

# **Ethics of Finitude: Nursing and the Palliative Approach**

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Go with what is most terrifying, the dizzying empty night and the lonely stars until night slows and you see the whole design. Always choose love over safety if you can tell the difference.

- Josephine Humphreys, *Dreams of Sleep*

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## Abstract

### **Purpose**

Within the contemporary socio-political context of palliative care and an aging demography, there is a called-for shift to an upstream provision of palliative care in the form of a palliative approach to care as well as to frame access to palliative care within a health equity perspective. In the literature, there is a paucity of nurses' experiences in the provision of palliative care within psychiatric settings. Moreover, little is known of the process by which nurses engage in a palliative approach to care for patients experiencing multiple marginalities, including institutionalization, mental health, and advanced age. This research explored how nurses in forensic and geriatric psychiatry engage with aging patients and mortal considerations to discern how ethical dimensions of care, aligned within the palliative approach, are enacted. An ethical lens by which to apprehend dimensions of human finitude, reflective of central elements of the palliative approach and public health palliative care, was proposed to help to delineate a process of recognition through which values can be identified in the care of patients. The purpose of this thesis was to explore the phenomenon by which nurses engaged with mortality as both an antecedent to adopting a palliative approach and as a phenomenon that captures nurses' continued engagement with patients within this approach.

### **Objectives**

There were three objectives to the project: 1) explore nurses' engagement with mortality within an ethics of finitude; 2) identify enablers and barriers, and related historical and socio-political discourses, to engagement of nurses with their patients within an ethics of finitude, and; 3) articulate and deepen understanding of the palliative approach, including ethical dimensions and considerations. The research was an analytical elaboration of a qualitative study at the

University of Ottawa that examined the palliative approach to nursing care in forensic and geriatric psychiatry at a mental health facility in eastern Ontario.

### **Methods**

Situated within a constructivist epistemic stance, the analytical framework elaborated for this analysis drew from both interpretive description (ID) and interpretive phenomenological analysis (IPA). Utilizing convenience sampling, eight Registered Nurses (7 women and 1 man) working in forensic or geriatric psychiatry completed interviews.

### **Findings**

Engagement of nurses within an ethics of finitude was revealed to surface through a process of recognition (recognition of mortality, recognition of the increased vulnerability of patients, and recognition of a corresponding increased responsibility for vulnerable patients) and through the affirmation of values including human connection, dignity, comfort, family, familiarity, and personhood. Barriers and enablers to this engagement emerged related to the care environment, the psychiatric nurse and patient construction, and factors related to family. The implications of the related discourses in the articulation of the palliative approach emerged in relation to health system considerations and to the language of the palliative approach.

### **Conclusion**

The process of recognition explored through the proposed ethical lens and revealed in the findings delineated values that underpin the palliative approach by offering an alternate conceptualization to their identification and enactment. Insights from this project underscore preliminary insights on a process to identify care practices aligned within the palliative approach as well as possibilities for critical questioning related to interconnected axes of an ethics of finitude in both the care of individual patients and in the enactment of health policy.

## Chapter 1: Problem Statement

In the context of an aging demography, access to palliative care is a growing public health issue (Stjernswärd, Foley, & Ferris, 2007). In *The Way Forward National Framework*, the Canadian Hospice Palliative Care Association (CHPCA, 2015), supported by funding from the Government of Canada and the Quality End-of-Life Care Coalition of Canada (QELCCC), articulated a vision for palliative care in Canada in which everyone who is facing problems associated with aging should benefit from a palliative approach to care. The palliative approach, as articulated in the *Framework*, focuses on meeting patients' and families' needs (physical, psychosocial, and spiritual) at all stages of frailty or chronic illness and in patients' preferred settings of care (CHPCA, 2015). While the CHPCA's *Framework* (2015) specifically includes shelters and prisons as examples of where a palliative approach can be provided, patients' settings of care necessarily include forensic and geriatric psychiatry inpatient units, the care context of this research. The need to improve palliative care access in forensic psychiatry settings is evident and pressing: there is a global growing population of aging inmates in need of palliative care services (Fowler-Kerry, 2003), there is limited research related to the development and implementation of palliative care programs within forensic environments (Fowler-Kerry, 2003), and there are many barriers to the provision of palliative care to psychiatric patients (Terpstra & Terpstra, 2012) including stigma associated with mental illness (Steves & Williams, 2016) and the lack of experience of psychiatric nurses in providing physical care (Morgan, 2016). Moreover, according to Burles, Peternelj-Taylor, and Holtlander (2015) there is a need to improve access to palliative care and to opportunities for a 'good death' in correctional settings, including the need for research on the experiences of health care providers in forensic settings relative to how they provide palliative care in an under-resourced context and the need to

develop initiatives related to palliative care to address misconceptions and stigma associated with forensic populations.

With a focus on psychosocial aspects of care, geriatric psychiatry aims to improve function and quality of life, manage symptoms, coordinate care provision and respond with a multidimensional approach to suffering (Irwin, 2012; Kollas, 2012). Despite parallels with palliative care pertaining to holistic care and the promotion of comfort, gaps are identified in this field of psychiatry related to symptom assessment and management, such as adequate pain management for patients with cognitive impairments, and advance care planning (Irwin, 2012; Shega et al., 2006). It follows that research on the enactment of palliative approach is needed to yield insights to help bridge these care gaps, through a better understanding of how nurses engage in the care of their aging patients.

Of the principles that underpin the goals of the *Framework*, that of equitable access to health services is of particular relevance (CHPCA, 2015). The principle of equity articulated in the *Framework* helps to delineate research priorities and context insofar that populations evidencing multiple health inequities merit additional critical attention. In so doing, this research responds to the call of Reimer-Kirkham et al. (2016a) to philosophically align palliative care as a social justice issue through a health equity approach and to account for health-threatening and life-limiting contexts informed by structural vulnerability. The principle of equity serves to legitimize the broader exploration of historical and socio-political discourses related to this research context, such as stigma, that influence and shape nurses' engagement with mortality; such a lens frames nursing as a political activity and in so doing underscores possibilities for nursing advocacy (Perron, Fluet, & Holmes, 2005)

The *Framework's* focus on chronic disease reflects the reality that this illness presentation now accounts for most deaths worldwide and for increased experiences of uncertainty related to the decline process from illness to death (CHPCA, 2015; World Health Organization [WHO], *n.d.*). There is therefore a need to explore how nurses engage with their patients and mortal considerations earlier on in their illness trajectories in order to ensure that care provided is aligned with the palliative approach. Moreover, a number of characteristics and values have come to define palliative care, including the element of an open awareness of death whereby mortality is regarded as part of the normal process of living, as articulated in the WHO's (*n.d.*) definition of palliative care. However, such an open awareness of mortality, insofar as it transcends treatment or curative aims, represents a challenge to cultural ideals of coherence and order and the social values that underpin modern science, including predictability, control, and certainty (Mishel, 1990). Dominant cultural values ingrained in progress and technological advancement, including a curative orientation in medicine, may function as discourses that stigmatize individuals with chronic life-limiting and terminal illnesses. It follows that patients who decline curative care goals may be socially positioned as aberrant from the culturally reified biomedical norms of predictability, control, and certainty identified by Mishel (1990).

The roadmap in the CHPCA's *Framework* (2015) articulates the need for a cultural shift in health care practice and attitudes that challenges some of the manifestations of mortality-denying societal discourses and biomedical values. Part of this called-for attitudinal cultural shift includes educating and supporting health care providers "to help them overcome their own fear of loss, dying, and death" and health care professionals in all settings are called to develop skills and competencies to integrate the palliative approach into routine care requiring that "they must

examine their own fears and attitudes about loss, dying and death and come to terms with their own mortality” (CHPCA, 2015, pp. 24-25). It follows that an inquiry into nurses’ engagement with mortality within marginalized care contexts, like forensic and geriatric psychiatry settings, is timely and needed to ensure appropriate and dignified palliative care and to heed the CHPCA’s (2015) call for a cultural shift in health care practice.

This research is an analytical elaboration of a qualitative study undertaken at the University of Ottawa that examined the palliative approach to nursing care in forensic and geriatric psychiatry at a mental health facility in eastern Ontario. The original study sought to understand: the values that guide nurses’ practice; how nurses conceptualize and make use of a palliative approach in the care of aging patients; and, to what extent their moral agency is furthered or constrained with respect to the enactment of a palliative approach in daily nursing practice. The purpose of the original study was to better understand the experiences of forensic and geriatric psychiatry nurses in the care of aging patients. Throughout this thesis, unless otherwise stated, reference to “the research” or “the project” is in relation to my own analytic elaboration of the original study.

My research project was not a secondary analysis but rather an analytic elaboration of the original study’s research objective. My project explored the phenomenon by which nurses engage with mortality as both an antecedent to adopting a palliative approach and as a phenomenon that captures nurses’ continued engagement with patients within a palliative approach to care, specifically:

1. The research explored nurses’ engagement with mortality within an ethics of finitude;

2. The research aimed to identify enablers and barriers, and related historical and socio-political discourses, to engagement of nurses with their patients within an ethics of finitude;
3. The research sought to articulate and deepen understanding of the palliative approach, including ethical dimensions and considerations.

With these aims, the project expands upon the conceptual work of Brinkmann (2006), who articulated the need for an ‘ethics of finitude’ that is existential-phenomenological and rooted in ‘facticities’ about human existence including human beings’ social, temporal, and mortal dimensions. These facticities refer to “some things” that “simply are the case, prior to any conventions or social constructions” including human interdependence as well as living in a community with other mortal beings (Brinkmann, 2006, p. 95). From these facticities stem moral demands of solidarity that are non-negotiable (Brinkmann, 2006). Mortality is therefore a condition for morality in that mortality and the related vulnerability it engenders makes possible the conditions for values, in that what is valued is what is inherently subject to loss, and virtues, such as courage, endurance, self-sacrifice, and justice (Brinkmann, 2006). Brinkmann’s work explored an ethics of care that informed how apprehending finitude could be conceptualized. Engagement, as a process term central to this project in relation to the nurse patient relationship, is understood to mean the interpersonal and active involvement of nurses to encounter patients in opportunities for emotional resonance, building upon Ekman and Halpern’s (2015) work on professional empathy, a term further elaborated upon in Chapter 3.

I critically reflected upon ethical dimensions that informed engagement as well as upon a central challenge facing palliative care provision: ensuring access to appropriate, timely, and dignified care to marginalized populations, such as forensic and geriatric psychiatry patients. It

follows that if communities fund what they know to value, this research serves to articulate values underpinning the palliative approach and in so doing supports the legitimacy of the claim of the palliative approach as an orienting force to palliative care philosophy and service provision as put forth in the CHPCA's *Framework* (2015). By developing and articulating values that underpin the process of ethical engagement within a palliative approach, the project may serve to yield insights to improve access to palliative care in a marginalized care context and to further conceptualize the approach called for by palliative care leadership in the CHPCA's *Framework* (2015).

The research is situated within the constructivist research paradigm. From this lens, truth is variable, subjective, and determined by the individual or cultural group (Weaver & Olson, 2006). Guba (1990) outlined three categories of philosophical inquiry that serve to understand paradigms: ontology, epistemology, and methodology. To understand the constructivist paradigm, each category is considered. First, ontology refers to the nature of reality. From a constructivist perspective, multiple realities exist and as such, reality is subjective (Appleton & King, 1997). Put another way, from a constructivist paradigm, reality is relative and beliefs and principles are context-specific (Appleton & King, 1997). The next category of philosophical inquiry is epistemology, which refers to the nature of the relationship between the researcher and what can be known (Guba, 1990). In other words, epistemology addresses what is considered to be "truth". Appleton and King (1997) observe upon the interplay of ontology and epistemology in constructivism, whereby it is impossible to consider the nature of reality without considering the relationship of the researcher to what can be known. Based on the inductive and exploratory nature of the research aims, it follows that the research is situated within a constructivist paradigm that reflects the perspective of a constructed and contingent reality. This points to the

interactive nature of constructivist research, whereby the “researcher must interact with study participants throughout the research process to access the multiple views of reality that may exist” (Appleton & King, 1997, p. 1). This reference to interaction helps to understand the last category of philosophical inquiry, methodological considerations, described in Chapter 4, from a constructivist paradigm.

The literature review informing this project is described in Chapter 2 which presents the evolution in search strategies and details a thematically-organized synthesis and critical appraisal of extant scholarship related to nursing aging patients, nursing forensic psychiatric patients, and an overview and critique of the historical development of palliative care. Each section includes a pertinent historical overview of dimensions contributing to the constructions of aging, and psychiatric and forensic patients to elucidate possibilities for nurses’ attitudes, perspectives, beliefs, and engagement in the study context.

According to Smith and Osborn (2003), the power of qualitative research is partly in the light that it can shed on claims within literature and within broader theoretical understandings. It follows that the significance of the theoretical underpinning of the research cannot be overemphasized. In the proposed theoretical scaffolding, the process of engagement is delineated and situated within the palliative approach to care. While the concept ‘palliative approach’ is increasingly used in palliative care literature, it is often inconsistently defined or left undefined. In order to accurately situate this project within palliative care nursing practice and to practically outline this project within current nursing care modalities, a modified conceptual analysis of the term palliative approach is provided, followed by a proposed conceptualization of this care. Second, the conceptualization of the palliative approach put forth is employed as an interface from which to introduce and articulate an ethics of finitude, based on human facticities as

proposed by Brinkmann (2006). The motif of *memento mori* is presented as a symbolic device that entreats human remembrance of mortal finitude and thereby serves as a functional link between foundational elements of the palliative approach and the elaboration of an ethics of finitude. Third, the dimension of place in relation to the lived experience of nursing care is an essential aspect to the social processes involved in the research project. Place, in the sense of relationship, is used to designate a form of social organization permeated by various diffuse power relations. In this understanding, the places of total institutions as theorized by Goffman (1961) and that of home are considered to delineate the loci of social processes of nursing and, as such, represent potentialities for ethical engagement reflective of human finitude. Fourth, a conceptual understanding of stigma using Goffman's (1963) seminal work is explored to understand these processes, often associated with aging, dying, and mental illness, and to identify how stigmatizing processes may be reflected and challenged in nursing discourses.

Situated within a constructivist paradigm and drawing on techniques from two related methodological designs, interpretive description (ID) and interpretative phenomenological analysis (IPA), this analytic elaboration aimed to gain in-depth and detailed description, understanding, and explanation of ordinary occurrences as they were experienced by participants in forensic and geriatric psychiatry as well as firmly ground this research in the clinical realities of nursing practice (Smith & Osborn, 2003; Thorne, Kirkham, & O'Flynn-Magee, 2004; Weaver & Olson, 2006). The methodological considerations of the project are described in Chapter 4.

Findings are presented in Chapter 5 which detail the engagement of nurses within an ethics of finitude. This engagement was found to surface in the theme of recognition (nurses' recognition of mortality, nurses' recognition of the increased vulnerability of their patients related to aging and life-limiting conditions, and nurses' corresponding increased sense of

responsibility for patients with increasing limitations) and the affirmation of values (human connection, dignity, comfort, family, familiarity, and personhood). Barriers and enablers to this engagement were explored related to the care context environment, the psychiatric nurse and patient construction, and factors related to family. The implications of the related discourses in the articulation of the palliative approach relate to health system considerations and to the language of the palliative approach.

Chapter 6 presents a discussion and analysis of the research findings. The findings are explored through the ethical lens based on the ideas of Brinkmann (2006). The values identified in the findings are explored in light of the values and guiding principles of the palliative approach (CHPCA, 2013; CHPCA, 2015). Each facticity (social, temporal, mortal) identified by Brinkmann (2006) is considered to illustrate an alternate way to conceptualize the values communicated by participants. The research findings examined through the proposed ethical lens are situated within existing literature. Insights related to the proposed ethical lens are explored related to initiatives that could enhance the process of recognition (training and enhanced involvement of nurses in advance care planning processes) and accounting for health inequities and stigma through a macro lens of social facticity (social determinants of health). Ontario's Home First philosophy is explored to illustrate how the proposed ethical lens could be used to reveal salient ethical considerations in public policy. The language of the palliative approach and conceptualization of it are reconsidered related to the semantic variability that emerged in the findings; the need for conceptual clarity is re-imagined to possibly include a social function underscored by the motif of *memento mori*, which serves to remind humans of their mortality. Lastly, limitations of the project are described.

## Chapter 2: Literature Review

A literature review serves to explore the body of existing knowledge on the research topic and, for a thesis, this includes an evaluation of the overall body of literature and critique of individual studies (Polit & Beck, 2012). The nature of the research problem and context was reflected in the literature search strategy that included numerous searches in bibliographic databases, ancestry and descendancy approaches (searching backwards and forward in citation indexes from pivotal research), and searching available grey literature, including governmental and non-governmental reports and resources and literature from professional nursing organizations. This chapter describes the evolution in search strategies and presents a thematically organized literature review synthesis and critical appraisal related to nursing aging patients, nursing forensic psychiatric patients, and an overview and critique of the historical development of palliative care. Each section includes a pertinent historical overview of dimensions contributing to the discursive contexts of aging, psychiatric, and forensic patients to consider how social constructions create possibilities for attitudes, perspectives, beliefs, and behaviours.

### **Literature Search Strategies**

Bibliographic databases were consulted to identify medical subject headings (MeSH) that corresponded to the initial key concepts and terms of the research. This led to a refinement in language, such as opting for the more appropriate MeSH term ‘death’ as opposed to ‘mortality’. Appropriate truncations (e.g. nurs\*, psy\*) as well as key phrases and terms (e.g. ‘palliative approach’ and ‘finitude’) warranting search in their entirety were also identified. The search began with a broad approach to the literature in Medline. No publication date, type, or language restrictions were initially placed in order to get a sense of available articles. The identified items

were reviewed for relevant titles, and abstracts were read for additional indication of pertinence. Search histories were saved to Ovid and references were exported into the reference management tool Zotero. After an initial search on Medline, insight was gained on some exclusion factors (language limited to French and English) and to exclude topics related to: physician assisted suicide; palliative sedation; diagnosis of psychiatric conditions among patients receiving palliative care; and, psychotherapies for the palliative care setting. Alternative and relevant search terms such as ‘chronic life-limiting condition’ and the concept of ‘good death’ were explored in this process. Similar searches were reproduced, with added restrictions, in Scopus and CINAHL. Numerous articles were identified with the approach detailed above, however the pertinence of these items was variable. For example, it was more straightforward to find articles on ‘palliative approach’ and topics well aligned to MeSH subject headings (e.g. ‘forensic nursing,’ ‘palliative care,’ ‘psychiatric nursing’). Literature searches related to social processes, such as total institutions and stigma, and to the historical development of palliative care required more diverse and creative approaches, including consulting primary texts and grey literature from professional associations.

As relevant articles were identified, the search strategy turned to ascendant and descendant approaches whereby these articles were mined for their references and by using ‘cited by’ and ‘related documents’ search functions, as appropriate. These strategies were helpful in identifying relevant articles, including one that proved to be a key resource by Brinkmann (2006) on the ethics of finitude—the author of which was contacted and directed me to further relevant references. To better grasp the wider context of the research problem, secondary sources were consulted in order to obtain an overview of the topic and to consult the bibliographies included (Polit & Beck, 2012). Secondary sources included books on the psychology of aging,

the social history of death and dying, gerontological, psychiatric and forensic nursing, and cultural and religious interpretations of the good death. The process was iterative and included ongoing searches in bibliographic databases and in grey literature.

As a central concept in the proposed research, a more refined search of the phrase ‘palliative approach’ was conducted within Scopus and the results of this search were explored with combinations of the search terms. A detailed description of this search and review process is presented in Chapter 3: Conceptual Scaffolding in which a modified concept analysis was undertaken of ‘palliative approach’ for the purpose of conceptualizing this thesis. Alerts were arranged in Medline and Scopus for this same phrase. During the literature search processes, a list of journals relevant to the research problem was developed for later reference should hand search be warranted. Lastly, grey literature was an invaluable resource as many palliative care organizations as well as governmental and non-governmental agencies have an online presence and relevant resources, such as the WHO’s (*n.d.*) frequently cited definition of palliative care. With this overview of the search strategies utilized, a review and critical appraisal of literature related to nursing aging patients is considered next as well as a historical overview of dimensions contributing to the constructions of aging to inform possibilities for nurses’ engagement.

### **Nursing Aging Patients**

In this section, literature on nursing aging patients is reviewed as it pertains to: the historical development of the speciality of gerontological nursing; discursive contexts, including the social constructions of aging and illness; and, relational approaches, including person-centred approaches that focus on the meaning of older peoples’ behaviour. The care of aging patients occurs in a context in which older Canadians are the fastest growing segment of the population (Statistics Canada, 2016). The growth rate of the population of Canadians 65 years and older is

about three times the growth rate of the entire population (Statistics Canada, 2016). Several factors account for the greater life expectancy and population aging, including a relatively high birth rate during the late nineteenth and early twentieth centuries as well as reductions in mortality related to public health measures, such as vaccinations and sanitation, reduced infant and maternal mortality, and the availability of antibiotics (Meiner, 2011). The increase in life expectancy of today's older adults and the growing recognition of the unique health care needs of older adults paralleled the development and specialization of the nursing care of this population (Dahlke, 2011).

According to Dahlke (2011), there is a paucity of literature on the development of the nursing care of aging patients. In 1966, the American Nurses Association established the Division of Geriatric Nursing Practice (Meiner, 2011). It was through this division that the first standards of practice for geriatric nursing were established in 1969 (Meiner, 2011). Now referred to as gerontologic nursing, this nursing specialty “involves assessing the health and functional status of older adults, planning and implementing health care and services to meet the identified needs, and evaluating the effectiveness of such care” (Meiner, 2011, p. 4). More recent initiatives include the Hartford Institute for Geriatric Nursing (HIGN) that was started in the United States in 1996 to advance geriatrics in nursing and that now houses The National Hartford Center of Gerontological Nursing Excellence (NHCGNE), a collaboration that extends to nursing schools and international institutions to promote the field of gerontological nursing (HIGN, *n.d.*). In Canada, the first gerontological nursing conference was held in 1983 and the national association, the Canadian Gerontological Nursing Association (CGNA), was formed in 1985 (CGNA, 2015; Dahlke, 2011). The CGNA elaborated competencies and standards of practice, the most recent of which were published in 2010.

### **Discursive Contexts of Nursing Aging Patients**

The Canadian Nurses Association (CNA, 2010) lists gerontology-specific competencies as part of its specialty certification program. According to the CGNA's *Gerontological Nursing Competencies and Standards of Practice* (2010), assumptions that underpin the standards are:

Gerontological nurses practice in a manner that incorporates normal age related changes in a socially constructed and culturally sensitive manner. The role of the gerontological nurse is influenced by a number of factors (e.g. legal dimensions, legislative authority, client rights, current social and political trends, growth of specialization and professional organizations that require inter-sectoral collaborations). Gerontological nurses work in a variety of roles and in their practice apply theoretical knowledge of aging (e.g. developmental theory, Erikson's stages of psychological development, critical age-related stress theory, relationship care theory). (CGNA, 2010)

While acknowledging and applying theoretical constructions of aging, the CGNA recognizes the social construction and cultural dimensions of aging. This is captured in the CGNA's

*Gerontological Nursing Competencies and Standards of Practice* (2010) conceptual framework:

Gerontological nursing is a dynamic interaction between the client and nurse to achieve health and wellbeing. The client and the nurse both contribute to the interaction. Clients bring their unique experiences, personal knowledge and expertise about themselves whereas nurses bring their specific body of knowledge of gerontology and geriatrics, their skills and the art and science of nursing. The historical and current social and cultural climates, political influence and values of the community and society also influence the interaction. (CGNA, 2010)

The acknowledgement in the CGNA's conceptual framework with respect to the social construction of aging and the wider social influences in the care of aging clients is significant. Indeed, Dahlke (2011) identifies the challenges faced by nurses in the care of older adults as related to "practices and care delivery systems that have been developed, perhaps unconsciously, from social ideas about aging and older people" (p. 47). It is this social construction of aging that was the subject of Phelan's (2011) discussion paper, a paper of particular relevance to appreciate the context in which nurses care for aging patients as well as to situate the various constructions of aging (such as the age of 65 years as 'senior' and theories related to aging such as Erickson's) referred to in the CGNA (2010) competencies and standards. Using a Foucauldian social-constructionist approach to investigate dominant discourse of old age, Phelan (2011) argued that "knowledge of older people is linked to the power of language to legitimate social reality" (p. 894). Discourses related to old age impact nursing knowledge, education, and practice because they have the power to shape what is possible and visible in the care of aging patients. Phelan argued that little attention has been given to the conditions that shape the internalized beliefs and practices of nurses who care for aging patients. The knowledge that sustains nursing practice is therefore produced and sustained in historical and cultural contexts that come together and are utilized to help make sense of the world (Phelan, 2011).

Phelan (2011) identified contributions to dominant ideology from discourses produced through disciplinary knowledge including theories of aging, such as the construction of the older adult as one of a particular age (typically 65 years and older), and bio-medical constructions of aging, such as that of gerontology. For example, chronological age is frequently cited as a measure of aging and the age of 65 and older is often used to demarcate advanced age. This delineation is socially constructed through its historical relation to the allocation of benefits and

services when social security programs were first established under the German chancellor Otto von Bismarck in the 1880s (Meiner, 2011; Phelan, 2011). Similarly, age stratifications such as Youdin's (2016) young-old adults as 65 to 74 years of age, middle-old adults as 75 to 84 years of age, and old-old adults as 85 to 99 years of age, are similarly socially constructed and such groupings fail to capture the heterogeneity of these populations. Dominant discourses related to aging include theoretical constructions of old age such as structural-functionalist theories of aging, of which examples are activity theory and disengagement theory. Disengagement theory, for example, proposes that the life space of an individual decreases with age (Cumming, 1975) which includes the voluntary surrender of social roles—a response that furthers the orderly transfer of power from older to younger generations (Diggs, 2008). Phelan (2011) also includes the political rhetoric of old age in dominant discourses related to old age, examples of which include parliamentary briefings relative to aging populations' impact on public pensions, health care, and caregiving (Parliament of Canada, 2011), and policies such as the WHO's Policy Framework on Active Aging (2002). Contemporary political discourse in the example of Ontario's Home First philosophy described below, provides a salient example of ideological constructions of the aging adult relevant to the study context.

Phelan (2011) also identified contributions to dominant ideology from the discourses related to ageism. Butler (1969) was the first to use this term to express the systematic stereotyping and discrimination against people based on their age, with a particular emphasis on this process related to those with advanced age:

Age-ism reflects a deep seated uneasiness on the part of the young and middle-aged—a personal revulsion to and distaste for growing old, disease, disability; and fear of powerlessness, 'uselessness,' and death (p. 243).

From the social construction of ageism stems related discourses, as evidenced in the social valorization of youth and in increased funding for anti-aging research, and in what Phelan (2011) refers to as “professional ageism” whereby the notion of deterioration associated with aging dominates the knowledge of health care education programs (p. 895). In the latter example, this process creates the potential for fatalism (i.e. viewing deteriorating health as a predetermined part of aging), paternalism, and neglect in the nursing care of aging patients (Phelan, 2011). Holroyd et al. (2009) summarize factors identified in the literature that influence how older adults are perceived in the nursing care context: the cultural environment in which nurses practice, the nursing workload, and the amount of gerontological knowledge of nurses. Liu, Norman, and While’s (2013) systematic review found that globally, registered and student nurses’ attitudes towards older people appeared to be less positive since 2000 and that the preference to work with older people and knowledge of ageing (i.e. education in gerontological nursing) were variables most associated with positive attitudes towards older people as measured through various instruments (i.e. Facts on Aging Quiz, Aging Semantic Differential, Perceptions of Working with Older People). Liu, Norman, and While (2015) sought to develop a model of nurses’ attitudes towards older people based on the finding that gerontological nursing is not a popular area of nursing practice and viewed as unchallenging and unrewarding. The authors found that nurses who expressed less self-ageing anxiety held more positive attitudes towards older people (Liu et al., 2015). It follows that nurses who work in the care of aging patients and who self-select to participate in research that aims to improve aged care may similarly express or hold correspondingly positive attitudes towards older people.

In Masse and Meire’s (2012) discussion paper, the authors propose that it is the fear of confrontation with one’s finitude that older adults represent that accounts, in part, for ageist

beliefs among health care providers. To this end, the authors acknowledge that this confrontation can be a source of suffering that requires support and self-reflection:

[L]a lutte contre l'âgisme ne passe pas seulement par une amélioration des connaissances sur les processus de vieillissement et les besoins des personnes âgées, mais par une réflexion sur les représentations et les attitudes des professionnels de la santé face à la vieillesse et à la mort (Masse & Meire, 2012, p. 340).

It is not only by furthering our understanding of the process of aging or of the needs of the aged that we counter ageism—it is also in reflecting upon the representations of aging and the attitudes of healthcare providers in the face of aging and death (Free English translation of Masse & Meire, 2012, p. 340).

It follows that reflection on the representations of aging and the attitudes held by care providers merits critical attention. The nursing profession and, by extension, the nursing care of aging patients, exists in the contexts of multiple discourses (Phelan, 2011). As such it is essential to consider how the social constructions of older adults create the conditions of possibility for attitudes, perspectives, beliefs, and behaviours. Phelan's contribution serves to legitimize consideration of contextual ideological discourses that can impact nursing care in the research context. Possibilities for care are revealed or obscured in the social construction of illness and health. With dementia as an example, research illustrates how engagement can be influenced by a care team's view of an illness, whether it is seen as a disability, a chronic condition, or as a terminal illness (Kydd & Sharp, 2016). The language that nurses adopt to describe the health condition of those under their care is therefore an indication of the possibilities for attitudes, perspectives, beliefs, and engagement itself.

According to Phelan (2011) nurses must challenge normative perspectives in both everyday life and professional education and practice in order to be able to provide equitable, individualized, and age-neutral care. Phelan's critique serves to situate the various and perhaps competing discourses that can emerge in the research data and to situate the CGNA (2010) standards of care. The CGNA's *Gerontological Nursing Competencies and Standards of Practice* (2010) identifies six standards of care all of which pertain to the care of aging patients in the current research context: physiological health; optimizing functional health; responsive care; relationship care; health systems; and, safety and security. Based on the research context, which included a forensic environment as well as the care of patients with behavioural and psychological symptoms of dementia (geriatric psychiatry), a closer look at the standards of responsive care and safety and security is warranted.

### **Relational Approaches in the Care of Aging Patients**

The CGNA's third standard 'responsive care' is detailed so that "nurses provide responsive care that facilitates and empowers client independence through life course changes" (2010, p. 10). This standard explicitly mentions the provision of support for those dealing with dying, death, and grief as well as the promotion of quality end-of-life care, advance care planning, and symptom management (CGNA, 2010). A 'responsive care approach' recognizes the cultural meaning of behavior as well as the role of contextual factors related to aging that can affect behavior and communication (e.g. sensory and cognitive changes, dementia, aphasia from stroke) (CGNA, 2010). The responsive care approach described in this standard is reflected in the curriculum of the Gentle Persuasive Approaches (GPA) in Dementia Care, a training program that is offered to nurses working in geriatric care at the research site as well as nationally across Canada.

The GPA in Dementia Care is a privately-run, person-centred dementia care education program for formal care providers offered through the not-for-profit organization Advanced Gerontological Education (AGE, 2014; AGE, *n.d.*). GPA is described as non-punitive (of persons with dementia) and self-protective (of care providers through physical containment techniques) curriculum with the goal of enabling learners to respond respectfully, confidently, and skillfully to behaviours associated with dementia using a compassionate approach (AGE, 2014). The training refers to the findings of Kitwood (1998) in identifying malignant interactions with dementia patients (i.e. infantilizing, outpacing, imposing, labeling, ignoring, negating, intimidating) and the value of personhood-promoting interactions (i.e. validation, collaboration, facilitation, play, celebration, relaxation) in de-escalating responsive behaviours and building positive relationships (AGE, 2014). The use of language such as “responsive behaviours” defined as a “set of reactions that arise from environmental stress or unmet needs” (Speziale, Black, Coatsworth-Puspoky, Ross, & O’Regan, 2009, p. 571) reflects a person-centered understanding whereby behaviours that could be perceived as aggressive can be reframed as self-protective and an attempt by a person with dementia to re-exert control (Dupuis & Luh, 2005). The program is delivered by GPA certified coaches, most of whom are located in Ontario, Canada (AGE, 2016).

In order to learn more about this curriculum, I took GPA training, in which the approach was described by facilitators as a “philosophy of care”. Within the training and in the workbook provided, emphasis was placed on Bell and Troxel’s (1994) 12-point Alzheimer’s Disease Bill of Rights. These rights include, among others: to be free from psychotropic medications if at all possible; to have physical contact including hugging, caressing, and hand-holding; and, to be with persons who know one’s life story, including cultural and religious traditions (Bell &

Troxel, 1994). GPA training also included the recognition that “all behaviour has meaning,” and that understanding behaviour requires knowing “the person behind the illness, including their strengths and the nature of their limitations” (AGE, 2014, pp. 13-14, 25). The phrase “all behaviour has meaning” is echoed in the guiding principles of the Registered Nurses’ Association of Ontario’s (RNAO) *Best Practice Guidelines on Promoting Safety: Alternative Approaches to the Use of Restraints* (2012) underscoring the link between appropriately identifying and responding to the behaviours of patients with neurocognitive disorders and ensuring patient and personnel safety.

Along with GPA, nurses at the research site have access to P.I.E.C.E.S. training, which was developed with a recognition of the need for a system-wide approach to understanding and supporting the care of complex and at risk older persons (P.I.E.C.E.S., 2013). The P.I.E.C.E.S. acronym refers to the recognition of the strengths and needs of these individuals related to Physical health, Intellectual abilities, Emotional wellbeing, Capabilities, Environment, and Social self (P.I.E.C.E.S., 2013). The goals of this training include using best practice approaches to assessment and care planning, interdisciplinary care, and risk management (P.I.E.C.E.S. Consult Group, Hamilton, Harris, Le Clair, & Collins, 2008). Given the prominence of GPA and P.I.E.C.E.S. training provision to nurses in the study context, the philosophical values and goals of these training programs may in turn influence the values enacted by nurses.

### **Safety and Risk in the Care of Aging Patients**

Safety is articulated in the fifth CGNA standard of practice, safety and security, whereby nurses are responsible for assessing clients and the environment for safety hazards and for maintaining a safe environment (CGNA, 2010). This standard explicitly mentions eliminating or minimizing the use of physical, chemical, and environmental restraints, and intervening to

promote health (including enhancement of quality of life and provision of palliative care). This is aligned with the RNAO best practices on restraints (2012), Ontario's *Patient Restraints Minimization Act* (2001), and as articulated in the College of Nurses of Ontario's (CNO) Restraints Practice Standard (2009) whereby "all possible alternative interventions are exhausted before deciding to use a restraint" (p. 4). The articulation of this standard, while relevant in all care contexts of aging patients, is of salience in forensic and geriatric psychiatry care contexts in which there may be competing institutional safety and security discourses. Authors have commented upon the emergence of risk as a dominant preoccupation in contemporary society (Rothstein, 2006). Resulting risk management policies may serve to prioritize the assessment of institutional risk and an organization's reputation may take precedence over meeting individual patient needs (Rothstein, 2006). Nurses in the study context may be similarly situated between competing mandates and may in turn engage competing discourses.

This section reviewed the development of the speciality of gerontological nursing as well as its discursive context, including the social constructions of aging, illness, and risk discourses, and relational nursing approaches, including person-centred care approaches that focus on the meaning of behaviour. An appreciation of the perspectives held and tensions experienced by nurses in the care of aging patients serves to help situate the context in which the process of engagement with finitude is proposed.

### **Home First Philosophy and Aging Patients**

The social constructions of aging adults create the conditions of possibility for attitudes, perspectives, beliefs, and behaviours, and therefore the current sociopolitical context warrants examination in order to consider possibilities for the enactment of an ethics of finitude. In Ontario, the nursing care of aging patients is situated in the context of the Home First philosophy

of Local Health Integration Networks (LHINs), another element of the discursive context in which the care of aging patients occurs. This philosophy emerged as a significant feature of the care transitions of aging patients. As background, under the *Local Health System Integration Act*, 2006, the Government of Ontario established LHINs to locally plan, coordinate, and fund health care services in the following sectors: hospitals, Community Care Access Centres (home care), addictions and mental health agencies, community support services, community health centres, and long-term care (LTC) homes (Champlain LHIN, *n.d.*; Government of Ontario, *n.d.*).

The Home First philosophy is described as “an evidence-based, person-centred, transition management philosophy” (Government of Ontario, 2011, pp. 4-5) with the aim of supporting patients to return to home upon discharge from acute care prior to assessment for and/or admission to LTC or other care settings (Government of Ontario, 2011). Under this philosophy, the transfer of patients from hospital directly to LTC is considered as a last resort, to occur only if other community-based care options are exhausted. In Ontario, a hospitalized patient is designated as ALC (alternate level of care) by a physician when a patient no longer requires the acuity of services provided in the care setting in which this patient is situated. Under the Home First philosophy, providing care in the home is considered to temper demand for costlier hospital care, such as by the occupancy of ALC patients in acute care beds as well as by helping to reduce the demand and wait lists for LTC (Government of Ontario, 2011).

