Ethical Conflicts in Community Health Care: A Qualitative Study of Individual and

Family Experiences

by © Anne C. Wadhwa

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Abstract

Background: Ethical conflicts experienced by health care clients and their families can generate feelings of stress and anxiety, compromise relationships, and lead to fragmented care. Despite the increased use of community health care services in recent years, very little is known about the types of ethical conflicts affecting community health care clients and their families, and hence further research is needed. **Purpose**: The two-fold purpose of this research practicum project was to increase understanding of the types of ethical conflicts experienced by community health care recipients and their family members, and to gain qualitative research experience by engaging in each aspect of the research process. **Methods**: Practicum objectives were met by: 1) reviewing existing literature on ethical conflicts; 2) planning and conducting a qualitative, exploratory study; 3) working collaboratively with community health care clients, colleagues, and mentors; and 4) disseminating my research findings. **Study Findings**: Ethical conflicts involved issues with: 1) accessibility to care, 2) quality of care, 3) compassion and respect, and 4) privacy. Management efforts included: 1) using personal connections, 2) reporting concerns, 3) switching health care providers, and 4) doing nothing. **Practicum Conclusions**: During this research practicum project, I advanced my qualitative research skills and generated new data on ethical conflicts that may inform community health care providers and other key stakeholders. In addition, my study design establishes the basis for future research aimed at further exploring ethical conflicts and management strategies, and identifying support needs at the community level.

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Finally, I must express my very profound gratitude for the support and encouragement received from my family and friends, especially my husband, Birender; my children, Rohan, Serena, and Ashwin; and my friend and colleague, Sue. This was truly a team effort and I am honoured to share this accomplishment with them.

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Practicum Introduction

In this report, I present my research practicum project entitled *Ethical Conflicts in Community Health Care: A Qualitative Study of Individual and Family Experiences*. This research study was part of a larger study (*Clinical Ethics Committees and Ethical Conflicts in Community Health Care*) that explores the ethical conflicts of nurses, physicians, clients, and family members in community settings; identifies conflict management strategies; and examines the structure, function, and effectiveness of community ethics committees and services.

Background

Ethical conflicts can arise in the context of health care whenever there are perceived differences in values, goals, or expectations among clients, family members, and health care providers in relation to care and care outcomes (Pavlish, Brown-Saltzman, Jakel, & Fine, 2014). Ethical conflict is an important research topic because of the detrimental effects it can have on one's emotional and physical health. Conflict can generate feelings of stress and anxiety, compromise relationships, and lead to fragmented care that can jeopardize client safety and well-being (McAndrew, Leske, & Garcia, 2011; Varcoe, Pauly, Storch, Newton, & Makaroff, 2012; Wiegand & Funk, 2012). There is a growing need for ethics research since the occurrence of ethical issues in health care appears to be on the rise. Factors such as extended life spans, greater cultural and religious diversity, and higher public expectations of the health care system, are believed to be some of the main contributors to this increase (Pavlish et al., 2014; Schlairet, 2009). Research that focuses on ethical conflicts in community care settings--health care settings outside of hospital institutions such as private medical clinics, nursing homes, and client

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residences--is of particular appeal, given the increasing utilization of community health care services due to aging populations, rising rates of chronic disease, and other changing health trends (Health Canada, 2012).

Goal and Objectives

The overall goal of my research practicum project was to engage in each aspect of the process of conducting a qualitative research study (e.g., the literature review, the design including participant recruitment, data collection, and data analysis) to generate data on ethical conflicts experienced by individuals and families that could be contributed to the larger ethics study. This goal was achieved by meeting the following practicum objectives:

1. To increase proficiency in conducting literature searches using a variety of electronic academic databases.

2. To gain and demonstrate understanding of the qualitative, exploratory design (Creswell, 1998, 2003) as it applies to the study of ethical conflict.

3. To develop the ability to synthesize and extract significant research findings using qualitative content analysis.

4. To gain specific knowledge about ethical conflicts experienced by individuals and families to inform nursing practice.

5. To hone my communication skills and my ability to collaborate with health care clients, colleagues, and mentors.

6. To advance my academic writing and oral presentation skills.

Literature Review

I conducted a review of the literature using PubMed, CINAHL, Cochrane, PsycINFO, Scopus, Web of Science, and Google Scholar. The main research question that guided my literature search was: "What types of ethical conflicts are encountered by community health care clients and their families?" My search terms included: *primary health care*, *community health services*, *home health care*, *ethics, ethical conflict, patient, family, patient attitudes,* and *patient experience*. These terms, and variations of these terms, were used individually and in combination to find full-text research articles relevant to my topic.

My global search yielded 206 research articles published in the last 12 years in journals of varying disciplines (nursing, medicine, education, social sciences, and ethics). A vast majority of these articles focused on ethical dilemmas encountered by nurses and physicians rather than individuals and families. I found only six research studies within the search results that explored ethical issues, concerns, or conflicts experienced by health care recipients and their family members, and located an additional two relevant studies through handsearching. Since the number of empirical studies that focused exclusively on health care received in community settings was limited, research articles that reported on individual and family ethics within hospital settings were also included. All reviewed studies were qualitative by design and published in peer-reviewed journals in nursing, medicine, and ethics. A comprehensive review of the literature, including summary tables for the eight studies that underwent critical appraisal, is located in Appendix A.

Major Themes

There were four main categories of ethical challenges described in the literature in relation to health care recipients and their family members: 1) treatment decisions, 2) access to health resources, 3) autonomy, and 4) dignity and respect.

Treatment decisions. Conflict situations described in many of the reviewed studies stemmed from making treatment decisions. Some of these conflict situations were interpersonal in nature, involving disagreements between individuals and families and their health care providers about preferred methods of treatment, while others concerned internal struggles experienced by health care clients and their relatives in choosing the best course of treatment when several options were available.

Interpersonal conflicts. Interpersonal disagreements about treatment decisions ranged from clashes between clients and health care providers over denied requests for prescription medications to battles over decisions to withdraw life-sustaining treatment in intensive care units (ICUs) (Breslin, MacRae, Bell, Singer, & University of Toronto Joint Centre for Bioethics Clinical Ethics Group, 2005). Interpersonal conflict was also reported when there were differing expectations about the types and level of involvement of family members in care and decision-making processes. For instance, in the study by Van Keer, Deschepper, Francke, Huyghens, and Bilsen (2015), it was found that while health care providers favoured an approach to care that was based on the biomedical model and that prioritized centralized decision making, families valued a more holistic approach to care and desired to be active participants in care activities.

Intrapersonal conflict. In situations where clients and families could freely choose one course of treatment over another, some described feeling torn about which

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option was the right choice. This decisional conflict stemmed from a lack of knowledge about treatment risks, benefits, and alternatives (Allen, Allen, Hilgeman, & DeCoster, 2008), or insufficient information about client values and expectations (Dreyer, Forde, & Nortvedt, 2009). In the descriptive study by Dreyer et al. (2009), for example, relatives who acted as substitute decision makers had poor knowledge about end-of-life care and were found to be largely unaware of the client's treatment preferences.

Access to health resources. Difficulty in accessing required health care was a common theme in the literature that was attributed to long wait times, the inequitable distribution of health resources, and financial barriers to treatment. Extended wait times for needed care were of ethical concern because of their potential to compromise clients' health status, reduce their chance of achieving optimum treatment outcomes, delay their ability to return to day-to-day activities, and threaten their psychological well-being (Breslin et al., 2005). Limited access to services resulting from the inequitable distribution of resources was described in terms of frequently under-funded areas in the health care system such as long-term care and mental health (Breslin et al., 2005), and disproportionate spending in urban centers in comparison to rural locations (Alkabba, Hussein, Albar, Bahnassy, & Qadi, 2012). Such inequitable allocation of resources limited the access for individuals in the underserviced areas and was viewed as discriminatory against some of the most vulnerable and disadvantaged groups in society (e.g., the elderly, individuals with mental illness) (Breslin et al., 2005). Access issues related to personal financial burden associated with costly, life-saving treatment was discussed in the context of human immunodeficiency virus (HIV) care (Kaposy et al., 2017). Difficulties encountered in securing medical insurance to cover the costs of

treatment, and the inability to pay the high deductibles often associated with the

insurance plans, resulted in significant numbers of individuals who were denied

necessary treatment (Kaposy et al., 2017).

Autonomy. Challenges to autonomy were reported in a number of nursing home

studies. For instance, a study of ethical challenges in nine nursing homes in Norway

revealed that residents perceived very little decision-making power with respect to care

and day-to-day activities (Bollig, Gjengedal, & Rosland, 2016). Residents described

being severely restricted in their ability to have visitors, go outside the facility, and

decide the timing of certain routines (Bollig et al., 2016). Another factor that challenged

nursing home residents' autonomy was their apprehension about speaking up about issues

or concerns for fear of being labelled by the staff as troublesome (Bollig et al., 2016).

This sentiment increased their vulnerability to coercion and threatened their sense of

well-being.

Additional violations to autonomy occurred when family members made

treatment decisions on behalf of competent individuals without obtaining their consent

(Dreyer et al., 2009). Instances were described where family members were given

information about nursing home residents and involved in care decisions, with little or no

consideration of the residents' ability or desire to provide informed consent (Dreyer et al.,

2009).

Dignity and respect. Threats to dignity and respect were identified by nursing

home residents and hospital clients in relation to day-to-day interactions and care. In one

study, nursing home residents indicated that there were very few opportunities to foster

dignity through the formation of meaningful social relationships with nursing staff and

the other residents (Pleschberger, 2007). This was often due to the frequent understaffing of nurses and the other residents' declining physical and mental health (Pleschberger, 2007). In the same study, the participants' sense of dignity was also endangered when they experienced physical or mental decline and required extra nursing care. This was because the concept of dignity was found to be rooted in aspects of the body and the notion of "not being a burden" (Pleschberger, 2007, p. 200).

Concerns about respectful treatment were reported when health care staff displayed negative attitudes or were apathetic, imposed excessive wait times, and were difficult to contact (Bollig et al., 2016; Foglia, Pearlman, Bottrell, Altemose, & Fox, 2009). Exposure to such interactions and experiences had negative effects on the client's psychological health and well-being. For example, a study of client perceptions of ethical challenges in hospital-based care reported that negative attitudes and poor reception by hospital staff served to intensify already-existing feelings of vulnerability and fear (Foglia et al., 2009).

Summary

My review of the literature revealed that there are numerous ethical issues that can arise during the delivery of health care, particularly in tertiary or long-term care settings, that can have serious consequences for clients and their families. Whether it is an issue affecting large segments of the population, such as wait times, or a challenge felt at the personal level, such as sense of dignity, the research clearly illustrates that those who are affected can incur physical and psychological harm that can threaten health and well-being.

My overall assessment of the nature and quality of the existing research on ethical conflicts revealed that a small number of good quality studies explored various aspects of the topic by employing several useful qualitative approaches. Important gaps identified in the literature highlighted the need for further research; specifically, studies that elicit client and family perspectives on ethical conflicts that arise in Canadian, community health care settings would serve to enhance understanding of the nature of ethical issues affecting Canadian community health care recipients and their families, and provide valuable insight into the ways in which such challenges are being managed.

Methods

A qualitative, exploratory design was used to carry out my study of ethical conflicts. This was considered a well-suited design given my interest in studying the personal experiences of individuals for which very little research data had been reported. My methodological approach to inquiry was based on the philosophical underpinnings of qualitative research described by Creswell (1998, 2003). These assumptions, which are related to issues of *ontology, epistemology, axiology, rhetoric,* and *methodology* (Creswell, 1998), served as the foundation for my qualitative inquiry and guided my approach throughout the research process. Detailed descriptions of the specific methods used in my research study, and how my research approach was reflective of the philosophical assumptions described by Creswell, are provided in my research report (see Appendix B).

