

**ETHICS IN LONG-TERM CARE: EXPLORING THE INTERACTION
BETWEEN PROVINCIAL AND ORGANIZATIONAL POLICY AND
FRONTLINE ETHICAL DECISION-MAKING**

by

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ABSTRACT

In partnership with five long term care (LTC) facilities in New Brunswick, this research project is on empirical ethics in LTC practices. There are studies on the normative ethical frameworks used by LTC staff, and studies proposing how staff *should* reason, but few studies explore how staff *actually* reason. The first stage of the project explores the ethical reasoning process of LTC staff in the provision of social care. Seven interdisciplinary focus groups were conducted with twenty frontline staff. Findings suggest staff typically do not have difficulty determining the ethical decision and/or action, though they frequently experience moral distress as they feel restricted to act in the ways they believe to be right as a result of institutional constraints. Participants describe a number of institutional constraints impacting their ability to act in the ways they believe to be right. The majority of the reported constraints are structural, meaning they could be solved, or at least reduced, by examining and addressing the larger sociopolitical factors influencing LTC organizational policies and procedures, and thus the ethical decision-making environment. To better understand these organizational constraints, the second stage of the project adopts a qualitative Delphi methodology, drawing on the views of stakeholder experts to explore the interaction between public policy and organizational policies and how these interactions impact frontline staff's ethical decisions/actions. This Delphi study used a two-round interview process to engage 24 stakeholder experts from the LTC sector in an iterative process of knowledge production, reflection and translation. The relative consensus achieved by Delphi participants suggest public and organizational policies influence organizational ethical cultures and thus the ethical decision-making environments of staff. In order to overcome

the constraints identified by staff in the focus groups, and foster change, innovation, and positive ethical cultures in LTC the sector must focus on: 1) establishing the right culture, leadership, and frontline staff in LTC organizations; 2) implementing strategic hiring processes; 3) create on-going and appropriate training; 4) providing government leadership, focus, and policies; and 5) creating a collaborative sector. Future possibilities are discussed.

DEDICATION

To my sweet boy Garion, and future generations. May you always question, and dare to imagine alternatives.

“I have found it is the small every day deeds of ordinary folk that keep darkness at bay.

Small acts of kindness and love.” - J. R. R. Tolkien

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List of Symbols, Nomenclature or Abbreviations

D/LTC	Dementia/long-term care
LPN	Licensed practical nurse
LTC	Long-term care
PAR	Participatory action-based research
RA	Resident attendant
RN	Registered nurse

Introduction

In this dissertation I report on a two-stage project, where the first stage informs the second. Both stages of my research project are part of a collaborative study conducted with the Centre for Interdisciplinary Research on Narrative (CIRN) at St. Thomas University. Contrary to a ‘standard dissertation’ presented as a monograph, my research is presented as an article-based dissertation, the methodology, methods, and findings being presented in the form of three papers. The first paper, “Ethical reasoning and moral distress in social care among long-term care staff,” was submitted to the *Canadian Journal on Aging* (January, 2018) and is currently under secondary review. This paper presents the findings from the first stage of the research, which fits well within the scope of the journal. The *Canadian Journal on Aging* seeks to published articles pertaining to a broad range of topic areas concerning the older adult population, particularly in a Canadian context, including quality of life, best practices, and policy (Cambridge University Press, 2018). The second paper, “Connecting findings to meaningful change: The benefits of using qualitative Delphi in empirical ethics and policy research in long-term care,” has been published in the *International Journal of Qualitative Methods* (2018: doi.org/10.1177/1609406918803271). The *International Journal of Qualitative Methods* is an interdisciplinary journal, which aims to publish articles describing original insights in qualitative methodologies and methods (SAGE Publications, 2018a). In this paper, I provide a theoretical justification of the methodologies used in the second stage of the research to explore the interaction between public and organizational policy and frontline ethical decision-making. I focus on the innovative use of Delphi as both, a qualitative method, and a method of ethics. Findings from the second stage of the

research are also explored. The third paper, “Empirical ethics in long-term care: Using Delphi method as a form of consensus building,” has been published in *SAGE Research Methods Cases* (2017: dx.doi.org/10.4135/9781526407511). This journal aims to provide the reader with practical accounts of the research process, including challenges, successes, insights, and inspiration for future researchers (SAGE Publications, 2018b). The third paper addresses a common critique of the qualitative Delphi method, that there is a lack of literature describing qualitative techniques or processes, by providing an overview of the specific processes used in this qualitative Delphi study.

Between each paper I present an *interlude*, written to provide a coherent connection between the papers and the various stages of the research. These interludes allow for additional information, findings, and bridging between the stages of the research to create a more complete picture of the two-stage research project that can appear somewhat disconnected if read as ‘separate papers.’ Contrary to a standard dissertation introduction, the purpose of the introduction here is to:

- 1) provide synthesis, including a broad overview of the background, relevance, and research components, and
- 2) provide an introduction to each of the papers and the information therein.

Consequently, there is possibly some information in the ‘introduction’ that might be expected to be found in other “chapters” (e.g. a methodology and methods chapter) of a standard dissertation. The dissertation ends with a ‘Concluding Reflections’ chapter, which explores possible avenues for future research.

Research Overview

In partnership with five long term care (LTC) facilities in New Brunswick, this is a research project on ethics in LTC practices, exploring how staff reason through ethical situations, and the interaction between provincial and organizational policy and frontline ethical decision-making¹. Throughout history there have been, and continue to be, many definitions and understandings of “ethics.” In the context of this research, ethics is understood as a “moral responsibility we have for others” (Clancy, 2007, p.72), and the question, what is ‘good’ and ‘right’ (Heller, 2009). Consequently, there are a number of different means of exploring and defining ethics, ethical behavior, and ethical decision-making. One such way, and the approach adopted in this research, is empirical ethics, taking as its dual starting points that ethical theory can benefit from empirical data and ethics and experience are integrally linked (van der Scheer & Widdershoven, 2004). LTC organizations often rely on ethical frameworks and values adapted from acute care settings despite the differences in the environments (Collopy et al., 1991; Waymack, 1998; Kuczewski, 1999; Carter, 2002). Typically, LTC staff, through codes of conducts and professional codes of practice, are taught ethical frameworks grounded in more normative ethical theories such as principlism, consequentialism, utilitarianism, and deontology (Woods, 2005).

Principlism is an ethical framework based on weighing the four principles of autonomy, beneficence, nonmaleficence, and justice (Beauchamp & Childress, 1989).

¹ Though it is typical to provide details of the research setting, in this case the partner LTC facilities, it is difficult to do so in the context of this research. New Brunswick is a small province, there are limited LTC facilities, and the LTC sector is highly connected and interwoven. As such, providing additional information regarding the partner facilities would create issues of confidentiality as the organizations could be identified.

Alternatively, using a consequentialist method, decisions are made based on the potential consequences or outcomes of the action(s). A utilitarian ethical framework aims to achieve the greatest good for the greatest number, and finally, deontology is a means of ethical decision-making that draws on rules and duties. Studies aiming to explore how staff reason in LTC typically stem from these normative frameworks.

Researchers such as Dunworth and Kirwan (2009), Van Thiel and Van Delden (2001), Mattiasson and Andersson (1995), and Jansson and Norberg (1992) have reviewed the ethical decision-making process of LTC staff using normative frameworks. Others like Bolmsjö, et al. (2006a/b), Fleming, (2007), Carter, (2002), Kuczewski (1999), and Mysak (1997) draw on normative ethical frameworks and propose how staff *should* reason through ethical dilemmas in LTC. These studies, however, were designed with an underlying assumption that LTC staff reason in a particular (normative) way. However, there are other ways in which LTC staff might reason ethically. For example, LTC staff might also draw on virtue ethics (Carr & Steutel, 1999), narrative ethics (Baldwin, 2015), feminist ethics (Card, 1991), and casuistry (Slettebø & Bunch, 2004b). Though more recently some researchers have challenged the applicability of normative ethics approaches in LTC (Agich, 2003) and have sought to understand the ethical challenges faced by LTC staff (Bollig et al., 2015) normative frameworks continue to be largely accepted, taught, and reproduced. There are few studies, which sought to explore and better understand staff's *actual* reasoning processes within a practice context and knowledge about ethical decision-making is limited (Bollig, 2017). Similarly, no studies were found that sought to understand how public and organizational policy impact the decision-making of staff.

Empirical Ethics

This research is grounded in empirical methodology, as the literature revealed a call for increased empirical studies with respect to ethics in LTC. The rise of empirical ethics is an example of multi/interdisciplinary work, striving to go beyond traditional normative ethical principles (Molewijk & Widdershoven, 2010). Empirical ethics emerged as a reaction to the problematic identification of bioethics as “unquestionably” normative (Molewijk & Widdershoven, 2010). Historically, ethical norms were established through theoretical means, rather than experiential means. Empirical ethics argues that theories cannot be arbitrarily developed outside of the practice context; “The way in which people reason and act in actual practice can inform ethical theory by providing normative considerations and experiences” (van der Scheer & Widdershoven, 2004). Empirical research is relevant for ethics in that it can make clear what normative views LTC staff *actually* endorse, rather than what ethicists theorize are normative guidelines (Widdershoven, Molewijk, & Abma, 2009).

In this study, ‘empirical ethics’ is understood as research approaches that “see a value in using empirical data to inform the ethical analysis of practical dilemmas” (p. 466) and which combine this empirical data with moral philosophical analysis (Dunn, Sheehan, Hope, & Parker, 2012, p. 467). According to the empirical ethics approach, theoretical frameworks for organizational philosophies must evolve from the practice context and actual staff activities. Empirical ethics has been examined in relation to a number of areas, e.g. anorexia (Tan et al., 2008), caring for someone with dementia (Baldwin, 2008) and other areas of psychiatry (Widdershoven et al., 2008). To date, empirical research into ethical practice in LTC facilities is extremely limited (Hasselkus,

1997; Powers, 2000; van der Dam et al., 2012; Edwards et al., 2013), and a comprehensive literature review [*see Background section below*] indicates minimal empirical research on the ethical reasoning deployed by LTC staff.

Social Care/ Everyday Ethics

By applying this approach to the LTC environment, this study explored the nature and extent of ethical issues in the provision of *social care* in LTC facilities, and the ethical framework(s) deployed by LTC staff in making decisions as to the right thing to do in such situations. While LTC staff are faced with numerous health-related ethical issues, they also deal with difficult ethical situations in the provision of social care, referred to as ‘everyday ethics.’ Powers (2000) defines everyday ethics as consideration of the ethical aspects of ordinary issues of daily life affecting nursing home residents and those who care for them. Powers (2000) asserts, “too often the attention of formalized ethical decision making in health care settings turns to hard to deal with life and death issues” (p. 143), which discount daily ethical issues and “actually obscure[s] a fundamental question that cannot be ignored for long in the setting of the nursing home or long term care facility: What is the goal of health care? Is it merely to preserve life? Most providers and patients would argue for something more” (p. 144). In fact, residents and family members report everyday ethics as more pivotal than end-of-life ethics (Bollig, 2017; Bollig, Gjengedal, & Rosland, 2016).

Ethical Cultures vs. Climates

A number of studies highlight the influence organizational culture and/or climate have on ethical issues, as well as on staff reasoning and actions (Jansson & Norberg, 1992; Powers, 2000; Slettebø & Bunch, 2004; Dierckx de Casterlé, Izumi, Godfrey &

Denhaerynck, 2008; Dunworth & Kirwan, 2009; Jakobsen & Sørлие, 2010; van der Dam, Abma, Kardol, & Widdershoven, 2011). Ethical *cultures* within organizations are established when leaders within the organization recognize ethics as an integral component to the organization's culture, and "identify, order, and communicate values so that in situations where they conflict, employees can more easily identify and weigh courses of action" (Messikomer & Cirka, 2008, p. 89). When organizational leaders understand the circumstances that could lead to potential ethical issues, it allows them to manage these issues more effectively by encouraging creative alternative courses of action, which the literature proposes can be effectively accomplished through fostering a safe environment for moral reflection and deliberation (Messikomer & Cirka, 2008; Solum, Slettebø & Hauge, 2008; Abma, Molewijk & Widdershoven, 2009; Widdershoven, Abma & Molewijk, 2009; van der Dam, Abma, Molewijk, Kardol, Schols & Widdershoven, 2011; Edwards, McClement & Read, 2013). Ethical cultures are 'preventative' and 'proactive,' as they prepare staff for potential ethical issues, and work to diminish, or minimize, possible ethical issues before they even arise.

Conversely, an ethical *climate* is a descriptive construct, where individuals within the organization are broadly aware of ethics, though frontline careers typically have a narrow understanding of responsibilities, and ethics training is limited to what regulations require (Messikomer & Cirka, 2008). Many LTC facilities seem to have adopted a business-model approach to care, which results in an ethical climate where decisions and actions are founded on economic and legal obligations, rather than the establishment of positive ethical cultures (Powers, 2000; Powers, 2001; Rees, King & Schmitz, 2009; Jakobsen & Sørлие, 2010). Ethical Climates are 'reactive,' as issues arise, or become too

large to manage, and then escalate quickly.

Research Questions

The goal of the research was to gain a better understanding of how LTC staff reason ethically in a social care context, in particular, addressing the following questions:

- 1) How does the ethical reasoning of LTC staff reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues?
- 2) On which ethical frameworks do LTC staff draw in their ethical reasoning?
- 3) How do provincial/organizational policies impact LTC ethical cultures and frontline decision-making?
- 4) How might the sector overcome barriers in order to see change, innovation, and positive ethical cultures in LTC?
- 5) How would addressing possible barriers improve ethical cultures, and thus ethical care, in LTC?

The research questions are addressed and discussed in the three papers of the dissertation as follows:

1. Ethical reasoning and moral distress in social care among long-term care staff.

- How does the ethical reasoning of LTC staff reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues?
- On which ethical frameworks do LTC staff draw in their ethical reasoning?

- How do provincial/organizational policies impact LTC ethical cultures and frontline decision-making?

2. Connecting findings to meaningful change: The benefits of using qualitative Delphi in empirical ethics and policy research in long-term care.

- How do provincial/organizational policies impact LTC ethical cultures and frontline decision-making?
- How does the sector overcome barriers in order to see change, innovation, and positive ethical cultures in LTC?
- How would addressing possible barriers improve ethical environments, and thus ethical care, in LTC?

3. Empirical ethics in long-term care: Using Delphi method as a form of consensus building.

- How do provincial/organizational policies impact LTC ethical cultures and frontline decision-making?
- How does the sector overcome barriers in order to see change, innovation, and positive ethical cultures in LTC?
- How would addressing possible barriers improve ethical environments, and thus ethical care, in LTC?

Background: How do LTC staff reason in social care?

A comprehensive literature review was conducted using the following online host databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), EBSCO, and Proquest. Within these host databases, relevant databases were selected,

including: Abstracts in Social Gerontology, Geriatric Nursing, SocINDEX, Sociological Abstracts, Social Work Abstracts, Social Services Abstracts, and Philosopher's Index. A number of Venn diagram literature searches were completed. Venn diagram literature searches are a visual display of partially overlapping circles, where each circle represents a main search topic. Each pair of figures overlap, with one area where all the figures overlap- this overlap represents the search results, or "hits," where each of the concepts intersect (Cull, 2014; Schooley, 1995). In this literature search, each circle represented a relevant research concept. The following keywords were used to search the literature: ethic*, long term care, nursing home, residential facility, staff, wander, relationships, restraints, sexuality, everyday ethic*, and social care. "Nesting" was used to group alternate search words in brackets to ensure all keywords were included in the search results; truncation, "the process of abbreviating or shortening a keyword to its stem in order to retrieve all possible word variations," (Cull, 2014, p. 4) was used to ensure all search terms were retrieved (truncated words are identified with an asterisk). Conducting a literature search in this way allows for thorough and specific search results tailored to research aims and objectives.

Each article was subjected to the following inclusionary criteria: Peer-reviewed scholarly articles published in the English language within the past twenty-eight years (1990-2018), and articles specific to the *social* care of older adults (seniors) in LTC (nursing homes) settings and the ethical reasoning processes of staff. Articles were reviewed comprehensively and a number of literature themes, as well as areas for future research, were identified, and are explored below.

Ethics in LTC

The literature on ethics in LTC reveals a number of reported ethical challenges and dilemmas, which are often grouped into two categories (Bollig et al., 2015; Preshaw, Brazil, McLaughlin, & Frolic, 2016; Bollig, 2017). The first is described as the “big ethical issues,” often comprising of end of life care, decisions to continue or terminate life-sustaining treatment, palliative care, and courses of treatment (Bollig, 2010; Bollig 2017). The second category is “everyday ethical issues,” such as food, bathing, use of restraints, dignity, resident and family relationships, and coercion (Bollig, 2010; Bollig 2017). This study focuses specifically on the “everyday ethical issues” in LTC, what are also called social care ethics, and *how* staff make ethical decisions in these situations. Few studies focus specifically on the reasoning processes of staff in social care, which is the focus of this review and research. Interestingly, there seemed to be a surge of research in/on LTC, including ethics, approximately ten years ago. This is likely due to a number of prominent global studies conducted that highlighted population aging, emerging challenges, and increased need for quality LTC (for example, United Nations, 2007; National Institute on Aging, 2007). Increased awareness also shifted the discourse, or social discussion, regarding the importance of preparing for population aging, which also encouraged increased exploration of LTC environments, care, and ethics. While there is still a need for research to better understand the complexities of LTC as a whole, and ethics specifically, in light of population aging, the research in this area appears to have slowed since approximately 2010. As a result, much of the literature cited in terms of this review on the *ethical reasoning processes* of staff regarding *social care issues* are dated prior to 2010. The findings, of course, are still relevant, but what this does suggest is that

this research is timely and more current research is needed in these areas.

Macro Influences of Social Care Ethics in LTC

Frequently in LTC, ethical decision-making processes and actions are learned through facility policies, as well as workplace socialization; ethical cultures are reproduced as staff stop asking questions and simply begin to model what others do (Jakobsen & Sørli, 2010). A number of studies highlight the influence organizational culture and climate have on ethical issues, reasoning, and actions (Jansson & Norberg, 1992; Powers, 2000; Slettebø & Bunch, 2004b; Dierckx de Casterlé, Izumi, Godfrey & Denhaerynck, 2008; Dunworth & Kirwan, 2009; Jakobsen & Sørli, 2010; van der Dam, Abma, Kardol, & Widdershoven, 2011).

As outlined above, an ethical *climate* is a descriptive construct, where individuals within the organization are broadly aware of ethics, though frontline carers typically have a narrow understanding of responsibilities, and ethics training is limited to what regulations require (Messikomer & Cirka, 2008). Conversely, a positive ethical *culture* is established when leaders within the organization recognize ethics as an integral component to the organization's culture, and "identify, order, and communicate values so that in situations where they conflict, employees can more easily identify and weigh courses of action" (Messikomer & Cirka, 2008, p. 89). When organizational leaders understand the circumstances that could lead to potential ethical issues, it allows them to manage these issues more effectively by encouraging creative alternative courses of action, which the literature proposes can be effectively accomplished through fostering a safe environment for moral reflection and deliberation (Messikomer & Cirka, 2008; Solum, Slettebø & Hauge, 2008; Abma, Molewijk & Widdershoven, 2009;

Widdershoven, Abma & Molewijk, 2009; van der Dam, Abma, Molewijk, Kardol, Schols & Widdershoven, 2011; Edwards, McClement & Read, 2013). It is important to note that in the context of this research, I draw on the work of Messikomer and Cirka (2008) who make a particular distinction between positive ethical cultures and ethical climates. However, other authors do not see such a negative binary between ethical cultures and climates (see, for example, Mayer, 2014).

Moral Deliberation

Moral deliberation can be defined as constructive dialogue among staff who systematically discuss and reflect on past, or present, moral issues and questions (Abma et al., 2009; van der Dam et al., 2011). Studies highlight the importance of dialogue and deliberation when determining ethical courses of action in LTC (Bolmsjö, et al., 2006a; Solum et al., 2008; Abma et al., 2009; Dunworth & Kirwan, 2009; Widdershoven et al., 2009a Edwards et al., 2013) and demonstrate that ethical environments with a tradition of reflection and deliberation result in higher moral skills among staff, and improved ethical cultures in LTC facilities (Bolmsjö et al., 2006a; Abma et al., 2009; Jakobsen & Sørlie, 2010; McDaniel et al., 2011; van der Dam et al., 2011b). Collective moral deliberation is particularly beneficial in the interdisciplinary setting of LTC, as it encourages a “fusion of horizons” (van der Dam et al., 2011b, p. 328) through a social learning process (Abma et al., 2009; van der Dam et al., 2011b), where staff develop a more nuanced understanding of their practice through the richness of a wide range of ethical perspectives (van der Dam et al., 2011b). Despite the reported benefits, moral deliberation is not often used in LTC, perhaps because moral deliberation can be a time consuming activity (Bolmsjö et al., 2006a). Despite being time-consuming, moral

deliberation has been proposed as a strategy to help reduce experiences of moral distress among staff (Schaefer & Vieira 2015).

Moral Distress

Moral distress is defined as being aware of the ethical action but feeling powerless to act accordingly as a result of either real or perceived institutional constraints, and thus engaging in ethical wrongdoing (Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2005). A number of studies have been conducted, particularly in acute care nursing contexts, to explore and better understand the contributing factors of moral distress, the impact it has on staff and the workplace, and to propose possible interventions (Oh & Gastmans, 2015; Zuzelo, 2014; Repenshek, 2009; Epstein & Delgado, 2010; Gallagher, 2011; Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2005; Beumer, 2008; Corley, 2002). Studies have found hospital nurses experience moral distress more intensely when they perceive a negative ethical environment, when there is a shortage of staff, when they feel pressure to act in ways they perceive are not in the best interest of the patient (Oh & Gastmans, 2015), when there are structural/policy obstacles to care, hierarchies of workplace power (Epstein & Hamric, 2009), when there is a fear of liability (Epstein & Hamric, 2009), and when they are working with unprepared/inadequate colleagues (Pijl-Zieber et al. 2016). The effects of moral distress negatively impact work life (Zieber et al. 2016), patient care (Todd & Watts, 2005), and staff well-being resulting in reports of guilt, frustration, helplessness, anxiousness, and in some cases physical manifestations such as headaches and stomach upset (Zieber et al. 2016). Experiences of moral distress also lead to increased incidences of staff burnout, increased use of sick days, and ultimately result in frequent staff turnover (Cummings, 2009). Frequently, however, staff

continue to work despite experiences of moral distress, which results in staff dissatisfaction and disconnection (Cummings, 2009; Zieber et al. 2016). Given the negative effects of moral distress, researchers have also sought to propose possible interventions. Gallagher (2008) and Murray (2010), for example, propose ‘moral courage’ as a strategy for overcoming moral distress and suggest possible ways organizations can foster courage amongst staff.

Less is known about the experiences of staff in LTC settings and moral distress (Zieber et al. 2016). More recently, however, some researchers (Zieber et al. 2016; Spenceley et al. 2017) have explored experiences of moral distress of LTC staff caring for individuals with dementia. These studies have found there are unique challenges and complexities in LTC contributing to experiences of moral distress, such as prolonged care, congregate living, and allocation of staff roles and responsibilities (Zieber et al. 2016; Spenceley et al. 2017). Considering the implications moral distress has on staff, residents, and workplace culture it is important for more research to be conducted regarding moral distress in the context of LTC, as well as to explore possible strategies to help mitigate staff experiences of moral distress (Zieber et al. 2016). Understanding the micro influences of social care ethics and the impact they have on staff can provides us with a clearer picture of the contributing factors of staff moral distress in LTC.

Micro Influences of Social Care Ethics in LTC: Everyday Ethics

Safety and Risk-Management versus Autonomy

In recent years, many LTC facilities have adopted “resident-centred” or “person-centred” mission statements and values, which emphasize the importance of residents’ autonomy and self-determination. While the notions of independence and freedom are

theoretically appealing, staff find themselves balancing between residents' rights and autonomy, perceptions of staff responsibility to ensure safety, and concerns of liability (Bollig, 2017; Bollig et al., 2016; Collopy et al., 1991; Hill & Schirm, 1996; Powers, 2000; Bollig, Rosland, Gjengedal, Schmidt, May, & Heller, 2017).

The idea of autonomy as of 'utmost importance' is challenged in LTC as many residents have diminished competency, which creates uncertainty about residents' self-directing abilities versus vulnerabilities (Powers, 2000; Powers, 2005). Residents with capacity issues have limited autonomy, which results in the preferences of others taking precedence; in this way, a covert form of paternalism is evident (Elander, Drechsler & Persson, 1993; Carter, 2002; Dunworth & Kirwan, 2009). Beauchamp (1982) defines paternalism as "the limitation of a person's liberty of action or liberty of information justified by reasons referring exclusively to the welfare, needs, or values of the person whose liberty is limited" (p. 65). In fact, often in LTC, even when residents are considered competent, they report lack of autonomy and involvement in decisions regarding their life and care (Bollig et al., 2016; Bollig, 2017). Residents' autonomy is overridden and rationalized as being in their "best interest" or to minimize risk of injury (Collopy et al., 1991; Elander et al., 1993; Schirm, Gray & Peoples, 1993; Slettebø & Bunch, 2001; Carter, 2002; Dunworth & Kirwan, 2009).

Within the "risk management" environments of LTC, research demonstrates that reducing potential harm or injury often takes precedence over other considerations, including autonomy (Mattiasson & Andersson, 1995; Hill & Schirm, 1996; Dunworth & Kirwan, 2009). While safety is one value among many, staff place overriding concern on preventing physical injury, despite recognizing potential adverse psychological

consequences of limiting resident autonomy (Mattiasson & Andersson, 1995; Hill & Schirm, 1996; Dunworth & Kirwan, 2009). Safeguarding from physical injury is good, yet rigid notions of safety resulting from institutional fear of litigation, can lead to overly invasive interventions (Collopy et al., 1991) and harmful restraint-use (chemical and physical).

Use of Restraints

Hughes (2010) provides an overview, drawn from international health and social care and academia, of the complex challenges of restraint-use, the impact restraint-use has on the health and well-being of older adults, and practical ways to minimize their use, thus increasing resident dignity and overall well-being. Hughes' (2010) experiential review and practical alternatives for carers contributes a critical review and perspective to the literature, which often finds high rates of restraint-use, despite staff, residents, and family expressing a desire for alternatives. Research suggests staff are more likely to use restraints (physical and chemical) in situations where there is heightened fear of liability and concern about injury; concern about increased falls and staff harm directly influence decisions to use physical restraints (Schirm et al., 1993; Hill & Schirm, 1996; Hasselkus, 1997; Heeren, Van, De, Boonen, Vleugels, & Milisen, 2014). The literature also reveals that licensed, versus unlicensed staff, have significantly different views of restraint-use (Schirm et al., 1993; Hill & Schirm, 1996). Unlicensed nurse assistants, who in recent years are being delegated increased nursing tasks and responsibilities (Collopy et al., 1991; Stone & Yamada, 1998) tend to be more hesitant about the reduction of restraints (Schirm et al., 1993; Hill & Schirm, 1996). I would suggest the delegation of nurse responsibilities to nursing assistants, who often have minimal training, is an ethical

concern in itself, as staff competency, job responsibilities and accountability are blurred.

Despite discrepancies in restraint-use perceptions between licensed and unlicensed staff, both share similar opinions regarding liability, and agree that in order to reduce the use of restraints alternatives are required (Schirm et al., 1993; Hill & Schirm, 1996). However, research results have not yet provided staff with sufficient and practical alternatives. Hasselkus (1997) proposed, “an appropriate guideline (for restraint-use) is to use the least restrictive alternative” (p. 647), which in theory is ideal. However, if less restrictive alternatives are not available, this guideline is futile. Staff identified realistic alternatives such as increased staffing for supervision and activities, as useful options in lieu of restraints (Schirm et al., 1993; Hill & Schirm, 1996). With respect to increased staffing, Heeren et al. (2014) found that patient characteristics such as restlessness, agitation, and risk for falls have greater influence on the use of restraints than staffing levels. They propose improved knowledge and skills regarding these characteristics for nursing home staff would decrease the use of restraints (Heeren et al., 2014). If activities are introduced in an effort to reduce restraint use, it is important to consider that such activities and programs must be desired and utilized by residents in order to be considered effective alternatives (Powers, 2000). Limited alternatives to restraint-use can be better understood as a lack of resources, such as minimal financial and personnel supports. Lack of resources is often reported by staff as an ethical dilemma and challenge in LTC (Olson, Chichin, Libow, & Martico-Greenfield, 1993; Bollig, Schmidt, Rosland, & Heller, 2015; Bollig, Gjengedal, & Rosland, 2016; Bollig et al., 2017). As a consequence of the lack of resources, staff often have difficulty managing competing needs.

Staff Management of Competing Needs

Rees et al. (2009) found that staff reported the lack of resources as a source of ethical issues, and that inadequate funding and staffing levels were perceived as causing unethical practices such as coercion and restraints (Dunworth & Kirwan, 2009; Bollig et al., 2017). Tension and conflict develop as staff believe residents' needs cannot be properly met, and the gap between needs and resources expands to the point where staff definitions of "good" and "ethical" care cannot be realized as a result of institutional policies and financial cutbacks (Collopy et al., 1991; Stone & Yamada, 1997; Slettebø & Bunch, 2004; Häggström & Kihlgren, 2007; Dunworth & Kirwan, 2009; Bollig et al., 2015). Staff often find themselves in difficult situations as a result of contextual limits, scarcity of resources, and limited autonomy (van der Dam et al., 2011a). Frontline care staff typically have great responsibility with minimal authority, creating an ethical issue as staff have limited autonomy to act outside of institutional guidelines (Elander et al., 1993; Stone & Yamada, 1998; Häggström & Kihlgren, 2007). Currently, minimal institutional support is available for, or to, staff to help them maintain the delicate balance between respecting the individual wishes of each resident, and serving the common good of a vulnerable population (Collopy et al., 1991). This creates tension as staff try to balance individual residents' wishes versus other residents'.

Sharing limited resources between a large group of residents is a source of ethical issues for LTC staff (Bolmsjö Sandman & Andersson, 2006; van der Dam et al., 2011a). Staff want to provide for individual resident needs, though feel conflicted if they cannot provide equally for all residents (Hasselkus, 1997; Bolmsjö et al., 2006a). Staff have to manage the care dependency needs of a number of residents while also balancing

individual resident wishes with those of other residents within a communal setting (Bolmsjö et al., 2006b; van der Dam et al., 2011a). This delicate balance results in staff being at risk of making decisions that are not in the best interest of the individual resident, as they have to weigh this choice with the best interests of others in their care (Bolmsjö et al., 2006b). Additionally, an ethical issue arises as staff interests are inevitably part of the equation and decision-making process, which generates the question of “whose best interests are actually being considered?” (Elander et al., 1993). Frontline staff are pulled in a number of directions as they respond to demands of their employer as well as residents, and frequently staff must also respond to residents’ families (Stone & Yamada, 1998).

Despite consistent research highlighting the importance of staff-family partnerships in LTC, and the positive effects this has on the delivery of care to residents (Puurveen, Baumbusch, & Gandhi, 2018; Pillemer, Hegeman, Albright & Henderson, 1998; Norris, 2000; Kemp, Ball, Perkins, Hollingsworth & Lepore, 2009), studies reveal, at times, this involvement is contested (Puurveen et al., 2018; Baumusch & Phinney, 2014) and staff sometimes have a difficult time developing relationships with residents’ family (McGilton, Guruge, Librado, Bloch & Boscart, 2008; Kemp et al., 2009; Utley-Smith, Colón-Emeric, Lekan-Rutledge, Ammarell, Bailey, Corazzini, Piven & Anderson, 2009). Staff have a particularly difficult time establishing positive relationships with family members when they have unrealistic expectations of care, do not consider the competing needs of other residents, and exhibit limited awareness of staff workloads (McGilton, Guruge, Librado, Bloch & Boscart, 2008; Kemp et al., 2009; Utley-Smith, Colón-Emeric, Lekan-Rutledge, Ammarell, Bailey, Corazzini, Piven & Anderson, 2009).

Whether it is *true* or not that families act in these ways is hard to measure, though what is noteworthy is that when staff *perceive* family as behaving in these ways it impacts the development of a positive relationship. For families, a number of factors influence their ability to engage with staff, particularly as they occupy rather ambiguous positions within the dynamics of LTC (Puurveen et al., 2018). In a synthesis of the literature on family involvement in nursing homes (encompassing LTC), Puurveen et al. (2018) found family members adopt a variety of roles and responsibilities, all of which were influenced by family dynamics, staff-family relationships, and structural factors. The structural challenges present in LTC (e.g. staffing levels, time constraints, limited recreational care, etc.) often prompt family involvement to fill the gaps in care delivery and to ensure their family member was receiving quality care (Puurveen et al., 2018). These factors, which are out of the control of both, staff and family, inevitably impact family members' perceptions of the care and affects their relationships with staff (Puurveen et al., 2018). A number of other factors influence staff-family relationships, including facility patterns of communication, policies dictating how staff should interact with families (professional versus personal), staff's personal interaction style (inviting versus non-inviting), family's affirmation and positive feedback to staff, and time-constraints (Pillemer et al., 1998; McGilton et al., 2008; Kemp et al., 2009; Utley-Smith et al., 2009).

Utley-Smith et al. (2009) found that staff identified interaction with family as the "most difficult part of the job," (p. 171) and described staff-family relationships as "difficult, problematic, and time-consuming" (p. 168). Conflict most frequently arises between families and staff when there is a lack of communication and ambiguity of roles within the relationship (Pillemer et al., 1998; McGilton et al., 2008; Utley-Smith et al.,

2009). Studies reveal conflicting findings with respect to family's expectations of their role in the care of residents; Utley-Smith et al. (2009) found that families expected continued involvement in care, while Norris's (2000) findings revealed that families expected staff to take responsibility for both, instrumental care (daily technical tasks), as well as preservative care (emotional well-being). Norris (2009) emphasized the importance of educating families upon admission that "family care does not end simply because home care does" (p. 22), and Utley-Smith et al. (2009) propose providing families with extra attention "soon after admission could alleviate many of their concerns" (p. 172).

Despite differences in findings, both studies propose improved interaction and communication between staff and family is required to improve relationships and decrease conflict (Norris, 2000; McGilton et al., 2008; Utley-Smith et al., 2009; Gjerberg, Førde, & Bjørndal, 2011). The literature revealed three different programs that could be used to improve staff-family relationships: Resident Enrichment and Activity Program (REAP), which focuses on establishing family-led activities in the facility (Norris, 2000); Family Involvement in Care Program, where family and staff work collaboratively to design a specific care plan in which family members can be appropriately involved in care (Norris, 2000) and; Partners in Caregiving, which utilizes parallel workshops to educate staff and family on respecting each other, resulting in decreased hostility and improved communication (Norris, 2000; Pillemer et al., 1998). Other than REAP, the other two programs might be limited in their application as they are time-consuming and difficult to maintain over time. Improving communication between family and staff is only one step, however, in addressing the complexities of relationship building between

family and staff. There are, as mentioned above, a number of structural factors impacting family care and family-staff relationships that are largely outside the control both groups (Puurveen et al., 2018). Addressing the structural challenges such as staffing levels and resulting time constraints, staff education and training, practical and applicable policy development, and increased recreational/social care, which impact quality of care would go a long way toward facilitating positive family-staff relationships (Puurveen et al., 2018; Baumbusch J., Phinney, 2014).

Disagreements Regarding Care and Balancing Opposing Opinions

Elander et al. (1993) discuss that within LTC there are a number of “actors,” individuals potentially involved in the development of conflicts, and this multi-faceted involvement of actors can result in disagreements regarding what is considered to be the “best interest” for the resident. Determining whose perspectives should be honoured and prioritized becomes an ethical issue (Collopy et al., 1991). Staff experience conflict when their personal perspectives of “best” care is incongruent with resident/family wishes, or institutional values (van der Dam et al., 2012; Bollig et al., 2015; Bollig et al., 2017). For example, Powers (2011) found that staff may not always agree with restraint-free policies, which generates ethical conflict. Ethical issues become increasingly complex when staff disagree among themselves (van der Dam et al., 2012), which generates concerns of how to professionally resolve the differences, while ensuring the delivery of quality care. There are three tensions the research identifies between family and staff.