In order to better understand the Home First philosophy and its potential to ideologically shape the nursing context in which the study nurses work, an examination of its principles is warranted. In the description of principles in the *Home First Implementation Guide & Toolkit* (2011), home is associated with words and phrases such as ‘comfort,’ ‘lower levels of stress,’ ‘best environment’ to make decisions, the presence of ‘loved ones,’ ‘quality of life,’ and ‘ideal

environment for post-acute care' (p. 9). These descriptors suggest an idealized conceptualization of home and delineate home as a place outside of the acute care environment, as iterated in the following definition from the Central East Community Care Access Centre (2015), "home means wherever the patient came from" (para. 2). The place of home excludes the place of acute care, the latter associated with risks of "contracting infectious disease, physical/mental deterioration and social isolation" (Government of Ontario, 2011, p. 9). Such a conceptualization of home (idealized and extrinsic to the acute care setting) is not without consequence—it serves to further the ends of governmental priorities and as such merits critical attention.

Home, defined as the place or setting where people live, is the predominant use of the term in scientific literature (Gillsjö & Schwartz-Barcott, 2009). The Home First philosophy, by appropriating the language of home as place, collapses the multifaceted conceptualizations of home. The narrow conceptualization of home as place is not simply a point of semantics but one of consequence in relation to the experience of nurses caring for aging patients and of importance regarding a place of enactment of the palliative approach, as detailed in the *Framework* (2015). While international literature reports an overall preference among people to receive care and die at home and, for many older adults, home is of considerable importance and central to daily life (Gillsjö & Schwartz-Barcott, 2009; Gomes, Calanzani, Gysels, Hall, & Higginson, 2013), the philosophy serves as a normative instrument that may silence divergence, casting those who do not conform to this norm as aberrant and thereby vulnerable to corresponding stigma. In so doing, an additional burden is imposed on those whose needs, wishes, and social situation do not correspond to the implied norm. The constructed 'good' older adult that emerges from the language of Home First is one that is efficiently managed, independently housed, and socially supported. As the philosophy reinforces the standard of

middle-class norms and affluence that presupposes a propertied or independently housed subject, aberrance is therefore a product of pre-existing disadvantage and the philosophy may in turn serve to reproduce vulnerability. In the articulation of the principles of Home First, LTC is to an extent precluded as a place of home as it is described as a place to go to *after home*. There is therefore a symbolic homelessness of individuals in LTC. From the ‘homeless’ home of LTC, come some of the patients in the geriatric psychiatry study context. This is to say that the homogenized presentation of home presupposed by the Home First philosophy can function to the exclusion of those who are homeless, marginally housed, or chronically institutionally housed, such as many of the psychiatric forensic patients and geriatric patients in the study context. Aging psychiatric patients are in many respects anomalous within the dominant Home First discourse and the philosophy may serve to reproduce discourses that reinforce marginality insofar as the articulated socio-political norms may permeate through to the care context and care provision to these same patients, including those at the research site.

The Home First philosophy underscores an effort to reduce wait times for acute care beds by means of minimizing lengths of stay which may come at a cost for patients, particularly those who need more time and care, in terms of their dignity (Calnan et al., 2013). If dignity “is most threatened when people do not have the resources (social, economic, psychological and physical) to control their lives and resist dependency and exclusion” (Calnan et al., 2013, p. 466), then older adults who are institutionalized for psychiatric care are particularly vulnerable to such a threat. In Calnan et al.’s (2013) research on the dignified care of older adults, the authors found that, in reference to maintaining optimal bed occupancy, it was “often the older person with multiple chronic conditions, who does not fit into any specialist setting, who gets moved the most” (p. 475). It follows that the ability to discern vulnerability and advocate accordingly

encompasses territory of an ethics of finitude, as conceptualized in Chapter 3. Identifying competing care priorities and contextual factors help to situate the research and delineate factors that can expand (e.g. promotion of dignity) or restrict (e.g. discharge care pathways) nurses' ability to engage with patients in the way explored by the research question. Moreover, the degree to which the philosophy is promulgated by management organizationally and/or on the study units will shape the significance of this orientation in relation to the care provided (e.g. early discharge may influence the possibility and/or willingness to engage with patients within an ethics of finitude).

This section critically reviewed literature related to the care of aging patients, including Ontario's Home First philosophy, pertinent to the study context. The next section continues this review with respect to the care of forensic and psychiatric patients and begins with a historical overview of dimensions contributing to the constructions of forensic and psychiatric patients to inform possibilities for nurses' engagement.

### **Nursing Aging Forensic and Psychiatric Patients**

According to Boschma and Groening (2010), until the 19<sup>th</sup> century, mentally ill people typically stayed at home where they were cared for by their families unless they expressed behaviour perceived as disturbing or dangerous, in which case they may have been detained in prison or in local poor houses. The historical evolution of approaches to address mental illness is aptly captured in the following excerpt:

Diverse approaches to deal with mental illness or attempts to treat it have been employed throughout history and reflect the beliefs of the time. Spiritual, biologic, and social explanations commonly were intertwined in popular perceptions of causes of mental illness. Evil spirits, sin, demonic possession, contagious environments or brain

disturbances figured in explanations of mental disorders and shaped people's responses and medical treatments accordingly. The various ways of caring for mentally ill people typically depended on a community's perceived notions of fears of those with mental disorders as well as communities' resources. (Boschma & Groening, 2010, p. 4)

This excerpt is of particular relevance given the emphasis on how the care of patients is shaped by societal views as well as by resource allocation, the latter of which is reflective of political forces. In contrast to gerontologic nursing, psychiatric mental health nursing spans a longer formal history, with the first 'mental nurse' training school established in Canada in Kingston in 1888 and the development of this nursing specialty beginning in the early 20<sup>th</sup> century (Boschma & Groening, 2010). In Canada, the *Canadian Federation of Mental Health Nurses*, an interest group of the CNA, formed in the 1980s and published the first Canadian Standards of Psychiatric and Mental Health Nursing Practice in 1995 (Boschma & Groening, 2010). Today it is possible to obtain certification in mental health nursing through the CNA's certification program. Of particular relevance here in relation to engagement is that the competency statement for this certification includes specific mention of addressing stigma, in that "stigma, consent, legal matters and capacity/competence are some issues that may affect the nurse-client relationship, and complex ethical dilemmas may arise as a result" (CNA, 2012, p. 2). Stigmatizing processes are explored further in Chapter 3 through the work of Goffman (1963). Moreover, 'safety' is an identified competency category whereby the psychiatric mental health nurse "understands predisposing safety risk factors in person(s); assesses changes in the person's physiological and mental status that indicate safety risk factors to the person, nurse and others; recognizes the impact of aggressive and abusive behaviours; and, applies risk management strategies to minimize risk to the nurse, care team and/or circle of support" (CNA, 2012, p. 11). Similarly to

nurses in the care of aging patients, nurses caring for aging forensic patients may be situated between competing discourses related to patient- and family-centered care on the one hand and organizational risk management policies on the other.

### **Discursive Contexts of Nursing Forensic and Psychiatric Patients**

To return to Phelan's (2011) work, the nursing profession and, by extension, the nursing care of geriatric and forensic psychiatry patients, exists within the context of multiple discourses. The literature review here again emphasizes that the social constructions of psychiatric and forensic patients create the conditions of possibility for attitudes, perspectives, beliefs, and engagement itself. An appreciation of the number of theories related to the care of this group exemplifies the multiple possible perspectives and orientations to engagement related to this population. Theories related to psychiatric mental health nursing include nursing theories, biological theories, psychological theories, behavioural theories, cognitive theories, developmental theories, social theories, and spiritual theories (Pagé, 2010). Nursing theories include Nightingale's environmental model (healthy surroundings help alleviate suffering and promote wellbeing), Peplau's (1988) *Interpersonal Relations in Nursing* (including the phases of the nurse-patient relationship and the interpersonal environment), and Barker's (2001) Tidal Model; the last of these is the model of care utilized in the research context (Pagé, 2010). Further description of the Tidal Model is therefore warranted to help contextualize facilitators and barriers to engagement in the study context.

The Tidal Model (2001) centers on the lived experience of the person (Pagé, 2010) and that the person's sense of self "is inextricably tied to her/his life stories and their various associated meanings" (Barker, 2001, p. 236). In so doing, the model affirms the centrality of the narrative as the intermediate of the expression of the self and in so doing, serves as a template for

health care providers to engage the person rather than the illness (Barker, 2001). The model is holistic and employs three dimensions and related assessments as means of representing personhood: world, self, and others (Barker, 2001). Barker (2001) stated that the Tidal Model assumes little about the correct journey of a person's life but affirms "that the kind of help needed by people in great mental distress is akin to developing a form of increased awareness" (p. 234). Water and fluidity provide the basis of the central metaphor of change in the Tidal Model whereby "life is a journey undertaken on an ocean of experience" (Barker, 2001, p. 235). According to the model, the focus is on providing support that people might need for them to be rescued from crisis (metaphorically, piracy), or to help put them (metaphorically, their ship) back on the life course (Baker, 2001). In this articulation, the model affirms that metaphorical language can help to describe part of the life experiences associated with mental illness (Barker, 2001). With specific consideration to the role of the nurse, Barker (2001) presents the Tidal Model as a counterpoint to the provision of nursing care in an increasingly technical and emotionally distant care context; instead, the model encourages nurses "to get close to the people in their care, so that they might explore (together) the experience of health and illness" (Barker, 2001, p. 237). Understanding the Tidal Model helps not only to understand the wider theoretical orientation of care in the study context but it may also serve as scaffolding upon which nurses may elaborate an ethics of finitude.

The Tidal Model, as the model of nursing care, represents a tension in relation to forensic nursing practice. According to Holmes and Federman (2006), forensic psychiatric nursing practice involves navigating different and contradictory mandates: to punish and to provide care (p. 15). Mason (2006) identifies five universal factors in the development of forensic psychiatry: 1) the need for the profession to be able to establish difference between normal and abnormal; 2)

the profession must be able to provide a diagnosis for the behavior or mental state under consideration; 3) a treatment program is required (e.g. pharmaceutical, psychological); 4) a prognosis is required, including prediction related to risk assessment and risk management; and, 5) there is a need to contend with the relationship between the mental state and the offensive behaviour (p. 2). Indeed, Barker (2001) contrasts the underlying assumptions of the Tidal Model with biological or organic theories of mental illness, as echoed in Mason's (2006) universal factors, that conflate "the public conception of mental illness as a function of a (largely irrecoverable) damaged or disordered brain" (p. 234). Forensic psychiatry is concerned with "the application of psychiatric and psychological practices and principles on people with mental health problems, or who have personality disorders, who have interfaced with the law at one level or another" (Mason, 2006, p. 2). It follows that nurses working in the study context may express differing if not contradictory understandings of their practice (i.e. punishment/provision of care, proximity to understand patients' experience of health and illness/distance to ensure safety and minimize risk) and these tensions may be reflected in their engagement with finitude. Moreover, forensic nurses are arguably involved in the governance of the mentally ill through various forms of power technique: sovereign (coercion, power exercised through authority), disciplinary (power operating through tools such as hierarchical observation, normalizing judgement, and examination) and pastoral (power exercised through care and therapeutic nursing interactions) (Holmes, 2002). In this vein, Jacob, Holmes, and Buus (2008) question whether nursing models such as the Tidal Model can account for the social processes characteristic of total institutions, as explored through the work of Goffman (1961) in Chapter 3. The exercise and diffusion of these powers shape the possibilities for nurses' engagement in an ethics of finitude.

### **Palliative Care and Forensic and Psychiatric Patients**

A literature search with the major heading ‘forensic nursing’ AND ‘palliative care’ OR ‘hospice palliative care’ in CINAHL yielded no journal articles. The paucity of research related to forensic nursing and palliative is identified; Fowler-Kerry (2003) observed upon the limited research in the development and implementation of palliative-care programs within forensic environments. Evenblij, Widdershoven, Onwuteaka-Philipsen, Kam, and Pasman (2016) reiterated this concern in relation to the lack of empirical research on the experiences of nurses in providing palliative care to patients with life-limiting illnesses in psychiatric health facilities. Terpstra and Terpstra (2012) identified literature on the palliative care of people with severe and persistent mental illness as sparse. It follows that a second search with the major heading ‘psychiatric nursing’ AND ‘palliative care’ OR ‘hospice palliative care’ in CINAHL yielded 42 results, of which 13 were of possible relevance to the research questions, and three of which specifically related to dementia care. The abstracts of the titles of relevance were reviewed. The bibliographies of relevant articles were mined for additional references and the search was replicated in other bibliographic databases (Medline and Scopus).

A study of relevance to the research context was that undertaken by Evenblij et al. (2016). These researchers engaged in a mixed methods study to explore nurses’ experiences with, and the barriers to, providing palliative care to psychiatric patients in Dutch mental health facilities. Three domains were identified as barriers to care, including physical, psychological, and organizational, explored below. While there are significant socio-political differences between the Dutch context of Evenblij et al.’s research setting as well as differences in care terminology, given the limited study of nurses’ experiences providing palliative care in a mental

health context, this research is of unique relevance to the research project in helping to delineate anticipated barriers to an ethics of finitude.

In the physical domain, psychiatric conditions were found to have a negative impact on access to physical care in the palliative phase (Evenblij et al., 2016). Nurses in the Evenblij et al. (2016) study reported that psychiatric patients might perceive and express pain differently and thereby present a challenge to nurses' ability to provide timely symptom management. Another barrier was the inability of some specialized psychiatric nurses to adequately attend to the physical needs of psychiatric patients related to organizational factors such as a focus on short lengths of stay and recovery-oriented models of care, under-staffing, and the lack of equipment needed in the provision of palliative care (e.g. catheters) (Evenblij et al., 2016).

In the psychological domain, the nature of psychiatric disorders can present a challenge to the communication of bad news in that "psychiatric patients might react more extremely and might be less effective in dealing with bad news" (Evenblij et al., 2016, p. 415). In other words, the psychiatric patient population may have an impaired ability to effectively cope with added stressors. It is important to consider that these findings reflect the perspective of nurses and it is worth questioning whether it is the patients who have an impaired ability to cope or whether it is providers who are impaired in their ability to support patients. The authors also found that it can be difficult to interpret the end-of-life wishes of some psychiatric patients and that palliative care provision in the psychosocial domain can be limited by the reality that many psychiatric patients are socially isolated (Evenblij et al., 2016).

In the organizational domain of care, the nurses interviewed described that shifts within the Dutch mental health system, including de-institutionalization and recovery-oriented mental health care, resulted in decreased admissions to and lengths of stay in facilities, resulting in

palliative care not seen as “core business” within mental health facilities (Evenblij et al., 2016, p. 416). While the participants recognized the need for palliative care provision within institutions, the organizational limitations resulted in the transfer out of patients to other care settings (Evenblij et al., 2016). Other organizational issues identified as presenting barriers to the provision of palliative care included the lack of staffing and equipment and the inability or unwillingness of some staff to provide physical care for psychiatric patients (Evenblij et al., 2016; Morgan, 2016).

Additional barriers to the provision of palliative care to psychiatric patients in the psychological domain were identified in a case study by Steves and Williams (2016) whereby some long-term psychiatric patients may lack insight in relation to the terminal nature of their illness. Indeed, the provision of palliative care to patients with severe and persistent mental illness can be complicated by the capacity of these patients to make end-of-life decisions and the lack of provider training and comfort in conducting end-of-life discussions with these patients (Moller, 2005). With respect to barriers in the organizational domain, Steves and Williams (2016) proposed that hospice facilities may be reluctant to accept patients with a psychiatric disorder because of the associated stigma and safety fears. It follows that there is a challenge in ascertaining the proper place of care of psychiatric patients requiring palliative care.

Morgan’s (2016) American study exploring nurses’ needs and attitudes toward people with severe mental illness at end-of-life directly addressed the challenge of the proper place of care. This research identified stigma as one of six themes that emerged from the interviews and this stigma is related to misunderstandings about mental illness and fears of providing end-of-life care (Morgan, 2016). Communication limitations related to the nature of severe mental illnesses emerged, similar to those identified by Steves and Williams (2016) and Evenblij et al. (2016).

The author identified numerous challenges related to the theme of difficult family situations when caring for people with severe mental illness, including the challenge presented by family members with their own psychiatric diagnoses and the role of substitute family assumed by some psychiatric nurses (Morgan, 2016). The study nurses described their work as advocates while some expressed regrets over their lack of advocacy for patients (Morgan, 2016). The author found that the challenging nature of the work led some nurses to express a need for greater support in dealing with their own reactions to the population (Morgan, 2016). Overall, the author identified the theme of “no right place” in that the issue of appropriate palliative care for patients with severe mental illness is lacking in many care contexts: psychiatric units, general medical units, geropsychiatric units, and hospice/palliative care (Morgan, 2016, p. 38). While the American research context presents differences from the current one, particularly in relation to differing health care funding structures, these findings enrich and nuance those of Evenblij et al. (2016). While Morgan (2016) noted that the “lack of experience caring for people with medical problems is common among psychiatric nurses,” (p. 32) and that resistance to providing medical care exacerbates this problem, the participants’ suggestions for improvements of palliative care echo these concerns in their suggestion to increase psychiatric nurses’ competencies in pain management and medical skills. It follows that the literature reveals there may be gaps in psychiatric nurses’ ability to provide appropriate care to patients requiring palliative care.

The literature overview by Woods, Willison, Kington, and Gavin (2008) underscored that the palliative care needs of people with severe and persistent mental illness are similar to those of the general population and that there is a need for cross training in palliative care and mental health. Indeed, McGrath and Holewa (2004) identified a number of correlations between mental health and palliative care philosophies including: compassionate and holistic care, respect for

autonomy and choice, and concern for quality of life as defined by the patient. Building on this, Terpstra and Terpstra (2012), highlighting challenges to the provision of palliative care to patients with persistent mental illness, emphasized that the philosophical similarities between mental health and palliative care can serve to facilitate the integration of both these areas of care. As to the aim of exploring the environmental factors that shape palliative care in correctional settings, Burles et al. (2015) narrative review of the literature highlighted how complex factors related to incarceration, including negative views held of those who are criminally involved and factors related to confinement itself, serve to hinder factors typically associated with a good death, namely: comfort, control, and closure. The authors described the challenging nature of providing health care in an environment of correctional priorities and in which criminally involved individuals are stigmatized:

Unfortunately, compassionate behaviours exhibited by health care providers are too easily misunderstood by correctional staff, whose mandate is security and public safety. As such, health care providers face the ongoing challenge of providing care and comfort to ailing patients amidst an atmosphere of animosity towards the individuals for whom they care. (Burles et al., 2015, p. 9)

This excerpt highlights how the provision of health care, including palliative care, within forensic settings is challenged insofar that nurses working within these settings may be caught between competing socio-professional mandates of punishment and care provision (Holmes, 2005). This tension is explored further in the work of Goffman (1961) on total institutions in the next chapter. In addition, environmental considerations in forensic settings related to security priorities can limit the possibilities for palliative care provision (Howe & Scott, 2012). Holmes (2005) described forensic nurses refraining from expressions of care, such as the use of touch, to

inmates as compared to patients in a more conventional care setting and put forth that this may be related to the process of abjection as the significant variable between the two groups. Without engaging in a conceptualization of abjection, it is possible to see this process in the context of the reproduction of wider social stigma held toward incarcerated individuals.

It is important to consider the unique challenges evident in the care of aging forensic patients. Fazel, Hope, O'Donnell, Piper, and Jacoby (2001) found that incarcerated older adults had higher rates of illness than a comparable population in the community and in their review of the literature, Burles et al. (2015) found that incarcerated men and women are generally considered to be 7 to 12 years older physiologically than their chronological age. These findings can be viewed as symptoms of structural vulnerability, that is the “intersecting social and structural forces that constrain decision-making, frame choices, and limit life options to make people vulnerable to risk and harm” (Reimer-Kirkham et al., 2016a, p. 2). Vulnerability is often intersected with stigma: Maschi, Marmo, and Han (2014) identified stigma as an understudied area of research in relation to its effects on the public and criminal justice personnel’s “attitudes toward the intersection of aging, death and dying, and crime and punishment” (p. 191). It follows that not only is the forensic population under the care of nurses at greater risk for poor health outcomes but it is additionally vulnerable in its historical marginality within research and in the provision of palliative care:

[C]urrent palliative care approaches do not make explicit the additional attention needed to address social and structural inequities that profoundly shape health, illness, and dying experiences for people who are made particularly vulnerable by a constellation of sociopolitical, economic, cultural, and historical forces. (Reimer-Kirkham et al., 2016a, p. 2)

Given the historical disadvantages shaping the possibilities for the health and care of forensic and psychiatric patients, consideration of sociopolitical, economic, cultural, and historical forces, as explored in this review, is warranted. While this section reviewed literature and historical considerations informing and structuring some of the possibilities for care of and engagement with forensic and psychiatric patients, the next section examines the historical development of the modern hospice palliative care movement more broadly, including drug policy as an example, to elucidate the legacy of possibilities for engagement within the study context.

### **Historical Development of Modern Hospice Palliative Care**

A critical appraisal of the history of palliative care, including public and academic discourse related to this topic, serves to illustrate the socio-political relevance of the research aims. In this section, a critical analysis of the historical development and conceptual underpinnings of the modern hospice palliative care movement through to the contemporary Canadian context characterized by the ‘palliative approach’ is presented, including the advent of the modern hospice palliative care movement, the historical development of palliative care in Canada, the evolution of the language of palliative care, and the concept of illness trajectories and prognostication. Broad socio-political forces that shape the perception and practice of palliative care are considered, and in so doing, forces that give shape to possibilities for engagement are delineated.

### **Modern Hospice Palliative Care**

In order to understand palliative care in today’s Canadian nursing care context, a brief historical overview of the evolution of this care from Western European origins is warranted to situate the language used related to this care and to appreciate historical tensions and influences, such as religion, that can be contemporaneously echoed in the study context. In Europe, the care

of the dying was usually provided and maintained by religious orders (Auger, 2007). Although the first hospices and the use of the term can be traced to the 4th century when Christians in Europe provided care to the sick and destitute, crusaders in the 11th century are thought to be among the first to establish homes for the ‘incurably ill’ (Auger, 2007). The European hospice movement began in 1842 in Lyon, France, where the Dames de Calvière hospice was founded for the “mortally ill” (Auger, 2007, p. 86). This was followed by the opening of Our Lady’s Hospice in Dublin, Ireland in 1879, and St. Joseph’s Hospice, London, in 1905, for those dying of tuberculosis (Auger, 2007).

The historical roots of modern hospice palliative care originate in the field of oncology, and a cancer focus continues to predominate palliative care (Carstairs, 2005; Clark, 2007). In the 1950s, cancer care was focused on curative treatment and patients dying from cancer were often overlooked or abandoned by physicians when the latter perceived that little more could be curatively done (Clark, 2007). The 1950s marked a time when new research emerged from medicine, social work, and social sciences that ultimately came to challenge the increased marginalization of death and medicalization of dying (Clark, 2007). Cicely Saunders, founder of the first modern hospice in 1967, wrote of the care of the dying as a medical student in 1957, publishing “Dying of Cancer” in 1958—a paper that is viewed by some as a manifesto for the hospice palliative care movement because the work was the first to delineate the central concerns of the care of the dying (i.e. pain, mental distress, spiritual care) (Saunders & Clark, 2006). In 1961, Saunders presented one of her early papers, “Terminal Illness” to the Congress of the Royal Society of Health and in so doing helped to disseminate her work more broadly, including to officials in the British Ministry of Health (Saunders & Clark, 2006). Beyond the considerable influence of Saunders, contributions to changing perspectives related to the care of the terminally

ill that emerged in the 1960s and early 1970s included the seminal ethnographic work of Glaser and Strauss on the care of dying patients in American hospitals: *Awareness of Dying* (1966) and *Time for Dying* (1968); Kubler-Ross's book *On Death and Dying* (1969), which identified and described five stages of grief; and Becker's non-fiction, *The Denial of Death* (1974), which explores death denial as a motivating force in human behavior and anxieties.

In parallel with the account of the modern hospice palliative care movement is the evolution of the field of oncology. Until the 1960s, surgery and radiotherapy dominated cancer therapy and medical oncology was not recognized as a clinical specialty (DeVita & Chu, 2008). It was in part due to drug research projects from the second world war that generated the momentum to establish a national drug development effort in the United States in 1955 (DeVita & Chu, 2008). Significantly, with the introduction of combination chemotherapy programs in the 1960s, the idea of cure in cancer treatment entered public consciousness after first becoming a reality for patients with childhood acute leukemia and for adults with advanced Hodgkin's disease (DeVita & Chu, 2008). The idea of cure can be seen to juxtapose that of comfort of the hospice palliative care movement and the rise in the visibility of the field of oncology can account for a corresponding effect in the prominence of palliative care (Sporn, 1996).

Founded in 1967, St. Christopher's Hospice in London, England, is considered to be the first modern hospice (Fallon & Smyth, 2008). At the time, the hospice palliative care movement was regarded as 'care of the dying,' 'end-of-life care,' or 'terminal care' (Clark, 2007; Fallon & Smyth, 2008) and such care was considered distinct from active or curative treatment (Saunders, 1965a). The program of care of the dying developed at St. Christopher's was based on the principles of pain control, family and community involvement, and engagement with the dying person's spirituality (Coward & Stajduhar, 2012). The work at St. Christopher's brought together

new skills and approaches that were emerging, such as the work at St. Luke's Hospital and St. Joseph's Hospice, to improve pain assessment and management and to recognize both spiritual and physical patient concerns (Saunders, 1965b; Saunders & Clark, 2006). St. Christopher's was associated with significant research projects that served to advance the field of palliative care (St. Christopher's Hospice, 2016) and stood "as a protest against the shortcomings of modern high technology medicine" (Twycross, 1980, p. 475). Important advances in end-of-life care that stemmed from Saunders' research included around the clock medication administration to control constant pain and the concept of 'total pain' that included physical, emotional, social, and spiritual components (Baines, 2011; Clark, 2007). This understanding of pain served to better appreciate individuals' multiple care needs at end-of-life and reflected a growing acknowledgement of the interplay between mental and physical distress at end-of-life. The care of the dying began to shift from anecdote to systematic observation, reflecting a more active approach to the care of the dying (Clark, 1999). For its time, the work of St. Luke's and St. Christopher's was considered to be outside the mainstream of medicine and teaching (Saunders & Clark, 2006), a perspective that persists to this day with respect to the integration of palliative care into mainstream health care (Benowitz, 2013).

The view of palliative care as a counterpoint to mainstream medical care is contested. On the one hand, the grass-roots movement of hospice care is a counter-hegemonic force to mainstream medicine in support of dying with dignity—on the other hand, as palliative care has grown, the movement is challenged insofar as to be routinized and institutionalized within mainstream health care and, in this shift, palliative care has become increasingly medicalized (Syme & Bruce, 2009). While Syme and Bruce (2009) propose a view whereby palliative care is a social movement that both augments and opposes a curative model of care, there is in this observation a

caution to this project insofar as it may rely on a care modality definition that may inadvertently further medicalize mortality. Reflection on linguistic consideration is provided in the modified concept analysis of palliative approach in the conceptual scaffolding in Chapter 3.

The principles informing the modern palliative care movement are important to consider for their continued legacy in the provision of this care. Captured in the work of the early supporters of St. Christopher's, this group produced a document that defined St. Christopher's as based on Christian religious foundations and themes of religion, medicine, and the notion of community (Coward & Stajduhar, 2012). This early work underscored the holistic principles in the approach to care in the modern hospice movement and also its religious influences. It is important to also consider the cultural and religious context from which the modern palliative care movement emerged insofar as to account for the possibility for a continued legacy of these origins in contemporary care provision. The modern palliative care movement began in a Christian context and, though Saunders herself was a committed Christian and member of the Church of England, the modern hospice was purported to be open to all religious traditions (Coward & Stajduhar, 2012). For Saunders, the medical and spiritual dimensions of the work of caring for the terminally ill were inextricably connected (Coward & Stajduhar, 2012). As many of the other early pioneers of the modern palliative movement shared a common faith rooted in Christian traditions, including Balfour Mount in Canada, it is worth considering, whether the Christian perspective is an essential part of palliative care or whether it is simply a shared motivating force (Coward & Stajduhar, 2012). The influence of religion in the provision of end-of-life care continues and has been recently rekindled in Canada with respect to debates upon and the accessibility of medical assistance in dying. Religious dimensions may shape engagement within a palliative approach insofar as they correspond to or diverge from care providers' beliefs about

palliative and end-of-life care. The features of the evolution of palliative care unique to the Canadian context are considered next so as to elucidate possibilities for nurses' engagement in the study context.

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

The palliative lexicon, as explored in the conceptualization of 'palliative approach' is of multi-faceted significance to the research context as it shapes and shadows possibilities for care provision, research, and funding (Benowitz, 2013). Although the modern hospice palliative care movement began in the 1950s, the term 'palliative care' was only coined by Canadian urologist Balfour Mount in 1974 (Baines, 2011; Clark, 2007). The term 'palliative' originates from the Latin word 'palliare', which means 'to cloak' (Lutz, 2011). Mount opted for this term as the French use of the word 'hospice' was used to describe "a nursing home for the poor and the destitute" (Pastrana, Jünger, Ostgathe, Elsner, & Radbruch, 2008, p. 222) and as such associated with negative connotations (Syme & Bruce, 2009). This choice of language is not without irony as Canadian palliative care services are currently poorly equipped to care for homeless populations and "most programs are built upon an infrastructure that is prohibitive for the homeless to access its services" (Huynh, Henry, & Dosani, 2015, p. 1). While the language of palliative care cannot readily account for social inequities, it does serve to give shape to possibilities for care.

The hospice palliative care movement started in the 1970s in Canada (Brooksbank, 2009). This included the palliative care programs opened at the Royal Free Hospital in Winnipeg in 1975 and at the Royal Victoria Hospital in Montreal in 1976 (Auger, 2007). Casey House, the first free-standing hospice was opened in 1983 (Auger, 2007). Along with initiatives led by Mount at the Royal Victoria Hospital, which included hospital-based palliative care services,

consultation service, home care and bereavement support services, hospice care in Canada evolved from a grass-roots movement with the participation of volunteers and care centered in the home, with inpatient facilities as a recourse (Brooksbank, 2009; Twycross, 1980). Nationally, the palliative care organization now known as the Canadian Hospice Palliative Care Association, the authoring organization of the *Framework and Model* (2013; 2015), was established in 1991 (CHPCA, *n.d.a*).

Williams et al. (2010) proposed a conceptual model of the evolution of hospice palliative care provision in Canada. In addition to an underlying death denying and bio-medically oriented culture, the model identifies three inheritances related to provincial and national policies and practices that shaped the development of hospice palliative care: foundational health policies (e.g. *Canada Health Act*); service structures (i.e. urban-focused health services); and health system decisions (i.e. identification of certain health services as ‘core services’) (Williams et al., 2010). The model assumes that the evolution of hospice palliative care is both advanced and hindered in relation to these inherited structures (Williams et al., 2010). While hospice palliative care can, most directly, emerge as a product of strict adherence to the inheritances listed above, the model identifies three forms of circumventions in relation to these inheritances: new alternative structures, interventions to shift the system; and, service innovations (Williams et al., 2010).

While the formalized structures of Canadian health care are not the only inherently organizing force relative to end-of-life care and death and dying, the model identifies important processes within the Canadian health care structure that order the current hospice palliative care landscape. Indeed, the scope and impact of specific national and provincial policies and practices shape how people access health care, and by extension, where people live and die. As such, the

public funding of palliative care services is one means to understand historical barriers and enablers to nurses' engagement in the care of patients with life-limiting illness. For example, Williams et al. (2010) found problematic the absence of dedicated funding for hospice palliative care as this money falls within the funding envelope for other core services regulated by the *Canada Health Act* (CHA), such as hospital care, long-term care, and homecare. Williams et al. (2010) argue that this has created an "uneven prioritization of palliative care across regions and provinces due, in part, to a lack of direction from the CHA, along with lack of standardization for, and thus inequity in, service provision" (Williams et al., 2010, p. 5). The authors found that the lack of funding in the Canadian public system for hospice palliative care was identified as a significant limitation of current health policy and services (Williams et al., 2010). With respect to health systems decisions, the authors found that greater accountability in the allocation and spending of funding can result from the identification of palliative care as a 'core service' (Williams et al., 2010). Williams et al.'s (2010) model can help to contextualize the service structure that is the setting of the research. As a tertiary psychiatric facility in an urban centre, the inheritances unique to this care context may be reflected in the data. For example, as situated in a large urban center, nurses in this context may have more encounters with palliative care service provision, including specialized tertiary services, than is likely in a rural context. Moreover, the structure and function of geriatric and forensic psychiatric care may present unique hindrances and opportunities for the evolution of hospice palliative care and the engagement of nurses.

As further context to the evolution of hospice palliative care, Canadian national attention on the need for palliative and end-of-life care was galvanized following legal decisions in the 1990s, including the Supreme Court of Canada's Sue Rodriguez ruling in 1993, which brought

assisted suicide and euthanasia to public and political attention (Parliament of Canada, 1995). As a result, a series of initiatives were undertaken at the level of the federal government. The Special Senate Committee on Euthanasia and Assisted Suicide Committee was organized and tasked to report on the legal, social, and ethical issues relating to euthanasia and assisted suicide (Parliament of Canada, 1995). This Committee recommended that governments make palliative care programs a priority in health care system restructuring as well as emphasizing the need to develop and implement national guidelines and standards and to improve the training of health professionals and access to respite services (Parliament of Canada, 1995). A subsequent federal report, *Quality end-of-life care: The right of every Canadian* (2000) described 14 recommendations, including the development of a national strategy for end-of-life care (Parliament of Canada, 2000). This took shape in the *Canadian Strategy on Palliative and End-of-Life Care* in 2002 that identified five priorities: best practices; research; public information and awareness; surveillance; and, education for professional health care providers (Carstairs, 2005). A number of initiatives related to palliative and end-of-life care marked the early 2000s. Established in December 2000, the Quality End-of-Life Care Coalition of Canada brought together approximately 20 national organizations to lobby for improved end-of-life care (Carstairs, 2005). In 2001, two federal leadership roles were established: the Minister with Special Responsibility for Palliative Care, which gave palliative care a formalized place in the Cabinet, and the Secretariat on Palliative and End-of-Life Care, established within Health Canada, to support the development of the national *Strategy* (Carstairs, 2005). In 2002, the CHPCA's *A Model to Guide Hospice Palliative Care* was first published, establishing norms of practice in hospice palliative care in Canada (Carstairs, 2005)—a document that is a key reference in this research's conceptualization of the palliative approach.

Despite these measures, in the 2005 report *Still Not There* on the progress of the 2002 *Canadian Strategy on Palliative and End-of-Life*, Carstairs noted that the *Strategy* had been incompletely implemented and failed to meet its objectives. The author reiterated the need for national leadership and identified a further ten recommendations to improve end-of-life care in Canada including: sustainable secure funding, ongoing education and training for health care professionals, continued research, disseminating best practices, enhanced support for caregivers (i.e. extending compassionate care benefits), and measures to inform the public (i.e. on regionally-available palliative and end-of-life services, how to apply for the compassionate care leave benefit) (Carstairs, 2005). In her report, Carstairs (2005) commented upon the legacy of the largely grass-roots and voluntary development of palliative care programs in Canada, which resulted in a high proportion of unpredictable charitable funding and therefore an uneven distribution of end-of-life programs across Canada, considerable differences in services provided, and unmet care needs. Again, using Williams et al.'s (2010) conceptual model, it is possible to see how the legacy of the voluntary service structures both advanced and hindered the evolution of palliative care. While the voluntary sector emerged to meet a community need, meeting this need through private funds perhaps hindered the public prioritization and funding of this care. It follows that this overview of some of the intersections of foundational health policies, service structures, and health system decisions helps to map dimensions of the landscape in which Canadian palliative care is situated and the possibilities for its enactment.

Beyond health policies, system decisions, and structures, the Canadian geopolitical context shapes the delivery of palliative care in both how this care is structured and in the kind of care modalities available. With respect to care modalities, pain management and drug policy are good examples of how political forces influence everyday practices, such as the type of analgesia

available to patients. In the United Kingdom, the medical use of heroin (diamorphine) is commonplace and sometimes preferred in palliative care as it is more soluble and potent than morphine when given parenterally (Gossop, Keaney, Sharma, & Jackson, 2005). Early innovations related to pain management in the hospice palliative care movement stemmed from clinical predominance of heroin as pharmacotherapy:

Although the importation of diacetylmorphine (Heroin) is illegal in the United States we use this drug almost exclusively. We have found that, although the other opiates and some of the synthetic drugs may relieve pain just as effectively, only diacetylmorphine will do so with so few side effects or leave the patients so alert and serene. (Saunders, 1965a)

Diacetylmorphine continues to be used for analgesia in the United Kingdom (Gossop et al., 2005). Indeed, pain management is a central component of palliative care (Dalal & Bruera, 2013) and according to the WHO's principles for analgesic administration for cancer pain, the importance of an individualized approach is highlighted (1996). This individualized approach is based on the considerable genetic variability in opioid metabolism and on the observation that the same patient may find different opioids effective for different types of pain and determining optimal analgesia can often be a process of trial and error (College of Physicians and Surgeons of British Columbia, 2015). Despite the importance of an individualized approach in the management of pain, diacetylmorphine is unavailable or prohibited in most countries and Gossop et al. (2005) contend that much of the concern around the medical use of heroin stems from popular discourse that presents this drug as the "archetypical illegal drug of addiction" (p. 81).