Ethical approval to conduct my study was obtained from the Health Research Ethics Authority. Informed written consent was provided by all study participants and participant confidentiality was maintained throughout the research process. Participants

were recruited in Newfoundland and Labrador, Canada, using purposive sampling. Data were collected from three study participants through in-person, semi-structured interviews that were audio recorded and transcribed verbatim. Interview data were carefully analyzed using qualitative content analysis as described by Elo and Kyngäs (2008) and Hsieh and Shannon (2005). The theoretical lens through which I conducted my inquiry and analysis was the "Human Rights in Patient Care" framework by Cohen and Ezer (2013). In my research report in Appendix B, I provide the details of each step of my data analysis, the value and applicability of my chosen theoretical lens, and the particular ways in which my methodological approach addressed the key supporting criteria for rigor described by Guba (1981) and Guba and Lincoln (1994).

Synopsis of Research Findings

Two females and one male participated in my study. All participants were between the ages of 59 and 67 years and lived in the province of Newfoundland and Labrador. Two of the participants encountered ethical concerns related to their own care and the care of a relative, while the third participant experienced ethical issues with the care of a family member only. Reported ethical concerns involved health care services received in a variety of community settings: family physician offices, medical specialist clinics, the clients' own homes, and a restorative care facility.

Main Categories

Ethical conflicts described by community health care clients and their relatives were situated within four main categories: 1) access to health care, 2) quality of health care, 3) compassion and respect, and 4) privacy.

Access to health care. Participants identified issues with access to health care services as a top priority ethical concern for themselves and their family members. One of the main barriers to access that was described was long wait times to see medical specialists and other health care providers. In one account, a participant described long delays in obtaining an eye specialist appointment for his or her relative, and reported feelings of helplessness and powerlessness in accessing care given the unavoidable wait time. The physical decline and prolonged inability to carry out day-to-day activities that resulted from long waits for care were major concerns for health care clients and their family members. The second main barrier to access identified by participants was a lack of support services for aging individuals in the community. This ethical issue was discussed in relation to difficulties in accessing homecare services for older relatives, and a lack of supportive measures to accommodate individuals with mobility issues who are required to attend medical appointments outside of their homes.

Quality of health care. Concerns for the quality of health care received in the community stemmed from incidents where medication errors were made, medical issues were not identified, health concerns were not adequately addressed, and safety protocols were not followed during the provision of client care. For instance, in one participant's account of an older relative receiving care in a community facility, the participant described a sudden and unexpected decline in the relative's health and the subsequent discovery that he or she had been administered the wrong dose of medication over a one-week period. Descriptions of such events included emphasis on the resulting harm to the client's health and well-being and a lack of accountability on the part of the health care staff for their wrongdoings.

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Compassion and respect. A lack of compassion was perceived when staff members neglected to verbally greet clients, did not use eye contact during face-to-face communication, showed little or no concern for the client's issues and struggles, and refused to accommodate seemingly simple requests. Lack of compassion was therefore a "stumbling block" that interfered with information sharing and threatened satisfaction with care. Feelings of disrespect among clients and family members were described in scenarios where they experienced poor communication from health care staff or were verbally reprimanded by staff for their words or actions. Lack of compassion and respect was harmful to relationship dynamics and made participants feel apprehensive about booking future appointments.

Privacy. Violations to privacy were described in the context of community health care in two different scenarios. In the first scenario, clients were expected to discuss their health care issues with staff members who were not directly involved in their care. This caused discomfort for the client given the personal nature of some of the health issues for which he or she was seeking care. The second scenario involved clients having to discuss health issues and concerns in areas that were within earshot of others awaiting care, such as talking to a secretary through a window from a waiting room. Failure to provide private spaces for clients to discuss the details of their health status and care placed these individuals in compromising situations that made them feel vulnerable and exposed.

Management Strategies

Although not the major aim of my study, I also inquired about the measures taken by participants to address their ethical conflict situations. Four main types of management strategies were described by participants: 1) using personal connections, 2)

reporting concerns, 3) switching health care providers, and 4) doing nothing. Forming

personal connections with health care staff by engaging them in friendly conversation and

showing interest in their personal lives was discussed as a useful strategy for eliciting

greater levels of compassion and respect, and gaining more timely access to care.

Reporting concerns to health care team members was used to manage such issues as

medication errors and incompetent care; however, there was expressed uncertainty about

the effectiveness of this strategy given the lack of response and follow-up. Switching

health care providers was a strategy for gaining more timely access to care, obtaining

safer and more competent care, and seeking more compassionate and respectful

interactions. Individuals and families who chose to do nothing to address their ethical

concerns did so because they did not want to jeopardize the client-provider relationship,

feared repercussions for the staff members involved, or did not believe that management

efforts would have any consequence.

Advanced Practice Nursing Competencies

Throughout my research practicum project, I had several opportunities to

demonstrate the core competencies of advanced nursing practice described by the

Canadian Nurses Association (CNA) (2008): *clinical, research, leadership,* and

consultation and collaboration.

Clinical

Clinical competencies are demonstrated when nurses work in collaboration with

clients in a particular area of nursing to identify situations or events that have health

implications for individuals and their families (CNA, 2008). This requires using a holistic

approach that considers the range of internal and external influences at play, and the

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clients' lived experience (CNA, 2008). During my study of ethical conflicts, I consulted

with community health care clients and their families to explore the types of conflicts that

negatively influenced their health and well-being. My use of semi-structured interviews

provided clients the opportunity to describe their experiences in their own words so that

their lived experience could be fully explored. Furthermore, the theoretical lens (Human

Rights in Patient Care by Cohen and Ezer [2013]) through which my research was

conducted promoted examination of the wide range of interpersonal and systemic issues

affecting clients and other key stakeholders in the particular setting under study. These

measures allowed me to gain a comprehensive understanding of events and their

circumstances.

Research and Leadership

Research and leadership competencies are displayed when nurses become actively

involved in the generation and dissemination of new knowledge that enhances nursing

practice and improves client care (CNA, 2008). By conducting my qualitative,

exploratory study of ethical conflicts, I was able to fully engage in each aspect of the

research process to increase understanding of the types of ethical challenges facing

clients and families in the community. My findings served to both reinforce themes found

in previous ethics research, such as limited access to health care services, and to identify

new ethical concerns, such as quality of care issues, that are affecting care recipients at

the community level. I reported my preliminary study findings to graduate students and

faculty at Memorial University School of Nursing, and I will also be contributing my

findings to the larger ethics study as discussed previously.

Consultation and Collaboration

Consultation and collaboration with clients and colleagues in a variety of settings involves such activities as participating in collaborative projects at an academic institution and working in partnership with others to generate new health knowledge (CNA, 2008). My research practicum project, which was affiliated with the larger ethics study being conducted at Memorial University, involved working in consultation and partnership with my practicum supervisor, other contributors to the larger study, and the individuals and families with whom I met to obtain health related data. I established and maintained good lines of communication with these groups to ensure that the purpose and objectives of my research practicum project were met.

Concluding Remarks

This research practicum project provided the opportunity to generate new data that will add to the existing body of knowledge on ethical conflicts in community health care settings and to advance my skills as a qualitative researcher. By engaging in each aspect of the research process, I was able to meet my practicum objectives and to demonstrate the advanced nursing practice competencies outlined by the CNA (2008). My study findings are useful for informing nurses and other key stakeholders in community health care settings about the kinds of ethical conflicts that clients and their family members experience and the strategies used to manage their ethical concerns. My study also provides a strong foundation for future nursing research that involves examination of ethical conflicts in the community and the identification of effective measures to promote client and family health and well-being.

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Appendix A

Literature Review

In this paper, I present an integrative review of the literature on the topic of

ethical conflicts experienced by health care recipients and their families. In the following

discussion, I provide an overview of my search strategy for academic literature on ethical

conflicts experienced by individuals and families receiving health care, describe the

critical appraisal tool used to evaluate each research study, and present the main themes

based on a synthesis of relevant articles. After having conducted this integrative literature

review, I contend that further research on ethical conflicts in health care is warranted to

address existing gaps in the literature. Specifically, studies that elicit *client* and *family*

perspectives on ethical conflicts that arise in *Canadian, community care settings* (health

care settings outside of hospital institutions, such as nursing homes, private medical

clinics, and client residences) would serve to enhance our understanding of the types of

conflicts affecting Canadian community health care recipients and their families, and

provide valuable insight into the ways in which such challenges can interfere with care

and care outcomes.

Literature Search Methods

I conducted a review of the literature using PubMed, CINAHL, Cochrane,

PsycINFO, Scopus, Web of Science, and Google Scholar. The main research question

that guided my literature search was: "What types of ethical conflicts are encountered by

community health care clients and their families?" My search terms included: *primary*

health care, *community health services*, *home health care*, *ethics, ethical conflict, patient,*

family, patient attitudes, and *patient experience*. These terms, and variations of these

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terms, were used individually and in combination to find full-text research articles relevant to my topic.

My searches yielded 206 research articles published in the last 12 years in journals of varying disciplines (nursing, medicine, education, social sciences, and ethics). A vast majority of these articles focused on ethical dilemmas encountered by nurses and physicians rather than individuals and families. I found only six research studies within the search results that explored ethical issues, concerns, or conflicts experienced by health care recipients and their family members, and located an additional two relevant studies through handsearching. Since the number of empirical studies that focused exclusively on community health care settings was limited, research articles that reported on individual and family ethics within hospital settings were also included. All reviewed studies were qualitative by design and published in peer-reviewed journals in nursing, medicine, and ethics. This was expected and deemed appropriate given the nature of my research question.

Critical Appraisal Tools

I assessed the quality and strength of each study using the evaluation framework for critical appraisal of qualitative studies described by Moralejo, Solberg, and Memorial University of Newfoundland (2014). This appraisal guide provided a comprehensive set of criteria for the systematic evaluation of study characteristics such as scientific merit, research clarity, methodology, rigour, ethics, discussions, and conclusions (Moralejo et al., 2014). Based on each individual appraisal, studies were ranked as weak, moderate, or strong. These rankings helped me to draw conclusions about the overall quality and strength of the body of knowledge on ethical conflicts experienced by clients and their

families. All eight relevant ethics studies that I located during my database searches underwent critical appraisal for this review. Literature summary tables for these studies are provided in the Appendix.

Major Themes

Research on ethical conflict experienced by individuals and families has been conducted using a variety of approaches. While some studies set out to broadly identify the types of ethical challenges experienced by this group, others focused on particular ethical issues or concerns for their inquiry. Among the research, there were four main types of ethical challenges discussed in relation to individuals and families: *treatment decisions, access to health resources*, *autonomy*, and *dignity and respect*.

Treatment Decisions

A major source of conflict that was reported in several studies was making treatment decisions. Some of these conflict situations were interpersonal in nature, involving disagreements between individuals and families and their health care providers about preferred methods of treatment, while others concerned internal struggles experienced by health care clients and their relatives in choosing the best of course of treatment when several options were available.

