:

We have all those books and of course stories and everything in between – and of course, death, because those are all life experiences that are part of who we are, and sometimes powerful messages can be conveyed through images in a book, or maybe a certain sentence will touch somebody's heart. (P07, line 68-72)

Another principal shared their relief at seeing appropriate books available for students: “I just remember the title thinking, oh, this is good, that we have something that helps the kids learn that this is a natural process of life.” (P03, line 212-213).

Sometimes, participants spoke of other activities that were used in the classroom such as writing cards, drawing to express grief, and sending thoughts of condolences to families. These in-class activities are grown organically through trial and error or personal interest in including such activities:

And so, you know, I have a collection of resources that I have – that have either been shared with me, or that I’ve picked up along the way in order to build my skillset on handling the topics in a sensitive way. (P03, line 219-221)

#### **Administrator Perspectives on the Inclusion of Formal Death Education**

Participants in this study had strong opinions on whether death education should be included as part of the regular curriculum. They agreed that these topics were not currently being addressed in meaningful ways: “Conversations about death and dying and grieving and bereavement and those kinds of things, I think are important, and we perhaps have not addressed them as we should.” (P04, line 62-64). Participants felt it is essential to normalize death because:

Death is part of life, so if we believe in teaching things like sex ed or talking to kids about private parts or “kids in the know” to protect themselves, I also believe that we do need to address death in class.” (P07, line 115-118)

Participants shared that there appeared to be a lack of understanding around death that could be addressed in classrooms because schools are “the one place, the one stop shop. You’ve got the kids here, their minds are open, they’re ready to talk, and if not, they’re going to listen. They will listen. And absorb from what others say.” (P05, line 480-484). Typically, as one

participant shared “I don't think there's opportunities to talk about death until they're on you, right.” (P06, line 428-429). There was a sentiment from administrators in this study that these conversations about death should start early, before there is a need to do so:

I think if we have those conversations young, about, yes, people die, and especially going – maybe starting with the older generation instead of random, whatever, it might – it can't hurt, I guess; it can't hurt when the time comes for them to experience that and they maybe have talked about, you know, in child form, the stages of grief and what they can do. (P02, line 174-179)

By allowing this topic to become part of normal teaching, one administrator felt it could benefit the children in many ways:

So it's building that resilience. And I think being able to talk about it... and being able to – You know, but I believe in talking about anything that's taboo to talk about, because those are the things that typically are the most important to talk about. Giving opportunities for people to have those discussions around death when they're not in it is important. (P06, line 443-448)

Administrators felt that gaining knowledge about death and grief could bring a greater understanding and help children to act when the time comes, thinking about ways to assist children “how do we share it in a universal way that helps your child understand that bad things happen? And understand that they can do stuff; they can be empowered when bad things happen.” (P06, line 161-163).

This interest in including death education in the curriculum was influenced by participant's personal attitudes towards death and dying, their beliefs about children, and their perceptions of the schools in which they work.



## Personal Attitudes

Administrators personal attitudes around death and dying were evident throughout the interviews. They often spoke of death being seen as taboo, misunderstood, or something to be feared. One participant shared:

I can tell you, from my own personal experience and experience at school in general, we don't understand a lot about death. And because of that, there's a lot of fear because it's so unknown. It's like anything – if you don't know about it, it can cause fear. (P04, line 279-282)

Furthermore, another participant felt it was important to talk about death so it did not become forbidden: “Don't make it taboo, so that when something happens it's not taboo” (P06, line 404-405).

Another shared that this normalization was necessary within our society at large, not just with school-aged children:

I just think a general acceptance of the idea of death and it not being this thing we don't talk about would be helpful, too, but that's more of a societal kind of thing, and how do you move in that direction? (P04, line 251-253)

Additionally, this principal agrees that normalization is necessary, especially for supporting those who are dealing with loss:

I think you then empower everybody around that person to be able to respond in ways that don't cause the person to feel alienated or alone or reinforce some of the thoughts that they're having in a negative way.

So yes, I'm all for normalising this conversation and giving people the tools that they need, and becoming more well-rounded in terms of this just being part of the cycle of life, and you know, why wouldn't we talk about it? (P03, line 423-428).

### **Beliefs About Children**

Participants in this study felt that normalizing death is especially important for children, as it would "...help get our kids better equipped for those kinds of things, because it's going to happen." (P04, line 284-285). Many felt that providing students opportunities to explore death in a safe, comfortable, and familiar environment before it's absolutely necessary is important and that "They [students] just need a safe space, where they can express whatever it is that they are feeling, and just feel heard." (P01, line 207-208)

There was a strong feeling amongst participants that children are open-minded, insightful, and have the capacity for complex subjects. Even with younger children, one principal thought "... early years should be the place where we explore and discuss everything is on the table, because they're so open-minded." (P02, line 183-184). With elementary years, "you're teaching young people, young minds that are developing, so you want them to see and be critical thinkers." (P04, line 152-153).

### **Nature of School Communities**

Administrators in this study saw their school communities as both an asset and a strength for including more difficult topics, like death and dying. They compared their schools to "...a second home for families." (P07, line 48-49) and a place where "...students feel safest in expressing a lot of those emotions. (P02, line 161-163). By being a close community, one participant felt that death is difficult for any community, "but it does have the potential of

bringing the community close together, and I would say we're a very tight school community, just within the school walls and outside the schools walls." (P03, line 394-398)

Overall, the administrators who participated in this study agreed that including death education into the curriculum, with the intent of normalizing death, dying, and grief, was important. These perspectives were shaped by their own attitudes towards death, their beliefs about children, and their own school communities. How administrators' felt these topics could be integrated into their schools is discussed in the follow section.

### **Integrating Death Education**

Administrators identified potential barriers and supportive measures to including death education into their schools. Administrators also shared their thoughts and opinions on how including formal death education in the curriculum could be accomplished, including specific strategies for introducing conversations about death and dying. When participants were asked about the curriculum itself (who, what, when, why, and how of formal death education), they felt that there would be a need to weave the concepts throughout the school years, possibly in the subject area of health, ensuring age-appropriate content, but starting early. Death, they shared, is not a single teachable concept. One administrator shared that "death is not something that's like a one and done." (P06, line 247-248). They also felt it would not be a stand-alone topic and should be "integrated throughout a year, because then the learning is, I think a little more long term and sticks, whereas if it's just one week, it maybe doesn't stick as much." (P04, line 138-140). This participant also felt it would be effective to:

Infuse it within your lessons, not make it its own thing necessarily, but infuse it all the way along, because what we know about effective learning, is that integrated projects,

hands-on, multi-sensory learning fits our learners better than one format only. (P04, line 109-112)

They also felt this content would need to be adapted to the age and stage of the learner with younger students because "...you're not going to use the same language that you would with grade 7, 8, 9, or 10, 11, 12 kind of kids." (P04, line 100-102). This participant also suggested that it would require thought to ensure that formal programming would fit anywhere and be embedded and "not as a standalone, but maybe as a continuous theme throughout the year" (P04, line 105-107).

Administrators in this study believed any trusted individual could teach these topics, with expert supports in place, but felt teachers would be best suited to do so. "For sure the classroom teacher is a great person as a focal point because the child should feel connected to his or her teacher as a moral compass." (P07, line 185-186)

### **Potential Barriers to Including Death Education**

Administrators in this study identified several perceived potential barriers to including death and dying in the curriculum. Identified barriers were parents, the system, and the teachers themselves. Participants also addressed culture and religion, which could be seen, to some, as a barrier and discussed the ways in which they would mitigate that potential.

#### ***Parents***

Participants spoke of parents being a perceived barrier, as they may see their kids as being too young and "shouldn't be caring about that [death]." (P04, line 181-182).

Administrators felt that parents may want to protect their children or have their own discomfort with the topic. Furthermore, principals in the study believed that while only a small minority may object to including such a topic in the classroom, parents can be "very vocal when they

don't like something.” (P02, line 92-93) which could lead to a few objectors speaking loudly for many.

### ***Systematic Barriers***

Administrators believed that there would also be system barriers such as time constraints on teachers and the already content-heavy curriculum: “Well, one of the barriers that teachers are going to feel instantly is what, we have to do more? What are you going to take off? If you're adding this, what are you taking away?” (P01, line 272-274). Another participant shared that teachers and schools “feel overwhelmed, and we keep on, we sometimes feel like a dumping ground for a whole bunch of initiatives” (P07, line 333-334). One administrator shared that when new content gets added into a teacher's load, “the teacher's got to work it in with the curriculum. Like all of that stuff gets – it's tricky” (P06, line 246-247) because it can take away from school time and other content.