Canada is influenced by American drug policy and geopolitics. It was at the urging of the United States and under the advice of the WHO that in 1954, the United Nations Economic and

Social Council entreated governments to prohibit the legitimate manufacture and export of heroin with the exception for scientific purposes and to which Canada complied in 1955 (Coomber, 1998; Gifford-Jones, 2000; United Nations Economic and Social Council, 1954). This was later followed by the 1961 United Nations Single Convention on Narcotic Drugs, part of the United States war on drugs (Laursen, 2016). Canadian doctor Gifford-Jones began campaigning in 1979 for the legalization of heroin in order to improve its access to cancer patients. Despite opposition and based on campaigning efforts, the *Narcotic Control Act* was amended in the 1980s to legalize heroin as an analgesic (Gifford-Jones, 2000). However, due to restrictions and opposition within the medical community, the use of heroin in advanced pain management in Canada was limited (Gifford-Jones, 2000). While today the drug is available by special permission under Health Canada's Special Access Programme (Woo, 2016), its use remains marginal (Gifford-Jones, 2000). In parallel, the international drug policy context influenced prescribing practices at St. Christopher's whereby morphine was at times substituted for heroin based on considerations of the leadership role of the organization in pain management and so as not to disadvantage other hospices around the world unable to access heroin (Gifford-Jones, 2000).

The restrictive drug policy context is contemporaneously echoed in the Government of Ontario's Narcotic Strategy that is purported to address the public health issues related to increases in opioid addiction, unlawful use of opioids, and opioid overdose deaths (Ministry of Health and Long Term Care, 2015). Part of the strategy included the delisting of higher strengths of long-acting opioids from the Ontario Drug Benefit Program formulary, such as fentanyl transdermal patches of 75mcg/hr and 100mcg/hr (Ministry of Health and Long Term Care, 2016a) and the institution of a fentanyl "Patch for Patch" pharmacy return program under the

Ontario Public Drug Programs Division (Ministry of Health and Long Term Care, 2016b). While the effect of these changes is most pronounced in community care settings, the socio-political discourse around opioids is significantly echoed in palliative care provision. For example, in the 2008 International Narcotics Control Board report, the main factors contributing to the limited availability of opioids for medical needs included: fears about opioid addiction, reluctance to prescribe or stock opioids, the existence of restrictive laws and regulations and the lack of training for health-care professionals. The restriction of pharmaceutical grade heroin and the Government of Ontario's Narcotic Strategy underscore the hegemonizing effect of drug policies and how the possibilities for the enactment of palliative care, such as the management of pain, are scripted in ways that may go unquestioned or be rendered invisible. With respect to nurses' engagement with finitude, fear and stigma are significant parallels in the construction of drug policy and biomedical discourses around illness; government policy may serve to reinforce fears of addiction at the expense of a patient-centered approach. Moreover, the Government of Ontario's strategy, with its emphasis on opioid addiction, functions so as to reinforce the distinction between patients living with the life limiting nature of substance use disorder from patients who may be amenable to a palliative approach and precluding both groups from the possibility of requiring pain management from higher strength long-acting opioids. While drug policies, like the US-led war on drugs, have the effect of shaping palliative care delivery, so too do respective Canadian health care policies and research funding priorities.

Another example of how the Canadian geopolitical context shapes the delivery of palliative care in both how this care is structured and the kind of care modalities available can be explored in the historical association of palliative care and oncology. By the 1970s, cancer was identified as a leading cause of death in the United States and in 1971, President Nixon

inaugurated the “war on cancer” by passing the *National Cancer Act* and establishing the National Cancer Institute (National Cancer Institute, 2016). The advances brought about by this initiative made the plight of those suffering from cancer more visible and the research and advances that stemmed from this served to improve palliative care options through the introduction of new devices, pumps, appliances, and drugs such as anti-emetics as well as through the overall improvement in basic scientific knowledge about cancer (Sporn, 1996). The *National Cancer Act* helped to improve the approach to cancer, “from increased public awareness to better surgical treatment and more humane management of terminal illness” (Sporn, 1996, p. 1377). Despite these advancements, the initiative served to perpetuate a public orientation on the cure for cancer (Sporn, 1996) and in its funding focus on cancer research, it served to prioritize cancer among other causes of mortality. The legacy of the “war on cancer” may correspond to more limited nursing experience and research in the care of less funded and as such less visible end-of-life trajectories, such as organ failure, dementia, and frailty (Murray, Kendall, Boyd, & Sheikh, 2005). Also, the legacy of the war on cancer illustrates how social and political discourses shape the possibilities for how patients are conceptualized, as Phelan (2011) argued in relation to the conceptualization of older patients. It follows that some patients with life-limiting illnesses may be more or less visible in their end-of-life trajectory. The consequences of this oncology-focus in palliative care in relation to the research context are explored further in the conceptualization of the palliative approach.

As the evolution of palliative care in Canada demonstrates, many socio-political factors shape the current context of palliative care provision. To reiterate the underlying death denying and bio-medically oriented culture in Canada identified by Williams et al. (2010), Dr. Balfour Mount stated “people who provide health care are so afraid of death themselves that fear

compromises their ability to administer to the needs of terminally ill patients” (Lowry, 1997, p. 301). Mount argued that it was the fear of death and dying that interfered with the realization of the full potential of palliative care (Lowry, 1997). While this article was written twenty years ago, access to palliative care continues to be a matter of public concern (CHPCA, 2015).

Mount’s contention that “perhaps the most powerful reason why physicians don’t meet patients’ needs involves their intrinsic anxiety about death,” while articulated in relation to physicians, echoes the very need for engagement with mortality (Lowry, 1997, p. 301). In contrast to the fear Mount identifies, in Sinclair’s (2011) ethnographic work on the early life experiences of hospice and palliative professionals’ experiences with death, the author refers to participants’ experience of the integrated death as “a positive experience, where death and dying was acknowledged, normalized and integrated into the continuum of life” (p. 182). It follows that while a number of characteristics and values have come to define palliative care, this includes the element of an open awareness of death whereby mortality is regarded as part of the normal process of living, as included in the WHO’s (*n.d.*) definition of palliative care. Providers’ awareness of mortality—and their fears surrounding it—shape possibilities for engagement within a palliative approach. Mount’s contention regarding health care providers’ fear of death and dying and its limitation on the advancement of palliative care is echoed in the roadmap of the CHPCA’s *Framework* (2015) which identifies ways to create the needed shift in health care practice and culture to bring about the called for transformation. Part of the cultural shift includes challenging attitudes within the health care system by educating and supporting “healthcare providers to help them overcome their own fear of loss, dying, and death” (CHPCA, 2015, p. 24). To this end, the *Framework* calls for health care professionals to “examine their own fears and attitudes about loss, dying and death and come to terms with their own mortality” to develop the skills and competencies to

integrate the palliative approach into routine care (CHPCA, 2015, p. 25). While it may be unrealistic for anyone to truly come to terms with their own mortality, a project that explores nurses' engagement in relation to mortality is situated within the scope of the *Framework* and the culture shift it proposes (CHPCA, 2015).

Research related to advance care planning also yields insights into the attitudes of health care providers in relation to engagement in finitude. Advance care planning is considered to include continued conversations about goals of care (Speak Up, 2015) and therefore the barriers identified in this research serve to contextualize challenges to the ongoing engagement with patients in an ethics of finitude. In Travers and Taylor's (2016) literature review, barriers to initiating end-of-life conversations in acute hospitals included health professionals' attitudes and behaviours. Under the category of 'attitudes', fear and hope, personal preference, lack of experience, and comfort were identified as barriers to initiating these conversations (Travers & Taylor, 2016). Of particular relevance is how the personal preference of the care provider was found to affect the ability to discuss advance care plans and how discomfort with death and dying or the perception of death as a taboo were barriers for nurses' engagement in care planning (Tay, Ang, & Hegney, 2012; Travers & Taylor, 2016). Travers and Taylor (2016) found that institutional factors or culture can influence clinicians' communication with patients approaching end-of-life such as an orientation focused on cure and treatment and stigma around palliative care. From research in the Singaporean context, Tay et al. (2012) found that oncology nurses were fearful and uncomfortable about discussing death and dying and that this impeded nurse-patient communication. This research underscored how cultural factors, such as those in the Singaporean Chinese community in which death is considered a taboo and discussions related to death are avoided as they are feared to bring misfortune, can influence nurses' engagement (Hsu,

O'Connor, & Lee, 2009; Tay et al., 2012). While this research may seem removed from the current research context, cultural factors that emerge from the diverse ethnic backgrounds of the Canadian population may be reflected in the values expressed by nurses.

This chapter presented a thematically organized literature review and critical appraisal related to nursing aging patients and nursing forensic psychiatric patients. Discursive contexts and the development of these nursing specialities were considered and in so doing were the social construction of related discourse, such as aging, illness, and security. Included in this chapter was an overview and critique of the historical development of palliative care, including the advent of the modern hospice palliative care movement and some of the socio-political influences shaping its evolution in the Canadian and Ontarian care environment. Additional contextual factors were considered related to the provision and language of palliative care, including policy direction and research pertaining to health care providers' engagement with mortality.

### Chapter 3: Conceptual Scaffolding

Theory is an organized conceptualization of statements or a symbolic depiction of aspects of reality that is related to a significant question and that is “communicated in a meaningful whole” (Meleis, 2007, p. 37). A concept, on the other hand, is used to “describe a phenomena or a group of phenomena” (Meleis, 2007, p. 33). The conceptual scaffolding in a research study is generally considered to serve an “integrating function between theories that offer explanations of the issues under investigation” (Leshem & Trafford, 2007, p. 99). Conceptual scaffolding operates as a mechanism to focus the research (Durham, Sykes, Piper, & Stokes, 2015); indeed, each element amplifies certain aspects of the issue at hand while leaving others in the dark (Bordage, 2009). The conceptual scaffolding here shapes the presentation of research findings by emphasizing the conceptualization of these within their respective theoretical context and this ordering helps to make the findings more accessible (Leshem & Trafford, 2007; Polit & Beck, 2012). In this chapter, the main conceptual constructs of the research and their interrelations are described. In line with interpretative phenomenological analysis (IPA), the analysis is a two-staged interpretive process, in which “the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2003, p. 51). It follows that the development, evolution, and [re]articulation of the conceptual scaffolding presented here reflects in part this double hermeneutic process and, in so doing, theoretically posits an approximate and partially organized conceptual accounting of “what it is like” from the perspective of participants (Smith & Osborn, 2003, p. 51). As further detailed in Chapter 4, IPA is employed as a methodological approach in conjunction with interpretive description (ID), the latter of which informs a departure from a strict methodology to offer a more comprehensive and contextualized interpretation of the phenomenon of interest within the clinical nursing environment (Thorne et

al., 2004). ID presumes that there is theoretical knowledge within which studies of human health phenomena are generated and therefore it affords me the opportunity to include reference to this scaffolding, as follows in this chapter (Thorne et al., 2004).

The research project explores nurses' engagement with patients' mortality by means of an ethics of finitude in the context of geriatric and forensic psychiatry within a specialized urban Canadian psychiatric hospital. Based on the qualitative and exploratory nature of the research project, ensuring fit between this purpose and the conceptual scaffolding is essential: the scaffolding therefore serves to bridge the research paradigm employed to explain the research issue with the practice of investigating that issue (Leshem & Trafford, 2007).

IPA is a research approach concerned with the construction of meaning within both social and personal worlds (Smith & Osborn, 2003). According to Strauss and Corbin (1990), writing on qualitative research in general, this approach is similarly echoed in the theoretical sensitivity of the researcher in that it is a personal quality of the researcher characterized by "the ability to recognize what is important in the data and to give it meaning" (p. 46). According to Glaser (1978), also in reference to qualitative research more generally, theoretical sensitivity helps to formulate theory that corresponds to the phenomena of study and it is based on technical literature, professional and personal experience, and through the research process and interactions with the data (Strauss & Corbin, 1990). As such, development of the conceptual scaffolding is one subject to iteration and revision, based on analysis of and interaction with the data.

In the proposed scaffolding, the process of engagement is first situated within the palliative approach to care. While the concept palliative approach is increasingly used in palliative care literature, it is often inconsistently defined or left undefined. To accurately situate

this project within palliative care nursing practice and to practically delineate this project within current nursing care modalities, a modified conceptual analysis of the palliative approach is provided, followed by a proposed conceptualization of this care. Second, the conceptualization of the palliative approach serves as an interface from which to introduce and articulate an ethics of finitude, as proposed by Brinkmann (2006). The motif of *memento mori* is explored and presented as a symbolic device that entreats human remembrance of mortal finitude and thereby serves as a functional link between foundational elements of the palliative approach and the elaboration of an ethics of finitude.

Third, the dimension of place in relation to the lived experience of nursing care is an essential aspect of the social processes involved in the research problem. Place, in the sense of relationship, is used to designate a form of social organization permeated by various diffuse power relations. In this understanding, the places of total institutions (Goffman, 1961) and that of home are considered to delineate the loci of social processes of nursing and as such the potentialities for an ethics of finitude. Fourth, a conceptual understanding of stigma using Goffman's (1963) seminal work is explored to understand stigmatizing processes, often associated with aging, dying, and mental illness, and to identify how stigmatizing discourses may be challenged or cemented in the discourse of nurses.

### **Palliative Approach**

The palliative approach is a central concept of the research scaffolding as it serves to articulate an approach to care for aging patients in geriatric and forensic psychiatry in which an ethics of finitude can be engaged and it is the approach articulated for all Canadians living with chronic illness and frailty, regardless of their context of care, in the CHPCA's *Framework* (2015). As background, the 'terminal care' of the early modern palliative care movement

evolved into the discipline of palliative care, which came to apply the same holistic principles of end-of-life care to the care of those earlier in their disease trajectory and in different care settings (Clark & Graham, 2011). In 2002, the WHO modified its definition of palliative care to reflect an understanding that the principles of palliative care should be applied early on in the course of life-limiting illness based on an understanding that problems at the end-of-life originate earlier on in the trajectory of disease (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). Today the WHO (*n.d.*) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of *early identification* [emphasis added] and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Significant in this definition is that the WHO (*n.d.*) defines palliative care as an *approach* and within the literature, it is increasingly articulated that a palliative approach should be adopted in varying care environments and with different patient populations (Bacon, 2012; Passmore, Ho, & Gallagher, 2012).

### **Process of Engagement**

The process of engagement is situated within the palliative approach to care. Engagement, as an interpersonal process in this project in relation to the nurse-patient relationship, is understood to mean the active involvement of nurses to encounter patients in opportunities for emotional resonance and empathy and includes a cognitive appraisal, and a motivation to act, building upon Ekman and Halpern’s (2015) work on professional empathy. These authors identify this opportunity to engage empathically and compassionately with patients as a central reason drawing care providers to the interpersonally challenging work of professions such as nursing (Ekman & Halpern, 2015). It is in this sense of emotional resonance

and empathic connection that engagement is proposed within this research and, within the subsequent conceptualization of the palliative approach, it is possible to see how this so defined engagement mirrors foundational elements of this approach.

### **Palliative Approach: Conceptual Clarity Required**

Despite its increased use and its articulated significance as a care modality, the term palliative approach is often left undefined or used interchangeably with other terms like palliative care, integrative palliative approach, and patient-centered care (Bacon, 2012; CHPCA, 2014). If palliative care is by definition an approach, the increasing use of the term merits conceptual clarity, as the term would appear to encompass conceptual territory that palliative care does not. Confusion results from using the same term with implicitly or explicitly different meanings and, without a clear conceptualization, the quality of subsequent research is weakened (Rodgers, 1989; Weaver & Mitcham, 2008). Situating this research within a clear conceptualization of palliative approach is important as it serves to clarify the palliative care lexicon, to understand what care practices are valued/funded, and to appreciate how an ethics of finitude can be situated within an evolving conceptualization of palliative care. While there is debate regarding the nature of concepts and their role in knowledge development, there is a need to clarify what is meant by a concept (Rodgers & Knafl, 1993). Rodgers (1989) presents concepts as cognitive in nature and comprised of attributes abstracted from reality, expressed in some form and utilized for some common purpose. This rather general understanding of concepts informs this analysis of the palliative approach.

### **Palliative Approach: Method of Conceptual Analysis**

A modified concept analysis of the term palliative approach was conducted based on Morse's (2000) pragmatic utility approach. Morse's (2000) approach was followed as it does not

promote adherence to particular steps or a linear format that can limit the cognitive effort and freedom needed to follow emerging nuances (Weaver & Mitcham, 2008). The approach was also selected because pragmatic utility can be used as a method for analysis if the concept of interest is partially mature, that is, if there is adequate and appropriate literature available but there are multiple definitions, ambiguous meanings, or confusion with use (Weaver & Mitcham, 2008; Weaver & Morse, 2006). The frequent use of palliative approach revealed in searches suggests an emerging, partially mature concept in need of further analysis. Pragmatic utility is based on guiding principles and critical appraisal, rather than a series of steps that can be used at the discretion of the researcher (Morse, 2000; Weaver & Mitcham, 2008). As such, this approach offers a degree of flexibility appropriate to this analysis. The approach undertaken and detailed in the following sections includes a description of the purpose of the analysis, the literature review undertaken, semantic and pragmatic analysis of the phrase ‘palliative approach,’ and critical analysis and conceptual definition of this same phrase.

### **Palliative Approach: Document and Literature Review**

A review of the literature was conducted. Initially, documents of analysis were selected systematically based on key word searches of palliative approach with CINAHL, Medline, and Scopus search engines. The inclusion criteria were based on relevance (nursing, medicine, and as rated by the search engines selected) and the frequency with which the documents were cited. Excluded were documents referring to a palliative approach in a narrow sense, such as improving the quality of something (i.e. surgical technique). The search was restricted in the application of palliative approach to contexts of whole person care, such as of those of persons with life limiting conditions. Although this systematic approach yielded many unique documents and enabled the identification of the research contexts in which the term appears, this approach was

problematic as it failed to yield relevant documents, including more recent articulations of the palliative approach informing Canadian policy (e.g. CHPCA's 2015 *Framework*).

Sawatzky et al. (2016) recently published a concept analysis of the palliative approach based on characteristics of the palliative approach found in empiric research from January 1990 and December 2011. While the findings of these authors are considered, the unique analytic and methodological approach here may enrich and nuance Sawatzky et al.'s (2016) work based on the inclusion of more contemporaneous and non-empiric sources articulating the palliative approach, as well as a Canadian focus, of unique relevance to the research context. Moreover, as the pragmatic utility methodology permits flexibility to engage with emerging nuances, this analysis permits questioning of the socio-political implications of the conceptualization of the palliative approach.

It follows that a purposive literature review was undertaken, which included reviewing the reference sections of previously selected items for the definitions given and examining items selected by convenience (grey literature, as encountered in the Canadian palliative care context). Questions guiding the review included: how do authors define/describe the palliative approach? Is a rationale provided for this definition/description? How do authors use the term in research and clinical practice? Do authors address social, political, or historical dimensions of the palliative approach? Resources explored included those of iPANEL, Pallium Canada, and the CHPCA, palliative care organizations described below. Definitions and references found were reviewed and, as appropriate, traced back to original sources. The identified sources, definitions, and rationales are considered next.

**Palliative Approach: Analysis of Documents and Literature***Semantic*

There are different ways to examine a concept; a practical point of departure is a semantic analysis of the palliative approach, in which existing definitions and descriptions are considered and contrasted (Weaver & Morse, 2006). To begin, consideration is given to the palliative approach as articulated in the Joint Position Statement of the CNA et al. (2015) in which the central aim of the palliative approach is to “help people live well until death, across the lifespan, in all practice settings” (2015, p. 1). In the document, person-centered care is identified as the ‘foundation’ of the palliative approach, and the approach is described as one using palliative care principles such as dignity, hope, comfort, quality of life, and relief of suffering and applying these to people facing chronic, life-limiting conditions at all stages of life. The palliative approach includes patient autonomy, patient and family participation and control, and focuses on conversations about needs and wishes. In contrast to the CNA et al.’s (2015) definition of palliative care, the palliative approach does not explicitly include family bereavement and care of the body.

Another semantic point of reference is iPANEL (Initiative for a Palliative Approach in Nursing Evidence and Leadership), a group of Canadian researchers, clinicians, and health administrators based in British Columbia, who are working to advance the palliative approach (iPANEL, *n.d.*). iPANEL (*n.d.*) defines the palliative approach as one focused on improving the quality of life of persons and their families and that is provided in all health care settings. The palliative approach is applied earlier in an illness, promotes comfort, reduces suffering and includes physical, psychological, social, and spiritual care, including an understanding of loss and bereavement (iPANEL, *n.d.*). This orientation to the dimension of time is echoed by Bacon

(2012) who describes a different focus of the palliative approach depending upon the progression of a patient's illness. Early on, such as at the time of diagnosis, the focus of the palliative approach is on open and sensitive communication, advance care planning, psychosocial and spiritual support and symptom management. In later stages of the illness, the palliative approach includes most of the previously stated foci but also the consideration of if and when to engage specialized palliative services (Bacon, 2012).

The CHPCA's Lexicon (2014) is another orienting definitional source. Its definition of palliative approach refers one to the definition of "Integrated palliative approach to care/community integrated palliative care." This latter definition includes holistic person and family centered care and reinforces autonomy, the active involvement of patients and families, the aim to enhance control, the provision of aspects of palliative care when appropriate, and a focus on communication (e.g. advance care planning, goals of care). However, the Lexicon defines integrated palliative approach in the context of all stages of chronic progressive illness. The CHPCA (2014) definition includes seeing "palliative care as less of a discrete service offered to dying persons [...] and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging" (p. 2). This excerpt suggests that chronic progressive illness includes aging itself and that the description of integrated palliative approach is one borne from a distancing from the perception of palliative care as a discrete service. Within the CHPCA Lexicon, no definition of palliative care is provided—however, the CHPCA website's definition of palliative care is of "a special kind of health care for individuals and families who are living with a life-limiting illness that is *usually at an advanced stage* [emphasis added]" (CHPCA, *n.d.b*). This latter definition underscores the temporal dimension of when palliative care is often accessed.

Pallium Canada, a leading organization in palliative care education, was consulted as a source of standardized, competency-based information (Pallium Canada, 2015). A definition of palliative approach is included in its training manual for its national Learning Essential Approaches to Palliative Care and End of Life (LEAP) curriculum whereby the palliative approach is referred to in the context of a ‘generalist level’ of palliative care, one that does not require a palliative care specialist and for which the degree of patient complexity is low (Pallium Canada, 2014). Specialists are referred to as “specialist-level palliative care teams” whereas generalists include primary care, oncology, internal medicine, cardiology and neurology (Pallium Canada, 2014, p. 32). This distinction is reiterated by Shadd et al. (2013) in an opinion piece in which the authors attempt to clarify the semantic confusion surrounding “palliative care” by observing that the phrase is used to “refer both to an approach to care, and to a specialized care team” (p. 1). The distinction between the palliative approach and specialized care is therefore one of degree of medical complexity. Shadd et al. (2013) explain that the palliative approach recognizes death as a normal life event and it includes good communication, clarification of goals of care, and focusing on quality of life. Within the primary care context, palliative approach means meeting the basic palliative care needs of patients and coordination and cooperation between primary care and consultant specialist teams as needed (Shadd et al., 2013). Moreover, the authors contend that the palliative approach should be practiced by all health care providers who look after patients with life-threatening illness (Shadd et al., 2013). The description of the palliative approach as distinct from specialist care is echoed by Finlay and Jones (1995) and Katz and Peace (2003) in which the palliative approach, considered a core skill of every clinician, is distinguished from specialist palliative care, associated with clinicians with

specialist accredited training. However, in the case of Katz and Peace (2003), their definition diverges in its reference to palliative approach as applying to the care of any sick person.

Kristjanson (2005) articulates three types of palliative care responses: a palliative approach, specialized palliative care services, and end-of-life or terminal care. For Kristjanson (2005), the palliative approach concerns the care of persons whose condition is not amenable to cure and whose symptoms require effective management, although active treatment may still be required; the primary goal of the palliative approach is to ensure patient comfort and maintain functioning. According to Kristjanson (2005), specialized palliative care (for complex symptoms and/or complex social, ethical, and relational issues) does not replace the palliative approach but rather serves to augment it. Kristjanson (2005) provides an understanding of the palliative approach akin to a spectrum of palliative care spanning from low complexity on one end (in which only the palliative approach is required) to complex symptoms and issues on the other end (in which the palliative approach is supplemented by specialized palliative care). There is overlap between the types of palliative care responses identified by Kristjanson (2005) that blur the distinctions of the palliative approach and specialized palliative care proffered by Shadd et al. (2013), Pallium Canada (2014), and Findlay and Jones (1995). Moreover, Kristjanson (2005) does not define the boundaries of end-of-life care with respect to the palliative approach or specialized palliative care. These findings indicate some fluidity in the degree of semantic conceptualizations of the palliative approach.

In summary, a semantic analysis of the palliative approach reveals that it is frequently and relatively consistently described as one of two kinds of palliative care: a universally applicable kind of care (palliative approach) and a specialized and tailored approach for complex cases (palliative care). Recurring elements of the palliative approach are identified, including

reference to its foundations (holistic and patient and family centered), the principles of palliative care (dignity, hope, comfort, quality of life, relief of suffering) and other goals of the palliative approach (autonomy, active patient and family involvement, enhanced control, and maintenance of function). Other emerging elements are the dimension of complexity (the palliative approach involves a lower level of complexity and the care of generalists), timing (related to the perceived threat to health) and communication (related to the expression of needs, wishes and goals, the formulation of advance directives and communication with specialized services as needed).

Another element that involves how and when the palliative approach is engaged is captured by the term ‘threat to health’ that relates to the type of patient that would fall within the scope of the palliative approach including: people facing chronic conditions, individuals at all stages of chronic progressive illness; individuals with life-limiting conditions at all stages of life; patients with life-threatening conditions, a person whose condition is not amenable to cure; any sick person; and aging itself. With this semantic analysis of the palliative approach considered, a pragmatic analysis of the term is now explored.

### *Pragmatic*

Next, consideration is given to how the palliative approach is operationalized in research and practice. When scanning the search results in CINAHL, Medline, and Scopus, palliative approach appeared in reference to a wide range of conditions and other factors, including: neurodegenerative diseases (dementia, post-stroke care, multiple sclerosis, ALS), aging (long-term-care/residential aged care), setting of care (rural area, long-term care facility), organ failure (heart failure, COPD, end stage kidney disease), cancer, multi-morbidity (children with multiple disabilities), metabolic disorders (diabetes), and other (AIDS, back pain, chronic anorexia nervosa, illicit drug use).

In describing the palliative approach, Stajduhar (2011) incorporates principles of palliative care as well as the application of the specialized knowledge of palliative care to wider range of patients, regardless of their illness. Interestingly, for Stajduhar (2011) the palliative approach “differs little from respectful, compassionate, knowledgeable nursing care for patients and their families at any point in the health-illness trajectory” (p. 10). This point is significant as it encourages questioning as to whether the palliative approach truly differs from impeccable patient and family centered care. Stajduhar’s (2011) perspectives also encourage questioning regarding the notion that perhaps different interpretations of the palliative approach reflect the needs and interests unique to various professional disciplines. For example, a more fluid understanding of the palliative approach may be suitable within nursing practice whereas the term may require more clearly delineated boundaries when approached from the perspective of research, health care funding and administration, or from the perspective of the physician most responsible.

In a review article by Passmore et al. (2012) on an ethical elaboration of the palliative approach for patients with behavioral and psychological symptoms of dementia, the authors do not explicitly define the palliative approach and use the terms palliative care, palliative approach, and palliative care approach. The authors state that the palliative approach does not necessarily mean defaulting to a “conservative” care plan or prioritizing quality of life over quantity of life (Passmore et al., 2012, p. 6). Instead, the palliative approach is operationalized within the context of Alzheimer’s disease with the aim of helping patients and families come to terms with the disease, informing consent decisions and undertaking illness management reflective of patients’ core values, reflected by patients’ personhood and dignity (Passmore et al., 2012). In so doing, the authors operationalize some of the principles of palliative care and illustrate that the

emphasis placed on these principles changes depending upon the population for whom the palliative approach is engaged. In the case of patients with advanced dementia, emphasis is placed on the maintenance of quality of life, comfort, and dignity (Passmore et al., 2012). However, Passmore et al.'s (2012) operationalization of the palliative approach suggests a piecemeal use of the term in which palliative care is a metaphorical “full menu” while the palliative approach represents a selection from it.

Panke and Volicer (2002) applied palliative approach to the clinical setting of a specialized dementia care unit based on a hospice approach to care. They described the palliative approach as a shift from a medical model of care to one of “individualized supportive care” that includes early conversations on treatment preferences and involves eliminating inappropriate aggressive medical interventions (Panke & Volicer, 2002, p. 144). The authors identify goals of the palliative approach as quality of life, dignity, comfort of the individual and controlling symptoms. In the context of dementia care, Panke and Volicer (2002) identify that behavioral symptoms and pain are the most important symptoms that decrease quality of life and comfort in individuals.

Three documents analysed referred to the “surprise” question when identifying patients who may be amenable to a palliative approach, usually framed as “which of your patients is sick enough that death within a few months/the next year would not be surprising?” (Kristjanson, 2005; Mead, Cowey, & Murray, 2013; Parker et al., 2005). This question is included in the Gold Standards Framework Proactive Identification Guidance (2016), an identification tool from the United Kingdom to help clinicians identify and plan care for patients who are approaching end-of-life within the next year. Although physicians are encouraged to identify patients approaching the last year of life to engage them in a palliative approach, poor prognostication for non-

malignant conditions that often fall under the umbrella of a palliative approach can limit this identification process (Mead et al., 2013). In summary, pragmatic analysis reveals recurrent elements of the palliative approach related to conditions that represent threats to health, the location of where a palliative approach is enacted, and approaches to identify those who could benefit from a palliative approach.

### **Palliative Approach: Critical Analysis**

The definitions, descriptions, and interpretations of the palliative approach that emerged from the semantic and pragmatic analyses require critical reflection (Weaver & Mitcham, 2008). First, is the distinction between palliative care and the palliative approach clear? Although this research reviewed documents related to the palliative approach that used this term interchangeably with palliative care or that failed to provide clear boundaries on the term, a few authors articulated a sufficiently clear and consistent distinction between palliative care and the palliative approach: the palliative approach is one kind of palliative care (a universally applicable kind of care, associated with generalists), while specialized palliative care (specialized and tailored approach for complex cases) is another. Considering these findings, how one accounts for the increased use of the term palliative approach intersects with questions about whose interests are served by using this terminology. The CNA et al. (2015) articulated a rationale for the palliative approach that recognizes that currently, most Canadians die in hospital settings and that this is expensive both financially and in human terms. This state of affairs underscored the CNA et al.'s (2015) statement calling for a primary health approach to palliative care. Another rationale for the increased use of the term palliative approach is promulgated by Stajduhar (2011); in her work as a teacher, she found that nurses working in areas like critical care, acute medicine and emergency did not identify themselves as providers of palliative care within their

practice environment. She attributed this to mistaken beliefs about palliative care (i.e. it is for a certain kind of patient [i.e. patient with cancer] in a certain kind of place [hospice, specialized unit, home]) (Stajduhar, 2011). The perceptions of the nurses may have also been influenced by an inherited expert discourse around palliative care; for example, Stajduhar (2011) identified that a reliance on a specialized palliative care service led nurses to perceive that they were not equipped to care for the dying. It is in the context of these observations on nursing, as well as in that of an aging population in need of greater access to palliative care services, that the author articulated a need for the palliative approach. As such, a clearer conceptualization of palliative approach could also serve to improve patient care to these aging patients and to inform related financial considerations.

Another point requiring critical reflection is whether the term palliative approach is increasingly used to create distance with that of palliative care. Palliative care has a history of euphemisms, as the term itself was selected in favor of the initial term hospice—the latter being associated with the care of the poor and destitute (Pastrana et al., 2008). However, only one article identified touched upon the challenges that may be associated with the language of palliative care. Mead et al. (2013) identified palliative approach as a term associated with dying and, in so doing, appeared to suggest that the palliative approach is something in which the care team can engage but that does not need to be explicitly communicated to patients or perhaps that the language of the palliative approach is more palatable than that of palliative care. Indeed, Fadul et al. (2009) found that among oncologists, advanced practice nurses, and physician assistants at an American cancer centre, the term “supportive care” was perceived as less distressing to patients and clinicians alike than that of “palliative care” (p. 2019). These considerations may be similarly echoed in the increased use of the term supportive care, a

concept found to reflect palliative care (Sawatzky et al., 2016). These examples aside, other authors, such as Panke and Volicer (2002), emphasized the importance of open communication and this is coherent with professional nursing practice standards and the notion that engaging in difficult conversations is crucial for the formulation of appropriate care goals (Marcus & Mott, 2014).

### **Conceptualizing the Palliative Approach**

Based on the critical analysis of the definitions and descriptions, what are the implications of conceptualizing the palliative approach? Conceptual clarity helps to further theory construction and research as well as to improve access to more appropriate care (Weaver & Mitcham, 2008). This is substantiated by Kristjanson (2005), who argued for the need to distinguish different palliative care services (including the palliative approach) to formulate research questions about who receives palliative care, how to structure services, when to offer palliative care and how to resource palliative care. For Finlay and Jones (1995), semantic clarity of the palliative approach and specialist palliative care are needed to ensure that conditions which are the legitimate province of palliative care are identified and to ensure logical decision making in the resource allocation for care. In Pesut, McLeod, Hole, and Dalhuisen's (2012) research on nurses' approach to palliative care in rural settings, an important concern was that sometimes patients do not access palliative care due to a narrowly conceptualized understanding of palliative care that equates it with specialized palliative care. Also, despite Shadd et al.'s (2013) emphatic distinction between the palliative approach and specialized palliative care, the authors note an absence of formal definition of a palliative approach in primary care (Shadd et al., 2013) and the article itself serves as evidence of existing semantic confusion. Moreover, Shadd et al. (2013) note that the statistics often used to cite the paucity of palliative care access

in Canada refer to palliative care as it is defined in terms of specialized palliative care—a different picture would emerge should these statistics reflect access to a palliative approach. All these observations legitimate the need to formalize a conceptualization of the palliative approach.

Based on the need to formalize a conceptualization, what is a useful definition/description of the palliative approach? Based on an appraisal of the documents, literature, and resources, the palliative approach is found to be one of two kinds of palliative care: the palliative approach being one, and specialized palliative care the other, and as such, it is a kind of palliative care provided beyond a specialized palliative care context. There are eight identified elements to the concept of the palliative approach, including: foundations (holistic, patient and family centered, death as a normal life event, principles based on those of palliative care), other goals (e.g. autonomy, patient and family involvement, maintaining function), threat to health (palliative approach engaged with a threat to health, it can be a type of patient or a health condition), communication (wishes, needs, goals, interprofessional), timing (early and late approaches, timing related to the threat to health), complexity (low degree of patient complexity, involves primary care and generalists), identification (use of the “surprise” question and poor prognostication as a flag), and, location (all health care settings, increased relevance to certain settings). Although there is variability in the degree to which these elements are engaged in practice and research, this synthesis helps to better delineate the palliative approach. The previous conceptualization corresponds, albeit in a less synthesized manner, to the work of Sawatzky et al. (2016), who identified three themes in their literature synthesis representing the essential characteristics of a palliative approach: 1) an upstream orientation to care; 2) adaptation

of palliative care knowledge and expertise; and, 3) operationalization of a palliative approach through integration and contextualization within health care systems (Sawatzky et al., 2016).

Absent from both Sawatzky et al. (2016) and the present modified concept analysis thus far is consideration of the social determinants of health and as such, to heed the call of Reimer-Kirkham et al. (2016a), there is a need to philosophically align palliative care as a social justice issue through a health equity approach. In order not to replicate the narrow origins of palliative care (such as a focus on the care of oncology patients) in a configuration of the palliative approach and in the interest of equity, a deliberately broad entry point into the palliative approach is warranted, one that encompasses individuals facing any health threat. Not only does this serve to disentangle the palliative approach from medicalizing processes, a connection that perpetuates a bio-medically narrow perception of who is a legitimate recipient of care, but a broad entry point to the palliative approach serves to account for health-threatening and life-limiting contexts informed by structural vulnerability (Reimer-Kirkham et al., 2016a). This broad entry point into the conceptualization of the palliative approach means that this approach overlaps with both specialized palliative services on one end and public health palliative care on the other.