Interpersonal conflict. The nature and severity of conflict situations involving health care providers and clients and families varied greatly, as did the settings in which they occurred. A Canadian study that found interpersonal disagreements about treatment decisions to be the biggest ethical challenge facing the public, described conflict scenarios that ranged from clashes between clients and community health care providers over denied requests for the antibiotic treatment of viral infections to battles over

decisions to withdraw life-sustaining treatment in intensive care units (ICUs) (Breslin, MacRae, Bell, & University of Toronto Joint Centre for Bioethics Clinical Ethics Group, 2005). This modified Delphi study found that from the clinical bioethicist's perspective, conflicts about end-of-life decisions for critical care cases were particularly difficult to navigate for all involved, since such situations were highly emotional with much at stake (Breslin et al., 2005). A common end-of-life conflict scenario involved a family member's desire to continue with aggressive treatment for a relative because of a hope of "beating the odds" or a devotion to deeply held religious beliefs, which was incompatible with the provider's commitment to protecting their client from unnecessary harm and suffering (Breslin et al., 2005). Recommendations for addressing conflicts over treatment decisions included teaching better negotiation and mediation skills to health care professionals, creating institutional policies that promote conflict resolution, and conducting additional research on client and family experiences with disagreements about treatment decisions to achieve a better understanding of their perspectives on this ethical challenge (Breslin et al., 2005).

In an ethnographic study of families and care providers in an ICU in Belgium, it was found that conflict between families and health care staff was often related to differing views on what constituted high quality care (Van Keer, Deschepper, Francke, Huyghens, & Bilsen, 2015). Health care providers frequently used an approach to care that was based on the biomedical model and that prioritized centralized decision making, while families valued a more holistic approach to care and desired to be active participants in care activities (Van Keer et al., 2015). The health care professional's view that end-of-life decisions were medical decisions rather than collective decisions

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involving family members was often contradictory to the relative's expectation to be informed and included (Van Keer et al., 2015). Similar to the findings by Breslin et al. (2005), conflict between families and providers about end of life decisions frequently occurred when a provider's decision to withdraw medical therapy was met with resistance from family members who remained hopeful that medical, technological, or divine interventions would prevail (Van Keer et al., 2015). The authors noted that although ethno-cultural differences were found to play a role in family-provider interactions, they did not cause the emergence of conflict. Conflict in the study was attributed to systemic factors; that is, the structure and care delivery approach of the ICU (Van Keer et al., 2015). The authors proposed that effective conflict prevention efforts for their study setting could include improving communication skills, increasing cultural competency, and promoting the formation of partnerships with family members (Van Keer et al., 2015).

Intrapersonal conflict. In situations where clients and families could freely choose one course of treatment over another, some described feeling torn about which option was the right choice. This decisional conflict stemmed from a lack of knowledge about treatment risks, benefits, and alternatives (Allen, Allen, Hilgeman, & DeCoster, 2008), or insufficient information about client values and expectations (Dreyer, Forde, & Nortvedt, 2009). In the descriptive study by Dreyer et al. (2009), for example, relatives who acted as substitute decision makers had poor knowledge about end-of-life care and were found to be largely unaware of the client's treatment preferences. In the same study, relatives also questioned their motives for initiating or discontinuing life prolonging treatments, and described feeling conflicted about their decisions even after the death of

the client (Dreyer et al., 2009). For instance, some indicated that their decision to choose life-prolonging treatment was influenced by guilt or fear of dealing with the loss of the client, and others described feeling haunted by the possibility that they agreed to limit medical intervention for selfish reasons such as caregiver exhaustion (Dreyer et al., 2009). One of the recommendations offered in the literature for minimizing decisional conflict was to improve client and family knowledge about treatment risks, benefits, and alternatives in order to reduce uncertainty and promote informed decision making (Allen et al., 2008). A second recommendation was the establishment of organizational policies that encourage early conversations between health care providers and clients and families about client preferences and care expectations (Dreyer et al., 2009). A third recommendation was that policy makers consider the use of health care providers as substitute decision makers rather than family members, given the competing preferences of family members that were revealed in the study findings (Dreyer et al., 2009).

Access to Health Resources

Difficulty in accessing required health resources was a common theme in the literature that presented numerous ethical challenges. Specific topics related to access included wait times, the inequitable distribution of health resources, and financial barriers to treatment.

In the study by Breslin et al. (2005), the second biggest challenge facing the Canadian public that was identified was long wait lists. Extended wait times for needed care were of ethical concern because of their potential to compromise the clients' health status, reduce their chance of achieving optimum treatment outcomes, delay their ability to return to day-to-day activities (e.g., employment), and threaten their psychological

well-being (Breslin et al., 2005). The authors also pointed out that wait lists can lead to

the inappropriate use of scarce resources, such as using acute care beds for long term care

residents awaiting placement (Breslin et al., 2005). Denying individuals the ability to

access timely medical care can therefore not only endanger the physical and emotional

health of those on the wait lists, but place strain on other health departments and impede

access for those with more urgent care needs (Breslin et al., 2005).

Limited access to services resulting from the inequitable distribution of resources

was described in the Canadian context by Breslin et al. (2005), who reported that long-

term care, rehabilitation, and mental health were hugely under-funded areas in the

country's health care system. Insufficient services and lack of programming in these

departments not only threatened the health and safety of those affected, but was seen as

discriminatory against some of the most vulnerable and disadvantaged groups in society

(i.e., the elderly and individuals with mental illness) (Breslin et al., 2005). In a similarly

designed study conducted in Saudi Arabia, there were reports of disproportionate

spending in the major urban centers, within which most of the financial resources were

directed towards "specialist" hospitals (i.e., secondary and tertiary centres) (Alkabba,

Hussein, Albar, Bahnassy, & Qadi, 2012). This placed significant limitations on the

access to care for individuals living in rural locations and those seeking primary or

preventative care, putting these groups at a major disadvantage (Alkabba et al., 2012).

Personal financial burden associated with costly, life-saving treatment was a

noteworthy barrier to access described in a study of ethical issues in human

immunodeficiency virus (HIV) care (Kaposy et al., 2017). This ethnographic study of

three HIV care clinics in Canada described the difficulties many of the clients

experienced in securing medical insurance plans to cover the costs of their treatments, and the high deductibles often associated with those plans. The authors described cases where there were delays in treatment because of long, complicated application processes for insurance coverage, which denied these clients the ability to receive timely access to necessary care. The researchers' finding that a significant number of individuals could not receive treatment at all because of their inability to pay the out-of-pocket expense (Kaposy et al., 2017) exposed ethical concerns about unequal access to care due to socioeconomic status.

Autonomy

Challenges to autonomy were reported in a number of nursing home studies. In a qualitative study of ethical challenges in nine nursing homes in Norway, in-depth interviews with residents revealed that they perceived to have very little decision-making power with respect to care and day-to-day activities (Bollig, Gjengedal, & Rosland, 2016). Residents described being severely restricted with respect to having visitors, going outside the facility, being able to smoke, and deciding on the timing of certain routines (Bollig et al., 2016). This limited self-determination was sometimes influenced by a lack of resources. In one nursing home, for instance, residents were routinely sent to bed at six o'clock in the evening because of scheduled reductions in staff shortly thereafter (Bollig et al., 2016). Another identified factor that challenged the residents' autonomy was their apprehension about speaking up about issues or concerns for fear that they would be labelled by the staff as troublesome (Bollig et al., 2016). This sentiment increased their vulnerability to coercion and threatened their sense of well-being.

Violations to autonomy were also documented in the nursing home study by Dreyer et al. (2009), and involved family members making treatment decisions on behalf of competent nursing home residents without obtaining their consent. The authors of the study revealed that family members were given information about the residents and involved in care decisions, with little or no consideration of the residents' ability or desire to provide informed consent (Dreyer et al., 2009). An additional finding was that family members had not been asked by providers about the residents' values or treatment preferences (Dreyer et al., 2009). This study serves as a particularly poignant example of the ways in which autonomy may be threatened, and the importance of establishing organizational policies and procedures (e.g., continuous competence assessments) to promote and protect client autonomy.

Dignity and Respect

Threats to dignity and respect were described by nursing home residents and hospital clients in relation to day-to-day interactions and care. In a grounded theory study of dignity as conceptualized by nursing home residents in Germany, study participants indicated that there were very few opportunities to foster dignity through the formation of meaningful social relationships with nursing staff and other nursing home residents (Pleschberger, 2007). This was often due to the frequent understaffing of nurses and the other residents' declining physical and mental health (Pleschberger, 2007). In the same study, sense of dignity was also endangered when residents experienced physical or mental decline. This was because the concept of dignity was rooted in aspects of the body and the notion of "not being a burden" (Pleschberger, 2007, p. 200). When extra care was

required from nurses and when insufficient care was received (a prevalent finding), the residents found it particularly challenging to lead a dignified life (Pleschberger, 2007).

Concerns about respectful, caring treatment were voiced by individuals who encountered health care staff who displayed negative attitudes or were apathetic, imposed excessive wait times, and were difficult to contact (Bollig et al., 2016; Foglia, Pearlman, Bottrell, Altemose, & Fox, 2009). Exposure to such experiences had negative effects on the client's psychological health and well-being. For example, an American study of client perceptions of ethical challenges in hospital-based care reported that negative attitudes and poor reception by the hospital staff served to intensify already-existing feelings of vulnerability and fear (Foglia et al., 2009). The same study described the frustration and disrespect felt by clients who were exposed to long wait times for appointments, and how poor communication and lack of empathy by the staff during such incidences contributed to client dissatisfaction with care. In the nursing home study by Bollig et al. (2016), disrespectful nursing behaviours, such as engaging in distracting behaviours while feeding residents and failing to knock before entering residents' rooms, reduced feelings of dignity and interfered with the residents' ability to exercise self-determination.

Discussion

It is evident from my review of the literature that there are numerous ethical issues that can arise during the delivery of health care that can have serious consequences for clients and their families. Whether it is an issue that affects large segments of the population (e.g., wait times, shortage of primary providers) or a challenge felt at the personal level (e.g., disagreements about treatment decisions, sense of dignity), the

research clearly illustrates that those who are affected can incur physical and psychological harm that can threaten their health and well-being. A frequently cited reason for the emergence of ethical conflict was differing treatment goals and care expectations between clients and families and their care providers (Breslin et al., 2005; Van Keer et al., 2015), and this precursor to conflict has been discussed in other, related ethics research papers (Edelstein, DeRenzo, Waetzig, Zelizer, & Mokwunye, 2009; Pavlish, Brown-Saltzman, Jakel, & Fine, 2014). In reading through the narratives provided in the reviewed studies, however, I found that at the root of each ethical concern and conflict, and perhaps a truer reason for their emergence, was the infringement, protection, or desire to exercise, *client* or *human rights*. For example, in the study by Dreyer et al. (2009), the major threats to the autonomy of nursing home residents were violations against the residents' right to information and right to consent. In the study by Van Keer et al. (2015), the withdrawal of treatment that was judged to be in violation of the client's right to protection from unnecessary harm and suffering was in conflict with substitute decision makers' wishes to exercise religious or cultural beliefs that were in favour of continued medical intervention. Whether explicitly stated or implicit in the authors' discussions, client and family rights were indeed at the centre of ethical conflicts described in the literature and emerged as a common theme throughout the reviewed studies, regardless of their variations in purpose, setting, sample, or design.

My overall assessment of the nature and quality of the existing research on ethical conflict affecting health care recipients and their families has revealed that there are a small number of good quality studies that have explored various aspects of the topic using several useful qualitative approaches. The majority of these studies have been

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conducted in European countries, with very few set in Canada. Among the two studies

conducted in the Canadian context, only one of them sought to broadly identify the

ethical challenges facing health care consumers (Breslin et al., 2005). This study's data

was obtained exclusively from the perspective of bioethicists, however, and although the

authors argued that these individuals were suitable informants due to their knowledge and

experience in the field of ethics (Breslin et al., 2005), the bioethicist reports likely

reflected the ethical issues for which ethics consults were most commonly sought, which

may not necessarily have been the ethical issues that occurred most often or that were of

greatest importance to individuals and families.