### ***Teachers***

Administrators in this study saw other potential barriers to including death education related to the teachers themselves. They suggested that teachers in their schools may have their own personal discomfort with the topic or have had past personal experience with loss and grief that close them to the idea of including death and dying into the curriculum. Participants suggested teachers may have “their own comfort level with the topic.” (P05, line 295-296) which might cause them to disengage with the subject. Because of the system barriers of an already full plate, participants suggested that teachers may be overwhelmed to add on a seemingly difficult subject to their teaching load. One administrator shared that with any change to teaching, “you're going to have a range of teacher acceptance...you would have teachers that might not be open to that” (P04, line 217-219).

### ***Culture and Religion***

While many administrators shared that culture/religion can be a sensitive topic itself that would inevitably be broached in teaching themes when integrating conversations about death into the classroom, none of the participants in this study saw this as a barrier that could not be overcome. Rather, they felt that diversity could be addressed and celebrated, “honouring how they’ve been raised.” (P04, line 279). One administrator felt that differences would need to be tackled head-on:

We’re so diverse, there are so many different countries represented at this school, so I think you’d want to look at death and dying from different cultural viewpoints, stay within that diversity. You can’t look at it just from a single perspective; I think it would be important to look at it from many perspectives. (P04, line 147-151)

By doing this and addressing diversity in this way, children can “...share a common understanding.” (P07, line 170).

### **Supportive Measures to Including Death Education**

Administrators in this study also suggested several perceived factors that would facilitate the inclusion and integration of death and dying into the classroom. They felt that administrative support, community and parent support, strong standardized content, a team approach, time and practice, and training and development were the essential components needed to include death and dying into the classroom curriculum and help instill a greater sense of confidence in staff to teach these topics.

### ***Administrative Support***

Many administrators believed that administrative support at the school, divisional, and government levels would assist with including the topics in a more formal way through standard,

supportive training to allow teachers to become more comfortable with topics. To make it easier, one participant felt that “having a supportive division and having them support the training” (P04, line 240-241) would help. Another administrator suggested that having formal death education “in a provincial document that was mandated” (P05, line 298) would help with ensuring content was included.

### ***Transparent Communication with Families***

According to participants in this study, another supportive measure would be communicating in an open and informed way with school families. Administrators felt it was essential to be “really up front with parents” (P06, line 286) and that “keeping those lines of communication open is really important when you are working through some of the sensitive topics.” (P03, line 302-303). Administrators agreed that being transparent about what is being taught “opens that communication for parents and their children.” (P01, line 305) and that schools would be “opening the door...to talk about how your own beliefs and values fit with this topic.” (P01, line 302-303).

Participants believed that their schools would need to ensure good communication around why these topics are important and that, overall, the community would likely be receptive to these new ideas. However, even with these open communication channels, there would still be a need for parents to decide what is best for their children by allowing families to opt out of participation: “And we still would have families that might opt out. I think we – I think in the beginning, until it becomes more normalized, that’s an option that would work.” (P05, line 337-339).

### *Standardized Content*

Administrators suggested that the content related to death and dying would facilitate inclusion. They perceived that the content should be kept simple, age-appropriate, and require little assessment by teachers to increase support for uptake in the classroom. One principal shared: “I think simple content. Just simple. No assessment. It just needs to be taught. With limited outcomes, this is the objective. This is the why that we want from it.” (P05, line 470-472). And of course administrators want to ensure that content is age-appropriate, with one participant sharing “We would want it to be kid-friendly.” (P04, line 149).

In addition, participants felt there would be a need for formal resources and activities and had many ideas of what should be included in a formalized curriculum: scripts for teachers, book lists, templates, videos, and materials related to culture/religion. “...giving teachers scripts, giving them some books and some activities, you know, that they can do with the children.” (P03, line 355-356). By providing scripts or a question-and-answer sheet for teachers, one participant believed teachers would know how to answer, “...like, where do I go if they ask me this?” (P05, line 321). They thought this would make it easier on teachers but still allow them to add their own style to it. Another participant thought bringing in older adults to share the joy of life with children would be a great place to start:

Maybe they [older adult] come into the class and they talk about their lives, and it's not related to death, oh you're closer to death than us, it's not that kind of talk, it's more about the joy of their life, and them coming in and talking about the things they've done in their life, and what it was like for them when they were younger. The younger kids are still relating to, oh, this is what it's like to grow up, rather than, I'm here, and you're way over there, I'm never going to be there. (P05, line 516-522)



### **Specific Teacher Strategies for Including Death Education**

Administrators identified many creative ideas on how teacher adoption could drive the learning in meaningful ways. Mainly, these participants felt that ensuring effective training and development for teachers, using a team approach, and allowing time for uptake would be useful for integration.

#### ***Training and Development***

Administrators believed that robust training and development would be needed to facilitate integration of death and dying into the curriculum and create confidence in teaching staff. There was an agreement from participants that training would be necessary and that teachers would need to understand the importance of the topic, reflect on their own experiences, and gain self-efficacy in teaching it. In trying to integrate these topics, one administrator suggested that “there’d be a real big training piece, and you’d have to push that amongst divisions.” (P04, line 222-223). One principal shared the importance of proficient training and how classroom instruction is enhanced “if they [teachers] benefit from it, they’re going to better understand it, and they’re going to teach it that much better. It’s going to be stronger, the delivery will be so strong.” (P05, line 450-452). One principal suggested that training could be done in many different ways: “something that I think either we would discuss as a PD [professional development day], as a staff together, or if the division or the university offered something where teachers would be suggested to do it.” (P02, line 280-282). The “expertise of the people doing the training” (P04, line 243) would be important to consider.

#### ***Team Approach***

Administrators felt that one way discomfort around the topic could be addressed with teachers, is through using a team approach to delivery. Co-teaching would be one way to ease

teachers into teaching a new and, perhaps, uncomfortable topic. “I don’t see why a counsellor wouldn’t be able to even co-teach that with the classroom teacher or model that teaching...” (P07, line 206-207). In this way “support teachers who go in and will do the gradual release with them, sort of do it and then they co-teach and then they let them go.” (P02, line 277-278), which can build that confidence to teaching a new topic.

### ***Time and Practice***

Like any new skill, administrators felt that time and practice would facilitate inclusion of a new topic. Administrators believed that teachers would need time to learn and become more familiar with the topic. They thought they would need to “meet them where they’re comfortable and then try to help them move along in terms of greater comfort.” (P03, line 273-274). When it comes to new content one administrator believed a teacher response would be “I might not be comfortable, yet, but probably the more that I teach it, I will become comfortable with it.” (P05, line 307-308). Administrators believed that by slowly growing their skills, teachers would become more confident in teaching about death in the classroom.

### **Summary**

This chapter presented the findings of this research study. The characteristics of the sample were described, followed by the qualitative findings that address if death, dying, caregiving, and grieving are discussed in schools, when and how they are discussed, and if there is formal guidance for schools or teachers. The perceptions of administrators on including death education into the formal curriculum and what supports would be needed for schools and teachers to be successful were also presented. The next chapter will present a discussion of the findings in the context of existing literature and outline the implications for nursing practice, education, and research.

## **Chapter 5: Discussion of the Findings**

The purpose of this study was to describe the current landscape of death education in the Manitoba school system and to explore school administrators' perceptions of introducing and integrating death education in the standard public-school curriculum. A qualitative exploratory descriptive design was used to elicit perspectives from administrators. The findings revealed that conversations about death do occur in schools, albeit in reactive, non-formalized ways, and schools respond to these conversations and even school deaths in the ways in which they best know how: by honouring the deceased, ensuring effective communication with the school and community, and offering different types of resources as necessary. Administrators have strong positive opinions about including death education as part of the regular curriculum. Their personal attitudes have shaped their views and they believe the normalization of death and dying is necessary within this milieu. They also feel that children have the capacity to begin acquiring knowledge regarding death, dying, and grief in the early years and that schools are a safe environment to include this subject and start these conversations. Administrators had a number of ideas around how the topic could be integrated within the current curriculum and identified a number of barriers and facilitators to doing so. This chapter will present a discussion of the research findings as they relate to the research questions posed, current empirical literature, and the theoretical framework underpinning this study. The limitations of the study will also be presented. Implications for those in the education system, including teachers, parents, and administrators are also presented. The chapter concludes with a discussion of the implications of the findings for nursing practice, education, and research.