### **Public Health Palliative Care and the Palliative Approach**

At the broader end of the palliative approach is the public health approach, of relevance both to the articulation of the palliative approach as well as in the care of those with impaired mental health and life-limiting conditions. A public health approach to palliative care is one that includes a population health promotion approach, based on the principles of the Declaration of Alma Ata (WHO, 1978). According to Public Health Palliative Care International (PHPCI) (*n.d.*) public health palliative care is one that “views the community as an equal partner in the long and

complex task of providing quality health care at the end of life.” Health promotion in public health palliative care extends beyond end-of-life care and includes a recognition of the universality of loss and the approaches that can be taken to mitigate the harms associated with it by:

directing attention of our prevention, harm reduction and early intervention efforts toward the social, psychological and spiritual morbidities and mortalities commonly associated with death, dying, loss and care. These include, but are not exhausted by, the human experience of stigma and discrimination, sexual dysfunction, grief and depression, lack of social support, suicide, meaning-making in the face of death and loss, loneliness, choice over place of death, ignorance and therefore ignorant responses towards bereavement or overwork when caring for those with cancer or dementia at home. (PHPCI, *n.d.*)

A means by which to actualize public health palliative care and to prevent the harms listed above is proposed in Kellehear’s (2005) *Compassionate Cities*. Kellehear (2005) articulated the idea of the compassionate city based on the Ottawa Charter for Health Promotion’s (WHO, 1986) ‘Healthy Cities’ public health approach for implementing community-wide health strategies (Kellehear, 2005). While there was an absence of death, dying, and loss in the latter ‘Healthy Cities’ approach, the emphasis on compassion in the Compassionate City Charter includes an explicit concern for the universality of loss as well as its implications for the cognitive and emotional wellbeing of populations:

Compassionate Cities are communities that publicly encourages, facilitates, supports and celebrates [*sic*] care for one another during life’s most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term

care. [...] Serious personal crises of illness, dying, death and loss may visit any us [*sic*], at any time during the normal course our lives [*sic*]. A compassionate city is a community that squarely recognizes and addresses this social fact. (Kellehear, 2014, p. 1)

The Compassionate City Charter calls for the support of measures such as annually reviewed school and work policies pertaining to dying, death, and loss, holding exhibitions on the experiences of ageing, dying, death, loss or care in city museums and art galleries, and that institutions that provide care for vulnerable populations, such as those who are homeless or imprisoned, ensure supports for end-of-life care, loss, and bereavement (Kellehear, 2014).

Reflecting upon public health palliative care helps not only to delineate broader dimensions of the palliative approach, such as measures that fall squarely within a population health approach, but also to situate the palliative approach within a continuum. While the palliative approach falls within primary health care, it intersects with tertiary care (specialized palliative care services), public health (public health palliative care), and the mental health of individuals and populations. Indeed, a further consideration in the conceptualization is that the palliative approach denotes a process and this can present a unique challenge because part of developing a concept concerns the connection between it and specific events or occurrences and a process concept may not have a clearly identifiable beginning or end (Rodgers & Knafl, 1993). Considering the range of policy and practice approaches to health, it follows that the conceptualization here is a reasoned approximation of a phenomenon.

The concern for a compassionate approach to the universality of loss expressed as underpinning public health palliative care serves to ground the articulation of an ethics of finitude in a broader value-based framework. It is at this juncture that one can conceptualize the

scaffolding for an ethics of finitude, whereby nurses' engagement within a palliative approach requires an antecedent and sustained engagement with mortal finitude.

### **Ethics of Finitude**

The concern for a compassionate approach to the universality of loss underscored in public health palliative care can be further understood through the work of Brinkmann (2006) who, in reference to the context of phenomenological research, articulated a way to think about human mortality (finitude) by proposing the need for an existential-phenomenological 'ethics of finitude' which challenges thinking devoid of the referentials of "existential facticity and finitude" (p. 102). The ethics of finitude proposed is a way to think about human existence rooted in what Brinkmann (2006) refers to as 'facts,' including human beings' social, temporal, and mortal dimensions. These more aptly named 'facticities' refer to "some things" that "simply are the case, prior to any conventions or social constructions" including human interdependence as well as living in a community with other mortal beings (Brinkmann, 2006, p. 95). Expanding upon this thinking about finitude, mortality is therefore a condition for morality as mortality and the related vulnerability it engenders makes possible the conditions for values, to the extent that what is valued is what is inherently subject to loss, and virtues, such as courage, endurance, self-sacrifice, and justice (Brinkmann, 2006). In other words, "without mortality and vulnerability, there would be no value in the universe" because what is valued is premised on its vulnerability to erasure (Brinkmann, 2006, p. 104). The author argued that from the facticities of human finitude and vulnerability stem moral demands of solidarity, including compassion and care that are non-negotiable (Brinkmann, 2006). In other words, human mortality and interdependence are features "from which undeniable moral demands arise" (Brinkmann, 2006, p. 95). Brinkmann's ideas set the groundwork for the elaboration of an ethics of care that informs how apprehending

finitude could be conceptualized. Indeed, the degree to which nurses engage with patients in their facticity (sociality, temporality, and mortality) may correspond to the extent to which nurses engage patients within a palliative approach. Brinkmann's work reflects a concern for conceptualizations devoid of an ethic premised on facticities of human existence, including flexible identities and identity morphing (whereby meaning can always be renegotiated), the denial of the tragic (whereby through science and technology vulnerability and death are sought to be eliminated), and the decline of referentials (elaborated upon below).

The articulation of an ethics of finitude reflects central elements of the palliative approach and public health palliative care with its emphasis on the importance of social and familial connection, dying as a normal part of living, and the mandate of compassion that comes from the concern for the universality of loss (PHPCI, *n.d.*; WHO, *n.d.*). An ethics of finitude can help to understand the importance attributed by nurses in engaging with the mortality of their patients within the palliative approach and to orient analysis to features included in Brinkmann's articulation. Of relevance to the psychiatric care context is not only the care of aging patients with life-limiting neurodegenerative illnesses such as Alzheimer's disease but the life-limiting dimensions affecting those with mental illness and involved in the correctional system, such as accelerated physiological aging (Burles et al., 2015). Brinkmann's (2006) articulation of the need for an ethics of finitude described above serve as a vantage point from which to explore forces that serve to obscure or make visible the facticities of human beings' social, temporal, and mortal dimensions. To this end, the next section explores the values that underpin modern science and the cultural significance of certainty, as explored in theory derivation of Mishel's (1990) reconceptualization of the uncertainty in illness theory.

The values that underpin modern science and the concept of uncertainty serve to shape how apprehending our mortal nature can mutate. Cultural ideals of coherence and order have emerged from the social values that underpin modern science, including predictability, control, and certainty (Mishel, 1990) and, “health, illness, and medicine appear to be epicenters of the increased malaise about uncertainty, and the anxiety about danger and risk that have surfaced in our society” (Fox, 1980, p. 3).

The proposed ethics of finitude, in its rootedness in the facticity of human mortality, does not seek to replicate a mechanistic biomedical view but rather to engage a probabilistic approach as described by Mishel (1990) in his reconceptualization of uncertainty in illness theory. As background, in Mishel’s (1988) uncertainty in illness middle-range theory uncertainty is the “inability to determine the meaning of illness-related events and occurs in situations where the decision maker is unable to assign definitive values to objects and events and/or is unable to accurately predict outcomes because insufficient cues are lacking” (Mishel, 1990, p. 256). As a middle-range theory suited to empirical inquiries (Polit & Beck, 2012), Mishel’s work has limited applicability given the theoretical underpinnings of this phenomenological project. Moreover, the intellectual ‘decision making’ processes of inference and belief construction implicit in Mishel’s theory may be of limited value for many patients in the study context, such as those diagnosed with advanced forms of neurodegenerative disease, and moreover, patients are not the direct focus of the research. Nonetheless, the cultural significance of certainty points to the possibility of theory derivation, which includes observing similar dimensions of a phenomenon in different fields and redefining the information from one phenomenon to another (Mishel, 1990).

Uncertainty is a characteristic of an increasing number of Canadians' end-of-life experiences, as many individuals are dying without a predictable period of decline from illness to death (CHPCA, 2015). At the same time, the average life expectancy of Canadians is at a historical high (Statistics Canada, 2015) and the social context in which this is occurring is one that is generally removed from first-hand experience as the recognition of dying have moved from "personally observed criteria by communities or individuals to less clear, institutional ones" (Kellehear, 2007, p. 251). These modern phenomena may account for the lack of cues needed to make meaning out of illness related events, eloquently framed by Thomas (1980):

Today, the average span of human life in our society stands at around 73 years, the longest run at living yet achieved. Obviously, most of the dying is done by old people. It makes a different sort of problem for the human mind. Dying is not so often the tragic striking-down that it was; it is more like the end of a slow process of running-down, more like a slow collapse. We know about its inevitability, but we do not have the same apprehension that it is there, waiting just around the corner, ready to leap. (Thomas, 1980, p. 3)

In Mishel's (1990) reconceptualization of the theory of uncertainty in illness to account for chronic illness and the related experience of long-term uncertainty, he illustrated how acknowledgement and engagement with uncertainty, when supported by family, friends, and health care providers, "can motivate people to work at creating the trusting relationships and mutual support necessary in a world where no one can have a sure or final answer" (p. 261). Mishel contrasts the mechanistic paradigm, as described in the values of modern science (predictability, control, and certainty) with a probabilistic paradigm in which uncertainty is

viewed as natural, inherent part of reality. In the latter ‘conditional world’, there opens multiple possibilities as certainty is no longer absolute:

There is a new ability to focus on multiple alternatives, choices and possibilities; to reevaluate what is important in life; to consider variations in personal investment to appreciate the fragility and impermanence of life situations. (Mishel, 1990, p. 260)

Situating the palliative approach within an ethics of finitude as a challenge to bio-medical discourse characterized by predictability, control, and certainty, illuminates the ‘culture shift’ identified in the CHPCA’s *Framework* (2015)—a shift that is needed to challenge the overriding focus on curative modalities and the fear of death in order to ensure a palliative approach in the routine care of people who are aging and/or have chronic illnesses. Indeed, the palliative approach is invariably situated in uncertainty and the called for cultural shift within health care is echoed in Mishel’s (1990) entreaty to move from a mechanistic to a probabilistic paradigm.

Uncertainty is also an important concept in relation to the health challenges and illness trajectories unique to aging patients in forensic and geriatric psychiatry that may not be captured by typical prognostication tools, such as the Gold Standards Framework Proactive Identification Guidance (2016). As described in the modified concept analysis above, poor prognostication can itself be a flag for a palliative approach.

Mishel’s (1990) conceptualizations of uncertainty can help to understand barriers encountered by nurses when engaging in an ethics of finitude, such as the push for curative modalities as an example of maintaining control and predictability. For example, theory derivation based on Mishel’s work can elucidate perceived barriers to a palliative approach in its tacit acknowledgement of human mortality to the extent that for some individuals, including family members, uncertainty can be appraised as desirable when faced with a high probability of

negative uncertainty, such as responding to an illness with a known downward trajectory (Mishel, 1990). In such circumstances, the promise of uncertainty, which may be maintained to uphold belief that the cause and cure of illness can be determined (such as that related to neurodegenerative disease), may hinder nurses' ability for engagement. Moreover, situating uncertainty in its cultural context helps to elucidate, as explored through Goffman's (1961; 1963) work on total institutions and stigma, below, how dominant cultural values ingrained in progress and technological advancement can serve to stigmatize those with chronic and terminal illnesses as these individuals necessarily represent aberrations from culturally reified norms.

Mishel's (1990) work orients one to the human need to make meaning, a need that is challenged in ambiguous illness-related events and shaped by wider bio-medical discourses. This process serves to outline how engagement with uncertainty may serve to hinder or support engagement within an ethics of finitude. Moreover, meaning-making is not only challenged by the ambiguity of illness related events—human mortality itself represents an existential challenge that can be explored through the motif of *memento mori*, a process of remembrance and reflection to this end.

### **Remembrance and Memento mori**

The importance of engagement with finitude has a long cultural history in which humans are entreated into a process of remembrance and reflection. It follows that the possibility of engagement within an ethics of finitude is premised upon the process of reflection on mortality and on the human facticities (social, temporal and mortal) noted by Brinkmann (2006).

Remembrance of mortality, in the cross-cultural and trans-historical motif of 'memento mori' serves as an entry point into an ethics of finitude; it is a mechanism to negotiate both cultural norms of predictability and control and the desirability of uncertainty in the face of possible

negative outcomes identified in the work of Mishel (1990). *Memento mori*, Latin for “remember that you must die,” is a theme that has served to remind humans of their mortality and the shortness and fragility of human life (Delamothe, 2007; Merriam Webster, *n.d.*; Wellcome Collection, *n.d.*). *Memento mori* creative representations include statues, architecture, engravings, drawings, paintings, and writings (Wellcome Collection, *n.d.*). The motif can also serve to contrast policies and practices that echo or dampen this invitation in the work of psychiatric nurses.

The exhortation *memento mori* served as a theme for contemplation, such as in the sermon of Clark (1699), from the Church of Scotland which exhorts Christians to “Frequently meditate on death and your frail state of life, let *Memento Mori* be often in your thoughts: for to contemplate of Mortality and Eternity, may dispose and frame your hearts to prepare for death and eternity” (Clark, 1699, p. 5). In the 16th and 17th centuries, Danish and Flemish still-life painting prominently included symbols, such as musical instruments, wine, jewelry, and books, that served to remind the viewer of the impermanence of worldly pleasures and possessions and to repent (Kearl, 2015; Tate, *n.d.*). While these examples predominantly reflect religious considerations, contemporary secular examples abound. The ‘Death Cafes’, popularized in the United Kingdom, are events where individuals gather without a formalized agenda to discuss death over tea and cake with the objective of increasing “awareness of death with a view to helping people make the most of their (finite) lives” (Death Cafe, *n.d.*). Another contemporary example is the Wellcome Collection’s 2008 exhibition of the work of Walter Schels and Beate Lakotta ‘Life Before Death’ which featured a series of photographic portraits of people in hospices that were taken soon before and shortly after their death (Moorhead, 2008). For the photographer, the project was one that served to confront his own fear of death (Parker-Pope,

2008). Schels also described the creative process as one that can be linked to the concept of authenticity:

I felt it enabled me as a photographer to get as close as it's possible to get to the core of a person; when you're facing the end, everything that's not real is stripped away. You're the most real you'll ever be, more real than you've ever been before. (Parker-Pope, 2008, para. 5)

The exhibition of this work served to similarly entreat the public into a process of reflection of mortality.

In his case study of the skull as a traditional symbol of *memento mori*, Kearnl (2015) argued that several cultural forces have come to transform the significance of this symbol and this in turn serves to underscore broader cultural shifts. The author argued that the skull, as “the longest-surviving remnant of an identifiable self” has become drained of its symbolic value through a transformation in its meaning, facilitated by mass media, to the ends of the marketplace (Kearnl, 2015, p. 7). Indeed, Brinkmann’s (2006) articulation of an ethics of finitude is premised upon concern for conceptualizations devoid of the facticities of human existence (social, temporal, and mortal), including the decline of referentials, which is “the tendency of signs and meaning in consumer society to become disconnected from their worldly referents” (p. 100). Kearnl illustrated this decline of referentials with a number of product and marketing examples in relation to the skull and observed that the symbolic function of *memento mori* is vulnerable to commercial appropriation to the extent that it may serve the ends of *mors mortua est* or death denial messages. Kearnl identified an important problem in the use of the symbols of mortality to engender remembrance in that they are fundamentally ephemeral and vulnerable to manipulation. Indeed, on the decline of referentials, Brinkmann observed that “money is the

hermeneutic medium that can transform anything into anything else” (p. 101). Herein lies the problematic nature of infusing external objects with the symbolic social function of mortal remembrance.

If external objects cannot be relied upon as mechanisms for remembrance, consideration turns to the human body itself to serve this function. While the physical manifestations of aging have served in the remembrance of mortality, this function is also vulnerable to mutability through commodification and medicalization. Global industries, bolstered by communication technologies and, to varying degrees, the labour of nurses, profit from the medicalization of physical changes of aging such as age-related changes in endocrinology and skin and muscle tone. To appreciate the scale of this phenomenon, it is worth considering that almost 14 million minimally invasive cosmetic procedures were performed in the United States in 2014, the most popular of which were botulinum toxin type A (Botox), soft tissue fillers and chemical peels (American Society of Plastic Surgery, 2014). Minimally invasive cosmetic procedures represent a multi-billion-dollar industry in the U.S. and many of these procedures were performed by registered nurses (American Society of Plastic Surgery, 2014; Jones, 2009). The comparable popularity of these procedures is documented in Canada (International Society for Aesthetic Plastic Surgery, 2012).

Androgen replacement is another example of the medicalization of aging. While the only therapeutic indication for testosterone is in replacement therapy for pathological androgen deficiency, testosterone sales increased 12-fold globally from 2000 to 2011, rising from \$150 million to \$1.8 billion, with the highest increase in Canada (Handelsman, 2013). Handelsman (2013) writes that while various theories account for the increase in testosterone prescriptions, including direct-to-consumer advertising in the United States, the mostly likely reason is changes

to testosterone prescribing guidelines that no longer distinguish between pathological androgen deficiency and age-related functional androgen deficiency (andropause). The endocrinology of aging has emerged as a subspecialty, focusing on disorders of the endocrine regulatory mechanisms including decreased estrogen production in women (menopause), decreased testosterone production in men (andropause), decreased adrenal function (adrenopause), and decreased growth hormone-insulin-like growth factor (somatopause) (Bellino, 2006). Indeed, the emergence of this subspecialty underscores the continued debate over whether aging itself is a disease and as such whether the target of interventions should be diseases of aging (metabolic, cardiovascular, neurodegenerative, and cancer) or the aging process itself (Partridge, 2014). In the medicalization and commodification of aging is a discourse that can not only serve to silence the process of remembrance of mortality but may also stigmatize those who do not or cannot participate in the social reconstruction of aging, including those living within health-threatening and life-limiting contexts informed by structural vulnerability, such as many patients cared for within the study context (Reimer-Kirkham et al., 2016a). The purpose here is not to dispute the therapeutic merit of particular procedures nor to articulate an account of ‘normal’ aging; rather the intent is to underscore cultural discourses and practices that can serve as a counterpoint to remembrance and reflection on mortal finitude and thereby present a cultural challenge to an ethics of finitude in which death and dying is normalized.

The social transformation of aging is further articulated by Harari (2014) who argues that while for 4 billion years, every living organism on earth evolved from natural selection, this process is profoundly challenged by a future in which scientists, equipped with the tools of biotechnology and computer algorithms, can alter biological life so as to fundamentally change human physiology, immune systems, life expectancy as well as intellectual and emotional

capacities. From this perspective, death becomes an increasingly technical problem rather than an existential necessity (Harari, 2016). At a time when such foreshadowing of human immortality is possible, and yet is so far removed from the reality of most, the need for remembrance of finitude becomes all the more salient, both as a counterpoint to privilege and to the promise of scientific progress. Moreover, an appreciation of the tension between remembrance of mortal finitude and its erasure may help to account for strains in diverging care approaches, whether from more palliative or curative modalities. This tension may be all the more evident in forensic and geriatric psychiatry, care contexts deemed acute and not commonly associated with dimensions of palliative care.

The symbolic representations and physical manifestations of mortal remembrance can be displaced not only by the mechanisms of commodification and medicalization, but also by transformations in the social constructions of aging. With this displacement, there is a corresponding shift in the socio-political landscape in which one apprehends finitude. It follows that while an open awareness of death is recognized as significant in the conceptualization of the palliative approach and in an ethics of finitude, commercial interests and the social reconstruction of aging may undermine opportunities by which some individuals may discern mortality and mortal remembrance.

Harari (2016) described the contract of modernity as one in which meaning is exchanged for power. The theme of *memento mori* is a vehicle to conceptualize the process of remembrance and as such underscores the importance of meaning-making to identify ethical values and how this meaning making can mutate in the face of social reconstructions of aging. Moreover, reflection on *memento mori* underscores the importance of symbolism to engage with the human condition and thereby exposes possible limitations to an inquiry into the phenomenon by means

of a methodology based on participant interview data, as opposed to, for example, ethnographic data collection that could include artifacts and other items, like photographs. Despite the vulnerability of external objects and the human body itself to symbolic transformation, the theme and expressions of the motif of *memento mori*, as a process with a long history of entreating human remembrance of mortal finitude, can serve as a functional link between the palliative approach and an ethics of finitude. This could perhaps be witnessed in nurses' engagement with material objects available on the unit, such as earlier photographs of their patients or with mementos from their patients' life, as well as recognition in physical manifestation of mortality in their patients (e.g. cognitive change).

### **Total Institutions and Home**

The dimension of place in relation to the experience of nursing care is essential to the research context. According to Kearns (1993) place, in terms of the relationship between people and their environment, is of profound significance to health and the focus on place "involves an interest in the context of an experienced place rather than its catalogued characteristics" (p. 140). Place is therefore used here to designate a form of social organization that is permeated by various and diffuse power relations. As the research project explores the palliative approach within the context of geriatric and forensic psychiatry in a specialized urban psychiatric hospital in Canada, a conceptualization of this environment is essential to inform the possibilities for and limitations of this place in the enactment of an ethics of finitude. Goffman's (1961) conceptualization of total institutions is considered and contrasted with that of home to illustrate divergent and intersecting manifestations of power relations in these care settings.

### **Total Institutions**

Despite considerable change in the provision of psychiatric and mental health care over the past half-century, including a shift toward community oriented services and de-institutionalization (Boschma, Yonge, & Mychajlunow, 2005), Goffman's (1961) work in conceptualizing psychiatric facilities as total institutions continues to resonate with respect to elements of the study environment. Goffman (1961) conceptualized psychiatric facilities as a type of 'total institution' that is, a type of institution in which social processes occur that have a wider function beyond strictly that of psychiatric care. Goffman (1961) defined the total institution "as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (p. xiii). As reiterated by Goodman (2013), the total institution is a 'living space' in which people who share a similar social situation (for example those in need of health and social care) are cut off from the wider society for a considerable time (p. 81). This configuration is echoed in the study context whereby patients are living on secure units with inherent restrictions to contact with wider society and are organized around commonly shared clinical and legal characteristics (e.g. behavioural and psychological symptoms of dementia, designation as "not criminally responsible").

Goffman (1961) described the central feature of total institutions as a breakdown of barriers that normally separate the spheres of life, sleep, play, and work and in which the organization of such a living space serves to facilitate surveillance. For the time of their admission, patients on the study units engage in all activities of life on these units or under the administration of the unit (e.g. during outside appointments) and surveillance is facilitated by the presence of cameras, centrally located nursing stations and windows allowing the viewing of

patients when they are in common areas. Goffman's (1961) work on total institutions has been used to characterize the care context and control structure within hospitals and the increased medicalization of dying within this context (Zweig & Oliver, 2009). The 'formal administration' of life described by Goffman (1961) is evidenced in the routines of the institution as well as in the organization of nurses' activities. These activities may be organized so as to prioritize organizational safety and the completion of patient care elements (e.g. medication administration, assistance with hygiene) and related documentation within established nursing work shifts, and as such may limit possibilities for psychosocial and spiritual engagement with patients.

In the social arrangement of the total institution there is a division between the larger managed group and the smaller supervisory staff. In the study context, the larger group would comprise the patients and the smaller supervisory staff would include nurses, physicians, and other members of the interprofessional team. Beyond the distinction in roles and occupations, the division that Goffman (1961) described has relational implications that are marked by separations: moral beliefs of superiority (held by supervisory staff), social distance, informational, and physical contact. These separations may manifest to varying degrees in the study context and in particular, the relational implications of separations engendered by the context of the total institution may shape nurses' possibilities for engagement in an ethics of finitude. For example, in relation to informational separation, Goodman (2013) states that "totalising is also related to the degree to which the patient or client is excluded from knowledge of the decisions taken about them concerning their treatments" (p. 81). Drawing on the notion of relational separations of age and social distance, Marson and Powell (2014) used Goffman's concept of total institutions to illustrate the process of infantilization that can occur in the care of

older adults. Based on the separations outlined by Goffman (1961), it follows that those working within total institutions may be placed to have considerable arbitrary power over those under their charge (Adlam et al., 2013), a dynamic that may be variably manifested in nurses' discourse.

Within the social arrangement of the total institution, Goffman (1961) wrote of the process of mortification as part of the moral career of the inmate that is composed of changes that occur in relation to beliefs about the self and significant others. Examples of this process included the inmate's loss of social roles, social experiences, personal possessions, and loss of name, by virtue of being in a place separated from the outside world (Goffman, 1961). The process of mortification within total institutions provides insight on how the social process of total institution can undermine the values of the palliative approach, such as autonomy, dignity, person and family centered care, and patient and family driven care goals (CHPCA, 2013). For example, in Burles et al.'s (2015) narrative review of the literature on palliative care in correctional settings, the authors provided the example of limitations placed on family visits and on involvement in care within correctional setting as potential barriers to the families' involvement in end-of-life care.

From these descriptions of the processes of the total institution, it is possible to understand how this construct can represent barriers to engagement within a palliative approach in a psychiatric setting; the physical configuration ordering social processes of total institutions juxtaposes the fluidity and flexibility inherent in a patient- and family-centered palliative care approach as well as the principle of patient autonomy. Moreover, the facticities of sociality, temporality, and mortality outlined by Brinkmann (2006) are situated in human solidarity, that is, engagement within an ethics of finitude necessitates recognition of interdependence and shared

conditions. The routinization, separations, and erasures characteristic of total institutions manifested in the psychiatric setting may function to impede possibilities for recognition of mutuality.

### **Home**

In considering the possibilities for the enactment of an ethics of finitude, it is worth exploring an alternative social arrangement to the total institution that could be presupposed in the enactment of a palliative approach: home. Home can be considered to delineate a locus of social processes of nursing and as holding within it the potentialities for the proposed enactment. As context, Goffman (1961) drew attention to the social organization of the 'household', by contrasting it as incompatible with that of total institutions and suggesting that it could be a source of resistance:

[T]he formation of households provides a structural guarantee that total institutions will not be without resistance. The incompatibility of these two forms of social organization should tell us something about the wider social functions of them both. (Goffman, 1961, p. 12)

Home is a form of social organization that can serve as a counterpoint to that of total institutions as well as a conceptual 'place' of diffuse power relations in which to situate the enactment of an ethics of finitude in the psychiatric setting. Home is one of the oldest themes in the texts of western culture (e.g. Jewish Bible and the Homeric epics) and served as a focal point to illustrate the potential for participation in the human community (Jacobson, 2012). Relative to the research, the importance of the home is iterated in the CHPCA's (2013) norms of practice for palliative care delivery, whereby:

The setting of care is safe, comforting and provides ample opportunity for privacy and intimacy. Where possible, settings of care are homelike, with access to the outdoors. (p. 16)

If the CHPCA's *Framework* (2015) is to serve as guidance in that the palliative approach is to be enacted wherever Canadians are aging and living with life-limiting conditions, it follows that the homelike setting proposed pertains to the environmental configuration of care of these same people, including those residing within psychiatric inpatient units. It is therefore worthwhile to consider conceptualizations of home that could juxtapose the totalizing processes described above. A homelike setting is seemingly more than a physical place and for many it is both a physical location and a set of feelings (Blunt & Dowling, 2006). In this relational sense, "home is a relation between material and imaginative realms and processes, whereby physical location and materiality, feelings and ideas, are bound together and influence each other, rather than separate and distinct" (Blunt & Dowling, 2006, p. 254). For Kearns (1993) "people feel more whole in places where they feel that they belong" (p. 144) and the place of home can be one of feeling "*in place* rather than *displaced*" (p. 140). It could be suggested here that the breakdown of barriers that normally separate the spheres of life, sleep, play, and work that is proposed to occur in Goffman's (1961) total institutions evokes a prior norm and perhaps a privileged state of separate spheres. Individuals who are chronically institutionalized or who have experienced life circumstances precluding the separation of spheres proposed may perhaps experience a greater sense of belonging and of feeling *in place* within an enclosed setting, such as a psychiatric unit. Home represents a separation of the private and public whereby "home is the place of the personal self, in contrast to the social self of the outside world" (Mortenson, Sixsmith, & Beringer, 2016, p. 104). The mortification described by Goffman (1961) is again a process

premised on the experience of loss relative to experiences and situatedness pertaining to the “outside” world. In other words, the process of mortification within the total institution presupposes a loss relative to the external world. What is worth considering is that for structurally vulnerable individuals, the world external to an institutionalized setting can perhaps represent a more individually erosive process than the internal world of a structured care environment governed by, at minimum, professional norms of practice (e.g. nursing, medicine) and health care governance mechanisms. This is to say that if for some individuals the institutional environment is more homelike than the “outside” world, it is the world outside to the institution that may in fact represent a greater threat to patients’ social roles, social experiences, and personal possessions.

Home can also be conceptualized as an experience, captured in the phrase ‘being at home’ (Gillsjö & Schwartz-Barcott, 2009, p. 6). In the understanding of home as experience, home is an embodied and dynamic concept (Gillsjö & Schwartz-Barcott, 2009). While home can be defined as the place or setting where people live, it can also be conceptualized as a form of social arrangement that, like total institutions, represents a special relationship between people and the environment (Gillsjö & Schwartz-Barcott, 2009). The internalized feeling of safety and control characterized by the relationship with and the separations resulting from home is iterated by Mortenson et al. (2016):

The idea of the “home” suggests a refuge based on the concealment that comes from the physical and symbolic enclosure of the dwelling space. The affordance of “inside-ness” defines the home as a place of shelter and safety, while “outside-ness” suggests potential dangers and exposure to the elements. (p. 104)

Jacobson (2012) observes that home also requires a degree of exchange: as the experience of interpersonal exchange, home is “where ‘exchange’ is understood as a necessary mediation with others in which we work to establish who we are with and through other people, with and through what is other to us” (p. 181). In contrast to Goffman’s (1961) social arrangement of the total institution, home can be conceptualized to be a place of residence (and, to varying degrees, work) where a small number of like-situated individuals, who are not necessarily cut off from the wider society, together lead an enclosed, privately administered round of life. While “total institutions disrupt [...] self-determination, autonomy, and freedom of action” (Goffman, 1961, p. 43), home can be understood as a social arrangement that supports these processes.

While both the concepts of home and total institution can embody and be apprehended within physical places, it is their ability to represent social arrangement within these physical structures that is elaborated here. Home, as a physical place, can be a locus of totalizing processes, such as physical, emotional or sexual abuse. The psychiatric setting, as a physical place, can be a locus that supports self-determination, autonomy, and freedom of action. This juxtaposition is one that parallels that of a bio-medically oriented model to one that reflects elements of the palliative approach and that is evidenced in efforts to de-institutionalize and de-medicalize dying as “a socially isolating experience where specially trained health care providers replaced family members and the rules and regulations of bureaucracy replaced the flexibility of the single family home environment” (Zweig & Oliver, 2009, p. 117). The challenge here is that whether the social arrangement of a place is that of a home or of a total institution is not dependent upon a physical configuration so much as it is premised upon relational separations and considerations of structural vulnerability. By considering separations, one can apprehend that aspects of a psychiatric unit could be conceptualized as a ‘home-like’ social arrangement

just as aspects of a home environment could be conceptualized as engaging the social arrangement of a total institution.

According to Goodman (2013), Goffman's typology should serve to question care practices, particularly in a context in which the health and social care needs of an aging population are increasing and "the pressures on the current system may lead to more rather than less of a totalising process in certain organisations" (p. 82). The advent of the Home First philosophy, described in the previous chapter, may serve as an example of this process and highlights the need to discern totalizing processes beyond the context and language of a particular care setting. While a particular context like a forensic psychiatric unit may consist of features that can enable totalizing processes (i.e. surveillance mechanisms, physical barriers between staff and patients, and between patients and the wider environment), because, as Goffman (1961) illustrated, these processes are associated with the provision of care in such a prototypical setting, there may be an attendant reflexiveness on the part of nursing staff who may be professionally sensitized to these processes and thereby engage in their care so as to attenuate these totalizing mechanisms. In contrast, in environments where totalizing processes are less well documented and researched, such as in the home, there may be less critical attention and reflexivity towards such mechanisms. For example, Mortenson et al. (2016) explored older adults' experience of home in relation to the use of home surveillance technologies that remotely track the health status, patterns of movement, and activity of older adults and generate an alert if variation is detected. The authors found few studies on how such surveillance might impact the lives of older adults and yet the nature of their work reveals fertile ground for the enactment of totalizing mechanisms:

[Home surveillance technology] increases the permeability of the home by extending the

power of observation into what was previously regarded as an intimate, private space.

[...] Within this extitution, the hiddenness of the intimate space becomes exposed, with regulatory effect on the actions of the person being observed and on the actions of the observer/caregiver shaped by the new categories of knowledge afforded by the surveillance system. (Mortenson et al., 2016, p. 111)

In this description, it can be seen how the use of surveillance technologies in the home engages features of total institutions in the breakdown of barriers that normally separate the spheres of life of sleep, play, and work and in which the organization of the living space facilitates surveillance. It follows that the engagement of nurses in an ethics of finitude may be variably shaped by the processes of social arrangement and whether these processes are more aligned to those of the fluidity and autonomy of home or to those of mortification within totalizing processes. Moreover, if the social arrangement of home is one that may serve to enact an ethics of finitude, it follows that, from nursing literature from home-based nursing care, nurses may assume, at least in part, the role of the guest or of host in this configuration of place (Öresland, Lutzén, Norberg, Rasmussen, & Määttä, 2013).

This section considered and contrasted the concepts of home and total institutions as representations of social arrangements possible within the physical structures of the research context. Reflection on the dimension of place and the potentialities embodied in this social configuration serves to delineate the loci of social processes of nursing and as such the possibilities for the enactment of an ethics of finitude. The potentialities embodied in the social processes of stigma, and their implications for nursing engagement, are considered next.

### **Goffman's Stigma Framework**

In the literature review, the concept of stigma emerged in reference to the social marginalization and corresponding vulnerabilities associated with aging (ageism) and to that associated with dying, death, and mental illness (Butler, 1969; Morgan, 2016; Phelan, 2010). While open awareness of death is recognized as an element of the palliative approach, the stigma associated with aging, dying, and mental illness may present barriers to engagement in an ethics of finitude. As such, a conceptual elaboration of stigma serves to understand these processes and to identify discourses that may reify or challenge their manifestation. Stigmatizing processes may be evident in how nurses view their patients or in their discourses regarding other nurses or members of the interprofessional team. In its original usage, stigma referred to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman, 1963, p. 1). Building on this, Goffman (1963) qualified stigma as a language of relationships rather than an attribute alone and that stigma constitutes a “special discrepancy between virtual and actual social identity” (p. 3). In other words, stigma is a special relationship between an attribute and a stereotype (Goffman, 1963).

According to Goffman (1963), stigma is an attribute that socially discredits an individual or a group, diminishes them and renders them tainted and discounted, abject and inferior. Pertinent types of stigma Goffman identified included abominations of the flesh (e.g. physical deformities) and of the character (e.g. mental disorder, imprisonment, suicidal attempts) (p. 4). Goffman referred to individuals who do not have undesired differentness from what is social anticipated as “normals” (p. 5). The person with the stigma is seen by “normals” as “not quite human” and, based on this inferiority, discriminatory practices are rationalized (Goffman, 1963,

p. 5). According to this framework, stigma is socially and contextually defined and thereby mutable; stigma resides in the social interaction rather than in the individual (Balfe et al., 2010).

As explored in the work of Mishel (1990) on uncertainty in illness and as illustrated by Goffman's (1963) stigma framework, dominant cultural values ingrained in progress, bio-medical advancement and curative orientations may serve to position chronic and terminal illnesses as representative of aberrations from culturally reified norms. According to Phelan et al. (2008) stigma serves a social function by reinforcing social norms and strengthening and homogenizing group identity by expelling unwanted or undesirable characteristics and creating a boundary between in and out group identity. With this function in mind, nurses may express reluctance to engage in an ethics of finitude that necessarily requires mutuality insofar as to recognize the shared facticities (social, temporal, and mortal) proposed by Brinkmann (2006) with patients deemed to manifest socially defined aberrance, such as a mental illness, a terminal illness, and/or a forensic identity. It follows that the stigma framework put forth by Goffman may be manifested in how nurses communicate their engagement with their patients.

### **Summary**

In the proposed theoretical scaffolding, the process of engagement was situated within the palliative approach. Conceptualization of the palliative approach served as an interface through which to introduce and articulate an ethics of finitude, as proposed by Brinkmann (2006). The motif of *memento mori* was explored and presented as a symbolic device that entreats human remembrance of mortal finitude and thereby serves as a functional link between foundational elements of the palliative approach and the elaboration of an ethics of finitude. The dimension of place in relation to the lived experience of nursing care is an essential aspect to the social processes involved in the research problem. The places of total institutions and that of

home were considered insofar as to delineate loci of social processes of nursing and as such the potentialities for an ethics of finitude. A conceptual understanding of stigma using Goffman's (1963) seminal work was explored to understand this process, often associated with aging, dying and mental illness, and to posit how these discourses may influence nursing engagement.

