ETHICAL DECISION-MAKING FOR COMMUNITY HEALTH CARE PROFESSIONALS WITH CLIENTS WHO ARE LIVING AT RISK

by

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Abstract

Nurses and other community health care professionals are often challenged by the ethical problems of clients who are living at risk, that is, clients who choose to make autonomous decisions related to personal situations that have the potential for negative outcomes. Although these encounters may cause some of the highest levels of stress in health care professionals, there is a noted lack of research in this area. This exploratory study, conducted using a constructivist qualitative methodology describes the experiences of nurses and other community health care professionals who are participating in ethical decision-making with clients who are living at risk. Constructivism was chosen in recognition that community health care professionals may describe their experiences with ethical decision-making in diverse ways and may experience a number of different realities of these experiences.

Participants, purposively sampled via one-on-one interviews, described the intensity of complex client situations that they cope with. Four main themes emerged from their descriptions: “Our clients who are living at risk”, “Worrying about our clients”, “Finding a better way-how we cope”, and “Frustrated by the system-hitting the brick wall”. Powerful emotions including anxiety, frustration, anger, fear, guilt and helplessness- emotions that sound like moral distress- were part of the experiences. Concepts associated with the four themes included: personal and professional values and beliefs, client capability, use of legislation, resource allocation, ethical climates in organizations, client-directed care delivery, and collaborative practice within interdisciplinary teams. The findings of this study suggest significant implications for clinical practice, leadership, research, and education. Overall, there is a critical need to
Abstract (continued)

ensure that professionals have opportunities to deal with their emotions and concerns when coping with all ethical problems. Strategies that will assist this process include the establishment of supportive systems such as highly functioning interdisciplinary teams, reflective practice, and flexible transformational leadership approaches.
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I hope you still feel small when you stand beside the ocean,
Whenever one door closes I hope one more opens...
I hope you never fear those mountains in the distance,
Never settle for the path of least resistance,
Livin’ might mean takin’ chances, but they’re worth takin’...

And when you get the choice to sit it out or dance
I hope you dance-hope you dance.
(Time is a wheel in constant motion, always rolling us along...)  
I hope you dance, hope you dance.
(Tell me who wants to look back on their years and wonder where those years have gone.)

[From: (I hope you) dance by Lee Anne Womack, 2001]

Words on their own do not really express what I want to say, or should say, but words will have to suffice. I can only hope that you will all read “between the lines”.

A very special thank you to all of these people who have made this “dance”- this journey- all worthwhile because I truly would not have been able to do this without you.

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CHAPTER ONE—INTRODUCTION TO THESIS

Community health care nurses and others are professionally responsible for providing ethical care. How do they cope with this challenge? In twelve years of home care nursing practice, I had often experienced conflicting feelings when care-planning with my clients, including those who appeared to live at risk, and I had seen that other nurses and community health care professionals had similar experiences. These encounters had shown me that working with clients who live at risk may cause some of the highest levels of anxiety and frustration for community health care professionals. This thesis outlines a qualitative research study implemented in order to describe the experiences of community health care professionals in ethical decision-making with clients living at risk. A qualitative research methodology was used.

Community health care professionals define clients who live at risk as those who make autonomous, yet seemingly imprudent, decisions related to personal situations that have the potential for negative outcomes. Additionally, clients who appear to live at risk may also include those who have had changes in decision-making capacity (Kaufman, 1995; Madder, 1997; Silberfeld, 1991). Clients who live at risk, for example, may include a frail older adult who falls frequently and refuses to use a walker, or a young, ventilator-dependent adult who refuses to live in a group home, and may be frequently left alone.

1 Community health care professionals include Registered Nurses, Social Workers, Physiotherapists, Occupational Therapists, Nutritionists etc., who may be working as “front line staff”; practice leaders or consultants, including Clinical Nurse Specialists; and Managers. These professionals often work in interdisciplinary neighbourhood teams. At present, approximately 60% of professional staff who work with adults/older adults in community practice in the organization where the research took place are Registered Nurses. Interdisciplinary practice is discussed in Chapter 3, 5, and 6.

2 In health care, risk is viewed as the chance or probability of a negative outcome or consequence of an action, inaction, behaviour, or decision (Blake, 1995; Browne, Blake & Donelly, 1997; Clemens & Hayes, 1997; Health Canada, 1996; Kaufman, 1995; Porter, 1994; Silberfeld, 1991, Thom & Blair, 1998; Vancouver/Richmond Health Board, 1997). The concept of risk and living at risk will be expanded later in this chapter, and in Chapter 2 & 5.
As a community health nurse, I felt stressed and concerned when I was unsure how to proceed in my care planning with situations that seemed to be ethical problems. I felt I had difficulty finding appropriate and adequate ethical decision-making support or resources when planning and providing care for clients. Now, as a Clinical Nurse Specialist (C.N.S.)/practice consultant for interdisciplinary health care professionals in the community, it is even more clear to me that, in order to help professionals with these ethical problems, we need to better understand their concerns and experiences with ethical decision making. I believe these professionals would be better supported in their ethical decision-making with their clients—especially those clients who live at risk—if we had a better understanding of what health care professionals experience in their practice. A research study was therefore designed that would advance our understanding of these experiences.

This thesis is presented in the following way: Chapter 1 provides a background to the study; Chapter 2 outlines appropriate literature that is related to the research problem, includes overall concepts of ethical decision-making with clients who live at risk, and further demonstrates the gap in literature that led to this research. Chapter 3 details the methodological approaches used in this study, while Chapter 4 describes the constructs and themes that form the research’s findings. Chapter 5 discusses and interprets these findings in light of specific concepts. Finally, Chapter 6 outlines both methodological and substantive conclusions, including implications for practice, education, leadership/administration, and future research.
Background to the Problem

"Shifting Sands" in Health Care: Health Care and Reform

The focus of this thesis is on health care professionals in community practice settings, however, health care practice and the delivery of health care services have become increasingly complex for professionals in all settings (Turkoski, 2000). A tension is developing between the increasing demands for the provision of quality health care services and the ongoing attempts to reduce health care costs. Canada has an aging population; Canadians live longer, often with multiple health issues (Boillat, 1997; Cradduck, 1995). Additionally, the “baby-boomer” age-group has built on their advanced education and exploding use of information technology with a recognition of increasing personal and civil rights and a demand for government and health care reform (Province of British Columbia, 1991). These informed consumers ask to participate in all levels of health care decision-making, often requesting access to sophisticated diagnostic and therapeutic technologies (Pal, 1997; Vancouver/Richmond Health Board [VRHB], 1996). Furthermore, during the 1980s, the federal funds transferred to provinces for health care were substantially decreased. Since then, provinces, including British Columbia, have struggled to cope with meeting the demands for maintaining acceptable health care levels, despite rationed health care services.

Adding to these tensions is a growing recognition that social factors such as poverty and unemployment affect health. Many Canadians struggle to maintain adequate income and health status. Those in marginalized population groups, for example, continue to face barriers in accessing health care services (Saul, 1999) and often have few personal and social resources. This decreases their health status and their access to health
care (Stewart & Langille, 1994), as, for example, seen with clients who appear to live at risk.

Many controversial reform strategies were employed in an attempt to decrease these tensions (Pal, 1997). For example, in British Columbia health care services underwent regionalization, and plans have long been underway to expand community-based health care services (Hollander & Pallan, 1995; Province of B.C., 1991; Province of B.C., 1999a; South Fraser Health Region, 2001; Simon Fraser Health Region, 2001; V/RHB, 1996, 1998, 2000b, 2000c). These reforms caused upheaval for many health care organizations in British Columbia (Kane, 1995; V/RHB, 1998a, 1998b, 2000b). Meanwhile, in many health care settings, health care professionals, especially nurses and physicians, increasingly voice concerns about increasing workloads and a shortage of trained personnel. In community practice settings, professionals comment on the increasing complexity of client health needs, the effects of shortened hospital stays, longer waitlists for surgery or cancer treatment, and the acuity of care that must be managed with community-based services.

All of these issues have challenged traditional methods of delivering health care, increased the number and complexity of clients' health and social problems, and could, I believe, contribute to increased reports of stress among health care professionals. Within an overall environment of turbulent health care change, health care professionals struggle to provide acceptable levels of care within complex, changing practice settings.

Ethical Problems and Stress

One outcome of health care and organizational change may be health care professionals' increased stress associated with the challenges of meeting clients' needs
and making decisions about their care. Stress for these professionals has multiple causes including client situations that present as ethical problems. What is known about the nature and meaning of the situations that create this stress? What type of ethical problems challenge health care professionals in current environments? In order to answer these questions, several terms need defining: 1) ethics; 2) health care ethics; 3) nursing ethics; 4) ethical problems in health care.

*Ethics,* as a field of philosophy, is concerned with the knowledge of what is right, good or obligatory (Nicoll, 1992). *Health care ethics* is a broad term describing ethical concerns affecting clients, families, health care professionals, health care organizations, and society as a whole, and consists of the application of theoretical ethics to moral problems (Browne & Sweeney, 2000). Health care ethics encompass a wide range of issues including such things as advanced directives and genetic cloning (Dossetor & Cain, 1997). *Nursing ethics* are often based on the profession’s code of ethics (Canadian Nurses Association [C.N.A.], 1997), and include at least four essential ethical principles (autonomy, beneficence, nonmalificence, and justice). Nursing values such as choice, dignity and accountability are also mentioned in the Code of Ethics for Registered Nurses (C.N.A.). Greipp (1995) believes that the foundation of nursing ethics comes from the experiences of nurses and those who receive their care, interacting with each other, and is inclusive of the nursing process and decision-making.