### **Situating the Findings in the Literature**

Viewing palliative care as a public health issue, Kellehear (2015b) makes a strong case for increased education, so communities are better informed to tackle important issues such as aging, chronic illness, loss, death, medical assistance in dying, and organ donation. Death education is considered an essential strategy within a public health approach to palliative care (Public Health Palliative Care International, n.d.). Moreover, the compassionate communities model, which is a large component of a public health approach to palliative care, aims to use death education to bring awareness specifically to death, dying, caregiving, and grief (Kellehear, 2013). Despite introducing participants in the study to death education being comprised of these concepts, the perspectives they shared focussed mainly on death and grief, while dying, as part of the chronic illness trajectory, and caregiving for those who are aging, ill, or at the end of life, were left out of the discussion. This highlights that although death education is recognized as an important part of a public health approach to palliative care, there is much work to be done to move this strategy forward in a more fulsome way.

### **Death is Everywhere**

Although engagement with death education in both academic journals and in classroom curriculum has diminished in the last few decades (Smilie, 2021), death continues to be present in schools and in the classroom leaving staff, mainly teachers and administrators, to handle these situations as they arise. Interestingly, the catalyst for having these conversations and addressing these topics is a response to a child broaching the issue or a reaction to a death in the school community. There were few examples from administrators in this study of proactively introducing these topics as part of the regular curriculum. In fact, only one administrator could share an example of being proactive in addressing death when they were still teaching.

Participants revealed that children, at all levels, bring up death in the classroom because someone they know has died and they are grieving that loss. Death is happening at home; worldwide estimates of the number of children who have lost a parent or caregiver during the pandemic are now over 10 million (Hillis et al., 2022). McGovern and Barry (2000) reported that 86% of teachers have dealt with the loss of someone close to a student, while Papadatou et al. (2002) found 33% of teachers reported having encountered a student dealing with the loss of a relative specifically. In another study, Talwar (2011) found that over 60% of teachers surveyed had spoken to a student about death and even one-third of student teachers had addressed this topic with children. Indeed, deaths of important others occur in the lives of children and can be significant experiences that shape their development (Corr et al., 2000). In fact, an estimated 20% of children will experience the death of someone they love (Children's Grief Foundation of Canada, 2022). Similar to that reported by participants in this study, Rodríguez Herrero et al. (2020) outline that the existence of death appears in school settings through a variety of channels: students dealing with loss or illness at home or experiencing extraordinary events such as natural disasters or the current pandemic. These deaths might occur with close relatives, a parent or sibling, friends, classmates, or even a pet, all of which support and assistance is owed to children.

Administrators shared that death is largely addressed in a reactive way. They reported that often when questions or conversations about death occur, they are typically in response to a sudden or traumatic death, including circumstances such as suicides, heart attacks, or car accidents. They also described those current events, such as the COVID-19 pandemic, the discovery of children's graves at residential schools, and the effects of war in Ukraine, encompass children as well and have brought up questions about death, dying, and grief over the

past two years. This is reflective of the literature, which describes that children are largely exposed to and talk about death during times of trauma or disaster (Corr et al., 2000; Cupit, 2013; King-McKenzie, 2011; Kortes-Miller, 2014). Discussions that naturally ensue and questions that may arise occur within children's social circles, including those at school. When these exceptional events occur, these tragedies tend to put schools into "crisis-mode" (King-McKenzie, 2011, p. 3). These moments of surprise, where children bring up death, ask a question, or a current event sparks some sort of conversation are defined as informal death education (Cupit, 2013). Furthermore, while these instances where informal death education occurs are often unanticipated, they provide "teachable moments" (Corr et al., 2000) that have the potential to provide insight and lessons for personal development.

The lack of formal training and guidance on tackling these conversations when moments do arise have created inconsistency in how these valuable teaching moments are handled in the classroom. Some administrators in this study were comfortable addressing questions or moments in an honest and straightforward way, while others shared classroom examples where these moments were handled differently. Furthermore, these teachable moments, while introducing the topic, may vary throughout schools. Relying solely on organic inclusion of topics into the classroom from an event such as a classroom pet dying or a natural disaster means that for some students, these moments may not occur. Insertion of subject content is not something that occurs on a whim. In general, Manitoba curriculum development is a systematic process that requires subject expertise, extensive research, needs assessment, review panels, field testing, validation from appropriate government bodies, evaluation, and continual updating (Government of Manitoba, n.d.-a). Without this standardized process, developed collaboratively with subject experts, children could progress through their school years without ever having an opportunity to

learn about death, dying, caregiving, and grieving. Leaving death education to chance will mean the topics of death, dying, caregiving, and loss are not guaranteed learning opportunities for all students. Furthermore, even when the topic of death surfaces, as shared in this study, only death and grief are being broached by students and schools. The topics of life-limiting illness, frailty and aging, or caregiving for those approaching end-of-life are currently not being considered.

### **Primary Prevention - Sooner is Better**

Rather than waiting for topics to arise and hoping that teachers have the knowledge and comfort to address them, integrating standard formal education about death would be better than scrambling to react. A study from Ireland elicited teacher's views on including death education in schools and found strong agreement amongst participants that death would be better discussed prior to encountering it firsthand (McGovern & Barry, 2000). A public health approach is proactive about both community and individual level health and well-being through early prevention of illness and promotion of good health practices (Government of Canada, 2022). Extending this to a public health approach to palliative care, these health promotion activities need to be applied in the context of death, dying, and grieving, and focus on early interventions that include education and community development to enhance quality of life for those who are living with life-limiting illness, nearing end of life, caring for those with illness or nearing death, and experiencing loss (Public Health Palliative Care International, n.d.). Aligning with the tenets of a public health approach to palliative care, administrators in this study believed that proactive death education would be better than the current reactive approach and normalizing death across the lifespan would be beneficial for students. They believed that addressing death education earlier and more deliberately would help students gain an increased understanding of aging and illness across the lifespan, be better prepared to cope with situations when they arise, build

greater resiliency, and develop empathy. Wass (2001), a pioneer in the death education movement, felt learning about death in the context of natural life sciences allows children to cultivate tolerance, empathy, and compassion. Sallnow et al. (2022) suggest a goal of creating stronger communities and building networks to support those at end-of-life, caregivers, and the bereaved. These networks would be comprised of not only professionals, but family and community members. Empathy and compassion are necessary to achieve this vision.

Formal death education requires planning and includes goals, a curriculum, and assessment (Cupit, 2013). This type of education is not typically seen in standard public-school curricula. In fact, even during its popular phase, death education, as part of the regular school curriculum was only present in 11% of public schools in the United States (Wass et al., 1990). Little research has been done into what formal options exist for Canadian schools, however, Pallium Canada, as part of their Compassionate Schools Initiative evaluated two programs that had been used in a small number of schools in some provinces (Downer et al., 2014). These large health and well-being programs have only small units on coping with loss and bereavement. They are, however, not widely used and do not contain information on death as part of the life span, living with life-limiting illness, or caregiving for those with serious illness or approaching end-of-life.

One example from the literature of a proactive or health promotion approach enlisted schools with students aged 9-16 years old to visit a local hospice in order to learn about loss and transition, which are mandated concepts under the United Kingdom school curriculum (Kellehear, 2013). In this example, engaging with the hospice created an increased understanding of death, dying, caregiving, and bereavement, decreased fear and stigma around death, and reduced the harm of social isolation for those who were at end of life. Another program, used in



the south-eastern United States and developed for non-bereaved grade five students, was designed to give children the proper information and language about death, to delve into individual death values, and allow children to grieve any prior losses and/or develop appropriate language in order to discuss feelings related to loss (Edgar & Howard-Hamilton, 1994). The curriculum included death in the life cycle, emotions that arise during grief, the finality of death, mourning practices of different communities and religions, which includes a field trip to a funeral home and a guest speaker from another culture. This program reported positive outcomes for students including increased knowledge about the dying process and bereavement and higher levels of self-responsibility and generativity.