#### Chapter 4: Methodological Considerations

This chapter describes the methodological considerations for this thesis. First, the background of the original research project is explored, including the original research aims, the empirical nursing ethics analysis undertaken, and research in press (Wright, Vanderspank-Wright, Holmes, & Skinner, 2017, in press). I describe my role as a research assistant in the wider project and detail my academic and professional background relevant to the research. Second, I describe my analytic elaboration of the original research project and research aims and how this undertaking fits within the original project. My project's constructivist epistemic stance is briefly reiterated to theoretically situate the research construction, followed by a description of the analytical framework developed for this analysis: interpretive description (ID) and interpretive phenomenological analysis (IPA). I describe both analysis methods and describe how drawing from these methodological approaches helps to explore the research aims, including: nurses' engagement with mortality within an ethics of finitude, apprehending discourses, and deepening understanding of the palliative approach. Third, the steps in the analysis undertaken are described, including sampling, data collection, and the data analysis process. Fourth, rigour and approaches to ensure reflexivity are described. Fifth, ethical considerations are explored related to the student project within its original research context.

#### **Background**

The original project, of which my project is an analytic elaboration, was an empirical nursing ethics analysis of forensic and geriatric nurses' descriptions of caring for aging patients. It was theoretically grounded in notions of moral experience (Hunt & Carnevale, 2011), moral identity (Liaschenko & Peter, 2016), and moral agency (Storch, Rodney, Pauly, Brown, & Starzomski, 2002) in nursing. The original project sought to identify nurses' values, as well as

descriptions of putting those values into practice, in order to analyze the relationships between the ethical foundations of a palliative approach and the moral landscapes of forensic and geriatric psychiatry nursing. Specifically, the original project sought to understand the values guiding forensic and geriatric psychiatry nursing practice, how nurses conceptualized and made use of a palliative approach in their care of aging patients, and to what extent their moral agency was fostered or constrained with respect to the enactment of a palliative approach to care in their everyday practice. At this time, one research article from the original project, based on the interviews conducted with forensic psychiatry nurses, is in press (Wright et al., 2017, in press). This paper explores the values of nurses working in forensic psychiatry and how these values might influence a palliative approach in the care of aging patients. A second article based on the findings from geriatric psychiatry nurses is in development.

As a Master's nursing student, I worked as a research assistant for the original research project. This work involved visiting the research site and introducing the project to clinical managers and unit nurses. I provided my university email address to potential participants, ensured recruitment posters were visible on the study units, and communicated via email and phone with interested participants to answer their questions and arrange interview times. Part of this work included communicating with the study site research liaison, which was accomplished via email and phone. I conducted all eight interviews with four geriatric and four forensic psychiatry nurses over a period of three months and transcribed each of the interviews. The interview lengths ranged from 25 minutes to over an hour and all interviews were conducted in a nurse training area provided as an interview space by the study site research liaison.

My interest in the project was multifaceted and stemmed from my academic training in law, human rights, and nursing, as well as my professional experience working for the Canadian

Human Rights Commission, the Correctional Service of Canada, and in palliative care on a specialized tertiary unit as well as in a hospice setting with homeless and street involved individuals. These experiences provided me with frames of references in terms of values, governance structures, socio-political considerations, and lines of questioning regarding broader notions of justice. My direct experience with people alleging human rights violation and involvement in the criminal justice system served to highlight for me some of the challenges in formal mechanisms of legal redress. The limitations of these mechanisms can be paralleled in the health care system; the legal and health systems intersect with social determinants of health and both are predominantly reactive rather than preventatively oriented. Moreover, both systems engage problematic ethical terrain relative to the limits of what can be corrected or cured.

It is often the broader notion of justice and guiding values that oriented my own questioning and learning. While on a placement in a correctional setting, I encountered a care context that crystalized some of my concerns and questions. Many inmates occupying the site beds were aged and living with significant life-limiting illnesses. Nursing access to each inmate required the presence of two correctional officers. An older inmate I cared for was unable to raise himself independently out of bed. When I moved to help him, the correctional officers dissuaded me from doing so. What I sensed then as a student nurse, yet unable to articulate, was that this man was dying.

I recognize that contexts, like the forensic environment, are premised on a sense of continuity, including that of the forensic identity. I also recognize the very real safety and security concerns engendered in the care of inmates. However, from the challenging experience described and others, I carry a sense of responsibility to improve palliative care access and have come to ask a new question related to justice: What values ought guide us in the care of others in

situations that cannot be corrected or maintained? Within a constructivist epistemic stance, described next, I situate the construction of realities, including some of my own.

### **Analytic Elaboration**

In the following section I describe the research aims of my analytic elaboration of the original research project and situate these within a constructivist epistemic stance. I describe the analytical framework constructed for this analysis which draws from both interpretive description (ID) and interpretive phenomenological analysis (IPA). I describe both analysis methods and detail how these approaches help to explore the research aims.

### **Research Aims and Epistemic Stance**

The research aims for my analytic elaboration of the original research project were to:

1. Explore nurses' engagement with mortality within an ethics of finitude;
2. Identify enablers and barriers, and related historical and socio-political discourses, to engagement of nurses with their patients within an ethics of finitude;
3. Articulate and deepen understanding of the palliative approach, including ethical dimensions and considerations, from an exploration of ethics of finitude.

As the original project sought to understand the values guiding forensic and geriatric psychiatry nursing practice and how nurses conceptualized and made use of a palliative approach in their care of aging patients, my analytical elaboration is situated within these aims as the research serves to explore the ethical engagement of nurses and enactment of a palliative approach informed with the theoretical scaffolding of an ethics of finitude. In other words, my project rests within the original research project in its focus within the palliative approach but engages the aims with unique and aligned research consideration related to ethical considerations, including those of relational engagement.

The rationale and evidence for my research project is described in Chapters 1 and 2. The research is situated within a constructivist epistemic stance in which multiple perspective and realities are held to exist and as such, reality is deemed subjective (Appleton & King, 1997). Put another way, truth is variable, subjective, and determined by the individual or cultural group (Weaver & Olson, 2006). Appleton and King (1997) observed upon the interplay of ontology and epistemology in constructivism, whereby it is impossible to consider the nature of reality without considering the relationship of the researcher to what can be known. It follows that it is important for me to situate myself within the research, as described above in my academic and professional interests and investment in the research, and to acknowledge my relationship as a researcher in terms of mediating what can be known (Guba, 1990). In other words, the interplay of ontology and epistemology points to the interactive nature of constructivist research, whereby the “researcher must interact with study participants throughout the research process to access the multiple views of reality that may exist” (Appleton & King, 1997, p. 1). Indeed, the selection of my research aims and the construction of all aspects of the thesis, including the literature review, conceptual scaffolding, and analytic framework, are mediated by me including my interactions with participants and with the data.

The analytical framework constructed for this analysis draws from both interpretive description (ID) and interpretive phenomenological analysis (IPA). Consideration for this framework was based on the need for epistemic and methodological congruence with the original project as well as meeting the needs of my own research aims. ID and IPA approaches are commensurate in that both approaches are inductive, idiographic (fully analyzes within case before moving across case), and interrogative (as exemplified in the questioning undertaken in the data analysis process) (Thorne et al., 2004). IPA is a dynamic approach that stems from the

field of clinical psychology and accounts for participants' perspectives while allowing for an active participatory role for the researcher (Smith & Osborn, 2003). Moreover, IPA methodology offers a more directive approach to analyzing the data than does ID and as such serves a practical function in the data analysis process (Smith & Osborn, 2003). ID on the other hand is grounded in the clinical realities of nursing practice and generated based on informed questioning (Thorne et al., 2004). While it is in many respects congruent with IPA, ID diverges so as to permit space for conceptual creativity and flexibility to work outside of strict disciplinary confines to "create a design logic that is consistent with the aims of an investigation of clinical health and illness phenomena" (Thorne et al., 2004). Given the unique consideration of my project's design as an analytical elaboration, ID affords me flexibility to create a project that accounts for the realities of the study structure while ensuring mechanisms to commensurately ensure accountability in this process, including transparency in the intersubjective construction of knowledge and in my positioning to it as a researcher (Thorne et al., 2004).

Description of and further rationale for each of the selected methodological approaches are considered next.

### **Interpretive Description**

ID is an inductive analysis approach that departs from but is not constrained by a theoretical scaffold, and is firmly grounded in the clinical realities of nursing practice (Thorne et al., 2004). In other words, ID "provides direction in the creation of an interpretive account that is generated on the basis of informed questioning, using techniques of reflective, critical examination, and which will ultimately guide and inform disciplinary thought in some manner" (Thorne et al., 2004, p. 3). As described by Thorne et al. (2004), ID is a non-categorical method of research aligned with "interpretive naturalistic orientations" (p. 3). In this constructivist vein,

ID yields constructed truths rather than facts (Thorne et al., 2004). It follows that this non-categorical approach enables intersection with other, more directive, qualitative research methods such as IPA, described below. ID can include multiple data collection strategies to ensure more comprehensive and contextualized interpretations of its central phenomena of interest (Thorne et al., 2004); this data collection process is outlined below with reflection on its congruence with IPA. In addition, ID presumes that there is theoretical knowledge within which studies of human health phenomena are generated and therefore it affords the researcher the opportunity to include reference to such scaffolding, as evidenced in the elaboration of the theoretical scaffolding in Chapter 3 (Thorne et al., 2004). Specifically, the recognition of existing theoretical knowledge affords the researcher the opportunity to introduce extant literature and theoretical positing regarding an interpretation about the enactment of a nursing ethic. The lens of an ethics of finitude was identified after undertaking considerable literature reviews and reflecting upon clinical and disciplinary experience in palliative care as well as in conjunction with broader ethical considerations from my academic and professional experience. Through a critical examination of the current socio-political context of palliative nursing practice, shaped by an aging geriatric and forensic psychiatry patient demographic, momentum for a palliative approach to care for all Canadians who are aging and living with life-limiting conditions, and a renewed interest in questions related to end-of-life, as exemplified in medical assistance in dying legislation, there is a need to guide disciplinary thought to ethical dimensions underpinning these phenomena. As such, ID is significant insofar as to support an alignment among analytic activities, the research paradigm, and the disciplinary context of geriatric and forensic psychiatry nursing. ID is employed as a methodological approach in conjunction with IPA, considered next.

### **Interpretive Phenomenological Analysis**

As this research is situated within a constructivist paradigm which aims to gain in depth and detailed description, understanding, and explanation of ordinary occurrences as they are experienced by participants (Weaver & Olson, 2006), IPA offers a congruent methodology relative to the research's epistemic stance as well as with ID's non-categorical method of research. IPA enables the researcher to explore how geriatric and forensic psychiatry nurses make sense of their personal and social world (Smith & Osborn, 2003) using semi-structured interviews. This strategy enables the gathering of rich descriptions of nurses' varied experiences on each of the study units that is suited to addressing the research aims related to the process of engagement and the identification of related barriers, enablers, and broader socio-political discourses.

IPA is particularly useful when the phenomenon of interest is one that engages complexity, process, or novelty (Smith & Osborn, 2003), and as such this approach is suitable in an exploration of engagement with mortality within a non-traditional context of palliative care. Moreover, the power of an IPA study is partly in the light that it sheds on claims within extant literature and within broader theoretical understandings (Smith & Osborn, 2003). It follows that the literature review and theoretical underpinnings of this research, detailed in Chapters 2 and 3, are significant and can be situated within the frame of the research aims.

IPA involves a double hermeneutic whereby the researcher is making sense of the participant who is making sense of their own practice (Smith, 2004). In other words, the aim of IPA is "to explore in detail how participants are making sense of their personal and social world" which "involves detailed examination of the participant's lifeworld" (Smith & Osborn, 2003, p. 51). In addition to analytic guidance from ID, detailed above, data was analyzed using Smith and

Osborn's (2003) approach to data analysis in IPA. According to this method, the researcher engages in an interpretive relationship with the interview data (Smith & Osborn, 2003). IPA is idiographic, that is, concerned with the individual case, and requires the detailed examination of the individual case until there is "some degree of closure" before there is cross-case analysis (Smith, 2004, p. 41). As described in the data analysis process, this idiographic approach was followed in order to get an understanding of the life-world of the participant prior to identifying broader cross-case categories (Smith, 2004), such as those that were found related to discourses of safety and security. In IPA, "meaning is central" and the purpose is to "understand the content and complexity of those meanings rather than measure their frequency" (Smith & Osborn, 2003, p. 64). It follows that meaning is not superficially apparent and requires sustained engagement with the data and in the process of interpretation (Smith & Osborn, 2003). The research aims related to engagement with mortality are congruent with an approach centered on meaning rather than quantification. For example, with respect to barriers and enablers, the research aim is to identify their meaning in relation to enacting an ethics of finitude rather than accounting for all the barriers and enablers encountered by nurses.

### **Methods**

Methods refers to the "steps, procedures, and strategies for gathering and analyzing data in a study" (Polit & Beck, 2012, p. 733). This section describes the steps and processes undertaken in the project, including sampling, data collection, and data analysis, aligned with the methodological framework outlined above.

### **Sampling**

Convenience sampling was used to select available participants and those who met the eligibility criteria were interviewed (Polit & Beck, 2012). According to the original project, it

was anticipated that 5 to 10 interviews would be conducted with full or part-time Registered Nurses (RNs) from the study units. The sample size of phenomenological studies such as ID and IPA are typically small (generally 10 or fewer participants) and as such the obtained sample size (n=8) was appropriate to meet the aims of both the analytical elaboration and the original research project (Polit & Beck, 2012; Smith & Osborn, 2003; Thorne et al., 2004). The selection of participants as either part or full-time RNs was driven by the practical consideration that nurses working in a more regular capacity on the units were more likely to experience the phenomena studied whereas the criterion of participants as RNs enabled the possibility of consistency across this dimension (Polit & Beck, 2012).

### **Data Collection**

Demographic information was collected to describe the basic characteristics of participants and to ascertain eligibility for the study (Polit & Beck, 2012). Participants were aged between 24 and 54 and two participants did not provide this information. Of the eight participants, one participant was male, the length of experience in nursing ranged from 2 years to over 30 years. In addition to geriatric and forensic psychiatry nursing, participants' prior nursing experience included orthopedic surgery, maternity and newborn nursing, long term care, complex continuing care, and occupational health and safety.

In-depth interviews, a common method of data collection in qualitative research, were used as the structure for data collection (Kvale & Brinkmann, 2009) and all interviews were conducted by me. The semi-structured interview format was used because it allows participants to introduce issues that may not have been considered by the investigator, facilitates rapport, and tends to produce richer data than more structured interview schedules (Smith & Osborn, 2003). The interview schedule, written for the original research, is included in Appendix A: Interview

Schedule. While this schedule guided the interviews, the questions were adapted and elaborated upon so as to probe interesting topics that arose and to follow the interests and concerns of participants, such as by prompting participants to “tell me more” about a situation or care experience (Smith & Osborn, 2003). This approach was congruent with the exploratory nature of the research. The interview questions in the schedule were framed broadly and openly without an intention to test a predetermined hypothesis (Smith & Osborn, 2003). Based on Osborn and Smith’s (2003) suggestions, broad issues to be covered, such as aging, transitions, and ‘palliative’, and probes for the different questions, while utilizing open and neutral language, were considered in developing the interview schedule. The interview location was based on the comfort and preference of each participant, so as to establish rapport and to minimize the researcher-participant power imbalance (Parnis, Mont, & Gombay, 2005; Polit & Beck, 2012). All participants opted to be interviewed onsite in the interview space provided by the site research liaison.

### **Data Analysis Process**

The interviews I conducted occurred from April to June 2016; the subsequent transcription of these interviews afforded me the opportunity for increased familiarity with their content. My detailed examination of the first interview included reading this transcript several times to develop familiarity with the account (Smith & Osborn, 2003). I made free annotations about interesting and significant passages in the margin of the document (Smith & Osborn, 2003). These annotations included my thoughts, related experiences, initial reactions, assumptions, and values emerging in response to the content. Next, I went through the interview and identified ideas, in keeping as closely as I could to the meaning communicated, a task that proved challenging at times as it was tempting to prematurely group ideas to more abstract

concepts. Because I was aware of this reflex, I was prepared to refrain from doing so and opted for additional free-notation (e.g. ?environment) when the urge to abstract occurred. After carefully reading the first interview, a list of over 80 ideas was produced. These ideas were grouped into three areas that corresponded to my three research aims, described above.

The identified ideas were preliminarily grouped under one, two, or all three research aims. Moreover, within the aims, related ideas were tentatively clustered under categories and subcategories. My decision to cluster information this way was provisional but also deliberate insofar as reflection was given to the construction of the research project and to the aim of ultimately making complex findings meaningful (Thorne et al., 2004). With respect to identifying ideas, my intention was to find expressions that, while connected to the original text, were sufficiently abstract to connect to the ideas of the other interviews (Smith & Osborn, 2003). To substantiate the categories and subcategories, text excerpts were either directly extracted from the data and used as a category or a text excerpt was placed adjacent to the selected category/subcategory in order to link the selected category and/or subcategory expression as closely as possible to the data. Excerpts were extracted from the first interview to substantiate the ideas identified and to establish a rough initial grouping of categories. The purpose of this initial organization was to gain early insight into the data while maintaining flexibility for later reorganization and re-imagination based on the ideas emerging from subsequent interviews. Reflections related to these questions were written in the margins of the interview transcript.

I then read each transcript sequentially with a similar analysis process. After the free annotations were done, I re-read each transcript and categories of ideas were identified. These categories were then grouped according to the research aims and within each of the aims, additional organization and sub-categorization was done. Once this scaffolding was in place, I

drafted text to summarize the findings and present them coherently. After drafting and re-reading the analysis, I once more re-read all the interview transcripts to determine if additional ideas or categories were omitted and to confirm the contextual accuracy of the presented findings. The research findings as identified through the process outlined above are detailed in Chapter 5: Findings.

### **Rigour and Reflexivity**

The issue of quality in qualitative research is not without controversy (Polit & Beck, 2012) and there are many criteria and concepts for qualitative excellence (Tracy, 2010). While different terminology is employed and various standards have been developed and critiqued (Polit & Beck, 2012), ensuring the quality of qualitative research is important in communicating the value of the work (Tracy 2010). The quality criteria of rigour and reflexivity were both engaged in the research project and are described next.

#### **Rigour**

Tracy (2010) refers to “rich rigour” as a criterion for excellence in qualitative research. For Tracy (2010), this richness is engendered through a variety “of theoretical constructs, data sources, contexts, and samples” (p. 841). In other words, the tools or methods used to conduct the research should correspond to the complexity and nuance of the phenomena of study (Tracy, 2010). To this end, the analytical framework that includes ID and IPA was constructed to meet the complex and nuanced elements of my project, both inherent to its stated aims and as an analytic elaboration situated within an original research project.

For Tracy (2010), the preparation and effort of the researcher is essential as “a researcher with a head full of theories, and a case full of abundant data, is best prepared to see nuance and complexity” (p. 841). Throughout the research project, I followed emerging nuances—this

including taking Gentle Persuasive Approaches (GPA) training upon encountering frequent reference to this from study participants. I remained up to date on emerging research by setting up key word alerts in research databases. Based on additional readings, conversations with peers and supervisors, and personal reflection, I repeatedly revised both my literature review and theoretical scaffolding.

Rigour is also engaged by asking critical questions regarding the data and analysis procedures (Tracy, 2010). Throughout the data analysis process described above, and congruent with ID's focus on the process of intellectual inquiry, critical questions informed the analysis including: what does this mean? What is happening here? Why is this here? (Thorne et al., 2004). This questioning occurred through direct engagement with the interview transcripts, in conversation with faculty supervisors and thesis committee, and by sharing an anonymized excerpt with other nursing researchers as part of a lab of the Nursing Palliative Care Research and Education Unit at the University of Ottawa. Reflection on these critical questions is captured in the free-notations in the interview transcripts and reflected in the thesis findings and discussion. Critical questioning is re-iterated in the discussion of the findings regarding the potential contributions of the proposed ethical lens.

### **Reflexivity**

Reflexivity is another means to ensure the quality of qualitative research (Tracy, 2010). Reflexivity is the process of "critical self-reflection about one's own biases, preferences, and preconceptions" (Polit & Beck, 2012, p. 740). As described above, I entered this project with my own academic and professional experiences. Identifying, describing, and reflecting upon my background and formative experiences helped me to delineate some of the preferences and biases that I might bring to the research process. Defining this history within the thesis was a way to be

self-aware within the research. Reflexivity also occurred through communication exchanges with the research team, my academic supervisors, and thesis committee (Clarke, 2006) that contributed to the refinement of the project, including the identification of possible different interpretations in the categorization process.

### **Ethics**

This research involved human study participants and as such, followed the *Tri-Council Policy Statement*; the original project required ethical review (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada 2014; Polit & Beck, 2012). The research was submitted for review by the Research Ethics Board (REB) of the University of Ottawa and by the REB of the research site. To ensure voluntariness and self-determination and avoid coercion, potential participants were not contacted directly by the researcher team; potential participants were invited, via an organizational email sent to nurses by the site research liaison to participate in the project. Participants could contact the research team by email or telephone. A poster was included in the invitational email as well as posted on the study units. To ensure informed consent and to ensure sufficient time for reflection, potential participants were provided with a written consent form in plain-language prior to the interview. As consent is an ongoing process, participants were offered continued opportunities in writing, by email, and verbally, in person, to ask questions and obtain additional information prior to and during the interview. The consent form included considerations related to the invitation to participate, the type of data collected, the nature of the commitment, participant selection, risks and benefits, compensation, confidentiality, voluntary consent, conservation of data, and contact information (Polit & Beck, 2012). Participants were asked to sign the consent form and a copy of this signed form was

provided to participants. The interview audio-recordings and transcripts were encrypted and saved on a secure server for the prescribed period (5 years minimum for the University of Ottawa). As my research project was an analytic elaboration of the original study's original research objective, it did not necessitate separate ethical approval.

## Chapter 5: Findings

This chapter analyses the interview findings. Analysis of the findings based on the research aims is presented sequentially related to: the exploration of nurses' engagement with mortality within an ethics of finitude; identification of enablers and barriers to engagement of nurses with their patients; and, an articulation and deepening of understanding of the palliative approach, including ethical dimensions and considerations. The engagement of nurses within an ethics of finitude was found to surface in the category of recognition (nurses' recognition of mortality, nurses' recognition of the increased vulnerability of their patients related to aging and life-limiting conditions, and nurses' corresponding increased responsibility for patients with increasing limitations) and the affirmation of values (human connection, dignity, comfort, family, familiarity, and personhood). Barriers and enablers to this engagement were explored related to the care environment, the psychiatric nurse and patient construction, and factors related to family. The implications of the related discourses in the articulation of the palliative approach emerged in relation to health system considerations and to the language of the palliative approach. To begin, a summary of the findings is provided, followed by a detailed presentation of the findings including supportive quotes. Discussion of the findings with respect to the research aims and implications for health care practice are presented in Chapter 6: Discussion.

### **Findings Summary**

This chapter presents the findings, grouped according to the stated research aims. With respect to the first aim the categories of recognition and values emerged. In the first subcategory, recognition, nurses expressed this by reflecting upon the increased vulnerability of aging patients and patients with life-limiting diagnoses as well as by seeing beyond a patient's "intact" physical status to apprehend vulnerability within the psychiatric environment. Participants acknowledged

the cumulative losses experienced by aging patients, including disconnection from family and familiar settings as well as the social losses experienced by younger forensic patients and their families. With respect to aging patients with neurodegenerative disorders on geriatric psychiatry units, nurses engaged in the process of recognition by identifying the continued emotional and physical needs of patients who lost their ability to communicate, and more generally, by recognizing patients' limitations related to aging and their life-limiting conditions. This recognition corresponded to an expression of increased responsibility on the part of nurses, such as an increased focus on the care needs of aging patients and heightened observation to ensure their safety.

Nurses engaged with mortality in affirming the values of human connection, dignity, comfort, family, familiarity, and personhood. Nurses affirmed the value of human connection by: valuing time and presence with patients appearing to require additional nurse involvement, valuing human connection above a particular format of care provision, and enabling opportunities for reciprocity and generosity with and among patients. Dignity was affirmed in the emphasis nurses placed on meeting the personal hygienic needs of patients and in the use of humour to help patients address care deficits. In affirming the value of comfort, nurses expressed recognition of the plurality of losses incurred by older patients (i.e. social, emotional, functional) so as to emphasize the importance of comforts as buffers against these losses. With respect to the value of family, nurses recognized the displacement and loss that can occur in a family relative to mental illness and to the forensic diagnosis of one its members. Familiarity, in the sense of continuity of care, was affirmed by nurses communicating the opportunity to be present with a patient over time in that this experience permitted understanding of patients' changes related to their life-limiting conditions. The importance of familiarity, as it related to recognition of

patients' sense of the familiar, was affirmed in nurses' awareness of the home-like place that the psychiatric unit represents for some patients. Nurses affirmed this by enabling patients to return to visit the forensic unit after discharge and by recognizing the importance of involving geriatric psychiatry patients in their care planning. Nurses also affirmed the value of personhood by seeking to maintain this in the face of threats to it such as those related to neurodegenerative illness and unfamiliar care provision contexts.

With respect to aim 2, enablers and barriers related to engagement of nurses with their patients were identified pertaining to the care environment, the psychiatric nurse and patient construction, and factors related to family. Within the category of environment, three subcategories were identified: the anomalous aging patient in forensic psychiatry, organizational priorities and funding, and safety and security. With respect to the first subcategory, the descriptions provided by some nurses suggested that older forensic patients could be considered anomalous whereby the arrangement of the forensic environment served to increase the visibility of this small group of patients. For some nurses, the anomalous state of older forensic patients was perceived positively based on the high ratio of nurses to patients in the forensic setting that allowed for greater engagement with aging patients. This arrangement was also viewed as problematic in that older, frailer forensic patients could be vulnerable relative to their declining physical health in an environment of younger, more physical able bodies and related to the competing demands relative to the two forensic patient populations (older and younger).

Organizational priorities was another subcategory related to environmental barriers and enablers. While nurses favorably referred to receiving organizationally-funded training related to geriatric care (i.e. GPA, P.I.E.C.E.S.), nurses commented upon the organizational priorities of nursing care that engendered more direct care of patients and less formal interaction with

families, such as conversations about goals of care. In part because of this arrangement, the knowledge disconnection related to patients' illness expressed by families hindered nurses' ability to engage families relative to this, with implications for care approaches. Participants working on the geriatric unit reflected upon the higher staffing levels and programming available during the day shifts in contrast to the increased care needs of sundowning patients on evening shifts. Moreover, nurses reflected upon experience with curative priorities in the care of patients for which benefits were not clear to nurses.

Safety and security, the third environmental subcategory, was identified as an organizing force on the unit. The presence of a patient in one environment (e.g. on geriatric unit) versus another (e.g. off geriatric unit) could alter the approach to care an aging patient might experience relative to the safety considerations unique to these contexts. Additionally, the primacy of maintaining a safe and secure environment on the forensic unit was such that the fluidity and flexibility required within a palliative approach could represent an aberration from established norms, such as facilitating family presence. The environment served to shape perspectives relative to safety and security and patient behavior, as mediated by language; behaviour that may be perceived more neutrally as "responsive" on a geriatric unit (i.e. all behaviour has meaning) might be labelled more negatively as "aggressive" or "intrusive" on a forensic unit.

The second category of barriers and enablers pertains to the construction of the psychiatric nurse. The psychiatric nurse, nurse comfort with the care of aging patients, and professionalism were identified as subcategories of the construction of the psychiatric nurse. All nurses (forensic and geriatric) mentioned the importance of closely monitoring aging patients in terms of their physical health as well as a recognition that this is sometimes overlooked in the psychiatric nursing care context; in so doing, nurses revealed elements of the psychiatric nurse

construction as one contrasted to expertise in physical care. With respect to comfort, participants referred to their level of experience with end-of-life care to impart their awareness of mortality and the importance of communication about end-of-life to alleviate suffering. Professionalism was identified as the third subcategory; some nurses described the work of caring for aging patients as requiring a form of professional adjustment to adapt to the level of familiarity required in the work.

The construction of the psychiatric patient, the third category of barriers and enablers, included two subcategories: the forensic patient and the devaluation of geriatric care. The forensic patient construction relates to expectations of what constitutes this type of patient and was perceived by some nurses as one with functional independence. As such, this construction problematized the care of forensic patients lacking this independence. The care of aging patients was devalued insofar as the geriatric units were described as the first from which nurses were pulled and to which the least experienced staff were sent.

Family is the fourth category that emerged under the second research aim. Mentioned by all nurses, the role of family was most frequently emphasized by nurses working in geriatric psychiatry. Two subcategories emerged with respect to family: families' knowledge of the patient, and families' understanding and expectations. Families knowledge of the patient served a humanizing role in helping nurses to understand what could be distressing to patients' and in turn perceive possibilities to promote comfort. Perceived challenges related to families' understanding and expectations included disconnection between families' understandings of illness trajectories and the goals of care for geriatric patients. Nurses' expressed feelings of devaluation in their care giving efforts in the face of perceived disconnection with respect to families' understanding and care expectations.

With respect to the third research aim, exploring how enactment of an ethics of finitude serves to articulate and deepen understanding of the palliative approach, two categories emerged: health system considerations and the language of the palliative approach. Health system considerations emerged most prominently by nurses' communicating their recognition of the vulnerabilities of patients, including the higher care needs of aging patients, community care continuity, organizational structure and priorities, and recognition of vulnerability premised on the continuity of care provision. With respect to the missing language of the palliative approach, it was found that although nurses expressed semantic confusion relative to the palliative approach and palliative care, ethical consideration were nonetheless engaged, explored through the lens of an ethics of finitude in Chapter 6: Discussion.

**Aim 1: Explore nurses' engagement with mortality within an ethics of finitude**

**Recognition:** mortality itself, the increased vulnerability of their patients related to aging and life-limiting conditions, and their responsibility for patients relative to their increasing limitations

**Values:** human connection, dignity, comfort, family, familiarity, and personhood

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**Aim 2: Enablers and barriers, and related historical and socio-political discourses, to engagement of nurses with their patients within an ethics of finitude**

**Environment:** anomalous aging patient in forensic psychiatry, organizational priorities and funding, safety and security

**Nurse construction:** the psychiatric nurse, nurse comfort, professionalism

**Patient construction:** forensic patient, geriatric care devalued

**Family:** families' knowledge of the patient, families' understanding and expectations

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**Aim 3: Articulate and deepen understanding of the palliative approach, including ethical dimensions and considerations**

**Health system considerations:** high needs of aging patients, community continuity, organizational structure and priorities, recognition premised on continuity

**Missing language of palliative approach**

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*Figure 1: Findings outline*

**Aim 1: Explore Nurses' Engagement with Mortality within an Ethics of Finitude****Recognition**

Nurses engage with patients in relation to mortality through a process of recognition and this process appears to serve for nurses as a prompt for further engagement with patients. Nurses engaged with mortality in their recognition of: mortality itself, the increased vulnerability of their patients related to aging and life-limiting conditions, and their responsibility for patients relative to their increasing limitations. These forms of recognition were often overlapping and intersecting, as illustrated in the excerpts. The process of recognition can be considered related to the human facticities of sociality, temporality, and mortality, proposed by Brinkmann (2006)—ethical considerations elaborated upon in Chapter 6: Discussion.

*Recognition of mortality*

Participant 6 described the importance of reflecting upon and preparing for their own death to alleviate the potential burden experienced by their family:

so, if I know it's coming or if I can prepare for it then I feel at least I'm taking some of the burden away from my family, so even if it's uncomfortable for me to discuss it.

(Participant 6 687-689)

Participant 6 communicated that their heightened existential awareness came in part from the experience of working with patients with dementia and a recognition of the limitations of modern science:

It's because personally I'm on a different, my expectation of what can be done is different.[...] I know the limitations of the medical field, I know there's no magic pill to fix things, I know with my family history, I could be diagnosed with dementia or

Alzheimer's, but knowing that helps me plan ahead, helps me talk about it to my loved ones. (Participant 6 675-680)

Participant 6 communicated their awareness of the progressive and terminal nature of a dementia diagnosis in contrast to witnessing a lack of this recognition among family members of patients in their care:

[O]ften there's a disconnect at times between ah, loved ones who have to make these hard decisions and, eh, where the trajectory goes of these diseases. Because, I'm working specifically with progressive terminal illnesses. (Participant 6 302-304)

Recognition of this disconnection in itself as well as in recognizing the vulnerability of patients relative to this disconnection in mortal awareness is highlighted in reference to treatment courses that are seemingly removed from patients' existential status, as questioned by participant 7:

well you know he's [patient] at a certain decline now, what really is ECT doing, he's not going to make a miraculous recovery. You know. He's, you know, he's now in a wheelchair, he doesn't really want to eat, like what are we doing? (Participant 7 636-638)

This passage highlights the distress, in the form of reflexive questioning "what are we doing?", experienced by a nurse who is aware of the disconnection between a patient's declining health status and the expectations of recovery associated with an electroconvulsive therapy (ECT) treatment regimen. Participant 7's questioning, in the form of "what are we doing" demonstrates an awareness of mortality in the form of critical questioning juxtaposing the existential state of the patient and treatment undertaken.

*Recognition of increased vulnerability- "you hear them"*

Participant 1, a nurse with experience both in forensic and geriatric psychiatry, communicated an understanding of the connection between care aims and health status in

speaking to the hidden vulnerability of a “physically intact” patient on a geriatric unit living with the effects of a rapidly progressing neurodegenerative disorder:

He’s huge. And he’s still quite, very like, physically intact. But just, I’m not sure what his official diagnosis is, but there’s something neurocognitive there and that’s getting worse and worse. (Participant 1 238-240)

Participant 1 evidenced understanding of the patient’s life-limiting diagnosis as well as seeing beyond the patient’s “intact” physical status to apprehend this patient’s vulnerability within the geriatric psychiatry environment. Participant 2, a nurse in forensics, spoke to the vulnerability unique to cumulative losses related to more advanced age within a psychiatric environment:

So you see them [the patients] and you hear them and when they need you, you get up and go and yeah and like talk to them. Because they have this need. They, they are, they left their family, probably you know, they’re elderly, leave their family, their surroundings, so they’ve lost all of that. Hmm. They are here with all these strangers. (Participant 2 126-127)

The nurse acknowledged the displacement of aging patients as well as the cumulative losses compounded in an aging patient on a psychiatric unit. The recognition of losses incurred by patients was frequently communicated by nurses, particularly those in geriatric care. Participant 8, a geriatric nurse, observed upon patients’ reduced ability to communicate their needs and discomforts and a corresponding need to recognize agitation as a generic form of communication requiring more on the part of the nurse in terms of discerning patient status:

Here, eh, if someone’s agitated, that’s the only cue they’re gonna give you that something’s wrong. You just know that if they look angry or sad or they’re you know, moving furniture around or closing, banging door and banging walls that they’re either,

you have to figure out what the problem is. They're not just telling you. So. You kind of have to. Again, you narrow it down, are they constipated, are they in pain, are they hungry, is it just a behaviour that's you know, an imbalance in the brain because of dementia that they're acting like this. (Participant 8 193-199)

For other patients with dementia, nurses demonstrated a recognition of their loss of abilities and culture, such as language and formal education described by participant 6, a nurse in geriatric psychiatry:

And we do have patients who don't even understand how to read or write their native tongue at this point. And there are some people even ah English, French speakers who never had a formal education, so they didn't learn how to write or read, so even if they don't quite understand, you can't show them a word. (Participant 6 128-132)

The recognition of vulnerability engendered by life-limiting illness was also communicated by nurses in reference to younger patients. Participant 5, a forensic nurse, was one of a few nurses who expressed recognition of younger patients' vulnerability to an early death in reference to younger patients with schizophrenia in describing palliative care as well as the life-limitations and related losses experienced by younger patients with mental illness:

And then at that point, that's when you're like, this is the only thing it seems that's working for them, nothing else, this is what we've got. And this is where you become palliative in nature because there's so little else for them in any other way. Like it's, it's just a spectrum of everything that you look at, and you're like, ok, it's, their days will be numbered because it's, there's nothing else. (Participant 5 287-291)

In relation to younger patients, nurses spoke of the vulnerability to loss and the grief experienced by the families of patients in forensic psychiatry. Participant 4, a forensic nurse with prior work

experience in palliative care, described this earlier experience as a form of preparation for work with grieving families on the forensic unit:

Well I think it gave me like a broad kind of range hmm of situations that we had to deal with and sometimes it helps here because we have families that come in and they're grieving, you know, their sons, it's difficult, it kind of gives you a picture of hmm, like some of the struggles they are going through. (Participant 4 58-61)

Participant 4 also demonstrated understanding of and compassion for the unique social losses experienced by younger patients and their families:

I think here it's like more difficult in a different way because they're so young, You're thinking a lot of them are never gonna get married, they're not gonna have jobs, they're not gonna be able to have families. You know. It's hard. So I think it's hard, harder in some ways, knowing that. (Participant 4 72-75)

Participant 3, a nurse in forensic psychiatry, demonstrated recognition of not only the chronic nature of mental illness in younger patients but also an awareness of the need for a beneficent approach with this patient population insofar as to help them to recognize their vulnerability in relation to their condition:

And then the goal is to help the patient learn, you know, to stabilize, to learn how to respect their illness. Many of them are too young to accept their illness or to accept they're gonna have this disease their whole life and that they're gonna need medication. And that's too much to ask them to accept that. But if you can get them to understand that their ultimate goal is freedom and to make choices for themselves by accepting that, you know. (Participant 3 75-83)

Also reflecting on the care of younger patients, participant 5, a nurse in forensic psychiatry, observed directly upon the vulnerability of some of these patients to early death:

I've termed people to be palliative in nature even when they're young.. [...] Early twenties in that eh they are more than likely never going to survive for long in that they're very very difficult to treat and the insight, the judgement isn't there and there are other determinants or grounds, eh this person, environment, and housing, and relationships, and whatnot, they are palliative in nature, and you know there's gonna be suicide, homicide, em or they'll die of some sort of circumstance. I've seen it, young gentleman, schizophrenia, and he would em, ah, would go into a diabetic, em, coma quite often. And that's eventually what em had happened and what had taken him. Another gentleman of mine, em, he had committed suicide. (Participant 5 240-250)

This participant's awareness of the vulnerability of younger patients with schizophrenia is more generally expanded upon in the recognition that some younger patients rapidly exhaust treatment options:

You are just sort of ticking off, you know what I mean, it's, sort of this, we've tried it, we've tried it, we've tried it, we've tried it. (Participant 5 293-294)

In the previous excerpts, participants demonstrated, through various expressions, the importance of the recognition of patients accumulated losses and vulnerabilities to inform nursing care.