An *ethical problem* is defined as “a problem that cannot be resolved solely through an appeal to empirical data … a conflict of values and uncertainty about the amount or type of information needed to make a decision, and the answer for which will have profound relevance for several areas of human concern” (Curtin, 1982, p. 38-39).
Storch (1999) describes one type of ethical problem "as a dilemma in which a difficult choice must be made between competitive and equally compelling arguments for opposing positions or actions" (p. 353). An ethical problem for a nurse may arise if there is disagreement about the type and amount of information needed to reach an acceptable decision (C.N.A., 1997). Furthermore, ethical problems may arise when ethical reasons, both for and against, one or more courses of action are present and choices need to be made (C.N.A; Registered Nurses Association of British Columbia, 1997; Rodney, 1997).

Such ethical problems occur, for example, when health care organizations, in the midst of change, lack clearly articulated values or policies to guide the process of resource allocation or priority setting when a client who is living at risk requires a high level of care. This may lead to an ethical problem for a health care professional. If he/she believes that the workload is too high, resources are not available for the provision of safe care, or the professional is unsure how to deal with the situation, this constitutes an ethical problem. An ethical problem may also occur when health care professionals try to prioritize care needs in a fair way when coping with many clients with complex needs, all of whom require professional care.

The ethical climate of the organization can affect both the health care professional’s perception of stress or ethical problems, and his/her ability to make ethical decisions within a stressful environment (Olson, 1995). In the midst of organizational change, the organization faces challenges in ensuring that health care professionals are supported in their decision-making in complex client situations. In addition, informed health care professionals, who seek coping strategies to deal with the overall stress of health care and organizational change, hear more about health care ethics from journal
literature, education sessions, and informal conversations with colleagues. In my experience, health care professionals seek opportunities to talk to others, and they describe their stress, experiences, and reactions to ethical problems.

In my role as a Clinical Nurse Specialist/practice consultant, nurses and other health care professionals have frequently described to me their lack of comfort and confidence in their own ability to assist clients and families to make health care decisions, including ethical decisions. They have described to me their feelings when trying to cope with an ethical problem—feelings of anger, frustration, powerlessness, or ambivalence. My professional experience also lead me to believe that in community practice settings, health care professionals are stressed and challenged by the ethical problems presented by clients who have complex health and/or social concerns and are living at risk in the home environment. Health care professionals described their concerns in making difficult decisions when an ethical problem appeared to have conflicting variables, choices, or options. Clients who are living at risk may have reflected on their health care or lifestyle options, made personal choices based on their understanding of their situation, and may have expressed their desire to take personal responsibility for those choices. Yet, nurses and other health care professionals working in the community continue to express concerns about the challenges of working with these clients and have little research to assist them to understand their ethical issues. There has been a paucity of literature to guide their practice or to assist those who, in leadership positions, support their practice. Therefore, I believed that qualitative research in this area might provide some insight into the ethical problems that community health care professionals encounter.
Ethical Decision-making with Clients Who Live at Risk

The concept of clients who are living at risk was introduced at the beginning of this chapter. Chapter 2 expands on this concept, and includes a discussion on professional risk assessments. This section describes the ethical situations that may arise for community health care professionals with clients who live at risk. An ethical problem in the community health care setting may occur, for example, when family members insist that a client who may be at risk should be removed from the home because it is not “safe” to be alone. Consider the situation of a frail elderly woman living alone in her apartment who eats little, weighs only 70 pounds, and no longer understands how to use a telephone or stove. Her son wishes to place her in a facility-a decision that he believes is for her benefit- yet she wishes to be able to stay at home. When a client’s situation contains so many conflicting variables, community health care professionals (and the client’s family and support network) may experience increased distress and anxiety. Professionals try to balance an understanding of the son’s worry with a genuine desire to honour the client’s request to stay home. Furthermore, the professional may have personal feelings of anxiety about the elderly client’s risk, and feelings of frustration with a community health care support system that can not provide comprehensive services.

Does “Place” Matter?

Introduction to Ethical Decision-making in Community Settings

Davis (1991) was one of the first to point out that little is known about ethical problems in settings aside from acute care. Chubon (1994) concurs that little research has been done on the ethical issues for home care nurses. Aroskar (1989), in the first published descriptive study to focus exclusively on ethical problems in the community,
found that most significant ethical problems “point to conflicts over the obligation to
honour the principle of autonomy versus the obligation to benefit the client by assuming a
more paternalistic position in order to prevent or avoid harm” (p. 969). Haddad (1992)
also warned that “ethical problems...take a different meaning in the home care setting”
(pp.49-50). Even less research has specifically addressed the ethical concerns related to
living at risk client populations, especially in the older adult population (Chubon, 1994;
Porter, 1994).

Many characteristics of community-based care may affect ethical decision-making. When community health care professionals provide care in the home, their
relationships with their clients may be different from those relationships established in
other settings, such as acute care, and may possibly be based on strong trust formation
(Brent, 1997). In these situations, professionals try to identify and assess the client's
perception of his/her own role and value system, yet must balance information regarding
the client's general response to illness, decision-making, and level of capability or
competence. These factors may complicate how community health care professionals
make difficult decisions.

Longer-term relationships between community health care professionals and their
clients may also influence ethical decision-making in community settings. Home
care/community care often extends over a longer period of time than acute care. The
community health care professional may see the client in a more realistic light (their
home environment) than those health care professionals who treat clients in acute care
(Haddad & Kapp, 1991). The community health care professional also may “know

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3 This concept will be discussed in Chapter 2.
his/her client better”—be more aware of the client as a person with values, goals and needs, than might be possible or realistic in an acute care environment. The community health care professional may have an excellent opportunity to view the client in his/her total social context. This deeply affects how the professional makes difficult ethical decisions, perhaps leading to the creation of ambivalent or powerless feelings. For example, community health care professionals have said: “I have known 'Mary' from the time her husband died—she never wanted to be a burden on anyone, or be kept alive by artificial means, and now we are trying to decide whether she should have tube-feeding!”

Furthermore, in many health care settings, including the community, the client is not the only person who actually receives care or support, or participates in the care. Family, significant others, friends, and the larger community may have decision-making conflicts when participating in care-giving (Green, 1997). The potential for conflict increases with the number of people (for example, professionals and home-support workers, who may be from several agencies, and caregivers/family) involved in decision-making.

Liaschenko (1996) wrote: “Awareness of place is essential to understanding concepts and issues of significance in ethics, such as social relations, power and autonomy” (p. 49). Health care professionals who are new to the community practice setting frequently notice the differences between community and acute care or facility professional practice, and comment: “We are in their home, on their turf—in the hospital, it's our turf. The clients can tell us to leave their home, we have to go and we may not be able to give them care, even if we really think that they need care. Then we also have to
deal with their family and friends a lot more and they don't understand the limitations that we have.”

The complexities of the community environment may affect how distress with ethical problems is perceived and/or how ethical decisions are made (Turkoski, 2000). A client's desire for personal autonomy and involvement in decision-making is most visible in the community health care environment where, ideally, clients and families share health care planning with professional staff. Additionally, the client in the community may live in an environment lacking personal, family, or social resources—all factors more likely to be observed in a community setting (Chafey, 1996). Furthermore, in British Columbia, government resources to adequately support clients who are at home with complex health and social concerns have not yet been shifted to the community despite policy commitment to do so (Province of B.C., 1991; V/RHB, 2000b). Scarce financial resources and increased time constraints for those who deliver health care services in the home may alter how community health care professionals make ethical decisions. Yet, there is little research in this area that has looked at how community health care professionals, including nurses, make these decisions.

Situational constraints may inhibit the community health care professionals' ability to respect the client's wishes. This type of ethical problem may cause feelings of distress in the community health care professional. For example, how does a professional make comfortable decisions when two clients are dying at home, both appear to be at risk and requiring 24 hour professional care, for instance, nursing care, and yet only one nurse is available? Generally, when a community health care professional attempts to be “fair” with resource allocation, the client who has the most “needs,” appears most at risk and
has less family support receives the extra care. When community resources are not available or adequate to supplement the family/caregiver resources, the health care professional (for example, the home care nurse) must attempt to provide the best home-based care that is possible.

Finally, similar to other organizations, the experiences of community health care professionals are affected by the context of the organization and its processes. Poor channels of communication, lack of consistent policy interpretation, and hierarchies of power found within large organizations, result in questions about professional’s authority to make decisions and affect how staff resolve ethical issues (Kelly, Marshall, Sanders, Raffin, & Koenig, 1997; Olson, 1995). Despite the uniqueness of the community care setting, discussions of an ethical culture in community health care organizations have had little mention in the literature. Kelly et al., in their ethnographic research focusing on ethics consultation within organizations, question whose voice may be heard or silenced when negotiating ethical problems. They write: “The...study raises questions about the cultural context within which ethics consults are initiated and the interpersonal and political aspects of the local work setting that precipitate, shape and define difficult decisions in patient care” (p. 146). I have also noticed that health care organizations may not always provide consistent support for the ethical decision-making concerns of their professional staff, for example, with leadership styles or education support. This may increase the stress for health care professionals who work with clients who appear to live at risk. Decisions made at a site level or program level, as well as organizational, regional, provincial, and federal level may also affect decision-making as seen, for
example, when home support budgets are cut for community clients. The organizational climate or context therefore becomes an important consideration in this research study.