First, van der Dam et al. (2012) reported in their study that one quarter of ethical issues are a result of diverging resident-family-staff perspectives of care. While family members can provide substantial insight into the care of the resident (Collopy et al.,

1991; Utley-Smith et al., 2009), their involvement is also seen as a complicating factor in care (Collopy et al., 1991). Second, ethical issues arise when the family disagrees amongst themselves, with the resident, with staff, and/or with institutional policies concerning care. For example, staff might feel the resident should be allowed to walk freely, despite risk, while the family is fearful and disagrees (Powers, 2001; Rees et al., 2009). Finally, Elander et al. (1993) found that staff sometimes pay too much attention to the wishes of the family rather than those of the residents, which can result in compromised quality of care for the resident and transgressions against their autonomy. As such, Elander et al. (1993) maintain that family wishes should only be considered once the needs of the resident have been met. This situation is further complicated when residents have cognitive impairment and are deemed incapable of making care decisions for themselves (Norris, 2000). Staff might feel conflicted if they do not perceive the family's decision as being in the "best interest" of the resident (Rees et al., 2009). If the resident is considered competent, staff are often caught between resident-family (or family-family) disagreements, attempting to satisfy diverging demands (Elander et al., 1993; Rees et al., 2009; van der Dam et al., 2011).

Staff encounter a number of everyday ethical issues impacting the provision of care, including: presence of ethical climate versus culture; opportunities for moral deliberation; ageism; safety and risk-management versus autonomy; restraint-use; management of competing needs; family-staff relationships, and; balancing opposing opinions. Given the complexities of the everyday ethical environment, it is important to understand what frameworks and values staff use to resolve these nuanced ethical issues, and the ethical reasoning process(es) employed in doing so.

Philosophical Normative Ethics not Sufficient for LTC

Ethical frameworks and values available to LTC staff are often borrowed from the acute care settings in which they evolved (Collopy et al., 1991; Waymack, 1998; Kuczewski, 1999; Carter, 2002). There is a risk of viewing LTC as an extension of acute care, as LTC poses a very different moral ecology than that of acute care (Pijl-Zieber, Awosoga, Spenceley, Hagen, Hall, & Lapins, 2016; Collopy et al., 1991; Waymack, 1998). The foundation of ethical frameworks in acute care is the competent adult, grounded in the context of temporary treatment (Collopy et al., 1991; Kuczewski, 1999; Powers, 2000; van der Dam et al., 2012), and while LTC and acute care share some ethical similarities, such as end of life care, there is a unique culture distinct to LTC that impacts ethical decision-making, such as ongoing treatment, diminished competency, limited resources, and congregate living (Collopy et al., 1991; Waymack, 1998; Powers, 2000; van der Dam et al., 2012). Despite these differences, insufficient ethical frameworks continue to be applied to LTC.

Arguably the most commonly applied ethical framework is principlism, developed by Beauchamp and Childress (1989), evolved within the acute care setting (Waymack, 1998). The question, however, is, “are the principles adequate beyond the acute care setting in which they evolved?” (Kuczewski, 1999, p. 16). I would agree with Clouser and Gert (1994) who argue that principlism oversimplifies moral reasoning, and while the theory may provide a rubric for ethical decision-making (Carter, 2002), the principles need to be supplemented or re-understood within the LTC setting in order to be useful in ethical decision-making (Collopy et al., 1991; Kuczewski, 1999). For example, the principlist understanding of autonomy, which focuses on independent individuals guiding

their life through free choice, is not congruent with LTC, as many individuals have physical and cognitive limitations, resulting in dependence and limited freedom (Collopy et al., 1991; van Thiel & Delden, 2001). Staff agree with the theoretical ideas of the four principles, however, in practice they are difficult to actualize (Hasselkus, 1997; van Thiel & Delden, 2001). The vague and diverging definitions of the four principles (Clouser & Gert, 1994; Hasselkus, 1997; van Thiel & Delden, 2001), and the failure to provide guidelines for action when equally compelling, yet discordant, principles conflict, limit their applicability in practice (Collopy et al., 1991; Clouser & Gert, 1994; Carter, 2002; Slettebø & Bunch, 2004b; Bolmsjö et al., 2006b).

Dominant frameworks such as principlism have permeated both the codes of ethics and policies, guiding ethical practice in LTC. These normative frameworks originate from philosophical normative ethics, derived from distant, context-independent, theoretical abstractions, resulting in ethical frameworks and values that are often too ambiguous to be applicable in the morally complex landscape of LTC practice (Jonsen, 1991; Kuczewski, 1999). A number of studies have demonstrated that LTC staff have very little knowledge of the codes supposedly guiding their practice, and report they had little impact on daily care (Stone & Yamada, 1998; Solum et al., 2008; Dunworth & Kirwan, 2009; Jonasson, Liss, Westerlind & Berterö, 2011). Jonasson et al. (2011) found that codes of ethics tend to act as an insurance policy, rather than guiding principles for ethical practice, and that staff tend to rely more on intuition and situated/professional knowledge than codes and policies (Hasselkus, 1997; Stone & Yamada, 1998; Solum et al., 2008; Dunworth & Kirwan, 2009).

Empirical Ethics Required

“There is incongruence between principle norms of providing good care and the reality of how ethics is incorporated into daily care” (Solum et al., 2008, p. 537) and using empirical ethics can clarify what normative views carers *actually* endorse and thus provide a better starting point for exploring practical ways to reason and act ethically in LTC settings (Widdershoven, Molewijk, & Abma, 2009). From this perspective, staff are understood as moral agents, and ethical frameworks emerge from the contextually specific ethical experience and knowledge of LTC staff (Stone & Yamada, 1998; Abma et al., 2009; van der Dam et al., 2012), which is essential, given the reported subjective nature of ethics in LTC (Hasselkus, 1997; Powers, 2000; Bolmsjö et al., 2006b).

Situational and Subjective Nature of LTC Ethics

Research demonstrates that broad general approaches to dealing with ethical issues do not suffice in LTC, as ethical issues are often nuanced and contextually dependent (Hasselkus, 1997; Powers, 2000; Bolmsjö et al., 2006a). For example, van Thiel and Delden (2001) found that staff valued different concepts of autonomy under different circumstances (e.g. competent versus incompetent individual) and that the diverse personal ethical values of staff influence decision-making (Powers, 2000; Jonasson et al., 2011). Similarly, Jansson and Norbert (1992), found in interviewing staff that their initial ethical decision would change if contextual details changed. Understanding how staff’s personal ethical values, and context, impact decision-making is essential, as research has shown staff rely on previous experiences to solve current ethical situations (Jansson & Norberg, 1992; Slettebø & Bunch, 2004a; Slettebø & Bunch, 2004b Solum et al., 2008). This has been linked to a casuistry approach to ethics (Kuczewski, 1999; Slettebø &

Bunch, 2004b).

Frameworks used by Staff to Solve Ethical Issues

Casuietry in LTC Ethics

Casuietry, “a systematic way of using paradigmatic examples and analogies to solve ethically difficult situations” (Slettebø & Bunch, 2004b, p. 164), was found to be the primary strategy used by LTC staff in resolving ethical issues in Slettebø & Bunch’s (2004a/b) study. Staff emphasized the value of experience and were found to go through three casuietry subprocesses in their decision-making process: 1) referring to earlier experiences with the same resident, 2) referring to a different situation that appeared transferable, and 3) referring to a negative reference, where they learned not to repeat the intervention (Slettebø & Bunch, 2004b). A criticism of casuietry is that it might lead to a “low standard of care” (Slettebø & Bunch, 2004b, p. 163) if actions are based on inappropriate or bad experiences from the past; staff may think their past actions were ethical, when in fact they were not. Furthermore, if staff experience is limited, they will have little to draw on in making decisions.

Slettebø & Bunch’s (2004a/b) studies were designed to explore staff reasoning in ethical decision-making, and proposed decisions were not guided by principles, but rather by experience. They identified the following strategies used by staff in solving ethical issues; 1) increasing awareness (about ways to ethically solve difficult care situations), 2) negotiation, 3) explanation, 4) restraint (Slettebø & Bunch, 2004b, p. 159). Slettebø & Bunch’s (2004 a/b) articles were unclear in their research goals and there was confusion regarding if they sought to determine *reasoning* processes or *strategies to resolve* ethical issues. There is an important distinction to be made between how staff *reason* and make

ethical-decisions and the strategies they employ to *resolve* ethical issues. For example, staff might reason in one way to determine what the ethical decision is, and yet draw on various strategies to essentially “make an ethical issue go away.” Drawing on ethical frameworks and ethical values results in ethical reasoning processes, while resolving ethical issues can actually be done without drawing on ethical frameworks. The former requires reflection and insight, while the later begins to blur towards the lines of conflict resolution. I would argue Slettebø & Bunch (2004a/b) identified resolution strategies used by staff, not reasoning processes, and would also propose that in using such strategies as restraint to “resolve” ethical issues, other ethical issues are created.

Deontology and Utilitarianism

Deontology is an ethical framework where decisions are made based on the concepts of duty and responsibility. Utilitarianism, on the other hand, is an ethical framework which places importance on the decision providing the greatest good for the greatest number. Using a structured questionnaire based on vignettes, designed to elicit deontological or utilitarian responses, Dunworth and Kirwan (2009) found LTC staff are deontologists in nature, though pragmatic and utilitarian in practice. Their findings suggest staff’s actions may embody an ethics of care approach, rather than a principles approach (Dunworth & Kirwan, 2009). Conversely, in researching staff’s understanding and preference of defining autonomy, van Thiel and Delden (2001) found that staff seldom chose an ethics of care approach to autonomy, suggesting an ethics of care approach does not appeal to staff. In specifically exploring what principles staff use to solve ethical issues, Jansson and Norberg (1992) found different results than Mattiasson and Andersson (1995). Through interviews, Jansson and Norberg (1992) found that staff

ranked autonomy as the most important principle, while Mattiasson and Andersson's (1995) study revealed beneficence as the primary principle, on their questionnaire.

The conflicting findings outlined in the above studies suggest staff do not reason in any one way. However, consistent in the literature is that staff tend to be somewhat conformist and conventional in their ethical decision-making processes (Mattiasson & Andersson, 1995; Dierckx de Casterlé et al., 2008). Staff appear to rely on rules and norms, trying to escape responsibility, rather reasoning in autonomous and postconventional ways, which reflect critical analysis skills and creative exploration to determine the best caring response (Mattiasson & Andersson, 1995; Dierckx de Casterlé et al., 2008). Reasoning in these ways can be problematic given the fast-paced environment, the nuanced nature of ethical decision-making, and the complexities of everyday ethics in LTC.

In addition to the above-studies, a number of researchers, drawing on theoretical research, propose how staff *should* reason, as opposed to understanding *how* they *actually* reason (Jansson & Norberg, 1992). A brief overview of these studies is provided below, though for complete details on the theoretical frameworks suggested by the authors references are provided. These studies propose ways staff should reason, and explore certain forms of decision-making, yet the studies were designed with the assumption that staff reason in a particular way, generating a subjective research bias rather than seeking to understand the ways in which staff *actually* reason. Bolmsjö, et al. (2006a/b) suggest staff require a structured model for ethical decision-making, and propose a utilitarian model grounded in dialogue and focused on resident outcomes, as the best approach. Fleming (2007) suggests an ethical decision-making framework, based on three rather

broad 'practical' ethical questions, followed by five pragmatic and sequential steps taken to reach an ethical conclusion (p. 252). Carter (2002) recommends staff should use an ethical framework based on Kant's ethical theory of respect for persons, which situates the resident as an end unto him/herself (p.67), while Kuczewski (1999) argues the concepts of candor (truthfulness) and 'responsibility for narrative integrity' are essential to an ethical reasoning framework. Conversely, Mysak (1997) proposed structured controversy as the ideal means of reaching ethical decisions.

Though, more recently, researchers such as Agich (2003) have challenged the applicability of normative ethics approaches in LTC and have sought to understand the ethical challenges faced by LTC staff (Bollig et al., 2015) normative frameworks grounded in theoretical knowledge rather than empirical research, continue to be largely accepted, taught, and reproduced. There are other ways staff can reason ethically, and the literature revealed no studies, which explore staff's *actual* reasoning processes. Further, in the theoretical and research-based research on ethics in social care ethics, no studies sought to better understand the impact of organizational or public policy on the ethical decision-making of staff; a critical factor given the conformist nature of staff decision-making.

Filling the Research Gap

Throughout the literature, there is a call for more ethics education and training to increase staff's ethical reasoning competence, as studies revealed staff tend to reason in heteronomous, conformist, and conventional ways meaning staff rely on rules and norms, trying to escape responsibility, rather than reasoning in autonomous and postconventional ways, which reflect critical analysis skills and creative exploration to determine the best

caring response (Mattiasson & Andersson, 1995; Dierckx de Casterlé et al., 2008). The literature calls for education and ethical training in order to increase LTC staff's ethical reasoning and decision-making skills and consequently their ethical competence in practice (Bollig et al., 2017; Bollig et al., 2015; Gjerberg, Førde, Pedersen, & Bollig, 2010; Preshaw et al., 2016; Mattiasson & Andersson, 1995; Bolmsjö et al., 2006a/b; Dierckx de Casterlé et al., 2008; Rees et al., 2009).

Ethics discussions in nursing homes often focus on the “bigger” ethical issues concerning end of life care (Bollig et al., 2015). However, everyday ethical issues occur more frequently, yet are seldom discussed/explored, receiving less attention and thus are not properly addressed (Bollig et al., 2015). With increasing emphasis on social care and everyday ethics in LTC, it is imperative that we first understand the ways in which staff actually reason and make ethical decisions (Dunworth & Kirwan, 2009) in order to tailor/design appropriate and relevant educational tools for them. As such, this study first aims to fill the research gap by exploring how staff reason ethically within social care. Second, my goal is to explore how staff's reasoning reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues, and finally to better understand what impact organizational culture has on ethical decision-making. Addressing these aims expands the scope of understanding to include external influencing factors and possible areas for improvement/change in order to foster positive ethical cultures and ethical reasoning environments in LTC. This is important because without considering (and ideally addressing) the larger factors impacting staff's ethical decision-making environments we risk arming staff with futile ethics education

and training they are unable to utilize in practice. In addressing these gaps, this research contributes to the literature in three ways.

Contributions to the Literature

First, in its use of an empirical ethics approach to frontline LTC ethical-decision making in social care contexts. It minimizes normative assumptions, focuses on social care, and makes clear what normative views LTC staff actually endorse, rather than what ethicists theorize are normative guidelines (Widdershoven, Molewijk, & Abma, 2009). Second, the use of a qualitative Delphi method to explore ethics and policy in LTC. Delphi method is usually quantitative and not used empirically, and particularly not in the fields of ethics and LTC. Finally, the findings contribute to our understanding of ethics, policy, and ethical decision-making in LTC. Each of these research contributions will be evidenced throughout the dissertation.

When conducting research in areas that impact multiple disciplines and stakeholders, such as ethics and LTC, adopting an interdisciplinary approach provides the inherent benefit of drawing on methodologies and methods informed by various academic theories and approaches. Similarly, interdisciplinary research also results in knowledge production that is relevant to multiple academic disciplines and fields of practice. Here, the fields most directly impacted by the new insights and knowledge are:

1. Long-term care
2. Nursing and other frontline health professions (LPN and RA)
3. Gerontology
4. Ethics
5. Policy

The implications and recommendations drawn from the research will be discussed throughout the dissertation, with particular focus in Paper One and Interlude Three. Particular recommendations for education are explored below.

Recommendations for Education

The data also suggest a number of recommendations for continued education generally in LTC, ethics education specifically, and the ethical implications of on-going training and education.

People don't come out with a Bachelor of something, or in this case, a certificate or a college diploma, or whatever, and exist at the same level of education for their entire career. (DM 006)

To see on-going education, specifically in ethics, the findings suggest a positive ethical culture in LTC is required. The data suggest this involves workforce planning, strategic hiring, and sectorial collaboration (see Interlude Three for a more in-depth discussion of each). Second, the data calls for a mix-method approach to education in order to meet the diverse learning styles of LTC staff. As one stakeholder expressed, “because we have such a...variety of staff who need education...we have to be flexible to their needs and their abilities, and their strengths, and how they learn best.” Proposed methods include: 1) peer-learning, 2) collaborative learning, 3) online learning and apps, 4) huddles with case-based learning and moral deliberation, 5) guest speakers, and 6) ‘lunch and learns.’

Because with a better informed staff then of course they're much more aware of the various ethical conflicts that come up. (DM 004)

Finally, the findings suggest on-going education in LTC is a shared responsibility involving government, LTC organizations, individual workers, and various academic disciplines' (e.g. RA, RN, LPN, NP).

But I think giving someone sub-standard care because the education's not there isn't really right either, because I think it's a responsibility of the home, and also the worker. (DM 007)

Stages of the Research

Stage One: Background

Considering the lack of studies exploring the *actual* ethical reasoning processes of LTC, the purpose of the first stage of the project was to better understand how staff reason ethically. In particular, I sought to explore the nature and extent of ethical issues in the provision of social care in LC facilities, and the ethical framework(s) deployed by LTC staff in making decisions as to the right thing to do in such situations. The first stage of the research addressed the following research questions:

- 1) How does the ethical reasoning of LTC staff reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues?
- 2) On which ethical frameworks do LTC staff draw in their ethical reasoning?
- 3) How do provincial/organizational policies impact LTC ethical cultures and frontline decision-making?

Stage One: Methodology and Methods

Critical Discourse Analysis. Critical discourse analysis was used as both the methodology of the research as well as a method of data analysis, to gain a deeper understanding of the contributing factors influencing the meanings and interpretations used in reaching a conclusion during the ethical reasoning and decision-making process of staff in LTC. Critical discourse analysis is “a form of analysis which exposes the multiplicity of possible meanings, contradictions and assumptions underlying our understandings and ways of knowing- to question, who benefits, and how, from the assumptions about our social world embedded in those systems of thought” (MacNaughton, 20005, p.78). My background is in social work and I believe that in order to see change in any capacity you must include, to the best of your ability, a multitude of voices who have a vested interest in, or will be impacted by, the research. I wanted my research to come from the “bottom up” rather than the “top down” in my effort to generate applicable and tangible findings and recommendations. I did not want to contribute to the silencing or oppression of an already marginalized group, and I wanted the voices of those most directly impacted by the issues to be included, rather than simply those with theorizing or assumptive voices. Adopting a CDA methodology allows a social analysis of the context of LTC to be conducted and encourages the illumination of power relationships, thus highlighting the origins and functions of particular discourses in LTC. In the context of this research, the purpose of using critical discourse analysis is to emphasize the importance of analyzing language to demonstrate how embedded power relations within dominant discourses, including dominant (normative) ethical frameworks, and texts serve dominant interests and ultimately impact LTC staff’s ethical

reasoning and decision-making processes.

What is a Dominant Discourse? While there are multiple discourses individuals can use to understand the world (O'Connor, 2003), these discourses often compete for the privileged position of “dominant discourse,” which then affords covert power to construct ‘valid’ knowledge, or ways of understanding the world, thus influencing language, thought, and behaviour (O'Connor, 2003; Phelan, 2011). Michel Foucault (1975, 1991, 2002) proposed a social constructionist approach to knowledge, suggesting that discourses are intersubjectively created and the product of a complex interplay of historical contexts, sociopolitical conditions, and the ability of certain groups to assert power and influence (Phelan, 2011; Cheek & Rudge, 1994). Foucault used two methodological tools to examine the social construction of knowledge, and thus power. The first, archaeology, permits a “history of the present” (Foucault, 1991, p. 31) by examining statements regarding certain constructions of social concepts (knowledge or discourse) through history, paying special attention to what is, and is not, said (Whitney & Smith, 2010; Phelan, 2011).

Archaeology asks *how*, and *why*, did this particular knowledge come into being, and who benefits from such a construction (O'Connor, 2003; Whitney & Smith, 2010; Phelan, 2011)? Genealogy, Foucault's second tool, shifts from a historical analysis of knowledge, to a ‘micro-physics of power’ (Foucault, 1975, p. 139 cited in Phelan, 2011, p. 895), which analyzes the connections between ideas and institutions, achieved through power relations of individuals (Phelan, 2011; Whitney & Smith, 2010). Genealogy questions the taken for grantedness of knowledge, thus allowing new ways of understanding discursive constructions (Phelan, 2011, p. 895).

Drawing on Foucault's theory of the social construction of knowledge, we begin to see that social systems, institutions, and ways of understanding our world are not neutral, but rather are rooted in sociopolitical and historical contexts, and represent particular interests (O'Connor, 2003; Phelan, 2011). Cheek and Rudge (1994) describe the discourse-power-knowledge relationship of social concepts as follows: "[T]here is a dynamic relationship between power and 'truth' where truth is a product of dominant discursive frameworks shaped and defined by power, whilst power is legitimated on the basis of expert ownership of such truth" (Cheek & Rudge, 1994, p.585). In other words, discourses become dominant when a certain group is able to exercise power through proclaimed expertise, widely circulate the discourse (through voice and language), and thus manufacture a particular knowledge as 'truth.' Proclamation and subsequent acceptance of a particular discourse as 'true knowledge' serves to reinforce the power of the group, and as such we see the cyclic and interrelated dynamic of discourse-power-knowledge.

In LTC, various discourses have gone through the cycle described above to gain the title of 'dominant discourses' [*for more on this, see Concluding Reflection*]. These dominant discourses then interact to legitimize *how* LTC is interpreted and offered (established through policy), which also establishes organizational cultures, in which staff are socialized and 'positioned.' Understanding subject positioning in terms of LTC is important to the exploration of ethical decision-making of staff, as it significantly influences how decisions can be made in the interdisciplinary setting.

Subject Positions and Binary Othering. 'Othering' is used to produce, and then legitimize, practices of oppression and marginalization of certain groups, while sustaining

and reinforcing the power of others (Fairclough, 1989 & 1992; van Dijk, 1993; MacNaughton, 2005). This is another way dominant discourses function to sustain superior positions of power within LTC. Organizational discourses, using binary opposites and the politic of ‘othering,’ do not only function to establish ‘regimes of truth’ regarding LTC, but also work to construct the identities of organizational members, and their corresponding position of power within the organization (Mumby & Stohl, 1991). Discursive practices grounded in organizational regimes of truths, construct and position the identities of organizational members within the ‘webs of meaning’ of the organization (Mumby & Stohl, 1991). Discursive frameworks within LTC persuasively represent a contrast of ‘us’ versus ‘them’ between groups (van Dijk, 1993), where the relationships between organizational members serve to sustain and reinforce the medical teams’ power and voice, while marginalizing the power of, and silencing, others. Often in LTC, the biomedical discourse positions resident attendants (RAs) as ‘other,’ situating these staff members within binary opposites such as educated/uneducated, medical/non, task-focused/person-focused, etc. [*see Paper One for evidence and discussion of this*].

Embedded in organizational discourse, imbalanced binaries create an illusionary “us” versus “them” between staff members. As staff engage in day-to-day relational exchanges, these binaries construct organizational members’ self-perceptions and identities, as well as their subject positions, thus situating them either in greater or lesser positions of power and autonomy (Fairclough, 1989; Mumby & Stohl, 1991; Crowe, 2004) [*see Paper One for evidence and discussion of this*]. Discoursal subject positions can be likened to a social script by which individuals learn to follow and act in accordance to different contexts. RAs, being constructed as the inferior and marginalized

‘other,’ are in a position of dependence and limited power. As organizational subjects, RAs often internalize these discourses, and learn to act in accordance to their marginalized position within the social hierarchy of the organization (Mumby & Stohl, 1991) [*see Paper One for evidence and discussion of this*]. By acting within their discursively prescribed role, RAs reiterate and reproduce their subordinate position of ‘other.’ Staff’s subject positions are further reproduced and maintained by other organizational members who neglect to challenge the statements and/or actions of positioned individuals, and thus through lack of action, and silence, contribute to further legitimizing the organizational discourse which positions the medical team as superior.

Through organizational discourses and dialectical exchanges, staff members in LTC are organized within fixed power relations of “autonomy and dependence” (Mumby & Stohl, 1991, p. 315), which consequently influences their decision-making (Sutcliffe & McNamara, 2001). Decision-making in organizations does not occur in a social vacuum, but rather is influenced by these social and power conditions, as well as the staff’s position within them (Sutcliffe & McNamara, 2001). Sutcliffe and McNamara (2001) propose that in order to better understand decision-making in organizational contexts, researchers must “pay more systematic attention to the social contextual forces at work within organizational systems” (p. 484), factoring in that decision-making is not simply a matter of individual choice, but is influenced by a “hierarchy of influences” (p.484).

Understanding how the biomedical discourse and unbalanced power binaries operate in LTC to position staff helps us better understand how, and why, ethical decisions are being made the way they are. RAs being positioned as subordinate and dependent within this dominant discourse results in an environment where rather than

acting autonomously, the expectation is RAs seek direction and guidance from superiorly positioned staff (e.g. LPNs or RNs) in order to minimize potentially unethical decisions and actions; further legitimizing and perpetuating the medical teams power and privileged discursive position within the organization [see Paper One for evidence and discussion of this]. The goal of using critical discourse analysis in the analysis of the first stage of the research was to deconstruct the dominant discourses and subject positions of LTC staff and the impact these have on the ethical decision-making process.

Importance of Deconstruction. Critical discourse analysis emphasizes the importance of language analysis to illuminate the subject positions of individuals within societal power relations, and to demonstrate how these unequal power relationships serve dominant interests (Simons, 2010). Through critical discourse analysis, texts, in this case the texts produced by the focus groups, were analyzed through deconstruction. The goal of deconstruction is not to understand what a text *says*, but rather what it *does* (Weinberg, 2004), and to expose the power relations operating through language, dominant discourse, and ideologies (McNaughton, 2005; Simons, 2010). During deconstruction, specifically when a Derridean deconstructive approach is used, there is a particular interest in, and emphasis on, binary pairs and ‘othering’ because of the normalized discursal values and assumptions they represent (MacNaughton, 2005; Simons, 2010). Binary analysis during deconstruction “ruptures logic to create alternative meanings” (MacNaughton, 2005, p. 92). Through deconstruction, social change is encouraged as discourse-laden language is highlighted, thus providing alternative ways of knowing and understanding the social world around us, and our position within it. By illuminating unequal power dynamics, there is the possibility of shifting power relations and thus

creating a transformative reconstruction of discourses (Fairclough, 1989). However, without the deconstruction of value-laden texts, power relations remain fixed and dominant discourses are conservatively reproduced as normative (Fairclough, 1989; Weinberg, 2004; MacNaughton, 2005).

In this analysis, the dominant discourse of LTC, and the dominant (normative) ethical frameworks therein, as well as staff's ethical reasoning and decision-making were "pulled apart" (MacNaughton, 2005) to reveal the inconsistencies within the discourses and how such inconsistencies connect to power and the production of inequality (Fairclough, 1989). During the deconstructive and analysis process, particular attention was given to staff language and styles of ethical understanding and reasoning, interpretive frameworks (e.g. principles, values, beliefs), and evidence of elements of different ethical frameworks. The deconstruction of the texts also included various other analytic strategies, as outlined by Barbara Czarniawska (2004): the examination of silences, asking what is not said and whose story is not heard; attending to contradictions and disruptions; interpreting metaphors as rich sources of multiple meanings; and analyzing double entendres (p. 92).

Using these methods, I sought to identify the participants' own meanings, concerns, and priorities in dealing with difficult situations, and their level of confidence in recognizing and dealing with ethical issues. I took special interest in issues of process regarding the identification of ethical issues, the processes and structures whereby these are resolved, and the ethical reasoning involved. I also used data from institutional documentation pertaining to the facilities' ethical policies, practices, and procedures to understand the context in which LTC staff operate.

Critical discourse analysis methodology and analysis allowed me to critically analyze the focus group discussions and ethical reasoning processes to factor in what impact dominant discourses, language, and subject positions had on the decision-making of staff in social care contexts. Evidence of this analysis can be found in the findings section of Paper One where excerpts are taken from the data to demonstrate evidence of the subject positions of staff, hierarchies of power, and language influenced by dominant discursal understandings of LTC (such as risk, liability, efficiency, and biomedicine). Critical discourse analysis resulted in the finding of moral distress and the subsequent strategies staff rely on to make ethical decisions and mitigate these experiences of moral distress [see *Paper One*]. Though critical discourse analysis informed the findings of stage one it is not the focus of the paper and there is the possibility to present the findings and research more specifically in the context of critical discourse analysis and the impact dominant discourses have on our conceptions of LTC, ethics, organizational culture, and policy. These possible avenues for future research are explored at length in the Concluding Reflections section.

Focus groups. Researching LTC communities that I did not belong to, nor had extensive previous experience with, could be problematic if I assumed a position of external authority and knowledge, rather than collaborating with those who have considerable experiential and practical knowledge of LTC (Lazar, 2007). Focus groups, defined as a group of people gathered together to engage in unstructured discussion guided by a moderator (Krueger, 1988; Peek & Fothergill, 2007; Acocella, 2011), allowed me as the researcher to collaborate with LTC staff and investigate a specific set of issues, and staff perspectives and experiences with those issues (Wodak & Krzyzanowski, 2008).

Focus group method has been criticized as a fashionable, ‘quick and easy’ qualitative method, adopted because it is cost effective and simple to organize (Peek & Fothergill, 2007; Acocella, 2011), regardless of whether it is the most suitable method for achieving the research goals (Acocella, 2011). However, the goal of focus groups is to provide increased understanding of a specific topic from the viewpoint of the research participants, and this research satisfies three of the four circumstances in which focus group method is said to be particularly valuable (Dilshad & Latif, 2013). Focus group is a beneficial research method when a) the researcher does not have substantial information about the participants or experience with the discussion topic(s), or the area is understudied, b) the research aims to gain an understanding of individuals’ understanding and experiences about the topic(s) and their pattern of thinking and reasoning, c) working with marginalized or oppressed groups, and d) researching sensitive issues (Peek & Fothergill, 2007; Dilshad & Latif, 2013).

Given the research goal of exploring how LTC staff reason through ethically difficult situations in social care, and the minimal empirical research on the ethical reasoning deployed by LTC staff, this research clearly meets the parameters of the first two circumstances conducive to focus group method. Further, LTC may not typically be considered a marginalized or oppressed group, yet when examined more closely, the population serving, and being served, in LTC is both significantly oppressed and marginalized. LTC staff, predominantly comprised of personal support workers, licensed practical nurses, registered nurses, and administrative staff, are all female-dominant professions, and despite advances, women continue to be a marginalized and oppressed population (Lazar, 2007). Additionally, the population served in LTC, primarily older

adults, though occasionally younger individuals with physical or mental disabilities, are also marginalized and oppressed populations in society, where the values and norms regarding aging and disability are predominantly negative (Collopy et al., 1991; Kane & Kane, 2005; Brooker, 2007; Rees, King & Schmitz, 2009; Morris & Morris, 2010). Thus, this research also meets the the third circumstance.

Focus groups, unlike other methods of collective inquiry, generate data explicitly through participant interaction, rather than solely interaction with the group moderator (Peek & Fothergill, 2007; Wodak & Krzyzanowski, 2008; Acocella, 2011; Dilshad & Latif, 2013). Focus groups are an effective method of inquiry when exploring collective experiences and perspectives, allowing further insight into the stability and strength of individual and collective opinions and perspectives (Wodak & Krzyzanowski, 2008). Focus group data allow for further understanding of the ethical awareness and reasoning of participants by helping to address the issue of theory-practice gap by giving direct access to the reasoning process of LTC staff that is inaccessible in other ways (e.g. observation) (Barter & Renold, 2000; Renold, 2002; Hughes & Huby, 2002).

When using focus group method, group organization and composition, as well as effective facilitation, are essential in order to obtain quality data. In comprising the groups, it was important to establish the delicate balance between heterogeneity and homogeneity of the groups (Morgan, 1997). In order to establish a safe environment in which participants feel comfortable to interact and discuss openly, it is advised that focus groups have a certain degree of homogeneity, meaning participants share similar cultural and educational levels, social status, and hierarchical positions (Krueger, 1988; Peek & Fothergill, 2007; Acocella, 2011; Dilshad & Latif, 2013). However, it is also important

that groups are not disproportionately homogenous, as this can result in skewed data and the collection of limited perspectives (Acocella, 2011). To assure a certain level of heterogeneity, and the collection of diverse perspectives, homogeneity should be achieved on the basis of background or personal characteristics, rather than on attitudes and opinions (Peek & Fothergill, 2007). In terms of this research, the focus groups had to have a certain level of heterogeneity relative to education and perceived social status, as ethical decisions are typically made in informal interdisciplinary teams ‘on the floor,’ which are comprised of staff from various professions, as well as education levels, and the research aimed to create an environment reflective of practice.

I used segmentation of participants in this research to eliminate rank and status differences among participants (Peek & Fothergill, 2007), and for this reason no staff were placed in a focus group with a supervisor and/or manager they directly report to in practice. An example would be placing a licensed practical nurse with the unit manager or care coordinator. Separating staff from managerial ‘superiors’ created a less hierarchical environment, encouraging staff to discuss more freely. However, it is important to note, “it is impossible to predict all the ways individual characteristics and social status may interact to influence group dynamics” (Peek & Fothergill, 2007, p. 15) and this must be taken into account during analysis.

During the first stage of the project I conducted seven interdisciplinary focus groups consisting of two-four participants [*see Appendix A for the focus group introduction script and possible questions used to promote discussion*]. The groups were interdisciplinary in that they were comprised of all frontline care providers, including RAs, LPNs, RNs, and NP. The focus groups averaged ninety minutes in length [*for more*

details on focus group composition and participant details see Paper One]. The focus groups were conducted over a span of six weeks, beginning late January 2015, and were completed early March 2015, and took place at various locations in the participating facilities.

Vignettes. During the focus groups, I presented staff with a vignette, which they read independently, and then discussed as a group. If time allowed a second vignette was explored. To design the vignettes, I drew on existing transcripts of qualitative interviews with LTC staff (conducted 2014 as part of the larger CIRN project). I wrote the vignettes to reflect situations that frontline staff describe as part of their daily activities in social care. These themes included: staff management of competing needs, limited resources (personnel and financial), sexuality, restraints, covert medication, safety and risk-management versus autonomy, and interaction with families [*Appendix B*]. The table below provides an overview of the vignettes, including the main themes, which focus group(s) they were used in, and their total use. Though five vignettes were created, time restraints only allowed for a maximum of two vignettes to be explored within the focus groups. Consequently, in an effort to ensure the themes could be appropriately explored within and across focus groups, I used three of the five vignettes.

Vignette	Main Themes	Use in Focus Group (1-7)	Total Use
Vignette 1: Jane Nguyen	<ul style="list-style-type: none"> • Interaction with families (POA, family visiting, disagreement regarding care). • Staff management of competing needs. • Limited resources. • Restraints. • Safety vs. quality of life. 	2, 5, 6	3

	<ul style="list-style-type: none"> • Risk-management and waivers. 		
Vignette 2: Louise Cormier	<ul style="list-style-type: none"> • Interaction with families (POA, family visiting, disagreement regarding care) • Limited resources. • Coercion. • Covert medication. 	1, 3, 4, 5, 7	5
Vignette 3: David Smith	<ul style="list-style-type: none"> • Interaction with families (POA, family visiting, disagreement regarding care). • Staff management of competing needs. • Task-focused environment. • Residents passive recipients of care. 	1, 2, 3, 4, 6	5
Vignette 4: Mr. Ingalls	<ul style="list-style-type: none"> • Limited resources. • Risk-management versus autonomy. • Coercion. • Residents passive recipients of care. 		0
Vignette 5: Burt MacDonald	<ul style="list-style-type: none"> • Interaction with families (disagreement regarding care). • Restraints. • Limited resources. • Staff management of competing needs. • Restraints. • Sexuality. 		0

Table 1: Overview of vignettes

I will note that in the qualitative interviews, staff often reported negative, or challenging, relationships with families as contributing to frontline ethical challenges. Consequently, the vignettes were written to reflect this finding from the data and thus

discussions surrounding family relationships and interaction from the focus group often present family as an obstacle. This finding is not a reflection of my personal perspectives or beliefs regarding staff-family relationships, nor a function of how the vignettes were written, but rather an outcome of the qualitative interviews with frontline LTC staff.

Vignettes are hypothetical short stories comprised of stimuli designed to reflect particular elements of reality and society, to which participants are invited to explore and respond (Finch, 1987; Barter & Renold, 2000; Hughes and Huby, 2004; Given, 2008). A strength of using vignettes is that beliefs and norms can be discussed in situated contexts, concerning hypothetical third party characters, thus distancing the participant from the issues and minimizing personal threat (Finch, 1987). The purpose of the vignettes is to provide participants realistic case scenarios, drawn from their experiences in LTC, providing access to how staff think and reason through these cases. This information is inaccessible in other ways (e.g. observation). The vignettes were not reports of any individual's situation but devised so as to raise ethical issues. As a result, they are composite cases, written (in form and content) to generate ethical debate.