In Manitoba, we have few hospice beds within a larger formal Palliative Care Program (Government of Manitoba, n.d.-c). Still, collaboration and partnerships are essential from a public health approach to palliative care perspective. Engaging and developing the community in which we live could prove to be useful in finding resources for our neighbourhood schools. It would be important to reach out to these local resources to see if similar programs to those described earlier would be feasible. There could also be opportunities for similar types of partnerships and programs outside of those that are typically considered end-of-life since there is limited availability of hospices in our province. There are 135 long-term care homes in the province with over 10, 000 beds (Long Term & Continuing Care Association of Manitoba, n.d.) where students could visit with aging elders, provide companionship to help combat isolation and loneliness for residents, and normalize aging and even death as part of the life cycle. Even outside of formal care institutions, like hospice and long-term care, Manitoba has an aging population. The most recent census data shows 17.1% of the total population is over 65 years (Statistics Canada, 2022). This means there could be many opportunities for students to

meaningfully interact with older adults and to see aging and possibly caregiving and grief as part of those exchanges. In addition, there would be opportunities to discuss cultural mourning traditions through places of worship or visit one of the 91 registered funeral homes in Manitoba (Government of Manitoba, 2022).

### **The Need for Guidance**

Administrators in this study shared that death education is not present in their schools in any formal way, nor have they or their teaching staff been provided with any formal training on the subject. These findings echo that of the literature, which reveals that training and education related to death and dying for teachers remains low. One study found that only 25% of soon-to-be elementary teachers reported having any training related to death and dying in their education training preparation program (Galende, 2015), while another study found this rate to be just 14.8% (Rodríguez Herrero et al., 2020). The latter study was comprised of 683 teachers from 12 regions within Spain including teachers from preschool, elementary, secondary, and adult education programs in both urban and rural settings. Papadatou et al. (2002) disclosed that 80% of the 1,792 teachers in their study felt they lacked sufficient training to address death in the classroom. This included teachers at each of the elementary, middle, and high school levels with equal representation from urban and rural settings. McGovern and Tracey (2010) shared that primary schools in their study recognized the need for additional teacher training and support. Talwar (2011) also found this to be a recurring theme, reporting teachers felt they lacked adequate preparation to handle such topics and wished for more training to know how to talk about death when children of all ages brought it up. King-McKenzie (2011) believed that educating teachers in death education before they graduate should be present in all teacher-preparation programs. In fact, another study reports that 72% of student teachers in elementary

and middle-years education felt they are not qualified to teach death related topics or provide interventions to students (Mahon et al., 1999) which means that new graduates are grossly unprepared when they encounter that first question or situation in their first classroom. Even in the absence of formal death education for students, teachers will, at some point, be required to address death, life-limiting illness, or grief in the classroom. Training for teachers is essential and educators should seek out opportunities to increase their confidence and knowledge in addressing these themes with students. Additionally, teachers will also have to reflect on their own relationship with these themes and address any discomfort around death, dying, caregiving, and grief in order to be comfortable in teaching death education and supporting students. This might require using techniques such as reflective writing or communicating with their own family members about past experiences.

It was evident from the response of each school administrator in this study that they have found ways of addressing death in schools even without formal guidance. Schools do the best they can to answer questions and communicate about death with students as the need arises. In many ways, they have created their own organic, bespoke toolkit through years of experience and circumstance. They may share these resources with their own circles but there is little, if any, guidance from those above them including within the school system. There is little research that describes what teachers do when the topic of death arises in absence of guidelines or a formal death education curriculum. In fact, Levkovich and Elyoseph (2021) found that teachers were unsure of what to say to grieving students in the classroom after the death of a parent, which left teachers feeling guilty about being unable to provide meaningful assistance to students.

As part of social networks, parents, guardians, and the larger school community will also face death, dying, chronic illness, caregiving, and grief. In fact, some parents of school age

children may already be caregivers for their own aging parents. Parents and teachers share in the responsibility of educating children and topics introduced in one setting should be reinforced in the other environment. This means that education may also be necessary for parents of school-aged children in order to model the same behaviours that students are learning in school settings.

### ***Resources to Address Death***

One of the ways in which schools in this study address did death in the classroom, is through literature. Many of the participants spoke of a library display or a poignant book to read as a class or even to send home with children. Picture books that talk about death can be used as a tool to support children's learning around trauma and bereavement (Wiseman, 2013).

Bibliotherapy, a strategy where literature is used to create an emotional or behavioural change, has been used to normalize death and loss for children who may struggle to express their thoughts in meaningful ways (Berns, 2003). There is a plethora of death-related books for children (Arruda-Colli et al., 2017; Corr, 2002, 2003; Corr et al., 2000; Seibert & Drolet, 1993; Wiseman, 2013) so it is not surprising that administrators and school staff rely on these readily available resources as a support for students.

However, even with these resources readily available, there is no consistency in which books are selected, little guidance on which books would best address situations that arise, or which books would be best for integrating into the curriculum for the normalization of death and dying. Resources can be integral to shift individual thinking and assist in changing behaviours to ensure, from a public health approach, that the responsibility of end-of-life care belongs to everyone (Kellehear, 2015b). Furthermore, Kellehear insists that this shift means that death, dying, and loss need to be seen as "normal and usual", rather than scary or a problem (p. 224). To ensure that this is done, evidence-informed guidelines, developed by experts, such as

psychologists, social workers, palliative specialists, and nurses as part of a formal program, would certainly aid with using appropriate and consistent literature as a classroom tool across the school system.

### **Strength of School Communities**

Each administrator in this study spoke affectionately of their school community, both within the walls of the school and within the broader community. There were numerous examples of schools being safe spaces for students to explore and learn about, with, and from each other. Administrators used concepts like “tight-knit” and “a second home” to describe their school’s relationship with the students and families. They spoke of effective communication and how important it was to have an open and transparent relationship with the community. Administrators also shared that when a death occurred within the community or even globally, they found themselves in a position of trying to support each other through honouring the deceased, having conversations with children and families, or simply providing appropriate resources and activities to support at both the individual and community levels.

In many ways, these school communities are operating much like a compassionate community, where they “encourage, facilitate, support, and celebrate care for one another during life’s most testing moments and experiences” (Kellehear, 2015a, p. 80). By schools addressing community deaths and providing support to the bereaved, they are recognizing that everyone is responsible for caring for others during this time – a core tenet of compassionate communities, because people age and die within their social spaces (Kellehear, 2015a). Understanding the significance of their role in the lives of students and families, schools can continue to work with parents and guardians to ensure these classroom conversations are continued at home and encourage parents to share with them when death, dying, caregiving, or grieving are occurring

outside of school so students can be better supported in their classrooms. Parents can also ensure that they are partnering with teachers and communicating moments when death, dying, caregiving, and grieving are happening outside of school such as a dying pet, a chronically ill family member, or if they are caregiving for a parent or family member. Ensuring that communication is happening in both directions will help support students in all the environments in which they are present.

Kellehear (2020) suggests that while dying and bereavement can play a role in creating fear and sadness, they can also bring social groups closer while building empathy and courage. Furthermore, the normalization of aging, dying, grieving, and even caregiving can remove the negative experiences and stigma that come from these universal events. Having children spend time learning these skills and developing this knowledge in their social spaces can be instrumental in creating positive behaviours they will carry with them throughout the life span. Social Cognitive Theory recognizes that in the school environment, children will be learning in ways that will challenge and grow their thinking and influence their behaviours (Bandura, 2001a). Death education also helps to prepare people, young and old, for both their social and professional roles as citizens (Corr et al., 2000). The strength of school communities could be used to shape future behaviours and change the nature of how society sees and reacts to death, dying, bereavement, and caregiving.

### **Relationship of the Findings to the Theoretical Framework**

As introduced in the first chapter, this study was guided by Social Cognitive Theory (SCT) (Bandura, 1986). This theory was not being tested, but rather used to guide the researcher in how the findings could be interpreted. The relationships between environments, behaviours,

and personal characteristics are important to consider when embarking on any type of change, especially one that involves new ways of thinking or changes to our current environments.

Administrators in this study provided many examples of students who encountered death or grief that then wanted to learn more about it. In these examples, children were challenged to consider thoughts and behaviours, based on what they observed within their environments both outside and inside of school. Furthermore, the ways in which individual schools addressed deaths that occurred within each school community were shaped by the personal attitudes and experiences of the administrators themselves. Even the resources that were suggested to help children in the classroom were evidence of this learning theory in action: books that demonstrated behaviours and characteristics that are only observed by the reader is a good example of observational modelling (Bandura, 1986).