In summary, ethical problems create stress and discomfort for nurses and health care professionals in all settings. The complexities of the health care needs and the tensions associated with providing health care in current environments changes the nature of these ethical problems. I have participated in complex ethical decision-making with clients, and witnessed the expression of complex feelings in community health care professionals who have participated in these decisions.

There is a plethora of literature, both research and opinion-based, that exists on the topic of health care and biomedical ethics. Nevertheless, much of the research in ethical decision-making in health care is acute care driven. I have found little direction from research literature for community health care practice. Overall, the ethical problems and ethical decision-making experiences of community health care professionals have not attracted extensive research interest.

Nurses and other health care professionals in all practice settings, including the community, face complex situations with their clients and families in a rapidly changing health care environment. The health care professional often experiences stress as he/she attempts to identify the nature of the ethical problem and decide appropriate decision-making strategies for ethical problems.

While many client situations in the community have inherent ethical problems for health care professionals and families, there is one situation that seems particularly troublesome for health care professionals: clients who live at risk. On a daily basis, all community health care professionals, including nurses who are working as home care
nurses or case-managers, approach me about their ethical problems with this client population as one source of their stress or anxiety. In my view, there may be no more complex environment for ethical problems than the community health care setting, especially with clients who live at risk. To support the practice of these community health care professionals, we need to understand how they deal with their ethical decision-making problems and how they cope with the feelings they experience.

Problem Statement

The literature provides little insight into the complexities and scope of ethical issues and concerns for community health care professionals and fails to provide significant direction or support for those who cope with ethical problems and ethical decision making with clients who live at risk (Thom & Blair, 1998). When health care professionals believe that clients who live at risk are making poor decisions, they may experience distress as they attempt to balance the client's right to make these decisions with what might appear beneficial for him/her (Koloroutis & Thorstenson, 1999).

I believe that this problem—effective professional ethical decision-making practice with clients who live at risk—is a significant area of concern for nurses and other community health care professionals. Gaps are apparent in the current research related to this problem. Findings from research on how ethical decision-making occurs will enhance the ethical dimensions of community health care professionals' practice.

Purpose of Study

The purpose of the study, therefore, was to examine the experiences and concerns of nurses and other community health care professionals who make ethical decisions about clients who are identified as living at risk. Nurses and other health care
professionals, including those who practice in complex community settings, will continue to be challenged by the ethical problems that may arise with clients who live at risk in the community. Much of what has directed ethical decision-making practice in the community with clients who live at risk appears to have been based on vague guidelines, supported by little or no research, with little specific attention to clients who may appear to live at risk. The findings from this study may begin to fill some of these gaps in the literature and give direction to practice.

Research Question

The primary research question was: What are the experiences and concerns of nurses and community health care professionals who participate in ethical decision making with clients who appear to live at risk?

Constructivist Methodology

Qualitative researchers study natural settings, attempting to interpret phenomena in terms of the meanings people bring to their own situations (Denzin & Lincoln, 1994). The nature of the research question led me to believe that the research should look at the ethical decision-making experiences of health care professionals in their natural setting (the community environment) including the researcher as a human instrument within the study (Appleton & King, 1997). The concept of human as instrument/researcher as instrument is discussed in Chapter 3. Using a qualitative research method that inductively develops beginning theory, I decided to design this study according to the paradigm of constructivist methodology, a design typically selected when little is known about a phenomena (Sandelowski, Davis & Harris, 1989). In this study, I hoped to explain
the experiences of community health care professionals who make ethical decisions with clients who live at risk.

Constructivist inquiry, originally called *naturalistic inquiry* (Appleton & King, 1997), includes elements of post positivist theories, supports a *relativist*⁴ ontology, and looks at process and inductive thinking in an *emic*⁵ perspective (Appleton & King; Guba & Lincoln, 1994). The aim of constructivist inquiry is an understanding and reconstruction of constructs⁶ that people, including the researcher, may initially have. A consensus of interpretation is sought, but new interpretations of the constructs may emerge (Guba & Lincoln, 1994). This approach allows for the creation and emergence of themes from the data, with interaction between the researcher and the participants (Appleton & King, 1997), and thus is most likely to achieve the results desired in this research.

As a novice researcher, I required a clear framework for constructivist inquiry (see Appendix A). A tentative plan for sampling, data collection, data analysis and verification has been adapted from the original work of Lincoln and Guba (1985), and is completely outlined in chapter 3. Rigor and trustworthiness aspects are also discussed in chapter 3.

**Significance**

I hope that the findings from this research study will give clearer direction for effective and consistent ethical health care practice for nurses and other community health care professionals who work with clients living at risk. Use of the results of the research

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⁴ Relativism is defined as involving "the view that beliefs and principles...have no universal or timeless validity, but are valid only for the age in which the social group by which they are held" (Appleton & King, 1997, p.14).

⁵ An emic perspective is the study and analysis of a setting or behaviour interpreted from the author's perspective (Morse & Field, 1995).

⁶ A construct is defined as "a term comprising several concepts...therefore, more encompassing and more abstract than a single concept" (Morse & Field, 1995, p. 24).
may lead to improved ways to support these community health care professionals as they cope with ethical problems for this population group. I had anticipated that an analysis of these experiences may give critical direction to practice leaders to develop strategies that will support, guide and educate staff who, on a daily basis, coordinate care with these clients, their families and others. Research in this area may support future development of ethical standards for required knowledge and capabilities for ethical decision-making, and ensure that the environment offers opportunities for professionals to share their moral concerns.

**Summary of Chapter One**

In complex community health care settings, nurses and other community health care professionals attempt to make ethical decisions with clients living at risk. A qualitative research study, using constructivist inquiry, was designed to address the fact that there is little research focusing on ethical issues in community health care settings for clients who live at risk. Furthermore, there is a need to examine how community health care professionals’ decision-making concerns are supported, and how care for clients who live at risk in the community can be improved.
CHAPTER TWO—LITERATURE REVIEW

This study was introduced as exploring the experiences and concerns of nurses and other community health care professionals who cope with ethical decision-making with clients who appear to live at risk. In Chapter 1, as a background to the research problem, I introduced the following concepts: stress within changing health care environments; clients who live at risk in the community; ethical problems, ethical knowing and decision-making in community health care environments; and, the development of ethical climates or cultures in organizations.

This chapter will expand on these concepts, examining the literature in depth, and includes a review of additional concepts: client autonomy and informed consent; risk and risk assessments; capability, capacity or competency; paternalism; and, micro, meso, and macro levels of ethical knowing and awareness, including values clarification for health care professionals. I believe these topics are all relevant to ethical decision-making for nurses and other health care professionals in health care settings including community practice settings. Furthermore, with many gaps in the research literature for the support of ethical decision-making in community health care practice, these topics are also important areas for consideration with decision-making for clients who live at risk.

Considering Autonomy

Client autonomy is recognized as a central value for all health care professionals (Artnak & Dimmit, 1996). Artnak and Dimmit define client autonomy as: “self-rule while remaining free from (both) outside interference from others...the meaning of autonomy lives within the moral significance people have of themselves as persons—their own identity” (p. 17). An autonomous action is the basis of informed consent, and requires the
client's adequate understanding of his/her own action (Fowler, 1989; Haddad & Kapp, 1991; Keatings & Smith, 1998). Keatings and Smith continue by describing autonomy as based on the idea that human beings have moral dignity and worth; to respect persons is to recognize them as worthy agents, as individuals who should not be disrespectfully treated as means to an end. This principle supports the Kantian view that all human beings should be respected as ends in themselves.

An examination of the "senses of autonomy" can also assist an understanding of whether a client's autonomy should ever be overruled. Haddad and Kapp (1991) outline Miller's senses of autonomy: Autonomy can be viewed as free action, as authenticity, and, as effective deliberation. Autonomy, as free action, is an action that is "substantially free, taking into account the numerous factors that influence all of our decisions" (p. 66). Autonomy, as authenticity, questions if a person is acting in character, while, autonomy as effective deliberation, considers an action taken after weighing the consequences of alternatives in a situation requiring a decision and choice of action.

The concept of autonomy may not be easy for nurses and other health care professionals to understand and integrate into their practice. In their study with nurses and their ethical problems, Oddi, Cassidy, and Fisher (1995) concluded that nurses generally perceived ethics as the main issue in situations that directly involved client's autonomy. Yet, Whitler (1996) studied the ethics of assisted autonomy through use of grounded theory methodology, and felt that while nurses recognized the importance of autonomy for long term care residents, the majority failed consistently to foster self-determination, and most inadequately understood the concepts of consent and decisional
capacity or competency. The concepts of capability and competency are discussed later in this chapter.