Chambers (1999) is somewhat critical of the use of vignettes, noting that they can be written to guide the reader toward a desired outcome. Being cognizant of this, I wrote the vignettes to incorporate multiple levels of ethical issues, as identified by frontline staff, and there was narrative space within the focus groups for participants to identify, or not, ethical issues. Within the focus groups, I engaged in the discussion as minimally as possible in an effort to reduce guiding the discussion or analysis. For example, narrative space was provided by asking participants to discuss the ethical issues they identified and what they would do in these situations, rather than suggestively asking, "what about the

issue of X.” The space and freedom for participants to explore and analyze based on their views and decision-making, rather than based on vignettes written to generate desired responses, was validated as participants did not identify all of the ethical issues I anticipated they would. Similarly, there are no ethical framework(s) inherent within the vignettes, which allowed participants the freedom to analyze the cases in a number of ways by drawing on concepts from a variety of ethical frameworks (evidence of this can be found in the findings section of Paper One, as staff adopted an eclectic approach to decision-making).

Stage One: Findings

Data from the first stage of the project revealed there is a misalignment between the organizational philosophies of care and staff perceptions of the environment. As a result, staff perceive, and therefore make ethical decisions and take action, within a very different organizational culture and environment. Despite this misalignment, the data demonstrated that staff typically do not have difficulty in determining the ethical thing to do, though at times disagreeing with one another on the right course of action. In fact, there is evidence throughout of staff drawing on a number of ethical frameworks and norms during the ethical reasoning and decision-making process. Though staff drew on a number of ethical frameworks and societal norms in the ethical reasoning processes, the data revealed they often feel restricted to act in the ways they believe to be right and ethical and consequently experience moral distress.

Participants described a number of institutional constraints that impacted their ability to act in the ways they believed to be right and ethical. The dominant constraints included: a hierarchy of power and lack of autonomy, staffing restrictions and task-

oriented environment, concern about liability, family power, and financial inequality. The majority of the reported constraints resulting in staff experiences of moral distress are structural. This means they could be solved, or at least reduced, by examining and addressing the larger sociopolitical factors influencing LTC organizational policies and procedures, and thus the ethical decision-making environment of staff [*see Paper One for a comprehensive presentation of findings and discussion from stage one of the research*]. To better understand these potential organizational constraints, I created a second stage to the research, expanding the inquiry to explore the interaction between public policy, LTC organizational policies and procedures, and how these interactions impact frontline LTC staff's ethical decisions and actions.

Stage Two: Background

In the second stage of the project, I built upon the findings from the focus group data, using Delphi method (Linstone & Turoff, 1975; Dalkey, 1969). Paper Two provides a comprehensive theoretical justification of the methodologies used in the second stage of the research; to reduce repetition, in the following section I will provide a brief overview of the methods used in stage two [*and direct the reader to Paper Two for specifics on the methodology of stage two*]. Similarly, Paper Three explores, in-depth, the specific processes of the qualitative Delphi method used in the second stage of the research [*for more details see Paper Three*]. The second stage of the research addressed the following research questions:

- 1) How do provincial/organizational policies impact LTC ethical cultures and frontline decision-making?
- 2) How might the sector overcome barriers in order to see change, innovation,

and positive ethical cultures in LTC?

- 3) How would addressing possible barriers improve ethical environments, and thus ethical care, in LTC?

Stage Two: Methods

Delphi method. I had a number of reasons for choosing a qualitative Delphi method in the second stage of the project. First, I wanted to generate an understanding of how public policy promotes and/or hinders the development of an ethical culture (vs. an ethical climate). Second, my goal in using Delphi method is that the research process and findings would inform decision-making, both organizationally and publicly, in a number of ways, while also including the voices of the marginalized ‘other’ group(s), who are frequently excluded from discussions of LTC, practices and policy development (both public and organizational). Finally, adopting the Delphi method, exploring how ethical and public policies might be brought into alignment, strongly connected the first stage (ethical decision-making, and policies and procedures in LTC) and the second stage (how public policy promotes and/or hinders the development of an ethical culture in LTC, and the interaction between public policy, organizational policies and procedures) of this research project, as ethics and policy are explored in conjunction, rather than as separate entities.

Delphi method draws on the views of identified experts and seeks opinions on a range of issues through consecutive rounds of consultation to explore, and gain a better understanding of, the interaction between public policy and organizational policies and procedures. In the context of Delphi, participants are considered “stakeholder experts” when they have knowledge and experience of the issues, are directly affected by the

subject, or have specialist skills in the area under investigation (Greason, 2017; Jamal, 2012; Gabb et al., 2006; Adler & Ziglio, 1996). In terms of this research, ‘public policy’ can be generally understood as ‘what government does.’ More specifically, public policy is a specific course of action, formulated by a political process, arising out of a perceived public problem. Once adopted, the course of action is implemented and enforced by governmental agencies. Public policies can take the form of law or regulation.

This Delphi study used a two-round interactive interview process to engage 24 stakeholder experts from the LTC sector. A wide range of experts were recruited for the second stage of the research, using purposeful sampling, including residents of LTC facilities, family members, volunteers, care aides/resident assistants, LPNs, RNs, recreational therapists, unit managers, senior managers, staff from professional bodies (e.g. NB Nursing Association, NB Association of Nursing Homes, NB Association of Social Workers), government departments, policy makers, local politicians and so on².

In the first round of Delphi interviews, I explored what changes needed to occur in the LTC sector to encourage better alignment between policy and practice in an effort to minimize the moral distress experienced by frontline care staff. Questions for the first round of Delphi were drawn from focus group data, where in vivo coding of interview and focus group transcripts identified a number of themes regarding how public policy promotes and/or hinders the development of an ethical culture (versus an ethical climate) in LTC, and the interaction between public policy, organizational policies and procedures, and frontline staff’s ethical decisions and actions. Following the first round,

² Though it would be ideal to share more specific information regarding the stakeholders of the study, it is difficult to do this considering how small New Brunswick is, and the highly connected and interwoven nature of the LTC sector and those with a stake in it. As such, providing additional information regarding the stakeholders would create issues of confidentiality as participants could be identified.

interviews were transcribed verbatim and coded for apparent content themes regarding participants' views. The emerging themes were collated into a 2000-word summary [*see Interlude Three*], and circulated to participants prior to the second round of interviews. In the second round of Delphi interviews, participants explored the range of comments from the first round. The goal of the Delphi method is to have expert stakeholders reach a consensus through the multiple rounds of consultative interviews; reflecting, discussing, and exploring the opinions and views of others, whether agreeing or disagreeing. The second round of interviews were transcribed verbatim and coded for content themes regarding participants' views. The relative consensus achieved in this round of interviews suggested five areas the LTC sector must concentrate in order to create practice-informed policies and to foster positive ethical cultures in LTC. These findings were collated into a 3000-word summary and circulated to participants summary [*see Interlude Three*].

Ethical Issues of the Research

Both stages of the research study did not pose any more than minimal risk. In the first stage, the use of focus groups means that total anonymity is impossible, which potentially raises the issue of breaches of confidentiality by members of the group. While I asked participants not to disclose information from the group, and asked them to sign the consent form agreeing to this, I could not guarantee that this would not happen. The risk from disclosure, however, was mitigated by the fact that I was not asking focus group participants to disclose anything about their individual practice, but to discuss hypothetical vignettes, which were drawn from interview data (stage one) so that they are based in real-life experiences. However, the vignettes were not reports of any individual's

situation but devised so as to raise ethical issues. As a result, they are composite cases, written in form and to generate ethical debate. No individual was identifiable from the vignettes themselves. The purpose of the vignettes was to allow me to analyze the ethical reasoning of participants, and not to identify ethical breaches that may have occurred in their practice. Discussion of the vignettes, therefore, raises no issue of ethical breaches in practice and thus no issue of whether there is a need to breach confidentiality.

In the second stage, using Delphi method, participants were asked for their views on a range of subject arising out of previously collected data from the first stage of the project. While participants addressed potentially fraught areas, I did not ask for personal experiences, and did not address intimate or personally sensitive subjects. As the participants engaged through individual interviews and data was collated before being shared, there was little, if any, possibility that participants will be identified during the research. However, when reporting the research, certain participants may possibly be identified because of their position – for example, should the Director of Social Development participate then her/his responses may be identifiable as there is only one such Director. All organizational participants participated because of their role, and as such spoke as representatives of their organization. LTC residents, family members, volunteers and staff who participated will not be identifiable in the above way.

Prior to both stages of the research, participants were provided with an information sheet, outlining the purpose of the research and what would be involved if they chose to participate. They had the opportunity to ask questions about the research prior to making a decision and were given at least seven days to read the information, ask questions and think about their decision. Participants were asked to sign a consent form prior to

participating in a focus group or individual interview.

Ethics approval was sought and granted for the first stage by both University Ethics Boards at the University of New Brunswick (UNB- REB2015-029) and St Thomas University (STU- REB #2014-05). The second stage also received ethics approval from both Boards (UNB- 2016-132; STU- REB #2015-10).

Relevance of the Research

Sharing the findings of this research (particularly stage one) with LTC staff and management allows staff and managers to reflect upon their practice and in turn develop more nuanced, flexible, and inclusive care. The research was particularly relevant to frontline LTC staff as they are the individuals who experience moral distress as a result of real and/or perceived organizational constraints when making ethical decisions (Pijl-Zieber et al., 2016); exploring how the alignment of public policy and organizational policies and procedures can be used to encourage the development of ethical cultures in LTC, rather than ethical climates, will improve the ethical decision-making environment for staff. A literature review on ethics in LTC revealed increasing concern about ethical practice in terms of social care in LTC and a 2014 survey of LTC facilities in New Brunswick demonstrated the majority of facilities do not have ethical codes or policies, training, or boards of ethics. Partner organizations in the study viewed the project as an essential part of professional and organizational development in providing social and health care and as the first step in enhancing training and staff support policies and procedures, based on detailed understanding of how staff reason in practice, and how such reasoning aligns with institutional values and ideals, leading to improved care and

the enhancement of the quality of life of older adults living in LTC facilities. Further, the second stage of the project explored how the alignment of public policy and organizational policies and procedures could be used to encourage the development of ethical cultures in LTC, rather than ethical climates, further improving care environments and quality of life. The research also brought the partner organizations into contact with wider policy makers and other stakeholders, thus facilitating and encouraging knowledge transfer.

The findings from my study are useful to academics, ethicists, professional educators in social work, gerontology, nursing and other areas. Further, the research has relevance for politicians, as they are the individuals who develop the social policies to address the changing needs of citizens, including the aging demographic of Canada, and NB in particular. The findings could be used to inform the assessment of current policies and how these policies inform delivery of care in LTC.

In 2016, the most recent Canadian census, older adults, classified as individuals sixty-five and older, made up 16.9% of the overall Canadian population, and for the first time out number children (Statistics Canada, 2016). The percentage in the Atlantic provinces is 19.9% (Statistics Canada, 2016). It is projected that by 2026, older adults will make up 21.2% of the Canadian population, greater than $\frac{1}{4}$, and increase to over eight million people (Statistics Canada, 2012). This dramatic demographic increase of older adults is partially due to the aging of the baby boomer population, longevity, and better healthcare. Though the aging population has much to contribute to our society, in a myriad of ways, there is some concern that the out-pacing of older adults will have a significant impact on the Canadian healthcare system (New Brunswick's Aging

Population).

Canadian older adults are living longer than ever before due to improved medical care, wellness initiatives, and technologies. This is arguably a good thing, as long as we can continue to adequately care and provide for the aging population. Caring for the increasingly aging population falls on families, communities, and professional institutions like LTC facilities (Statistics Canada, 2012; Statistics Canada, 2013).

Unfortunately, it does not seem as though Canada is prepared to care for the demographic increase of older adults. Currently, in New Brunswick (NB) older adults occupy 20% of hospital beds, primarily as a result of long LTC facility wait lists, and it is predicted that the exponential aging of the baby boomer population will result in 100% of hospital beds in NB being occupied by older adults by the year 2026 (New Brunswick's Aging Population, 2013). Further complicating the management of the aging population is the societal shift we are experiencing in the nature of caring for our aging family members. Traditionally, many families cared for aging parents or relatives, however, there is a shift to increased facility-based LTC, as a result of a number of cultural and societal changes, including: changes in gender role expectations as more women are working full-time and not remaining home; out-migration of children from home Provinces for employment; increased longevity and family carers experiencing 'burnout' or tiredness, and; intense focus on individualism in our society compared to community-based practices of the past.

In an effort to address the issues resulting from of the aging NB population, including the increasing demand for nursing home beds, the provincial government of NB conducted a three-phase review of the 2009 nursing home plan to ensure the projects therein were the most cost-effective, given the financial challenges of the province, and

that they would adequately meet the increasing needs of the aging population (New Brunswick, 2015). The three-phase review included a demographic review, nursing home facility assessments, and a design standards review. Despite governmental attempts to acknowledge and make improvements to LTC infrastructure, there has been limited, if any, focus on how public policy and organizational philosophies of care promote and/or hinder the development of an ethical culture in the provision of long-term and dementia care, and if the current policies and philosophies of care in LTC are the most cost effective and adequate approaches in terms of providing social and health care to the aging population.

Considering the exponential increase of the older adult population in NB, the cultural and societal shift to facility-based LTC, and the shortage of placements for older adults, it is essential to critically analyze how public policy and organizational philosophies of care influence the ethical culture within LTC facilities, and thus the level of ethical care provided to the increasing number of older adults who will spend the final years of their lives living in these homes.

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Paper One: Ethical reasoning and moral distress in social care among long-term care staff

Abstract

There are studies on the normative ethical frameworks used by LTC staff, and studies proposing how staff *should* reason, but few studies explore how staff *actually* reason. This study reports on the ethical reasoning process, and experiences of moral distress of long-term care staff in the provision of social care. Seven interdisciplinary focus groups were conducted with twenty frontline staff. Staff typically did not have difficulty determining the ethical decision and/or action however, they frequently experience moral distress. To manage these experiences of moral distress in making ethical decisions staff selected one, or a combination, of four strategies: 1) comply with being told what to do/fear of consequences; 2) defer decisions to family; 3) “have a meeting;” 4) adopt and defer to existing workplace culture. Findings suggest that to better understand how/why staff make ethical decisions the way they do, and improve quality and ethical care, we must explore the interaction between frontline practice, and organizational and public policy.

Introduction

LTC organizations often rely on ethical frameworks and values adapted from acute care settings (Collopy et al., 1991; Waymack, 1998; Kuczewski, 1999; Carter, 2002). However, there is a risk in viewing LTC as an extension of acute care, as LTC poses a very different moral and decision-making environment than that of acute care settings (Collopy et al., 1991; Waymack, 1998). The foundation of ethical frameworks in acute care is the competent adult, grounded in the context of temporary treatment

(Collopy et al., 1991; Kuczewski, 1999; Powers, 2000). On the other hand, LTC tends to include aspects such as ongoing, long-term treatment, increased numbers of residents with diminished competency, limited resources, and congregate living in a 'home-like' environment (Collopy et al., 1991; Waymack, 1998; Powers, 2000; van der Dam et al., 2011; (Pijl-Zieber, Awosoga, Spenceley, Hagen, Hall, & Lapins, 2016). Despite these differences, the ethical frameworks that are predominantly taught to frontline care staff in LTC are typically grounded in more normative ethical theories (Woods, 2005). The most common normative ethical theories include, principlism, consequentialism, utilitarianism, and deontology (Woods, 2005).

Principlism is an ethical framework based on weighing the four principles of autonomy, beneficence, nonmaleficence, and justice (Beauchamp & Childress, 1989). Alternatively, using a consequentialist method, decisions are made based on the potential consequences or outcomes of the action(s). A utilitarian ethical framework aims to achieve the greatest good for the greatest number, and finally, deontology is a means of ethical decision-making that draws on rules and duties. Studies aiming to explore how staff reason in LTC typically stem from these normative frameworks.

Researchers such as Dunworth and Kirwan (2009), Van Thiel and Van Delden (2001), Mattiasson and Andersson (1995), and Jansson and Norberg (1992) have reviewed the ethical decision-making process of LTC staff using normative frameworks. Others like Bolmsjö, et al. (2006a/b), Fleming, (2007), Carter, (2002), Kuczewski (1999), and Mysak (1997) draw on normative ethical frameworks and propose how staff *should* reason through ethical dilemmas in LTC. These studies, however, were designed with an underlying assumption that LTC staff reason in a particular (normative) way. However,

there are other ways in which LTC staff might reason ethically. For example, LTC staff might also draw on virtue ethics (Carr & Steutel, 1999), narrative ethics (Baldwin, 2015), feminist ethics (Card, 1991), and casuistry (Slettebø & Bunch, 2004b). Though more recently researchers such as Agich (2003) have challenged the applicability of normative ethics approaches in LTC and have sought to understand the ethical challenges faced by LTC staff (Bollig et al., 2015) normative frameworks continue to be largely accepted, taught, and reproduced. The literature reveals no studies which sought to explore and better understand staff's *actual* reasoning processes - also known as an empirical ethics approach - within a practice context. Empirical ethics is understood as research approaches that “see a value in using empirical data to inform the ethical analysis of practical dilemmas” (p. 466) and which combine this empirical data with moral philosophical analysis (Dunn, Sheehan, Hope, & Parker, 2012, p. 467).

It is important to understand how staff are making ethical decisions because of the association of inadequate ethical decision-making and experiences of moral distress (Schaefer & Vieira 2015). moral distress is defined as being aware of the ethical action but feeling powerless to act accordingly as a result of either real or perceived institutional constraints, and thus engaging in ethical wrongdoing (Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2005). Solum et al. (2008) propose an incongruence between norms of good care and their implementation into daily care. The translation of these norms into policies and procedures carries the risk of becoming restrictive. In these circumstances, staff are potentially subjected to the effects of moral distress, which include feelings of guilt, frustration, helplessness, anxiousness, and at times physical symptoms such as stomach pain and headaches (Zieber et al. 2016; Todd & Watts, 2005). Such experiences

of moral distress result in increased staff burnout, more sick days, and staff turnover (Cummings, 2009)

By applying an empirical ethics approach to the LTC environment, this research project sought to explore the nature and extent of ethical issues in the provision of *social care* in LTC facilities, and the ethical framework(s) deployed by LTC staff in making decisions as to the right thing to do in such situations. While LTC staff are faced with numerous health-related ethical issues, because the LTC environment is heavily weighted as a daily on-going activity as compared to acute care, they also deal with difficult ethical situations in the provision of social care, referred to as ‘everyday ethics.’ Powers (2000) defines everyday ethics as consideration of the ethical aspects of ordinary issues of daily life affecting nursing home residents and those who care for them. Powers (2000) asserts, “too often the attention of formalized ethical decision making in health care settings turns to hard to deal with life and death issues” (p. 143), which discount daily ethical issues and “actually obscure[s] a fundamental question that cannot be ignored for long in the setting of the nursing home or long term care facility: What is the goal of health care? Is it merely to preserve life? Most providers and patients would argue for something more” (p. 144).

The goal of the research is to gain a better understanding of how LTC staff reason ethically in a social care context, in particular, addressing the following questions: 1) How does the ethical reasoning of LTC staff reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues? 2) On which ethical frameworks do LTC staff draw in their ethical reasoning? and 3) How do LTC staff choose between competing or differing ethical values and frameworks? In

exploring these questions, it became apparent that staff drew on a combination of strategies during the ethical decision-making process in an effort to minimize experiences of moral distress, and this data informs the present article.

Methods and Data Collection

Below I provide an overview of the research methods and data collection procedures. I contextualize the study by discussing the setting and recruitment, participants, research design, and ethics approval.

Setting and Recruitment

I conducted the research in partnership with four LTC facilities in an Atlantic Canadian Province. The four LTC facilities represent two LTC organizations- one public and one private (the latter having three separate locations across the province that participated in the research). The facilities provided for 72-190 residents and typically staff are responsible for the care needs of, on average, nine to ten residents.

To recruit participants, I worked closely with management at each organization. A letter of invitation to participate in the study and additional information was emailed to staff. Information posters were hung in staff lounges and in nurses' stations at each participating location. Contact information for the researcher was included on all materials. RNs, who act as "floor managers," also directly informed their teams about the research and encouraged participation (teams working days, evenings, and nights were informed and invited to participate). Staff were informed they would be paid for their time and that a replacement staff member would be hired for the duration of their absence. Once staff expressed an interest in participating and contacted me I provided them with an introduction letter via email.

Participants

Twenty frontline care staff were recruited to participate in the focus groups. Participants comprised: ten registered nurses (RN), six licensed practical nurses (LPN), three resident attendants (RA), and one nurse practitioner. It is important to note that a limitation of the study is the small number of RA participants and that some research suggests there may be a difference in how LPNs and RAs experience moral distress (Pijl-Zieber et al., 2016).

Participants were predominantly white women (one male participant), and while this is a limitation, it is also reflective of the reality of the work environment of these organizations. Women are responsible for 90% of the hands-on care provided in Canadian LTC homes (Baines, 2007). The majority of the participants worked in LTC settings for greater than 15 years, and four of the participants were less than two years from retirement, having worked in LTC the majority of their careers. Five participants were closer to the beginning of their careers in LTC.

Research Design

Focus groups. Focus groups are defined as a method which engages participants in unstructured discussion guided by a moderator (Krueger, 1988; Peek & Fothergill, 2007; Acocella, 2011). Importantly for this research, focus group helps to address the issue of theory-practice gap by giving direct access to the reasoning process of LTC staff that is inaccessible in other ways (e.g. observation) (Barter & Renold, 2000; Renold, 2002; Hughes & Huby, 2002). The goal of focus groups is to provide increased understanding of a specific topic from the viewpoint of the research participants (Dilshad & Latif, 2013). Unlike other methods of collective inquiry, focus groups generate data

explicitly through participant interaction, and allow for the exploration of collective experiences and perspectives (Peek & Fothergill, 2007; Wodak & Krzyzanowski, 2008; Acocella, 2011; Dilshad & Latif, 2013). Further, through participant dialogue of the focus groups I was able to observe the reasoning process in action.

I conducted seven interdisciplinary focus groups consisting of two-four participants, averaging ninety minutes in length. The focus groups took place at various locations in the participating facilities. Although my goal was to have between three and five participants in each group, the number of participants was affected by participant “no shows,” and winter weather conditions. There is disagreement in the literature on the ‘ideal size’ of focus groups. However, the primary concern is the quality of the data, which is located in the interaction and discussion (Gill, Stewart, Treasure, & Chadwick, 2008; Peek & Fothergill, 2007; Morgan, 1996). Smaller focus groups are typically more appropriate and effective when exploring emotional and personal topics that are likely to generate high levels of participant opinion and debate (and thus engagement), when participants have an interest in and extensive experience with the topic, and when participants are familiar with one another (Morgan, 1997; Gill et al., 2008; Dilshad & Latif, 2013). This was the case for all of the members of these focus groups.

Because focus groups were comprised of staff with various status (e.g. RA, LPN, RN, NP), I wanted to ensure the voices of all were heard, and that differentials in power and/or status did not silence others. For this reason, I segmented participants in an attempt to eliminate rank and status differences (Peek & Fothergill, 2007) by ensuring no staff was placed in a focus group with a supervisor and/or manager to whom they directly report. Separating staff from managerial superiors created a less hierarchical

environment, encouraging staff to discuss more freely. However, it is important to note, “it is impossible to predict all the ways individual characteristics and social status may interact to influence group dynamics” (Peek & Fothergill, 2007, p. 15). There were situations where more dominant personalities controlled the discussion. It was in these instances that I intervened to redirect the conversation back to the vignettes, or to engage others by asking, for example, “would there be other ways to think about this?”

Vignettes. During the focus groups, I presented staff with a vignette, which they read independently, and then discussed as a group. If time allowed a second vignette was explored. I presented staff with a vignette, which they read independently, and then discussed as a group. If time allowed a second vignette was explored. Vignettes are hypothetical short stories comprised of stimuli designed to reflect particular elements of reality and society, to which participants are invited to explore and respond (Finch, 1987; Barter & Renold, 2000; Hughes and Huby, 2004; Given, 2008). A strength of using vignettes is that beliefs and norms can be discussed in situated contexts, concerning hypothetical third party characters, thus distancing the participant from the issues and minimizing personal threat (Finch, 1987).

To construct the vignettes, I drew on existing transcripts of qualitative individual interviews completed in a previous phase of the research. I wrote the vignettes to reflect situations that frontline staff describe as part of their daily activities in social care. These themes were related to the following: staff management of competing needs, limited resources (personnel and financial), resident sexuality, use of physical restraints, covert medication, safety and risk-management versus autonomy, and interaction with families.

The vignettes are composite cases, written to generate ethical debate and discussion. They were written to provide participants realistic case scenarios drawn from their experiences in LTC, providing access to how staff think and reason through these cases. In order to explore how staff themselves reason through ethically difficult situations, I asked participants to discuss how they would handle the presented situation(s) and why they chose a particular path (Finch, 1987; Hughes & Huby, 2004).

Recognizing “the way representation affect[s] the examination of moral problems” (Chambers, 1999, p. xiii), I took great effort in the design of the vignettes to accurately reflect staff experiences and encourage moral exploration rather than a specific moral response (Chambers, 1999). For example, I used the individual interviews to determine and represent the common social dilemmas staff experience, to reflect use of language and emotional sentiment, and to emulate narrative framing used by staff in their accounts of ethical dilemmas.

To strengthen the internal validity, defined as the extent to which the vignettes capture social reality and the research topics in question (Hughes & Huby, 2004), each vignette was sent to three external readers with extensive experience and knowledge in the area of LTC- management at each of the participating facilities, and the CEO of the Alzheimer Society of New Brunswick, for feedback prior to use. All agreed the vignettes were reflective of real-life ethical dilemmas staff encounter, relevant, and applicable. Further, the internal validity and reality of the vignettes was proven during the focus groups as staff immediately recognized and accepted the situations as experiences of frontline care and engaged with the material.

In addition to the focus group data, to gain a better understanding of the working environment of staff I reviewed both of the partner organizations philosophies of care, policies and procedures, and values. Reviewing organizational documentation allowed me to explore how the ethical reasoning of LTC staff reflect, align with, or conflict with declared organizational philosophies in managing ethical issues.

Data Analysis

Focus groups were audio recorded, transcribed verbatim, and subjected to critical discourse analysis (Fairclough, 1989). critical discourse analysis is “a form of analysis which exposes the multiplicity of possible meanings, contradictions and assumptions underlying our understandings and ways of knowing- to question, who benefits, and how, from the assumptions about our social world embedded in those systems of thought” (MacNaughton, 20005, p.78). In the context of this research, the purpose of using critical discourse analysis is to emphasize the importance of analyzing language to demonstrate how embedded power relations within dominant discourses, including dominant (normative) ethical frameworks, ultimately impact LTC staff’s ethical reasoning and decision-making. I analyzed the data to explore how language, knowledge, discourses, social relations, and power/inequality are constructed, sustained, or reconstructed, and how these elements impact the reasoning processes and decision-making of LTC staff. In vivo coding was conducted in ATLAS.ti, followed by clustering codes to create more generic “theme families.” The clustered themes allowed me to determine the dominant emerging themes. By deconstructing the texts using critical discourse analysis, I sought to identify the ethical reasoning of staff in LTC, as well as the participants’ own meanings, concerns, and priorities in dealing with difficult

situations, and how power relations embedded within language influences these processes. In so doing, it became apparent that staff rely on four strategies in making their ethical decisions in an effort to minimize experiences of moral distress, and it is that finding which informs this paper.

Ethics Approval

Research ethics board permission was received from two university ethic boards in the province prior to the commencement of the research, and written informed consent was sought and granted by each participant prior to beginning the focus groups. Because of the personal nature of the data, transcripts were written anonymously and digital files were password protected.

Findings

In the following section I will discuss the findings of the research. First, I will explore the misalignment between organizational philosophies of care and staff perceptions of the environment, which often creates tension and moral distress. Second, how staff reason through ethical situations, drawing on a number of frameworks, only to dismiss these decisions and rely on four strategies in an effort to minimize experiences of moral distress.

Organizational philosophies of care

Though the two LTC organizations that participated in the research have distinct characteristics, in reviewing their philosophies and values I found that both organizations largely espouse the same philosophies of care:

1. An environment in which resident-centred care is paramount,

2. Residents' independence and dignity are protected and they have maximized opportunities to make decisions,
3. Shared decision-making occurs,
4. Residents' choices are respected,
5. Safety is prioritized, and
6. Staff are competent and caring.

Despite organizational efforts to achieve these fundamental care concepts, findings from the focus group data demonstrate staff perceive, and therefore make ethical decisions and take action, within a very different organizational culture and environment.

Staff perception

Throughout the focus groups, staff discuss their perception of the complex environment of LTC in which they work and make ethical decisions. Staff describe an environment rather contradictory to the environments of care outlined in organizational philosophies. As staff discuss the vignettes, a number of themes emerge in relation to the environmental characteristics of LTC. The dominant themes demonstrate that staff predominantly perceive the organizational environment and culture as one characterized and/or shaped by: 1) hierarchy of power and lack of staff autonomy; 2) staffing restrictions and a task-oriented environment; 3) concern about liability; 4) family power superseding that of the resident, and; 5) financial inequality. Each of these impact staff's ethical reasoning and contribute to their experiences of moral distress, and are expanded upon below.

Hierarchy of power and lack of staff autonomy

The themes of hierarchy of power and lack of staff autonomy emerge as predominant and recurring themes within, and across, all seven focus groups. Through analysis it is apparent staff perceive the environment as very hierarchical in terms of certain individuals holding authority and autonomy more than others. Staff within all of the focus groups make reference to the power of the medical team, including physicians, dietitians, pharmacists, occupational therapists, physical therapists, and at times, RNs: “...if that’s the medical team’s recommendation we’d have to pretty much go with that” (LPN, LTC 002). An example from one focus group is a competent resident wanting to walk independently outside and members of the medical team asserting their power to restrict or prohibit the resident from doing so. This is also a good example of the tension between the organizational values of a) resident choices being respected and b) prioritizing safety. Staff explore how, at times, they act in ways that conflict with, or contradict, what they believe to be ethical and/or in the best interest of the resident, simply because those with more power have directed them to do so. As one staff describes, “...they may not have liked it any more, but they’re following the orders of the nurse and the care plan in doing it...” (RN, LTC 001).

In some discussions staff overtly describe themselves (and more generally “frontline staff” as a whole) as having very little autonomy. This was especially apparent in relation to the RA’s. RAs both portray themselves, and are framed by others, as having the least power and autonomy. RAs often use binary language of “us” versus “them” when discussing the hierarchy and imbalance of power, displaying their perception that amongst co-workers they have the least autonomy. As one RA says, “*us ourselves* would

not, we wouldn't have anything to say about it. *The RN's themselves* would have a little bit more..." (RA, LTC 003 - emphasis added). Staff participants, who are not RAs, also discuss this power imbalance, framing RAs as less capable and describing the expectation that RAs "look to registered staff" (RN, LTC 005) for guidance and direction to minimize potentially unethical decisions and actions, rather than acting autonomously.

In discussing the lack of autonomy or involvement of RAs in the independent decision-making process, some staff will make reference to the vignettes, saying, "I know sometimes that person (RA) might be more comfortable asking the RN." Interestingly, however, it is more common in the focus groups for staff to *not* to discuss this power imbalance and it was seemingly accepted as 'the way it is'. The acknowledgement of this power imbalance amongst staff appears commonplace and suggests the strength and acceptance of this discourse in LTC settings.

Although discussions within and across the focus groups reveal an obvious perception of power imbalances specifically between RAs and other staff members, the data reveals almost all staff, regardless of position, perceive themselves as lacking autonomy and being restricted by the hierarchy of power within the LTC environment. Consequently, almost all staff report they often make decisions and act in ways that contradict their personal or professional values regarding care. Very seldom (only two instances) did licensed staff make reference to their professional organizations/standards/codes of ethics in terms of making ethical decisions and the conflict experienced in making ethical decisions. The conflict staff explore and express is in direct relation to their personal and professional values.

Perhaps in recognition of the hierarchical nature of the organization, it is apparent staff often follow directions, or “do as they are told,” (RN, LTC 001) for fear of consequences during the ethical decision-making process.

I'm quite sure, in a run of a day that I do at least fifty things that I totally disagree with and think are very wrong...Even though I totally, totally 100% disagree with a lot of stuff that goes on here...But you get used to it. Eventually (laughing). Takes quite a few years. (LPN, LTC 002)

Here we see a clear expression of moral distress as the staff member describes the pressure she/he feels to act in ways she/he perceives as not in the best interest of the resident (Oh & Gastmans, 2015). The staff member went on to describe feelings of guilt and helplessness following these incidents, both effects of moral distress (Zieber et al. 2016).

Staffing restrictions and task-oriented environment

In contrast to the stated values of resident-centred care and the protection of dignity and independence found within the LTC organizational philosophies of care, the data reveals the majority of staff perceive the LTC environment as being understaffed, thus undermining resident-centred and quality care. For example, staff cited “staffing issues” (LTC 002), “not having enough staff” (LTC 003), and “being too busy” (LTC 005) to provide holistic, quality care to residents. The following exchange typifies the perceptions expressed by many:

Respondent 1 (R1):...yeah, it's that, there's a time constraint there.

Respondent 2 (R2): Leading to there's not enough staff in nursing homes...

R1:...No...

R2: ...you can put that down (laughs).

R1: You can imagine doing personal care on nine people and this population is really busy, and we do help them but, in the mornings, but that care doesn't end after you wash them up and get them dressed in the morning...

R2: ...No...

R1: ...you know I would say, half to three quarters of our clients are incontinent...you know, so it's ongoing through the day that you're looking after them, it's not just, you get them up...

R2: ...Yeah. The little formula that you use, for whatever it is now three point such and such hours per day...

R1: ...Yeah...

R2: ...you know in nursing home, [um] you've used it all up, by eleven o'clock in the morning. Right, so you have another, few hours. (RN & LPN, LTC 004)

Staff express how an understaffed environment necessitates a task/routine environment in order to fulfill workload demands and meet the basic care of residents. As noted above, they drew attention to inadequate staffing formula being used to determine care requirements. The tension between responding to physical care needs in light of inadequate staffing lead to moral distress for the participants of this study. Understaffing is a commonly reported factor contributing to moral distress (Oh & Gastmans, 2015).

Most staff felt that an understaffed environment results in time constraints, leaving very little time for more than basic care, and increased difficulty in balancing competing residents' needs. "You know, you may have three or four bells ring at once, out of those four bells you need to determine which one's priority" (RN, LTC 006).

Further, the data reveal that for many staff, as a result of the routine/task-oriented environment, residents' physical needs are often prioritized above social/emotional needs.

I find here, too, and this is the reality in a nursing home we tend to focus more on the physical needs of a client...because they are the most time consuming, you know... But the emotional side of clients here tend to get put down on the priority list. (LPN, LTC 006)

Staff also describe residents as passive recipients of care, lacking involvement in decision-making and care. There are some instances where staff overtly discuss and describe residents' as passive recipients of care. For example, a staff member points out how neither staff nor family had thought to approach one resident for her opinion, stating, "Like no one's asked her, everyone's forced their decisions on her" (LPN, LTC 005). Throughout the focus groups many staff explore how many residents "feel their choices have been taken away" (RN, LTC 004). More common in the data than this explicit acknowledgement are discrete examples of the underlying assumption of residents as passive and uninvolved recipients of care, identified through the analysis of the language used by staff. A common example of objectifying language, thus highlighting residents' passivity, emerges frequently as staff discuss residents and walking, "Like at the first, you *take her*, go for a walk..." (RN, LTC 003). In this quote a staff participant corrects the language, though initially portrays the resident as a passive object "to be walked," rather than "walking with" the resident. Here, perceiving/treating residents as passive recipients of care and using objectifying language is reflective of disconnected staff-

resident relationships, a common effect of moral distress and staff burnout (Cummings, 2009).

Concern about liability

A dominant theme across all of the focus groups was staff's awareness of, and concerns regarding, liability. The data reveals all staff are very cognizant of the realities, and possible ramifications, of liability within their scope of practice, and this consequently influences the ethical decision-making process. Staff express an uneasy balance and tension between risk and liability, impacting their ability to act in ways they believed to be ethical. Staff describe situations where a possibly "risky" decision is perceived as the ethical one, and yet such action will be thwarted by their fear of liability. As staff openly discuss this awareness, and the importance of protecting themselves, the related sub-theme of documentation emerges.