When considering the ways in which death education could be integrated, administrators discussed approaches that would continue and be built upon throughout the school years. This method of teaching demonstrates the reciprocal nature of the relationships within SCT. It is not enough to teach something once and expect it to change an individual's thinking but rather the continued interaction with the material, the ways in which it is taught, and environment can create the shift that is desired over time.

As a learning theory, the SCT framework was integral to this research. It assisted the researcher in clarifying some of the reasons for our current school environments, the perceptions and perspectives of the participants, the implications of the findings, and in considering how these findings might best be implemented to create change. SCT provided context to the ways in which individuals learn new behaviours and create new environments.

### **Impact of COVID-19 on Interviewing**

Using Zoom video-conferencing technology to conduct virtual interviews was necessary given that data collection occurred during the COVID-19 pandemic. Typically, interviews for a qualitative study are conducted face-to-face, and it is customary to have the participant choose the location to establish trust (Morse & Field, 1995). Furthermore, an in-person environment allows the researcher to establish rapport and note observation and body language easily (Polit & Beck, 2017). While some of this may have been lost in using a virtual platform, Archibald et al. (2019), found that using Zoom still allowed for creating and maintaining this rapport. Convenience has also been described as an advantage to using Zoom video technology for qualitative interviewing (Archibald et al., 2019). Participants in this study were able to participate during a break in their schedule or before leaving at the end of the day. However, the setting of video calls has been identified as a challenge for qualitative researchers (Hicks et al., 2021). Because most principals joined the virtual meeting from their schools, there were distractions that came up, such as students walking by the window and waving, or an announcement being played over the intercom. Overall, while in-person research would have been preferable for this study, having to pivot to an alternative way of collecting data allowed for this study to continue during a time when in-person research was not being conducted.

### **Limitations**

There are some limitations to this study. The findings of this study are not generalizable to all school administrators given the qualitative research design of this study. Furthermore, all participants were located within the city limits so the perspective of school administrators from other geographic locations (e.g. rural schools) is not known. In addition, all administrators were currently working in elementary or middle schools and the perspective of high school



administrators was therefore not explored. Finally, there is a possibility of selection bias in that those who volunteered to participate in the study may have had strong opinions on the topic that they wanted to share.

### **Implications for the Education System**

The findings from this study highlight the interest in and need for including death education in more formal ways. Many stakeholders collaborate to advance student knowledge within schools. Based on the findings from this study, the following recommendations for teachers, parents, and administrators include the following:

1. Develop an advisory committee comprised of teachers, parents, and administrators to discuss issues related to current engagement with death, dying, caregiving, and bereavement in the classroom and consider the evidence supporting the inclusion of more formalized death education at all levels;
2. Establish a resource webpage for teachers and parents looking for guidance on having conversations with children that focus on death, dying, caregiving, and grief;
3. Develop and refine two-way communication channels so parents, families, students, and schools can communicate openly around death, dying, caregiving, and grief to best support students in all environments;
4. Seek out or organize educational opportunities for administrators, teachers, and parents to enhance their own knowledge and confidence in having these difficult discussions such as death education training through a massive open online course (MOOC) like Dying2Learn (Tieman et al., 2018) or through participation in a local or virtual death café that uses the “World Café” approach (McLoughlin et al., 2016).

5. Continue to look for creative opportunities to include conversations about death, dying, caregiving, and bereavement into classroom learning, even in absence of formal curriculum, such as partnering with other organizations to consider broader themes that may fit in history, health, or life skills classes.

### **Implications for Nursing Practice, Education, and Research**

The following section discusses the implications of the findings from this study for nursing practice, education, and research. The main implications for nursing practice include the need to integrate PHPC and CC models into public health and strengthen the relationship between health care and education sectors. The implications for nursing education include enhanced training for those in undergraduate nursing programs in both palliative care and community health and to develop programs for those nurses currently in practice. Finally, the implication for nursing research includes next steps for death education research including understanding the perspectives and interests of teachers, parents, and students and addressing other components of public health palliative care, mainly caregiving, dying, and living with life-limiting illness.

### **Integrating Palliative Care and Compassionate Communities into Public Health**

While it is acknowledged that many people, including patients and caregivers, have a role to play in the provision of palliative care (Health Canada, 2018), public health palliative care and compassionate communities are not part of the public health portfolio (Government of Canada, 2022). Instead, stakeholders and other organizations have their own mandate and focus for improving palliative care. Specifically, Canadian Hospice Palliative Care Association (CHPCA) and Pallium Canada have paid some attention to the compassionate communities model (Canadian Hospice Palliative Care Association, 2022; Pallium Canada, 2020b), but it seems to

take a back seat to the other traditional, reactive approaches to death and dying – mainly provision of care towards the end of life. Health Canada’s framework on palliative care is guided by; i) the need for a culture shift in the ways in which we talk about death and dying; and ii) that palliative care is a shared responsibility. Despite this, the initiatives for training and education seem to focus on formal care providers, both regulated and unregulated (Health Canada, 2018) without considering the need for capacity building and education for everyone at every stage, including children and adolescents in our national school systems. Public health education related to death, dying, caregiving, and loss aims to increase end-of-life literacy, change attitudes about death, prepare communities with knowledge and skills for illness, death, and bereavement, and provide tools to think and plan for the future (Patterson & Hazelwood, 2022). This can be done in a variety of ways, including through public awareness campaigns, formal courses, experiential learning, peer education, self-led learning, and integrating these topics into mainstream education at all levels. While death education has been a difficult area to advance (Tompkins, 2018), there is a need to see greater advocacy from those involved in public health palliative care and compassionate communities to promote inclusion of death education into the public school system and beyond. Nurses, as both proponents of upstream, holistic public health approaches and trained in educator roles, are well-positioned to use their knowledge and skills to lead these initiatives. In Manitoba, according to our most recent data, approximately 15% of registered nurses and 60% of nurse practitioners work in community health roles (Canadian Institute for Health Information, 2021). For those already working in these community roles, relationships between healthcare and communities have been built. Nurses can use these already established networks to promote introducing death education in more formal ways at many levels, including within schools.

### **Strengthening the Relationship Between Education and Health Care**

One way that nurses can promote the integration of more formal death education into the school system, is to further strengthen the relationship that already exists between health and education sectors. As part of their Healthy Schools Initiative, Manitoba utilizes the Comprehensive School Health (CSH) framework to guide and support provincial school health (Government of Manitoba, n.d.-d). The CSH framework sees partnerships as an integral part of student health and well-being, especially having the health and education systems working together (Pan-Canadian Joint Consortium for School Health, 2022). This includes integrating learning around healthy lifestyle behaviours, so that students develop skills for life. Prior to adopting this Healthy Schools approach in 2003, Manitoba utilized a method called “Nurses-in-Schools” which promoted health and well-being within school communities (Government of Manitoba, n.d.-b). Nurses were not inside schools daily, but rather assigned to a portfolio of schools through public health offices. The Healthy Schools framework was later developed and broadened in response to community need.

In the United States school nurses are considered a speciality practice focussed on health promotion, harm prevention, care coordination, student health advocacy, and healthy child development (National Association of School Nurses, 2022). The National Association for School Nurses takes the position that to optimize student health and well-being school nurses should be “present in every school all day, every day”. In Canada, however, school nursing is not considered a speciality (Buduhan & Woodgate, 2021; Sanders et al., 2019). Public health nurses (PHNs) practice within a shared public health system working in a variety of locations, including schools (Canadian Public Health Association, 2010). PHNs focus on primary prevention strategies such as promoting healthy behaviours and utilizing harm reduction

strategies, solving and preventing health problems before they happen, using health education to build resiliency, skills, and capacity to improve individual and community health. Examples of this type of work include protecting health through programs that address food and water safety, promoting health through education programs on injury or illness prevention such as teaching about tobacco use or bike helmets, health surveillance programs for early detection of illness, such as milestone screening at well-baby groups, health assessment, and emergency preparedness and response, as seen during the COVID-19 pandemic (Stanhope et al., 2017). Some of this work takes place in schools, but most occurs in other venues such as in client homes or the regional public health office. The PHNs list of roles and responsibilities does not include any discussion around what their role in death or grief might be (Canadian Public Health Association, 2010). Unfortunately, time constraints and other workload priorities create barriers for PHNs in both building and maintaining relationships within community schools (Buduhan & Woodgate, 2021). Additionally, there is confusion around the PHN role and what nurses in these roles can offer schools. Regardless of this, PHNs are still considered essential in our schools (Sanders et al., 2019).