Sherwin (1998) has introduced the concept of *relational autonomy* as an alternative to dominating interpretations of the concept of autonomy. Within a relational viewpoint, autonomy can be understood as "a capacity or skill that is developed (and constrained) by social circumstances" (p. 36). This feminist perspective, while not diminishing the prominence of respect for individual self-determination, proposes that all health care professionals reflect on individualistic approaches to autonomy. According to Sherwin, illness tends to make clients dependent and reduces their ability to exercise autonomy as well as making them vulnerable to manipulation or coercion. Furthermore, power issues may exist between clients and those who care for them. An individualistic approach to autonomy may neglect to address the social causes and conditions that may contribute to health and illness, or power and dependency. Sherwin recommends a broader political perspective that takes into account the impact of political and social structures such as oppression on the lives of individuals (p. 37). In Sherwin's words: "In a world where most cultures are plagued by...oppressive patterns, fundamental respect for the humanity, dignity and autonomy of members of disadvantaged groups...seems very important and in need of strong ethical imperatives." (p. 23). Sherwin does not dismiss the concept of individual autonomy, but suggests mechanisms to strengthen autonomous roles of individuals, believing that autonomy can be combined with the commitment to social justice and a removal of barriers to oppression. This is an important interpretation of autonomy when viewing the contextual aspects that may be found within the community health care setting. A relational view
may help us understand how the social settings of community clients who live at risk may influence how they exercise their autonomy, thus influencing the decision-making of professionals and possibly increasing their moral distress. Within these interpretations of autonomy lies the element of risk and its impact on how ethical decisions are made with community clients. Additionally, the context and influence of a hierarchical health care organization structure on professional decision making could be viewed in light of relational autonomy because of related power issues.

Clients Who Live at Risk – The Health Care Professional’s View

The exploration and description of risks encountered by adults or older adults have been well described in the literature. Unfortunately, the concept of risk is often linked closely to the concept of harm. Still, the term *at risk* has been considered a significant improvement over the previously common term *vulnerability*. The term *senior at risk* is generally meant to encompass “persons whose health, well-being and independence are threatened by virtue of the situations or conditions they live in…” (Health Canada, 1996, p.6).

In health care literature, and thus for health care professionals, risk is viewed as the chance or probability of a negative outcome of an action, behaviour, or decision. (Blake, 1995). When reviewing a risk outcome, individuals and health care professionals may perceive a potential outcome of a risky behaviour or decision as ranging from merely annoying to catastrophic, ie. at a level of no risk, tolerable risk, or intolerable risk. Risk is the sum of the magnitude of harm that may result from a person’s behaviour and decisions, and the probability that harm may occur. Negative risk outcomes may increase with cumulative risk factors. Yet, the assessment of the magnitude of risk must examine
the full outcome or consequences of choices or behaviour, not only the specific risk factor in isolation. A client’s decisions about risk behaviour are based on such variables as their values, resources, and life experiences (Blake; Silberfeld, 1992).

For individuals, no environment or decision is without risk (Silberfeld, 1992). A person's interpretation that a certain behaviour may result in a negative outcome is only one aspect of their decision-making related to that behaviour. The positive aspects of a risky action must be considered in the context of the value or meaning that a client attaches to that action. Decreasing or eliminating risk may actually remove those aspects of life that create pleasure and meaning for an individual. Risk should be balanced by examining harm/benefit ratios for clients and others. But the positive and negative perceptions of actions and their outcomes may be viewed differently by individuals, health care professionals, family and significant others, and society (Silberfeld). The differing perceptions may lead to feelings of distress in those individuals involved in the situation.

Mitchell (1996) writes that reducing risk factors for older people may lead to health improvements in that population group, especially positive outcomes which appear linked with a sense of personal control. Furthermore, Huston, Allen, and Roy (1993) write: “...it should be remembered that quality of life does not necessitate the absence of risk and, in fact, quality of life and risk may coexist for the elderly despite the fact that risk by its very nature increases the probability of an adverse outcome” (p.29). Future research in this area should help advance health care practice in this area.

Unfortunately, discussions of risk assessments often lead to thoughts of protection by well meaning care providers—the verbalized perception of health care professionals’
feelings of anxiety or stress, and their sense of responsibility “to fix things—to make them right.” Drawing conclusions about acceptable or unacceptable risk and the most appropriate ways to address the risk does not appear to be a neutral process and such conclusions may be based on value judgments. The research of Clemens and Hayes (1997) suggests that the risk assessments (especially of older adults) often reflect the values of the individual practitioner’s profession and the agency culture.

The recognition of a need for a consistent approach to risk assessments has led to the development of various screening tools and assessment frameworks for use in a variety of health care settings. Respondents in the Clemens and Hayes study (1997) asked for both support in the decision-making process as well as clearer guidelines for ethical risk assessments. Risk assessments can be an important aspect of overall client assessment, but cannot be expected to “stand on their own.” Such assessments should be supported and augmented with other frameworks or concepts such as ethical principles or ethical frameworks, to ensure the appropriateness of their role in care planning and service delivery.

Literature related to risk assessments has appeared divided on how to assess and manage risk and the degree of involvement that a client should have in such assessments (Thom & Blair, 1998). In fact, little research has explored this area, especially relative to clients with dementia (Thom & Blair). The health care professional in the community, when assessing clients, may be examining how devastating the consequences of a risk might be (i.e. magnitude). Probability estimates would attempt to determine whether an outcome is likely to happen (Blake, 1995). Alternatively, an older adult’s safety may be considered using a benefit/harm analysis of the outcomes of the identified risk. That is,
what are the benefits of a client's decisions or wishes weighed or balanced against the potential harms or risks, for example, weighing the benefits of living alone with possible harms?

Magnitude and probability assessments also examine specifics about risk, including whether the consequences of the risk are reversible (low or tolerable risk), or irreversible (high or intolerable risk). The magnitude of the risk should also be clarified by the client's perception of the risk. One of the difficulties in assessing risk is that subjective data from a client will be based on their goals and values, and may not always be objective or accurate (Browne & Sweeney, 2000). Additionally, the outcome of the risk may have to be predicted or estimated, and data may be in conflict with that of significant others. When describing the outcome of the risk, my experiences show that it is helpful to use the client's own words whenever possible, for example "I feel safer when my daughter is here when I have my bath, but she can't always be here". However, once again, more specific research is required to understand the nature of these risks and the potential of negative outcomes. Recent literature also recommends that health care professionals respect principles of autonomy, examine risks, and look at client's perceptions and goals, while searching for evidence of positive strengths, capacities, retained abilities in their clients, and current accessible resources (V/RHB, 1997, 2000a).

Informed Consent and Client Capability in Assessing and Minimizing Risk

The concepts of living at risk and client capability are often linked when professionals discuss how they might minimize risk situations. What are competence, capability, and capacity? Generally, these terms are synonymous. The terms capacity or capability are now seen more frequently in the literature, yet competence (or competency)
is still primarily used in practice situations. Capacity is used in legal terminology, whereas competence describes the mental ability to perform a specific task or set of tasks. For medical or legal purposes, Silberfeld (1992) writes that no single definition of capacity can be used for all purposes while the V/RHB risk assessment tool (2000a) believes that capacity or capability looks at what people actually do in the circumstances of their lives. According to Kane (1998), competence refers to an individual’s capacity to understand and act reasonably. Silberfeld (1992) continues by writing that a person should be considered competent when he/she is capable of communicating pertinent information, possesses a set of values and goals, and possesses the ability to reason about choices. Capability or incapability assessments, related to acceptance of support and assistance plans or consent for health care, are also described in B.C.'s Adult Guardianship Act and Health Care Consent legislation (enacted in February 2000), and are discussed in more detail in Chapter 5.

When a client appears at risk, capability or competency may be questioned (Clemens & Hayes, 1997). As our population ages, there may be an increased demand for capability assessments. A capability assessment should distinguish those who are capable of making choices from those who are not and should specify the nature and extent of any incapability or incompetence (Kane, 1998). Furthermore, incapability should not be based merely on the presence of a medical condition alone, such as Alzheimer’s disease, especially in its early stages. Similarly, incapability assessments should not be based on fluctuations in competency, such as those found in individuals living with alcoholic addiction, and do not necessarily mean that a client’s risks are intolerable (Kane).
Furthermore, a statement of incompetence of person is not the same as being “pinked”–committed under the Mental Health Act (Province of B.C., 1999). In British Columbia, until recently, this assessment had to be completed by two physicians, and the client had to be admitted to a designated psychiatric facility. Changes to the Mental Health Act, effective November 1999, allow committal by one physician with review by a second physician within 48 hours. Most clients who live at risk in the community will not be committed, ie. they do not have a mental health problem such as dementia, depression, or a psychosis that affects their decision-making ability and is treatable (V/RHB, 1997).

Clemens and Hayes (1997), and Haddad and Kapp (1991) state that the strongest concern regarding the nature of competency may be that the finding of incapability is too easily obtained and may lead to deprivation of client autonomy. Families and health care professionals who state that the person is “incompetent” and needs to be protected, for example, by placement in a facility, often rationalize interference in risky client situations. Less invasively, he/she could be supported with services in the home, where risk may be decreased to tolerable levels. Community health care professionals often face this moral dilemma, and express anxiety related to a family's pressure to facility-waitlist a client. However, community health care professionals could carefully consider the effect of possible decisions of incapability as well as how the client may feel about undergoing the testing.