...I mean, we end up on a stand somewhere and you don't have any documentation to back up anything that we've, any conversations that we've had with families or whatever, or what we did, you know how we handled things then, we're really, up the creek without a paddle basically. (RN, LTC 004)

While staff recognize the importance of documentation, more than half of the staff highlight how time-consuming it is. As a result, documentation is ultimately perceived, and described, as vying for staff's time in competition with residents.

Despite having liability concerns, staff consistently emphasize their desire to enable residents' to "have good things and enjoy today" (LTC 004) and to "be happy" (LTC 005). However, at the same time staff discuss the potential risks and safety concerns associated with resident autonomy. In exploring the vignettes, and discussing

residents' safety versus risk and autonomy, staff support and respect residents' rights, and in all of the focus groups staff express and support the statement, "the resident has a right to choose." However, if these choices were counter to that of LTC policy or the medical teams' direction, staff stress the necessity of having the family and/or the resident sign a waiver. As one staff highlights, "so, we do get the family to sign something... saying that it's kind of our, not our responsibility if something was to happen" (RA, LTC 003). It is interesting, however, that while having waivers signed was raised in all focus groups, there was some disagreement between focus groups on the significance, or warrant, of waivers. Some staff express the importance of having waivers signed to ensure they, and the organization, are protected. Others believe waivers would not "hold up" in court. "Well, the waiver's...it's not worth a pinch in court" (LPN, LTC005).

All staff members eagerly engaged in the discussions regarding liability, expressing their concern, uncertainty, and fear. The level of engagement suggested this concern is a common and prominent one for staff. Research has demonstrated that staff experience higher levels of moral distress when there is a fear of liability, which often leads to stress, anxiousness, and ultimately burnout and staff turnover (Epstein & Hamric, 2009; Cummings, 2009).

Family power superseding the resident

While the first three themes were not entirely unexpected, analysis reveals an unexpected theme within and across all of the groups, where staff perceive the family as having utmost power, superseding that of the resident, regardless of the resident's cognitive and/or competency status. Staff describe how "families call the shots more than they should" (RN, LTC 004), and express how staff sometimes make decisions and

act in ways to appease the family, rather than the resident: "...so they're [staff] doing whatever they have to do to please the family members which is what happens even here a lot...It's not about the resident, it's about the families" (LPN, LTC 002).

For example, one staff member explains how, at times, family's perceptions of the staff, and their perception of the quality of care being provided, can begin to emotionally impact and influence staff actions, saying, "...'what kind of nurse are you?' and after you hear that every day for months and months you actually, you know it's like, oh my goodness this is terrible, look at her, I'm going to make her have a bath (slight laugh)" (LPN, LTC 002). The impact of familial influence on their ethical decision-making, was identified as contributing greatly to experiences of moral distress.

The power of the family is most apparent as staff explore the vignettes in which characters (residents) are presented as both competent/non. In all of the focus groups, regardless of competency and cognitive status, staff emphasize the importance of family involvement and present family as crucial to the decision-making process. In some discussions, staff express more overtly the perceived power of the family, and how this ultimately supersedes even a competent resident, stating, "If family wants her bathed every day against her wishes it probably is going to be done. And there's nothing that anybody can do about it, I guess" (LPN, LTC 002). This quote highlights the disempowerment staff experience when hierarchical power relations influence decision-making, a known contributing factor to moral distress (Epstein & Hamric, 2009).

Not only is it disempowering, "dealing with the family sometimes is ten times more difficult than dealing with the clients themselves" (LPN, LTC 007). In one group a staff member says that family members can be "unrealistic people that definitely need a

reality check” (LPN, LTC 002). Others discuss that as a result of families not understanding the “bigger picture” complexities of the LTC environment, they have unrealistic expectations and demands of staff and the organization. Staff explore how, at times, overt and unwritten policy requires them to include family in decision-making, resulting in competing commitment to both, work with and appease the family, while also wanting to maintain and uphold resident’s wishes and best interests. Staff express how there is often tension between these commitments, complicating the decision-making process, and frequently resulting in staff feeling conflicted and constrained, conditions of moral distress (Pijl-Zieber et al. 2016).

Staff share three situations in which decision-making becomes increasingly complex related to family involvement. First, when family disagree on a care plan: “they need to establish who is going to make the decisions because the son, or the daughter and the husband *are on different tracks*” (LPN, LTC 006). Second, when family perspectives differ from, or contradict, those of the residents’. Third, when staff and family perspectives differ, further complicating the ethical decision-making process. Staff members consistently shared that despite disagreeing with family perspectives regarding care, they “move forward with whatever the decision was made” (RN, LTC 004).

Financial inequality

Given the constraints of the work environment and gaps in service availability, during the ethical decision-making process, staff frequently suggest the solution of family hiring private care, or services, to meet the residents’ needs. This is always discussed in terms of the family’s ability to pay for these additional services:

... But there's other, you know, like some people we always offer like, you know they, on the waiting list for physio and things like that, that they can get on that list but they can also go privately if they're, if they want that physio right now, if they want it very quickly... (RN, LTC 006)

Staff also perceive residents' limited finances as contributing to the ethically complex environment in which they make decisions. For example, staff explain residents recognize the cost of their prescriptions and will be non-compliant with taking medications in order to increase their "surplus" income each month. The fewer prescriptions residents take the more money they have to engage in activities or purchase items they want. Staff explain many residents only receive a comfort allowance of a hundred and eight dollars each month, from which many must pay for their prescriptions. In New Brunswick where this research was conducted, medications are secured and dispensed to residents. However, if for example a resident is prescribed Vitamin D and consistently refuses the medication, eventually during medication/drug review it is likely the medication will be discontinued from the monthly ordering for the resident, which means they no longer have to pay for it. Under the provincial drug plan residents pay a co-payment for each prescription, which can add up quickly. The only time prescriptions cost less is when a resident happens to still have a personal drug plan covering their prescriptions costs, though this is rare. As one participant says, "my residents would choose a night out entertainment over a vitamin pill, because they only have a hundred and eight dollars a month, and if they're thinking their quality of life, they can live without a vitamin D..." (RN, LTC 004).

Evidence of ethical frameworks

From the data, it is apparent there is a contrast and misalignment between the declared organizational philosophies and staff's perceptions of the culture and environment in which they work. Despite this misalignment, the data demonstrate staff typically do not have difficulty in determining what they believe is the ethical thing to do, though at times disagreeing with one another on the right course of action. In fact, there is evidence throughout of staff drawing on a number of ethical frameworks and norms during the ethical reasoning and decision-making process. Within and across all focus groups, as staff work and reason through the ethical issues within the vignettes it is apparent they did not limit their ethical exploration and reasoning to a single framework. Staff use insights from multiple ethical frameworks during the decision-making process, including principlism, consequentialism, deontology, utilitarianism, and the Golden Rule. Further, there is evidence staff draw on a number of social norms unrelated to these ethical principles during the ethical decision-making process. I define and illustrate below.

In the following quote, a staff member can be seen weighing the principles of autonomy, beneficence, and nonmaleficence regarding the right to fall.

*When you get into the, you know, **right to fall** and that, those sort of things, **which is worse, her being agitated in a chair**, is it, you know, **taking a chance** she might **fall and have a bruise**, or whatever. And I mean we go with this everyday, it's, you know...are we going to let somebody fall, which is, you know, **for some people that's, the better choice.** (RN, LTC 003)*

Using a consequentialist argument, this staff member discusses a resident's risk of falling.

So many people that we have are up and around and we know they're at risk or fall, but we don't tie them down, you know, the quality of life is, if somebody is sitting in a chair, tied to a chair twenty-four hours a day, is nil. They can still fall even if they are in the chair. They can injure themselves in the chair, and then the risks are even greater. You know, if you know, you've put somebody in a chair and they wiggle down under the tray and they, they asphyxiate themselves on the tray I mean, that's an even greater risk than somebody haven't fallen. (NP, LTC 001)

At times staff draw upon the concept of duty (deontology): "It almost killed me to put food in that tube. But *as a licensed nurse* I had to do that. It's *part of my job*" (LPN, LTC 002). Others draw on a utilitarian framework when making decisions: "For the good of everybody," "For the greater good," and "then you're forced to make that decision *for the sake of the whole unit*" (RN, LTC 004). Finally, staff also use the more societally common 'Golden rule', basing ethical decisions on the motto, 'do unto others as you would have them do unto you'; "I think it goes back to, treat people how you would want to be treated" (RN, LTC 006).

In addition to drawing on insights from a number of ethical frameworks, there is also evidence staff use the societal norms of not forcing others to do things, for example, succumb to expectation around bathing and cleaning, in making various ethical decisions.

I don't, don't think anybody, ever, should be forcing something in somebody's mouth...well, we shouldn't be forcing anything on anybody. (RN, LTC 004)

Maybe it's not ethical, and we're not supposed to do that, but sometimes it just, you have to do something... Because if she's here for a whole month and she hasn't washed so much as anything... (RN, LTC 003)

All staff drew on each of these normative frameworks, though in no apparent order or consistency. It seems staff adopt an eclectic and context-dependent approach to ethical reasoning, as they use insights from the various theories and societal norms to make decisions. The purpose of ethical frameworks is to provide a set of values to direct individuals in making ethical decisions, and presumably mitigate experiences of doubt and moral distress. Despite the extensive evidence and use of the various ethical frameworks in the reasoning process, staff implicitly and explicitly express feeling restricted to carry through with, or act upon, the decisions they have made as a result of organizational constraints and ultimately experience moral distress. Consequently, despite having used frameworks to make an ethical decision, staff often disregard that decision and in an attempt to mitigate or manage these experiences of moral distress, rely on four strategies to make the 'final' ethical decision.

Managing Experiences of Moral Distress

To manage these experiences of moral distress, in practice, staff rely on four strategies to make ethical decisions: 1) comply with being told what to do/fear of consequences; 2) defer decisions to family; 3) "have a meeting;" 4) adopt and defer to existing workplace culture. Below I outline the strategies and share examples from staff discussions.

1. *Complying with being told what to do/fear of consequences.* The RN in the quote below highlights how s/he felt staff do not always agree with the ethical decisions but follow orders because they are afraid to get in trouble if they question, or go against, them.

And some others (staff) is you do as your told or you're written up. ...they may not have like it any more, but they're following the orders of the nurse and the care plan in doing it. (RN, LTC001)

2. *Deferring decisions to family.* Regardless of whether the resident was competent or not, staff frequently express the need to “include family” in the decision-making process. Staff across all focus groups also discuss the need to appease family members in situations where opinions/values differ, and the conflict this creates.

On my unit where the majority would be, you know, competent, [um] I still do the family meetings because the family play a part, a huge role in all of this. (RN, LTC004)

3. *Having a meeting.* “Yeah like she says sometimes you can make the decision on your own but other times you need the group” (LPN, LTC007). As this LPN highlights, throughout the focus groups staff discuss the ability to make independent decisions regarding ethical situations and take action accordingly. However, in exploring the vignettes and when asked what the course of action would be for a given situation, staff almost always fall back on “having a team meeting.” They frequently express concern about making the “wrong decision” and wanting allies in the decision-making process. While this is seemingly a good

thing, in actuality it can be problematic given the fast-paced environment of LTC that often requires prompt decision-making. In some “bigger” decision-making situations one can respect the need to facilitate a meeting (e.g. a resident wanting to stop taking a particular medicine), while in other instances staff should feel confident to make an autonomous decision (e.g. a competent resident wanting to walk outside).

4. *Socialization into and acceptance of workplace culture.* “Even though I totally, totally 100% disagree with a lot of stuff that goes on here... But you get used to it- eventually. It takes quite a few years” (LPN, LTC002). Here we see a LPN discuss the process of workplace socialization, where she/he has learned to accept the culture and processes of the organization over time, despite disagreeing with them. Workplace socialization includes the formal and informal experiences where staff learn about policies, hierarchy, internal culture, and the day to day function of the organization (Korte, 2007). The concern with making ethical decisions based on socialization and acceptance of culture is when the culture and foundation for making decisions is problematic, which I explore in the discussion below.

All four means of ethical decision-making avoid individual responsibility and autonomous decision-making, and support the idea of ethical *climates*, where staff are broadly aware of ethics, rather than the active development of ethical *cultures*, in which ethics is an intentional and integral component of the workplace.

Discussion

The disconnect between organizational philosophy and staff experience can be understood in the light of the distinction between ethical cultures and ethical climates.

An ethical *climate* is a descriptive construct, where individuals within the organization are broadly aware of ethics, though frontline carers typically have a narrow understanding of responsibilities, and ethics training is limited to what regulations require (Messikomer & Cirka, 2008). Many LTC facilities seem to have adopted a business-model approach to care, whether this is purposefully or as a result of provincial policy and constraint, results in an ethical climate where decisions and actions are founded on economic and legal obligations, and there is a greater demand for efficiency, resulting in task-oriented routines (Powers, 2000; Powers, 2001; Rees, King & Schmitz, 2009; Jakobsen & Sørli, 2010). Ethical climates founded on schedules and strict standards rather than what is right and good for residents, creates an external barrier to achieving the best care, and limits opportunities for ethical practice (Slettebø & Bunch, 2004a; Bolmsjö, Edberg & Sandman, 2006b; Dierckx de Casterlé et al., 2008; Dunworth & Kirwan, 2009). This description of ethical climates is similar to the environments and constraints described by staff.

Conversely, a positive ethical *culture* is established when leaders within the organization proactively recognize ethics as an integral component to the organization's culture and success, and "identify, order, and communicate values so that in situations where they conflict, employees can more easily identify and weigh courses of action" (Messikomer & Cirka, 2008, p. 89). Organizational leaders play a vital role in establishing ethical cultures, as they "set the tone" and are essential in sustaining a

culture over time through employee empowerment, support, and education (McDaniel, Roche, & Veledar, 2011, p. 80). When organizational leaders understand the circumstances that could lead to potential ethical issues, it allows them to manage these issues more effectively by encouraging creative alternative courses of action, which the literature proposes can be effectively accomplished through fostering a safe environment for moral reflection and deliberation (see, for example, Abma, Molewijk & Widdershoven, 2009; Widdershoven, Abma & Molewijk, 2009; Edwards, McClement & Read, 2013; and Jakobsen & Sørli, 2010).

The emerging theme of moral distress, and the subsequent strategies staff rely on to make ethical decisions within the actuality of LTC practice suggest, in order to better understand how/why frontline staff make ethical decisions in social care in ways that avoid *individual responsibility and autonomous decision-making*, we need to explore the real, or perceived, organizational constraints staff describe as restricting their ethical decisions and actions. To better understand these potential organizational constraints, we must expand the inquiry to include the larger sociopolitical context(s) which influence LTC organizational policies and procedures, and thus the ethical decision-making environment of staff. Pijl-Zieber et al. (2016) similarly found organizational constraints (e.g. understaffing, limited recreational therapy, lack of resources, etc.) resulted in staff experiences of moral distress. Here, I support and echo the recommendations made by Pijl-Zieber et al. (2016), as they propose, "... the experience of moral distress is a symptom of a greater problem within the continuing care sector, and that the most productive solutions can be arrived at by framing moral distress as essentially a *structural concern* [emphasis added]" (p. 30). Exploring the interaction between public policy, LTC

organizational policies and procedures, and how these interactions can promote and/or hinder the development of an ethical culture in the provision of LTC would contribute to a better understanding of frontline LTC staff's ethical decisions and actions as well to help address and rectify the constraints resulting in staff experiences of moral distress.

Such an exploration is particularly relevant to frontline LTC staff as they are the individuals who frequently experience moral distress (Pijl-Zieber et al. 2016). Exploring how policy alignment/changes could be used to improve the ethical environments for staff (thus reducing moral distress) through the development of ethical cultures rather than climates. Further, such changes would also improve care environments and quality of life for residents. Expanding the research to gain a detailed understanding of how public policy influences organizational policy, and thus frontline care environments, is a pivotal first step toward the development of a) relevant and appropriate LTC policy change, and b) informed ethics training and professional support for frontline staff. While this is not the forum for discussion, a second phase of this research has been developed in light of the findings, which aims to explore how the interaction between frontline practice, organizational philosophies, and public policy promotes and/or hinders the development of an ethical culture in LTC, using a qualitative Delphi method (for more see, Author, 2017).

The majority of the reported constraints resulting in moral distress are in fact structural, meaning they could be solved, or at least reduced, by examining and addressing the larger sociopolitical factors influencing LTC organizational policies and procedures, and thus the ethical decision-making environment of staff. The reported constraint of family power superseding that of the resident, and the resulting moral

distress, is much more complex, raising issues of relationships, values, culture, and inter- and intra-personal dynamics. Family involvement and the associated ethical dilemmas and moral distress experienced by staff is not a constraint that is easily resolved. Similarly, other studies have also identified the complex interactions between residents, staff, and families as a unique characteristic of the LTC that contributes to staff experiences of moral distress (Spenceley, Witcher, Hagen, Hall, & Kardolus-Wilson, 2017). In light of this finding, perhaps we need to consider that regardless of the ethical culture of the organization, some moral distress is inevitable in the context of LTC as staff and family encounter competing claims, values, and beliefs about what is “right” and “good.” If this is the case for carers in LTC, developing strategies or interventions to support staff through these inevitable experiences of moral distress is critical. Gallagher (2010) and Murray (2010), propose organizations foster moral courage among staff as a strategy for overcoming moral distress.

Another possible avenue of reducing moral distress, given the complexity of family involvement, is drawing on Jurgen Habermas’ theory of discourse ethics (Finlayson, 2005). Discourse ethics is a method of ethical reasoning founded on communication, emphasizing the importance of considering the viewpoints of everyone involved, and designed to bring about consensus (Finlayson, 2005). Through the communicative action inherent to discourse ethics, individuals can talk about differences and come to a common understanding and ethical decision, thus maintaining family involvement, while also reducing the experiences of moral distress reported by staff. There are, of course, limitations and constraints to using this method in LTC settings, which would need to be considered and overcome (e.g. time constraints, facilitation,

location of family, etc.). However, it is a possible avenue forward, which could help reduce the reported moral distress experienced by staff as a result of family power superseding that of the resident.

In light of the findings that staff continue to experience moral distress despite drawing on a number of ethical frameworks to make decisions, more research is needed in LTC settings to determine the impact public policy has on the development of ethical cultures/climates and thus decision-making environments for frontline care staff, and to find solutions to the structural constraints resulting in staff experiences of moral distress. Broadening the scope of exploration to include a larger sample size and to include the voices of more RAs would also be beneficial.

Limitations

One limitation of this research is that it is a relatively small sample size of seven focus groups, consisting of a total of twenty participants from four LTC facilities, representing two organizations. While findings seem to resonate with staff from other LTC organizations, ideally future research would be conducted to broaden the scope of exploration to include a larger sample size and to include the voices of more RAs. Further, participants were predominantly white women, and while this is a limitation, it is also reflective of the reality of these agencies.

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Interlude One: Expanding the inquiry

In the first paper I explore the findings from the first stage of the research. Focus group data reveals frontline staff typically do not have difficulty determining the ethical decision and action, though frequently experience moral distress as they are aware of the ethical thing to do, but feel powerless to act accordingly as a result of either real, or perceived, institutional constraints, and thus engaging in perceived ethical wrong doing. Staff describe five institutional constraints which impact their ability to act in the ways they believe to be right and ethical:

- 1) hierarchy of power and lack of staff autonomy;
- 2) staffing restrictions and a task-oriented environment;
- 3) concern about liability;
- 4) family power superseding that of the resident, and;
- 5) financial inequality.

The majority of the reported constraints, with the exception of family power, are in fact structural. This means they could be solved, or at least reduced, by examining and addressing the larger sociopolitical factors influencing LTC organizational policies and procedures, and thus the ethical decision-making environment of staff.

In light of the findings from the first stage of the research, I suggest more research is needed in LTC settings to determine the impact public policy has on the development of ethical cultures/climates and thus decision-making environments for frontline care staff. Consequently, I expanded my PhD research to include a second stage of the project, which explores the interaction between public policy, LTC organizational policies and procedures, and how these interactions can promote and/or hinder the development of an

ethical culture in the provision of LTC. It is my hope that this exploration would contribute to a better understanding of frontline LTC staff's ethical decisions and actions, as well as provide possible solutions and/or ways forward to improve ethics and care in LTC.

A number of different methodologies and methods could be used to explore the interaction between public and organizational policy and frontline ethical decision-making. However, I adopted an empirical ethics approach with the aim of consensus building (based on Habermas' communicative ethics) amongst the array of stakeholders involved in frontline ethics and policy in LTC. Though various consensus building methods exist, I adopted an innovative qualitative Delphi method to explore ethics and ethical reasoning in LTC, and the interaction between frontline practice, and organizational and public policy. Using a qualitative Delphi approach to explore ethics and policy in LTC resulted in deeper, more rich findings on ethics, an area seldom empirically, or qualitatively, explored. In the following paper I share my rationale and the benefits of using these approaches.

Paper Two: Connecting findings to meaningful change: The benefits of using qualitative Delphi in empirical ethics and policy research in long-term care

Abstract

There is a symbiotic relationship between qualitative research and knowledge mobilization. However, there is often a significant lag between the conduct of research and the findings reaching the public (including those it impacts and those with the power to make change). In designing my study on ethics and policy in long-term care (LTC) with the aim of improving quality care, I sought a method that would not only generate broad data but data on which stakeholders would be able to more readily act and thus promote meaningful and timely change. With this goal in mind, I adopted an empirical ethics approach with the aim of consensus building and used an innovative qualitative Delphi method to explore ethics and ethical reasoning in LTC and the interaction between frontline practice and organizational and public policy. While the Delphi method is starting to gain more recognition alongside more well-known qualitative methods, it has yet to be used in the exploration of empirical ethics and policy in LTC. The rich findings from this study suggest it has the potential of expanding the breadth of qualitative inquiry, as it draws on real-world practice and decision-making to promote consensus in areas of organizational, policy, and practice change. There is a need for further research using a modified qualitative Delphi method in empirical ethics and policy research in LTC, as well as other areas. However, the results of this study suggest the suitability and benefits of the approach for qualitative inquiry and propose researchers

seeking to expand research findings, knowledge mobilization, and to connect findings to meaningful and practical change should consider adopting the Delphi method.

Keywords: ethical inquiry, discourse analysis, critical theory, focus groups, methods in qualitative inquiry

What Is Already Known?

- Qualitative Delphi method is gaining more recognition alongside more traditional qualitative methods.
- The qualitative Delphi method has been used successfully in the areas of policy analysis, nursing, health services, and service-planning, though there are still a number of areas where it has yet to be used.
- There is a symbiotic relationship between qualitative research and knowledge mobilization. However, there is often a significant lag between the conduct of research and the findings reaching the public.

What This Paper Adds?

- A theoretical justification for using qualitative Delphi method in the exploration of empirical ethics and policy in long-term care.
- A brief demonstration of how qualitative Delphi can be used successfully in areas seldom explored qualitatively or empirically (such as ethics and policy in long-term care).
- A discussion regarding the advantages and benefits to using qualitative Delphi, specifically the significant implications Delphi has on reducing the lag between

the conduct of research and the findings reaching the public—highlighting the suitability and benefits of the approach for qualitative inquiry and propose researchers seeking to expand research findings, knowledge mobilization, and to connect findings to meaningful and practical change—should consider adopting the Delphi method.

Introduction

There is a symbiotic relationship between qualitative research and knowledge mobilization and dissemination. Seldom is qualitative research conducted without some form of mobilization taking place. Typically, however, knowledge mobilization/dissemination is perceived as a separate stage, occurring after the research has been completed; data are collected, analyzed, and summarized into findings that must be translated and then mobilized. As a result, there is often a significant lag between the conduct of research and the findings reaching the public (including those it impacts and those with the power to make change). In designing my study on ethics and policy in long-term care (LTC) with the aim of improving quality care, I sought a method that would not only generate broad data, but data on which stakeholders would be able to more readily act and thus promote meaningful change. With this goal in mind, I adopted an empirical ethics approach with the aim of consensus building (based on Habermas' communicative ethics) among the array of stakeholders involved in frontline ethics and policy in LTC. Although various consensus building methods exist, I adopted an innovative qualitative Delphi method to explore ethics and ethical reasoning in LTC and the interaction between frontline practice and organizational and public policy. Using a

qualitative Delphi approach to explore ethics and policy in LTC resulted in deeper, more rich findings on ethics, an area seldom empirically, or qualitatively, explored.

The purpose of this article is to discuss the benefits and ethics implications of using a qualitative Delphi method in empirical ethics and policy research. First, I will contextualize the study, providing a synopsis of the multistage research project. Second, I will provide an overview and rationale for using an empirical ethics approach and consensus building method, followed by a brief overview of Delphi as a qualitative method, and finally, I will highlight the benefits of adopting this approach in this empirical ethics and policy research.

Contextualizing the Study

This is a two-stage research project, where the first stage informed the second. The first stage of the study aimed to explore the nature and extent of ethical issues in the provision of social care in LTC facilities and the ethical framework(s) deployed by LTC staff in making decisions as to the right thing to do in such situations. The goal of the first stage of the research was to gain a better understanding of how LTC staff reason ethically, in particular, addressing the following questions: (1) How does the ethical reasoning of LTC staff reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues? (2) On which ethical frameworks do LTC staff draw in their ethical reasoning? and (3) How do LTC staff choose between competing or differing ethical values and frameworks?

In the first stage, seven interdisciplinary focus groups were conducted with 20 frontline care staff in four LTC facilities. Research Ethics Board permission was received prior to the commencement of the research, and written informed consent was sought and granted

by each participant prior to beginning the focus groups. Participants were presented with one to two vignettes of complex ethical cases to discuss and deliberate. The findings revealed staff typically do not have difficulty determining the ethical thing to do and, in fact, draw on a number of ethical frameworks during the decision-making process.

Despite this, the findings demonstrated staff frequently experience moral distress, defined as being aware of the ethical thing to do, but feeling powerless to act accordingly as a result of either real, or perceived, institutional constraints and thus engaging in perceived ethical wrongdoing (Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2005).

Participants described a number of institutional constraints that impacted their ability to act in the ways they believed to be right and ethical. The dominant constraints included a hierarchy of power and lack of autonomy, staffing restrictions and task-oriented environment, concern about liability, family power, and financial inequality.

The majority of the reported constraints resulting in staff experiences of moral distress are structural. This means they could be solved, or at least reduced, by examining and addressing the larger sociopolitical factors influencing LTC organizational policies and procedures and thus the ethical decision-making environment of staff. To better understand these potential organizational constraints, I expanded the research inquiry by adding a second stage of the research to explore the interaction between public policy, LTC organizational policies, and procedures, and how these interactions impact frontline LTC staff's ethical decisions and actions.

A qualitative Delphi method (more on this below) was used to engage 24 stakeholder experts from across the LTC sector, including residents, family members, LTC staff, professional bodies, policy makers, and organizations. In this Delphi study, participants

were interviewed twice in an effort to reach relative consensus. Research Ethics Board permission was received prior to the commencement of the research, and written informed consent was sought and granted by each participant prior to beginning the interviews. In the first round of Delphi interviews, I explored what changes needed to occur in the LTC sector to encourage better alignment between policy and practice in an effort to minimize the moral distress experienced by frontline care staff (for details on the interview processes, including examples of open-ended interview questions, see Greason, 2017). The first round of interviews identified a number of barriers to change in LTC, and stakeholders suggested whether we want to see change and policy alignment, the sector needs to address the following four areas: (1) having the right workers, (2) having strong leadership (government and organization), (3) funding and budgeting (and the rigid policies flowing from this), and (4) divided sector. The dominant themes were collated into a 2,000-word summary, which highlighted areas of convergence and divergence in opinion on the topics. For example, under the theme “funding and budgeting,” some participants suggested increased funding would allow for improved ethical care in LTC. However, others believed better spending and allocation of current funding was necessary. The summary was circulated to participants and they were asked to carefully review the document, keeping the following in mind:

- What do you agree with?
- What do you disagree with?
- Are there ideas/perspectives you had not considered before?
- Have you changed your opinion on any points or themes since the first interview?

The goal of the second round of Delphi interviews was 2-fold. First, to identify how to overcome the identified barriers in order to see change, innovation, and positive ethical cultures in LTC. Second, to further explore how addressing these four areas would improve ethical environments, and thus ethical care, in LTC. Responding to, and working off of the summary of stakeholder opinions/suggestions, participants identified and reached consensus on a number of possible solutions and proposed changes during the second round of interviews. The suggested solutions and proposed changes included:

1. Establishing the right culture, leadership, and frontline staff;
2. Strategic hiring processes;
3. Ongoing and appropriate training;
4. Government leadership, focus, and policies;
5. Sector working collaboratively for change, innovation, and improved ethical environments.

The findings from the second and final round of interviews were collated and summarized into a 3,000-word summary, which included a number of participant quotes to provide greater detail and context. The summary was distributed to participants who were first encouraged to share the findings with their organizations, colleagues, and peers and, second, as part of the Delphi process, were further encouraged to act upon and implement the discussed and agreed upon necessary changes. Now that the research has been broadly contextualized, I will provide an overview and rationale for using an empirical ethics approach and consensus building method to explore ethics and policy in LTC.

Empirical Ethics

In this study, “empirical ethics” is understood as research approaches that “see a value in using empirical data to inform the ethical analysis of practical dilemmas” (p. 466) and which combine this empirical data with moral philosophical analysis (Dunn, Sheehan, Hope, & Parker, 2012, p. 467). The rise of empirical ethics is an example of interdisciplinary work, striving to go beyond traditional normative ethical principles (Molewijk & Widdershoven, 2012). Empirical ethics argues that theories cannot be arbitrarily developed outside of the practice context, for “the way in which people reason and act in actual practice can inform ethical theory by providing normative considerations and experiences” (van der Scheer & Widdershoven, 2004, p. 72). Within under theorized areas, such as the ethical practice in LTC facilities and the ethical reasoning deployed by LTC staff (Edwards et al., 2013; Hasselkus, 1997; Powers, 2000; van der Dam, Abma, Kardol, & Widdershoven, 2012), empirical research is opportune, as “clarity about social phenomena must precede the generation of hypotheses for the purposes of prediction” (Weinberg, 2004, p. 39). In this project, empirical research is relevant for ethics in that it can make clear what normative views LTC staff actually endorse rather than what ethicists theorize are normative guidelines (Widdershoven, Molewijk, & Abma, 2009). Further, with empirical ethics, the views and the reasoning staff actually use, rather than what the official philosophy of care is within the LTC facility, are clearer. The goal is to do research for LTC staff, rather than merely about LTC staff, and qualitative research and empirical ethics begin to bridge the theory–practice gap by allowing staff to inform and guide the research, rather than external researchers arbitrarily theorizing and making assumptions about LTC staff and their ethical reasoning processes. For this project,

empirical ethics, along with the methodologies and methods adopted, allows for collaboration with those who have considerable experiential and practical knowledge of LTC (Lazar, 2007), further bridging the theory–practice gap by giving direct access to the reasoning process of LTC staff that is not necessarily available via the interview transcripts and is inaccessible in other ways for both practical and ethical reasons (e.g., observation; Barter & Renold, 2000; Hughes & Huby, 2004; Renold, 2002). Rather than using normative principles and theories alone to establish moral conclusions, the aim of adopting an empirical ethics approach in this research is to avoid the folly of assuming ethics begin from the “top-down” (philosophical theories), as described by Callahan (1999) and rather to begin at the bottom (experience and practice), where the people, practices, ethics, and concerns are, and build up.

There has been growing interest in empirical ethics and the “empirical turn” (see, e.g., Borry, Schotsmans, & Dierickx, 2005; Goldenberg, 2005; Willems & Pols, 2010), and empirical ethics has been examined in relation to a number of areas, for example, anorexia (Tan et al., 2006), caring for someone with dementia (Baldwin, 2008), and other areas of psychiatry (Widdershoven, MacMillan, & van der Scheer, 2008) and medicine (Hope, 1999). It is not, however, a popular approach to exploring frontline ethics and policy in LTC, and empirical ethicists often encounter a number of criticisms in the domain of practical ethics (Dunn et al., 2012). Dunn, Sheehan, Hope, and Parker (2012) suggest one of the reasons empirical ethics face criticism is a result of being used as a “catchall term to describe each and every approach to using empirical data within ethical analysis” (p. 466), resulting in diminished validity and distinctiveness. However, empirical ethics can be a distinguishable and valid approach if properly explicated, which

requires a shift in focus from methods to methodologies (Dunn et al., 2012). The methodologies adopted are pivotal, as they must be able to facilitate the development of logically sound, carefully reasoned, and convincing arguments with respect to the practical ethical problems at hand that actually convince those in the position(s) to make changes to these practices (Dunn et al., 2012).

In this two-phase project, the adopted methodology, critical discourse analysis (CDA), guides and informs the research practices and methods used to integrate empirical and ethical analysis and to generate “practice-oriented” spaces to engage in critical reasoning and the co-development of sound arguments (Dunn et al., 2012). In order to better understand how, and why, staff make ethical decisions in social care the way they do and how public and organizational policy hinders and/or promotes ethical cultures in LTC, we must look at the discursive forces that influence and shape LTC organizational cultures and consequently the members in them. A CDA approach to empirical ethics acknowledges that the experiences and ethical decisions of LTC staff “are wholes that cannot be understood in isolation from their contexts” (Lincoln & Guba, 1985, p. 39) and therefore focuses on the contextual and personal perceptions and values of participants (Jamal, 2012) to allow for the “nuances of multiple realities” (Lincoln & Guba, 1985, p. 40). CDA methodology facilitates the required disentanglement of the interconnected and complex facts and ethical values of the LTC practice context, while also recognizing and encouraging the integration of empirical data (individuals’ experiences and attitudes) with normative arguments. CDA achieves this disentanglement through deconstruction,

a form of analysis which exposes the multiplicity of possible meanings, contradictions and assumptions underlying our understandings and ways of knowing—to question, who benefits, and how, from the assumptions about our social world embedded in those systems of thought. (MacNaughton, 2005, p. 78)

Guided by a CDA methodology, the research practices and methods of this project aim to explore how language, knowledge, discourses, social relations, and power/inequality are constructed, sustained, or reconstructed and how these elements impact ethics in LTC.

An empirical ethics study, rooted in CDA, recognizes the importance of language and conversation in the deconstruction and reconstruction of discourses and thus directly challenges the dominant discourses in LTC, offering direct access to the voices that are seldom heard, though most directly effected, by the complex and interconnected facts and ethic values in the LTC setting. It is in this way that we see the integration of the empirical and the normative, as “individual’s share their experiences and attitudes, which are then used to inform normative arguments about how one ought, and ought not, to act in specific domains of practice” (Dunn et al., 2012, p. 471). In this research, the empirically derived normative ethic claims (arguments) are established through interdisciplinary focus groups with frontline LTC staff through the use of vignettes. The vignette is a method which is particularly valuable when exploring attitudes, beliefs, values, perceptions, meanings, and behaviors and how these facets are situationally positioned (Finch, 1987). In the first phase of the research, open-ended questions were used to facilitate the critical exploration of staff experiences and attitudes—questions were used to challenge participants’ immediate responses and encourage participants to

move beyond initial socially desirable responses, to responses more accurately reflective of the realities of practice.

Once empirically derived normative arguments are established, they should then be used in further research to help challenge, influence, and shape individual's experiences and attitudes toward ethics, as well as further contributing to the broader understanding of "ethics." Dunn et al. (2012) propose an iterative process of data collection and analysis during which the ethical reasoning of participants (practical and experiential knowledge) and relevant concepts and principles (theory) are interrogated repeatedly through multiple iterative cycles of participant interactions and analysis (of the empirical arguments derived from this process as well as the theoretical principles) in order to establish convincing empirical ethics claims/arguments. In this study, I adopted the notion of a cyclic approach to empirical ethics, though rather than interrogating participant reasoning with theory to establish empirical ethics claims, the first stage of the research aimed to empirically seek out what the ethics in practice are and then in an iterative cycle return these empirically derived normative ethic claims to the people involved in LTC practice to make a decision about how policy could potentially hinder/promote these claims. In so doing, this empirical ethics research strategy aims to make "normative ethics claims about practical situations" (p. 467) through the successful facilitation of a cyclic pattern of empirical ethics research (Dunn et al., 2012). The empirical ethics research cycle can be facilitated in a number of ways, however, being guided by a CDA lens, and in an attempt to establish and promote the flexible practice-oriented spaces for ethics researchers (me) and practitioners (participants) to co-construct relevant ethics claims, the second phase of this project adopted a consensus building

approach for further exploration of the normative ethic claims made by frontline care staff in the first phase of the project and for further determining ethics in LTC.

Why Consensus Building?