Administrators in this study reported death education inclusion within the school system would likely be hindered by time constraints and heavy teaching loads. In addition, they shared that teachers may lack confidence and comfort in teaching these topics, especially on their own. Having training and development delivered by experts and using a team-teaching approach could allow for a more successful integration. Administrators in this study shared the need to seek out expert advice and support to both create content and to teach this content in the classroom. Nurses are well-situated to take on greater responsibility within the school system, based on the key roles outlined in the Canadian Public Health Associations' document on the roles and

activities of PHN in Canada as outlined above (Canadian Public Health Association, 2010).

Nurses, as part of an interprofessional team of experts, would be essential in the creation and delivery of this content in the classroom.

Overall, the findings reveal that there is a desire and enthusiasm to including formalized death education into the school system from the administrators in this study. While there are barriers to creating and maintaining the relationships between PHNs and school communities (Sanders et al., 2019), it is essential that nursing, as an integral component of the health care system, continues to build and maintain these relationships with structured education systems, concentrating on providing health education to students and school communities. These strengthened relationships would place nurses as a strong resource for death education programs. Because issues related to death, dying, caregiving, and grieving are not simply medical issues but social ones (Abel & Kellehear, 2016), collaboration with other disciplines both within and outside of healthcare, as well as community members, caregivers, patients, and others is also essential.

### **Considerations for Nursing Education**

In order for nurses to adopt using a PHPC framework, they need to be aware of its existence and how they might use such a framework to guide their practice. While current palliative care theory courses, when available, incorporate entry-to-practice competencies that align with a PHPC approach, such as communication, bereavement care, and recognizing caregiver needs (Canadian Association of Schools of Nursing, 2011), there are many concepts that should be considered as part of a holistic, upstream approach to palliative care. Additional education on building capacity within communities to share in the care of those with life-limiting illness and what types of social supports may be available for patients and families outside of the

traditional palliative care specialist programs would be a start. Integrating teaching around compassionate communities has the potential to enhance the whole person approach by considering the social support circles that surround those who are facing death, dying, caregiving, and bereavement and ensuring they are connected to networks within their community that bring meaning to them (Abel et al., 2018). In addition, these public health approaches to palliative care could also be further reinforced in community health theory and clinical courses. Offering undergraduate students opportunities to use health promotion within the communities where they are placed and apply these principles in the context of death, dying, caregiving, and bereavement would emphasize palliative care approaches exist outside of institutional care spaces. Using a social model of care, supports the whole person approach to nursing practice.

Consistent with social cognitive theory, individual behaviours and thinking change through observational modeling (Bandura, 2012). By seeing and hearing death, dying, caregiving, and loss being normalized by health care professionals, there is an opportunity for nurses to shape the ways in which communities and individuals consider these concepts. Nurses still exhibit discomfort around death (Pererson et al., 2010; Peters et al., 2013; Üstükuş & Eskimez, 2021), but they will need to overcome these anxieties in order to model the behaviours we would want to see in others. Death education applies to everyone, at every level, even after completing formal undergraduate training. Üstükuş and Eskimez (2021), who strongly support continuing education, found that nurses who receive post-undergraduate training and development are more confident in end-of-life care. Cheong et al. (2020), found there was a decrease in death anxiety, fear of death, and death avoidance in nurses after participation in a two-day workshop centered around end-of-life and evidence-informed palliative approaches to

care. While adapting content within undergraduate is one future direction for nursing education, ensuring continuing education for those in practice should also be an area of focus.

### **Next Steps for Nursing Research**

This study was a first step in understanding the current landscape of death education in Manitoba schools and exploring administrators' perspectives on introducing and integrating death education into the standard curriculum. Further research is needed to ascertain the interests from teachers, school communities (including parents and students), other health care professionals, and the community at large. A thorough understanding of all stakeholder perspectives would help to inform the design, implementation, and evaluation of an evidence-informed death education curriculum. Furthermore, the findings from this study reveal that there is opportunity for other aspects of a public health approach to palliative care and the compassionate communities model, such as living with life-limiting illness, aging and frailty, dying, and caregiving to be explored in future research. These concepts should be explored in greater detail with administrators but also with other school community members such as teachers, parents, and students.

Much of the literature on death education within elementary, middle, and senior-year education is especially dated. Furthermore, there are gaps in knowledge about the existence and characteristics of current death education programs at various school levels and the outcomes associated with these programs. Additional research is needed to map the existing literature and begin to address these gaps.

### **Summary**

Formal death education is an integral part of public health palliative care, which aims to prevent negative outcomes associated with death, dying, caregiving, and grieving and promote



health and well-being of those at the end of life, those caring for the dying, and the bereaved (Public Health Palliative Care International, n.d.). Research in death education programs for children and adolescents is decades old and administrator perspectives are an overlooked gap within the literature. This study aimed to address this gap by describing the current landscape of death education in the Manitoba school system and exploring school administrators' perceptions of introducing and integrating death education in the standard public-school curriculum.

Overall, findings illustrate that deaths do occur in schools and schools react and respond in the ways in which they best know how. These reactions to death and grief have been organically grown in each school, and there is little guidance and consistency on how to respond to these situations. This study also illustrates that there are opportunities for a more robust public health approach to palliative care by including topics such as caregiving, life-limiting illness, and dying into these informal lessons. Administrators in this study, had strong positive opinions about including death education in the regular curriculum, which was shaped by their personal attitudes, views, and beliefs that the normalization of death is necessary. They also felt that children have the capacity to acquire knowledge in the early years and schools are a safe space to do so. These findings demonstrate that there is an appetite for including the last taboo, death, in meaningful ways within the public school system. All stakeholders within the education system, teachers, parents, and administrators have a role to play in normalizing death and ensuring death, dying, caregiving, and dying are topics that are learned from a young age. By using a public health approach to palliative care, community nurses could play a strong role in collaborating with schools to create and deliver death education in the classroom. In these safe spaces, children would learn, in age-appropriate ways, to normalize death, dying, caregiving, and loss. By shaping knowledge and reinforcing behaviours over the duration of the formal learning years, the

environments in which we live would change, perhaps becoming more aligned with compassionate communities where families are supported and resources available for the chronically ill, the dying, and the bereaved (Kellehear, 2013). Nurses have the potential to participate in this culture shift, to address these gaps, and to ensure a kinder, more compassionate community in which all of us can live and die.

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**Appendix A: Access Approval Email to Divisions**

**University of Manitoba** | Rady Faculty of  
Health Sciences

College of Nursing  
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F: 204 474 7682  
nursing@umanitoba.ca

**Exploring School Administrators' Perceptions of Death Education in Public Schools**

**Date:** XXXX

**To:** School Division Superintendent

**From:** Jane Kraut RN, BN, BA, Graduate Student, College of Nursing, Rady Faculty of Health Sciences, University of Manitoba

**Re:** Seeking access approval to reach principals and vice principals within the School Division XXXX to participate in a research study entitled, "Exploring School Administrators' Perceptions of Death Education in Public Schools"

Dear Superintendent,

Public health education, started early, can promote individual and community health and well-being, creating positive habits that will last a lifetime. Within school settings, we educate students and school communities about nutrition, healthy sexuality, substance misuse, physical activity, mental health, and injury prevention. These conversations can be uncomfortable for some, but in starting a dialogue children and adolescents can ask questions in a safe space to make better informed health decisions as the age.

One topic that is noticeably absent from these important health topics is death and dying.

Research in a public health approach to palliative care suggests that death education can normalize death as part of the lifespan and create better outcomes for those living with or caring for those with life limiting illness.

Principals and vice principals have an important role working with school boards and government to implement curricula and support teachers who directly educate students.

I would like request access to invite principals and vice principals in School Division XXXX to participate in a one-on-one discussion to gain a better understanding of the current landscape of death education in the Manitoba school system and their perceptions of introducing and integrating death education in the standard public-school curriculum. This research study has been approved by the University of Manitoba Ethics Review Board, Fort Garry Campus.