*Recognition of increased responsibility – “you have to establish a new relationship”*

The process of recognition is operationalized in engagement with patients, which includes observation of and developing familiarity with patients as described by participant 1, a nurse working in both forensic and geriatric psychiatry, when describing the care of a geriatric forensic patient prone to confusion and vulnerable in relation to this confusion:

I would always sit in the nursing station while we were doing report so I could see him walking by because he was always up in the early morning. He almost always did this everyday. You direct him at 0713 or whatever to go the washroom. But if you don't have staff that is familiar with this. Or, in this case, I was very familiar with this patient. So it was easy to move him around, to redirect him. But if you don't have staff who is used to being vigilant in that sense. Hmm, in the sense that, hmm, because, he's not, he's confused, he's not intending to, you know, get into girls' rooms and stuff. (Participant 1 284-289)

In the above excerpt, the nurse identifies the vulnerability of the patient in the ease with which this patient's behaviour could be misinterpreted by those unfamiliar with his routines and by those who would omit similar close recognition and observation. Participant 1 also underscored an awareness of broader discourses that cast unexpected male behaviour in proximity to females as necessarily predatory and meriting correction. It follows that the vigilance described by the nurse corresponds to a heightened awareness of the responsibility to buffer this patient from this predatory optic and its consequences, the gravity of which are likely enhanced by taking place within a forensic care context.

Participant 6, a nurse in geriatric psychiatry, described the continued emotional and physical needs of patients who have lost the ability to communicate and have their needs met because of the nature of cognitive decline as well as related social losses:

[T]o hug a patient on our unit is much different than, you know, they don't have that ability for physical contact quite often, families don't come very often. That's just a basic human need. Whereas someone in an acute care hospital or outside of mental health would be able to get that from their families and their loved ones. They go home. It's a

different type of environment so. [...] So it's a little bit more, all nursing is caring, but this is more of a physical caring, to show the care because often they can't understand it, you can't explain your concern for them. You have to show them. So often that's the easiest way for them to understand. So gentle touch on the shoulder, a hug, listening to music, or dance, just, these kinds of things. Very basic communication level seems to work better with that population. (Participant 6 249-260)

In recognizing the physical, social, and emotional needs of these patients, the nurse affirms a recognition of these needs in the wider context of their vulnerability to the loss of their expression and recognition over time. In stating the contrary position of patients that "go home" this nurse acknowledges the need to establish a familial, home-like, context for the patients in their care as well as underscoring the different needs engaged by the vulnerability of patients in this setting.

Participant 7, another geriatric psychiatry nurse, compared the losses experienced by the families of patients in geriatric care to those witnessed in previous work with families on a mother-baby unit. The different nursing roles evoked in this nurse's recognition of the parallels related to losses and the development of new social roles at both the beginning and nearing the end-of-life:

And much like you know when things go wrong with the baby, it's heart wrenching and difficult, it has many family aspects and I find the same thing sometimes [with patients on a geriatric unit]. As much as a parent feels that for their children, children feel that for their parents. So watching your parent decline suddenly or drastically or a huge change in your personality, I feel like the grief is similar. (Participant 7 209-213)

In this parallel, participant 7 evokes existential poignancy related to life changes associated with these two care contexts. In the recognition of the poignancy of the time and social experiences of families, this nurse affirms a nursing responsibility in the integration of families into care:

Integrating them [families] into the care, you know what I mean. 'Cause you're establishing a new relationship, just like a mom with a baby, you're like or, for some parents, they're like what do I do with it, you know what I mean? The same with dementia, your father isn't really the same person anymore, you have to [help the family] establish a new relationship with them. I think that's a huge aspect of, especially with dementia care. (Participant 7 218-222)

Nurses engagement with patients and families appeared modified and deepened corresponding to the perception of cumulative losses incurred in the care context. There is also the underlying recognition that families are in the gradual process of losing loved ones from their previously known referentials and as such are in process of apprehending newly revealed finite dimensions of this person. Recognition of losses for nurses serves as a cue for deeper and more involved engagement with patients as well as shifting priorities to what is recognized as most valuable. The affirmation of values in the engagement of nurses related to an ethics of finitude is considered next.

### **Values**

Values are a second category that emerged in exploring nurses' engagement with finitude. Nurses engaged mortality in their communication and affirmation of values including human connection, dignity, comfort, family, familiarity, and personhood. The affirmation of these values was often related to the increased limitations and vulnerability of aging patients in that the increased fragile state of certain patients threatened the enactment of values and imparted

a correspondingly higher responsibility on nurses so that these values were safeguarded in the care of their patients. Expressions of values cannot strictly be considered in isolation from the process of recognition identified in the nurses' excerpts above. In the following section, the varied expressions of these values are considered with attention to efforts to buffer against losses relative to each of these values. Indeed, values are valued in that they are vulnerable to loss and erosion.

*Human connection – “it’s also like a huge bonding moment”*

Participant 7 expressed a preference for working evening shifts because on days “I didn’t have as much time to spend with my patients” (Participant 7 64). In so doing this nurse expresses valuing time and presence with patients who appear to require additional nurse investment in terms of overcoming communication limitations and establishing bonds:

For that, especially in dementia and stuff, when they can’t communicate with you, or like, the care is a huge problem for many of them but it’s also a huge bonding moment. When you are able to have a human connection with somebody or when they trust you and you trust them, it’s really for me, I kind of enjoy that part of it. (Participant 7 159-163)

Human connection was lived through shared humorous moments, such as the openness and acceptance with which participant 7 described the care plan of one patient:

[P]retending to shoot each other, and having a sense of humour about it, and then trying to do your care. We’ve had some strange, like approaches, [...] yeah, but whatever works. (Participant 7 142-144)

In valuing human connection above the particular format of care provision (i.e. pretending to shoot each other), the nurse affirms the primacy of the interaction of the patient.

Human connection can also be engaged in relation to engagement with the meaning of the institutional environment to some older patients as a place of comfort, as described by participant 3, a forensic psychiatry nurse:

And I [participant] just say, it's okay, I've had enough fun. Let's go back. And he'll [patient] come back to the unit. But. They're [patients] able to do it not for long because they are fairly institutionalized because they feel more secure in their own room.

(Participant 3 194-196)

Human connection can also be engaged in the enactment of possibilities for reciprocity. This is touched upon by participant 6 who described a “nugget” moment of nursing work when there was an attempt on the part of a patient for reciprocity:

So I could have a patient who's been, you know, very challenging and resistive. And they'll come up, and you'll ask them everyday, you know, you've had them for months, and you ask them, how are you today, and they're just swearing at you, telling you to get lost and then one day they'll say “I'm great and how are you?” [Laughter] And that rarely happens. People don't ask you. The patients don't ask you, how are you doing? Right. The focus is always about the patient, so you just, you take that nugget, and that's it.

(Participant 6 426-431)

In the above there is recognition of the value of human connection based on the expression of the patient that, to the nurse, perhaps signals a form of wellness that can be masked in mental illness. A similar interconnection and apparent reciprocity were described by participant 7 in the care of an indigenous patient on the geriatric psychiatry unit:

The more that the nurses took more interest in her, and that could teach us things, I think, it was really interesting.[...] You know, sitting with her and with her books and her like

showing us how do you catch fish.. [...] How do you prepare fish, and going through books.. [...] And then [patient] asking you to teach her things, you [patient] need to be more independent, this is a schedule and we kind of work together sort of figure it all out.

(Participant 7 734-743)

In the nurse's account, the patient was described as increasingly receptive to learning care approaches, such as establishing a schedule for herself, when she was first able to teach the nurses about herself. The excerpts in this section demonstrate a concern for others and connection that is independent of the limitations engendered by illness and premised instead on the patient him or herself. Human connection engages values such as dignity, comfort, and personhood, explored in the following sections.

### *Dignity*

Participant 5, a forensic nurse, affirmed the value of dignity when perceiving it to be threatened by a patient's poor hygiene as well as in the type of approach that a nurse could take to attempt to assist a patient with unaddressed hygienic issues.

I said [to the patient], I think you've gone nose blind [laughter]. What. And I said, and you know, you do like to sit and talk with people and enjoy people's conversations and I said, they may, you know, [laughter] they may not be able to enjoy your conversation 'cause all they will be able to think is that this person has a certain odor to them. And I said, I'm letting you know, you know, you seem to appreciate my [laughter] eh telling you things, you know, eh, being realistic, and eh, telling you the truth, and I'm telling you, you need to have a shower. [Laughter] So like. Well, ok, you know, since you put it that way. And so. And I go, listen you don't have to have one everyday, you just need to

make sure you're buffed up once, and just sort of have a little splash bath at the sink, and I said, you know, you just, we'll work on it together and so, yeah. (Participant 5 182-190)

This nurse's use of humor and light-hearted approach helped a patient to address their care deficits, and in so doing functioned so as to doubly preserve this individual's dignity (the hygienic care need itself and the patient's self-image). It is also noteworthy that the nurse's concern for hygiene appeared to reflect a concern for the patient's ability to be in relationship with others.

Dignity, in the form of hygiene, was of both primary and personal importance for participant 1, a nurse with experience in both forensic and geriatric psychiatry, who shared the following while reflecting upon the care of their loved ones:

The personal part of it for me is making sure that hmmm the people in your care have, yeah, I'll just use, you know, hygiene, I think is a big concern for these individuals. Hmm. And it's more like how would I want my loved ones to be treated. I would want them to be clean, and to have, you know, to be well dressed, and to be to be treated well, right. Yeah so. And. That's for me at least, that's the most important (Participant 1 436-440)

*Comfort – “Knowing that it makes him so happy”*

Comfort was a value specifically identified by many participants. For participant 2, the recognition of the plurality of losses incurred by older patients, such as those related to a familiar setting, company, and food, served to recall the importance of comforts as a buffer to losses, such as those incurred by social losses and displacement:

So when a patient gets a little bit agitated. We. Sometimes we say. You think like at lunch time you will be worried, is this the food you eat in your home? Maybe it's the

food. May they're irritated by all these people around them. Maybe this food isn't anything comparable to their traditional food. (Participant 2 133-136)

For this participant, the traditional food serves a symbolic role for patients relative to home and comfort. Participant 3, a forensic nurse, communicated the importance of various efforts to make a patient "so happy":

Knowing that it [following patient's routine] makes him so happy. Hmm. And you can see it on when he is with regular eh staff. He's so appreciative. So you're not having involved conversation but then we get more the family involved, so we speak to the family, the daughter, we ask how, that we're observing a lot more behaviour because he's not able to tell us everything. So we have to figure things out, symptoms based on how he's acting. Because he's not able to communicate with us in that certain way.

(Participant 3 149-154)

In the above, the participant reflected upon the involvement of family to communicate for the patient what he cannot as well as to corroborate the perceived comfort of the patient. Participant 8 described getting patient into their pyjamas early in recognition that this activity can become more distressing to patients when they are already tired:

Even if they are not ready to go to sleep we'll get them into their pyjamas and everything. [...] So that whenever they are ready, because a lot of them will get ah upset if we try to change them if they are already falling asleep. (Participant 8 84-87)

This excerpt illustrates care reflecting early recognition of the needs and vulnerabilities of patients to ensure that measures are taken to sustain patient comfort.

*Family – “I can’t say what’s ideal for someone else’s loved one”*

The value of family is engaged by participant 2 in relation to empathizing and communicating with a patient’s family. In the excerpt, this forensic nurse recognizes the displacement and loss that can occur in a family relative to the mental illness and forensic diagnosis of one its members:

The family is also part of the care. And educating them. And telling them.. like certain things about like, when they do the index of offence. Which is whatever they are charged with. Originally, the person was sick. So telling the family you know, that’s part of the illness. [...] It’s not just, you know, your mom waking up one day and doing those things. (Participant 2 205-209)

The statement illustrates how the nurse, in providing the family with education, acknowledges the important role of family and attempts to protect both family and patient against the threat of stigmatizing processes related to the construction of a forensic identity. This construction and the subject of stigma are explored further in Chapter 6: Discussion. By affirming the importance of family and helping to minimize the potential losses that this relationship could suffer, the nurse acts to prevent the compounding of losses already experienced by the patient. Participant 2 also identified the importance of the family in helping to understand how best to care for and engage with the patient:

And eh, once the patient lets you talk to their family members that things gets easier. So they tell you how this person was. Were they early riser or did he always sleep in? You know, their history. (Participant 2 239-241)

Engagement of the family, as communicated above, serves to promote patient comfort and provide a humanizing social context to a patient unable to claim this for him or herself. To know

how to care for the patient requires knowing who the family knows the patient to be, as illustrated in the following excerpt by participant 6:

I think for me, safety and comfort, and again it depends on the person, it depends on the family. I can't, I can't say what's ideal for someone else's loved one. I can't. (Participant 6 366-367)

Participant 8 illustrates this humanizing role in their request for photographs from family, both to help the nurse know the patient but also to socially orient the patient:

Again comfort. Obviously comfort, and eh, making sure that it's quality care and eh, that eh, they're calm and seem happy, you don't want them to seem like upset all the time or tired and that they're following their routine, I do like to know what likes they had, what they used to do, I talk to them about their family members so that they feel, because a lot of them, sometimes they don't get visits very often 'cause their families live far away so. I like, when the family members do come in, I try to ask them to bring in pictures. So that you know I can look at the pictures with them and talk to the patients about their family members. (Participant 8 365-372)

The value of family in sustaining a patient's personhood is compounded by the losses incurred because of degenerative disease such as dementia. The family helps in the actualization of other values and knowing what is comfortable or meaningful to the patient. In other words, the family helps to orient nurses to the patient.

Family can also be a point of ethical reference for nurses in reflecting upon the experiences of their own loved ones in relation to life-limiting illness and in reference, below, to the themes of futility and letting go. Participant 7, who described caring for their own family

members with dementia, communicated recognizing “my family members” in the distress and suffering vocalized and otherwise communicated by some patients on the geriatric unit:

Unless they're in discomfort and things, what, what are we doing. It's really sad to see sometimes. We have a few, we have one [aging patient] in particular and we had one before, they're non-communicative, they're stuck in a wheelchair, all they do is scream all day, you can tell that they're like literally in agony, they just, they're frustrated, they, you know, they, there's not these bright moments of like yeah! [...] You know, I recognize my [nurse's own] family members, like they [patient's family] don't and they're [patient] uncomfortable and like you can sort of like see in their eyes they're [patient] ready to go, the families aren't ready to go. (Participant 7 565-572)

*Familiarity – “Because they get to know you for their lives and you become part of their life”*

The importance of continuity of staffing with patients with limitations such as those related to neurodegenerative disease can be further understood in the idea of journeying with or the familiarity gained by knowing a person over time. Participant 1, a forensic nurse with experience in both forensic and geriatric psychiatry, iterated the value of working with patients and observing them over time:

So it was like that shift, moving in that hmm, like direction right. And. I guess we were lucky 'cause or I was lucky at least to see his progress through that. And to understand that [progressive life-limiting illness]. Well, it's kind of sad to say this is where he came from and this is where he is right now but that's just the nature of his illness. So. Again. And when he was well, he was also aggressive [laughter] hmm but then understanding like the nature of these aggressive and responsive behaviours was changing through that period of time. (Participant 1 499-504)

In the above excerpt, participant 1 appeared to value the opportunity to be present with a patient over time in that this shared experience permitted the nurse to understand the patient's changes related to the trajectory of the life-limiting condition. Participant 1's choice of the word "luck" suggests that the potential for such continuity with a patient as they approach end-of-life is not guaranteed or may represent an aberration from typical care provision.

Further, participant 1 also described "correctly" perceiving a patient's behaviour as a sign of neurocognitive deterioration by contrasting it with the difficulty in gaining such an informed perspective with an unknown patient such as "somebody coming in off the street" (Participant 1 327). It follows that shared experiences over time engender familiarity. The sense of familiarity, communicated by some nurses, including participant 3, a forensic nurse, extended to viewing patients and nurses as a family-like unit:

[O]ne of the elderly patients, hmm, he's actually been looked at to go to a nursing home. Uh hum. Things always take time. [Laughter] None of use are umm. And I think because they are part of our family... nobody is in a hurry to see them go. We very much like these patients. [...] we're very happy to have them in here. So if they do go, we'll probably be sad more than anything. Because we've had them for so many years.  
(Participant 3 367-372)

The familial relationship of the unit is commented upon by another forensic nurse, participant 5. This participant referred to all patients, not simply geriatric patients, in commenting upon the familial relationships that develop between nurses and patients on the unit:

They spend a lot of time with us. So. It's eh. There is a professional relationship but there's also some sort of em, you become some sort of em familial professional

relationship with them somehow too. It's eh. Because they get to know you for their lives and you become part of their life and it's eh. (Participant 5 23-26)

Participant 3 observed that the familial type bonds that develop are not limited to the relationship between patients and nurses but also among patients themselves in the forensic setting.

And when they get discharged, a lot of them have a hard time, so then we let them come in on the weekend, come and sit with the patients, 'cause it's very hard for them when they're discharged [...] They miss the camaraderie. They miss sitting together at meals. Try to imagine if you were discharged. (Participant 3 237-239, 243-244)

Communicated in this passage is an awareness of the feelings experienced by some forensic patients after their discharge to a home or community setting. It follows that patients may experience an adjustment period following discharge or again that the forensic unit itself may represent a more home-like environment than some discharge contexts. The nurse mentioned that some discharged patients do return to the unit to spend time and communicated an awareness of the importance of maintaining this connection for patients' wellbeing. In so doing, the nurse communicated an awareness of the symbolic place of the unit for some patients, such as one of familiarity and intimacy. The above passages are reflective of an appreciation of unconventional yet meaningful values related to family, home, and personhood.

*Personhood – “maintaining a sense of themselves”*

Nurses reflected upon efforts to maintain patients' sense of personhood in the face of threats to this from the nature of neurodegenerative illness, evocatively and succinctly captured in the words of participant 6, a geriatric nurse, “It's important to keep what little you have” (541).

By attempting to involve patients as much as possible in their own care direction, nurses affirmed a recognition that the degree of this involvement is time-sensitive regarding the illness trajectories of patients with neurodegenerative disorders in geriatric psychiatry:

It really depends. And I think, for the aging population, I think maintaining a sense of themselves is very important, that eh, independence when you can. And again with our population is quite unique but in general, for, for aging patients, I think it's important for them to have some autonomy, to have some say in in how they want to be treated, what direction their care can or should go while they are still capable. (Participant 6 523-527)

Nurses affirmed the importance of engagement with patients' personhood in their recognition of care contexts that can disconnect them from personhood-affirming referentials such as family, life experience, or the materialities of a physical home. In the following excerpt, a geriatric nurse conveys an awareness of a patient's previous life experience as a police officer to make sense of a patient's current behaviours:

[I]f your memory of you being a [laughter] police officer then and there's all these people, rummaging around and whatever [laughter] you believe it's your duty as a police officer to sort everybody out, and you know what I mean, you have this idea of who you are and used to be. So, you don't know that your body isn't able to do the same thing anymore, you kind of lose that, but I think still in their heart they're, this person, and they want to uphold that. (Participant 7 508-513)

While participant 7 related personhood information important in understanding what can be distressing to a patient, participant 6, another geriatric psychiatry nurse, referred to the importance of identifying sources of joy for patients, the sources of which are linked to personhood:

Maintaining a sense of the person is important. I think. Because again, you know, if I know somebody listens to country music, then I will make a point of trying to set that up even if I really can't stand it, [laughter] I'll make a point of it, whatever is special or unique to that person, that gets them any joy. (Participant 6 512-515)

Closely linked to the affirmation of personhood is the value of comfort. In the following excerpt, participant 6 illustrates how, in affirming the personhood of the patient, the patient appears to know to be cared for:

We still have one pair of fake beads, we put that on, you get a, you'd get a smile, and she knew that someone cared enough to put that little effort in. Because that's what's important to her. (Participant 6 546-548)

In affirming the personhood of this patient, the nurse also provided comfort to the patient and helped to bridge a gap between who the patient was and continued to be and the limited ability of this patient to affirm this personhood.

The values articulated by the participants (human connection, dignity, comfort, family, familiarity, and personhood) explored under the aim of exploring nurses' engagement with mortality within an ethics of finitude correspond to those aligned with a palliative approach, as discussed in Chapter 6.

## **Aim 2: Enablers and Barriers, and Related Historical and Socio-Political Discourses**

Barriers and enablers to engagement within an ethics of finitude are overlapping and intersecting and interaction between these factors is iterative. For this analysis, distinct categories are presented below; however, the fluidity represented therein reflects the diffuse movement of power and discourses reproduced. For example, participant 1 emphasizes the difference between specialized psychiatric nurses:

there's a big difference between being a forensic nurse and being a geriatric nurse at least within this organization. (Participant 1 98-99)

This statement can be taken to speak to the construction of forensic and geriatric nurses but this construction is also shaped by the environment of practice and the construction of the psychiatric patient. It follows that each of these categories are considered below, in addition to that of family.

### **Environment**

The first category that emerges from the transcripts is that of environment. The environment, encapsulated in the psychiatric care environment, is found to facilitate and hinder engagement.

#### *Anomalous older patient in forensic psychiatry – “they are so different”*

Within the forensic environment, the descriptions provided by some nurses indicated that older patients in a forensic setting could be considered as an anomaly. The anomalous state of older patients, engendered by the arrangement of the forensic environment, serves to increase the visibility of these patients on the unit. Forensic nurse participant 3 described the heightened ability to engage with these patients because of their anomalous status:

I think they get excellent care here. [...] And I guess for here we are very privileged because we only have two [older patients] we get to do two things perfectly well. We don't get tired or anything like that just because. In a way, they are really nice patients to work with because they are so different from our other patients. I think if we had 25 like that, hmm, you'd need to have a new mindset so that you could be so, you know what I mean, so you could have the energy, here we're quite privileged. (Participant 3 175, 179-184).

For this nurse, it is in part the relatively small number of older patients on the unit that makes it possible to do things “perfectly well” and as such the anomalous state of these patients enables a privileged care context. Despite the privileged feeling expressed by participant 3, some aging patients in forensic psychiatry represent an aberration relative to their context of care, as highlighted in participant 1’s reference to the prolonged length of stay of some older psychiatric patients designated to be alternate level of care (ALC) for “600 days or something” (Participant 1 89).

Participant 2, a forensic nurse, referred to the high ratio of nurses to patients in the forensic setting, particularly in contrast to the nurse to patient ratio in long-term care, from or to where many older patients are transferred. Because of the better staffing ratio in the forensic setting, this nurse considered it a boon:

It’s a good thing here. They have a more support. We sit with them in the morning, and when they’re eating or, they teach you about their native language or something. You always have something to talk to them about. So that’s one good thing, is the patient ratio. (Participant 2 181-183)

This nurse valued the environment’s nurse-patient ratio because they recognized the possibilities it affords in terms of social engagement with the patient. It follows that the nurse-patient ratio is such as to enable opportunities for engagement needed for recognition and values enactment described above under aim 1.

The demographic arrangement engendered on the forensic unit is another force shaping possibilities for engagement. The forensic environment is one described by participants as predominantly young. Along the age dimension within the environment, aging patients are again anomalous. The social arrangement engendered means that older, frailer patients may be

vulnerable relative to their declining physical health in an environment of younger, more physical able bodies. Participant 4, a forensic nurse, described concern for the physical wellbeing of an older patient experiencing health complications:

Because of the weakening of the muscles. And he would cough, like incessantly, the minute he woke up, he would be coughing, coughing, coughing. After meals, all until he fell asleep. And you'd actually have other patients coming up to you, shut him the f up or I'm gonna f'ng shut him up. He was like, so poor little thing [laughing] was being physically threatened you know. So it was something that we were struggling with to try take care of because we knew it was putting him at risk. (Participant 4 87-92)

Participant 4 also described the challenge of balancing the physical care needs of older forensic patients with the needs of younger patients. At times, this nurse appeared to encounter competing demands relative to the two patient populations that were not easily reconciled and could function to the detriment of younger patients in terms of time and attention from the nurse:

And some of the patients understand the amount of care he [older patient] gets and some don't. You know, they'll like [ask] why can't you take me as a patient, and I'm like, when I have a certain patient load, I can't, I just, I don't have the time, 'cause you know you [nurse] won't have time talking to them [younger patients], with whatever issue they may have to deal with. (Participant 4 135-138)

There are diverging views as to the social arrangement engendered by the two demographic patient populations (younger and older patients) in the forensic environment. Participants 3 and 4, both forensic nurses, referred to positive aspects of the combination of older and younger patients on the unit:

I think it's good for the younger patients to have them [older patients] here as well because they learn about respect, they learn that they [younger patients] have patience. Because sometimes you might have three nurses helping an elderly patient if they, something happened to them. (Participant 3 200-202)

Also for participant 3, the positive aspects of this arrangement were reflected in the example of the relationship between one "very complex" younger patient and an older patient: "We have one patient who actually sits with one of the patients everyday, sings with him" (216-217). For this nurse, the combined patient population of older and younger patients was of therapeutic value to both groups:

I think it's been a win win. Because our patients are not the ones who, let's just say, it's hard for them to recognize the needs of others or that other people have feelings. You know. It's part of their diagnosis that it's hard for them to recognize this. (Participant 3 230-239)

Beyond a strictly therapeutic function, the presence of older patients requiring more care serves as an opportunity for younger patients to express concern and to offer help:

They'll help too, like with our elderly patients, they'll say oh so and so needs to, needs a nurse, or you know, 'cause they know they can't, you know, communicate that sometimes, or, so they'll let us know, or they'll help them, they'll have little, I don't know, their food or something, do you want me to get you a tea or something. So there are some that are, you know, exceptionally kind to them. (Participant 4 100-104)

The social context engendered by a diverse social environment on the forensic unit and the connections established through, for example, expressions of help and concern, means that

younger patients are proximal to older patients who may die or experience complications from life limiting health conditions, as also described by participant 4:

Well I remember when this particular patient took a downturn, the other patients were like, he's gonna die, he's gonna die, right, he's gonna die. So there was a lot of teaching you had to do with the other patients. You know. [...] Just kind of like no one knows exactly when that is gonna happen. And then he pulled through. So there's a lot of support that you have to give to the other patients. (Participant 4 204-209)

The dichotomy of older adults on a forensic unit is one way that patients, as well as nursing staff, may directly engage with mortality, as this serves to contrast the limitations in physical functioning and fragile health of older patients relative to younger, more able-bodied, patients. Nurse participant 4 in the above excerpt identified the importance of educating other patients as well as supporting them in their experiences relative to death and dying. Participant 5 described the fear experienced by "all" when a patient approached end-of-life in the forensic environment.

Because we had a close call with one of the patients and now the patient is doing a lot better. We actually had like a mini-practice of everything that could go, you know, when they were having an acute episode. Now they're more stable. When we did have that episode, actually, most of us thought this patient would die and we were all very afraid.

Sad to say but we learnt a lot from that situation. (Participant 3 320-325).

This excerpt illustrates that end-of-life care for aging patients remains exceptional in the forensic environment in that it represented a fear-provoking possibility that required additional preparation and practice.

*Organizational priorities and funding – “the first place they pull from is geriatrics”*

Nurses referred in positive terms to receiving training related to geriatric care including GPA and P.I.E.C.E.S. training. Forensic psychiatry participant 4 reflected upon the application of P.I.E.C.E.S. care planning in the approach to the care of an older patient:

You know, like being rushed with him [older patient], like rushing, areas like that, just to kind of, I don't want to say it in a bad way, but to sensitize, you know, staff and all of us, to say, he's, you just have take your time, explain what's going, and, going on. What's going to happen. And just to leave them. If they're getting aggressive, just to walk away. Leave them. If you can, give them medication. But it's not something you can rush and fit into a little box, you know. (Participant 4 280-284).

The context of this excerpt illustrates that the organization itself supports a fluid approach to patient care by funding the GPA and P.I.E.C.E.S. training of its nurses. Despite this, nurses described various scenarios where organizational priorities served to hinder possibilities for engagement with patients and families. For example, participant 6 described the role of nurses as “frontline” with less direct contact with families. This participant compared the study site with earlier work experience elsewhere the latter of which involved close collaboration with a physician and direct communication with families about the life-limiting nature of dementia.

Here I don't know how much of an education they [patients' families] had, I don't know if their physicians, and their social workers, and their outreach teams, I don't know what their knowledge is, or their base level of, you know, comfort is with the diagnosis or prognosis. I don't know. But when I was in long term care it was different because I was there at the moment of admission and together we [nurse, doctor, family] all discussed this. So they could, the family could grieve, openly cry, and they could tell us, we don't

know, this is, can you explain a bit more, we could talk about it, in a kind but gentle way so it was more informative and it initially set them up with resources if they wanted to access resources. (Participant 6 347-354)

Participant 6 described more direct care of patients and less interaction with families, particularly in relation to exploring their knowledge about the illness trajectory of their loved ones. Because of this arrangement, the resulting knowledge disconnection hindered nurses' ability to engage with families, with implications for care approaches as they relate to goals of care.

Participant 7, a geriatric psychiatry nurse, reflected upon the higher staffing levels and programming available only during the day time on the geriatric psychiatry unit and contrasted these to the increased care needs of sundowning of patients during evening shifts. This reflection led the participant to remark upon the higher support needs missing for geriatric patients during evening shifts:

I think it's really cool that we have that [specialized geriatric] unit [...] but still the programming and activities, you know, keeping peop--, keeping people busy, and preoccupied [...] we know that people sundown so why are all the staff that we could use the most [during the evening] here during day? (Participant 7 384-387)

For this participant, the organization of a general geriatric unit, in agglomerating patients with various psychiatric conditions on the common variable of advanced age, was itself worthy of critique:

But sometimes they forget the acuity of the floor. And that's how, you know how they see it is, how we deal with such a vast array of people [...] it's mixed, we have dementia, schizophrenia, we have mood. [...] We have everything. We're like kind of like general

psych there, it just happens to be an age but you know, 65 isn't what it used to be.

(Participant 7 403-408)

This participant's observation serves to illustrate that organizational structures may serve to reinforce social constructions of aging, such as in the grouping of patients foremost according to their age. This same nurse critically reflected upon the curative organizational priorities in asking "what are we doing" of the medical order for the application of an ointment for a patient with responsive behaviours:

Why am I, almost get punched in the face, to try to like give somebody certain ointments and stuff? If they're not bothered by it then, what are we doing, you know what I mean?

(Participant 7 559-561)

Participant 8, another geriatric nurse, described various means by which nurses attempted to provide a patient-centered approach and accommodate unique needs and preferences. The participant points to the limits of this accommodation relative to the ordering of time within the psychiatric environment, particularly around the scheduling of medications:

We try to accommodate. The one thing that we can't accommodate, is times of day. Which I've always thought is a little weird. Because I don't eat breakfast at 830 every morning. [...]. But I guess that's the way hospitals work, right. We can't accommodate to everyone. We try to accommodate as best we can. If we know someone likes to sleep in till 11 o'clock, the doctors will change their medication times, we let them sleep in, we can just make them toast or something for breakfast for them when they wake up.

(Participant 8 421-426)

While operational considerations serve to shape the possibilities to accommodate patient-centered approaches, so do safety and security considerations within the environment.

*Safety and security – “usually we don’t let people sit in the rooms with clients”*

Reflection on the dimension of safety and security emerged in most of the interviews. Safety and security is communicated as an organizing force on the unit, as captured in the comment from geriatric psychiatry nurse participant 6:

Basically, just, as soon as we get in, first thing you have to do is get your CAT tag [personal security device] because it’s a safe unit, we need to keep people secure. [...]

And safety is a high priority for ourselves as well as the patients. (Participant 6 26-31)

Reference to obtaining safety tags was one of the first thing mentioned by participant 6 in the interview and in so doing, the value of safety and security may come to juxtapose those identified in ethical engagement. In this excerpt, “keep people secure” suggests environmental containment of patients as a form of safety. The idea of containment is salient when considering the example provided by participant 1 of a “physically intact” older patient with a neurocognitive disorder who left a secure geriatric unit:

So anyway he left the unit and then a code was called because he’s confused, he thinks he’s going home or something. I’m not sure what the issue was. Hmm. So yeah, so we did what we would do in another place of the hospital, you have as many people as you can. Sometimes. I think he was physically lifted off the ground and taken back to the unit. The next time that happened, because again, the door you know, are open and shut. I think it was one staff that went with him, they sort walked with him around [...]. So he was back on the unit. So this is like code white versus GPA. Very different reactions between the two. The initial one, nobody got hurt, but the patient was traumatized, because we used the Broda chairs. (Participant 1 240-248)

Beyond of the secure geriatric unit, the patient appeared to be more vulnerable to non-therapeutic approaches. It follows that the presence of a patient in one environment (e.g. on geriatric unit) versus another (e.g. off geriatric unit) shapes the approach to care a patient will experience.

While the patient him or herself does not fundamentally change from one environment to the next, safety discourses attendant to different environments shape the approach taken towards this patient. This is evidenced in the recounting by participant 1 of a confused older male patient on a forensic unit who at times inadvertently entered into female patient rooms:

[O]ne day, he [older patient] was going into, he walked into some individual's room. This individual happened to be a female patient. So they started yelling and screaming. [...]

Yeah. And he wasn't trying to go in this individual's room. He was probably just looking for the bathroom. (Participant 1 273-275, 279-280)

The primacy of maintaining a safe and secure environment on the forensic unit is such that the fluidity and flexibility required within a palliative approach may represent an aberration, in the form of accommodating a family, from established norms:

This is the medium secure unit. And. One accommodation, we did like, they want to sit with the patient, usually we don't let people sit in the rooms with clients. (Participant 2 254-255)

In order to accommodate families, participant 2 referred to the need to obtain approval from management and consultation with the team as well as their own agency as an experienced nurse on the unit. It follows that safety considerations in the organization may serve to limit opportunities for engagement, such as those involved in facilitating patients' social interaction with family.

The environment of care, whether on a forensic or geriatric unit, is described as shaping the perception of and approach to patient behaviour and pertains to varying constructions of safety and security. To this end, a behaviour that might be perceived more neutrally and labelled as “responsive” on a geriatric unit might be labelled more negatively as “aggressive” or “intrusive” on a forensic unit, and as such is more likely to be interpreted as a threat to the maintenance of safety:

on the geriatric units we are very good at hmm, [pause] we’re very good at realizing where behaviour comes from. And by that I mean, when someone is being intrusive or someone is being hmm demanding, we understand that that’s a nature of the neurocognitive issues going on, whatever that may be. Because if there’s any kind of dementia. On the forensic unit, when we’re seeing something like being intrusive, when the individual goes to female co-patient’s room, that is sort of typically perceived as somebody wanting to do to something bad, right. (Participant 1 303-310)

Clinical divisions related to geriatric and forensic units shape care approaches in part by through the language used related to patient behaviours. The perception that the patient might be doing “something bad” is one that is related to stigmatization of forensic patients, a subject explored further in Chapter 6.