Critical theory, such as CDA, has two goals: first, to identify the issues (diagnostic aim) and second, to use this knowledge to create environments of change and improvement (remedial aim; Finlayson, 2005). In this sense, critical theory aims to not only theorize and describe what the issues are but to also do something about the issues. Habermas (1984) is considered one of the leading critical theorists of the second generation of critical theory, and it is his theory of communicative action and social ontology which form the theoretical and philosophical basis for using a consensus building approach for further determining ethics and policy in LTC.

Habermas (1984) proposes that through socialization, individuals learn what is “right” and what is “not” based on punishment or affirmation and begin to identify with the collective moral consciousness of the society they are in (Finlayson, 2005). This, Habermas (1984) suggests, is accomplished through the use of language and “validity claims,” which serve to establish ethics through discourse (known as discourse or communicative ethics. Validity claims are commitments individuals make to justify her or his actions and words to others through sound reasoning and result in obligations (through commitment) toward other individuals and thus carry a moral status (Finlayson, 2005; Habermas, 1984). Validity claims “provide the invisible lines along which sequences of interaction unfold, and which guide agents away from conflict” (Finlayson, 2005, p. 27). Thus, we see how mutual agreement of sound reasoning, through language and interaction, “coordinates the actions of a plurality of individual agents” (p. 34) and

results in conflict-free social order (Finlayson, 2005). Language is able to achieve this order because of its “inherent aim (or telos) of reaching understanding or bringing about consensus” (Finlayson, 2005, p. 34). Through validity claims, communicative action—where compliance of requests is attained on the basis of another accepting the reasons for the request—is possible rather than instrumental action—where individuals are coerced into complying with requests (Finlayson, 2005; Habermas, 1984). With communicative action, acceptance of requests and consensus is not forced but rather the result of inviting another to participate in a two-way dialogical process of agreement (Finlayson, 2005; Habermas, 1984).

In capitalist societies, there is a growing disregard and unimportance placed on participatory democracy practices such as communicative action (Frank, 2000). Communicative action, where individuals can talk about differences and come to a common understanding, is increasingly replaced by the domination of certain individual(s) (or interests) because they have more money or power (Finlayson, 2005; Frank, 2000). Individuals have fewer spaces for communicative action (Frank, 2000). Without communicative practices, individuals’ validity claims are rejected (vs. having them accepted), and there is little (or no) opportunity to have a moral discussion and to reach mutual acceptance and understanding of the claim; that is, there is no room to establish and repair consensus (Finlayson, 2005). In terms of ethics, not having the opportunity to engage in communicative practices results in two areas of concern. First, it produces socialized moral agents who have learned what is “right” and how to act based on a framework of conflict and coercion, rather than truly agreeing with their actions, frequently resulting in experiences of moral distress. Second, without communicative

action and discussion, ethics approaches often ignore the social factors, which create the contexts and limits of the moral decisions and actions individuals can make (Callahan, 1994), consequently separating ethics knowledge from the context of everyday life; thus, “the gap between what we know, and how we live, widens” (Finlayson, 2005, p. 65).

Adopting an analytical framework, as communitarian ethics suggests, which looks not only at the personal level of ethics (individual decisions) within a vacuum, but rather at the social dimensions of such individual decisions (the discursive forces influencing the context and “options”) allows for a better understanding of why people make ethical decisions in the ways they do. Similarly, such an approach to ethics expands the scope of analysis to include a multitude of voices within the community in an effort to blend individual judgment (personal judgment) and collective judgment (cultural/environmental/organizational judgment; Callahan, 1994). Blending individual and collective judgment within pluralistic environments such as LTC requires a common effort, for without this, individuals will continue to make decisions and take action based on coercion, flowing from those with the most money and power, and real change in ethics can never occur. Habermas emphasized, “all successful action in the real world depends on the capacity to reach consensus” (Finlayson, 2005, p. 49), and to reach consensus, we need to foster environments of dialogue exchange and communication. To see collective/organizational changes in ethics in LTC, all of the individuals involved in, and impacted by, this collective judgment should be invited to participate in the discussion (Habermas, 1984; Moody, 1984).

In discussing the “ethics of ambiguity” (p. 95) in dementia care, Moody (1984) proposes that the response to complex and ambiguous ethical contexts

is communication, and while my research does not specifically focus on dementia, LTC environments are morally complex and ambiguous landscapes (Kuczewski, 1999). Using a communicative ethics approach to facilitate consensus building and establish ethics requires us to widen the scope of analysis to include more facets and interests than those typically included in ethics research and policy development (Moody, 1984).

“Communicative ethics, in sum, offers a powerful alternative to the ethics of rules and principles so pervasive in contemporary thinking about ethical issues” (Moody, 1984, p. 99) and could be a transformative approach to ethics in LTC by offering a wider, and more empirically derived, perspective. When individual players reach a consensus, it creates an active participatory process, reduces the tension between groups, promotes ownership, fosters an environment supportive of change, and narrows the gap between philosophy and the daily lived experiences from where it draws its insights (Finlayson, 2005). Further, consensus building challenges and aims to rectify the oppressive effects of silencing and marginalization inherent to many of the dominant discourses in LTC, including the discourses of biomedicine (Estes & Binney, 1989), efficiency (Tonuma & Winbolt, 2000), risk (Clemens & Hayes, 1997), and ageism (Butler, 1975).

There are, of course, a number of methods to facilitate group research, consensus building, and establish communicative ethics. One such approach, and the approach adopted in this empirical ethics study, is a qualitative Delphi method.

Qualitative Delphi Method

The Delphi method originates from a Cold War study, “project DELPHI,” conducted by the RAND Corporation to forecast the impact of technology on warfare (Dalkey & Helmer, 1963). Since its inception, the Delphi method has expanded and more

recently is beginning to gain more recognition and support as a qualitative method; the Delphi method has been used qualitatively to explore health leadership (Fletcher & Marchildon, 2014), community organizing (Brady, 2015), public policy (Alexander, 2004), and social justice and human rights issues (Jamal, 2014). As a quantitative method, Delphi is systematic and uses a series of controlled and preformulated questionnaires to reach statistical consensus among experts on a particular issue. Many modifications have been made to the original structured approach of the Delphi method to meet diverse research applications (Fletcher & Marchildon, 2014). Despite adaptations to the method, the fundamental purpose of using the Delphi method is to enable “structured communication” with the goal of reaching “convergence of opinion concerning real-world knowledge solicited from experts within certain topic areas” (Hsu & Sandford, 2007, p. 1). “Structured communication,” as described by Linstone and Turoff (2002), involves an iterative multistage process. As such, Delphi method requires (1) some feedback of individual contributions of information and knowledge, (2) assessment of the group judgment or view, (3) some opportunity for individuals to critically revise their personal views, and (4) some degree of anonymity for the individual responses (Hsu & Sandford, 2007, p. 3). While there is some disagreement on the “best way” to accomplish these aspects of Delphi (Linstone & Turoff, 1975, 2002), the emphasis is to ensure these criteria are met, in some way, in order to facilitate an iterative multistage process, which enables the transformation of individual perspectives into group consensus (Jamal, 2012).

As a qualitative method, this “structured communication” can take many forms; however, typically, Delphi involves multiple (at least two) rounds of interviews (Ziglio,

1995). During the first round of interviews, referred to as the “exploration phase” (Ziglio, 1995, p. 9), individual participants draw on their expertise to explore and contribute pertinent knowledge and insights relating to the subject under analysis (e.g., ethics and policy in LTC). Once the first round of interviews is completed with all participants, the responses are analyzed and coded thematically as to participants’ views, with emerging themes being collated and circulated to participants, prior to a second round of interviews, in which they are invited to comment on the themes from the first (Greason, 2017). Further exploration and evaluation of participants views occur in the second round of interviews, which Ziglio (1995) refers to as the “exploration phase” (p. 9). In the exploration phase, the researcher(s) pay close attention to areas of agreement or disagreement and invite individual participants to further explore and reevaluate their responses in relation to those of other participants. This multistage approach fosters an iterative process of knowledge production, reflection, and translation, as the findings from each Delphi round form the basis of discussions in the subsequent round (Brady, 2015; Fletcher & Marchildon, 2014; Linstone & Turoff, 1975; for more details on how the qualitative Delphi process operated in this project, see Greason 2017).

Panel members are considered “stakeholder experts,” not simply because they are the individuals in positions of power or superiority, but because they have knowledge and experience of the issues, are directly affected by the subject, or have specialist skills in the area under investigation (Adler & Ziglio, 1996; Gabb, Balen, Gibbs, Hall, & Teal, 2006; Greason, 2017; Jamal, 2012). Emphasizing the importance of including a diversity and multiplicity of voices, Linstone (1978) highlights Delphi method cannot be confined to only including “experts” in the traditional sense, but in matters of policy change, the

greater public must be included; "...it is therefore important to include in the Delphi representatives of a large or wide spectrum of vested interests, ranging from bureaucrats to minority groups" (p. 294).

Hsu and Sandford (2007) suggest if your research aims to achieve any of the following objectives, Delphi is an appropriate method for your research (1) to determine or develop a range of possible program alternatives, (2) to explore or expose underlying assumptions or information leading to different judgments, (3) to seek out information that may generate a consensus on the part of the respondent group, (4) to correlate informed judgments on a topic spanning a wide range of disciplines, and (5) to educate the respondent group as to the diverse and interrelated aspects of the topic (p. 1). Despite having various applications and being modified over the years, the fundamental purpose for using the Delphi method "remains the collection of informed judgment on issues that are largely unexplored, difficult to define, highly context and expertise specific, or future-oriented" (Fletcher & Marchildon, 2014, p. 3).

Qualitative Delphi approaches have been adopted and successfully used in a number of areas, including policy analysis, medical, nursing, health services, and service planning (Gibson, 1998; Jamal, 2012; Williams & Webb, 1994). However, Delphi has not been used to explore ethics and policy in LTC, despite the many benefits of using such a method in this underexplored area of research (Fletcher & Marchildon, 2014; Ziglio, 1995).

Advantages and Benefits of Using Delphi in Empirical Ethics and Policy Research

Adopting a qualitative Delphi method to explore ethics and policy in LTC was extremely successful and resulted in deeper, more rich, findings on ethics and policy

change in LTC that would not have been achieved if other consultative methods had been used. Below I will explore the promising advantages and benefits of using a qualitative Delphi method in empirical ethics and policy research specifically. However, the benefits are transferable to many other qualitative areas, and as this study suggests, adopting a qualitative Delphi approach has vast potential for both qualitative research findings and knowledge mobilization.

Broadly, Delphi method addresses some of the shortcomings of alternative consultation research methods: it starts from a position of openness, it allows participants to question the assumptions of other experts as to the issues, preferences, and ways forward, it aims toward consensus (and thus commitment to the outcome), it is comprehensive and inclusive, and it allows for the transfer of knowledge as part of the process (Powell, 2003). One of the benefits of Delphi is that through its communicative and inclusive approach, consensus can be reached in an area where there is a lack of empirical knowledge (Fletcher & Marchildon, 2014; Mead & Moseley, 2001; Murphy et al., 1998; Powell, 2003; Ziglio 1995, 1996) and where there are a number of diverse and invested individuals/groups. This makes it a particularly valuable and pertinent technique for achieving consensus building in terms of ethics and policy in LTC. The landscape of LTC is complex and ambiguous, thus the complexities of ethics, decision-making, and policy in LTC cannot, and will not, be resolved by any single group. Given the interconnected and interdisciplinary nature of LTC, adopting a qualitative Delphi method allowed for relative consensus to be reached among a vast array of players. In reaching consensus, the iterative nature of Delphi created an active participatory process, reduced tension between groups, promoted ownership, fostered an environment supportive of

change, and narrowed the gap between philosophy and the daily lived experiences from where it draws its insights (Finlayson, 2005). The resulting consensus ultimately reflects a collective view rather than an individual view that would have resulted from using other consultation methods.

The resulting collective view also goes a long way in facilitating timely action toward meaningful change. While there is a growing body of literature on ethics in LTC, often the findings are philosophical in nature, making the translation into practice challenging, at best. A different approach to researching the ethical dilemmas and policy implications in LTC is needed if we want research in these areas to move beyond philosophies and research papers and into the realm of practice and change. Adopting an empirical ethics approach in conjunction with the Delphi method moves the research in this direction, allowing for more practical, tangible findings that can/should be acted on. Having a multitude of stakeholders participate in the research means those in positions of power to change policy at the LTC organizational and public levels are actively involved in the generation of knowledge, its evaluation, and assessment of its potential application. This is where Delphi moves beyond the typical “sharing of findings” that is standard in qualitative research. First, Delphi is an active research method, which goes further than merely seeking individual stakeholder opinions and perspectives. Delphi challenges stakeholders, asking them to reflect and reconsider their perspectives and opinions based on those shared by others in an effort to reach consensus. Second, by drawing on the views of various stakeholders, achieving consensus, and producing tangible practice/policy outcomes, Delphi inherently involves an array of knowledge mobilization activities including knowledge synthesis, transfer, exchange, and co-creation/production

by researchers and knowledge users (Social Sciences and Humanities Research Council, 2018). Further, as Delphi iteratively aims to establish consensus on “ways forward” and produce tangible and applicable outcomes in underexplored areas, it involves up to stage three of the knowledge transition portion of Graham’s Knowledge to Action-Ethics cycle, which “represents the process of knowledge creation and its translation into practice and policy” (see Graham et al., 2006).

In addition, the final summary of findings, containing tangible and applicable solutions and/or directions needed for change, is circulated to all participants. Those in influential positions, or positions of power, are encouraged to act upon the findings, thus facilitating meaningful change. Circulation of the final summary to all of the diverse participants also means the findings reach a wider audience more quickly, as stakeholders are asked to circulate and share the results with their colleagues and within their organizations. Similarly, in this way, the lag between the conduct of the research and the findings reaching the public (including those most impacted by the results) is notably reduced.

Despite taking the research further than traditional ethics and policy exploration, there are still challenges to facilitating the translation of findings into policy and practical changes. Particularly, in this research, where the some of the findings identified ethical issues related to high-level policy and governmental operations. Although the Delphi method allowed for various stakeholders, including those at political and governmental levels, to discuss and explore these issues and propose possible avenues for change, instituting such changes will require significant policy and procedural changes at a *systemic* level.

For example, one of the main findings of the Delphi interviews was the need to have strong government leadership, focused on LTC, and the development of relevant LTC policies. Stakeholders expressed "...for nursing homes and long term care, there's been very little investment in the sector outside of the bricks and mortar." Many stakeholders demonstrated an appreciation and understanding that governments "are pulled in many directions." However, also expressed minimal investment and focus on LTC and aging in the province has resulted in (1) no strategic plan for aging and LTC and (2) an outdated system made up of irrelevant and inflexible policies and models of care. Stakeholders suggested a number of possible reasons for the lack of investment/focus on LTC at a government level. Stakeholders shared that elected officials are afraid to make difficult decisions and "get turfed out of office" or "be on the front page of the paper" and are often more concerned with election/reelection than truly making change. Others suggested getting rid of fixed election dates and "allow[ing] governments to sit for five years" would make a big difference in what governments could accomplish, while others expressed that the frequent turnover of ministers does not allow for engagement and/or change. Further, stakeholders discussed how at a governmental level, the sector serving nursing homes and LTC is understaffed and has limited resources and autonomy, resulting in minimal space for discussions about change and innovation. Further, stakeholders overwhelmingly agreed that the majority of LTC policies are outdated and inflexible and need to be updated. When asked whether policy makers were aware of the realities of LTC, stakeholders all responded "no" or "I don't think so." Many stakeholders suggested that the lack of government/policy maker understanding and limited focus on LTC results in decision-making that negatively

effects LTC staff and residents: “Government officials are...they’re focused on funding, licensing, and monitoring. They’re not focused on quality of life.” Stakeholders repeatedly said policy makers need to “come and spend a day here and really see, you know, what a real day is in the life of a resident,” and similarly, “those policy makers need to have a good understanding of each, what’s going on in the homes—they need to go and see what’s going on...to see what’s working and what’s not working.”

Additionally, stakeholders expressed how “not one size fits all” in LTC, and that policies need to be developed with an understanding “that what works in one home might not work in another,” and that “not everything has to be carried out in every home.”

Stakeholders also agreed that while there is a need for policies and regulation in LTC, current policies and inspection processes are rigid and do not provide an accurate report of residents’ experiences or the quality of care in homes. Stakeholders agreed that inspection processes need to change to include more holistic and resident-centered quality indicators.

While these suggested changes provide tangible solutions and reflect a collective view, the identified issues and proposed resolutions are multifaceted. Implementing such changes would require collaboration across sectors, political will, and significant investment (both personnel and financial). Further, instituting the proposed solutions would impact a number of systems and processes, including provincial budgeting and funding streams, employment regulation, political organization, and legislative procedures (to name a few). So while adopting a qualitative Delphi method to explore ethics and policy in LTC brought the findings further than typical methods used in this area of research and resulted in agreed upon solutions and ways forward, there can still be

significant challenges to connecting the findings to meaningful change. However, not all of the proposed solutions from the collective view present such systemic hurdles. When asked what could be done to ensure the LTC sector was getting the “right” administrators, RN leaders, and frontline workers, stakeholders consistently discussed the significance of hiring practices, stressing the importance of adopting more strategic hiring processes. Stakeholders proposed a variety of strategic hiring process changes that are applicable at every level of staffing/hiring. Participants consistently expressed how potential staff, whether the administrator or frontline worker, need to be asked about their values and “why” they are interested in working in LTC. Some stakeholders suggested exploring values could be accomplished by conducting more purposeful interviews where individuals were asked specific questions about character and personality. Others proposed using a personality/psychometric test as a hiring tool to provide a more holistic understanding of the individual. Stakeholders also discussed how job descriptions are often vague and suggested that more specific descriptions, outlining qualifications, characteristics, and expectations of the role are necessary if we want to get the “right people” working in LTC. Finally, regarding all levels of staff hiring, the importance of involving peers, and in some cases residents, in the hiring process was suggested. As one stakeholder shared, “Because there’s been people hired and we’ve just went, “Pfft. Great. That’s just great now, isn’t it?” We could have told them a long time ago, you know, “No, this person was lazy as a [RA], do you think they’re going to be any better as an RN? I don’t think so. They’re going to be worse.” While the majority of stakeholders agreed that changes were needed in LTC for strategic hiring to take place, they also

recognized and emphasized that once the “right” individuals were hired, they required continuing support and encouragement through ongoing and appropriate training.

Although these suggested solutions would require organizational will and commitment to change, there is minimal investment required to implement the proposed strategic hiring and ongoing training. Yes, there will always be the argument in LTC of staff availability and funding for training, however, there are a number of creative ways to incorporate free training and encourage staff to attend at minimal expense (e.g., lunch and learns where the education is provided by professional bodies, researchers, and/or students). Of course, for qualitative Delphi to be truly impactful, at least in this context, it also takes commitment from the researcher to follow-up with participants to see whether they have any questions regarding the final summary (and proposed ways forward) and to encourage the adoption of the suggested changes. This might require ongoing discussions, support, collaboration, and resource connection. However, given that the LTC sector continually expresses the barriers of limited staff and funding, and management being stretched thin, it is unlikely that without such follow-up and support, the changes will be implemented. Consequently, successful use of the qualitative Delphi method in the areas of ethics and policy in LTC requires, first for the researcher(s) to develop a trusting relationship with stakeholders, and second, serious commitment to the project and the translation of findings into meaningful change.

Another significant advantage to adopting a qualitative Delphi method in the exploration of ethics and policy in LTC is that through the iterative nature of Delphi, knowledge translation and mobilization are built into the method itself. As participants engage in multiple rounds of interviews, they are invited to reflect upon, discuss, and

explore their own views and opinions in relationship to those of other participants, in a safe and anonymous context. Interacting with the findings in this way encourages an iterative process of knowledge production, reflection, and translation, which sets a strong foundation for *further* knowledge translation and mobilization. It is beneficial that within the research process, knowledge translation and mobilization can occur rather than waiting for a secondary stage of mobilization following the conduct of the research, as is typically the case.

Adopting a qualitative Delphi approach to ethics and policy in LTC may have been innovative, involving some reimagining of the approach, yet the successful use of the method in these areas of research is promising and suggests the applicability of qualitative Delphi in these, and other qualitative, areas. Here, Delphi allowed for deeper, more rich, findings on ethics and policy in LTC because the method inherently works from the bottom up, involving those most directly affected by the topics rather than a select few individuals arbitrarily theorizing about ways forward. In this way, the ethics practices and concerns staff truly endorse are explored and accounted for in the research. This results in practical and applicable research findings rather than arbitrary theories, thus promoting meaningful change.

Qualitative research is inherently exploratory, with the purpose of gaining insights into particular areas and/or developing hypotheses with respect to ways forward and toward change. While the Delphi method is just starting to gain more recognition alongside more well-known qualitative methods, it has the potential of taking qualitative and empirical research further, expanding the reach and depth of inquiry and findings, as it draws on real-world practice and decision-making to promote consensus in areas of

organizational, policy, and practice change. There is a need for further research using a modified qualitative Delphi method in empirical ethics and policy research in LTC, as well as other areas. However, the results of this study, and those of others using Delphi in qualitative research (see, e.g., Brady, 2015; Fletcher & Marchildon, 2014; Jamal, 2016), suggest the suitability of the approach for qualitative inquiry and propose researchers seeking to increase the breadth of research findings, knowledge mobilization, and practical change should consider adopting the Delphi method.

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Interlude Two: On qualitative Delphi techniques

Paper two provides a theoretical justification of the methodologies used in the second stage of the research to explore the interaction between public and organizational policy and frontline ethical decision-making. However, a critique of the qualitative Delphi method is that there is a lack of literature describing qualitative techniques or processes (Fletcher & Marchildon, 2014; Brady, 2015). Thus, the following chapter aims to contribute to the literature on the specific processes used in this qualitative Delphi study, providing a step-by-step guide.

This paper is a published article in *Research Methods Cases*. The Case Studies are designed to be a resource to inspire and guide students and early career academics on their own research journeys by providing experiential accounts of conducting research using particular research methods. Authors are asked to address the challenges and benefits of using a particular research approach, the reasons for choosing one methodological approach over another, tips for conducting research using a particular method, practical lessons learned, etc. Thus, the article is written to be more conversational than academic and includes exercises and discussion questions.

This article was written while the second Delphi interviews were being conducted and consequently the sections on completing the second round of analysis and collation are discussed more generally [*more on the second round of exploration can be found in Paper Two*].

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Paper Three: Empirical ethics in LTC: Using Delphi method as a form of consensus building

Abstract

This case study reports on a two-stage empirical ethics research project, focusing on the second stage of the research where Delphi method was used as a form of consensus building. Conducted as part of my MA-PhD, the goal of this project was to better understand empirical ethics in long term care (LTC) practices, and the interaction between public policy and the ethical environment in LTC. Findings from the first stage of the project revealed that frontline staff frequently experience moral distress- being aware of the ethical thing to do, though feeling powerless to act accordingly as a result of either real, or perceived, institutional constraints. The emerging theme of moral distress informed the second stage of the research where Delphi methodology was used to facilitate consensus building amongst stakeholder experts, through an iterative process of knowledge production, reflection and translation. The goal of this case study is to provide a better understanding of the Delphi method generally, and specifically as a consensus building method in empirical ethics research. The case study will:

- 1) Provide a brief overview and context of the project;
- 2) Share my experiential account of designing the research project, examining methodology, empirical ethics, and consensus building;
- 3) Explore the method in action; a step-by-step account of how the Delphi method was carried out;
- 4) Provide a candid report of the research practicalities I encountered, and;
- 5) Share some practical lessons I have learned, which I hope will be helpful to you in

some way as you journey through your research.

Key Words:

Delphi method, empirical ethics, consensus building, long term care, qualitative research

Learning Outcomes

By the end of this case students should be able to:

- Demonstrate an understanding of Delphi as a qualitative, empirical method;
- Demonstrate an understanding of empirical ethics;
- Explain the benefits of using Delphi method generally, and in an empirical ethics study;
- Recognize and prepare for the methodological and research practicalities/challenges involved in using a qualitative Delphi method;
- Broadly describe the different stages of the Delphi method.

Case Study

Project Overview and Context

In 2014 I began my Master's degree and subsequent research project exploring ethics in long term care (LTC) at the University of New Brunswick. The research quickly grew and before I knew it the research had evolved into a PhD. The result was a two-stage research project, where the first stage informs the second. Below we will briefly explore both stages of the research, providing an overview and context of the project before digging a bit deeper into: 1) the design of the research, 2) the method in action, 3) research practicalities, and 4) concluding with some practical lessons I have learned throughout this process, which I hope will be helpful to you in some way as you journey

through your research.

Both stages of my research project are part of a larger study developed and organized in collaboration with the Centre for Interdisciplinary Research on Narrative (CIRN) at St. Thomas University. The first stage of my research project (discussed below) informs subsequent phases of the larger research project. In partnership with five LTC facilities in New Brunswick, this two-stage research project focuses on empirical ethics in LTC practices, and the interaction between public policy and the ethical environment in LTC. In the **first stage** of my research I examined the nature and extent of ethical issues in the provision of social care in LTC facilities, and the ethical framework(s) deployed by LTC staff in making decisions as to the right thing to do in such situations. The goal of the first stage of the project was to explore and better understand how LTC staff reason ethically, in particular, I addressed the following questions: **1)** How does the ethical reasoning of LTC staff reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues? **2)** On which ethical frameworks do LTC staff draw in their ethical reasoning? **3)** How do LTC staff choose between competing or differing ethical values and frameworks (e.g. principlism, ethics of care, consequentialism), **4)** How and do LTC staff structure their arguments in deciding upon the ethical thing to do? **5)** What is the impact of organizational culture on ethical decision-making among LTC staff? For stage one I drew on existing transcripts of qualitative interviews with LTC staff and designed five vignettes describing hypothetical situations in which ethical issues arise for LTC staff. The purpose of the vignettes was to provide participants realistic case scenarios, drawn from their experiences in LTC, providing access to how staff think and reason through

these cases. Seven interdisciplinary focus groups were conducted, each consisting of two-four frontline staff participants who were presented with, on average, two vignettes for discussion. Organizational documentation (e.g. philosophies of care, policies, etc.) was also collected and analyzed to understand the context in which LTC staff operate.

Data from stage one revealed frontline staff perceive, and therefore make ethical decisions, within a very different organizational culture and environment than the one the LTC facilities espouse and seek to achieve through policies and procedures. Despite this misalignment, the findings suggest frontline staff use a variety of normative ethical frameworks to make decisions, and typically do not have difficulty determining the ethical thing to do, though frequently experience moral distress; defined by Austin et al. (2005) as being aware of the ethical thing to do, though feeling powerless to act accordingly as a result of either real, or perceived, institutional constraints, and thus engaging in perceived ethical wrong doing.

The emerging theme of moral distress informed the **second stage** of the research, which sought to explore how the interaction between frontline practice, organizational philosophies, and public policy promotes and/or hinders the development of an *ethical culture* in the provision of LTC. The second stage of this project adopted a consensus building approach for further exploration of the normative ethic claims made by frontline care staff in the first stage of the project, and to further understand the interaction between public and organizational policies and the impact on frontline ethics in LTC. Delphi method, developed by Dalkey and Helmer (1963), was used, which draws on the views of ‘stakeholder experts’ (residents/family/staff, professional bodies, and policy makers) and seeks opinions on a range of issues through consecutive rounds of

consultation. The practicalities and details of the Delphi method will be further explored below (see, ‘method in action’ and ‘research practicalities’), however first we should begin with *why* Delphi method was chosen for this research, which is rooted in the research methodology and design.

Research Design

This is a research project on empirical ethics, taking as its dual starting points that ethical theory can benefit from empirical data and ethics and experience are integrally linked. Molewijk and Widdershoven (2012) express that empirical ethics emerged as a reaction to the problematic identification of bioethics as “unquestionably” normative, and the rise of empirical ethics is an example of interdisciplinary work, striving to go beyond traditional normative ethical principles. Empirical ethics argues that theories cannot be arbitrarily developed outside of the practice context. Within under-theorized areas, such as the ethical practice in LTC facilities and the ethical reasoning deployed by LTC staff, empirical research is opportune as it can make clear what normative views LTC staff *actually* endorse, rather than what ethicists theorize are normative guidelines. Further, with empirical ethics, the views and the reasoning staff actually use, rather than what the official philosophy of care is within the LTC facility, are clearer. The goal is to do research *for* LTC staff, rather than merely *about* LTC staff and qualitative research and empirical ethics begin to bridge the theory-practice gap by allowing staff to inform and guide the research, rather than external researchers arbitrarily theorizing and making assumptions about LTC staff and their ethical reasoning processes.

For this project, empirical ethics, along with the methodologies and methods adopted, allow for collaboration with those who have considerable experiential and

practical knowledge of LTC, further bridging the theory-practice gap by giving direct access to the reasoning process of LTC staff that is inaccessible in other ways for both practical and ethical reasons (e.g. observation). Rather than using normative principles and theories alone to establish moral conclusions, the aim of adopting an empirical ethics approach in this research is to avoid the folly of assuming ethics begin from the “top down,” (philosophical theories) as described by Daniel Callahan (1999), and rather, to begin at the bottom (experience and practice), where the people, practices, ethics, and concerns are, and build up.

In this two-phase project, the adopted critical discourse analysis methodology guides and informs the research practices and methods used to integrate empirical and ethical analysis. In order to better understand how, and why, staff make ethical decisions in social care the way they do, and how public and organizational policy hinders and/or promotes ethical cultures in LTC, we must look at the discursive forces that influence and shape LTC organizational cultures and consequently the members in them. A critical discourse analysis approach to empirical ethics acknowledges that the experiences and ethical decisions of LTC staff cannot be understood in isolation from one another, but rather seeks to explore how language, knowledge, discourses, social relations, and power/inequality are constructed, sustained, or reconstructed, and how these elements impact ethics in LTC. An empirical ethics study, rooted in critical discourse analysis, recognizes the importance of language and conversation in the deconstruction and reconstruction of discourses, and thus directly challenges the dominant discourses in LTC, offering direct access to the voices that are seldom heard, though most directly effected, by the complex and interconnected facts and ethic values in the LTC setting. It

is in this way that we see the integration of the empirical and the normative.

Critical theory, such as CAD, aims to not only theorize and describe what the issues are, but to also do something about the issues. In this study, the goal is to empirically seek out what the ethics in practice are, and then return these normative ethic claims to the people involved in LTC practice to make a decision about how policy could potentially address the claims, thus providing possible solutions and/or alternatives to achieving an ethical culture in LTC environments. Because the landscape of LTC is complex and ambiguous, and involves a variety of invested individuals, the complexities of ethics, decision-making, and policy in LTC cannot, and will not, be resolved by any single group. Given the interconnected and interdisciplinary nature of LTC, an empirical ethics approach, with a goal of reaching consensus amongst the vast array of players, is imperative for successful action and change.

In this study, the goal is to empirically seek out what the ethics in practice are, and then return these normative ethic claims to the people involved in LTC practice to make decisions about, and reach consensus on, how policy could potentially address the claims. A consensus building approach expands the scope of analysis to include a multitude of voices within the community in an effort to blend individual judgment (personal judgment) and collective judgment (cultural/environmental/organizational judgment) (see Callahan, 1994). When individual players reach a consensus it creates an active participatory process, reduces the tension between groups, promotes ownership, fosters an environment supportive of change, and narrows the gap between philosophy and the daily lived experiences from where it draws its insights. Further, consensus building challenges and aims to rectify the oppressive effects of silencing and marginalization

inherent to many of the dominant discourses in LTC by including a wide range of voices in the discussion. While there are a number of methods to facilitate group research and consensus building, the adopted approach in this empirical ethics study, is the Delphi method.

Delphi Method

Defined by Linstone and Turoff (2002), the Delphi method, is an approach that allows a number of individuals to collectively work through a complex problem through group communication. Aligning well with principles of critical discourse analysis and empirical ethics, Delphi method aims to achieve a “collective view” about an issue on which there is limited knowledge, and where better understanding of that issue is necessary before effective decision making can occur. To obtain a “collective view,” Delphi emphasizes the importance of including a diversity and multiplicity of voices, from bureaucrats to marginalized groups, as “stakeholder experts” in the group communication and consensus building process. Participants (panel members) are considered “stakeholder experts” because they have knowledge and experience of the issues, are directly affected by the topic, or have specialist skills in the subject matter. Contrary to other consultative methods, the Delphi method seeks to identify “what could/should be,” rather than “what is,” which aligns with, and addresses, the dual aims of critical theory and critical discourse analysis (not only theorize and describe what the issues are, but to also do something about the issues). Powell (2003) suggests Delphi method goes a long way in addressing some of the failings of previous consultation methods: it starts from a position of openness; it allows participants to question the assumptions of other parties as to the issues, preferences and ways forward; it aims

towards consensus (and thus commitment to the outcome); it is comprehensive and inclusive; and, allows for the transfer of knowledge as part of the process. Hsu and Sandford (2007) highlight that Delphi method can be (and has been) used to facilitate policy-making and to successfully: 1) determine or develop a range of possible program alternatives, 2) explore or expose underlying assumptions or information leading to different judgments, 3) seek out information that may generate a consensus on the part of the respondent group, 4) correlate informed judgments on a topic spanning a wide range of disciplines, and 5) educate the respondent group as to the diverse and interrelated aspects of the topic.

Delphi method was originally designed as a quantitative method, however more recently, Delphi method has expanded and gained more support and significance as a qualitative method. As a qualitative method, consensus is achieved as participants engaged in multiple rounds of consultative interviews, evaluating and re-evaluating their perspectives and responses based on collated feedback from group responses. During the first round of interviews, individual participants freely explore and contribute knowledge and insights they believe to be pertinent to the subject under analysis (e.g. ethics and policy in LTC). These interviews are analyzed and coded thematically as to participants' views, with emerging themes being collated and circulated to participants, prior to a second round of interviews, in which they are invited to comment on the themes from the first. During the second round, further exploration of participants views are conducted, paying close attention to areas of agreement or disagreement, and inviting individual participants to further explore their responses in relation to those of other participants'. The Delphi process involves an iterative process of knowledge production, reflection and

translation as the findings from each Delphi round form the basis of discussions in the subsequent round. Through Delphi method, individuals are invited to *actively* participate through critical exploration and reevaluation of their initial perspectives and values, in light of the responses of a diverse panel of participants. Such an interactive and explorative process transforms individual perspectives and experiences into group consensus. Through this empirical ethics consensus building process, my goal is to reduce tension between players, promote ownership through participative action, and foster an environment supportive of policy and ethics change in LTC, rooted in the experiential knowledge of those living and working within the practice context.

Linstone and Turoff (1975) propose that group communication and a “collective view” established through Delphi method requires, 1) some feedback of individual contributions of information and knowledge, 2) assessment of the group judgment or view, 3) some opportunity for individuals to critically revise their personal views, and 4) some degree of anonymity for the individual responses (p. 3). While there is some disagreement on the “best way” to accomplish these aspects of Delphi the emphasis is to ensure these criteria are met, in some way, in order to facilitate an iterative multistage process which enables the transformation of individual perspectives into group consensus. Let’s now take a look at the “method in action” to further explore how my research project accomplished these aspects of Delphi.

Method in Action

My Delphi study was completed as a two-stage qualitative interview process conducted between December 01, 2015 and October 31, 2016. Below I will expand on each stage of the process: 1) first round of interviews, 2) data analysis and summary of

round one findings, 3) second round of interviews, and 4) data analysis and summary of round two findings.

Round one interviews

Following the recruitment of participants (for more on this see below) I had a wide-range of stakeholder experts representing various players in the LTC sector, including residents, family members, LTC staff, professional bodies, policy makers, and organizations. Twenty-four stakeholder participants engaged in the first round of interviews. The goal of the first round was to discuss and explore how policy promotes and/or hinders an ethical environment in LTC, flowing from the findings of stage one focus group interviews, which identified the misalignment between public/organizational policies and the organizational environments and moral distress experienced by frontline staff. During the first round of interviews participants were asked appreciative inquiry questions to generate open-ended discussions about ethics in LTC. Appreciative inquiry asks positive questions about a topic, in this case policy and ethics in LTC, in order to promote constructive discussions and inspire action. Examples of the appreciative inquiry questions used:

- What do you believe current approaches to LTC are doing well?
- What inspires you to continue working/engaging in issues re: older adults and LTC?
- What do you hope to contribute?
- What small changes do you think could be made right now in LTC?
- What partnerships do you think we need to move forward in some of the ways you've suggested?