Concerns about capability are also linked to the client's ability to give and remove consent. Silberfeld (1992) states that a person is capable of giving consent if he/she understands the reason for which consent is sought, and appreciates the consequences of giving or withholding consent. Additionally, a distinction between implied consent and
informed consent must be clear. Implied consent may be viewed as interpreted agreement, ambiguous, and presumptuous. Informed consent includes three components: voluntariness, information, and competency (Kane, 1998). An informed consent relates to a specific treatment and is freely given once the client is informed. There is at least one important caveat for health care professionals considering capability and informed consent issues: until proven otherwise, every person is presumed capable of making decisions about personal care, health care, legal matters, or financial matters (Public Guardian & Trustee of B.C, 2001; Registered Nurses Association of British Columbia, 1999). Nurses and other health care professionals often must balance their concerns about a client’s capability, ability to provide consent, and need for autonomy with their professional obligation to “do good” for the client, and to prevent harm.

Paternalism

Despite the client’s right to autonomous choice, a common ethical problem for community health care professionals who are making ethical decisions may involve the concept of paternalism and how much to intervene in a client’s life to reduce risk (Kaufman, 1995). How do health care professionals minimize their clients’ risks when planning care? Paternalism, as a health care concept, is defined as the strength of professional interference or interventions with clients when they are making their own decisions or are making “non decisions” (Browne, Blake, & Donelly, 1997). There may be good reason for concern about the intrusiveness of professional interventions that are intended to decrease a client’s risk. A community health professional, when coping with his/her own moral anxiety and sense of responsibility associated with their client’s risk,
may act in a paternalistic way or demonstrate power over the client (Clemens & Hayes, 1997; Collopy, 1993; Silberfeld, 1991).

*Weak paternalism* advocates interference only with "the encumbered client." An encumbrance, according to Browne (1997), will include distorting conditions that may lead to an assessment of incompetency, such as mental illness, emotion states, coercion, or an absence of information. *Strong paternalism* encourages interference with encumbered or unencumbered clients if the client will be "better off" and/or will subsequently "be grateful." Weak paternalism has been powerfully supported by two arguments. First, unencumbered individuals know their interests best. That is, any attempt to interfere with them in their own interest may do them a disservice (John Stuart Mill, in Browne, Blake & Donelly, 1997). Second, Immanuol Kant (Browne, Blake & Donelly) argues that strong paternalism is wrong because it does not show "suitable respect" for an individual. Unlike Mill, Kant was not concerned about bad outcomes or consequences, but considered dignity as more important (Browne, Blake & Donelly). In the full spectrum of interference (explanations, pressure, and physical coercion), if a risk is substantial, interference is only justified if beneficial, and not discriminatory (Browne & Sweeney, 2000).

Rationalizing a need for interference or interventions may alleviate the health care professional's fear about "leaving the client at risk." Yet, legally and ethically, a competent or capable person's decision to live at risk is supported by his/her right to autonomous choice, free of interventions or interferences. A competent person, when making choices, should be informed of the consequences of all alternatives or possible outcomes of risks that he/she may accept. This is an aspect of informed consent. Some
clients who want to manage or direct their own care have been described as “non-compliant” (Haddad & Kapp, 1991), but may be only struggling to maintain or regain independence, or may be acting on different values or goals than the professional, or may not agree that the recommended treatment or intervention will be effective. This is an area that future research may examine.

In rare cases, a Committee of Person through a court order may be requested from the Public Trustee for protection or assistance of vulnerable adults. The public often does not understand that a Committee of Person authority has limitations and may not be the appropriate authority to help ensure an adult's safety. When the Public Trustee receives a request to act as Committee of Person, several principles will be applied, including the fact that all adults are presumed capable until the contrary is demonstrated (Public Guardian & Trustee of B.C., 2001). The least intrusive intervention or interference may be partial guardianship—when the guardian only controls areas in which the client has trouble functioning and “needs protection”, and can be considered as an alternative to full guardianship. In this way, the client maintains autonomous choice in other areas (Kane, 1998).

Society has become less tolerant of paternalism, and collaboration with health care professionals is more desirable (Koloroutis & Thorstenson, 1999). Health care professionals, as true partners in the decision-making process, can ensure a two-way educative process which may avoid non-productive decisions, and demonstrate respect for client self-determination or autonomy. This process is a shared decision between health care providers and clients, such as those who are living at risk. Interference with a client’s autonomous decision-making may be considered if there is potential significant
risk to self or others. If there is no risk or minimal risk, then no interference should be considered. If a treatment is offered to a client and they are competent, the principle of client autonomy cancels out the family’s wishes (ie. their autonomy). Principles of non-malificence or beneficence for the client must also be considered. A truly autonomous choice should be considered as beneficent for the client (Brown, 1997).

Bandman (1994) identified three conditions as necessary for a client to share in making an ethical decision: competence, voluntariness, and knowledge related to the condition of illness including informed consent. If a client is incompetent to make a particular decision, health care professionals, family or surrogates may make a decision. A surrogate decision-maker should consider the best interest of the client, and therefore should be the person who best knows the client's values. This may be based on two types of judgment: substituted judgment (what that person would choose if competent) or best interest judgment (what the reasonable person in that situation would choose) (Browne & Sweeney, 2000). Current ethical thought appears to support the practice of substituted judgment. Nurses and other professionals are attempting to consider all of these issues as they make ethical decisions with their clients who live at risk. Levels of ethical knowing and awareness will also impact these decisions.

Examining literature in professional ethical decision-making practice for at risk clients appears to elicit more questions than answers. How do community health care professionals plan care with their clients in a manner that maintains the client’s right to self-determination and avoids strong paternalism? Research into health care professional’s ethical decision-making experiences may demonstrate how this process occurs.
Micro, Meso, and Macro Levels of Ethical Knowing and Awareness

In this section, the concept of ethical decision-making for professionals is introduced and linked to the concepts of micro, meso, and macro levels of ethical knowing and awareness. The concepts that are included in this section are: values and values clarification, ethical climates in organizations, and ethical decision-making frameworks. These concepts are critical to our understanding of how community health care professionals experience ethical problems and decision making with clients who live at risk, and also provide us with a better understanding of the levels of ethical knowing and awareness.

Starzomski and Rodney (1994) have written: “If we are going to meet the ethical challenges confronting us in our professions...we need to think about our professional roles, as they fit three levels of responsibility...the micro level, which is the level of individual professional responsibilities for patients and families under our care...the meso level, which is the level of institutional responsibilities for programs of care...[and] the macro level, which is the level of societal responsibilities for the health of the total population” (p.6). Benatar (1999) expanded on this idea by delineating her five major ethical principles that should govern health care systems (micro, meso and macro):

1. Health care is a human right.
2. The care of individuals is at the centre of health care delivery but should be viewed and practised as continuing work that generates the greatest possible health gains for populations.
3. Prevention of illness and alleviation of disabilities are included in a health care delivery system’s responsibilities.
4. Those working with the health care delivery system must cooperate with each other and with their clients.

5. Individuals and groups involved in health care have a continuing responsibility to help improve its quality.

Health care professionals, regardless of their practice setting, are not only isolated individuals attempting to provide ethical care to various client populations, including those who are living at risk. They are working within micro, meso, and macro levels of ethical knowing and awareness. Within community practice, Benatar's principles may help give direction for population-based health care reform at all levels and for all client populations. The following sections discuss these levels in more detail.

The Micro Level of Ethical Knowing – Values and Values Clarification

At the micro level, health care professionals, when experiencing distress with ethical problems, may not consistently recognize the ethical implications inherent in their practice (Chubon, 1994). Chubon's research found that nurses rarely used the term ethical dilemmas to describe their problems with their clients. In my experience, nurses often describe their problems with client situations as complex. Furthermore, although ethical knowing has been put forth as an essential component of nursing knowledge, fundamental to the development of theory (Carper, 1978, from Reed, 1989), many traditional education programs in health care fields do not adequately provide training in ethical decision-making. Research findings also stress the importance of recurrent education in ethics and availability of individualized support (Åström, Furaker, & Norberg, 1995; Cloonan, Davis, & Burnett, 1999) as well as group discussions that can help staff deal with ethical issues, and feelings of discomfort or anxiety (Olson, 1995).
Critical ethical reflection has also been described as important not only in the testing and application of ethical knowledge, but also in the conceptualization of this knowledge (Reed, p. 170). One of the first steps in this critical reflection may be the process of values clarification for professionals. Ethical problems are complicated when practitioners are unaware of their own personal values and biases, and how these may influence their decision-making process. Keatings and Smith (1998) define a value as "an ideal that has significant meaning or importance to an individual, a group, or a society" (p. 16).

Primary values are often the foundation for professional codes of ethics. All health care professionals have codes of ethics, including the C.N.A. The C.N.A. Code of Ethics (1997) defines a value as "something that is prized or held dear; something that is cared about" (p. 3). The C.N.A. code describes seven primary values that are central to ethical nursing practice: health and well-being; choice; dignity; confidentiality; fairness; accountability; and practice environments that are conducive to safe, competent, and ethical care. In addition to the values articulated in the Code, professional identity is defined as the values and beliefs that guide professional thinking, actions and interactions (Fagermoen, 1997), and the internalization of values, are fundamental to the socialization process of the health care professional (Fagermoen).