### **Nurse Construction**

*The psychiatric nurse – “you know, we are trained psychiatric nurses”*

Barriers and enablers to engagement pertain to the construction of the psychiatric nurse within the forensic environment. All nurses interviewed mentioned the importance of their role in monitoring aging patients more closely in terms of their physical health status. Participant 2

described the importance of monitoring the physical health status of patients as well as a recognition that this is sometimes overlooked in the psychiatric care context:

The most important to me is that their physical health shouldn't be overlooked. Because we, you know we are trained psychiatric nurses. [...] We've been here forever, 15 years, 30 years, some of us here being 30 years. [...] So the most important thing, I would say is to pay attention, especially if you have a forensic elderly, an elderly patient who is in forensic. To also check on their physical health. (Participant 2 194-200)

The importance of monitoring aging patients' physical status is strongly emphasised. For one older patient, participant 2 went on to describe uncertainty with respect to nurses' understanding of the patient's physical status as well as nurses checking this patient's vital signs "all the time":

Like we were doing his vital signs all the time. We were checking him. Like anything that comes up, you don't know what's going on with the person physically. (Participant 2 218-219)

While the first excerpt from participant 2 suggests a correction to the characterization of psychiatric nurses as inattentive to medical concerns, the second excerpt seems to indicate a possible overextension of assessments to compensate for uncertainty related to "what's going on". In the next excerpt, participant 1 provides an example of a geriatric nurse "correctly" perceiving a geriatric patient's anger related to not having chocolate as progression of his dementia:

A good example in this behaviour or a good example for this individual is that he became incredibly like verbally aggressive at having like his cigarettes or, no no, it was, he was not allowed to have chocolate. Because he's diabetic. But. And we were supposed to do a blood sugar test and he wasn't allowed to have it. He just. His level of anger was totally

hmm out of context for what the situation was right and so, hmm, and so hmm the nurse at the time like correctly perceived it as a sign of the progression of the illness as opposed to like, receiving verbal threat from somebody coming in off the street or who has a long history of aggressive incidence like that. This individual didn't have any history like that, at least when he was with us. (Participant 1 320-327)

While the participant presented this as an example of an accurate nurse perception, the participant described the priority of the blood sugar test as precluding an aging patient from having the chocolate he wanted. It follows that this situation illustrates how medical priorities in nursing practice may supersede those of comfort and patient autonomy and that the psychiatric nurse construction may serve to reshape nurse identity so as to further a medicalized approach that diverges from the palliative approach.

*Nurse comfort – “I talk about it like I’m going to buy my groceries”*

Engaging patients in ways that acknowledge their life-limiting condition requires an openness or comfort on the part of the nurse relative to this kind of existential consideration:

I talk about it like I’m going to go buy my groceries. Because for me I think the exposure to people who have been dying, to palliation of patients, and I have a lot of that long-term care, so, for me the mystery and the fear is not there. (Participant 6 671-673)

Participant 6, also a geriatric nurse, refers to their background working with patients at end-of-life to impart their awareness of mortality. For this nurse, communication about death and dying itself serves a valuable function of alleviating suffering related to the fear it generates because “it’s not discussed” (682). Nurse comfort with conversations related to life-limiting conditions was not shared by all nurses. Participant 8, a geriatric nurse, expressed discomfort discussing the life-limiting nature of dementia with families, as illustrated in the following excerpt:

I don't like telling the family member, if they don't know it's a terminal illness, and that their family member will never get better, it's kind of a hard thing to tell someone if they don't really know, and accept it so. (Participant 8 329-332)

The degree of comfort felt by nurses around discussions related to life limiting illness, beliefs relative to the responsibility for the occurrence of these conversations, and organizational supports shape the possibilities for engaging families to existential realities and earlier engagement within a palliative approach.

*Professionalism – “it's hard, it's more familial”*

Some nurses, like participant 6, described the work of caring for aging patients as requiring a form of professional adjustment to adapt to the level of familiarity required in the work.

It was very difficult to get used to it initially, when I first started in geriatrics but eh, it's, it's, it's hard, it's more familial. We try to make the patients more comfortable with us in that sense. (Participant 6 253-255)

Participant 6 acknowledged their original discomfort in relation to responding to the emotional needs of patient in a “more familial” way but seemed to recognize that maintaining a certain degree of professionalism would in effect be starvingly untherapeutic to this patient population. The above passage may provide insight into why some nurses may decline to work in this field in that some may perceive geriatric nursing as threatening to a certain professional construction of nurse identity. Participant 7 illustrates the professional flexibility involved in geriatric care though a description of the use of humour and musical theatre to connect with a patient and provide care aligned with the value of comfort.

We have one patient who's really aggressive with care but who was really into theatre and stuff, so I did some show tunes for him last night. [...] Super embarrassing if anyone saw. But nobody's there. And it calmed him down. We did his care no problem. We figure out as we go. (Participant 7 117-121)

The above excerpt illustrates that the flexibility required for a patient-centered approach may require an acceptance to the unexpected on the part of the geriatric nurse of what may constitute nursing work, such as the use of song and dance.

### **Patient Construction**

The construction of the psychiatric patient and nurse are intertwined and iterative in that what constitutes a patient relies upon a particular construction of a nurse. The iterativeness involved is such that the patient construction cannot be considered in isolation from that of the nurse as well from the wider environment providing overarching parameters.

*Forensic patient – “you're supposed to have independence”*

Participant 5 remarked upon the current forensic environment in which there are patients with higher physical care needs that do not necessarily correspond to the expectations of some nurses that come to work on the unit. For some nurses, the perceived construction of the psychiatric patient is not one with heavy physical needs:

They feel that this is forensics and you're [patients] supposed to have independence. [...] And they, some people [nurses] will not change that at all. It's, that's not part of their job. Which is really, a lot. So it's. So they do not, they will not attend to those needs. And if they do it's very basic. (Participant 5 126-134)

This excerpt highlights the power of the construction of the forensic patient to shape care provision expectations. Forensic patients who are not functionally independent, as referred to by

participant 5, are therefore considered out of place by some nurses. These same patients are described by another forensic nurse as hard to place in the community because of the negative associations with the “label of forensics”:

That’s the more difficult part too, is finding the proper placement for them, homes that will accept them. And depending too on their offences, I mean, yeah, they can hit out just like the other nursing home patients, you know what I mean, especially when they lose their ability to ambulate, like he can’t ambulate anymore. [...] So that kind of decreases his risk. He may hit out with his hands, it’s just that whole label of forensics that’s on them, makes it hard. (Participant 4 233-239)

The construction of the aging patient, by virtue of the “label of forensics”, is such that the patient is effectively in a double bind: he is anomalous on the forensic unit and yet unplaceable in the community. With respect to this nurse’s wording of the patient’s forensic “label” and “risk,” such language can be considered pertaining to stigmatizing discourses related to forensic patients, a topic explored further in Chapter 6. Participant 4, a nurse with prior experience in palliative care, also described a sense of disorientation with respect to aspects of palliative care provision within the forensic practice context:

And I think before, you could, where I was, you could make patients comfortable, you know, positioning them, and eh good skin care, and you know, eh nice meals, and eh feed them [...] you feel you were doing something whereas here it’s sometimes harder they’re not able to talk with you. They don’t want, you know. (Participant 4 77-80)

With this expression of disorientation in relation to comfort measures with forensic patients approaching end-of-life, this nurse communicates that forensic patient may present a challenge to their understanding of palliative care provision.

*Geriatric care devalued – “you pretty much go to geri”*

Participant 7 observed upon geriatric psychiatry as “the first place” from which nurses are pulled suggesting that the complexity of patient care in this population may not be recognized:

Ah, this hospital, in general, I think that the nurses that don't come to geriatrics. If the hospital is short anywhere, the first place they pull is from geriatrics. (Participant 7 399-401)

As the geriatric psychiatry units were described as the first place from which nurses are pulled emerges the notion that geriatric patients may be an undesirable focus of care. Participant 1 appeared at times hesitant to mention the perceived antipathy of some nurses towards geriatric nursing, referring instead to turnover in this practice area:

but if you have people [nurses] that are coming in that aren't familiar with the [geriatric] units then it's different right because you have people [nurses] coming in who are used to other units in the hospital, so they aren't necessarily familiar or they don't want to participate actively in people's care or what's necessary to have a, you know, functioning team and a functioning unit essentially. (Participant 1 189-193)

Participant 7, a newer nurse to the organization stated, “you pretty much go to geri” (16) when working as casual staff. For participant 1, days when regular staff presence was limited represented a barrier to optimal engagement with patients:

What's my worst day is when I'm going to geriatrics and I have the most experience there. [...] This isn't, that's not an environment where you can support your patients to the best of their ability. That's where you're trying to get through the day right. (Participant 1 660, 668-669).

It follows that perceived antipathy toward geriatric nursing, as illustrated in that it is perceived as the first place from where staff is pulled and to where the most inexperienced staff is sent, limits broader possibilities for nurses' engagement.

### **Family**

While the role of family was frequently mentioned by all nurses, this was most frequently referred to by nurses working in geriatric psychiatry. All of the excerpts in the following section are drawn from the interviews with geriatric psychiatry nurses.

*Families' knowledge of the patient – “we always ask the family, what are they?”*

The value of family was highlighted under findings in aim 1; indeed, the role of family is important in enabling nurses and the care team to know the patient. Information from families about the patient helped nurses to understand what could be distressing to the patient and in turn the possibilities for engagement to promote comfort. Geriatric nurse participant 6 described this as follows:

So it gives us clues on how to approach the care. I mean if we knew they grew up in a family where it was all girls or we knew that they grew up in a particular area and they didn't see female doctors, and they know, you know, sometimes they wouldn't even acknowledge that a woman could be a physician but they also have difficulty

understanding that a man can be a nurse, to do that personal care. (Participant 6 108-111)

The information provided by family helps nurses to understand what is comforting by knowing what is distressing to the patient. The above nurse and participant 8 pointed out that there are situations where there is no family or friend available to provide information for and about the patient:

Like I said with dementia, they can't tell us what they like and what they don't like and sometimes the family members don't come in, that's like, we always ask the family members, what are they? How were they, what did they like, did they even wash up before they went to bed, did they brush their teeth, wash their face? 'Cause some people don't do that, hmm, we kind of of, trial and error, go in, play it by ear, you know, see if they'll do on their own first, stuff like that. (Participant 8 389-394)

In addition to providing needed information about the patient, involvement of the family can serve a role in humanizing patients, such as for those patients who exhibit particularly challenging or aggressive behaviours:

[...] it's interesting aspect to kind of see it, people in different lights you know [...] maybe we have this literally aggressive angry difficult patient but then you see their families and how you know and they [families] tell stories about them [patients] or what they used to be like and stuff and that gives you a different perspective, having more compassion and maybe not taking it personally when they are aggressive. You realize what they used to be [...]. (Participant 7 233-238)

While family can play a role in humanizing their loved one, families also validate nurses' approach insofar as to ascertain whether patients are indeed cared for in an approach that brings them comfort and is aligned with their values. Without this external validation, nurses may lack reference points to know whether the care of a patient is in fact appropriate, as described by geriatric nurse participant 8:

They're a big help in saying like, you know, if they think that their family member looks good, and happy, then that's a huge deal because we don't know these people until they come in to us and we see them at their worst because that's why they're with us, is 'cause

they're in the worst behaviour. So when the family members tell us that they're doing much better and that they seem that they're doing well. That's a huge help. Really so that we know that we're helping them become more relaxed and better to go back to their home. Hmm. Just make sure that they're not agitated anymore. (Participant 8 377-383)

While families and friends can be instrumental in providing information to nurses about patients to further possibilities for engagement, memories held by families of their loved ones may at times no longer reflect the current state of the patient:

Ah sometimes, we're looking at family and friends, of the patient, loved ones [who will say] 'oh well they used to do this,' and often, that's a blessing and a curse because ah cognitively they've [patient] changed so much, it's no longer the case, how they [family] remember, the image that they hold in their minds of how the patient was of what they liked changes. You know. Dad used to always eat oatmeal in the morning. Actually, no now he doesn't like oatmeal, he wants eggs and toast and that's it. (Participant 6 568-572)

More than a challenge to knowing patients as they currently are, the above excerpt illustrates that nurses must contend with the cumulative losses experienced by families as they are also in the process of engaging with patients. Families' knowledge of patients can also be limited with respect to their loved ones' behaviours:

[...] when they [family] don't understand that their family member's being aggressive, they'll say [of the patient] 'but they've never been like that, they've never been aggressive, they never hurt a fly' and sometimes they [family] need to see the aggression and not that we try to show them and it just happens that they're there and they see the

aggression and that can be a huge shock to them to see what's actually happening.

(Participant 8 346-351)

As described by participant 8, families may experience distress in encountering information that challenges their understanding related to their loved ones' behaviours.

*Families' understanding and expectations – “well why isn't dad shaved today?”*

The needs of families and challenges related to interactions with them was frequently commented upon by geriatric nurses. Some of those challenges related to nurses perceiving a disconnection between families' understanding of disease trajectories and goals of care:

I've had a couple of challenging, you know, interactions, where, what you believe might be in the best interest for the patient, understanding where the prognosis and disease progression leads, to see where it goes, and to look at more, what I would think, is more bigger goals, bigger goals, more valued to, goals of safety, and comfort, as opposed to someone coming in and saying well why isn't dad shaved today? (Participant 6 293-297)

The nurse above expresses a sense of disconnection between what matters in their work with patients and what is valued by families. This sense of disconnection is elaborated upon by participant 7 describing families who may not witness patient behaviours that warrant nursing care approaches:

[...] but it's a lot the patients' like family, we deal a lot with patient's family. It's different maybe on other units, but especially in geriatrics but a lot of them are incapable so like the SDMs, substitute decision makers, are the family members so ah, like it can be really challenging, and like you, we, some of them, like we spend a lot, like, 4 days, 5 days, 8 hour shifts, with their family members and they come in one day and they have

their certain objectives, and we have ours, and like trying to figure it out, and like what's best for the patient and it can be really challenging. (Participant 7 224-231)

Disconnection of family with respect to patients' current health status is perceived by some nurses to be manifested as grief. This disconnection is problematic in that nurses are caring for patients in the current manifestation of their illness progression while the families of these patients many not be cognitively or emotionally prepared for the state of advanced illness. One nurse described families as actively grieving the original diagnosis when the disease had far progressed.

We do have families, and eh, they're still grieving, they're in an active phase of grieving with the diagnosis and then their loved one can be very far progressed and there's a disconnect between the education on what the disease is, where their loved is, and what we can do. Some people still think there's gonna be a cure tomorrow and we just gotta get dad to hang in there, live a little bit longer and we can fix it. And it's, it's very, eh hard because I'm coming from ah a different place. I've been through it so many times. (Participant 6 313-319)

Families may not be aware or accepting of the progressive and terminal nature of neurodegenerative diseases like dementia. What participant 6 described above could reflect a form of denial or a way for families to maintain hope in the face of a life-limiting illness.

Participant 7 reflects upon the decline of a patient and the apparent disconnection with families related to the life-limiting prognosis:

And hmm the patient eh wasn't doing well, and was like declining, and then so the family was like really upset about that. [...] Eh but I mean the patient is essentially, you know, you forget that dementia is fatal. (Participant 7 276-279)

While participant 7 attributed the “really upset” expression of the family to forgetting the fatal nature of dementia, an alternative interpretation could be that nurses working with patients with life-limiting illnesses may conflate varied emotional responses to grief and loss with a misunderstanding as to the nature of diseases like dementia. The limited perspective described by participant 7 could also be reflected in this nurse’s perception of family as problematic: “Sometimes dealing with like the dementia patient is the easy part” (266). Diverging perspectives between nurses and families is reflected by the many geriatric nurses who commented upon the differing and sometimes competing priorities held by families compared to those of the nurses and care team:

And I can have a clearer goal, but it’s very hard for the families, and it can be very difficult sometimes for the staff because we try very hard and sometimes, when eh, a family member approaches you about something you think is very insignificant and not on the radar, and it’s very important to them, and you try to value that, but it’s very hard because you feel devalued in what you’re trying to do in the bigger spectrum. (Participant 6 325-329)

Nurse’s experience of feeling devalued in care giving efforts could impede further efforts to engage with patients and thereby present a barrier to patient engagement. Curative expectations held by families may be disconnected from what nurses perceive to be possible for patients, as the following excerpts from participant 7 illustrate:

You know. Instead of like, I think that people sometimes come to the hospital hoping there’s some sort of miracle fix but there isn’t, we may be able to cope or deal or improve behaviours. [...] But like there isn’t a miracle fix. How to accept the person that they are now and like make the better of what they have to come. (Participant 7 550-554)

Nurses described the need for families to witness certain behaviours in order to fully grasp the gravity of patients' behaviour and illness:

So you try to explain that to them. Sometimes they still don't even accept it, they're like, it should just be done, just get it done, no matter how you can. And sometimes they actually have to see what's happening. (Participant 8 343-345)

Depending on the presence and involvement of families in care, opportunities for such witnessing and related understanding are increased or limited. The degree of involvement of families therefore impacts the shared understanding that families and the care team can have regarding the patient's situation and corresponding goals of care.

Barriers and enablers to engagement within an ethics of finitude are overlapping and intersecting and interaction between these factors is iterative. The previous section presented the categories of environment, construction of the psychiatric nurse and patient, and family as categories encapsulating barriers and enablers to engagement.

### **Aim 3: How Enactment of an Ethics of Finitude Serves to Articulate and Deepen Understanding of the Palliative Approach**

In the theoretical considerations described in Chapter 3, central elements were identified in the modified concept analysis of the palliative approach: foundations, other goals, threat to health, communication, timing, complexity, identification, and location. Stemming from the analysis of the interviews, two categories were identified in relation to articulating and deepening understanding of the palliative approach that touch upon these elements: health system considerations and the language of palliative care.

### **Health System Considerations**

A number of health system considerations emerged in the interviews, most prominently in the implications of nurses' communicating their recognition of the vulnerabilities of their patients. The health system considerations identified are discussed in relation to a deepened understanding of the palliative approach are further detailed in Chapter 6.

#### *High needs of aging patients – “but it is more”*

Nurses revealed the high physical and emotional needs of aging patients in their care. Forensic nurse participant 3 spoke of the sense of being “privileged” by having only two older patients thus enabling nurses to do “things perfectly well” (179-180)—an arrangement that would not be so perfect with a higher proportion of geriatric patients. A prominent consideration generated in the recognition and values enacted by nurses is challenged in the realization that some aging forensic patients are currently deemed longstanding ALC patients for “600 days or something” (Participant 1 89).

While some aging patients on a forensic unit may appear to be anomalous and deemed to require a lower acuity of care, participant 2 points to the multiple demands of their care: “But it is more, it needs, it needs more skills” (163). From participant 2's vantage point, a forensic nurse working in a setting in which patients are involved in the correctional system and have severe mental health issues, including substance use issues, caring for aging patients “needs more”.

#### *Community continuity – “'cause he won't have that”*

Geriatric nurses lamented gaps in care continuity and questioned whether it was the care context from which a patient came or factors related to the patient him or herself that most contributed to the problematic behaviour that led to the patient's admission to a specialized service:

We're trying to kind of coordinate all that together. So we're frontline, so we're giving feedback on our frontline experiences, because often the patient came with an issue or a behavioural challenge that can no longer be managed, that cannot be managed in their home, which is long-term care or their own home, that's why they come to us, so we have to try to assess the causes, some of the eh, the instigating factors, maybe is it, purely the disease related process or is it the approach? Sometimes it's approach because as much of the fact that they are not understanding anymore but maybe it's, it's the fear and confusion. (Participant 6 150-156)

It follows that improving care provision, including the palliative approach, cannot be considered in isolation from the broader healthcare system, described by participant 8 as “revolving doors”:

A lot of patients sometimes we have revolving doors, where they do really well here and then they go back to their home and then it's just a way more busy environment, they don't have as much attention because of the nurse to patient ratio in long term care homes is much less. (Participant 8 428-434)

Indeed, without consideration to care continuity, patients are potentially at risk for harm. For example, patients may be harmed by returning to a long-term care setting only to perceive it as less home-like because of the more patient-centered approach in an acute care setting. Participant 8 also described nurses receiving instruction to deliberately limit the attention provided to a patient who would not receive comparable care in his home residence:

And so the doctor specifically said don't comfort him unless he's like immediate, like needs help, but if you see that he's getting worked up, just let him be, let him walk around, let him be around the patients 'cause he won't have that, that support in the long-term care home, that a nurse will always look to him and talk to him. [...] So we had to

start doing that. So we'd see him getting a little bit anxious and we wouldn't be able to talk to him 'cause we knew he wouldn't have that support in a long term care home.

(Participant 8 451-457)

It follows that the availability and funding of community care shapes possibilities not only for the enactment of the palliative approach but also for how we come to define the palliative approach, as discussed in Chapter 6 in relation to the Home First philosophy as well as the language of palliative care.

#### *Organizational structure and priorities*

Issues related to health care delivery were also engaged in consideration of the role of nurses in relation to conversations with patients and families pertaining to goals of care. Nurses in the study described themselves as “frontline” with “less interaction with the families” (Participant 6 362). Conversations about goals of care were also described by geriatric nurse participant 6 as part of the role of the physician and social worker. The result was a disconnection in terms of what the nurses hoped families knew about patients' prognoses and these families' actual understanding:

And, I hope, my hope is that once the families bring them to our hospital, because this is acute care, that between their their medical doctors, their interactions with the medical system prior to, that they would've had some education or help from social work or maybe from the Alzheimer's Society or peer groups or support. My hope is that when they come to us, that they would have a clearer picture of the diseases process, so prognosis and have, maybe have reviewed what their expectations are for care and what they think is the most important goal. (Participant 6 306-311)

The acute care environment of the study context was such that nurses described working more directly with patients and less involvement in conversations about patients' goals of care. In this context, nurses' work is prioritized with direct patient care. As such, nurses are removed from opportunities to connect with patients and families around goals of care and thereby constrained in providing patient- and family-centered care to this end.

*Recognition premised on continuity – “I would have had no idea what was going on”*

Engaging with patients and families within an ethics of finitude requires a degree of continuity for the process of recognition to occur. Participant 1 iterated the need for continuity of care so as to recognize when to modify the approach with patients in forensic psychiatry from one of limit setting to one of redirection:

Typically we would be very firm in ah setting those limits. Being like, ok, you understand that you're supposed to come back at this time. You didn't do it so, for the next 48 hours you're not allowed to leave the unit. [...] Something like that right. But that doesn't happen. [...] Because we're like, eh, he fell asleep, [laughter] in like the hallway or something or he was just talking to somebody and lost track of time or he wrote down the time that he was gonna leave and then he went to the washroom and then he did his laundry and then he went outside. (Participant 1 299-308)

The above captures how the overriding forensic environment with its focus on limit setting and security is one that can appear absurd, as illustrated by the participant's laughter during the recollection of the above situation, when juxtaposed with the care needs of some aging patients. Participant 1 shared a recognition of the vulnerability of the patient based on his life-limiting illness. The importance of safety priorities became laughable to this participant when considering the predicament of the aging patient described; the absurdity of the situation is apparent to

participant 1 because the patient is known to this nurse. However, the recognition of vulnerability cannot be presumed from the patient presentation itself, as evidenced in a later statement by this same participant:

Was he [patient] able to respond to his own name? No. Not in most cases right. Hmm. Were we, is, was the staff that was familiar with him able to understand his needs? Yes, because we'd seen him you know a couple of months earlier and he was fine. But hmm would it, it would have been very challenging if I'd come in and seen this guy for the first time, I would have had no idea what was going on. (Participant 1 516-520)

Participant 1 acknowledged that to someone for whom this patient would be unknown, the approach undertaken, with a recognition of the patient's losses and vulnerabilities, would not necessarily be assured. The participant points to the importance of nursing continuity to ensure that an approach is congruent with the patient's cognitive, physical, and existential state.

### **Missing Language of Palliative Approach**

The second category that emerged related to articulating and deepening understanding of the palliative approach was the missing language of the palliative approach, a subject further discussed in Chapter 6. The terms used by participants, while iterating elements of the palliative approach and an ethics of finitude, frequently equivocated palliative care with end-of-life care.

Basically it [palliative] means em end of life. It could mean an exacerbation of you know a person's condition, because of their condition, like 'cause of their disease process, so it's eh, it just means to be able to understand and handle their symptoms in order to keep them comfortable. (Participant 4 159-161)

The terminology used by nurses represents a semantic challenge in that those indicating practices corresponding to a palliative approach do not necessarily identify them in such terms. Some

nurses, such as participant 5, expressed elements of the palliative approach, such as in relation to timing, goal of comfort, and a threat to health:

Palliative, well I think it's gone along with how things, eh, have changed, em, over the last decade or so. I think palliative used to be assumed to be the last stages of life whereas now palliative is, palliative to me is a couple of thing. Palliative is comfort measures. [...] You are not gonna seek out any aggressive eh type, em, you treat things that are minor, but if someone comes up as having cancer, you might eh give a certain amount of treatments just to relieve the burden of the cancer's nature, to go with the course, but you're not gonna beat it in any sort of way. Eh. Ah. The person is still living, it's still, they are still with illness, you are still treating them day to day. And end of life is end of life, and that's more, death is imminent. (Participant 5 213-222)

In saying that the term palliative “used to be assumed to be the last stages of life” participant 5 demonstrates an awareness of the evolving and increasingly broader meaning of the term palliative care. Participant 6 referred to palliative care with a longer view to the life of patients that could fit within the palliative approach as follows:

That's all it means. It doesn't mean I'm dying tomorrow. I could die in fifteen years and be palliative today. (Participant 6 438-439)

However, this same participant used the term “palliative” to refer to patients that the geriatric psychiatry unit “rarely get”:

On occasion we get a patient who becomes palliative while they are here. So it does happen but it is more rare. (Participant 6 466-467)

Similarly for forensic nurse participant 2, palliative care is care provided near the end-of-life and within the forensic environment, the “palliative patient” is rare:

It is the comfort you provide toward the end of life cycle. [...] And the life cycle at that point, you provide most physical care, and emotional support for the family and the client, you be more with them, we don't usually get palliative patients. (Participant 2 302-305)

There was semantic confusion among participants relative to the palliative approach. For those geriatric nurses working on a unit where all patients have a neurodegenerative disorder, that the term "palliative" did not necessarily apply to all patients could suggest that there is not necessarily an embedded palliative approach, such as that related to consideration of goals of care. Despite the semantic confusion commented upon above, participants demonstrated upholding values underpinning the palliative approach. In summary, a congruent ethical approach can be engaged despite inconsistencies in the use of language around the palliative approach, a topic discussed further in Chapter 6.

## Chapter 6: Discussion

This chapter discusses the findings presented in Chapter 5. First, the findings are examined through an ethical lens related to human finitude based on the ideas of Brinkmann (2006). The values identified in the findings, including human connection, dignity, comfort, family, familiarity, and personhood, are explored in light of the values and guiding principles of the palliative approach (CHPCA, 2013; CHPCA, 2015). Each facticity (social, temporal, mortal) identified by Brinkmann (2006) is considered to illustrate an alternate way to conceptualize the values and process of recognition communicated by participants. The findings examined through the proposed ethical lens are complemented by extant literature. Second, insights related to the proposed ethical lens are explored relative to initiatives that could enhance the process of recognition (training and enhanced involvement of nurses in advance care planning processes) and serve to account for health inequities and stigma through a macro lens of human facticities (including the social determinants of health). Third, Ontario's Home First philosophy is revisited to illustrate how the proposed ethical lens can be utilized to critically question government policy to reveal salient ethical considerations. Fourth, the language of the palliative approach and its conceptualization are reconsidered in relation to the semantic variability that emerged in the findings; the need for conceptual clarity is re-examined to possibly include a social function as underscored by the motif of *memento mori*. Fifth, limitations of the project are considered, including: the nature of my research as an analytic elaboration of the original project, the challenges presented by the mixed nursing population within the study context, and the nature of the researcher as an instrument of inquiry.

### **Ethics of Finitude**

Brinkmann (2006) offers ideas on how to think about finitude through his articulation of the need for an ‘ethics of finitude’ that is existential-phenomenological. The ethics of finitude proposed is rooted in facticities about human existence including human beings’ social, temporal, and mortal dimensions (Brinkmann, 2006). For Brinkmann, mortality is a condition for morality in that mortality, and the related vulnerability it engenders, makes possible the conditions for values, in that what is valued is what is inherently subject to loss, and virtues, such as courage, endurance, self-sacrifice, and justice. In other words, the facticities Brinkmann described serve to delineate what is at risk of dispossession; indeed, values are regarded as such because their expression is vulnerable.

Brinkmann (2006) argued that from the facticities of human finitude and vulnerability, stem moral demands of solidarity based on human interdependence, including compassion and care, from which undeniable moral demands arise. Brinkmann’s ideas served to establish the groundwork for an ethics of care that informs how apprehending finitude could be conceptualized. Indeed, the engagement of nurses with respect to the facticities of the patients under their care was found to relate to engagement within a palliative approach as explored next in an examination of the values and process of recognition.

### **Values and the Process of Recognition**

The values identified in Chapter 5: Findings, namely, human connection, dignity, comfort, family, familiarity, and personhood, are found to be aligned with the palliative approach. In the CHPCA’s *A Model to Guide Hospice Palliative Care* (2013), guiding values are identified as autonomy, self-actualization, dignity, and community while in the CHPCA’s

*Framework* (2015) dying as a part of living, autonomy and respect, and patient and family driven care are identified as guiding principles.

It is possible to draw links between the description of the CHPCA's *Model* guiding values (2013), such as autonomy guided by quality of life as defined by the person, and nurses' articulation of the importance of, for example, comfort as it relates to each patient as a unique individual. To illustrate the enactment of corresponding values, one participant questioned whether the agitation of an older patient could be related to cultural considerations such as unfamiliar foods and surroundings, and described measures to redress this possible source of discomfort. In a similar vein, participants referred to the importance of family to better know what quality of life and autonomy could mean for a patient for whom communication is limited by the progression of neurodegenerative disease.

With respect to the guiding principles of patient and family driven care identified in the CHPCA's *Framework* (2015), whereby services are sensitive to personal, cultural, and religious values, nurses communicated enacting these principles by identifying and facilitating sources of joy (e.g. food, music, clothing) and buffering patients against sources of distress based on the latter's life histories, as corroborated by family. For example, in the geriatric psychiatry context, nurses described putting a string of beads on a patient who used to enjoy being fashionably dressed, obtaining photographs from families to help patients with recollection and belonging, ensuring the availability of familiar objects to connect patients to their sense of identity (e.g. books about fishing). In the forensic psychiatry context of study, nurses affirmed personhood and enhanced comfort by playing familiar music and posting comforting images for the aging patients in their care as well as by facilitating family presence for meals; in so doing, these

nurses also engaged in the guiding principles of the CHPCA's *Framework* (2015) related to patient and family driven care and autonomy and respect.

In the findings, the enactment of values was found to be paralleled with nurses' recognition of patients' unique vulnerabilities relative to the enactment of these same values. These vulnerabilities were identified in the form of advanced age, progressive illness, communicative limitations, the setting of care, and social displacement as well as through a process of self-reflection on the part of nurses (including reflection upon their own mortality). In other words, the enactment of values was premised upon a process of recognition in which nurses engaged.

While the values articulated by the participants corresponded to those aligned with a palliative approach (CHPCA, 2013; CHPCA, 2015), these same values can be understood within the lens of an ethics of finitude in that their enactment is at least in part premised on the recognition of accumulated losses related to the facticities (social, temporal, mortal) described by Brinkmann (2006). The process of recognition explored through the proposed ethical lens and identified in the findings can serve to better understand the values that underpin the palliative approach by proposing an alternate process to conceptualize their enactment. While the values expressed by nurses (human connection, dignity, comfort, family, familiarity, and personhood) are certainly essential to most individuals beyond the particulars of the study context, recognition of these same values in light of the facticities outlined by Brinkmann (2006) infuses them with imminence relative to the ethical dimensions of time, sociality, and mortality. In other words, the facticities help to conceptualize ethical dimensions in the enactment of values. The recognition of values is paralleled with a recognition of a patient's unique proximity to the loss embodied by human facticities and these facticities can in turn be conceptualized along interconnected axes of

sociality, temporality, and mortality. In the following section, each facticity is considered with reference to the data and literature to illustrate how recognition and engagement related to these serves in the enactment of the values and guiding principles of the palliative approach.

### *Social*

The enactment of values by nurses was generated through a process of recognition of the social connections and dimensions of aging patients in their care. The social facticity was engaged on both the individual level as well as on a broader environmental and societal level. On an individual level, social dimensions in the recognition of values were identified by nurses drawing on their own social connections; for example, a nurse reflected upon their own social connection to loved ones to identify the value of dignity and the importance of maintaining the hygiene of patients. Nurses communicated a recognition of the social facticity in the social dimension of the care of a patient; when the latter is affected by neurodegenerative disease, nurses expressed the need to know who the family knew the patient to be in order to provide patient and family driven care. The information provided by family helped nurses to understand what was comforting to the patient by gaining a better understanding of what was distressing to the patient. Similarly, family presence was found to play a humanizing role with respect to the care of their loved one, such as by providing a nurse with a richer patient history for a challenging patient. Families' knowledge of the patient also served a role in validating nurses' approach insofar as to confirm whether patients were indeed cared for in a manner that brought them comfort and that was aligned with their values. Nurses expressed that without validation from external sources like patients' families, they lacked reference points to the appropriate care of patients. As such, recognition of the family's social knowledge helped nurses to actualize values by knowing what was comforting and meaningful to the patient.

The social information and context provided by patients' families helped to orient nurses in the care of the patient. From these examples, of which participants provided varying iterations with respect to values, it is possible to discern that it is not only the disease process itself that threatens patients' ability to live with dignity, comfort, and personhood but also the extent to which patients' dignity, comfort, and personhood are sustained in the care of those around them. This observation finds footing in the notion of relational autonomy in contrast to more traditional individualistic understanding of autonomy (Pritchard-Jones, 2017). Relational autonomy or socio-relational autonomy recognizes that "the ability to act autonomously is not black and white" but rather rests on a spectrum—to this end, this understanding of autonomy accounts for the reality of those, such as aging patients with neurodegenerative disease, who regularly depend on others to live their choices, such as the personhood value identified in the findings (Pritchard-Jones, 2017, p. 77). This understanding of relational autonomy intersects with the moral demands of human interdependence identified by Brinkmann (2006).

Reflection upon the social facticity dimension also helps to identify how the enactment of values can be hindered. While the examples above highlight how the knowledge of families could enable possibilities for engagement within an ethics of finitude, memories held by families of their loved ones could at times no longer reflect the current state of the patient; this disconnection could in turn present a barrier to nurses' engagement in relation to care approaches and with families. Moreover, curative expectations held by families were found at times to be disconnected from what nurses perceived to be possible and/or therapeutic for patients given their current health status. Families' understanding of the health status of their loved one was in part connected to their presence and involvement in care, such as by witnessing problematic patient behaviours and understanding related care rationales. A higher degree of involvement by

families could be found to impart a greater shared understanding with the clinical care team regarding the patient's situation and corresponding goals of care. Again, this example serves to underscore the social facticity in the enactment of values and in the process of recognition.

Consideration of social facticity can also be considered on a broader environmental and social level. For example, the importance of familiarity, as it related to patients' sense of the familiar, was affirmed in nurses' awareness of the home-like place that the psychiatric unit represented for some patients. Indeed, the idea of home has served as a focal point to illustrate the potential for participation in the human community (Jacobson, 2012). For Kearns (1993) "people feel more whole in places where they feel that they belong" (p. 144) and the place of home can be one of feeling "*in place* rather than *displaced*" (p. 140). With respect to the notion of home, nurses affirmed the value of familiarity by communicating an understanding of the need for some patients to return to visit the unit after their community discharge. The findings with respect to patients who are "fairly institutionalized" suggests that the breakdown of barriers that normally separate the spheres of life, sleep, play, and work conceptualized in Goffman's (1961) total institutions evokes a prior norm, and perhaps a privileged state, of separate spheres. Individuals who are chronically or "fairly institutionalized" may perhaps experience a greater sense of belonging and of feeling *in place* within the enclosed setting of the unit. Here emerges potential for critical questioning with respect to totalizing social processes based on Goffman's (1961) work insofar as they underscore the limitations of broader social inclusion for "fairly institutionalized" patients beyond the forensic psychiatry environment. The sense of belonging of the patient on the unit could be paralleled with that of exclusion from the wider society and of structural vulnerability (Reimer-Kirkham et al., 2016a), as reflected in participants' comments on the difficulty of the community placement of older forensic psychiatry patients. Critical

questioning based on social facticities is considered further in the section below related to accounting for inequities.

The importance of shared values among nurses reflects another social dimension of the process of recognition and enactment of values. In the identification of barriers and enablers to enactment of the ethical lens, nurse construction with respect to professional identity emerged. Nurses identified the work with aging patients as “more familiar” and requiring a form of professional adjustment. It follows that the social facticity helps to identify dimensions of shared group values in supporting a shared ethical lens. From literature on teams of nurses working with street involved individuals, the importance of shared values among the team was found to be important to the recognition and enactment of respectful, non-judgmental care (Pauly, 2008). Pauly’s (2008) research is of relevance given its attention to underlying value tensions impacting ethical nursing practice and equity in access to care to a marginalized population. It follows that when a study participant described the challenge of working with nurses unfamiliar or that did not appear to want to participate actively in patients’ care, they identified both the importance of shared values among nurses as well as the importance of sustained social interactions to provide care that recognizes and accounts for the vulnerability of aging patients.