Research Implications

Given the prevalence and serious health consequences of ethical conflict, and the

paucity of research that has explored ethical conflicts in community health care settings

in Canada from the client and family perspective, further research is warranted. Based on

my appraisal of the literature on this topic, I believe that a qualitative approach to inquiry

would be most useful for understanding the complexities of the ethical issues facing

community health care clients and their families. A valuable theoretical lens for guiding

this inquiry would be one based on the "Human Rights in Patient Care" framework by

Cohen and Ezer (2013). This lens would guide the researcher in identifying the range of

concerns associated with such matters as informed consent, confidentiality, privacy,

bodily integrity, and non-discrimination, and help to reveal underlying issues of

discrimination, social exclusion, and power imbalances that contribute to conflict

situations (Cohen & Ezer, 2013). Furthermore, a human rights lens would promote a

broad approach to inquiry that extends beyond the client to other key stakeholders such as family members and other caregivers.

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Appendix

Literature Summary Tables

Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
"Top 10 health care ethics challenges facing the public: Views of Toronto bioethicists" Breslin, MacRae, Bell, Singer, & University of Toronto Joint Centre for Bioethics Clinical Ethics Group (2005) **Objective** - To identify the ten most common ethical challenges experienced by clients and their families in health care.	**Sample** - 12 clinical bioethicists. - Members of the Clinical Ethics Group of the University of Toronto Joint Centre for Bioethics. - Experienced working in a wide range of health care settings. **Setting** - University of Toronto, Canada.	**Design** - Qualitative, modified Delphi study. **Data Collection, Analysis** - Each participant asked to generate a list of 10 ethical challenges, with rationales, using a list of 38 themes as a guide. - Initial lists with explanations submitted to researchers via email. - Identification and clustering of themes carried out by the authors in collaboration with participants during face-to-face meetings. - Consensus on 10 themes reached after 3 rounds of analysis.	Top ten ethical challenges: 1) Disagreements about treatment decisions. 2) Wait times 3) Access to resources. 4) Shortage of primary care providers. 5) Medical error. 6) Use of pain medication and palliative care. 7) Informed consent. 8) Subject participation in research. 9) Substitute decision making. 10) Surgical and technological innovation. - Within the #1 challenge, conflicts about end-of-life decisions for critical care cases were cited as the most difficult scenario.	**Strengths** - Study objective clearly stated. - Study design and methodology appropriate for research question. - Key concepts well defined. **Limitations** - Little information provided about participant recruitment and enrolment. - Findings from the ethicist perspective may not be reflective of the client/family experience. The data should therefore be interpreted with caution. - The top 10 challenges reported by ethicists are likely the issues for which individuals most frequently seek counsel. These may be reflective of the most frequent/challenging issues facing the public.	**Conclusion** - This study identified a wide range of ethical issues that affect the Canadian population and highlighted the need to direct more attention towards the most common challenge- disagreements between clients/ families and health care providers regarding treatment decision. **Rating** - Moderate strength.

Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
"Conflicts between health care professionals and families of a multi-ethnic patient population during critical care: An ethnographic study" Van Keer, Deschepper, Francke, Huyghens, & Bilsen (2015) **Objective** - To study factors that contribute to conflict between health care professionals and families of critically ill patients from ethnic minority groups.	**Sample** - Purposive sample of: 10 patients (4 females, 6 males; 40 to 82 years old) who received intensive care from 1 to 15 weeks, and their family members. - 92 health care professionals (80 nurses, 12 doctors; 61% women, 39% men). - Patients originated from Turkey, Southern Europe, Central Africa, and North Africa. - Almost all nurse and doctor participants were Caucasian. **Setting** - ICU in a hospital in Belgium.	**Design** - Qualitative, ethnographic research. **Data Collection, Analysis** Data collected over a 6 month period through: - Interactive observation on an ICU ward. - In-depth interviews with 9 health care professionals. - Reviews of patient medical records. - Field note taking. - Reflective writing. - Data analysed using a grounded theory approach. - Interview data underwent a 3-step coding process supported by NVIVO 8. - Data collection and analysis ceased once saturation was reached. - Analysis by multidisciplinary team consisting of study researchers, a health scientist, nurse, sociologist, 2 anthropologists, and an ICU specialist.	- Conflict occurred between families and health care professionals in 9 out of the 10 cases. Conflicts related to: - Visiting restrictions. - Care requests. - Differing levels of emotional involvement in patient care (family versus health care professional). - Requests for health information. - End-of-life treatment decisions. - The family's approach to care was driven by a holistic view of health and health care whereas the health professionals approach was based on the biomedical care model. - Conflict was more likely to occur for patients who received more frequent visits.	**Strengths** - Diverse patient sample. - Good adherence to ethical principles and protocols. - Research design allowed for a deep understanding of the complex nature of ethical conflict in an ICU setting. - Measures taken to strengthen validity and reliability of findings. **Limitations** - No interviews conducted with family members. - Lack of diversity in sample of health care professionals.	**Conclusion** Ethical conflicts between health care professionals and migrant family members were attributed to differences in ethno-cultural backgrounds and the structural and organizational contexts of critical care. Conflict prevention efforts should strive to increase cultural competency, teach effective communication, and promote the formation of partnerships with family members. **Rating** - Moderate strength.

Note. ICU = intensive care unit

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Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
" Autonomy at the end of life: Life-prolonging treatment in nursing homes-relatives' role in the decision-making process" Dreyer, Forde, & Nortvedt (2009) **Objective** - To explore how relatives' experience the role of substitute decision maker and how patient autonomy is protected.	**Sample** - Purposive sample of 15 relatives (children, spouses, or children-in-law) of 20 nursing home patients. - Participants recruited by nurses. - Each member of the sample had discussed life-prolonging treatment with health care personnel. **Setting** - 10 nursing homes in Norway.	**Design** - Qualitative descriptive study. **Data Collection, Analysis** - Relatives participated in semi-structured in-depth interviews 2-12 months after death of the patient. - During interviews, relatives were asked about their role as substitute decision-makers and how they made decisions about life-prolonging treatment. - Interviews lasted 30-60 minutes. - Transcribed interview texts were condensed, coded, and subcategorized. - A constant comparative approach guided the analysis.	Substitute decision-making: - Relatives lacked knowledge about end-of-life care treatments and relied on physician decisions. - Few relatives were aware of patient preferences for end-of-life care. - Relatives often questioned their motives for choosing life-prolonging treatment (e.g. fear, guilt) or not choosing life-prolonging treatment (e.g. exhaustion). Violations of patient autonomy: - Relatives were included in treatment decisions without assessing the patient's competence to give consent. - Relatives of competent patients were given patient health information and involved in treatment decisions without the patient's consent. - Few relatives reflected on patient autonomy or considered involving competent patients in care decisions.	**Strengths** - Research questions clearly articulated. - Purposive sampling at multiple sites allowed for variations in setting and participant characteristics. - The use of an established interview guide provided a consistent and informed approach to data collection. - Good adherence to research ethics protocols. **Limitations** - Potential recall bias during interviews. - Although a qualified team was involved in data analysis, there was no mention of member checks to validate the findings.	**Conclusion** - Relatives require better preparation and support in their role as substitute decision maker. Patient autonomy must be better protected by increasing awareness of the challenges to autonomy and conducting ongoing competence assessments for nursing home residents. **Rating** - Strong study.

Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
"The major medical ethical challenges facing the public and health care providers in Saudi Arabia" Alkabba, Hhussein, Albar, Bahnassy, & Qadi (2012) **Objective** - To identify the 10 major ethical challenges encountered in the health care system in Saudi Arabia.	**Sample** - 90 members of ethics committees (medical doctors, clinicians, non-medical hospital staff, pharmacists and other paramedical technicians) - Participants had experience teaching or working in medical ethics, administration, or academics. **Setting** - 10 hospitals in 5 cities in Saudi Arabia.	**Design** - Qualitative cross-sectional, descriptive. **Data Collection, Analysis** - Modified Delphi process - Participants were asked to create and submit a list of what they perceived as the top 10 ethical challenges in health care. - Researchers compiled and ranked the data, and sought feedback from participants during three rounds of ranking. - Researchers also collaborated with expert health professionals during data analysis.	The top 10 medical ethics problems facing the public and health care providers in Saudi Arabia: 1) Protecting patient rights. 2) Equal access to health resources. 3) Confidentiality of patient information. 4) Patient safety. 5) Conflicts of interest. 6) Privatization of health care. 7) Informed consent. 8) Providing treatment to the opposite sex. 9) Birth and end-of-life issues. 10) Disagreements among health care team members.	**Strengths** - High response rate. - Participants drawn from multiple settings. - Measure taken to validate the data. **Limitations** - Limited demographic information provided for the participants. - Limited information on participants' knowledge base and level of experience. - Some key concepts not well defined. - Data addressing ethical challenges facing the public was not obtained from the public's perspective but rather the ethicist's perspective.	**Conclusion** - This study identified important ethical concerns being raised in Saudi Arabia and highlighted the need to increase efforts to address them. **Rating** - Moderate strength.

Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
" Clinical ethics issues in HIV care in Canada: An institutional ethnographic study" Kaposy et al. (2017) **Objective** - To identify the types of ethical issues experienced in HIV care, and to explore how they are managed.	**Sample** - Purposive sampling. - 22 individuals with HIV. - 20 health care providers (physicians, nurses, nurse practitioners, social workers, pharmacists). - Client characteristics varied in terms of socioeconomic status, sex, race, sexual orientation, and physical ability. **Setting** - 3 HIV clinics in two Canadian provinces; Newfoundland and Labrador and Manitoba. - All clinics provided care to urban, suburban, and rural residents.	**Design** - Qualitative study using an institutional ethnography methodology. **Data Collection, Analysis** - Data collected from observed clinical interactions between clients and clinicians, semi-structured interviews with clinicians and clients, and reviews of medical records. - Analysis of interview transcripts, observation notes, and other data sources carried out independently and as a group until consensus reached on the major ethical issues in HIV care.	Ethical issues in HIV care: 1) Barriers to accessing essential medications. Managed by advocacy efforts by the health care team. 2) Protecting confidentiality. Managed by scheduling and waiting room policies that promote privacy and anonymity. 3) Conflict between clinician's duty to carry out the most effective care regime for maximizing client health/minimizing spread of HIV within the population and his/her duty to respect patient autonomy/informed consent. Managed by giving priority to informed consent and helping to problem-solve issues related to treatment adherence.	**Strengths** - Key concepts well defined. - Study purpose and objectives clearly articulated. - Study design appropriate for addressing research questions. - High degree of diversity in the sample. - Study conducted in multiple settings. - Data analysis carried out by a multidisciplinary team of experienced and qualified analysts. - Measures taken to enhance reliability and validity of findings. **Limitations** - Findings cannot be generalized to other clinics or populations in or outside Canada.	**Conclusion** - There are ethical issues that present challenges to clients and their clinicians during the provision of HIV care that are navigated using a collaborative client-clinician-system approach. There is a need for an increased understanding of the social determinants of health that contribute to the everyday ethical issues in HIV care. **Rating** -Strong study.

Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
"Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes" Bollig, Gjengedal, & Rosland (2016) **Objective** - To explore the ethical challenges experienced by Norwegian nursing home residents and their families.	**Sample** Purposive sampling. - 43 participants (25 nursing home residents, 18 relatives). - Resident ages ranged from 66 to 100 years; relative ages ranged from 41 to 91 years. **Setting** - 9 nursing homes in Norway.	**Design** - Qualitative **Data Collection, Analysis** - Semi-structured, in-depth interviews with nursing home residents. - Focus group interviews with relatives. - Residents and relatives asked to explore the meaning of leading a good life in the nursing home, and to describe the types of ethical challenges that can arise. - Analysis based on Interpretive Description. - NVivo 9 used for analysis and coding.	Ethical challenges from residents' and relatives' perspectives: 1) Transition into nursing home care: - Preserving dignity (residents) - Overcoming guilt (relatives). 2) Achieving a sense of well-being: - Being engaged and respected by nurses (residents). - Establishing caring relationships with nurses (relatives). 3) Reduced autonomy: - Limited decision making power (residents). - Strained relationships with nurses and fear of speaking up (patients/relatives). 4) Insufficient resources: - Limited access to health care and leisure activities (residents and relatives).	**Strengths** - Study objective clearly stated. - Study design and methodology appropriate for research question. - Interviews conducted in private locations. - Data collected across a variety of settings. - Consistency in data collection and analysis. - Measures taken to validate the findings. **Limitations** - Theoretical orientation not clearly stated. - Possible selection bias. - Limited details on participant characteristics.	**Conclusion** - Ethical challenges experienced by residents and relatives were primarily related to day-to-day life and care activities. Factors that promoted prosperity among residents included social interaction, active engagement in daily activities, and self-determination. **Rating** - Moderate strength.

Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
"Dignity and the challenge of dying in nursing homes: The residents' view" Pleschberger (2007) **Objective** - To explore the meaning of dignity as it relates to end-of-life care issues.	**Sample** - Theoretical sampling. - 20 nursing home residents. - 17 heads of nursing homes. **Setting** - 6 nursing homes in West Germany	**Design** - Qualitative, grounded theory **Data Collection, Analysis** - Narrative interviews conducted with residents and heads of nursing homes. - Open coding, axial-coding, and selective coding carried out by research team. - Atlas/ti used to support the coding process. - Focus groups with interdisciplinary teams including residents and heads of nursing homes for data validation and interpretation.	Dignity was characterized in two ways: 1) An interpersonal concept (constructed by personal beliefs and the physical self). 2) A relational concept (socially constructed, fostered by recognition and social encounters). - Relational dignity challenged by staff shortages, health decline and dementia. - Interpersonal dignity threatened during times of illness, when residents require additional care.	**Strengths** - Study purpose and objective clearly stated. - Strict adherence to ethical guidelines. - Diverse sample drawn from multiple settings. - Consistency in data collection procedures. - Measures taken to validate data. **Limitations** - Possible selection bias since participants selected by nursing home managers. - Inability to obtain the perspectives of some of the most vulnerable groups- those with dementia, or those who could not speak.	**Conclusion** - There are several interpersonal and social factors that can threaten the dignity of nursing home residents, and residents feel that it is particularly difficult to maintain dignity during times of illness. **Rating** - Strong study.

Name, Author, Date, Study Objective	Sample (size, characteristics, setting)	Design, Methodology	Key Results/ Findings	Strengths, Limitations	Conclusion, Rating
"Ethical challenges within veterans administration health care facilities: Perspectives of managers, clinicians, patients, and ethics committee chairpersons" Foglia, Pearlman, Bottrell, & Altemose (2009) **Objective** - To characterize ethical challenges in the delivery of health care at VA medical centres.	**Sample** - Convenience sample of 32 veteran patients receiving outpatient care. - Stratified random sample of 55 clinicians (physicians, nurses, social workers, and other health care personnel). - Stratified random sample of 21 ethics committee chairpersons. - Purposive sample of 38 managers; stratified sample of 11 managers. **Setting** - 3 VA medical centres in the United States.	**Design** - Qualitative **Data Collection, Analysis** - Focus groups. - Semi-structured telephone and face-to-face interviews. - Participants asked to describe the most ethically challenging issues at their facility and the factors that contributed to these challenges. - Data analyzed using content analysis (focus group data) and qualitative factoring (interviews).	Ethical challenges from participants' perspectives: Patients - Receiving treatment that is respectful, fair, and caring. - Access to care (e.g., wait times) Clinicians - Providing quality care with limited resources. - Balancing duty to patients with obligations to health care institution. - Information sharing about resource allocation. Chairpersons - Providing quality end-of-life care. - Delayed patient transfers to palliative care. Managers - Fair distribution of resources. - Limiting care.	**Strengths** - Research purpose and objective clearly stated. - Study design and research methodology appropriate for study purpose. - Diverse sample drawn from multiple settings. - Extensive measures taken to enhance reliability and trustworthiness of the data. **Limitations** - Detailed demographic data not provided. - Sampling methods may have introduced bias. - Possible interviewer bias where interviews were not transcribed. - Findings may not be applicable beyond VA health care settings.	**Conclusion** - Support for the establishment of ethical norms and behaviours in health care settings can be drawn from a greater appreciation of the types of ethical challenges that occur. Given the variation in study participant responses, ethical challenges are best understood by eliciting the perspectives of key stakeholders, including patients. **Rating** - Moderate strength.

Note. VA = veterans administration

Appendix B

Research Report

In this report, I describe my research practicum project entitled *Ethical Conflicts in Community Health Care: A Qualitative Study of Individual and Family Experiences*. This research study was part of a larger study (*Clinical Ethics Committees and Ethical Conflicts in Community Health Care*) which explores the structure, function, and effectiveness of community ethics committees and services; the ethical conflicts of nurses, physicians, clients, and family members in community settings; and identifies conflict management strategies. In the following research report, I describe the purpose and rationale; research methodology, study design and procedures; main findings, followed by a discussion of these findings; and study limitations. Finally, in the concluding remarks, I consider the implications of my study findings for nursing research and practice.

Purpose and Rationale

The purpose of this research practicum project was to describe ethical conflicts encountered by community health care recipients and their families and to explore the ways in which they managed their ethical concerns. The central research question was, "What are the types of ethical conflicts experienced by community health care clients and their family members?" Additional research questions were, "In what contexts are ethical conflicts occurring?", "How are ethical conflicts defined by individuals and families?", and "What measures, if any, have been taken to address ethical concerns or conflicts?"

As discussed in my review of the literature on ethical conflicts included in my practicum report, despite the prevalence and serious health consequences of ethical

conflict, very little research has been conducted to explore ethical issues affecting community health clients from the client's perspective. As well, much of the existing literature on this topic describes studies that have been carried out in European and Asian countries, with few set in North America. Given these identified gaps in the literature, further study of ethical conflicts in the Canadian context was warranted. As health care reform efforts in Canada continue to shift toward a more community-based model, it is crucial that research studies, such as the one I describe in this report, are conducted to increase understanding of the types of ethical conflicts affecting Canadian, community health care clients and families, the strategies used to manage such issues, and the kinds of support interventions needed to address ongoing ethical concerns.

Research Methodology

My methodological approach to the study of ethical conflicts was based on the philosophical underpinnings of qualitative research described by Creswell (1998, 2003). According to Creswell (1998), there are five philosophical assumptions that function at a broad, abstract level to guide the design of qualitative research. These assumptions are related to issues of *ontology, epistemology, axiology, rhetoric,* and *methodology.*

Ontology

The ontological issue concerns the nature of reality. In qualitative inquiry, reality is constructed by those involved in the research process--researchers, individuals being investigated, and the audience interpreting the study--and therefore multiple realities exist (Creswell, 1998). These realities are reported by the researcher through the use of quotes, development of themes using the words of study participants, and presentation of different perspectives on each of the identified themes (Creswell, 1998).

Epistemology

The epistemological assumption addresses the relationship between the researcher and that which is being researched (Creswell, 1998). Qualitative researchers must strive to minimize the distance between themselves and those who they are studying (Creswell, 1998). Closeness can be achieved through time spent in the field and collaboration with study participants (Creswell, 1998).

Axiology

The axiological assumption is concerned with the role of values in a study (Creswell, 1998). According to Creswell (1998), the qualitative researcher acknowledges that research is "value-laden" (p. 76) and reflects on both their own values and biases and those that may be embedded in the data that is collected from the field.

Rhetoric

Grounding qualitative research in the rhetorical assumption means that the researcher uses particular terminology and a literary style that contains the language of qualitative research (Creswell, 1998). For example, instead of the terms *internal validity, external validity, generalizability,* and *objectivity* that are commonly used in quantitative research, the qualitative researcher uses *credibility, transferability, dependability,* and *confirmability* (Lincoln & Guba as cited in Creswell, 1998). Furthermore, the researcher's writing style should be "personal and literary" (Creswell, 1998, p. 77). For instance, the first-person pronoun "I" is preferred over the more distant third-person voice (Creswell, 1998).

Methodology

The methodological assumption reflects how the researcher conceptualizes the entire research process (Creswell, 1998). The researcher uses an inductive approach, where categories are developed from the collected data rather than from some knowledge gained prior to conducting the study (Creswell, 1998). Initial codes or themes that emerge from individual statements are grouped together into broader and more abstract categories (Creswell, 1998). The inductive development of ideas and concepts is guided by the views of the participants and the particular contexts in which they occur (Creswell, 1998). The researcher uses an emerging design; the inquiry begins with general questions that are refined as the study proceeds (Creswell, 1998).

These five basic assumptions shape how research problems are defined, research questions are composed, and information for answering these questions is gathered and analyzed (Creswell, 2007). It is therefore essential that researchers have a good understanding of the philosophical assumptions that underlie qualitative research and that they are able to articulate them in written and oral presentations of their work (Creswell, 2007).

Study Design

A qualitative, exploratory design, as guided by Creswell (1998), was employed to carry out my study of ethical conflicts affecting individuals and families. A qualitative design was well suited since qualitative research allows the study of human and social problems within natural settings and contexts, and from the perspectives of those who are experiencing them (Creswell, 1998). The exploratory nature of my approach was also warranted, given that few researchers have reported on the types of ethical conflicts

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encountered by Canadian community health care recipients and their relatives.

Procedures

In the following section, I describe my study sample and recruitment, setting, data collection, data analysis, theoretical lens, rigor, and ethical considerations. I also demonstrate how my research approach was reflective of the philosophical assumptions and research methodology described by Creswell (1998).

Sample and Recruitment

In keeping with Creswell's (1998) approach to qualitative sampling, individuals considered suitable were those who were accessible, willing to provide information, and who could shed light on the phenomenon of interest. Eligible participants for my study were individuals and their family members who: had received community health care services, had experienced ethical conflict, and were available and willing to talk about their conflict experiences. Additional eligibility requirements were the ability to speak and read English, and a minimum age of 18 years.

Participants were recruited using purposive sampling. The purposeful selection of participants is considered a logical and valuable strategy for qualitative inquiry since it allows the researcher to choose individuals from whom a deeper understanding of the phenomenon under study may be gained (Creswell, 1998). Recruitment activities involved posting an approved recruitment flyer (see Appendix A) in various locations within the province of Newfoundland and Labrador. Permission was obtained from businesses and organizations before flyers were placed at their respective locations.

Recruitment occurred until the enrolment target goal of three participants was met. The data collected from this number of interviews was deemed sufficient for

achieving my research practicum project learning objectives and gaining valuable insight into the types of ethical conflicts affecting individuals and families in the community.

Setting

The study was conducted in Newfoundland and Labrador, Canada. Face-to-face interviews were carried out at participants' homes in order to ensure a familiar and comfortable environment.