If approval is granted, I would ask to have the attached “Invitation to Participate” letter emailed to principals and vice principals within School Division XXXX on my behalf.

If you would like to learn more or have any questions about this study, please contact Jane Kraut, Principal Investigator/Graduate Student by email at [jane.kraut@umanitoba.ca](mailto:jane.kraut@umanitoba.ca) or by confidential voice mail message at [REDACTED]

Alternatively, you may reach out to the other members of the research team:

Genevieve Thompson, RN, PhD  
College of Nursing  
Rady Faculty of Health Sciences  
University of Manitoba  
89 Curry Place  
Winnipeg, MB R3T 2N2  
Tel: 204-474-8818  
Email: [genevieve.thompson@umanitoba.ca](mailto:genevieve.thompson@umanitoba.ca)

Jamie L. Penner, RN, PhD(c)  
College of Nursing  
Rady Faculty of Health Sciences  
University of Manitoba  
89 Curry Place  
Winnipeg, MB R3T 2N2  
Tel: 204-474-9315  
Email: [jamie.penner@umanitoba.ca](mailto:jamie.penner@umanitoba.ca)

Thank you,

Jane Kraut, RN, BN  
Graduate Student  
[jane.kraut@umanitoba.ca](mailto:jane.kraut@umanitoba.ca)  
[REDACTED]

**Appendix B: Recruitment Email Invitation to Participate**

**University  
of Manitoba** | Rady Faculty of  
Health Sciences

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nursing@umanitoba.ca

**Exploring School Administrators' Perceptions of Death Education in Public Schools**

**Date:** XXXX

**To:** Principals and Vice Principals at public schools in various divisions in the province of Manitoba.

**From:** Jane Kraut RN, BN, BA, Graduate Student, College of Nursing, Rady Faculty of Health Sciences, University of Manitoba

**Re:** Invitation to participate in a research study entitled, "Exploring School Administrators' Perceptions of Death Education in Public Schools"

Dear School Principals and Vice Principals,

Public health education, started early, can promote individual and community health and well-being, creating positive habits that will last a lifetime. Within school settings, we educate students and school communities about nutrition, healthy sexuality, substance misuse, physical activity, mental health, and injury prevention. These conversations can be uncomfortable for some, but in starting a dialogue children and adolescents can ask questions in a safe space to make better informed health decisions as the age.

One topic that is noticeably absent from these important health topics is death and dying.

Research in a public health approach to palliative care suggests that death education can normalize death as part of the lifespan and create better outcomes for those living with or caring for those with life limiting illness.

As principals and vice principals, you have an important role of working with school boards and government to implement curricula and in turn support the teachers who directly educate students. To that end, I would like to hear from you!

I would like to invite you to participate in a one-on-one discussion. I want to understand the current landscape of death education in the Manitoba school system and your perceptions of introducing and integrating death education in the standard public school curriculum.

Individual interviews will be held via a licensed version of the Zoom video communications application and be approximately 60 minutes long. Individual interviews will be audio-recorded (using a digital recorder) and confidentiality will be maintained outside the individual interviews.

You can choose a time that best suits your schedule.

In appreciation of your participation, you will be offered an honorarium in the form of a \$25 coffee gift certificate, which will be e-mailed to you prior to the interview. This honorarium is yours to keep, even if you withdraw from the study at a later time or choose to not answer all the questions.

Participation is voluntary and refusal to participate will in no way impact you.

If you are interested in participating in the study or would like to know more about the study, please contact:

Jane Kraut, Graduate Student by email at [jane.kraut@umanitoba.ca](mailto:jane.kraut@umanitoba.ca) or by confidential voice mail message at [REDACTED]

Alternatively, you may reach out to the other members of the research team:

Genevieve Thompson, RN, PhD  
College of Nursing  
Rady Faculty of Health Sciences  
University of Manitoba  
89 Curry Place  
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Tel: 204-474-8818  
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Jamie L. Penner, RN, PhD(c)  
College of Nursing  
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Winnipeg, MB R3T 2N2  
Tel: 204-474-9315  
Email: [jamie.penner@umanitoba.ca](mailto:jamie.penner@umanitoba.ca)

Thank you,

Jane Kraut RN BN BA

## Appendix C: Recruitment Poster

# ARE YOU A PRINCIPAL OR VICE PRINCIPAL?

AN INVITATION TO PARTICIPATE IN A RESEARCH STUDY

### WHAT IS INVOLVED IF I PARTICIPATE?

You will be asked to answer questions on a demographic form about yourself. You will be asked questions during a one-on-one meeting (via video-conferencing) about your experiences with and your opinions about the topic of death in schools .

In appreciation of your time (approximately 60 minutes) you will be given a \$25 coffee gift card.

### WHAT DO WE WANT TO LEARN?

We want to learn more about the current landscape surrounding death education in public schools and understand your perspectives around introducing and integrating death education into the school curriculum.

**Title of the Study:**  
**Exploring School Administrators' Perceptions of Death Education in Public Schools**

### WHO CAN PARTICIPATE?

Principals and vice principals currently employed at a public school at **any level** in Manitoba, where division has granted approval (determined during screening).

### QUESTIONS?

For more information or to participate, please contact:  
 Jane Kraut by email:  
[Jane.Kraut@umanitoba.ca](mailto:Jane.Kraut@umanitoba.ca)



This study has been approved by the Research Ethics Board 1 at the University of Manitoba

## Appendix D: Interview Guide

Date of interview:

Interviewer name:

---

The purpose of this proposed study is to describe the current landscape of death education in the Manitoba school system and to explore school administrators' perceptions of introducing and integrating death education in the standard public-school curriculum.

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1. In your role as principal/vice-principal, would you say that the topics of death, dying, caregiving for those with life-limiting illness, or grieving come up in the classroom?  
Prompts:
  - a) What happens if there is a death within the school community? How is it talked about at the school level? How is it talked about at the classroom level?
  - b) Can you think of a situation where a student brought up death at school? How was that handled?
  - c) If a student brought up death, how might it be handled by the school? In the classroom?
  - d) Can you think of a time or share an example of death/dying/caregiving/grieving being discussed at school?
  
2. To your knowledge, are there any formal guidelines from the division/government about how to talk about death/dying/caregiving/grieving in a school setting?  
Prompts:
  - a) Is there a formal curriculum to address these topics?
    - a. If so, can you share what that looks like?
  - b) In your experience, would you say addressing death/dying/caregiving/grief within your school are proactive or reactive?
  - c) Can you think of any examples of how death/dying/caregiving/grief might be addressed through formal learning in the classroom? Are there any specific units, literature, history, or science teachings that might cover these topics?
  
3. From your perspective, what type of training or guidance is given to teachers to help address these themes with students at school?  
Prompts:
  - a) Have you ever heard of or participated in an in-service about death/dying/caregiving/grieving?
  - b) Have teachers ever approached you for advice or guidance about bringing up these topics, or discussion them in the classroom? What have you said/would you say in response to this?
  
4. How would you feel about including conversations about death, dying, caregiving, and grieving in the curriculum?  
Prompts:

- a) Can you expand on what makes you feel that way?
- b) Where would you feel the best place for children and adolescents to learn about death, dying, caregiving, and grief be?
- c) Who do you feel would be best suited to teach this topic to children/adolescents?

5. What would you need to feel supported in including death education into the curriculum?

Prompts:

- a) What would see at barriers to including these topics?
- b) What would make including these topics easier?

6. What do you think teachers would need to feel supported in including death education in the classroom?

Prompts:

- a) What would see at barriers to including these topics?
- b) What would make including these topics easier?

7. Is there anything about death education or including death, dying, caregiving, and grieving in the classroom that I haven't asked that you would like to share with me?