### *Temporal*

As illustrated by engaging the social facticity described above with respect to the values of familiarity and family, these values, as well as that of human connection and the process of recognition, are situated within social interconnections that occur *over time*. As such this section draws upon the findings to examine how Brinkmann’s (2006) temporal facticity serves to delineate how the values of the palliative approach can be engaged through the proposed ethical lens on both the individual level and in a wider care context, such as environmental

considerations and organizational priorities, with insights reaching beyond this to population-based public health and harm reduction considerations.

With respect to valuing human connection, one nurse expressed a preference for working evening shifts with geriatric psychiatry patients because this afforded the nurse more time with patients. Another nurse referred to a particularly valued care moment when a patient acknowledged the nurse after a considerable period of not doing so; this example could be seen to reveal that what is valued in human connection is what is sustained in connections and interactions that occur over time. In describing the care of a geriatric forensic patient, a nurse reflected upon the vulnerability of the patient in the ease with which this patient's behavior could be misinterpreted by those unfamiliar with his routines and by those who would omit close observation of this patients. In so doing, the nurse underscored the temporal dimension to enacting the value of familiarity as well as the embedded process of recognition it entails. In addition, nurses' recognition of vulnerability itself extended to apprehending vulnerability related to cumulative losses engendered by advanced age and vulnerability compounded by living in a psychiatric setting. From the findings examined on the temporal axis of human facticities stem possible insights to ensure greater continuity of care for similarly vulnerable patients as well as considerations related to the placement of long-term ALC patients.

Additional dimensions related to the temporal facticity and the process of recognition emerged in the findings. One participant reflected upon the cycles of life related to birth and death in the paralleled losses experienced by the families of patients in geriatric care to those of families on a mother-baby unit. These reference points serve in the recognition of the vulnerability engaged by the temporal facticity and the corresponding social roles engendered in the care of those most vulnerable in relation to this axis. In recognition of the poignancy of time

and the social experience of families in relation to births and deaths, the participant affirmed an additional nursing responsibility to the integration of families into care: supporting the establishment of new relationships between children and their parent when the latter is living with a neurodegenerative disorder. In so doing, the principles of the palliative approach are engaged with respect to integrated, holistic care, which includes the emotional and psychosocial needs of families, and dying as a part of living, which includes the opportunity to be prepared for death (CHPCA, 2015). In this vein, it is worth noting that low preparedness on the part of the caregiver for a patient's end-of-life is a predictor of post-loss depressive symptoms and complicated grief (Nielsen et al., 2017). The process of recognizing a time dimension in the care of patients can function to identify practices, such as helping families to establish new relationships, that support care aligned with the palliative approach.

### *Mortal*

An open awareness of death is recognized as significant in the conceptualization of the palliative approach (CHPCA, 2013; CHPCA, 2015; WHO, *n.d.*) and by extension this is also the case within an ethics of finitude. The third facticity identified by Brinkman (2006) pertains to the mortal dimension of human existence. Nurses engaged in the process of recognition of the mortal dimension of aging patients through critical reflection on both micro and macro levels. On both levels, it is possible to conceptualize the process of engagement with mortality as symbolically mediated, as explored through the memento mori motif.

On an individual level, nurses reflected upon their own death, such as by identifying the future possibility of a dementia diagnosis for themselves and the importance of speaking openly about death "like I'm going to buy my groceries". Similarly, Sinclair's (2011) study on the impact of death and dying on the lives of palliative care professionals underscores the mortal

awareness dimension and inter-relations of this area of care; participants expressed that facing their own mortality was “perhaps a necessary prerequisite” to effectively caring for patients at end-of-life and enacting elements of a good death (p. 185). Nurses in my research communicated an awareness of the progressive and terminal nature of dementia and identified the enhanced vulnerability of patients when similar mortal awareness did not appear to be shared by these patients’ families, an issue underscored in nurses’ reference to treatment courses seemingly removed from patients’ existential status. While these examples could be conceptualized as barriers to engagement with mortal facticity on an individual level, emphasis on curative modalities, such as the questioned use of ECT for a patient “now in a wheelchair, he doesn’t really want to eat” could serve as an example of the social reconstruction of aging and mortality as a medical or technical problem to be overcome, as described by Harari (2016). Emphasis on treatments in the context of a patient’s functional decline can serve to undermine the process of mortal remembrance and engagement in the mortal facticity of a patient and thereby threaten the enactment of the values of a palliative approach (CHPCA, 2015). As described by Maynard (2006) in his study of patients with cystic fibrosis who undergo lung transplants, “[t]he potential for restoring what has been lost represents a reassuring promise to once again delay disability and death” (Maynard, 2006, p. 218). Remembrance of mortality via nurses’ own processes of reflection on mortality (of self and of patient) could be an entry point into apprehending mortal facticity and an example of the memento mori motif. This process of reflection on mortal facticity was illustrated in the critical reflection of a participant who asked “what are we doing?” in thinking about the continued treatment of a patient with advanced disease for which the therapeutic benefits were not apparent.

Another example of the motif of mortal remembrance can be discerned in the forensic psychiatry setting; the contrasting populations of older and younger patient demographics served to render older patients more visible. This arrangement helped to contrast the limitations in physical functioning and fragile health of older patients relative to younger, more able-bodied, patients. The presence of older patients on the forensic psychiatry unit meant that younger patients were proximal to aging patients who might die or who were more likely to experience complications from life-limiting health conditions. Some participants found that the combined patient population of older and younger patients was of therapeutic value to both groups, such as by providing opportunities for younger patients to demonstrate expressions of concern and care for older patients. The dichotomy of older and younger patients is one way that patients, as well as nursing staff, could more directly apprehend and engage with mortality. Nurses found that the contact this arrangement fostered created conditions which allowed some younger patients to “practice” skills related to compassion, empathy, and concern for older patients—care values that could be found to rest within a palliative approach. The contrasting arrangement on the forensic psychiatry unit can be seen to serve as a form of memento mori insofar as the remembrance of mortality helped to identify values at risk, including comfort—values seemingly engaged by some younger patients, such as in the description of a younger patient regularly sitting with and singing to an older patient. Interestingly, the demographic arrangement of the forensic unit is one that juxtaposes a broader social context in which dying is generally removed from first-hand experience (Kellehear, 2007); the observations of the nurses underscore the interrelationship of social recognition and mortality in human solidarity.

## Insights

### Process of Values Engagement

In the previous section, the intersections between the values of the palliative approach and those expressed by nurses were identified. While values and guiding principles of the CHPCA's *Model* (2013) and *Framework* (2015) were linked with those expressed by nurses, the proposed ethical lens was explored to present an orientation to value identification reflective of individuals' unique considerations and vulnerabilities relative to human facticities. The approach underscored by the ethics of finitude lens can be contrasted with a values identification approach based on the enumerations of values (e.g. patient and family driven care, autonomy) in which patients and the values they hold are situated. While the listing of universal values and principles does not imply the absence of a personalized process to their enactment, the ethics of finitude lens is an approach that is more inductive in that it begins with the person and recognition of their human facticities, in order to identify and engage broader values and principles. In writing about the establishment of norms of practice and the core values of palliative care, which resulted in an enumeration format of values within the CHPCA's *Model* (2002), Syme and Bruce (2009) observed of this process that "homogeneity and uniformity run the risk of ignoring different priorities" (p. 22). It follows that a central insight is that of a complementary approach to values identification—one that can be coupled with values as described in guidance documents such as the CHPCA's *Model* (2013) and *Framework* (2015). For example, with respect to autonomy, reflection on facticities helps to envisage dimensions of relational autonomy, inclusive of social dimensions, such as those related to the social determinants of health, described below. The emphasis here is on the complementarity of values identification approaches (enumerative versus inductive) as consideration of both approaches may yield richer

reflection in the enactment of care practices, including that pertaining to the training and involvement of nurses in care planning.

### *Nurse training*

While this research did not study the Gentle Persuasive Approaches (GPA) or P.I.E.C.E.S. training referred to by nurses, participants attributed considerable significance to these trainings in supporting their approach to the care of older adults. Nurses' expressions of recognition of vulnerabilities and values as well as my own experience of taking GPA training, in which participants were encouraged to consider communication and interactions with patients with dementia from the latter's lifeworld, leads me to support the perceived value of this education in the enactment of an ethics of finitude. Moreover, the previous observation serves to consider the need for additional research to this end in care contexts encapsulated by the CHPCA's *Framework* (2015). Application of the proposed ethical lens to the analysis of these training modalities could yield additional insights into how they help participants to enact values for patients in their care and in turn possibly support funding for such training to promote the integration of the palliative approach in dementia care contexts. On this subject, Liu et al. (2013) found that positive attitudes towards older people were associated with increased knowledge of aging, including education in gerontological nursing. It follows that education and training may have a social function related to countering ageism, at least within the nursing profession. Training modalities, such as GPA, underscore the challenges and rewards of working with patients with dementia, and in so going may serve to challenge negative views held by nurses of gerontological nursing (Liu et al., 2015) and stereotyping discourses related to devalorization of advanced age (Phelan, 2011).

*Involvement of nurses in advance care planning*

Another dimension of care practices that require ethical reflection is the involvement of nurses in advance care planning and goals of care conversations. As part of the goals of the palliative approach in the CHPCA's *Framework* (2015), patients are to discuss advance care planning with their care providers early and often. Participants reflected upon the organizational priorities of nursing care that engendered more direct patient care and less participation in communication about goals of care and exploring families' knowledge about illness trajectories. Because of this care arrangement, nurses found that the knowledge disconnection related to patients' illness expressed by families hindered their ability to engage with families and patients relative to this. Beyond this, nurses expressed feeling at times devalued in their caregiving efforts when such disconnection was perceived.

Reflection on the human facticities, helps to support the importance of nurse participation in care planning conversations, substantiating goals articulated in the CHPCA's *Framework* (2015). The involvement of nurses in goals of care conversations is an opportunity to strengthen social linkages of patient through participation with family and also to discuss dimension related to mortality, including a shared understanding of care priorities and preparation for end-of-life. The enhanced involvement of nurses is supported in Reimer-Kirkham et al.'s (2016b) study of nurses' perspectives of the palliative approach; the authors proposed embedding practices structures in care settings so as to enhance nurses' role in relation to conversations about illness trajectories and goals of care.

**Accounting for Inequities**

The proposed ethical lens presents an orientation to value identification reflective of unique considerations related to human facticities; this approach supports gaining further insights

into consideration of patients' social facticity, an under-attended dimension in access to palliative care provision (Reimer-Kirkham et al., 2016a). On this point, Pauly (2008) lamented the "lack of attention in bioethics to the dominant societal and organizational values that shape health care interactions and injustices in health care". It can be proposed that interpretation of the social dimension of human facticities can be extended to the wider societal context. To this end, nurses in the study did not restrict consideration of social dimensions to immediate friends and family but included reflection on societal discourses shaping patients' care, such as one participant expressing the belief that the personal care of older patients was not valued societally. A wider consideration of social facticities can be understood to encompass a public health approach to palliative care—one that includes a population health promotion approach and that "views the community as an equal partner in the long and complex task of providing quality health care at the end of life." (PHPCI, *n.d.*). Indeed, Reimer-Kirkham et al. (2016a) identified patients that are both in need of palliative care services and experiencing deficits in the social determinants of health as doubly vulnerable and therefore structurally vulnerable. From the vantage point of the social facticity, critical questions accounting for this vulnerability can emerge, including: how vulnerable or sustained is this person socially/societally? This question can be paired with reflection upon the social determinants of health (Public Health Agency of Canada [PHAC], 2016), total institutions, and stigmatizing social processes as conceptualized by Goffman (1961; 1963).

How could this broader perspective of the social facticity yield insight on care? A process that supports the recognition of social vulnerabilities, such as those related to negative impacts of the social determinants of health, such as social status and social support networks (PHAC, 2016), can serve to identify challenges and opportunities to sustain the enactment of values.

Moreover, in Chapter 3, attention was given to the use of the Gold Standards Framework Proactive Identification Guidance (2016) to identify patients who may be amenable to a palliative approach—a tool that includes the “surprise question” and general and condition-specific indicators of decline. In the tool, the need to consider “additional contributing factors” when anticipating needs, including mental health and social care provision, was indicated (Gold Standards Framework, 2016) but a way to account for these additional factors was not included into the guidance document. The Proactive Identification Guidance (2016), with its bio-medical focus on clinical indicators related to illnesses, is reconsidered here as it is a useful point of comparison from which to consider additional social insights for which an ethics of finitude lens can help to account. For example, reflecting upon the relational dimensions of autonomy and how social vulnerabilities, such as homelessness, can help to discern how some patients may have had limited opportunities to develop decision-making capacities (Pauly, 2008) and thereby possibly constraining their ability to engage in advance care planning. Beyond this, the interrelated nature of facticities is such that questioning related to broader social facticities can lead to consideration of mortal dimensions such as by helping to identify those at risk of premature mortality given life-limiting social contexts, as exemplified by a nurse reflecting upon quickly exhausting options in the care of younger patients with schizophrenia. Reimer-Kirkham et al. (2016a) critiqued current palliative care approaches that “do not make explicit the additional attention needed to address social and structural inequities” (p. 2); through critical questioning, the proposed lens helps to put into focus socio-political forces that engender unique vulnerabilities in aging patients.

While beyond the scope of this research, further exploration of this ethical lens in the context of harm reduction could serve to illuminate other values dimensions. For example, in

Pauly's (2008) research with nurses working in harm reduction related to drug use, the participants were not only trying to minimize harm to individuals from drug use itself, but also trying to minimize social harms impacting clients' health. To this end, the participants engaged in reflective questioning such as "What can be done to reduce harm for this person in this situation?" (Pauly, 2008, p. 199). It follows that the harm reduction philosophy *prima facie* engages recognition of the human facticities described above and the questioning used by the nurses in Pauly's (2008) study could be re-proposed here, more generally, as: "How vulnerable or sustained is this person socially/societally?" In so doing, this could help to respond to the need to build linkages in ethical underpinnings and to link perspectives on social justice with ethical dimensions such as those related to harm reduction, as called for by Pauly (2008). This questioning also serves to incorporate considerations related to the social environment, including those related to social exclusion as it relates to the conceptualization of total institutions and stigma (Goffman, 1961; 1963) as well as underscoring nursing as a political activity (Perron et al., 2005) with possibilities for nursing advocacy.

### **Sustaining Recognition in Obscuring Contexts**

Safety and security considerations were communicated by nurses and came to juxtapose, at times, those identified in the enactment of an ethics of finitude. For example, the presence of a patient in one environment (e.g. on geriatric unit) versus another (e.g. off geriatric unit) was described as altering the approach to care an aging patient might experience. This example serves to illustrate aspects of the process of 'formal administration' of life described by Goffman (1961) with respect to total institutions, as evidenced in the separations of the patients into units, the routines of the institution with respect to security management, and the organization of nurses' activities related to responding to patients in one unit versus another. Additionally, the

primacy of maintaining a safe and secure environment on the forensic unit was such that the flexibility required within a palliative approach (i.e. accommodating family on forensic psychiatry unit) represented an aberration from established norms and as such subject to formal administration.

In Chapter 3, Mishel's (1990) re-conceptualization of uncertainty was posited to help to understand barriers encountered by nurses when engaging in an ethics of finitude, such as the push for curative modalities as a way to maintain control and predictability. While families actively hoping for a cure for dementia when their loved one's disease is far advanced is one example, another parallel could be in the attachment to the structures and operations of a secure unit to contain the uncertainty that forensic patients can represent. The physical vulnerability of aging forensic patients, described in terms of increased functional limitations, may serve to symbolically disrupt the social arrangement conceptualized in the total institution. Nurses' recognition of the increased functional limitations of forensic patients might serve to humanize these aging patients (and perhaps serve to counter the process of mortification). For the nurses who were described by participants as reluctant to provide care to aging forensic patients, one could speculate that the functional limitations of patients in a forensic setting may have a disruptive effect in term of the characteristic divisions between the managed group (patients) and supervisory staff (nurses). This possibility can be situated within the process of recognition identified, whereby engagement with mortality included reflection to one's own mortality and thereby fertile ground for the identification of commonalities and possibly solidarity. The resistance to care for aging patients may be less about ageism and more about maintaining control and predictability. More research would be needed to explore this contention.

At the junction of the construction of the aging psychiatric patient is stigma related to aging described by nurses in terms of the lower organizational priority with respect to staffing of geriatric psychiatry units and in the perceived attitudes of some nurses towards aging forensic psychiatry patients, reflective of the ageism first described by Butler (1969). These examples illustrate how stigma related to aging can function as an attribute that discredits and diminishes these patients (Goffman, 1963), with consequences for the administration and delivery of their care. On the other hand, nurses in the study demonstrated efforts, through the process of recognition, to attempt to buffer both patients and families against the threat of stigmatizing processes related to the construction of a forensic identity through education and acknowledging the importance of family.

While the proposed ethical lens will not end stigmatizing social processes, it can provide insight into the identification of forces contributing to them through critical questions. Given the socially constructed nature of stigma, questioning related to the social facticity for patients amenable to a palliative approach can be considered, such as the aforementioned: “How vulnerable or sustained is this person socially/societally?” and also “How does this social/societal context shape the possibilities for the enactment of values for this person?” On the forensic psychiatry unit, it was found that older patients were more visible by their small number among a much younger and more numerous patient population. This arrangement was frequently perceived positively by nurses with respect to social considerations (i.e. opportunity for younger patients to practice expressions of concern, social role for older patient in relation to this). It follows that critical questions related to the proposed ethical lens can help to identify social dimensions related to the enactment of values.

Insights reflected in this section represent an early conceptualization of an ethics of finitude. The proposed ethical lens engenders possible insights with respect to the formulation of questions related to human facticities and the application of such questioning to aspects of care, including government policies, related to the care of patients amenable to a palliative approach. Such questions could include: Does this [e.g. policy, philosophy, model of care] support the enactment of values for a patient who is vulnerable related to the interconnected axes of sociality, temporality, and mortality? How vulnerable or sustained is this person socially/societally? How does this social/societal context shape the possibilities for the enactment of values for this person? The use of such questioning is explored through the example of Ontario's Home First philosophy, considered next.

### **Home First and an Ethics of Finitude**

In Ontario, the clinical designation of ALC is applied when a patient is occupying a bed in a hospital and does not require the intensity of resources and/or services provided in this care setting (Cancer Care Ontario, 2016). From the data emerged a disjunction in the accounting of older patients in forensic psychiatry who are anomalous by virtue of their long-term ALC status and because they are seemingly un-placeable elsewhere in the community. This observation aligns with the findings of a study of the ALC status in mental health in-patient units across Ontario, in which it was found that ALC patients were substantially more likely than non-ALC patients to be older and to be diagnosed with schizophrenia or a cognitive disorder (Little, Hirdes, & Daniel, 2015). The example of the long-term forensic psychiatry ALC patient can be explored through the proposed ethical lens to critically question Ontario's Home First philosophy, first described in Chapter 2. Ontario's Home First philosophy underscores an effort to reduce wait times for acute care beds by means of minimizing lengths of stay, including those

related to ALC designated patients (Government of Ontario, 2011). It is important to note that reducing the number of ALC designated patients is important to ensure access to appropriate health care resources and that the ALC designation is linked with negative outcomes at the patient level (functional decline, delirium, infection) and organizationally (emergency room backlogs, surgery delays) (Little et al., 2015). The point here is to question whether other ethical considerations can be introduced that, when appropriate, nuance interpretation of the Home First philosophy.

Barker and Church (2017) analyzed regional health authorities that emerged in Canada, of which Ontario's LHIN is an example, and identified shortcomings pertaining to the politically contested values underpinning performance measures and that "measurements related to access to acute care outweigh efforts to measure outputs or quality of care" (Barker & Church, 2017, p. 338). Between Home First's description as patient centered and reflective of considerations of quality of care, there is room to introduce the notion of critical questions when patients are found to be in states of exceptions as exemplified by lengthy ALC designations, including: Does the Home First philosophy support the enactment of values for a patient who is vulnerable related to the interconnected axes of sociality, temporality, and mortality? How vulnerable or sustained is this person socially/societally? Reflection upon these questions may generate regard to the possible negative outcomes, including stigma, for patients who are labelled ALC, particularly when this label persists over months and even years. Stigmatizing processes can be further considered by reflecting upon McCloskey, Jarrett, and Stewart's (2015) research on the care experiences of patients and families designated as ALC; the authors found that the ALC designation could generate feelings of being unworthy of care and lead some patients to try to minimize the work they created for staff, such as using a bedpan rather than seeking assistance to

ambulate to the bathroom. Similar critical questioning regarding social dimensions and stigmatizing processes can be engaged related to the discharge of a long-term ALC patient: Given this person's prognosis and functional status, does the proposed discharge context afford social possibilities for this person to be known in their care? Returning to the interviews, nurses communicated that it was not merely the disease process itself that could impact patients' ability to live their personhood but also the extent to which patients' personhood was sustained in the care from those around them. It follows that the critical questions proposed could serve to better account for the social dimensions of patients approaching end-of-life, including the ability to absorb social disruption. While it is perhaps anathema to inscribe discretion into policy, there is opportunity to explore twinning the Home First philosophy with ethical considerations aligned with a palliative approach. In so doing, this may serve to answer the CHPCA's *Framework* (2015) called-for shift in practice culture to ensure the integration of the palliative approach in all care settings.

### **Language of the Palliative Approach**

The impetus for this project was rooted in seeking greater understanding of the ethical dimensions underpinning the enactment of the palliative approach and by extension, to gain enhanced conceptual clarity of the term palliative approach. In Chapter 3, I undertook a modified concept analysis of the term palliative approach using Morse's (2000) pragmatic utility approach with the aim of contributing to clarity in the palliative care lexicon. Based on a critical analysis of the semantic and pragmatic iterations of the palliative approach identified through the literature review, I asked whether it was useful to propose a conceptual definition of the palliative approach. I answered this in the affirmative based on a critical appraisal of the literature and reflection to pragmatic considerations identified by Morse (2000). For example, the

literature review included the work of Kristjanson (2005), who argued for the need to distinguish different palliative care services (including the palliative approach) to formulate research questions about who receives palliative care, how to structure services, when to offer palliative care, and how to resource palliative care. Therefore, with respect to pragmatic considerations, my response was grounded in the understanding that conceptual clarity helps to further theory construction and research and, by extension, helps to ensure funding for and improve access to more appropriate care aligned with this approach (Weaver & Mitcham, 2008). Based upon the findings, further reflection on the literature, and my continued experience as a clinician, a reconsideration of the conceptualization project of the palliative approach is in order.

To begin, consideration of the findings is needed. The semantic variability related to the palliative approach identified in the literature review conducted for the modified concept analysis was echoed in nurses' use of language in the interviews. There were various articulations by nurses regarding the meaning of the term "palliative" when they were asked "what does the term palliative mean to you?" The language used by participants, while iterating elements of the palliative approach and an ethics of finitude, frequently equivocated palliative care with end-of-life care. Some nurses associated the term palliative with elements of the palliative approach, such as in relation to timing, goals of comfort, and a threat to health. One nurse acknowledged that palliative "used to be assumed to be the last stages of life" indicating cognizance of the broader application of palliative care principles prior to end-of-life. The varied conceptualizations of palliative terminology expressed by nurses were echoed in the study by Reimer-Kirkham, Sawatzky, Roberts, Cochrane, and Stajduhar (2016b) on nurses' perspectives of the palliative approach. The terminology used by nurses in the present study represents a semantic challenge in that while nurses were found to communicate to be engaged in practices

corresponding to the values and principles of the palliative approach, they did not identify this term or their practices within the language of the palliative approach.

Re-imagination of the initial assertion regarding the need for clarity of the palliative lexicon pertaining to the palliative approach is also informed by my ongoing work as a palliative care practitioner. Upon personal reflection following the experience of providing tours to potential private donors to a palliative care facility, I have come to better appreciate the social role of the language of palliative care in remaining to some extent ambiguous to maintain the power of its association with end-of-life and mortality. To clarify, it is worth recalling that Mead et al. (2013) identified the palliative approach as a term associated with dying and as such it is difficult to untangle the term palliative from its association with end-of-life. It follows that perhaps the symbolic function of the language of palliative care, as it relates to end-of-life, may not necessarily be equivalent when applied to a context and population perceived as more remote in terms of proximity to mortality and end-of-life, as presupposed in a palliative approach. In other words, it may be the association of palliative care with mortality that renders it a special status and social function pertaining to the remembrance of mortality. Recalling the motif of *memento mori* explored in Chapter 3 serves to nuance this observation in that engagement with matters related to remembrance of mortality are multifaceted and its symbolism is vulnerable to re-imagination reflective of symbolism's ever-changing social function. Indeed, it is worth considering the social function of the language of palliative care; it is unclear whether the poignancy with respect to the language of palliative care could be maintained if the term was associated with the care of *anyone* aging with life-limiting illnesses. It may be the mortality-recollecting dimension of the language of palliative care and palliative approach that is central to its social function.

It is important to further reflect upon the social dimension of the language of palliative care and the palliative approach; the language of palliative care can serve as an entry point for some individuals with respect to remembrance and reflection on mortal finitude. Recalling examples provided in Chapter 3 related to the medicalization of aging (e.g. androgen replacement therapy), in addition to the language of palliative care and medical prognostication, it could be argued that many secular touchstones of mortal remembrance are correspondingly clustered in the bio-medical field. This is echoed by the underlying bio-medically oriented culture in Canada identified by Williams et al. (2010) insofar as medical language not only mediates but legitimates human experience. In other words, the legitimacy of bio-medical discourse serves not only to shape the social function of language but also engagement with the human facticity of mortality. This helps to illustrate how the nursing profession and, by extension, the nursing care of geriatric and forensic psychiatry patients, exists within the context of multiple discourses, including those [re]produced related to palliative care (Phelan, 2011). Recalling Mishel's (1990) conceptualization of uncertainty as a mechanism to negotiate both cultural norms of predictability and control and the desirability of uncertainty in the face of possible negative outcomes, it is possible to consider the use of symbolism, including the language of palliative care itself, as a way to reconcile humans to a mortality that cannot ultimately be controlled.

Considering the findings, literature on the language of palliative care, and my experience as a palliative care clinician, I have come to further critical appraisal so as to question the "pragmatics" of seeking conceptual clarity of the term palliative approach. To be pragmatic in the context of an aging population for which the need to ensure access to palliative care is an identified public health concern (Stjernswärd et al., 2007), efforts at conceptual clarity require re-

imagination. Indeed, a narrow focus on the use of language could detract from the values underpinning a given approach, as illustrated in the use of language and the idealized conceptualization of home in the description of Ontario's Home First philosophy (Central East Community Care Access Centre, 2015; Government of Ontario, 2011) detailed in Chapter 2.

The exercise of engaging in a modified concept analysis of the term palliative approach is nonetheless valuable for had I not undertaken this process, it would not have been possible to arrive at this more nuanced perspective with respect to the intersection of language, pragmatics, and values. It might not be a worthwhile effort to push for conceptual clarity related to palliative approach given the intersecting meanings of the term palliative and the pragmatic implications for the various usages of the term. There are various entry points into enacting the values that underpin the palliative approach and it is perhaps more "pragmatic" (to re-engage the language and questioning of Morse [2000]), to focus on the enactment of values that underpin the approach than it is to ensure that the utilized approach is recognized as a "palliative approach".

If the history of the language of palliative care is any indication, inconsistencies, as identified in the modified concept analysis, and the use of euphemisms (Pastrana et al., 2008; Syme & Bruce, 2009), in this area care are likely to persist. The observations of nurses in my research may also reflect the influence of an inherited expert discourse around palliative care identified by Stajduhar (2011) whereby even nurses working with patients with advanced dementia do not necessarily identify themselves as palliative care providers, reserving this association to specialized palliative services or to other care setting. While these challenges do not negate academic and practical considerations (i.e. health care funding) for which to conceptualize the palliative approach, they do nuance the endeavor. Given the variety of contexts in which the palliative approach is proposed to be enacted as per the CHPCA's *Framework*

(2015), there is a need to complement conceptualization of this approach with the lens of an ethics of finitude that can be engaged despite inconsistencies in the use of language related to palliative care and the palliative approach. The proposed ethical lens can help to identify values at stake in care practices and, as such, presents the groundwork for a process to delineate practices and training aligned with this approach, such as GPA in Dementia Care, which emphasizes the value of personhood-promoting interactions (AGE, 2014) and P.I.E.C.E.S. training, which includes recognition of the strengths of older at risk individuals (P.I.E.C.E.S., 2013).

### **Limitations**

Several limitations pertain to the project and as such, they constrain the insights that emerged from the findings. A general limitation pertains to the self-selection to participate in the research; the perspective of nurses who are less passionate and/or knowledgeable about the care of aging patients is likely underrepresented in this research. Central limitations, explored below, relate to the elaboration of the research within a larger project with specific consideration to the constraints this engendered in the data collection stage, the challenge of the mixed nursing populations under study, and the limits of the researcher as an instrument of inquiry within a phenomenological project.

### **Analytic Elaboration of Original Project**

As my project was an analytic elaboration of a larger research initiative, my inquiry was limited to the aims of the original research. Because of this structure, the data collection process and findings were constrained to the extent that specific questions about mortality were not asked to participants. Questioning, such as asking participants' reflections on mortality in the care of aging patients, could have served to elucidate and further articulate some of the categories that

emerged, such when nurses thought about their own mortality in reflecting upon the care of aging patients on the study units. For example, some participants spoke about their experiences with the loss of family members or caring for family members with advanced disease as a way that helped them to identify values (e.g. dignity) and to recognize the limits of bio-medicine. While these examples were rich, mortality was not the direct focus of inquiry. Direct open-ended questioning regarding personal experiences with advanced illness and mortality may have yielded further insights into these experiences in relation to the engagement of nurses with aging patients.

Another limitation related to the aims and theoretical underpinning of the original project is that the latter did not specifically engage in an exploration of the language used with respect to palliative care and the palliative approach. My project may have been enriched by more nuanced questions related to the use of language and ascertaining participants' baseline understanding related to palliative care. As part of the interview schedule, participants were asked "what does palliative mean to you?" While beyond the purview of the current project, the inquiry may have benefitted from also asking participants: what does palliative approach mean to you?

### **Mixed Nursing Population**

Another limitation of the project pertains to the mixed forensic and geriatric psychiatry nurse participants. While the mixed population reflects, in part, research design considerations pertaining to the small potential number of participants, it also reflects a challenge in terms of yielding an in-depth understanding of the nuances of each nursing population on its own as well as a challenge in relation to interpreting and communicating the findings. With respect to interpreting and communicating the findings, it was challenging to do so clearly; from the vantage point of data collection, it was not always evident to which patient population some

nurses referred. For example, some participants worked in both geriatric and forensic psychiatry and at times referred to different patient populations interchangeably. While some clarification was obtained during the interviews, it was not always possible to do so while following IPA data collection methodology with a focus on participants' lifeworld and their subjective experiences (Polit & Beck, 2012) and within the interview time allotted. Despite limitations with respect to the mixed nursing population, the diversity in nursing backgrounds and work contexts may have enriched the project insofar as to permit the identification of the proposed ethical lens in different nursing care contexts.

### **Researcher as Instrument**

The last limitations considered relate to those which I personally bring to this project as a researcher. These limitations first pertain to the methodologies engaged. With respect to IPA, studying participants' lifeworld required my interpretation and, while various attempts were made to ensure rigour in this process, it must be acknowledged that the results, in the form of findings and discussion, are a best effort and an approximation of a phenomenon constructed by a novice researcher. Thorne et al. (2004) offer a more eloquent account of the inextricable limitations of the researcher as an instrument of inquiry:

No matter how participatory and collaborative the method, it is the researcher who ultimately determines what constitutes data, which data arise to relevance, how the final conceptualizations portraying those data will be structured, and which vehicles will be used to disseminate the findings (p. 6).

ID does not yield "facts" but rather "constructed truths" and the defensibility of these constructions depends upon my ability to make the phenomenon of study meaningful in a new and useful way (Thorne et al., 2004, p. 6). The novelty and utility of the project are not merely

determined in the current account but also in how this project informs the care of patients. To this end, the proposed ethical lens is certainly in its conceptual infancy and further exploration of its relevance and utility in other health care contexts is needed.

## Chapter 7: Conclusion

The CHPCA's *Framework* (2015) articulated a vision for palliative care in Canada in which everyone who is facing problems associated with aging should benefit from a palliative approach to care. With an orientation to this vision and in recognition of a demographic context of aging adults and persistent inequities in access to palliative care, this research explored how nurses in forensic and geriatric psychiatry engage with patients and mortal considerations in the care of aging patients to discern how ethical dimensions of care, aligned with the palliative approach, are enacted. As an analytical elaboration of a qualitative study undertaken at the University of Ottawa, the project also sought to identify barriers, enablers, and related social discourses pertaining to ethical engagement in nursing care related to human facticities described by Brinkmann (2006).

The research was situated within the literature pertaining to the care of aging patients, forensic and geriatric patients, and historically, within the context of the modern hospice palliative care movement. Pertinent conceptual considerations included conceptualization of the term palliative approach itself and how this relates to broader health discourses, including public health palliative care, and social processes, such as total institutions and stigma (Goffman, 1961; 1963). The process of engagement with mortality was also explored through the trans-historical motif of *memento mori*. Significantly, an ethical lens by which to apprehend dimensions of human finitude was proposed, as inspired by the ideas of Brinkmann (2006) related to human facticities of sociality, temporality, and mortality. The articulation of an ethics of finitude is of significance in that it reflects central elements of the palliative approach and public health palliative care (PHPCI, *n.d.*; WHO, *n.d.*) and was found to help to delineate a process of recognition through which values can be identified in the care of patients.

The process of recognition explored through the proposed ethical lens and identified in the findings was found to delineate values that underpin the palliative approach by offering an alternate conceptualization to their identification and enactment. While values (human connection, dignity, comfort, family, familiarity, and personhood) expressed by nurses in the research are essential to most individuals beyond the current study context, recognition of these same values in light of the facticities outlined by Brinkmann (2006) infuses them with imminence and helps to delineate unique ethical dimensions related to their enactment for a particular patient. The recognition of values is paralleled with a recognition of a patient's unique proximity to the loss embodied by these values and these losses can in turn be conceptualized along interconnected axes of sociality, temporality, and mortality.

Heading the call of Reimer-Kirkham et al. (2016a) to philosophically align palliative care as a social justice issue through a health equity approach and to account for health-threatening and life-limiting contexts informed by structural vulnerability, insights from this project underscore the need for critical questioning not only in the care of individual patients but also in the enactment of public policy, such as Ontario's Home First philosophy. While the lens of an ethics of finitude will not end stigmatizing social processes, it can provide insight into the identification of forces contributing to them through critical questions. For example, given the socially constructed nature of stigma, questioning related to the social facticity for patients amenable to a palliative approach could include: "How vulnerable or sustained is this person socially/societally?" and "How does this social/societal context shape the possibilities for the enactment of values for this person?"

In addition to the possibility to identify care practices aligned with the palliative approach, such as GPA and P.I.E.C.E.S. training and the enhanced involvement of nurses in

advance care planning, the research also yields insights pertaining to the language of the palliative approach, including that the language of palliative care can serve as an entry point with respect to remembrance and reflection on mortal finitude. While conceptual clarity of the term palliative approach is not without value, a narrow focus on the use of language can detract from the values underpinning a given approach. Given the variety of contexts in which the palliative approach is proposed to be enacted, there is a need to complement conceptualization of this approach with the lens of an ethics of finitude that can be engaged despite inconsistencies in the use of language related to palliative care and the palliative approach. The proposed ethical lens can help to identify values at stake in care practices and, as such, presents a mechanism to delineate practices and training aligned with this approach.

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## Appendix A

## Interview Schedule

**Research questions of larger research project (not student questions):**

1. Can you describe a typical day here as a nurse on this unit?
2. What is the overall role of nursing here?
3. If participant has worked in mainstream nursing contexts (e.g., medical/surgical care): To what extent is nursing in this environment similar or different to nursing in other contexts where you have worked?
4. How would you describe the nurse-patient relationship in this environment?
5. Talk to me about aging patients on this unit. In your view, what would ideal nursing care look like for these patients?
6. In what ways is the reality on this unit similar or different to what you've just described? In your view, what contributes to these similarities or differences?

**Research questions specific to student's research (student questions):**

1. What is important to you as you think about the care of aging patients?
2. What does "palliative" mean to you?
3. As a patient changes, such by advancing in age or becoming more affected by advanced illness, what does the care look like? Tell me about this.
4. What informs your approach to caring for your patients?
5. Wrap up questions: Is there anything else you would like to tell me? Are there any other questions that you think I should have asked you?