Data Collection

In keeping with the methodological approach to qualitative research described by Creswell (1998), data collection occurred using more than one procedure: demographic data sheets and semi-structured interviews.

Demographic data sheet. I completed a demographic questionnaire (see Appendix B) with participants, either in-person or over the telephone prior to their first interview. Gathering such information was useful for guiding my recruitment efforts to ensure that different perspectives could be presented in the data.

Semi-structured, in-depth interviews. Qualitative interviews were the primary data sources. Interviewing is one of the most common strategies for collecting qualitative data and is often the most suitable tool for exploring the perceptions and meanings of life experiences (DiCicco-Bloom & Crabtree, 2006). The direct verbal communication between researcher and study participant that characterizes this strategy of data collection allowed participants to provide detailed accounts of their experiences with ethical conflict in the context of community health care from their own perspectives. The back-and-forth nature of the interview process enabled me as the interviewer to elicit in-depth descriptions of reported events so that the research questions could be fully explored.

Among the three major types of interviews--structured, semi-structured, and unstructured--the semi-structured interview was best suited for my study's purpose. In contrast to the structured interview format, that consists of a pre-set list of questions that each research participant is asked to answer (a method more applicable to quantitative studies) (Streubert & Carpenter, 2011), the semi-structured interview promotes more flexibility due to its use of open-ended, guiding questions meant to engage participants in dialogue about the particular event or experience of interest to the researcher (Streubert & Carpenter, 2011). The semi-structured interview is viewed as an effective stand-alone method of data collection, unlike unstructured interviews, that are most often used together with participant observation to provide meaning to observed behaviours (e.g., ethnographic research) (DiCicco-Bloom & Crabtree, 2006).

Each one-on-one interview with study participants was scheduled at a time that was most convenient for the participants. I conducted all interviews using guiding questions and probes that were similar to those used in the larger ethics study. The list of guiding interview questions can be viewed in Appendix C. I began each interview by expressing my interest in learning about the participant's experience with ethical conflict and then providing a basic explanation of what ethical conflict entails. For example, I would say, "Ethical conflict happens when what *you* think is important is different than what your *doctor* or *nurse* thinks is important." I then asked them to tell me about an experience they had with ethical conflict while they or their family members received care in the community. During each interview, I asked participants to describe the types of care they received or were involved with, the kinds of ethical issues that arose, and how they dealt with those issues. Prompts were used, when needed, to elicit richer

descriptions or clarification.

Each interview lasted approximately one hour. All sessions were audio recorded using two digital recorders. Audio recordings were transcribed verbatim after the completion of each interview.

Data Analysis

Data were analyzed using qualitative data analysis. Qualitative data analysis involves an initial review of all gathered information to obtain a sense of the overall data, followed by a series of coding and categorizing procedures to systematically reduce the data so that a broad description of the phenomenon can be obtained (Creswell, 1998). Qualitative content analysis, the approach to data analysis that was employed in my study, is a useful and frequently used technique across many different disciplines, including nursing, due to its flexibility in terms of the types of text that can be analyzed (Elo & Kyngäs, 2008); data can be in verbal or written (print or electronic) form and can be obtained from interviews, focus groups, observations, open-ended survey questions, or print media (Kondracki & Wellman, 2002). Recently, qualitative content analysis has been used in a variety of nursing studies, including explorations of nursing students' perspectives on the nursing profession (Andersson, Sjöström-Strand, Willman, & Borglin, 2015); nurses' experiences with a newly implemented self-directed quality improvement tool (Hamilton et al., 2014); and, nurses' views of caring in coronary care (McKenna, Brooks, & Vanderheide, 2017).

There are numerous methodologists that have provided step-by-step instructions on how to carry out qualitative content analysis (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Mayring, 2000; Schreier, 2014). Data analysis

for my study was guided primarily by the approaches described by Elo and Kyngäs (2008) and Hsieh and Shannon (2005).

Phase one: Preparation. The first step in qualitative content analysis is deciding on the unit of analysis (Elo & Kyngäs, 2008). The whole texts from each participant interview were treated as the units of analysis in my study of ethical conflict since interview texts are considered sufficiently large to be treated as discrete entities and small enough to provide context during the analysis (Graneheim & Lundman, 2004).

The next step in this first phase of analysis is to read the interview transcriptions several times to become "immersed in the data" (Elo & Kyngäs, 2008, p. 109). Engaging in the process of reading and re-reading the interview texts allowed me to become familiar with the data and provided opportunities to reflect on the meaning and significance of key words and phrases in the narratives.

Phase two: Organization. In the second phase of the inductive analysis process, qualitative data are organized through *open coding*, *creating categories*, and *abstraction* (Elo & Kyngäs, 2008). In keeping with the approaches described by Elo and Kyngäs (2008) and Hsieh and Shannon (2005), I engaged in the open coding process by highlighting key words and making notes about my thoughts and impressions of the text during word by word readings of the transcripts. Headings that were representative of the highlighted and written content were generated, and served as the initial code labels.

Next, the codes were arranged into categories based on how the individual codes were similar to, or different from, one another. During this step, the aim was to group similar codes together within each category to create "meaningful clusters" (Hsieh & Shannon, 2005, p. 1279) that could then be grouped into broader categories to further

reduce the data (Elo & Kyngäs, 2008). Throughout the categorization process, I reflected

on the rationale for assigning each code or subcategory to its respective group to ensure

that the higher level categories were truly representative of the text.

Abstraction is defined as the process of generating a description of the research

topic through the categorization of data (Robson as cited in Elo & Kyngäs, 2008). The

abstraction process--the grouping of similar subcategories into higher, main categories--

was carried out until it was determined that the categories adequately described the

phenomenon of interest; that is, the types of ethical conflicts experienced by individuals

and families.

Phase three: Reporting. Consistent with the final steps of analysis described by

Hsieh and Shannon (2005), names and definitions for the main categories, subcategories,

and codes were established so that they could be presented and described. Concepts,

categories, and definitions containing abstract meanings are illustrated in the written

findings using examples from the text. The use of storylines and quotations from the

narratives are included to provide clarity to the analysis process (Elo & Kyngäs, 2008;

Schreier, 2014) and to showcase the varied perspectives on each of the broad data

categories.

Theoretical Lens

The theoretical lens through which I conducted my inquiry and analysis was

drawn from the "Human Rights in Patient Care" framework by Cohen and Ezer (2013).

This framework served as an applicable and valuable lens since *client* and *family rights*

was a common theme throughout much of the ethics literature that I reviewed prior to

conducting my study. The broad focus of Cohen and Ezer's framework promoted

examination of the wide range of interpersonal and systemic issues affecting all those involved in client care activities as well as underlying factors that may have been contributing to the identified tensions. Furthermore, the extended focus of the framework beyond the health care client to other key stakeholders was well suited since I was interested in eliciting the perspectives family members.

Rigor

A rigorous approach was necessary to ensure that the main research question was addressed in a way that yielded trustworthy findings. In the context of this qualitative study, the goal of rigor was to accurately represent the study participants' experiences with ethical conflict in community health care settings. The following section describes the particular ways in which my methodological approach served to enhance the key supporting criteria for rigor presented by Guba (1981) and Guba and Lincoln (1994), and endorsed by Creswell (1998): credibility, dependability, confirmability, and transferability.

Credibility. Measures were taken in each step of the research process to ensure that the data addressed the intended focus of the study. For instance, during participant recruitment, I endeavoured to find individuals that differed with respect to gender, age, and types of experiences. Such diversity enables exploration of the research question from a variety of angles and allows for a richer description of the phenomenon under study (Graneheim & Lundman, 2004). For the collection of data, credibility was enhanced by my selection of the most appropriate collection procedures for my study's purpose (semi-structured interviews) and my commitment to the collection of a sufficient amount of good quality data. Throughout data analysis, various efforts were made to

maximize the degree to which the codes and categories accurately represented the data contained within the narratives. In accordance with recommendations by Graneheim and Lundman (2004), I addressed this by ensuring that relevant data were included in the analysis, irrelevant data were excluded, and reasonable inferences were made about similarities and differences between categories. I also consulted with an experienced academic researcher to obtain feedback on the sorting and labelling of data. As well, I conducted member checks, the act of "taking the final report or specific descriptions or themes back to participants and determining whether these participants feel that they are accurate" (Creswell, 2003, p. 196). Engaging participants in a review of the research findings gave them the opportunity to correct errors of fact, challenge interpretations, volunteer additional information, and provide approval of the overall adequacy of the findings (Lincoln & Guba, 1985). Having the opportunity to review interpretations and conclusions ensured that their thoughts and ideas were adequately represented, which strengthened the credibility of the findings.

Dependability. An important concern regarding dependability of the data is variation in researcher decisions during the collection and analysis of data (Graneheim & Lundman, 2004). Inconsistencies in my research approach were minimized by using the same interviewer for each interview (myself), following the same guiding questions during each interview, and adhering to the established qualitative content analysis protocol.

Confirmability. In order to demonstrate confirmability of the findings, I generated and maintained an audit trail throughout the research process. An audit trail is a record of research activities over time that another individual can follow to arrive at the

study results (Streubert & Carpenter, 2011). My audit trail was organized using several of the audit trail categories described by Halpern (as cited in Lincoln & Guba, 1985): raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, and materials relating to intentions and dispositions.

Transferability. While it is ultimately the reader's task to make judgements about the extent to which study findings are transferable to other groups or settings (Lincoln & Guba, 1985), I took several measures identified by Graneheim and Lundman (2004) to facilitate this process. These included providing clear, detailed descriptions of the study setting and contexts, recruitment strategies, participant characteristics, data collection, and data analysis, and providing a "rich and vigorous presentation of the findings" (Graneheim & Lundman, 2004, p. 110) that includes quotations from the narratives. Including such detail puts the reader in a better position to make an informed decision about whether or not the findings are transferable to another context (Graneheim & Lundman, 2004).

Ethical Considerations

Ethical approval and informed consent. Ethical approval to conduct the study was granted by the Health Research Ethics Authority on June 20, 2017. Informed written consent was obtained prior to each participant interview. The participant consent form, which was similar to the one used in the larger ethics study, can be viewed in Appendix D. The consent process was guided by the key elements described in Creswell's (1998) approach to obtaining informed consent. I provided participants with a written consent form with a Flesch-Kincaid reading level below the recommended maximum level of grade eight (Johns Hopkins University, 2016), a verbal explanation of the information

contained in the consent form, answers to questions from the participants, and adequate time for the details of the consent to be considered. I then facilitated the signing and witnessing of the consent. Given the evolving and unpredictable nature of qualitative research, process consent was implemented. Process consent permits the researcher to "continuously renegotiate the consent, allowing participants to play a collaborative role in the decision-making process regarding their ongoing participation" (Polit & Beck, 2006, p. 93). This was achieved by regularly reiterating the study purpose, reviewing the risks and benefits of participation, keeping the participants informed of new concerns as they arose, and ensuring continued participation was desired.

Emotional discomfort. It was acknowledged that the interview process might elicit strong emotional reactions for some participants. If discomfort was noted, participants would have been given the choice to continue or withdraw from the interview. I did not detect any emotional discomfort or distress from participants during our interactions that warranted intervention of any kind.

Participant confidentiality. I ensured participant anonymity by assigning an identification number to each participant upon enrolment that was used on all documentation including demographic data sheets and interview transcriptions. In addition, any names that were used during the interviews were omitted in the written report of the study findings. Quotes taken from the interview data were carefully screened for identifying characteristics.