In addition to the appreciative inquiry questions, small “snap shots” created from the focus group data were used to promote further discussions regarding the frontline experiences of ethics in LTC, as well as to bring real life examples of ethical issues and moral distress to light for stakeholders who may have less experience with frontline work. The snap shots covered a number of topics identified by frontline staff as ‘institutional constraints’ influencing their ability to provide ethical care.

Interviews, on average, were one hour and were audio recorded, transcribed verbatim, and following the completion of interviews were coded and analyzed for emerging and dominant themes.

Data analysis and summary of round one

Twenty-three interviews were completed in round one (two participants, volunteers at a LTC home, completed the interview together) and there were a variety of emerging themes covering a wide range of topics- which is to be expected given the range of stakeholder participants. The initial interviews were coded for each possible theme, however, as subsequent interviews were analyzed dominant themes became clearer and coding became more specific based on the dominant topics of conversation within and across interviews.

Following the completion of analysis there was still a wide range of themes and in an effort to choose themes reflective of participants concerns, opinions, and priorities, topics discussed and explored by at least 80% of the participants (18-19 of the 23 interviews) were chosen as the dominant themes from round one. The four dominant themes emerging from round one identified stakeholders’ perceptions of a) possible explanations as to the misalignment between frontline staff experiences in LTC and

public/organizational policy, b) possible barriers to change in LTC and, c) the ethical implications thereof. The dominant themes were:

- 1) Having the right workers in LTC;
- 2) Leadership: governmental and organizational;
- 3) Funding and budgeting and;
- 4) Divided sector and conflicting goals

Within each ‘dominant category’ the overarching themes were expanded to include a number of relevant and recurring sub-themes, as well as areas of convergence and divergence in opinion on the topics. For example, under the theme ‘funding and budgeting’ some participants expressed a need for increased funding in order to provide ethical care in LTC, however others indicated that increased funding was not the answer, but rather better spending and allocation of the current funding was. Numerous quotes and examples from the first interviews were used in the summary to provide greater detail and context.

The emerging dominant themes and sub-themes were collated into a 2000-word document representing a wide-range of perspectives and ideas. The summary was circulated to participants via e-mail and participants were asked to carefully review the summary, keeping the following in mind:

- What do you agree with?
- What do you disagree with?
- Are there ideas/perspectives you had not considered before?
- Have you changed your opinion on any points or themes since the first interview?

Participants were given at least two weeks to read and review the summary prior to

scheduling the second interview.

Round two interviews

With possible barriers to an ethical environment in LTC identified, as well as explanations as to the misalignment between frontline practice and policy, the goal of the second round of Delphi interviews was to discuss how to overcome these barriers, and to explore what impact addressing these areas of concern could have on the ethical environment in LTC. The questions used to guide discussions in this round of interviews were more direct and guided than those of round one in an effort to link back to the other two stages of interviews (focus groups and Delphi round one). Having found that 1) having the right workers, 2) leadership: governmental and organizational, 3) funding and budgeting, and 4) a divided sector with conflicting goals impacts the misalignment of policy and frontline experience as well as ethics in LTC, this round of interviews aimed to explore and discuss:

- How addressing each major theme could have a positive impact on the ethical environment in LTC; e.g. What impact does having a strong administrator have on the ethical environment?
- How improving the four dominant areas identified as barriers could address various concerns expressed (sub-themes) in round one; e.g. The first interviews revealed that the fear of risk (litigation) often results in rigid notions of care, how could having the right workers help address this?
- How possible policy changes could address the four major themes, sub-themes, and the impact this could/would have on the ethical environment in LTC; e.g. policies exist to encourage certain practices, how would you frame a policy to

encourage more psychosocial attention and supports?

Other examples of questions asked to facilitate further discussion, possible solutions, and reach consensus included:

- 1) How can we reduce moral distress in LTC?
- 2) How would greater alignment between the sector improve care and frontline practice?
- 3) If you had a policy-maker in front of you, what would like them to know?
- 4) How do these four areas need to change and adapt for the next generation of older adults coming into LTC?

Interviews on average were an hour and a half and were audio recorded, transcribed verbatim, and following the completion of interviews were coded and analyzed for emerging and dominant themes.

Data analysis and summary of round two

At the time of this case study, the second interviews were being conducted and so data analysis had not yet been completed. Consequently, the process of completing the second round of analysis and collation will be discussed more generally. Again, interviews will be coded and analyzed for emerging dominant themes, seeking areas of consensus and exploring areas of agreement and disagreement amongst stakeholders. Once dominant themes are identified, a second summary of findings is compiled and circulated to participants in order to encourage the iterative process of knowledge production, reflection, and translation.

Research Practicalities

There are some research practicalities to keep in mind when using the Delphi method. First, **sampling** and **recruitment** were interesting exercises which created some challenges. The Delphi literature does not specify the ideal panel size nor does it specifically define criteria for how to choose ‘experts’ (see above). The general perspective is that the quality and suitability of panel members is more important than the number of participants. For these reasons *purposive sampling* was used to select a wide range of panel experts with varying and relevant backgrounds representing the diverse sector of LTC. Once stakeholder experts are identified and selected to be panel members, you have to engage the individual and recruit them for the research. At times this was challenging, and there were some identified panel members who were unwilling and/or unable to participate. Consequently, you must be patient and flexible during the sampling process, being prepared to re-work and reconstruct your panel if needed. Similarly, once I began the first round of interviews it was apparent I had failed to recognize an important stakeholder expert within the LTC sector, and as a result ended up adding another panel member later.

Scheduling initial and secondary interviews is another practicality to consider when using the Delphi method. While there are always scheduling challenges with research participants, the somewhat ‘longitudinal’ nature and the commitment to multiple interviews inherent in the Delphi method can sometimes result in scheduling difficulties and the possibility that participants may be unable to participate in subsequent rounds of Delphi. Similarly, depending on your research topic, some of your panel members might be somewhat ‘higher profile’ individuals (e.g. politicians and/or government officials)

with full schedules and multiple commitments making scheduling more difficult (see #4 below for more on this).

Practical Lessons Learned

As a new researcher there is undoubtedly a lot to be learned from the literature about how to conduct a qualitative empirical Delphi study. That said, there are a number of aspects about conducting a Delphi study I did not learn prior to embarking on this journey- that I wish I had- and so below I share seven practical lessons I have learned, which might be helpful to you as you engage in a research project using the Delphi method.

- 1. Carefully develop your interview questions.** Make sure your questions are open-ended and prompting responses and discussions that lead back to your research questions and overall research goals. Practice your research questions to get comfortable and familiar with them prior to starting interviews. That said, you have to be prepared and willing to re-develop questions if they are not working to elicit rich discussions and explorations during interviews. This happened during my second round of interviews; after completing two interviews I found my questions were not generating the discussions I imagined they would and so recreated my questions. Using the new questions my subsequent interviews were much better!
- 2. Listen carefully, be flexible, and stay engaged.** I found during my interviews if you truly listen and base follow-up questions on what the interviewee is saying the interview will be much more in-depth and rich. If you are too focused on “sticking to your script” of questions and agenda you are less likely to get the spontaneous and passionate responses (these are the best ones).

- 3. Follow-up and stay connected with participants.** Because the Delphi method is a longer length study with multiple interviews you want to keep connected with your participants and provide them updates- so they do not forget you or the project. I sent participants a follow-up e-mail between their first and second interviews to inform them when the first stage of interviews was completed, that I would be contacting them shortly with the summary and to schedule a second interview.
- 4. Be politely persistent with scheduling interviews.** Sometimes following-up and scheduling an interview can be difficult especially with some stakeholders' schedules. Continue to ask and follow-up, but allow time in your research timeline/schedule for delayed interviews. During round one I gave participants a four month window to schedule interviews, though with scheduling/rescheduling delays the first interviews actually took five months. I learned from this and for the second round of interviews I provided participants a three month window to schedule interviews, however fully expecting this round to take an additional month (a total of four months). If participants did not respond to my initial e-mail request to schedule an interview I: followed-up by e-mail two weeks later and called one month later if still had no response. Expressing that you know their schedules are busy and you are happy to accommodate is important. Also, be clear that you would like a response even if that response is "no."
- 5. Finding and choosing participants.** Finding representatives to be Delphi panel members was a challenge, as you want to have fair representation and not miss anyone. The reality is you might miss someone, but do not be too difficult on yourself. If you did due diligence, and truly tried to get representatives from across

the sector, be proud of that.

- 6. Summarizing the data and pairing down.** This was difficult for me as I wanted to include everyone's voice, and *all* of the interesting data. However, there will likely be too much data and you will have to exclude some stories and experiences. I kept thinking it was unfair that I got to choose what should be included (despite being the researcher). However, I was lucky to meet and discuss my dilemma with a researcher who had used Delphi before and he advised me to look to the data for what should be included: what percentage of people said X, Y, Z? The higher the consensus (the majority) is what should be included in the summary. You will still have to choose what exactly goes into the main areas, but being aware of your perspectives and opinions allows you to be self-reflective and critical of that process to ensure you are choosing the findings that are best representative of participants voices and not yours.
- 7. Personal disagreement with the findings.** You might not like or agree with all the findings (majority consensus on what was said), however it is not your place as the researcher to decide what the consensus is; the goal of the Delphi method is to a "collective view" and voice on the issue from the panel members. Regardless of your opinion, summarize the data, share it, and talk about it.

Concluding Remarks

My research project aimed to bridge the gap between theory and practice by examining the discursive and social factors influencing ethics, ethical decision-making, and policy in LTC environments. The complexities of ethics, decision-making, and policy in LTC cannot, and will not, be resolved by any single group, given it's interconnected

and interdisciplinary nature. It is for this reason that an empirical ethics approach, with a goal of reaching consensus amongst the vast array of players, was imperative. Through Delphi method, individuals were invited to *actively* participate through critical exploration and reevaluation of their initial perspectives and values, in light of the responses of a diverse panel of participants. Such an interactive and explorative process transforms individual perspectives and experiences into group consensus. Through this empirical ethics consensus building process, my goal was to reduce tension between players, promote ownership through participative action, and foster an environment supportive of policy and ethics change in LTC, rooted in the experiential knowledge of those living and working within the practice context.

I hope the background information and candid account of the Delphi method used in this research project was beneficial to you in some way as you design and work through your research project. Regardless of the methodology and methods used, every research project will be uniquely original as a result of the *individual* researcher(s) designing the project. My advice to you is that you remain authentic, and your project unique, rather than attempting to fit into the pre-established formats of a particular method or previous study. Use case studies like this and literature as guidelines rather than absolutes, and you will find that you remain more engaged with, and excited by, the project, which results in more authentic research (and a more enjoyable journey for you!).

Exercises and Discussion Questions

- This case study predominantly explores the benefits of using Delphi as a qualitative empirical method. Discuss possible limitations of this method.
- List some differences between empirical and normative ethics.
- Are there other methods of consensus building you think would be better suited for this project? Explain your answer.
- During the sampling process, what measures could you take to ensure you have comprised a suitable and qualified panel of stakeholder experts?
- In the ‘practical lessons learned’ section I express the importance of remaining self-reflective and critical during the summarization process. Explore some of your feelings, attitudes, and beliefs about your 1) research method, 2) research topic, and 3) research participants that may influence how you conduct and compile your research.

Further Readings

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Web Resources

None

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Interlude Three: Delphi consensus findings: The summaries

Paper two provided an in-depth theoretical justification of the methodologies and methods used in the second stage of the research, while paper three described the techniques and processes adopted in this qualitative Delphi study. The purpose of this interlude is to provide further details about the analysis conducted in the Delphi stage of the research in order to reach relative consensus, and thus the suggested solutions and proposed changes compiled by stakeholders: 1) establishing the right culture, leadership, and frontline staff, 2) strategic hiring processes; 3) on-going and appropriate training, 4) government leadership, focus, and policies, and; 4) sector working collaboratively for change, innovation, and improved ethical environments.

Typical quantitative Delphi studies utilize structured questionnaires in multiple (typically three) rounds of inquiry (Brady, 2015). The initial questionnaires are often broad, while subsequent questionnaires are informed by the responses from the previous rounds and thus become increasingly structured and specific (Brady, 2015). The goal is for consensus to be reached on the topic by the end of the final questionnaire round (Brady, 2015).

In this qualitative Delphi study, a similar process was utilized, though rather than subsequent rounds informing questionnaires, they informed summaries, which were distributed to participants prior to the next round of interviews. The summary was used to collate emerging themes, representing a wide-range of stakeholder perspectives and ideas, and highlighting areas of convergence and divergence in opinion. The summary was then used to inform and guide iterative questions and discussion in the second round of interviews.

Research suggests that when using a qualitative Delphi method thematic analysis should be used (Brady, 2015; Dalkey & Helmer, 1963). As such, I conducted a thematic analysis to first, identify broad concepts and themes, and then second, to move toward the identification of explanatory ideas and perceptions of participants within the broader themes (Brady, 2015; Bazeley, 2009). Thematic analysis is relevant for qualitative Delphi in that it allows large categories to emerge from the data with areas of convergence and divergence within, which allows for the determination of relative consensus. Thematic analysis also illuminates what was/was not discussed within and across interviews, and the extent of that discussion. I conducted in vivo coding in ATLAS.ti, followed by clustering codes to create more generic “theme families.” The clustered themes allowed me to determine the dominant emerging themes, with a number of sub-themes, as well as the areas of convergence/divergence within each.

While achieving consensus is the primary concern of Delphi research, there is disagreement in the literature on how to define consensus (Diamond, Grant, Feldman, Pencharz, Ling, Moore, & Wales, 2014). Percent agreement, with a threshold of 75%, was the most common definition of consensus found in the literature (Diamond et al., 2014). In this Delphi study, I used 80% as my threshold for participant discussion in an effort to choose themes reflective of participants concerns, opinions, and priorities. As such, topics discussed and explored by at least 80% of the participants (18-19 of the 23 interviews) were chosen as the dominant themes. The resulting summaries from each stage of the Delphi interviews, outlining the dominant themes and relative consensus, are provided below. Some themes from the first round/summary are not carried forward into the second round. This is reflective of the iterative nature of Delphi, as participants

worked to reach consensus and agreement on solutions and proposed changes the priorities and themes shift accordingly.

Round One Delphi Summary

There were a number of interesting themes that emerged from the first round of interviews. Below, you will first find a summary of the themes identified by the majority of the participants as possible “barriers to change” in long term care (LTC) in New Brunswick (NB). The second section is a summary of some “alternative ideas” suggested by participants.

Barriers to Change

1) Having the Right Workers in Long Term Care

Participants suggested that having the ‘right’ people, or staff, working in LTC influences: the environment, the quality of care, and the model of care (for example, task-focused versus person-centred). It was frequently noted that “there are some staff who *really* care” and that it “takes a special kind of person to work in LTC.” During the first interviews, it was suggested that staff who truly care have some or all of these characteristics:

- See working with older adults and in LTC as a passion and more than just a job
- Are dedicated, patient, compassionate, and empathetic
- Have a sense of humour, positive attitude, and are able to be flexible
- Are willing to adapt and change based on both, resident needs and organizational culture change
- Prioritize the residents’ needs first; paying attention to their emotional and social needs rather just the clinical care/task

Emerging with this theme was the idea that management (leadership) need to be sure they are hiring the right people, rather than hiring based solely on qualifications. Some participants also noted that just because someone has completed a course or degree does not necessarily mean they can, or should, work in LTC. Similarly, a theme emerged that management needs to be putting strong leaders in frontline management positions (house or unit managers), and that these positions should not be filled simply based on seniority. The point was also made that the majority of hands-on care delivery in LTC is completed by resident attendants (RA), and that the RA course is the least expensive and shortest, and perhaps does not adequately prepare individuals for the dynamics of working in LTC.

In line with the theme of having the right workers in LTC was the suggestion that staff need to be adequately supported. Support can take the form of appreciation from management, proper monetary support, prioritizing staff personal well-being, and investing in staff members.

2) Leadership: Governmental and Organizational

Another theme that emerged from many interviews was the importance of having strong leadership in the LTC sector, at the level of both government and organizations. Many participants echoed one another as they discussed that change cannot occur without strong people in the positions of leadership; “everything in this world rises or falls on leadership.” Participants discussed that without strong leadership in LTC organizations and the government we get “stuck” in traditional ways of thinking about LTC and aging and lack innovation in the LTC sector, which limits change; “they just can’t imagine it being different.” Similarly, without strong leadership we do not have a vision of what we

want LTC to be, or look like, and continue to do things “the way they’ve always been done,” which many participants noted does not work anymore because of the change in the type of residents living in LTC (increased acuity and complex needs). In fact, more than one participant stated, it’s not because of lack of money, it’s because of lack of vision and organization.

In terms of government leadership, many participants expressed that the government needs to be more serious and engaged about what is going on in LTC and place more importance and priority on this vulnerable, yet very valuable, population. We need to see federal government supporting the provincial government in making changes. To do this the provincial government needs to engage those working and living on the frontline of the sector with the expertise and first-hand experiences and knowledge to make relevant and meaningful suggestions for change. The government also has to be prepared to support, in whatever form that might be, the proposed changes; we need less talk and more action. In NB we often hear we are the “province of innovation,” and yet many participants noted that this is more of a slogan than a reality and said they would like to see the government supporting true innovation, and creating a climate that empowers the LTC sector. One size does not have to fit all and we need to be willing to try new things, even if they might fail. We need a strong leader who is willing to take some risks and maybe “tip the system upside down.”

In discussing leadership within LTC homes, participants highlighted that change has to be “top-down,” starting with the administrative team and flowing throughout the organization. Administrative teams are the ones who set the tone for the home and establish the culture. Part of successful leadership is having the right people in the

positions of leadership and management. Participants noted that for a leader to be successful in LTC they would ideally have these characteristics:

- Are hands-on, present, involved, and engaged at all levels
- Model what you want to see in staff and the type of culture you're aiming to establish- "walk the talk"
- Value staff and their input, trust staff, and delegate to them
- Not be afraid to try new things, even if they might fail
- Communicate a compelling vision and be open to change

Participants also pointed out that one single person may not have all of the necessary characteristics needed to be a successful leader in LTC, and in this case expressed the importance of building an administrative team who together have the necessary skills and characteristics.

3) Funding and Budgeting

A common theme identified as a barrier to change in LTC was the limited funding and budgetary restrictions of LTC homes. Many participants expressed a belief that the government did not pay enough attention to LTC in NB, but rather identified acute care (e.g. hospitals) as the funding priority, resulting in LTC receiving the "left overs" of the budget and "being pushed to the side." Many participants highlighted the inflexibility in the set budgets given to LTC homes to work with. For example, wanting to slightly reduce nursing care in order to have more social care (e.g. a counsellor), which was an identified need the administrator believed would improve the environment for all and reduce staff workload, but not being allowed, despite staying within budget. Many LTC homes turn to volunteers and fundraising to fill gaps in services and care, yet participants

expressed that even with fundraising the government places restrictions on how that money can be spent. On this note, participants pointed out that not all homes have the ability to fill gaps with fundraising, particularly in more rural communities.

One participant highlighted that currently, the NB government spends 367 million dollars on operations alone (salaries, mortgages and loans, food, power, etc.) and expressed that changing anything is very expensive. That said, many participants believed that we do not need more money, but need better allocation of the funds, and a restructuring of how LTC operates, with more flexibility. As a result of limited funding and lack of budgetary flexibility in LTC, many participants describe an environment where only the bare minimum of care is getting done; “The reality of the budgets are such that the primary emphasis has to be on providing the daily care, the personal care, the feeding, and there’s little room for anything else.” Such budgetary constraints result in policies, standards, and regulations that create an environment of care that is predominantly task-focused, and one focused on the medical model, strongly lacking adequate psychosocial attention or supports. Participants also expressed that such policies and regulations create an environment that is hyper-concerned with safety and has a fear of risk and liability.

Participants believed that when the government wants to save money they seem to always make cuts to the human element, the frontline staffing. Consequently, we see less qualified/educated individuals doing jobs in LTC, and limited attention paid to the range of professions (e.g occupational therapy, rehabilitation, social work, psychiatry, physiotherapy, etc.) in LTC, which many participants described as a barrier to culture change and improved care in LTC. It was suggested that perhaps spending less on

multiple levels of ‘managers’ would allow for more frontline care staff. One participant noted that we are providing the best kind of person-centred care we can in NB given the restrictive budgets. It was suggested that in order to see changes in funding and to policies the government must broaden the scope of what they are looking at for “quality indicators” in LTC; it is more than the physical task-focused piece, and until we start including the person-centred and psychosocial aspects in documentation and measures of quality the attention will remain on the medical task.

The interviews revealed a belief that LTC homes are not funded properly and the government “can barely make ends meet” with the current budget, and so asking for anything more, or new, is a major challenge. It was suggested that despite lacking the budget to build new LTC homes, or adequately funding current homes, the government was/is reluctant to allow the private sector into the province; is our model a sustainable one? Perhaps allowing more private care, for those willing and able to pay for it, is a possibility. On this note, some participants had strong opinions *against* private LTC homes. Or, would LTC be better funded if it was under the health care system, rather than social development? Participants also proposed that maybe if more attention and funding was provided to Extramural services, or in-home services, more older adults could live safely in their homes longer, reducing the number of older adults in hospital.

4) Divided Sector and Conflicting Goals

It was often expressed by participants that the LTC sector is very disconnected, lacking meaningful communication between all groups involved, which creates tension and prevents change. It was believed that this disconnect results in a system that is difficult to navigate and the duplication of services. Participants noted that when groups

have differing interests or goals, and are unwilling to compromise or work together, it can hinder innovation and new approaches to care. One example was the ‘competition’ experienced between groups for project funding. A second common example was the differing interests between LTC homes and the unions; it was discussed that at times, it appears the inflexibility created by some union contracts prevents innovation in LTC. Common examples included preventing volunteers and/or residents from performing certain tasks because it could be perceived “as taking union jobs,” inflexibility in staff roles (“helping with meal time is not in my job description”), and unions as staff-focused versus LTC aiming to be person, or resident-focused.

Alternative Ideas

Community based integration for older adults in New Brunswick

- More services going to older adults in their homes (physical and social care)
- Bringing people from the community to nursing homes for social engagement
- Community seniors health clinic with multi-disciplinary team
- LTC as a service-hub

Forums for innovative discussions and collaboration across LTC sector

- Opportunities to share visions, dreams, ideas with others in the sector, and put them into motion
- Open communication and collaboration across diverse sector

Day Cares

- In LTC homes for older adults to come for the day to provide social engagement, as well as respite for family caregivers
- In LTC homes for children; fully integrated in the home and not separate from

residents (e.g. eat together)

Introducing therapeutic/alternative approaches to care based in true person-centred care

- Listening to residents (past history and present needs) and focusing on individual care needs
- Music therapy, pet therapy, sensory therapy, aromatherapy
- Narrative approaches to care
- Residents more involved in the daily workings of the home; cooking, cleaning, meaningful contribution
- Smaller facilities that are more “homey”
- Increased hospice/palliative care in NB

Round Two Delphi Summary

In the first round of Delphi interviews we explored what changes need to occur in the LTC sector to encourage better alignment between policy and practice in an effort to minimize the moral distress experienced by frontline care staff. Moral distress is when staff are aware of the ethical thing to do, but feel powerless to act accordingly as a result of either real, or perceived, organizational constraints. The first round of Delphi identified a number of barriers to change in LTC, and stakeholders suggested if we want to see change and policy alignment, the sector needs to address the follow four areas: 1. Having the right workers, 2. Having strong leadership (government and organization), 3. Funding and budgeting (and the rigid policies flowing from this), and 4. Divided sector.

The goal of the second round of Delphi interviews was twofold. First, to identify how to overcome these barriers and to see change, innovation, and positive ethical cultures in LTC. Second, to further explore how addressing these four areas would improve ethical environments, and thus ethical care, in LTC. Below is a summary of these findings from the second round of interviews.

Overcoming Barriers in LTC to see Change, Innovation, and Improved Ethical Environments

1) Culture, Leadership, and Frontline Staff

One of the dominant findings, agreed upon by almost every stakeholder, was that the culture of the LTC home is one of the most important factors contributing to ethical care in LTC, and to innovation and change in the sector: “It’s trying to figure out a concrete way to move, because it really is moving attitudes in a long way, and moving culture, and changing culture.” It was frequently noted that even with restrictions and sectorial challenges (e.g. financial constraints, policies, staffing levels), if the right culture and team is established, innovation and change can be made within the home to foster positive ethical cultures and care. As one stakeholder expressed, “I think sometimes we under-estimate what you can accomplish when you have the right team in the right environment, at the right place, with the right leadership. When all of those things combine I think that has more to do with it than the money, so.”

In order to see the development of these necessary positive cultures in the Homes, stakeholders emphasized how important it is to have the right administrators, right nurses as leaders on the floor, and right frontline workers.

Right administrators. Stakeholders shared that when the ‘right’ administrator is hired he/she is in a position to either positively or negatively effect the culture of the Home through the vision he/she implements and the priorities that are set. The impact the ‘right’ administrator has on the culture of the home was discussed in terms of a “trickle down” effect, impacting quality and ethical care.

Culture trickles down from the top and the board needs to clearly establish what sort of a culture do you, do you want here? A lot of boards in New Brunswick aren't sufficiently sophisticated at this point to be able to articulate that, but they darn well better be sure that they are, the person they hire as the CEO, Executive Director, understands culture, and understands how to shape culture, and what culture means, the importance of culture. And that can mean the difference between do our residents get looked after really, really, really well, the way you want your Mom looked after? Or do they just get the basic service? And it all starts at the top.

“Leadership have to be comfortable with change themselves, and I would suggest to you that... Ninety percent of those people who are in those positions aren't comfortable with the change.” Further, a ‘right’ administrator is one who is trained or has experience in LTC in some capacity, sets priorities and fosters innovation and change, values and supports staff by being present and engaged, invests in training, and empowers staff decision-making.

...the administrator is out and about on the floors, she knows what's going on... And she knows her staff, and she knows the needs of her staff, and they're pro-education and they are creative, and everything is appreciated. And...they

support the staff..like they've gone above and beyond. They have a happy staff, a happy staff stays for a long time, they're devoted."

Right nurses as leaders on the floor. *The nurse as a leader is a new phenomena in a formal way. I think nurses were leaders before, but not necessarily - they got the care piece, too. I think the challenge is that many nurses go into nursing to deliver hands-on care. They don't go in to lead, and so what we've done is they come out, we put them in a position, and we say, "Okay. So now you're in charge. You lead." And they go, "But I wanted to give bedside care.*

Many stakeholders echoed the sentiments of the above quote, highlighting how there are significant gaps in the RN curriculum and education, which do not adequately prepare RNs for leadership/management positions. Many stakeholders expressed that "not everyone can be a leader" and that we need to hire nurses "by more than how long they've been there" (seniority).

Stakeholders expressed that, similarly to a right administrator, a 'right' RN leader dramatically effects culture and quality of care on the floor. Stakeholders emphasized 'right' RN leaders must: value, support, and empower staff, be a team player and establish a team environment, have professional relationships with staff based on mutual respect, and have strong communication and conflict resolution skills.

Right frontline workers. Stakeholders highlighted having the right frontline workers, who are "there for the right reasons," significantly impacts the culture and the quality/ethical care of residents. The 'right reasons' was typically described in terms of "being there for the resident." It was expressed by a number of stakeholders that frontline workers need to receive proper education prior to working in LTC, suggesting RA and

LPN curriculum should have more of a focus on the social aspects of care in order to adequately prepare individuals for the realities of working in LTC. Additionally, frontline staff need to be supported and valued by leadership (RNs and administration) and stakeholders expressed the importance of encouraging and fostering the passion and positivity of frontline workers.

Stakeholders also agreed that in order to get the ‘right’ administrators, RN leaders, and frontline workers the hiring processes for all levels of staffing need to be revisited and improved- resulting in another dominant theme: the importance of strategic hiring practices in LTC.

2) Strategic Hiring

When asked what could be done to ensure the LTC sector was getting the ‘right’ administrators, RN leaders, and frontline workers, stakeholders consistently discussed the significance of hiring practices, stressing the importance of adopting more strategic hiring processes. There were some proposed changes to hiring that were very specific to each level of staffing, which will be further explored below. However, stakeholders also proposed a variety of strategic hiring process changes that are applicable at every level of staffing/hiring.

Stakeholders consistently expressed how potential staff, whether the administrator or frontline worker, need to be asked about their values and “why” they are interested in working in LTC. Some stakeholders suggested exploring values could be accomplished by conducting more purposeful interviews where individuals were asked specific questions about character and personality. Others, proposed using a

personality/psychometric test as a hiring tool to provide a more holistic understanding of the individual.

Stakeholders also discussed how job descriptions are often vague and suggested that more specific descriptions, outlining qualifications, characteristics, and expectations of the role are necessary if we want to get the “right people” working in LTC. Finally, regarding all levels of staff hiring, the importance of involving peers, and in some cases residents, in the hiring process was discussed. As one stakeholder shared, “Because there’s been people hired and we’ve just went, “Pfft. Great. That’s just great now, isn’t it?” We could have told them a long time ago, you know, “No, this person was lazy as a [RA], do you think they’re going to be any better as an RN? I don’t think so. They’re going to be worse.”

Proposed changes for strategic hiring of frontline staff and RNs on the floor.

in addition to the above suggestions for hiring, in terms of frontline workers and RNs, stakeholders highlighted the importance of 1) having the proper people training frontline workers, and 2) ensuring administrators are coaching and training RNs in leadership/management roles. Stakeholders also expressed the importance of using the probationary period effectively to monitor and coach new employees, and similarly discussed the need to work collaboratively with the union if an employee is “not working out,” both before and after the probationary period. Finally, stakeholders highlighted that the individual doing the hiring must “know how to interview” and needs to consider how the possible interviewee fits in with the team, and in the greater scheme of the organization’s values and mission.

Proposed changes for strategic hiring of administrators. Stakeholders

discussed the important role *boards* have in ensuring the “right” administrator is hired to lead the organization/home. Stakeholders expressed that boards “set the direction of the home” and that without a clear vision they are not likely to hire the “right” administrator who will be able to promote change and a positive culture. It was highlighted that boards need to be made up of individuals with “a variety of different skills and knowledge bases.” Unfortunately, many stakeholders stated that boards are often not properly equipped or trained for effective and strategic hiring. “The board needs education. They need governance education, a lot of them don’t know about board governance, they don’t even know what the roles are like...some of them think oh it’s a nice little outing, right. They have to make major decisions.”

There was some disagreement among stakeholders of who/where this support should come from. Some suggested the government has a role: “There needs to be presentations from the government to the boards in regards to their responsibility, in regards to board governance- how serious of an issue is this.” While other stakeholders outlined how government involvement could be problematic and alternatively suggested the New Brunswick Association of Nursing Homes (NBANH) could have a role to play in supporting boards in the hiring process: “I can’t even say that that government, you know, because then [boards] get all excited and upset if government says, “This is what you need to do. We’re imposing this on you,” right? Whereas the Association [NBANH], I believe, has a huge role in this right? So as an Association, they need to be giving governance and giving those tools to those homes.”

While the majority of stakeholders agreed that changes were needed in LTC for strategic hiring to take place, they also recognized and emphasized that once the “right” individuals were hired, they required continuing support and encouragement through ongoing and appropriate training.

3) Ongoing and Appropriate Training

Stakeholders continuously expressed the importance of investing in on-going training for all levels of staffing. As one stakeholder expressed, “I think, you know, one of the things we’ve done and it’s very short-sighted in my view, you know, we cut all the training in long-term care. Worse thing you could do.” iTacit (online module-based training) was often discussed in terms of training, and while stakeholders appreciated why this method was being promoted (e.g. it is flexible, relatively quick to complete, progress/results can be monitored, etc.) many echoed this stakeholders’ view, “iTacit is one facet of education that should be offered, but because we have such a... variety of staff who need education, that we have to be flexible to their needs and their abilities, and their strengths, and how they learn best.”

Stakeholders also suggested the benefit of staff “learning from peers” in a collaborative setting (within and across different facilities) and discussed that investing in ongoing training “makes staff feel valued and appreciated” and also encourages current and relevant care practices, which results in improved quality and ethical care for residents.

Stakeholders expressed that the government should be investing in more staff training, but also recognized that with the right administrator and culture within the home there are ways to facilitate ongoing training; “if it’s a priority you [administration] will

make it happen.” Stakeholders suggested some ways to “make it happen” include having huddles, in-service learning, lunch and learns, bringing in free speakers, etc.

The findings so far have mostly focused on what could be done *inside* LTC homes to overcome the barriers to change and innovation in the sector. However, stakeholders also explored ways in which government leadership, focus, and policies need to change if we want to overcome sectorial barriers and improve ethics and care.

4) Governmental Leadership, Focus, and Policies

Stakeholders expressed “...for nursing homes and long term care, there’s been very little investment in the sector outside of the bricks and mortar.” Many stakeholders demonstrated an appreciation and understanding that governments “are pulled in many directions.” However, also highlighted that minimal investment and focus on LTC and aging in the province has resulted in 1) no strategic plan for aging and LTC, and 2) an outdated system made up of irrelevant and inflexible policies and models of care.

Stakeholders suggested a number of possible reasons for the lack of investment/focus on LTC at a government level. Stakeholders shared that elected officials are afraid to make difficult decisions and “get turfed out of office” or “be on the front page of the paper” and are often more concerned with election/re-election than truly making change. Others suggested getting rid of fixed election dates and “allow[ing] governments to sit for five years” would make a big difference in what governments could accomplish, while others expressed that the frequent turn-over of ministers does not allow for engagement and/or change. Further, stakeholders discussed how Nursing Home Services is under-staffed and has limited resources and autonomy, resulting in minimal space for discussions about change and innovation.

Outdated Policies. stakeholders overwhelmingly agreed that the majority of LTC policies are outdated and inflexible and need to be updated. When asked if policy-makers were aware of the realities of LTC, stakeholders all responded ‘no’ or ‘I don’t think so’. Many stakeholders suggested that the lack of government/policy-maker understanding and limited focus on LTC results in decision-making that negatively effects LTC staff and residents: “Government officials are... they’re focused on funding, licensing, and monitoring. They’re not focused on quality of life.” Stakeholders repeatedly said policy-makers need to “come and spend a day here and really see, you know, what a real day is in the life of a resident,” and similarly, “those policy makers need to have a good understanding of each, what’s going on in the homes- they need to go and see what’s going on...to see what’s working and what’s not working.” Policy-makers were also called to truly engage/talk to those involved in the frontline delivery of care:

I think you need to involve the stakeholders, and not just government and management, because I mean, I know I’ve been to some of the stakeholder meetings and usually it’s upper management. It’s people that are not on the floor, people that are not dealing with the people. [um] They need to involve the care staff, you know, it has to be from the bottom up. Otherwise, it’s not going to be effective.

Additionally, stakeholders expressed how “not one size fits all” in LTC, and that policies need to be developed with an understanding “that what works in one home might not work in another” and that “not everything has to be carried out in every home.” Stakeholders also agreed that while there is a need for policies and regulation in LTC, current policies and inspection processes are rigid and do not provide an accurate report

of residents' experiences or the quality of care in homes. Stakeholders agreed that inspection processes need to change to include more holistic and resident-centred quality indicators.

Stakeholders highlighted that the government is not the only group responsible for overcoming barriers to change and encouraging improved ethics and care in the sector. A dominant theme, shared by the majority of stakeholders, was the importance of the sector working collaboratively toward change.

But one of the biggest things that we know is that, as a province, we've created the culture we have in long-term care. All of us have, not just government, not just management, but we all have, and therefore, we all have a responsibility to change it, and it's not just saying government needs to do it. We need to do it together. Government needs to be able to be open to let us do it. But we need to do it together.

5) Sector Working Collaboratively for Change, Innovation, and Improved Ethical Environments

Stakeholders explored how the sector is largely unprepared for the next generation of older adults who will be living in LTC, highlighting the next generation will be more consumer-based, more demanding with particular preferences, and that care will have to be more person-centered (individualized). In order to effectively, and ethically, care for residents in the future, stakeholders agreed the sector will need to be less competitive and more collaborative.

Stakeholders proposed a number of ways the sector could be working more collaboratively in order to overcome the identified barriers to change and innovation, and

ultimately see improved ethical cultures and care in LTC. A number of stakeholders explored the benefits of “sharing across homes” with respect to training, policy/procedure development, and creative/innovative ideas. As one stakeholder expressed, “I think the, one of the things that I’m always disappointed in is the lack of sharing, because if there was just effective sharing with what we have right now, we could be so much better.” Stakeholders also expressed the importance of the sector working collectively, with a united purpose/vision, toward advocacy for policy and system changes: “...if they want it to look different they have to come forward in a unified voice...”