There is evidence that individual health care professionals' personal beliefs, lifestyle issues, life experiences, and values strongly influence those situations that the professional identify as ethical problems (Chubon, 1994; DeRenzo & Strauss, 1997; Greipp, 1995; Turner, Marquis, & Burman, 1996). Furthermore, Golden and Sonneborn (1998) concluded that a therapeutic relationship is not the same as other relationships; it
is first a fiduciary relationship where the practitioner is expected to be trustworthy and competent, but may have characteristics of unequal power and responsibility. By upholding values such as fairness, professionals earn and maintain the trust of those in their care. Conflict between a health care professional's personal values and professional responsibility in health care decision making practices have been noted as emerging concerns in the research literature (Turner, Marquis, & Burman). But decisions regarding care delivery should be based on professional, ethical, and moral principles rather than personal preferences (Erlen, 1998; Maupin, 1995). Is this how nurses and other health care professionals actually practice, especially with clients who are living at risk?

At a micro level, Clemens and Hayes (1997) describe counter-transference issues in staff working with older adults, such as fear of growing older or the need to be needed. These issues may lead to pitfalls such as over-compensation, paternalism, and premature termination of the therapeutic relationship (Clemens & Hayes). It has also been suggested that an equation of aging and illness constructs the elderly person, often seen as frail and at risk, as dependent (Clemens & Hayes). Furthermore, Elsner et al. (1999), as evidence of possible personal and professional values and biases, makes reference to issues in long term care and aging, and asserts that clients must be seen as human beings, not objects to be disposed of or warehoused until death. A practitioner's personal code of ethics may decide the nature and quantity of care provided. If the health care professional, for example, values independence, then he/she will more likely do things *with* a client, rather than *for* a client. (Golden & Sonneborn, 1998). These are all considerations for professionals who are working with clients who live at risk.
Values clarification is critical in any discussion of ethical decision making for all health care professionals, including those who practice in community setting. Values clarification is a process where individuals learn to understand the values they hold and the importance of such values relative to others (Keatings & Smith, 1998). The process of values clarification can also relate to the personal and organizational development of an ethical conscience or culture, and may be integrated into professional practice.

Examining one’s own biases, beliefs, and values are critical to skill development in ethical decision-making (Raines, 1993), but identification of one’s own values can be guided with education and support as part of an overall ethics curriculum. Coveney (1998) writes: “By fostering the means by which individuals (alone or collectively) become more self reflective, we can ensure more ethical practice” (p.466).

Golden and Sonneborn (1998) write: “Practitioners who comfortably and consistently explore their own personal prejudices and biases will practice more effectively” (p. 82). Yet, how do health care professionals learn constructive self-reflection, and do organizations encourage their staff to practice self-reflection?

Assessment tools are available for examination of professional and personal values, but there is a scarcity of research specific to community health care practice in values clarification and examination of bias. Abramson (cited in Golden & Sonneborn) developed a framework for self-assessment in professional values, and focused on these areas: prejudgments, character and virtue, principles, ethical theories, free will and determinism, spirituality, individuals, and community. However, I found no evidence in the literature that this type of framework had been consistently applied in health care or community practice settings. Once again, this may be an area for future research studies.
The Meso Level—Ethical Climates within Organizations

The concept of ethical climates was introduced in Chapter One. The ethical climate "may be viewed as the personality of an organization" (Olson, 1998, p. 346) and may have an impact on how decision-making occurs for all health care professionals, including community health care nurses and other professionals. At the meso level, an ethical climate within organizations can provide the context in which ethical behaviour and decision-making can occur. An organization with a positive ethical conscience makes decisions about client care through dialogue and a sense of mutual respect. Olson (1995) reported: "An organization's policies, procedures and practices for ethical issues can influence the amount of risk nurses will take in voicing their opinions about patient care issues" (p. 321). Olson (1998) continued by reiterating that how nurses and other professionals perceive their work setting can affect their attitudes about ethical issues and their role in that decision-making process. Engelhardt (1999) writes that "many institutions discover in their confrontations with bioethical quandaries their own lack of a sufficient moral basis to answer the moral questions they face...in need of a morality...that can guide the institution's behaviour" (p. 90). Macdonald (1999) concurs with: "...no dispersed organization with continuous change can survive without clearly enunciated minimum standards of values and behaviour" (p. 25); standards that ensure that ethical thinking becomes a part of the decision-making within the organizational network.

Unsupportive environments for ethical decision-making have been correlated with the presence of conflicts in home care or community health care practice (Olson, 1995). To assist in this decision-making process, there is a need for ethics committees in
community agencies to provide forums for discussions of ethical issues and to provide
opportunities for education to community health care professionals as well as formal and
informal debriefings or case conferences (Olson, 1995). Olson (1998) confirmed that little
was found in the literature about ethical climate and the need to create an ethical climate
within organizations through the development of strategies to support staff. An
organization's ethical climate may be assessed by measuring either the organizational
practices that affect how ethical decisions are made or the presence of conditions that
encourage ethical reflection (Olson, 1998). Olson's study (1998) provided evidence that a
reliable instrument to measure ethical climates in organizations and assessments of
specific types of climates within an overall health care organizational environment are
needed. Olson also demonstrated the use of an instrument within an acute care
environment which had not been trialed in a community practice setting.

At the meso level of ethical knowing, ethical decision-making frameworks for
professional practice have been readily available in the reference literature (Robbins,
1997), yet few completely address the needs of any speciality practice area such as
community health, especially when considering clients who are living at risk. This is
significant because an ethical framework introduces “a capacity and concern for ethical
inquiry into all aspects of organizational life” (Koloroutis & Thorstenson, 1999, p.16).
Furthermore, ethical decision-making grids and processes can give staff a greater sense
of safety, spontaneity, focus, and commitment to their groups. They also foster
environments of honesty and caring (Kuhl & Wilensky, 1999). Koloroutis & Thorstenson
(1999) write that development of an organizational ethical framework is the first step in
creating an ethical organization and that the most important step in the process will be the integration of such a framework into practice.

Jonsen, Winslade, and Siegler (1989) developed an ethical decision-making framework that called for data collection with four areas or quadrants: health care indicators, client preferences, quality of life, and contextual factors. Others have adapted or refined this framework in attempts to develop more effective frameworks for their own agencies, including those working in community practice (V/RHB, 1999). This ethical decision-making framework, often combined in practice with a risk assessment tool (see Appendix G), was developed, in part, for professionals who cope with clients who live at risk, and was intended to be collaborative and comprehensive. This approach encourages a more “inclusive, less clinically driven model, facilitating discussion among all parties of values and conflicts, and recommendations for actions” (Kelly et al. 1997, p. 140). It encourages community practice professionals to balance information about factors such as the client’s prognosis and level of care, the client’s wishes about where they wish to live, available family support, and capability or legal concerns. If a client wants to refuse a treatment, such as surgery, the ethical decision making framework and guidelines might ask: what is the nature of his/her decision and his/her capacity to make that particular decision, what is the harm/benefit ratio of the treatment, and who else should be involved in making the ethical decision?

The Macro Level of Ethical Knowing-Health and Social Policies

Theoretically, the macro level of ethical knowing-ie. society’s responsibility for the health of a total population- could form the foundation of population-based health care delivery, especially in community practice settings that are undergoing health care
reform. Literature related to this level of ethical knowing in community settings is only starting to emerge. While it is recognized that underlying values in our health care system have developed from the Canada Health Act, there are critical challenges for those who will develop health and social policy (Kenny, 1999). These include the development of policies related to the privatization of health care, or the redistribution of health care resources within regional health boards. However, I could find little literature in this area that is specific to community settings, and this may be a gap that future health care research should address.

In summary, the micro, meso and macro levels of ethical knowing, awareness, decision-making and support in organizational contexts must be considered by community professional staff and those attempting to advance professional practice. Yet little research appears to have been done in this area for community health professionals, especially at the meso and macro levels of community based organizations. Ethical decision-making for community health care professionals, or those ethical problems that community health professionals experience, has not attracted extensive research interest.

Summary of Chapter Two

This chapter has outlined literature findings for key concepts related to this research study, including autonomy, risk, capability, paternalism, and micro, meso, and macro levels of ethical knowing and awareness. Although many of these concepts have, for the most part, been well described in the literature, there is a noted lack of research in the area of ethical issues that address those concerns specific to the community context, especially with clients who live at risk. Furthermore, the organizational context can affect decision-making for professionals, possibly increasing distress for the health care
professional. The gaps in the research indicate a need for specific research that explores the experiences of community health care professionals, and would aim at developing supportive theory for practice implications for professional community health staff who care for clients living at risk in the community.
CHAPTER THREE-METHODOLOGY

Constructivist Methodology

A constructivist methodology was chosen as the design for this research study. This method was chosen in recognition that community health care professionals may describe their experiences with ethical decision-making processes in diverse ways, and the research should be completed within a natural setting. I have given a brief introduction to constructivist methodology in chapter 1. This chapter will detail the methodology, outline procedures used for data collection and data analysis, and clarify issues of ethics and rigor associated with the methodology in this study.

Constructivism, as a research paradigm, has a relatively short history (Appleton & King, 1997). Over the past decade, this methodology has become more accepted in qualitative research work (Guba & Lincoln, 1994). Appleton and King believe that constructivism may be emerging as a leader in research inquiry especially in the field of evaluative and consumer-oriented health care research, such as in community practice settings. Based on the original work of Lincoln and Guba (1985) in naturalistic inquiry, constructivism grew from discourse surrounding philosophical paradigms underpinning basic questions regarding the nature of research inquiry.