Data storage and destruction. All paper forms were kept in a locked storage cabinet in a home office. The office was locked at all times when not in use. The digital audio recorders and all computer files pertaining to the study were password protected for

added security. Access to the research data was limited to the other members of the research team.

In accordance with Memorial University's (2001) policy statement on integrity in scholarly research, research data will remain in locked storage for five years beyond the conclusion of the research project. All data files (paper and electronic) will be destroyed after that time period.

Participant debriefing. Participants will be invited to attend a formal presentation of study findings. I will notify participants of the date, time, and location once such details are decided.

Findings

Sample Characteristics

Two females and one male participated in the study. The average age of participants was 62 years, with ages ranging from 59 to 67 years. All participants were Caucasian and lived in the province of Newfoundland and Labrador. The highest level of education achieved by each of the three participants was a college diploma, a bachelor's degree, and a master's degree. Two of the participants encountered ethical concerns related to their own care and the care of a relative, while the third participant experienced ethical issues with the care of a family member only. Ethical concerns involved health care services received in a variety of community settings: family physician offices, medical specialist clinics, the clients' own homes, and a restorative care facility.

Main Categories

Four main categories emerged from the data within which the types of ethical conflicts reported by community health care clients and their relatives were embedded.

The categories are: 1) access to health care, 2) quality of health care, 3) compassion and respect, and 4) privacy. Each is explicated below along with descriptions of the ethical conflicts.

      Access to health care. Participants identified issues with access to health services as a top priority ethical concern for their own care and the care of family members. The specific access issues centered on barriers including long wait times and lack of support services for the elderly.

      Long wait times. Exposure to long wait times to see medical specialists and other health care providers interfered with the ability to gain access to much needed medical assessment and intervention. In one account, a participant described long delays in obtaining an eye specialist appointment for his or her family member:

> . . . the referral had been dropped off, two weeks later when we checked for an update, we were told that the referral is not even in the system, it's still sitting on the desk, the backlog would be six months, and if we checked back in six months' time, they *might* be able to tell us then where she is in the pecking order.

The participant described feeling helpless and powerless in accessing care for his or her family member, given the seemingly unavoidable wait time, and expressed concern for the family member's emotional and physical well-being: "At 91 years of age, she perseverates over 'when's my next appointment.' . . . She can't knit now cause she can't see, she can't read very well. When she does try to read, it creates eye strain." The participant acknowledged that while the other individuals on the wait list likely also had important health concerns, frustration remained regarding quality of life issues that perpetuated as a result of the long wait for care.

A second scenario that inhibited access to timely health care, from the client's perspective, was when primary health care clinic staff enforced a "one problem per visit" policy. Having to return for additional appointments to address existing health concerns was troubling, because those issues then went unchecked for extended periods of time. The additional health care visits were also viewed as time consuming and disruptive to personal and work schedules. One participant said,

> I lead a busy life, just as I'm sure my physician does, and I don't want to make five trips to the physician, where I've got to rearrange heaven knows how many other things, just to talk about one or two issues at the time of presentation. . . . I want to take care of whatever my medical needs are in one visit.

Dissatisfaction regarding the delays in treatment and personal inconvenience imposed by this clinic policy was, I was told, a shared sentiment among many health care clients in the community.

Lack of support services. Access to necessary care was also impeded by a lack of support services for older members of the community. This ethical issue was discussed in relation to individuals in need of regular homecare support, and those with mobility issues who experienced difficulty attending medical appointments outside of their homes.

One participant described the challenge of finding and securing a qualified personal homecare worker for an aging relative, attributing the access issue to both the absence of a homecare provider registry and a shortage of trained homecare workers in the region. Hiring homecare support in the participant's community therefore involved relying on "word of mouth" for both identifying available care providers and obtaining their work performance histories. Concern was expressed regarding the apparent lack of

formal training received by many of the homecare workers in the community and the

absence of a regulatory body for these providers given the vulnerable positions of the

clients with whom they work. As one participant stated, "There's no standardized

training. . . . You don't know what kind of job they're going to do until they start

working." The participant went on to say that "these people are going into . . . your

mother's home. They are taking their bank cards and going into grocery stores to pick up

groceries for them. . . . You have to have trust in these people, right?" The perceived

shortages of qualified personal care workers and lack of established "checks and

balances" for these essential care providers were viewed as significant obstacles to

accessing care for members of the aging population.

The absence of support services in the form of "measures to accommodate" was

identified as a significant barrier to care for older individuals affected by chronic pain or

decreased mobility who were required to attend medical appointments outside of their

homes. One participant described the challenges encountered by his or her parent and

family members in having to make regular trips to a physician's office every three

months for prescription renewals. There was expressed frustration about the physician's

refusal to renew prescriptions over the phone or to prescribe for longer periods given the

chronic nature of the client's illness, the client's history of treatment compliance, and the

impact of making frequent trips to the clinic on the client and family's health and well-

being. The participant said,

My mother has had two hip surgeries. . . . Her rods keep slipping out of her hips

every time she has to transfer from her chair. . . . It creates huge issues for her--

pain related issues and discomfort. . . . Emotionally, it's affected us. It's affected

our lifestyle because we have to make arrangements to be able to help her.

Attending such medical appointments was described as being especially difficult when

health care providers fell behind schedule, requiring ailing clients to sit for long periods

of time in the waiting room. One participant explored the ethics of such a scenario as he

or she described a health care encounter experienced by a relative:

She was [waiting] there three hours. . . . She was miserable, her feet were

swelling; she had no comfort . . . it was awful. . . . They should make exceptions

for people. . . . I can sit there for three hours and read a book. She can't.

A suggested accommodation in such a situation was that clients be informed of expected

wait times upon check-in and given the option of waiting elsewhere and receiving a call

when the appointment time is near. Another suggested accommodation was to schedule

clients with pain and mobility issues earlier in the day when appointments are more likely

to be on time.

Quality of health care. Concerns for the quality of health care received in the

community were raised during discussions with community clients and their family

members. Instances were described where health care providers made medication errors,

failed to identify medical issues, did not take the necessary measures to address health

concerns, and neglected to follow safety protocols during the provision of care. The

details of such incidents were described with emphasis on the resulting harm to the

client's health and well-being and the lack of accountability on the part of the health care

staff for their wrongdoings.

In one account of a medication error involving an aging relative receiving care in a community facility, the participant told of a sudden decline in the relative's health and the subsequent discovery that the relative's diabetic medications had been ordered incorrectly. The participant said, "she [became] useless in the bed. So we went out and got the doctor. . . . We looked at her chart." When the family realized that the wrong dose of insulin had been administered over a one-week period, they became "very upset." Adding to this disconcertment was the health care staff's failure to discuss the error with the family and to document the incident.

In another similar story, a participant described the family's quest to identify the cause of a rapid decline in a relative's health status, and the finding that the event could have been prevented with greater attention from the health care provider. The participant said, "When I went in this evening, [I] couldn't even wake her up, hardly. She couldn't even lift up her head, she didn't want to eat, didn't want to drink." Worry and concern prompted the participant to ask a nurse to check the relative's most recent blood work results, who reported back to the participant that "her blood work [was] done ten days ago, her thyroid is out of whack, her cholesterol is up, and it hasn't been looked at." This apparent "neglect" in the family member's care was extremely troubling to the participant; it inflicted harm and suffering on the relative and compromised the family's trust in the care providers.

Compassion and respect. A lack of compassion was perceived when staff members neglected to verbally greet clients, did not use eye contact during face-to-face communication, showed little or no concern for the client's issues and struggles, and refused to accommodate seemingly simple requests. The effect of a lack of compassion

on client-staff interactions was articulated by one participant who recounted his or her dealings with a front-line staff member:

> When you have somebody who greets you with such a lack of compassion and a lack of concern, why would I want to tell her if . . . I've gone through a rough time and I feel like I need to talk? . . . The last person you want to tell is that person."

Lack of compassion was therefore a "stumbling block" that interfered with information sharing and threatened the satisfaction with care.

Feelings of disrespect among clients and family members were described in a number of different scenarios involving health care providers and their staff members. In one account, a participant reported feeling disrespected by health care providers who made little effort to keep him or her informed about his or her medical conditions or appointment schedules. The participant said, "We're not told about things, there's no collaborative dialogue that occurs between the client and the physician or the physician's representative." This poor communication from health care staff was described as harmful to relationship dynamics. As one participant said, "It's not helpful to our perception of the physician, and I think it creates an antagonistic and negativized system where we're actually supposed to be partnered and collaborative."

Lack of respect was also described in situations where participants felt chastised by health care providers and staff members for their words or actions. One participant, who was accustomed to communicating with his or her physician on a first-name basis, described the discomfort that he or she felt when the physician's secretary expressed blatant disproval of this practice. The participant said "[it was] almost like she was

reprimanding me because I wasn't using [the physician's] professional designation," adding that other similar "unpleasant" encounters made him or her reluctant to book appointments unless it was absolutely necessary. This resulting strain on relationships between clients and health care professionals was further emphasized by a participant who described a change in dynamic between his or her relative and the relative's homecare worker when the homecare worker challenged the relative about the severity of his or her condition and his or her need for homecare services. The exchange was described as distressing, inappropriate, and unprofessional.

Privacy. Privacy is the last main category that emerged. Violations to privacy were described in the context of community health care in two different scenarios. In the first, clients were expected to discuss their health care issues with staff members who were not directly involved in their care. This caused discomfort for the client, given the personal nature of some of the health issues for which he or she was seeking care. The second scenario involved clients having to discuss health issues and concerns in areas that were within earshot of others awaiting care, such as talking to a secretary through a window from a waiting room. As one participant pointed out, "If I was going through a major depression and I needed to talk to a doctor. . . . it's a private matter. . . . and anybody [in the waiting room] could hear that." Failure to provide private spaces for clients to discuss the details of their health status and care placed these individuals in compromising situations that made them feel vulnerable and exposed.

Conflict Management Strategies

Although not the major aim of my study, I inquired about conflict management strategies. When participants were asked about the measures they took to address their

conflict situations, four types of management strategies were described: 1) using personal connections, 2) reporting concerns, 3) switching health care providers, and 4) doing nothing.

Using personal connections. Forming personal relationships with health care providers and staff members was reported to be a useful strategy for eliciting greater levels of compassion and respect. Engaging these individuals in friendly conversation and showing interest in their personal lives helped participants to establish a good rapport that promoted desirable communication styles. Connecting with staff in this way also helped health care clients and their family members gain more timely access to care. This was articulated by a participant who said, "You learn to treat the secretaries, the doorkeepers, with the utmost degree of respect and dignity . . . you establish a personal relationship with them and they're more likely, if there's an opportunity, to fit you in a little ahead of anybody who they don't have a personal connection with."

Reporting concerns. Reporting concerns directly to members of the health care team was a strategy used to manage such issues as medication errors and incompetent care. There was expressed uncertainty about the effectiveness of reporting care issues, however, given the lack of response or follow-up from those with whom they spoke. In one account of a medication error that was reported to the medical and nursing staff, the participant said there were "no answers, no, nothing. They just walked away to the nursing station." In another account of a medication error report, the participant reported, "I don't know if anything was done."

Switching health care providers. A commonly cited strategy for dealing with ongoing care issues was attempting to seek the care of a new provider. Switching to

providers who had shorter waitlists allowed clients to gain more timely access to care. As well, moving away from providers whose competence was in question helped clients to achieve safer, more competent care. Changing health care providers also gave participants the opportunity to find the compassionate and respectful care that they required.