Stakeholders explored there may be a role for the NBANH to play in facilitating both, ‘sharing’ across homes and in uniting the sector. It was also expressed the sector would benefit from pooling resources, and in some cases, the regionalization of services. Additionally, a number of stakeholders agreed that greater on-going collaborative communication with government is needed to facilitate true change.

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Concluding Reflections

The aims of this two-stage research project were to explore:

- 1) How the ethical reasoning of LTC staff reflect, align with, or conflict with declared institutional approaches, policies, and procedures in managing ethical issues;
- 2) Which ethical frameworks LTC staff draw on in their ethical reasoning;
- 3) How LTC staff choose between competing or differing ethical values and frameworks, and;
- 4) What impact organizational culture has on ethical decision-making among LTC staff.
- 5) How might the sector overcome barriers in order to see change, innovation, and positive ethical cultures in LTC?
- 6) How would addressing possible barriers improve ethical environments, and thus ethical care, in LTC?

The findings from the first stage demonstrate there is a misalignment between the organizational philosophies of care and staff perceptions of the environment. As a result, staff perceive, and therefore make ethical decisions within a very different organizational culture and environment. Despite this misalignment, staff do not typically have difficulty determining the ethical decision and action, and in fact draw on a number of ethical frameworks and norms during the decision-making process. Staff do, however, report feeling restricted to act in the ways they believe to be right as a result of a number of institutional constraints, resulting in experiences of moral distress. To manage these experiences of moral distress in making ethical decisions staff: 1) comply with being told

what to do/fear of consequences; 2) defer decisions to family; 3) “have a meeting;” 4) adopt and defer to existing workplace culture. These findings align with those of Casterlé et al., (2008) and Mattiasson et al. (1995) who found LTC staff often rely on rules and norms, trying to escape responsibility, rather reasoning in autonomous and postconventional ways.

These findings led to the second stage of the research where I sought to expand my understanding of the ethical decision-making environment of LTC staff by exploring the interaction between public and organizational policies, and how these interactions impact frontline staff’s ethical decisions/actions. Findings from the second stage suggest five areas the LTC sector must concentrate in order to create practice-informed policies and to foster positive ethical cultures in LTC:

- 1) establishing the right culture, leadership, and frontline staff in LTC organizations;
- 2) implementing strategic hiring processes;
- 3) create on-going and appropriate training;
- 4) providing government leadership, focus, and policies; and
- 5) creating a collaborative sector.

While adopting a qualitative Delphi method inherently promotes timely knowledge dissemination and encourages relevant change at both organizational and public levels, meaningful innovation in LTC is often difficult to achieve.

Implementing policy and culture change in LTC is often difficult as there are a number of discursive forces that influence and shape LTC. In order to challenge these discourses and overcome barriers to innovative change, we need to better understand the

complex interplay of dominant discourses impacting LTC. While critical discourse analysis was used in the first stage of the research [*evidenced in Paper One and in the discussion below*], the focus of the findings was not inherently discursal. As such, there is room for future research to explore the influence dominant discourses have on LTC environments, the ethical decision-making of staff, and consequently their experiences of moral distress. There are multiple discourses impacting on LTC, and in this research we see evidence, in particular, of four: biomedicine, family power, risk, and efficiency. Below, I begin to tease apart, or deconstruct, these dominant discourses, exposing how they interact to influence our current knowledge and conceptions of LTC.

Biomedical Discourse

The social concepts of aging and LTC are constructed and understood based on discourses embedded in historical and cultural contexts (Phelan, 2010). As a result, our knowledge of aging and LTC are dynamic and shift according to time, place, and various sociopolitical factors. Prior to the nineteenth century, ‘senility’ or the decline in cognitive and/or physical functioning, carried less of a negative connotation, and was perceived and accepted as part of the natural progression of the life cycle (Ballenger, 2006; Kaufman, Shim, & Russ, 2004). In the nineteenth century, with modernization and increased industrialization, the understanding of ‘senility’ shifted, being seen as a threat, as the aging body and mind was socially constructed as an “obstruction to progress” (Ballenger, 2006, p. 108) within the hectic pace of the modern era, which emphasizes economic contribution and worth (Ballenger, 2006; Phelan, 2010). It was also in this century that the modern phenomena of ‘old age’ as a separate phase of life with distinct problems and needs was normalized to ages sixty-five and older, as a result of Bismarck (1815-1898)

establishing the first old-age social insurance plan in Germany, which provided social assistance pensions for those aged sixty-five and older who were ‘disabled from work by age’ (Phelan, 2010). Ages sixty-five and older continues to be upheld as the ‘retirement age’ (Phelan, 2010) and the measure of ‘old age’ in Western societies today; evidence by Statistics Canada (2012), United States Census Bureau (2014), and the National Institute on Aging (2011), all using sixty-five as the benchmark age of being a “senior” and “retirement age.” The nineteenth century also saw ‘old age’ become synonymous with dependency and inevitable mental decline, and as we moved into the twentieth century, discourses depicted old age negatively and as something to fear, reverse, avoid, and ultimately *control* (Ballenger, 2006; Phelan, 2010).

The twentieth century, with a rise in scientific thinking and biomedical approaches, attempted to control, and explain, the aging process by defining ‘old age’ as an inevitable biological phenomenon, fostering a reductionist medical approach based on etiology and “isolating the smallest possible units of analysis” (Estes & Binney, 1989, p. 588). The biomedical discourse, aligning itself closely with science, a predominant and powerful way of thinking in Western societies in the twentieth century (Estes & Binney, 1989), resulted in the medicalization of aging (Conrad, 2007; Lyman, 1989; Estes & Binney, 1989). ‘Medicalization’ is when “a [non-medical] problem is defined in medical terms, described using medical language, understood through the adoption of a medical framework, or “treated” with a medical intervention (Conrad, 2007, p. 6). The medicalization of aging gave rise to the diagnosis of Alzheimer’s (and other forms of dementia). In an attempt to destigmatize and legitimize ‘senility’ and the cognitive changes experienced by some in older adulthood, professionals in the fields of medicine

and gerontology established ‘diagnostic criteria’, scientific evidence, and a medical diagnosis for certain characteristics and expressions of aging, ultimately resulting in the classification and diagnosis of Alzheimer’s and dementia as a ‘disease’ (Ballenger, 2006). One aspect of the medicalization of aging that has been particularly influential in the discursive construct of older adults and LTC is the Cartesian dualism inherent to the biomedical approach (Koch & Webb, 1989).

Cartesian dualism, a model introduced by Descartes (1596-1650), suggests that the mind and body are two separate entities, composed of different substances. Descartes proposed the mind is a nonphysical conscious substance (separate from the brain) and thus an indivisible entity, while the body is physical, comprised of automatic actions, and a divisible entity occupying physical space and size (Baker & Morris, 1996). While Cartesian dualism proposes the mind and body can interact, they are perceived as distinctively separate entities, which has had a significant influence on Western medical thought. Western medicine has adopted the mind/body divide of Cartesian dualism, focusing primarily on the physical body, with little regard of the mind. As such, a mechanistic view of the person has prevailed, where the metaphor of a ‘machine’ is used to describe the body (Koch & Webb, 1989; Baker & Morris, 1996). In this metaphor, the mass and motion of the body are seen as primary qualities, the machine is perceived to be made up of independent and inspectable parts, and non-measurable qualities are ignored (Koch & Webb, 1989). There is evidence of this mind/body divide in the data as participants across the focus groups describe the concentration of care is on the *physical*, while the emotional and social needs of residents are often ‘forgotten.’

The focus is more on the physical needs, unfortunately... And then of course their

motional needs are getting by the weigh side. (RN, LTC 006)

I struggle too with a gentleman here that he's okay physically, and like can go to the bathroom on his own, but he struggles with depression. And a lot of the times he would prefer if we just sat ad talked to him, but then it goes back to like, you know, we don't, we are wanting to address the physically needs over mentally, sort of needs...I struggle with that because I feel like...mental problems are just on the back burner. (LPN, LTC 006)

With this construct of the aging body, the *person* is overshadowed, becoming a biomedical object of knowledge and intervention (Koch & Webb, 1989; Phelan, 2010). A more in-depth discussion of this biomedical focus and mind/body divide can be found in Paper One findings section. Staff express the distress (and moral distress) they experience as they witness the unmet social and psychological needs of residents [*see Paper One findings*]. Focusing so intently on the 'machine' has resulted in a discourse of aging and older adults that narrowly focuses on pathology and thus constructs aging in terms of decline and decay (Koch & Webb, 1989), neglecting the psychosocial factors that influence the construct of aging and older adults' experiences of aging (Lyman, 1989); knowledge about aging is often constructed by those with little experience with it. With a biomedical construct, the focus remains on increasingly sophisticated diagnosis, the search for biological markers or underlying mechanisms, and state-of the art technologies for interventions (Koch & Webb, 1989) to "stave off death yet not prolong meaningful life" (Kaufman, Shim, & Russ, 2004, p. 736). In other words, emphasizing the biomedical discourse and failing to take into account the *holistic* person (versus the

‘machine’) has resulted in a generation of older adults who, yes, are living longer than any previous generation, yet often have fewer relationships, limited purpose and contribution, and a dwindling *quality* of life.

My residents would choose a night out entertainment over a vitamin pill, because they only have a hundred and eight dollars a month, and if they’re thinking their quality of life, they can live without a vitamin D... ” (RN, LTC 004)

With seemingly little regard to the effect on older adults, the biomedical discourse of aging appears to have monopolized the knowledge and management of aging, and continues to shape knowledge about aging and approaches to care (Estes & Binney, 1989; Kaufman, Shim, & Russ, 2004). The power and acceptance of the biomedical model is apparent in society, as “medicine today is considered the right (and perhaps the only) tool for managing problems of aging” (Kaufman, Shim, & Russ, 2004, p. 731), while alternative ways of knowing and understanding aging are inconceivable (Kaufman, Shim, & Russ, 2004; Estes & Binney, 1989; O’Connor, 2003). Alternative discourses about aging are silenced as the biomedical discourse powerfully permeates what Estes and Binney (1989) refer to as the “praxis of aging.” Through a dialectical relationship, the biomedical discourse functions at multiple levels in society to reinforce its knowledge and power; what is considered ‘knowledge’ of the discipline, how professionals in the field are educated and trained, as well as how they practice within the workplace, the impact on research, funding, and public policy formation, and the general public’s perception of aging (p. 587).

Put more generally, the dominance of the biomedical model has influenced everything else- other research, policymaking, and the way we think about aging and

even science, as it is defined and evaluated in terms of a biomedical structure of thought. Indeed, the biomedical model has become the “institutionalized thought structure” (Warren, Rose, and Bergunder, 1974) of the field, despite increasing evidence of the importance of social and behavioural factors in explaining health and aging. (Estes & Binney, 1989, p. 588).

There is evidence that the biomedical discourse has become an “institutionalized thought structure” in LTC and that this dominant discourse has become instituted in routine “discursive practices of organizational life” (Mumby & Stohl, 1991, p. 315). The medicalization of aging has resulted in LTC policy and organizational settings where medical monitoring and physical care are prioritized above psychosocial activity/care (Cohen et al., 2006) [*see above and Paper One findings section for further evidence of this*] and where diagnostic overshadowing replaces critical analysis of our social systems and practices:

The medicalization of [aging] shifts attention from problems in the social situations of caregiving to locate problems in the pathology and misbehaviour of the [aging] person. This focus overlooks the impact of the treatment context and caregiving relationship on the experience of [aging]. (Lyman, 1989, p. 603)

The practice of locating problems within the aging person, rather than examining the treatment/environmental context, was illustrated to me during a discussion with a LTC nursing staff member. She explained that a resident living with dementia in the LTC facility where she works was rising early, between 4:30-5:00 a.m.. This was reportedly becoming problematic for the staff, as the resident was ‘wandering’ and they could not get him back to sleep. The morning staff did not arrive until 7 a.m. and breakfast was not

served until then. The staff member explained that to resolve this problem the resident was medicated, and was now experiencing difficulties walking and communicating, where previously there were no concerns. The staff also highlighted that this man rose early his entire adult life for work. Rather than focusing on the environmental contexts or the caregiving relationships, and perhaps offering the resident breakfast (cereal is available, despite hot breakfast not being served until 7 a.m.), or a newspaper to accommodate his desired *routine*, the behaviour was attributed to the “progression of his illness/aging” and he was given a new prescription. This story is illustrative of two important concepts of discourse. First, it highlights how stories/narratives are not created within a sociopolitical vacuum (Mumby, 1987), but rather are influenced by, and embedded with, ideologies:

[N]arratives punctuate and sequence events in such a way to privilege a certain reading of the world. They impose an order on “reality” that belies the fact that such a reading is a largely ideological construction that privileges certain interests over others. (p. 126)

In this story we see how the interests of staff and organization take precedence over those of the resident, and in this way the staff/organization is privileged while the resident is marginalized. Second, this story illustrates how the medicalization of aging results in a pathologized lens, lacking psychosocial consideration.

As a result of the biomedical discourse being naturalized into a position of superiority, individuals belonging to this privileged ‘way of knowing’ are also situated in a greater position of power and authority than those who do not. There are numerous examples of the power of those belonging to the ‘biomedical group’ throughout the data

[see Paper One findings section for further evidence of this]. Staff within all of the focus groups make reference to the power of the medical team, including physicians, dieticians, pharmacists, occupational therapists, physical therapists, and at times, RNs.

But I always do what the medical team says and what the next of kin says. (LPN2, LTC 002)

..And I think sometimes it's not explained to them (families) well enough and the families don't get enough knowledge or enough information maybe and then they kind a just go with the medical teams' opinion instead of maybe I mean talking to [um] maybe actually the resident themselves, what they want. They just go with what the medical team might feel. (LPN1, LTC 002)

An example from one focus group is a competent resident wanting to walk independently outside and members of the medical team asserting their power to restrict or prohibit the resident from doing so. Often in LTC, the biomedical discourse positions resident attendants (RAs) as 'other,' situating these staff members within binary opposites such as educated/uneducated, medical/non, task-focused/person-focused, etc. [see Paper One findings section for further evidence of this].

While typically in LTC individuals belonging to the discursively dominant biomedical group (e.g. physicians and nurses) are perceived as having more power in the hierarchy of the institution, families seem to be negotiating their way into greater positions of power and thus have a significant influence on the ethical decision-making of staff [see Paper One findings section on family power for a comprehensive discussion].

I: So what if the family decides something that you really disagree with, and the powers that be say, no we're going to go with what the family does and then you are the ones that have to...

R:...Then you have to do it.

R: You have to do it yeah, you have no choice. (RA & LPN, LTC 007)

Family Power

The unexpected and unfamiliar discourse of family in a privileged position of power in LTC results in a shift in the organizational power dynamics, where the medical team is subordinately positioned in relation to family; similarly to how RAs were positioned in relation to the medical team [*see above, Introduction, and Paper One for a more complete discussion of binary othering and subject positions*]. The decision-making environment is further complicated by family's new (or newly acknowledge) position of power, as staff who were previously in a position of power and could make autonomous decisions, are now challenged by family power and authority.

Staff describe how "families call the shots more than they should" (RN, LTC 004), and express how staff sometimes make decisions and act in ways to appease the family, rather than the resident: "...so they're [staff] doing whatever they have to do to please the family members which is what happens even here a lot...It's not about the resident, it's about the families" (LPN1, LTC 002).

A staff member also explains how, at times, families perceptions of the staff, and their perception of the quality of care being provided, can begin to emotionally impact and influence staff actions, saying, "...'what kind of nurse are you?' and after you hear that every day for months and months you actually, you know it's like, oh my goodness

this is terrible look at her, I'm going to make her have a bath (slight laugh)" (LPN2, LTC 002).

Staff report the stress and disempowerment this shift results in, two known contributing factors of moral distress. Staff share how, at times, "dealing with the family sometimes is ten times more difficult than dealing with the clients themselves" (LPN, LTC 007). In one group a staff member says that family members can be "unrealistic people that definitely need a reality check" (LPN, LTC 002). Others discuss that as a result of families not understanding the "bigger picture" complexities of the LTC environment, they have unrealistic expectations and demands of staff and the organization. Staff explore how, at times, overt and unwritten policy requires them to include family in decision-making, resulting in competing commitment to both, work with and appease the family, while also wanting to maintain and uphold resident's wishes and best interests. Staff express how there is often tension between these commitments, complicating the decision-making process, and frequently resulting in staff feeling conflicted and constrained.

Seemingly, family is deconstructing the dominant discourse power relations of LTC, challenging their previous subject position in relation to the medical team, and discursively negotiating a position of greater power. In so doing, the hierarchical arrangement and positioning of organizational members, which is often taken-for-granted as 'truth' in LTC, is ruptured, creating a contradiction in terms of 'how we have always understood LTC' (Mumby & Stohl, 1991). When the discursive 'truths' of LTC are challenged and re-understood as a result of family shifting the power dynamics within the organization, the identities of organizational members also shift, creating discrepancies

and gaps in the social script organizational members have become accustomed to, generating conflict in terms of how members should act in relation to this new and unfamiliar script. One consequence of this rupture is staff now rely on deferring decisions to family in an attempt to reduce experiences of moral distress and mitigate fears of liability. In the data, it is apparent that regardless of whether the resident of the vignette was competent or not, staff frequently express the need to “include family” in the decision-making process. Staff across all focus groups also discuss the need to appease family members and the conflict this creates.

On my unit where the majority would be, you know, competent, [um] I still do the family meetings because the family play a part, a huge role in all of this. (RN, LTC 004)

The fear of liability, interwoven with, and the result of, the dominant discourse of risk, impacts how staff make ethical decisions in LTC. The preoccupation with liability and risk, Ulrich Beck (1992) proposes is a result of the construction of ‘risk society’ within modernity (more on this below).

Well, if family doesn't want the seatbelt on, if mom doesn't want the seatbelt on, well they sign the form and they're taking the risk themselves. (RA, LTC 007)

So, we do get the family to sign something... saying that it's kind of our, not our responsibility if something was to happen. I mean, we'll do whatever we can to help them, but, also we have to know, they have to know that they have to sign something to say it's okay to do that. (RA, LTC 003)

Risk Discourse

Anthony Giddens, influential for his work on modernity and risk society, defines modernity as follows:

At its simplest, modernity is a shorthand term from modern society or industrial civilization. Portrayed in more detail, it is associated with (1) a certain set of attitudes towards the world, the idea of the world is open to transformation by human intervention; (2) a complex of economic institutions, especially industrial production and a market economy; (3) a certain range of political institutions, including the nation-state and mass democracy. Largely as a result of these characteristics, modernity is vastly more dynamic than any previous type of social order. It is a society- more technically, a complex of institutions- which unlike any preceding culture lives in the future rather than in the past. (Giddens & Pierson, 1998, p. 94)

Having a general understanding of the social, political, and cultural norms and attitudes adopted within modernity- modern society- as outlined by Giddens above, is important to understanding risk society, as both, Giddens and Beck (1992), suggest that risk society is a direct result of modernity. Beck (1992) suggests 'risk society' is a systematic solution to responding and coping with the "hazards and insecurities induced and introduced by modernization itself" (p. 21). The concept of 'risk society' might suggest a modern era that has become increasingly hazardous. However, as Giddens and Pierson (1998) note, this is not necessarily the case. While Giddens and Pierson agree that characteristics of modernity have created a 'risk society,' they differ from Beck in defining the concept. Rather than seeing 'risk society' as the *response* to modernity, Giddens and Pierson state

that modernity has generated a society that is “increasingly preoccupied with the future (and also with safety), which generates the notion of risk” (Giddens & Pierson, 1998, p. 209). ‘Risk society’ is a way of describing how we, as a modern society, have become preoccupied with, and dominated by, the social construct of risk. Through the drastic changes society has seen in the modern era, particularly with advancements in science and technology, the construct of risk has shifted and is now constructed in a way that serves to control, normalize, and regulate society (Adams, 2001; Giddens & Pierson, 1998).

As is the case with all social constructs, risk is not fixed, but rather dynamic, and our societal understanding of risk has shifted across time and place. Historically, constructs of “risk” were associated with bravery, adventure (Beck, 1992), and exploration (Giddens, 1999). In the past, “risk” was “synonymous with chance,” (Green, 1997, in Ballinger & Payne, 2002, p. 306) and understood as subjective, having potentially good and bad outcomes (Ballinger & Payne, 2002). However, more recently with our modern era shift to a ‘risk society,’ “risk” is constructed as a positivist and objective construct (Stallings, 1990; Adams, 2001; Ballinger & Payne, 2002), largely understood in negative terms and associated with hazard, threat, and loss (Beck, 1992; Ballinger & Payne, 2002; Adams, 2001).

Constructing risk from a positivist perspective as an objective and real phenomenon is “problematic because it fails to recognize that risk is constructed through social and discursive processes...[and] fails to take account of social and cultural factors associated with risk” (Adams, 2001, p. 307 & 308), and ignores the circumstantial and negotiated nature of risk (Ballinger & Payne, 2002). When risk is explored as a subjective and

discursive construct it is increasingly difficult to define, and we see evidence of the ambiguous nature of the construct of risk, in a number of studies.

Adams (2001), exploring the social construction of risk, found psychiatric nurses defined risk differently than family carers. If family members define risk differently than professionals (staff), we can conclude that family would also make decisions, and manage risk differently than staff. Thus, if staff's professional opinions differ from the decision of the family, the fear of liability is introduced, and as a result we see an emphasis on the use of waivers, and documentation, to mitigate personal or professional litigation. Clemens and Hayes (1997) found that the definitions of elder risk, safety and autonomy differed among diverse professionals, including nurses and social workers, and that among these diverse professionals, there were variable thresholds for risk tolerance, where some professionals tolerated higher degrees of risk for service-users than others. The study suggests that experience, age, professional socialization, and personal characteristics were key factors in determining risk thresholds (Clemens & Hayes, 1997). In an inherently interdisciplinary environment such as LTC, where organizational members of various professional backgrounds work, and make decisions, inconsistent definitions of risk, safety, and autonomy, as well as variable risk thresholds could be problematic, further complicating the decision-making process, particularly if staff are not provided with opportunities to discuss and constructively deliberate the varying perspectives, and suggestions, of their interdisciplinary team members (Abma et al., 2009; van der Dam et al., 2011).

Another problem with the current positivist construct of risk is that it creates a dominant discourse of risk, particularly in health research and services, that focuses on

the physical aspects of risks, neglecting the psycho-social, personal, and cultural aspects (Ballinger & Payne, 2002). In studying the construction of the risk of falling among, and by, older people in a day hospital setting, Ballinger & Payne (2002) found that service-providers' risk discourse focused on the management of physical risks, such as falls, diet, and medication. Conversely, the older adult service-users' discourse of risk focused on the potential risks to their personal and social identities (Ballinger & Payne, 2002). The dominant discourse of risk in healthcare research and services results in a rigid notion of risk, where risk-aversion and prevention concentrates on physical and functional aspects of risk, neglecting to acknowledge that focusing merely on such preventative measures can actually *generate* further risk; risk to the personal and social identity of older adults (Ballinger & Payne, 2002).

Relying on “common knowledge” of risk, which is generated through discourse, results in elevated risk-aversion and “exaggerated fears of liability” (Clemens & Hayes, 1997, p. 18) within society, though particularly for healthcare providers. When the dominant discourse of risk is unquestionably accepted and reinforced it “excludes the possibility that there may be positive benefits associated with risk (Adams, 2001, p. 308), and results in “absent accounts” of the meaning of risk, excluding possible understandings of, or ways of knowing, what risk “means.” We see examples of this above where alternatively risk could be constructed and understood as threat(s) to personal and social identity. Emerging as a result of our modern ‘risk society’ there is a heightened awareness of, and obsession with risk (and safety) and the prevention/aversion of it. Staff in this study describe the conflict they experience as they try to manage risk and safety versus autonomy in decision-making, which often results in

feelings of anxiousness or worry, as well as moral distress [*see Paper One findings for a more in-depth discussion*]. Evidence from the data of different risk thresholds and the tension between risk and autonomy is highlighted in the following quotes.

When you get into the, you know, right to fall and that, those sort of things, which is worse, her being agitated in a chair, is it, you know, taking a chance she might fall and have a bruise, or whatever. And I mean we go with this everyday, it's, you know...are we going to let somebody fall, which is, you know, for some people that's, the better choice. (RN, LTC 003)

R: And, you know these people with dementia, you see them wandering around, they're, they're happier when they're wandering around...regardless of the fall risk...I mean, they are happier. (LPN, LTC 005)

...then you have to start looking at whose, you know, who is going to make that decision and and what are they comfortable with for as far as risks go... (RN, LTC 003)

Well if she's only falling, you know, once in a while, but I mean if someone's constantly falling and you know they're going, they're definitely going to fall, why take the risk? (LPN, LTC 002)

Risk discourse seems to be more prominent within certain demographics, resulting in variable risk thresholds and acceptability of risk for certain demographics over others. For example, belonging to the 'young-adult' demographic of under thirty awards me greater rights to risk than my nearly eighty-year-old grandfather; should someone find out

I live in a bachelor apartment, sleep on a futon, and eat only Kraft Dinner and canned vegetables they might not agree with my decisions, though would likely justify my actions with a dominant discursive excuse along the lines of “student poverty!” or “got to do, what you’ve got to do, to get through schooling!” or at the very least, “it’s her life.” Conversely, should someone find my grandfather in the identical situation, the societal response would likely sound something like, “he must have Dementia!” “call adult protection, he can’t live like this!” or, “how does his family let him live like that!” Here we begin to see how the ageism discourse interacts with the discourse of risk to influence LTC.

A participant in Clemens and Hayes’ (1997) study illustrates how multiple discourses interact to legitimize each other, demonstrating how risk tolerance levels are reduced as a result of ageism (ageist discourse):

Well, let’s look at this... is it that you fear for him and there’s some risk, but is it any greater than somebody who’s in their 40’s and choose to live in that same kind of way?... That’s my initial point of who is it that is you’re 70 you can’t make the same lousy decision you made when you were 40 and nobody cared? Yes, you can...back to the ageism piece. When you’re older, it’s less okay to make lousy decisions. Wrong, folks! You’ve got that right ’til the day you die...” (p. 16)

Ageism discourse interacts with the discourse of risk to generate heightened risk-aversion and reduced risk thresholds among older adults, and also functions to further legitimize the dominant discourse of risk, understood in physical and functional terms, by developing a construct of older adults that devalues their societal contribution and worth, therefore creating an ageist discourse where the personal and social identities of older

adults are perceived as less important, and therefore requiring less protection from risk, than their physical selves. Conversely, while the risk-aversion for younger demographics still concentrates on the physical, there is greater consideration for risks to the personal and social selves.

How risk is managed is also impacted by staff availability and routine. A focus on routine and efficiency in healthcare, including LTC, is not a new phenomenon, and in Western societies the field has typically been “characterized by rigid routines, rituals and care delivery organized to meet the needs of nursing staff or ward administration” (Tonuma & Winbolt, 2000, p. 215).

Efficiency Discourse

Efficiency in healthcare is not necessarily a negative goal, as Barnard (2016) highlights, “nobody would seriously want to be exposed to an inefficient and inept healthcare system” (p. 11). The concern, however, is when care becomes so standardized within routines of efficiency that it creates impersonality through conformity, predetermined causal relationships, uniform action and processes, prescribed ways of thinking, and the belief that there is “one best way to achieve any designated objective” (Ellul, 1964, p. vi; Barnard, 2016). There is evidence of in the data of impersonality and causal relationships as staff describe residents as passive recipients of care. There are some instances where staff overtly discuss and describe residents’ as passive recipients of care. For example, a staff member points out how neither staff nor family had thought to approach one resident for her opinion, stating, “Like no one’s asked her, everyone’s forced their decisions on her” (LPN, LTC 005). Throughout the focus groups many staff explore how many residents “feel their choices have been taken away” (RN, LTC 004).

More common in the data than this explicit acknowledgement are discrete examples of the underlying assumption of residents as passive and uninvolved recipients of care, identified through the analysis of the language used by staff. A common example of objectifying language, thus highlighting residents' passivity, emerges frequently as staff discuss residents and walking, "Like at the first, you *take her*, go for a walk..." (RN, LTC 003). In this quote a staff participant corrects the language, though initially portrays the resident as a passive object "to be walked," rather than "walking with" the resident. Here, perceiving/treating residents as passive recipients of care and using objectifying language is reflective of disconnected staff-resident relationships, a common effect of moral distress and staff burnout (Cummings, 2009).

Ellul (1964) also warned of the dangers of striving for the "one best way," in the concept of "la Technique:"

Technique refers to any complex of standardized means for attaining a predetermined result. Thus, it converts spontaneous and unreflective behaviour into behaviour that is deliberate and rationalized. The technical man is fascinated by results, by the immediate consequences of setting standardized devices into motion. (p. vi)

Technique is not an objective entity, but rather is a particular way of thinking that seeks to influence how a number of human activities are experienced and understood through the creation of systems of logical order (Ellul, 1964; Barnard, 2016). Ellul (1964) proposed that with the rise of technology, technique was required to encourage the necessary thinking for technology to advance and be efficiently and rationally applied to multiple facets of the human experience (Barnard, 2016). While in the healthcare sector

technological advancements have resulted in improved equipment, scientific evidence, and broader skills and knowledge, a significant element of technological advancements in healthcare has been the emergence of efficiency-driven practices fuelled by technique (Ellul, 1964, Menninger, 1981; Barnard, 2016).

With the establishment of systems of efficiency and order, the influence of technique is apparent in LTC policy and assessment as there is greater demand for measurable outcomes based on efficiency and task-oriented routines (Powers, 2000; Powers, 2001; Rees, King & Schmitz, 2009; Jakobsen & Sørli, 2010; Barnard, 2016). Efficiency, driven by technique, creates LTC environment where care is informed primarily by policies, standards and regulations, manuals, and hierarchical structures (Barnard, 2016; Tonuma & Winbolt, 2000). In this kind of environment there is little, if any, room for carer autonomy, creativity, and action based on individuals' needs/desires (Ellul, 1964; Barnard, 2016).

And the more we try and streamline the processes, the more difficult it is for people to think outside the box and to be able to get that hollistic approach. (DM 002).

The discourse of efficiency, complimented by technique, has become so immersed in the cultures of LTC that those working in the sector can struggle to conceive other ways of imagining LTC (Barnard, 2016). Efficiency and task-oriented routines are further encouraged and perceived as “the one best way” by minimal staffing levels, which often require rigid routines in order to ensure all of the residents' basic physical care needs can be met, despite failing to meet specific or psychosocial needs. Findings from this study demonstrate under staffing and routine/task driven environments often lead to

experiences of moral distress [*see Paper One findings for more discussion on this*].

The majority of staff perceive the LTC environment as being understaffed, thus undermining resident-centred and quality care. For example, staff cited “staffing issues” (LTC 002), “not having enough staff” (LTC 003), and “being too busy” (LTC 005) to provide holistic, quality care to residents. The following exchange typifies the perceptions expressed by many:

Respondent 1 (R1):...yeah, it's that, there's a time constraint there.

Respondent 2 (R2): Leading to there's not enough staff in nursing homes...

R1:...No...

R2:...you can put that down (laughs).

R1: You can imagine doing personal care on nine people and this population is really busy, and we do help them but, in the mornings, but that care doesn't end after you wash them up and get them dressed in the morning...

R2:...No...

R1:...you know I would say, half to three quarters of our clients are incontinent...you know, so it's ongoing through the day that you're looking after them, it's not just, you get them up...

R2:...Yeah. The little formula that you use, for whatever it is now three point such and such hours per day...

R1:...Yeah...

R2:...you know in nursing home, [um] you've used it all up, by eleven o'clock in the morning. Right, so you have another, few hours. (RN & LPN, LTC 004)

Staff express how an understaffed environment necessitates a task/routine environment in order to fulfill workload demands and meet the basic care of residents. The tension between responding to physical care needs in light of inadequate staffing lead to moral distress for the participants of this study. Understaffing is a commonly reported factor contributing to moral distress (Oh & Gastmans, 2015).

With a dominant discourse of efficiency, LTC staff encounter difficult ethical issues and conflicts as they struggle to maintain quality-care for residents while also meeting the increasing demands within the routine-driven and cost-efficient models prevalent in LTC today (Kirpal, 2004) [*see Paper One findings*]. Most staff in this study felt that an understaffed environment results in time constraints, leaving very little time for more than basic care, and increased difficulty in balancing competing residents' needs.

You know, you may have three or four bells ring at once, out of those four bells you need to determine which one's priority. (RN, LTC 006)

Staff struggle with that because, if there's a particular resident who requires a lot of time it's going to come from somebody else. (RN, LTC 003)

I mean and this is like me I can sit with her for so long but I have these other things that are supposedly more important that I have to do. (LPN, LTC 002)

Staff often make decisions based on the discourse of efficiency, which is confined by the limitations and expectations of the technique's "one best way" routine model, rather than what they believe to be the right or ethical decision and action (for example, deviating

from routine tasks to accommodate a residents' request/needs) (Jakobsen & Sørli, 2010); thus resulting in moral distress. The emphasis on productivity and efficiency in LTC conflicts with the ethical treatment of residents (Rees, King, & Schmitz, 2009) and staff experience feelings of distress and failure as a result of not acting in patients' best interests in situations where short-term daily nursing goals were prioritized above long-term resident goals (Tonuma & Winbolt, 2000; Rees, King, & Schmitz, 2009). Despite the ethical issues and conflicts experienced by staff, "efficiency and order resonate for many and they pervade nursing [and LTC] discourse" (Barnard, 2016, p. 11).

Concluding Thoughts and Possibilities

Exploring and de-constructing the dominant discourses of biomedicine, family power, risk, ageism, and efficiency, as well as how they interact to influence LTC and staff experiences of moral distress, requires us to challenge the taken for granted and normative perspectives of LTC (Phelan, 2010). By examining, and questioning, these dominant discourses, we are better able to see how the discourse-power-knowledge cycle operates to position individuals, perpetuate power imbalances, and circulate knowledge- while silencing alternatives- in LTC. Without such exploration, we risk the folly described by John McKinlay (1986) in an essay where he warns of the dangers of using all one's energy and resources to rescue an endless flow of people from a stream without taking the time to see what is causing the people to be in the stream in the first place (Estes & Binney, 1989). That is, without understanding the underlying discourses circulating in LTC, and the implications they have on policy development, environment, ethics, and decision-making, we risk "abandoning the search upstream" (Estes & Binney, 1989, p. 596) and neglecting possible alternative solutions, approaches, and responses to

the current questions and concerns in LTC, and the implications on staff, residents, family, and more generally, society.

From this multi-stage research project other questions arise, providing opportunities for future research. First, the findings from this research demonstrate staff experience a number of institutional constraints, impacting their ability to act in the ways they believe to be right. This finding suggests the ethical culture of an organization significantly influences the ethical decision-making processes and experiences of moral distress of staff. A possible way to expand the research in this area would be to explore ethics change in LTC organizations through participatory action-based research (PAR) guided by a micro-citizenship lens (Baldwin & Greason, 2016).

PAR has the primary purpose of taking real world problems, determined and defined by involved stakeholders, and aiming to solve them based on group collaboration. PAR is also well-positioned to provide insight into organizational ethics change and change management, as the participative and collaborative approach works to break down and re-establish the organizational culture of shared beliefs and values, which shape behavioural norms in the workplace (Koustelios & Belias, 2014). With PAR organizational members are invited to be actively involved in the change process, which fosters collaborative commitment to the outcomes.

Recently there has been increasing interest in citizenship as a lens through which to understand dementia and long-term care (D/LTC) practice (see, for e.g., Bartlett & O'Connor, 2007; Gilmour & Brannelly, 2010; Kelly & Innes, 2013). The term MC refers to those actions and practices of individuals, in immediate relationship, which uphold the liberties and freedoms of those involved while generating or supporting a sense of

identity and belonging (Baldwin & Greason, 2016). For those living in LTC, engagement might be realized at a variety of levels: decisions regarding one's care; participation in the everyday work of the facility, or caring for others; including individuals in the workings/governance of the organization itself. Micro-citizenship as a practice moves beyond the dominantly accepted personhood (Kitwood, 1997) conceptualization of D/LTC and calls us to re-envision much of D/LTC in terms of relationships and power, roles, responsibilities, care planning, risk assessment, and policies and procedures. The benefits, however, of doing so, may be enormous for a number of reasons. First, for staff who may experience reduced moral distress and increased work satisfaction (thus improved relationships with residents and enhanced quality care). Second, to increase organizational effectiveness/efficiency. Finally, and most importantly, through a micro-citizenship model of care, the scope of resident engagement is broadened, recognizing and promoting meaningful citizenship engagement at multiple levels. Thus, residents living in D/LTC are perceived, and treated, not just as individuals (as in person-centred care), but as citizens with power – power to initiate and shape, and become equals in the D/LTC community, contributing as much as they receive (Bartlett & O'Connor, 2007; Baldwin & Greason, 2016).