According to Lincoln and Guba (1985), a paradigm is a systematic set of ideas or world view—a general perspective—that guides the investigator not only in the choice of method, but in ontologically and epistemologically fundamental ways. Lincoln and Guba outline four competing paradigms of research inquiry—positivism, post-positivism, critical theory, and constructivism. According to Lincoln and Guba, all paradigms or beliefs can
be classified by a basic set of assumptions or beliefs that correspond to the responses to three philosophical questions—the axioms of the naturalistic paradigm. 7

These questions are:

1. The ontological question—what is the form and nature of the reality and therefore what is there that can be known about it?

2. The epistemological question—what is the nature of the relationship between the researcher, the participant, and what might be known about the reality?

3. The methodological question—how should the researcher gather knowledge to answer the research question? (Appleton & King, 1997).

Ontologically, realities can be obtained in the form of multiple intangibles or constructs (Guba & Lincoln, 1994). Reality is constructed, complex, and subjective (Erlandson, Harris, Skipper, & Allen, 1997; Sandelowski, Davis & Harris, 1989). Constructivism supports a relativistic ontology, a move away from ontological realism (Appleton & King, 1997; Denzin & Lincoln, 1994). Relativism has been defined as involving “the view that beliefs and principles, particularly evaluative ones, have no universal or timeless validity but are valid only for the age in which, or the social group or individual person by which, they are held” (Appleton & King, p.14).

Epistemologically, the constructivist approach involves interaction between the researcher and the participant to allow the creation of research findings during the process of the study and access to multiple forms of reality that may exist (Sandelowski, Davis, & Harris, 1989). Thus, the researcher must closely interact with study participants when accessing all possible viewpoints of this reality.

7 Lincoln & Guba (1985) actually describe five axioms with their comprehensive structure, but only three are described here.
Methodologically, the constructivist paradigm uses a hermeneutic approach. *Hermeneutics* is defined as "the art, the skill, the theory of interpretation, of understanding the significance of human actions, utterances, products, and institutions" (Appleton & King, 1997, p. 15). The use of hermeneutics ensures an in-depth understanding of any constructions. Furthermore, the hermeneutic approach searches for conflicting ideas or viewpoints and divergent thoughts. It recognizes that constructivists may not find a single explanation or reality for complex phenomena, and researchers may find that others have beliefs very different from their own. This may be especially true in a complex community setting.

Thus, in the emic perspective, this methodology allowed data collection and analysis to occur in a natural setting, such as a health care organization. It also allowed for examining behaviour—in this case, the ethical concerns and experiences of professional staff working with clients who live at risk. Inductively, explanations and patterns of professional behaviour were discovered within the cultural context of a large health care organization. These explanations are constructed as beginning theory and explain the observed relationships and processes as they emerged from the data. Constructivist research is very dependent upon context (Erlandson, Harris, Skipper, & Allen, 1997). The context—the organizational setting—would also be considered part of the phenomena.

Furthermore, constructivist methodology has been appropriate for this study because it acknowledges the relevance of personal, professional, or cultural values in shaping inquiry outcomes. Excluding the influence of values is discouraged in Lincoln and Guba’s original work (1985). As I described in chapter 2, personal values and biases
often shape ethical decision-making; therefore this aspect of inquiry may be extremely relevant. Furthermore, use of a methodology that reflects inherent values may have improved the validity of this study (Lincoln & Guba). This topic is also discussed in Chapter 5.

Constructivist inquiry, within the natural setting and using the researcher as a human instrument, includes four elements: purposive sampling (using in-depth one-on-one interviews), inductive analysis of obtained data, development of constructs and/or negotiated outcomes, and the projection of “next steps,” all encompassed within an emergent design (Lincoln & Guba, 1985). This research is characterized by “simultaneous and ongoing collection, categorization, and interpretation of data, [and] deliberate sampling of comparative groups of subjects” (Sandelowski, Davis & Harris, 1989, p. 99). These steps are outlined in the following sections.

A Framework for Constructivist Investigation

Based on Lincoln and Guba's original work, a framework for constructivist investigation is offered by Appleton and King (1997) and includes these areas: personal intuitive experience, issues of rigor, issues of ethics, access to the natural setting, researcher as instrument (“human as instrument”), tentative research design, qualitative methods and purposive sampling, inductive analysis, constant comparison analysis, interpretation of findings, and presentation of interpretation. I adapted Lincoln and Guba’s original framework (1985) to meet the needs of this study. This “flow of constructivist inquiry” is included in Appendix A. The elements of this “flow” are included in the following sections.
Personal Intuitive Experience

Experiences, interest, and knowledge as well as a personal intuitive understanding of the field of investigation should stimulate a researcher (Lincoln & Guba, 1985). I chose this research question following much discussion with others and personal attempts at critical thinking in this clinical area of ethical decision-making. I had no preconceived hypothesis to test, although I had some hunches.

My current position as a Clinical Nurse Specialist/practice consultant for community health care professionals had encouraged many discussions with front line and management staff related to the experiences of staff who care for clients who appear to live at risk, thus supporting the knowledge that this was an area that required further investigation. Additionally, ethics in health care settings has been an area of personal interest to me for many years and had become the basis of much of my current work in my work setting, thus stimulating my interest in pursuing relevant research.

Human as Instrument/Researcher as Instrument

The concept of “human as instrument” (Lincoln & Guba, 1985) was a natural fit to allow me, as the researcher, to feel responsive, sensitive, and adaptable to community health care professionals’ concerns. I believe that, as an experienced community practice consultant, I have had a unique opportunity to process data, generate hypotheses, and test hypotheses “on the spot.” Since I am knowledgeable about the setting and the nature of practice for community health care professionals, there have been opportunities to achieve deeper levels of understanding than might have been possible in a setting where I was not known, or in settings where I had not had extensive nursing experience. As a community professional, I have also experienced intense feelings of stress with ethical
decision-making, and I believe I can relate well to professional concerns and problems with ethical decision-making. However, several areas related to rigor and ethical aspects were challenging for me and I have addressed these issues later in this chapter.

**Characteristics of the Target Population**

This topic was introduced in Chapter 1. The target population group was community health care nurses and other interdisciplinary community health care professionals. For the purposes of this study, interdisciplinary community health care professionals have been defined as:

1. Registered Nurses in home care nursing (clinical services) or case management roles
2. Rehabilitation staff including physiotherapists and occupational therapists, in clinical services or case management roles
3. Social workers in clinical or case management roles
4. Nutritionists, practice consultants, managers, and other staff who are employed by the organization, and who have opportunities to participate in ethical decision making with clients who appear to live at risk

I chose to interview and examine the experiences of an interdisciplinary professional group, rather than only nurses, for several reasons. Community clients, who may have complex health and social issues, often require the expertise of several health care disciplines, and community health care professionals seldom make decisions about complex clients on their own. Furthermore, in the organization used for the study, community nurses and other professionals work in interdisciplinary neighbourhood teams. Teams are encouraged to make collaborative decisions using the experience and
expertise of all team members as well as partnering with the client, family, and significant others. The concept of “teams” became an important contextual factor in this study.

General Characteristics of Client Group

Generally, the client group was: clients who were known to the organization, are nineteen years old and over, and who were living in community settings, such as their own homes or apartments. Community health care professionals in this study frequently identified these clients as “complex” as well as living at risk. Many of these clients are elderly, have variable diagnoses, including mental health conditions, and many have multiple diagnoses, such as Alzheimer’s disease, diabetes and heart disease. However, community health care professionals also care for younger adult clients who are living with complex health conditions such as Multiple Sclerosis or quadriplegia. I will describe client characteristics mentioned in the study in more detail in Chapter 4.

Ethical Considerations

The importance of ethical concerns in research is paramount in the constructivist paradigm because participant values are included in the inquiry (Guba & Lincoln, 1994; Lincoln & Guba, 1985). Furthermore, the dialectic methods may provide strong safeguards against deception. Nevertheless, the close interactions that are required by the interviewer to obtain rich data may produce problems of voluntariness, confidentiality and anonymity. These areas are among those that must be addressed when considering ethical aspects of a study.
Participant Voluntariness, Informed Consent, Handling of Raw Data, and Ethics

Approval

Formal ethics approval was obtained from both the organization’s Office of Research Services, and the University Research Services Department. Confidentiality of all participants was protected during one-on-one interviews. Participants were informed that individual or identifying data would be deleted from all reports and would not be “reported” to management. This aspect was also important to promote trust and open communication with those professional staff recruited for interviews. Participation in the study did not affect employment status and all staff were free to withdraw from the study at any time with no penalty, or could refuse to answer some questions. I received no requests from any participant for withdrawal from this study. Some participants did not fully answer some questions but did not refuse completely.

I have discussed my role as “human as instrument/researcher as instrument” earlier in this chapter. Additionally, as a Clinical Nurse Specialist (C.N.S.) within the organization, I considered the possible effects of doing research in my own practice setting. In this organization, although I am in what is considered as a “leadership role” as a community practice consultant, no staff members report directly to me. Nevertheless, it was important to ensure that my role as a practice consultant within the organization did not create an undue influence in participant behaviour in the field, nor the appearance of uneven “power” with “insider” interviews. I needed to be extremely proactive and sensitive in ensuring that participants felt completely comfortable about volunteering to participate in this research. Otherwise, professionals may have felt vulnerable and distrustful and may have questioned possible motives that I had as a researcher. There
were no known risks for participants. No money or financial incentives was offered to participants. All participants were capable of giving their own consent to participate in the study. Yet, participants did take the opportunity to share personal and sensitive information about their experiences with ethical decision-making with their clients. I believed that I should be honest and forthright with those who volunteered. There could be no sense that they had been coerced or pressured to participate. This was achieved by specifically asking the participants if they were totally comfortable with my dual role as researcher and as a practice consultant, and by being receptive to their responses. All professionals needed to feel that they were participating completely of their own free will.