Doing nothing. In some circumstances, clients and family members opted not to address ethical concerns because they did not want to jeopardize the client-provider relationship. In one participant's account of a relative who experienced care concerns with her personal homecare worker, the participant said, "She didn't want to push back because she's in a dependent position, and if she becomes assertive and totally turns off this care provider, she feels that she can be punished." Another reason for not dealing with care issues was fear of repercussions for the staff member. One participant, who wanted to report an incident that had serious, negative health implications for his or her parent, was ordered by the parent not to speak up for this reason. The parent said, "I'm alright . . . don't go getting some people in trouble. . . . leave it alone. . . . don't you go putting any concerns in." A third reason for not acting on health care concerns was the belief that efforts made to address or correct the issues would have little consequence. For instance, when a participant told a physician friend that a family member wanted to report a treatment error involving another health care provider, the physician said, "Well, she can if she wants, but it's going to be just as hard, just the same [as] if you're trying to get through any of the ministers in government."

Discussion

Indeed, ethical conflict scenarios occurred when there were discrepancies between care expectations and care experiences. Similar to previous findings reported in the literature, the ethical concerns identified in my study involved problems that were interpersonal in nature, such as a lack of compassion from health care staff, as well as systemic issues, including wait times and lack of support services. The four main categories within which ethical conflicts were identified served to both reinforce themes found in previous ethics research and provide new insights into the types of care issues and subsequent inequities that exist in community care settings.

Issues with access to health care services have been identified previously in several studies, with contributing factors reported as disproportionate spending (Breslin, MacRae, Bell, Singer, & University of Toronto Joint Centre for Bioethics Clinical Ethics Group, 2005), the inequitable distribution of resources (Alkabba, Hussein, Albar, Bahnassy, & Qadi, 2012), and individual socioeconomic status (Kaposy et al., 2017). While there was some speculation among participants in my study about the root causes of wait times, such as physician shortages attributable to "hospital and university politics," the chief concern was the impact of the identified access issues on health and daily functioning. Participant accounts echoed many of the concerns described in the findings by Breslin et al. (2005), such as declines in health status, delays in the ability to return to day-to-day activities, and negative effects on psychological well-being. The call by participants for better community support services for individuals with pain and disability added a new topic to the discussion on access, and highlighted the unique ethical challenges that arise in community health care. Participants acknowledged that

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access issues often stemmed from larger, systemic issues to which there was no quick fix; however, the management strategies described by participants identified the types of short-term measures that were useful for overcoming some of the associated burdens.

Professional incompetency and unsafe care practices were important study findings that were not explicitly discussed in the reviewed literature. Breslin et al. (2005) considered harm to clients that was caused by aggressive end-of-life care treatments requested by family members, and Van Keer, Deschepper, Francke, Huyghens, & Bilsen (2015) deliberated quality of care issues related to the biomedical model of care and centralized decision making, but these studies (and the others that were reviewed) did not report on the types of errors and omissions in care that were described by the participants in my study. The finding that many of the issues with professional competency and client safety were not reported, and that the effectiveness of reporting events was questioned by participants, highlights an important community care need--a safe and effective reporting system for clients and family members who experience adverse events and other health care concerns.

Issues related to lack of compassion and respect in health care have been reported previously (Bollig, Gjengedal, & Rosland, 2016; Foglia, Pearlman, Bottrell, Altemose, & Fox, 2009; Pleschberger, 2007), and were associated with such factors as understaffing and the declining health of the client (Pleschberger, 2007). The seriousness of interpersonal conflict between client and provider was emphasized by Foglia et al. (2009), who reported that health care staff who displayed negative attitudes (i.e., were apathetic or were difficult to contact) resulted in clients feeling disrespected along with fear, vulnerability, and a lack of control. In my study, participants who encountered

negative behaviours by health care staff were less likely to share health information, reported strained relationships, and had decreased satisfaction with care. While one participant reported seeking care elsewhere to avoid additional negative interactions with staff at his or her physician's office, not all participants and family members were able to address issues in this way. The findings revealed that those who were in particularly vulnerable positions (i.e., those residing in community care facilities or receiving homecare support services) were more likely to do nothing to manage issues associated with compassion and respect, for fear of repercussions. Similar findings were reported in the nursing home study by Bollig et al. (2016), where residents were hesitant to speak up about issues or concerns because of a fear that they would be labelled as uncooperative by the staff. This apprehension increased their vulnerability to coercion and threatened their sense of well-being (Bollig et al., 2016).

Privacy concerns were identified in the study by Bollig et al. (2016), such as the common practice of staff entering residents' room without knocking. Such violations of privacy were related to undesirable systems of interaction (also a finding in my study), and were associated with a reduced sense of dignity and self-determination. Findings from my study add to the discussion on privacy by reinforcing the need for health care organizations to reflect on their current ways of doing things from the client's perspective and to consider changes or additional measures that could be implemented to protect the privacy of their clients. The study findings also draw attention to the need for private spaces in medical clinics and other community health care settings in which clients will feel comfortable discussing personal matters.

A final point for discussion is the finding that family members were heavily involved in the care of their loved ones and acted as strong advocates when issues arose. This reinforced the value of including these key stakeholders in conversations about ethical conflicts in health care, particularly in community settings.

Study Limitations

While the study was conducted using a methodological approach that yielded data rich in detail and description, several limitations of the research were identified. First, the voluntary nature of study participation presented the risk of self-selection bias; that is, the decision to participate in the study may have been influenced by particular motivations or character traits of the participants. Second, I was unsuccessful in recruiting more than three participants, and in addition to the small number, all participants were Caucasian and the age range was narrow (between 59-67 years). Greater numbers and diversity in the study sample could have contributed more varied perspectives that would have further enriched the data. Third, data collection and analysis relied on the participants' ability to recall past events and experiences; therefore, reporting bias may have influenced the study findings. Lastly, I acknowledge that research quality is heavily dependent on the individual skill of the researcher. As a novice researcher, I endeavoured to use a rigorous approach to the study of ethical conflicts, and made every effort to minimize personal biases throughout the research process.

Concluding Remarks

This study informs nurses and other key stakeholders in community health care settings about the kinds of ethical conflicts that clients and their family members experience and the strategies used to manage their ethical concerns. The knowledge

gained from this study can be used to guide the development of clinical and educational initiatives in the community that help to minimize the occurrence of ethical conflicts and better facilitate their management. This study provides a strong foundation for future nursing research that increases understanding of the complexities of ethical conflict in the community and the measures that can be implemented to protect client and family health and well-being.

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Appendix A

Recruitment Flyer

MEMORIAL
UNIVERSITY
School of Nursing

Western
Health

Research Study:
Ethical Conflicts in Community-Based Health Care:
A Qualitative Study of Individual and Family Experiences

Have you or has anyone in your family
received health care outside of the hospital?
If so, we would like to talk to you about your experience.

For more information about this study or to take part,
please contact Anne Wadhwa at
(xxx) xxx-xxxx or anne.wadhwa@mun.ca

Appendix B

Demographic Questionnaire

Ethics Study
Demographic Data Collection

Date: _____   Participant ID: _____

Gender: _____   Age: _____

Province: _____

Ethnicity: _____

Education (highest level attained): _____

Relationship to community health services recipient (e.g., self, parent, child, sibling, etc.):

_____

Type(s) of community health service(s) received:

_____

Appendix C

Interview Guide

Semi-Structured Interview Guide [for community health clients and family members]

Interview questions:

1. Please tell me about an ethical conflict that you experienced while you (or your family member) received health care in your community. [Note to interviewer: Explore what happened first, second, third, etc]

2. How did you feel when this happened?

3. If you could use one word to describe the feelings you had during this process, what word would best describe how you felt?

4. What did you do to manage this conflict? [Note to interviewer: Explore the process the client/relative followed] (i.e., self-talk, seeking/mobilizing resources, strategizing)

5. Did you talk to anyone else about the conflict? How did that help you (or not)?

Probes:

Can you tell me a little more about...?

Can you tell me a little more about how you felt when [described event]?

Appendix D

Consent Form

Consent to Take Part in Research [Community Health Patients and Family Members]

RESEARCH PRACTICUM TITLE: Ethical conflicts in community-based health care: A qualitative study of individual and family experiences

PRINCIPAL INVESTIGATORS: Drs. Alice Gaudine and Caroline Porr

You have been invited to take part in a research study. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time.

Before you decide, you need to understand what the study is for, and if there are risks, and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researcher will:

- Discuss the study with you.
- Answer your questions.
- Keep confidential any of your information.
- Be available during the study to deal with problems and answer questions.

1. Introduction/Background:

There has been little research on ethical conflicts related to health care in the community. As well, few studies have included patients and family members in studies about concerns when receiving health care outside of the hospital. More health care is being provided in the community rather than hospital, and therefore it is important to do this study.

2. Purpose of study:

The purpose of this study is to describe the ethical conflicts of patients and their family members related to health care in the community. Another purpose is to look at what is helpful to deal with ethical conflicts.

3. Description of the study procedures:

If you agree to be in the study, you will meet with a researcher in a private setting. You will be interviewed for no more than 90 minutes. You are free not to answer any question or to

stop the interview at any time.

4. Length of time: The interview will last no more than 90 minutes.

5. Possible risks and discomforts:

A risk is that you may become upset when discussing ethical conflicts. If this occurs, we will stop the interview and if you wish, we will help you to contact your doctor or go with you to a medical clinic or a hospital Emergency Room.

6. Benefits:

It is not known whether this study will benefit you.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

When you sign this consent form you give us permission to:

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

The members of the research team will see study records that identify you by name.
Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

Use of your study information

The research team will collect and use only the information they need for this research study.

This information will include your:

- Age
- Gender
- Information from study interviews

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for five years after the publication of the study in an academic journal.

If you decide to withdraw from the study during your first interview, the information collected up to that time will not be used by the research team. We will check your typed interview with you, and at that time you may request information to be removed. After that time, the interview data will continue to be used even if you decide to withdraw from the study. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored at the Nursing Research Unit, School of Nursing, Memorial University of Newfoundland, St. John's, NL. Joanne Smith-Young (Nursing Research Unit Coordinator) is the person responsible for keeping it secure.

Your access to records

You may ask the study researchers to see the information that has been collected about you.

9. Questions or problems:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr. Alice Gaudine.

Principal Investigator's Name and Phone Number

Dr. Alice Gaudine
Tel: 709-777-6972
Email: agaudine@mun.ca

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office
Health Research Ethics Authority
709-777-6974 or by email at info@hrea.ca

Study involvement includes:

A face-to-face interview

After signing the consent form you will be given a copy.

Signature Page

Study title: Ethical conflicts in community-based health care: A qualitative study of individual and family experiences

Name of principal investigator: Dr. Alice Gaudine

To be filled out and signed by the participant:

Please check as
appropriate:
I have read the consent.   Yes { } No { }
I have had the opportunity to ask questions/to discuss this study.   Yes { } No { }
I have received satisfactory answers to all of my questions.   Yes { } No { }
I have received enough information about the study.   Yes { } No { }
I have spoken to **Anne Wadhwa** and she has answered my questions.   Yes { } No { }
I understand that I am free to withdraw from the study: Yes { } No { }
   ● at any time
   ● without having to give a reason
   ● without it affecting my future care
   ● without it affecting the future care of my family member
I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }
I understand how my privacy is protected and my records kept confidential.   Yes { } No { }
I agree to be audio-taped.   Yes { } No { }

I agree to take part in this study.   Yes { } No { }

_____   _____   _____
Signature of participant   Name printed   Year/Month/Day

To be signed by the investigator or person obtaining consent

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

_____   _____   _____
Signature of investigator   Name printed   Year/Month/Day

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