The second question arising from the research is how to implement meaningful change at a systemic/policy-level in order to see innovative change, and policy alignment, in LTC. How do the dominant discourses and power relationships actually interact to establish policy, and consequently our conceptions of LTC? Latour's (2010) ethnography work on actor network theory provides a possible framework for future research to answer these questions. Actor network theory suggests all social explanations (e.g. LTC

policy and conception) are the result of “associations” between networks of certain individuals. In his book, “The Making of Law: An Ethnography of the Conseil d’Etat,” Latour (2010) provides an unprecedented account of how French laws come into being following years of privileged access to private conversations and decision-making processes of counsellors. Through this process Latour (2010) explored the shifting networks of relationships impacting decisions and consequently the “close knitting of legal reasoning” (viii). Because the impact of discourses and power relations can be insidious, it is difficult to challenge policy-making processes in an effort to implement meaningful change. Adopting an actor network theory ethnography study to explore the LTC policy-making processes would allow for the networks, discourses, and associations to be illuminated and, hopefully, challenged as the first step toward implementing change and daring to imagine alternative approaches of LTC; alternatives that could improve care environments and quality of life/citizenship, reduce staff experiences of moral distress and increase workplace satisfaction, and enhance organizational and governmental efficiency in the LTC sector.

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Interlude Four: Reflecting on the research process

I never intended on completing a Master's, let alone a PhD. This was an unexpected opportunity and journey that I am so grateful for. I have learned so much personally, professionally, and academically as a result. Below I critically reflect upon my research journey.

I am not going to be one of *'those'* researchers

I admittedly used to be particularly critical of research practices. I specifically disliked that research often provides theoretical and/or philosophical findings to a select few (arguably an elite few with high cultural capital with the ability to access academic conferences and journals) without any *real* tangible or applicable change. Consequently, going into this research I was determined to not only provide theoretical knowledge but also tangible solutions with the real possibility of instituting some, albeit small, change. My background in social work coupled with this critique of research, significantly influenced my methodological approach and methods. I believed (and still do) that in order to see change in any capacity one must include, to the best of one's ability, multiple voices who have a vested interest in, or will be impacted by, the research. I wanted my research to come from the "bottom up" rather than the "top down" in my effort to generate applicable and tangible findings and recommendations. I did not want to contribute to the silencing or oppression of an already marginalized group, and I wanted the voices of those most directly impacted by the issues to be included, rather than simply those with theorizing or assumptive voices. I was determined not to be "one of those researchers that goes in, does research, and leaves."

Of course, as the research developed and findings were generated, I learned very quickly how challenging it can be to institute change (even in small ways). Of course, I expected some of the lessons from the findings to be more difficult to implement given the structural nature of the issues, particularly in the second stage of the research using Delphi. Even though adopting a Delphi method approach took the research further than traditional ethics and policy exploration, there were still significant challenges of translating findings into policy and practical changes. Although the Delphi method allowed for various stakeholders, including those at political and governmental levels, to discuss and explore these issues and propose possible avenues for change, instituting such changes would require significant policy and procedural changes at a *systemic* level. While the findings from Delphi provided tangible solutions and reflected a collective view, the identified issues and proposed resolutions are multifaceted. Implementing such changes would require collaboration across sectors, political will, and significant investment (both personnel and financial). Further, instituting the proposed solutions would impact a number of systems and processes, including provincial budgeting and funding streams, employment regulation, political organization, and legislative procedures (to name a few).

This realization was significant for me. First, it provided me with a much needed “reality check” and perspective regarding research practices. Second, it encouraged critical reflection and analysis in an effort to better understand why it is often challenging to implement change. I came to appreciate that typically the issues under investigation are not independent issues, but rather they are part of a complex system. As such, issues are interconnected at micro, meso and macro levels of societal operation and as a result there

is no easy solution. This of course means that findings from a single (or for that matter, even multiple) study have a hard time infiltrating the complex network to implement change.

I also quickly realized how challenging it can be to implement even small changes at the organizational level. Surely, if change was complex and thwarted at a structural level, we could at least implement some minor changes based on the findings at an organizational level. Though I have not given up, I also experienced significant challenges in my attempts to implement minor changes based on the research recommendations in the partner facilities. I believe this is reflective of the influence of organizational culture and the security individuals experience within such cultures. “This is how it’s always been done.” “This is the way we understand it.” Challenging organizational cultures and processes generates a sense of insecurity and fear, something individuals would rather avoid.

Insider Perspective and Appreciation

Following the first stage of the research I was fortunate to be able to work as a social worker in one of the partner agencies. This granted me insider perspective on the day-to-day operations of the organization and first hand experience working in the complex ethical environment I was researching. I felt validated to see that the vignettes used in the focus groups were reflective of actual practice contexts. However, I also felt discouraged in some ways to witness staff struggle to make autonomous decisions and avoid individual responsibility. Rather than being a ‘spectator’ to hypothetical focus group discussions regarding ethical issues, I was now positioned as an interdisciplinary team member and empathized with staff as they encountered numerous social care ethical

issues where they felt conflicted and restricted to act in the ways they believed to be right and ethical. I also witnessed how relying on the four strategies to reduce autonomous decisions-making resulted in further ethical issues regarding the care of the resident. For example, making a resident wait until the “unit manager” returned from vacation to have a meeting in order to determine if the resident could leave the facility unsupervised. Interestingly, a new strategy emerged on the units I worked to manage experiences of moral distress: refer to the social worker! Staff repeatedly expressed how thankful they were to have me there, as the issues were “outside their scope of practice” or they “didn’t have time to work through this.” Generally, the issues were not outside their scope of practice, but they were arguably time consuming and complex. I also think as a part-time staff member whose career was not dependent upon this position, I was in a different position to make ethical decisions, and was less intimidated to make autonomous decisions, within my scope and abilities.

Drawing on individual interviews with LTC staff to design the vignettes for the focus groups, a theme emerged where staff often reported negative, or challenging, relationships with families as contributing to frontline ethical challenges. Consequently, focus group discussions surrounding family relationships and interaction often present family as an obstacle. This finding is contrary to organizational philosophies and efforts, which emphasize the importance of family involvement and the promotion of a collaborative environment between the resident, family, and staff. Working in the partner agency, I was able to observe, and engage in, interactions between staff and family. I was delighted to see that, contrary to the problematic or negative framing of families that emerged from the data, generally relationships between staff and family members are

positive and mutually beneficial. There were instances, however, where certain relationships were strained and the interaction and involvement by family was perceived as an obstacle by staff. While in certain circumstances family could present somewhat of an obstacle for staff, typically in these instances I noticed two factors contributing to the perception of family as an obstacle. First, when family appeared disrespectful, demanding, and/or belittling toward staff, or when family seemed controlling of the resident. I realized a lot of the tension in these situations came from a place of misunderstanding on behalf of staff and family. Family were often unsure of their place within the organization, felt scared, guilty, and deep sadness that their family member was transitioning into LTC. This did not translate well when they approached staff about questions or concerns. The second contributing factor was when staff were feeling threatened (e.g. being questioned about their actions/work), over-worked, and burnt-out. Consequently, during my time working at the partner agency I attempted to narrow the gap between family and staff in an effort to reduce instances where family were perceived as an obstacle. I met with family members when a new resident moved in, explaining the importance of, and encouraging, their involvement, as well as the organization's desire to have them be a part of the "family." When necessary and desired, I also worked with family members to explore and work through feelings of uncertainty, guilt, and sadness regarding their family member's transition into LTC. In a less formal way, I spoke to staff to try and shift discourses about family, explaining the possible causes of family's sometimes abrupt or demanding interactions. Addressing the issues of staff feeling over-worked and burnt-out is, of course, a larger issue that the overall research provides recommendations for.

Prior to the focus groups, I did not have very much exposure to the LTC environment and I was sometimes critical of the discussions and positions staff took in terms of what was “right” during the focus group discussions. For example, in discussing time constraints, staff frequently reported “not having enough time” to walk with residents with Alzheimer’s and consequently the resident would be restrained in a wheelchair for a “short period of time” in order to reduce the risk of falling. I was, admittedly, judgmental of these discussions and could not appreciate any context in which a resident would be restrained simply because the environment necessitated it. After spending considerable time working in the LTC home, and with individuals living with Alzheimer’s, I gained a new appreciation for the environmental context that gave rise to staff thinking a wheelchair restraint was “right” to provide the resident with rest. I was able to experience the nuanced environment and witness staff, working tirelessly to support and love residents who, understandably, almost continuously sought their attention and care. At times, the environment was so restrictive that there truly were no other alternative options (e.g. have someone else walk with the resident while you attend to other tasks or issues) and staff were doing the best they could within the current context. While I still disagreed with the practice, I gained a better understanding of the context and this actually validated the importance of the second stage of the research to explore policies (e.g. staffing levels and scope of care) and their impact on ethical cultures in LTC.

Having this insider perspective helped me gain an appreciation of how important it is for researchers to truly understand the lived realities of their research participants. By this I mean, actually engaging in the day-to-day workings of the context as it has a significant impact on the holistic understanding of the research findings. While I know this is not

always a possibility for researchers, it had a big impact on how I viewed the research findings, recommendations, formulated questions for the Delphi interviews, and presented the data in my writings. This appreciation and perspective also helped me understand the significance behind frontline carers call for policy-makers to “come spend a day in our shoes.” Though, I would argue one day is not enough to experience the complexities of the LTC ethical decision-making environment.

Inspirational Participants

I was overwhelmed and continuously inspired by those working in LTC who do so much with so little. As a social worker, and social work educator, I am acutely aware of the restrictive environments in which those in the helping professions find themselves. There are increasing demands on workers, while resources and supports decrease annually. It can be challenging to remain optimistic, creative, and engaged, and I frequently discuss the issues of stress, burnout, and turnover with colleagues and students. Engaging in this research, and my work in LTC, I was profoundly moved and inspired by stories of creativity and resilience within and amongst the stories of barriers and challenge in LTC. Staff and families found ways to foster meaningful engagement with residents and promote elevated standards of care and ethics, despite systemic barriers. This was empowering for me professionally as I was able to witness first hand how small acts of kindness and love can begin to challenge and overcome deeply rooted structural barriers, oppression, and marginalization.

If I could do it Again

If I could go back and make changes to the research processes, I can honestly say there is very little I would change. I am truly excited about the research, methods, and

findings. I think the first stage necessitated the second stage, and I am glad I embarked on the Delphi method journey, though it was unexpected when I began this research.

Looking back, I still think the methods are relevant and strengthened the research, and also believe they aligned well with my methodologies. I will say that, at times, I felt I chose more challenging or time-consuming approaches to the research. For example, writing vignettes drawn from staff's actual experiences, rather than using a pre-designed case study. Or, using Delphi as a method of consensus, which necessitated multiple interviews per participant, significant time commitment, investment, and relationship-building. Despite this, I would not change the methodology or methods, particularly because I believe they were among the most pertinent in meeting the research objectives. Though at times tedious (who wants to transcribe focus groups? Not me, ever again), the research was also reflective of my personality, professional background, and values. Thus, I was interested in the research, engaged with the methods and data, and invested in the findings and recommendations.

Above are the main critical reflections that emerged from my research journey. I am grateful for this unexpected journey and for those who paved the way before me in the field of qualitative research. I am thankful for the participants for sharing their knowledge and stories, without whom this research would not be possible. I know I am not done engaging with the data, findings, and recommendations and am excited to see in what other ways the research will impact my personal, professional, and academic identities in the future.

Appendix A: Focus Group Introduction Script and Possible Questions

Welcome!

Points to Discuss:

- Sign consent forms.
- As you know, the project is about ethics in LTC and I am specifically doing my research on the focus group section, so I am very thankful you are all here and willing to participate!
- As you saw on the content form, I'm going to be audio recording today and then will transcribe the discussion, however no personal information will be used and you won't be identified as the sources of the discussion. The conversation won't be shared with anyone other than my supervisors.
- At times I might have to check the recorders to make sure they are still recording, but don't let that stop your conversation.
- I have a number of 'hypothetical' case study scenarios written to incorporate ethical issues.
- Even though the case studies are hypothetical, I think you will find them to be reflective of some of the ethical issues you encounter working in LTC.
- You'll have time to read the case study and then the idea is to talk about what issues you see in the cases and how you would go about resolving them- if you can come to a conclusion, great! If not, that's okay too!
- There are no right or wrong answers! I want everyone to feel comfortable to talk openly.
- I have five case studies, and we can discuss a number of them depending on how

the discussion and conversation goes. If it takes an hour to go over one, that's great. If it takes 15 minutes, we will do another case study.

- I might make some prompts at times throughout the discussion, though my hope is that you can work through the issues you all identify and discuss how you would make a decision.
- I will ask that we try not to speak over one another, just out of respect. If someone is talking, and you either agree or disagree, wait until they are finished to continue the conversation please.

Potential Questions (if needed):

- Is there a difference between medications when thinking about covert medication?
- Whose interests are prioritized based on this case study?
- What tensions do you see in the case- and how might you resolve them?
- Decision: How would you justify that to someone questioning it?
- How does your conclusion address X?
- How might you balance individual and collective rights in this case study? (family, staff, residents, mission)
- Are the risks in the case acceptable? What are acceptable risks, what are not acceptable risks?

Appendix B: Vignettes

Vignette 1

Mrs. Jane Nguyen is a seventy-eight year old that lives in New Brunswick with her husband Jack. The Nguyen's had three children, two girls and one boy. The family lived an active lifestyle and frequently travelled to Vietnam, where both Jane and Jack have extended family. Anna, their older daughter, moved to Vietnam twenty-five years ago.

Following retirement, the couple would go for long walks and began exploring alternative exercises such as tai chi, and soon came to appreciate the psychological and physical benefits to their well-being. The Nguyen's were actively involved in the tai chi community until five years ago when Mrs. Nguyen was diagnosed with Alzheimer's disease. One year following her diagnosis, Jane was admitted to a long term care facility.

Following admittance, Jane often appeared agitated and would become aggressive with staff, pushing them away, slapping, and at times kicking. Jack would drive to visit his wife daily at 2 p.m. and the couple would walk around the indoor courtyard for approximately an hour, and then would practice tai chi together. The staff noticed an observable difference in her behaviour following Jack's visit and their tai chi practice. The staff reported Jane would appear relaxed, happy, have increased coherence, and was minimally aggressive in the hours following her walk and tai chi.

Jane's younger daughter and son lived locally, and would occasionally visit, though did not frequently come in. Jack continued to make daily visits, though driving in the winter months became increasingly difficult for him, and there were days when he was not able to make the drive. On these days, Jane would wait by the door all afternoon, becoming increasingly agitated.

Staff reported difficulties getting Jane to bed on days when her husband did not visit and the Care Coordinator e-mailed her daughter, Anna, who had POA to discuss the possibility of giving Jane Melatonin, a natural hormone produced in the body that signals time to sleep, on days when she would not settle. The Nguyen's had both designated Anna as their POA prior to her moving to Vietnam. The couple kept saying they "had to switch it (POA) over to Ben, as he was local," though never got around to completing the paperwork prior to Jane's diagnosis and aggressive progression of the disease.

Anna did not agree with the Care Coordinator, and believed that if her mother was not tired, she should not have to sleep. Communications continued back and forth, as staff attempted to explain the difficulties and risks inherent in Jane refusing to get into bed, and the natural benefits of Melatonin. Despite the efforts to educate Anna, she maintained her position. During Jack's next visit he spoke with the nurses regarding his wife's refusal to go to bed. He said he thought using Melatonin was a good idea as well, though was not able to convince his daughter of this. Jack said he spoke to their family doctor who wrote Jane a prescription for Melatonin, which he filled and presented to the nurse. Jack said staff should use it as needed, and said he would do his best not to miss visits.

Three months ago, the Care Coordinator received a call from Anna who tearfully informed her that her father had suddenly passed away from an ischemic stroke. In the weeks following Jack's death, Jane became increasingly agitated and aggressive. Staff found taking her for a walk around the courtyard would reduce behavioural problems for a short time, though Jane would always want to walk longer than staff could. Jane would try to practice tai chi alone following the walk, which concerned staff. Jane required

assistance with some activities of daily living, though remained ambulatory.

In recent weeks, Jane continued to wander around the courtyard, attempting to practice tai chi, losing her balance and falling. She incurred a number of bruises and scrapes, though has not sustained any serious injuries. Anna was contacted each time Mrs. Nguyen injured herself. At times, staff would sit Jane in a wheelchair with a lap tray, to allow her time to rest and make sure she would not attempt to practice tai chi and get injured. At times, Jane would fall asleep in the chair, though on other occasions would shake her head back and forth and tap on the tray.

Jane's son, Ben, who had not visited for five months, stopped in one day and saw his mother sitting in the courtyard in the wheelchair. He took her for a brief walk and left a half hour later. The following day the Care Coordinator received an upset e-mail from Anna, who said her brother had informed her their mother was sitting in a wheelchair, restrained by a tray. Anna was very clear she did not want her mother in a wheelchair, despite risks of falling and being injured. She maintained that her mother "had very little left in life and being confined to a chair is not what she would want." The Care Coordinator explained Anna could sign a liability waiver if she did not want her mother in the chair, which was sent to her. Anna refused to sign the form and maintained her directions as POA was all that was needed.

Vignette 2

Mrs. Louise Cormier is a ninety-one year old woman who has been living in a long term care facility for one year. Mrs. Cormier and her husband, Joseph, raised nine children- six boys and three girls. Joseph died thirteen years ago.

Louise is primarily in good health, though was diagnosed with epilepsy fifty years ago and takes medication to control this (Sodium valproate, 200mg). More recently she has had high blood pressure, which is managed with Moduretic orally (5mg/50mg). Louise lived completely independently prior to transitioning into the long term care facility. Louise maintains, “the secret to a long life is staying busy,” and filled her spare time knitting, quilting, and gardening prior to moving into the facility.

Two of Louise’s grandchildren, Marc and Celine, who lived in the same neighbourhood, frequently visited her at her home. Marc, a lawyer, helped her write her will and assign POA. Louise named Marc and his brother, Jean, as executors of her will, gave enduring POA of property and finances to Marc, and gave joint enduring POA of personal care to Marc and Celine.

One day, Louise tripped over the carpet in her living room and fell. Louise went to the hospital where it was determined that she had broken her left hip and her left wrist. Louise was “shaken up” by the experience but was eager to return home. Her family was concerned she would get hurt again if she returned home, as her mobility was declining, and requested a home assessment be completed. It was determined Louise’s home was not suitable for her mobility restrictions and arrangements were made for Louise to move into a long term care facility.

Marc and Celine visited frequently during the first few weeks following her

admission, though the facility was approximately twenty-five minutes from their homes and workplaces and they found it increasingly difficult to find time to make the commute and started visiting less frequently. Louise had a very difficult time adjusting to the facility.

Louise shared a room with Mrs. England, though did not talk to her often, and spent the majority of her day sitting in her room knitting. As months passed, staff noticed she would stay in bed for a large part of the day, would not get dressed or do her hair, and was beginning to skip her scheduled bathing time. Mrs. England started to complain to staff about Louise's hygiene and the smell of their room.

Marc stopped to visit one afternoon and found Louise sitting alone in her room, the drapes were drawn and she was still in her nightgown. Marc was furious, and following his visit stormed to the nurses' station and demanded to speak to the head nurse. He told the nurse, "they were not paying an arm and a leg for their grandmother to be here just to have her sitting alone in a dark room and not being cared for!" Marc said, "you will make sure she is bathed and dressed or I will report you!" he then stormed out of the facility before the nurse could say anything.

In the weeks that followed, staff tried to negotiate with Louise to get her to dress and bathe, which always upset her. After another week (it had now been a month), two staff were particularly worried about Marc accusing them of "poor care" if Louise was not bathed and dressed, and determined "it was in her best interest to give her a bath." That afternoon, the staff kindly explained to Louise she *had* to bathe, even though they knew she did not want to. The staff asked if she would walk to the bath with them, or if she needed to go in a wheelchair. Louise protested, saying she didn't need a bath and was

“fine.” The staff helped Louise out of her chair and walked on either side of her to the bathtub. Louise continued to resist and staff assisted her into the tub.

One nurse, who had only been working at the facility for two months, was particularly bothered by the nurses’ actions and went to the head nurse to report what had happened. In the weeks that followed, staff continued to bring Louise to the bathtub to bathe, despite her continued resistance.

The following morning when staff brought her, her medication Louise refused to take her blood pressure medication. Louise continued to inconsistently refuse her medications over the next week and a half, though could often be convinced to take her epilepsy medication. On days she refused her blood pressure medication, some staff would put it in her yogurt and/or applesauce, while others did not. Louise started to refuse both medications and certain staff stopped asking Louise, saying, “it is a waste of time because she won’t take them anyway,” and simply put the medications in her food.

Louise had a mild stroke and has primarily recovered, though now has difficulty swallowing. She continued to eat solid foods, though now has aspiration pneumonia as a result of breathing food into her lungs. Marc and Celine decided she should only be given pureed foods, as this decreased her risk of pneumonia. Staff found that Louise would refuse the pureed foods and were concerned she was not getting the nutrients she needed. Staff noticed she would accept and eat solid foods. Marc maintained Louise should only be given pureed foods, while Celine believed “if she would eat solid foods and enjoyed it, she should be allowed to eat solid foods.”

Vignette 3

David Smith is an eighty-nine year old man who was diagnosed with amyotrophic lateral sclerosis (ALS) at age seventy. David is in a wheel chair and requires assistance with most activities of daily living. He has been living in the long term care facility for seven years and until recently has been coping fairly well. Staff describe David as a very outgoing and active member of the residence community, participating in all activities and spending most of his day socializing with other residents and staff.

David never married or had children and spent his life devoted to his career as a firefighter and was very involved in the community, participating in many volunteer initiatives and playing baseball for many years. David was also active in his Catholic church. David has one younger sister Margery, who is sixty-seven. Margery and her adult son Jeremy live nearby and both visit on a weekly basis. When admitted to the long term care facility, power of attorney (POA) forms were signed by David, giving Margery and Jeremy joint POA for financial matters, as well as joint POA for social and healthcare decisions once David was deemed unable to do so.

Whenever the weather was good, Jeremy would take his uncle to the nearby park to fish or feed the ducks. During the past six months, David's ALS has progressed considerably. He began to notice he had decreased energy and would complain to staff of exhaustion and extreme pain in his joints. Little seemed to help David with the pain and he started spending more time alone in his room, socializing less and less. Staff found David wanted to get out of bed less frequently in the morning for breakfast, as he said the pain was worse in the morning.

One morning David felt somewhat better and wanted to try to go for breakfast.

Staff had not come to see him yet and so he ‘paged’ them. A few minutes later a staff arrived and abruptly explained “they had five other lifts this morning and they would come get him as soon as they could.” David waited a long time to be assisted out of bed and by the time he arrived in the dining room most of the other residents had finished eating. David was discouraged by this and became more and more withdrawn.

Staff were increasingly worried about David, as he was displaying depressive symptoms, and talked to him about the possibility of taking an anti-depressant. David was not interested in taking “anymore medication” and told staff he was “just ready to go home.” Jeremy came to visit and despite his efforts was unable to cheer up his uncle. David continually told Jeremy “his time was up and he was ready to go home.” David then began losing his ability to speak and struggled to communicate his needs. He also lost the ability to chew and swallow. A tube feed was put in at his sister Margery’s request due to his inability to eat on his own.

Jeremy felt that his uncle was unhappy and had poor quality of life. He told his mother, “he lost the sparkle in his eyes mom, it isn’t him and he wouldn’t want to live like this.” During recent visits, Jeremy sits and holds his uncles hand and reads to him. Jeremy has notice that some staff do not speak or interact with David anymore when they are helping him with his daily routine, and talk to each other about unrelated topics, or to him. Margery has directed staff to continue David’s tube feedings and has stated that all means should be taken to ensure he does not die. Jeremy disagrees with this decision and has vocalized to staff that he feels prolonging David’s life is not fair to him.

Margery sees the removal of the tube feed as a form of euthanasia and therefore morally wrong in both Margery and David’s strong Catholic beliefs. It is evident through

David's behaviour (lack of sleep, sounds of anger/agitation, tears in his eyes) even with pain medication that he continues to be agitated and unhappy. Almost a year ago David signed a life care directive that permitted tube feeding however, Jeremy argues that there have been significant changes during the last year and he does not believe his uncle would agree to the same terms today. Facility policy enforces the revision and signature of the life care directive every year. Due to David's changes in cognition, this year the care directive must be revised and signed by Jeremy and Margery, as POA. Both Margery and Jeremy are adamant that they know what is best for David and refuse to be persuaded otherwise.

Vignette 4

Mr. Ingalls is an eighty-two year old man who moved into a long term care facility two years ago after his wife died of cancer. Both of Mr. Ingalls' daughters became concerned about their father in the months following their mother's death, as they noticed his personal hygiene was declining, he was not taking his medications, and the homestead was increasingly neglected.

Prior to retirement, Mr. Ingalls was a prominent farmer in New Brunswick and he and his wife were well known for their community involvement and volunteer initiatives. Mr. and Mrs. Ingalls loved hosting bridge nights and book clubs at their home.

As part of the process of moving into the long term care facility, Mr. Ingalls named his elder daughter his POA. The enduring POA currently allowed his daughter to manage his financial affairs, as he had increasingly found budgeting and investment management confusing and stressful. The POA was specific that should Mr. Ingalls ever be deemed incompetent, his POA would have the ability to make social and care decisions on his behalf.

Mr. Ingalls had somewhat of a difficult transition, and although he was polite with staff, he frequently complained about "having nothing to do." Mr. Ingalls' daughters could not understand why their father felt bored, as the monthly activities calendar was full. One day, Mr. Ingalls told the recreation coordinator it was difficult to do the activities he liked because so many of the other residents did not have the cognitive abilities to do so. He asked if they coordinated trips for the residents. He later learned there were occasionally outings, though the recreation budget did not cover these trips and he did not have enough surplus income to go.

Six months after Mr. Ingalls moved in, he began volunteering for a literacy program at a local elementary school. The school was only a few blocks from the long term care facility, and Mr. Ingalls enjoyed the leisure walk. Mr. Ingalls' daughters noticed an immediate difference in their father's demeanour and were relieved to see him "acting like himself." Mr. Ingalls' daughters were uncomfortable with their father walking in winter weather, and tried to coordinate their schedules so they could pick him up and drop him off at the school. Mr. Ingalls assured his daughters he enjoyed the walks and felt close to their mother during these times. He also told them volunteering had given him a sense of independence for the first time since he sold the homestead.

Mr. Ingalls continued to walk to the school through the winter months, though staff were concerned about the poor sidewalk conditions. The Care Coordinator met with Mr. Ingalls and his daughters to discuss staff concerns, and when Mr. Ingalls could not be convinced to stop walking, the family decided to buy Mr. Ingalls 'ice and snow grips' for his winter boots to minimize the risk of falling. Mr. Ingalls used the 'grips' for approximately two weeks, though did not like how they felt and stopped using them. Mr. Ingalls' daughters and staff were unaware that he stopped using the 'grips' until one afternoon Mr. Ingalls' daughter received a call from the emergency department advising her father had slipped on the ice and sprained his ankle. Mr. Ingalls did not need a cast, though had to use crutches and/or a wheelchair for six weeks.

Mr. Ingalls was anxious to get back to volunteering after the six weeks, though his daughters were less enthusiastic about their father walking and were concerned "next time the fall might be fatal." The staff were also concerned for Mr. Ingalls' safety, as he had diminished balance since the sprain and thought he might be lacking insight into the

potential risks of falling at his age. The daughters were convinced Mr. Ingalls was “getting old and was not able to understand the risks associated with walking alone outside.” A family conference was held with Mr. Ingalls’ daughters and some staff, and the decision was made to have Mr. Ingalls undergo a mental competency assessment. Mr. Ingalls was unaware of this decision until a physician, whom he had never met, asked to meet with him privately in the conference room the following day, without explaining the reason for the meeting. Mr. Ingalls was unsure why the doctor was asking so many questions and was very nervous, suspicious, and brief during the conversation.

Mr. Ingalls was deemed not to have the capacity to make care decisions for himself and was furious when his daughters explained this to him. Mr. Ingalls insisted he was “caught off guard” and that he knew the risks of walking, but insisted “it was worth it.” As weeks passed, Mr. Ingalls would sit in the lobby, attempting to escape when the doors were opened. He was withdrawn and brief with his daughters when they visited. One day, he called a friend who had legal connections, asking for her help. A lawyer met with Mr. Ingalls pro bono and found him to be competent, understanding the risks associated with walking, and able to make care decisions for himself. Following their meeting, the lawyer contacted the Care Coordinator to discuss Mr. Ingalls’ assessment and challenge the competency assessment.

Vignette 5

Burt MacDonald is an eighty-three year-old man who has been diagnosed with Alzheimer's. Before Burt developed Alzheimer's he was a highly regarded lawyer in his local community. Burt and his wife Patricia, who still consider themselves best friends after 60 years of marriage, raised four children together. When Burt retired from his law practice they began spending more and more of their time together. Everyone who knew the couple considered them to be soul mates.

Patricia cared for Burt for almost a year until his condition progressed to the point that Patricia could no longer care for Burt in their home. The family made the decision to move Burt into a long term care facility once Burt started to become aggressive with Patricia.

Burt had a difficult time adjusting to the move and Patricia visited with him everyday. Burt became increasingly withdrawn and isolated and during his first month at the facility he became increasingly aggressive. Patricia was adamantly against restraining Burt- using a lap tray or any medication- despite the fact that he was injuring staff as they attempted to care for his daily needs. Patricia believed that "if staff were patient, did not "rush" him, and listened to his body language he would not get aggressive with them. Staff spent a lot of time educating Patricia regarding the limited restraints used in the facility and their importance for his, other residents', and staff safety. Patricia was Burt's POA and worked closely with staff, making healthcare decisions she hoped were in his best interest.

Patricia did not like that Burt was locked in the facility at all times and could not move freely from his unit. Patricia believed this might be contributing to his agitation and

aggression towards others. Prior to his diagnosis, Burt loved spending time outdoors on the golf course and would become “cranky and difficult to live with” when he didn’t get his golf time in. Burt’s agitation and aggressive behaviour was very difficult for all family members; Patricia said, “Burt was not like this before the diagnosis and would be mortified if he knew what he was doing.” The family was adamant that Burt should be able to spend time outside with the help of staff, when family was not there to do it. Staff struggled to accommodate this request and worried it would be unfair to other residents if they took Burt out and did not have the time to do the same for everyone else.

One day at lunch, Burt began socializing with another resident, Alice. Alice has dementia and has lived at the facility for four years. Her husband died of cancer almost ten years ago and she does not have any family locally. Alice looks a lot like Patricia; they both have short grey hair and are of about the same build. Staff at the facility started to notice that Alice and Burt were frequently sitting together in the common rooms and during mealtimes. This progressed quickly into Alice laying her head on his shoulder, hand holding, and showing affection towards each other in common areas.

Staff began to notice a difference in Burt’s behaviour and demeanour following time spent with Alice. Burt was less agitated and aggressive and seemed much happier and “at peace.” Staff were thrilled and were able to more easily complete their daily tasks with Burt, saving a lot of time. Some staff were worried what Patricia would think of his new relationship with Alice and the Care Coordinator decided they would talk to Patricia about it during their next family conference at the end of the week.

The following day, Patricia came in earlier than usual for her daily visit and found Burt sitting on the couch with Alice cuddled up next to him; she also saw him kiss her

cheek. Patricia was furious, left the facility immediately, and did not return until the family conference at the end of the week. Patricia and her daughter, Dana, attended the conference. Dana comforted her mother, and tried to explain Burt did not understand what he was doing. Dana tried to explain to her mother how much happier and “himself” her father seemed and how this relationship might be good for him. Dana wanted her father to be happy because he had been so confused and aggressive and “unlike himself” for so long. Dana was in favour of the relationship continuing for her father’s overall well-being and quality of life, a stance against her mother’s wishes. Patricia became more and more upset about the relationship and demanded staff separate Alice and Burt as much as possible.

Staff began separating Burt and Alice following the family conference, which led to Burt becoming aggressive and shouting. Burt was also more aggressive and agitated with Patricia when she visited. Staff continued to try and separate Alice and Burt for over a week when Burt had an outburst and physically assaulted a staff member to the point where he had to be sedated. Patricia was livid that Burt was given a sedative and asked that Burt be moved to a different unit, away from Alice.

Appendix C: SAGE Research Methods Case Study Permission Letter



Dear Ms Greason,

This is to confirm that you have our permission to include your SAGE Research Methods Case Study entitled "Empirical Ethics in Long-Term Care: Using Delphi Method as a Form of Consensus Building" in your doctoral dissertation.

Kind regards,

Kasia

A handwritten signature in black ink that reads 'K Figiel'.

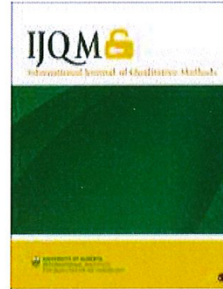
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Appendix D: International Journal of Qualitative Methods Permission Letter

To: Michelle Greason, Submitting Author
From: Kiley Allen, Publishing Editor

September 18, 2018



Dear Michelle Greason,

Thank you for submitting your research to *International Journal of Qualitative Methods (IJQM)*. The following manuscript has been accepted to *IJQM*:

Connecting Findings to Meaningful Change: The Benefits of Using Qualitative Delphi in Empirical Ethics and Policy Research in Long-Term Care

On behalf of the Editors of *International Journal of Qualitative Methods*, we approve that you use your article as part of your PhD Dissertation. Thank you for your fine contribution to *IJQM*.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Kiley', is written over a horizontal line.

Kiley Allen
Publishing Editor, *International Journal of Qualitative Methods*
SAGE Publishing Open Access

Curriculum Vitae

Candidate's full name: Michelle Rose Ouellette Greason

Universities attended (with dates and degrees obtained):

University of New Brunswick, MA-PhD Interdisciplinary Studies, 2014-2018

St. Thomas University, BSW, 2013-2014

St. Thomas University, BA, 2009-2013

Publications:

Greason, M. (2017). Empirical Ethics in Long Term Care: Using Delphi Method as a form of Consensus Building. *SAGE, Research Method Cases*, Part 2.

Baldwin, C. & **Greason, M.** (2016). Microcitizenship, dementia and long-term care. *Dementia: The International Journal of Social Research and Practice, Special Edition on Dementia and Citizenship*, 15(3), 289-303.

Greason, M. (2018). Connecting findings to meaningful change: The benefits of using qualitative Delphi in empirical ethics and policy research in long-term care. *International Journal of Qualitative Methods*. Retrieved from:
<http://journals.sagepub.com/doi/full/10.1177/1609406918803271#articleCitationDownloadContainer>

Greason, M. (forthcoming). Ethical reasoning and moral distress in social care among long-term care staff. *Canadian Journal on Aging*. Under Review.

Baldwin, C. & **Greason, M.** (forthcoming). Narrative and argumentation in a case of alleged child abuse. *Narrative Works*. Under review.

Conference Presentations:

Greason, M. (2017). Ethical reasoning and moral distress in social care among long-term care staff. Crossroads Interdisciplinary Health Research Conference. Halifax, Nova Scotia, 10th – 12th March, 2017.

Greason, M. (2016). Transferring Knowledge into Policy in Long-Term Care Using the Delphi Technique. Canadian Association on Gerontology Conference: Fostering Innovation in Research on Aging. Montreal, Quebec, 20th – 22nd October, 2016

Greason, M. (2016). Transferring knowledge into policy in long term care. York Care Centre Board of Ethics, Fredericton, NB, 20th June, 2016.

Greason, M. (2016). Transferring Knowledge into Policy in Long Term Care: An Empirical Ethics Project. Graduate Research Conference 2016. University of New Brunswick, Fredericton, NB, 22nd April 2016.

Greason, M. (2016). Ethics in LTC: From frontline experience to policy change. Loch Lomond Villa Ethics/Research Board, Saint John, NB, 3rd March, 2016.

Ouellette, M. (2015). Ethical decision-making in long-term care. Qualitatives 2015.

Brescia University College, London, ON, 23rd – 26th June 2015.

Ouellette, M. (2015). Ethical Decision-Making in the provision of social care in LTC.

Atlantic Centre for Qualitative Research and Analysis Qualitative Seminar, St. Thomas University, Fredericton, NB, 27th March 2015.