## Appendix E: Demographic Form

### Demographic Questionnaire

#### Death Education in Public Schools as a Public Health Approach to Palliative Care

PARTICIPANT #: \_\_\_\_\_

DATE: \_\_\_\_\_

1. Age: \_\_\_\_\_

2. Gender

- Male
- Female
- Prefer to self-describe as
- Prefer not to say

3. Highest level of education completed

- College diploma
- Attended university
- University degree
- Master's degree
- Post-graduate degree
- Other (please specify):

4. How many years have you been in your current role?

5. How many years did you spend in a teaching role?

6. Have you ever participated in any formal training related to death and dying?

- Yes
- No

7. Please indicate your current administrative role.

- Principal
- Vice Principal

8. Please indicate your school setting:

- Winnipeg
- Central
- Southeast/Interlake
- Northern/Remote
- Parkland/Westman

**Appendix F: Consent Form**

**University of Manitoba** | Rady Faculty of Health Sciences

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nursing@umanitoba.ca

**RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM**

**Title of Study: “Exploring School Administrators' Perceptions of Death Education in Public Schools”.**

**Principal Investigator:**

Jane Kraut, RN, BN, BA  
Graduate Student  
College of Nursing  
Rady Faculty of Health Sciences  
University of Manitoba  
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**Co-Investigators:**

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College of Nursing  
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Tel: 204-474-8818  
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89 Curry Place  
Winnipeg, MB R3T 2N2  
Tel: 204-474-9315  
Email: [jamie.penner@umanitoba.ca](mailto:jamie.penner@umanitoba.ca)

**This consent form, a copy of which will be kept by you for your records, is part of the process of informed consent. It describes the research and what your participation will involve. You are being asked to participate in a research study involving an individual interview. Please take your time to review this consent form and discuss any questions you may have with the study staff, your friends, or family before you make your decision. This**



**consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.**

### **Purpose of this Study**

This research study is being conducted to study the current landscape of death education in the Manitoba public school system and to explore school administrators' perceptions of introducing and integrating death education in the standard curriculum.

You are being asked to participate in this study because as a principal or vice principal at a public school in Manitoba, you may be able to share your perspectives and experiences with death education in schools you have worked in. A total of 15 participants will be asked to participate.

### **Study Procedures**

If you agree to participate in this study, you will be asked to take part in an individual interview. This will involve you speaking with a researcher in a one-on-one conversation for approximately one hour. The interview will take place via Zoom video communications at a time that is convenient for you. You will be asked some questions relating to your experience with death education in schools. These questions will help us to better understand what death education topics are currently being discussed in schools and if there is a willingness to include this topic in the curriculum.

Prior to the start of the individual interview, you will be asked to provide demographic information related to age, gender, education level, number of years spent as an administrator, number of years spent teaching, and any formal training or education related to death, dying, or grief you may have.

The researcher will also take field notes during or immediately after the discussion. Field notes are the ideas, questions, and thoughts of the researcher that may arise in the interviews. They help to describe the context of the discussion and describe features of the interview that may have affected the data-collection.

### **Recording Devices**

Interviews will be audio-recorded using an external digital recorder and the audio-recordings will be transcribed by a transcriptionist service to ensure accurate reporting of the information that you provide. Transcribers will sign an oath of confidentiality that they will keep all information confidential and that they will not discuss any item on the recording with anyone other than the researchers. Names will not be asked or revealed during the individual interview. However, in the event that this happens, the transcriber will be instructed to remove all names from the transcription. The audio-recordings will be kept on a password protected computer that only the Principal Investigator has access to before and after being transcribed. Recordings will be destroyed within 1 month of completing the transcriptions and the transcriptions will be destroyed 3 months after the completion of this evaluation.

### **Risks and Benefits**

There are no anticipated physical risks to participants. During the interview, it is possible that minor discomfort related to sitting could occur. If necessary, participants can take a break to stretch. The topics being explored in this study focus on death education, death, and dying. This could be distressing for some people. It is possible that the researcher may ask a question that may make you feel uncomfortable or distressed. You do not have to answer any question that makes you uncomfortable or that you find too upsetting. Should you need any additional help or support, we will refer you to additional resources or help you to find other counselling help.

While we cannot guarantee that participation in this study will have any direct benefit we hope that information gained may help provide new ideas about how to engage school communities in talking about death and dying. Sharing your perspectives, experiences, and ideas have the potential to create meaningful change. In addition, it is hoped that you may have increase insight into your own attitudes towards death, dying, and grief. It may also be helpful to you to share experiences about death education, death, and dying which, you may have not had an opportunity to do previously. Furthermore, collaboration between educators and nurses can add to the advancement of interprofessional relationships across sectors.

### **Confidentiality**

We will do everything possible to keep your personal information confidential. All members of the research team will sign an Oath of Confidentiality and will be bound by the standards laid out within the document. Your name will not be used in the study records and you will be assigned a unique code identification number which replaces your name. A list of names and addresses of participants will be kept in a secure file so we can send you a summary of the results of the study. All data collected will be kept on a password protected computer, to which only the Principal Investigator/Graduate student researcher will have access. A professional transcription service will have access to audio recordings to prepare electronic transcriptions for further analysis. Audio recordings will be destroyed by December 2022 or after the verification is complete, whichever is earlier.

For the purposes of monitoring research, the University of Manitoba Research Ethics Board 1 (REB1) may review records including those with potentially identifiable information. This person has a professional responsibility to protect your privacy.

### **Costs and Compensation**

There is no cost to you to attend the interview.

In appreciation of your participation in this study, you will be offered a \$25 coffee e-gift card after your consent form is received, which will be sent via email. You may keep the gift card even if you choose to withdraw from the study at a later time.

### **Voluntary Participation/Withdrawal from the Study**

Your decision to take part in this study is voluntary. You may choose to participate now and decide to stop participation later. You may decide to withdraw participation by telling a member of the research team or it may be stopped with or without your consent if the graduate student researcher feels it is in your best interest to withdraw from the study.

If you choose to withdraw or are withdrawn your data will be removed from the study. In qualitative research, data analysis is an iterative process that begins almost immediately after data collection. This process allows the researcher to delve deeper into certain areas with future participants. Data analysis will begin almost immediately after the transcription of the interview audio-recording. The deadline to withdraw data from the study would be 2 weeks after the completion of the interview, after which data cannot be withdrawn.

As a current employee in a public school, your participation or discontinuance in the study will not constitute any element of your job performance or evaluation nor will it be part of your personnel record at any of these institutions.

### **Dissemination of Research Results**

The results of this research will be communicated in a variety of ways. To ensure findings from this study promote greater understanding of the inclusion of death education in the school system, I plan to:

- 1) Publish findings in a peer-reviewed journal (e.g. Death Studies, Palliative Care and Social Practice, Mortality, Omega);
- 2) Deliver oral or poster presentations at local and national conferences (e.g. Palliative Manitoba, Canadian Hospice and Palliative Care, or International Public Health Palliative Care);
- 3) Share findings with College of Nursing in through the Graduate Poster Competition;
- 4) Develop an infographic to share with participants and divisions.

Your identity and any other identifying information will not be disclosed in any publications, presentations, or report. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. All reporting will be in a group format and any individual comments will remain anonymous.

### **Summary of Results**

A brief (1-2 page) summary of the results will be available to participants at the end of the study. This summary should be available by March 2023. You can choose to receive this summary by email or regular mail and will indicate your choice at the end of this form.

### **Questions**

If any questions come up during or after the study, contact the principal investigator and the study staff: Jane Kraut at (204) 795-5933, Jamie Penner at (204) 474-9315, or Genevieve Thompson at (204) 474-8818.

For questions about your rights as a research participant, you may contact The University of Manitoba, Fort Garry Campus Human Ethics Board Office at (204) 474-7122 or by email at [humanethics@umanitoba.ca](mailto:humanethics@umanitoba.ca)

**Statement of Consent:**

1. I have read all 6 pages of the consent form.
2. I have had a chance to ask questions and have received satisfactory answers to all my questions.
3. I understand that my participation is voluntary.
4. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
5. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator/Graduate student researcher and the agencies and organizations listed in the confidentiality section of this document.
6. I understand that I may withdraw from the study at any time prior to data analysis.
7. I understand I will be provided with a copy of the consent form for my records.
8. I agree to participate in the study.

**Participant signature:** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

**Participant printed name:** \_\_\_\_\_

**I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent**

**Printed Name:** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

**Signature:** \_\_\_\_\_

**Role in the study:** \_\_\_\_\_

**Please complete this section for a summary of results:**

Would you like to receive a summary of the results of this study?

\_\_\_\_\_ Yes    \_\_\_\_\_ No

If yes, please provide the following information:

Name of person to whom the results should be sent (please print):

\_\_\_\_\_

Preferred method of receiving the summary:

\_\_\_\_\_ Email: \_\_\_\_\_

\_\_\_\_\_ Regular Mail: \_\_\_\_\_

\_\_\_\_\_