I continually examined any personal issues within this research; for example, did the participant perceive that I had power in the organizational hierarchy? Is the participant changing the descriptions of his/her experiences accordingly?

I also needed to reassure the participants that I was available at all times for their concerns about the research process itself, its results, or ethical decision-making issues. I also reminded them that they could contact the chair of my thesis committee or the University of British Columbia Research Services Department. Many of these issues were addressed in the information letter and consent form, and before and after each interview (see Appendices D and E). In addition, I have noted in Chapter 6 that issues around voluntariness may be a possible limitation of this study.

I personally transcribed all taped data obtained during the interviews. Untranscribed audio tapes were kept in a locked filing cabinet. All transcribed tapes were erased following transcription. Transcribed data will be retained for five years. The data was only intended to be used for this study. Coded data will be maintained for five years.
following the completion of the study. All data will be maintained in a secure computer file, accessible only through my password which is not given out to any other person, or in a locked filing cabinet. At the end of the five year period, all data will be destroyed.

No correct initials of participants or clients were used in transcripts. Each participant was assigned a participant number, for example, “P#4.” Clients were not identified by name in the transcript of the interview, but labeled only as, for example, “Mr. R.”, and this initial was changed when any quotations were used in written reports. The interviewer was identified as “J.”. Other individuals mentioned were also only known by their roles (for example, case manager) or by one initial. As the researcher, I intend to publish my findings in appropriate journals and/or present these findings in appropriate settings. Biographic data from the study will be removed from all journal publications to ensure confidentiality of any clients, staff, or situations that may be recognizable.

Support for Professionals When Disclosing Sensitive Information

 Earlier in this chapter, I discussed the importance of ensuring that professionals be comfortable volunteering to be interviewed in this study. I needed to anticipate that some participants might become “emotionally upset” during an interview. Although this did not actually occur, if needed, they would have been referred to support from a clinical social worker that does counseling services within the organization. I would have also followed up personally with each of these individuals to ensure that no further support was required. Should an individual have required this emotional support, only myself, the clinical social worker, and the individual would have known the names of the individual and what had led to the need for professional counseling. The individual and the social
worker would only have known details regarding the actual support. My plan also considered that the findings of the study would only reflect the numbers of those who required follow-up and a general comment regarding reasons for the follow-up, with no other identifying data.

Furthermore, if at any point during the interview a participant had described client care or client situations that may not necessarily be within professional standards of practice, I planned to discuss the issues with my faculty advisor, ensuring that the participant’s identity was protected. If the participant had requested additional assistance with his/her experiences with ethical decision-making issues, I would have offered the professional an opportunity to review his/her practice with a practice consultant (other than myself). This review would have been offered following the interview (i.e. outside of the research process) and no results of this practice review would be reported in the final results of the study or to the management of the organization. The individual would not have been forced to participate in this practice review. However, no situations of this type arose during the study.

Reflexivity and Controlling Bias

The impact of “human as instrument/researcher as instrument” has been described earlier in this chapter. Further discussion related to issues of rigor follows later in this chapter, but specific aspects must be addressed when considering access of researcher and use of the researcher as an instrument of the research. As a C.N.S./practice consultant, primarily working with staff in certain areas of the organization, it was important that this role not interfere with unbiased data collection. The constructivist paradigm allowed me, as a researcher attempting to obtain worthwhile data, to closely interact with the
participants and the data. It was not required that I totally set aside my “practice consultant” role during interviews. Yet, to obtain rich data, the participants needed to feel that they could be honest and reflective. They could not be made to feel they were under examination. Furthermore, a perceived status position of a researcher can affect reliability, and over-familiarity with staff could have been a concern related to validity (Jorgenson, 1989; Morse, 1998). I needed to continue to be clear with staff about my researcher role and ensure that a balance of these two conflicts was achieved. These issues could have been a challenge, and I needed to continually monitor my own participation in the interview to ensure that I was not being biased.

This was not always easy, and, at times, I could feel as if I wanted to “slip back” into my C.N.S. role and give the participant guidance or support in his/her ethical decision-making or problem solving. During one interview, a participant spoke about her needs for support at her site and her concerns regarding the lack of support for decision-making with her clients. During the interview process, I tried to ensure that I maintained my researcher role. However, following the interview and once the tape had been turned off, she continued to stay to talk to me. I coped with this situation by clearly stating to her that, at this point, I was no longer in my researcher role, but would resume my C. N. S. role to discuss her concerns. I informed her that none of the remainder of our conversation would be included in my field notes. She stated that she was very comfortable with this approach, and this situation was discussed with two of my faculty advisors.

Concerns in this area were also addressed by primarily doing data collection with community professional staff in community health areas other than neighbourhoods.
where the majority of my practice was. Nevertheless, I attempted to ensure that the sampling reflected demographics of the populations served by the organization. When professionals who had not been given information letters, but had heard about my study, approached me from areas where I practice (one from each site), and volunteered for the study, I did agree to interview them. I felt I was able to remain non-biased throughout these interviews.

Bias is a reality for all researchers, but a researcher must continually be aware of personal bias and how his/her thinking might influence or be influenced by others. Researchers must attempt to ensure that their own assumptions not shape the data collection process (Ahern, 1999). The use of reflexivity is one method of controlling bias. It was important that I acknowledged the importance of reflexivity in this study because I was doing research within my own practice setting and needed to be careful to ensure confidentiality, trust, voluntariness, and lack of bias. My personal or professional biases also needed to be acknowledged clearly and honestly to ensure that trust was maintained. It was extremely important that I attempted to set aside any preconceived ideas or personal assumptions—for example, an assumption that all health care professionals value autonomy—to maintain critical objectivity and neutrality during participant observation. Personal journaling done during the research process encouraged critical reflection and enabled me to review any biases or assumptions that may emerge during the study.

Bracketing is one means of demonstrating the validity of the data collection and analytic processes (Ahern, 1999) and was used to control any possible researcher bias, especially associated with my dual role as practice consultant and researcher in the community practice setting. Reflexivity, (Hammersley & Atkinson, 1995) or objectivity,
can be difficult to maintain and bias must be clarified. Such reflexivity was enhanced by those recommendations outlined by Ahern. Reflexive bracketing is a means of demonstrating the validity of the data collection and analytic processes and may be useful for facilitating the process of data collection (Ahern). Preconceived ideas or assumptions must be “bracketed” to maintain critical objectivity and neutrality. Bias can also be controlled when all sides of an issue are represented, thus this type of “sharing” will be encouraged during interviews. I have described examples of how I bracketed my biases in Chapter 6. These are especially related to bracketing my own personal beliefs about autonomy and organizational support within ethical climates.

Data Collection and Analysis Procedures

Qualitative methods of data collection are critically important in constructivist inquiry (Appleton & King, 1997). In constructivist theory, data collection, sampling, and analysis occur simultaneously (Sandelowski, Davis, & Harris, 1989). Analysis also continues once the data collection is completed. Concurrent and ongoing analysis enables the researcher to interact closely with the data and encourages creative interpretations.

Morse (1991) reminds us that the methods used to select the sample must facilitate understanding of the subject. Purposive sampling, a non-probability sampling technique commonly used in qualitative research, directs the researcher to recruit those individuals who can articulate their experiences. Purposive sampling allows for typical and divergent data collection to discover the variety of constructs that may exist. In this study, potential participants from the target group of community health care professionals were asked to volunteer for interviews. Subsequent sections in this chapter expand on specific sampling methods used in the research study.
Maximum variation in purposive sampling requires a sufficient sample size to reach theoretical saturation since inadequate sample sizes can undermine the credibility of research findings (Sandelowski, 1995). Once theoretical saturation appears close, the type of information still required guides further sampling. Emerging theory determines ongoing selection of participants, and “thin areas” of data need more selective sampling. Informational adequacy is important in qualitative research sampling. The researcher must always consider what is needed in the development of theory, and therefore it would be difficult to predict the number of subjects required in this study (Morse, 1991). However, Morse (1991) also recommends approximately six participants for studies that plan to discern “the essence of experiences” (p. 182.)

**Recruiting Participants for Data Collection**

As described earlier in this chapter, the target population was interdisciplinary community professionals. Using purposive or theoretical sampling to obtain “good informants,” information letters (see Appendix D) were sent out to professional staff at several sites in the region, asking for volunteers to call me or e-mail me if they were interested in participating in the project. No telephone recruiting was used.

I anticipated that six to eight one-on-one interviews would be required, subject to the evolving needs of the study. I had hoped to sample a ratio of 60% of nurses and 40% of other professionals within the organization to ensure appropriate sampling. The final sample ratio was slightly less than 60% of nurses. Only non-professionals and those not employed by the organization were excluded. Demographic characteristics of the participants are included in Chapter 4.
As the researcher with a variety of contacts within the organization I did not anticipate major problems with access to participants for interviewing. I was proactive, flexible, and responsive to participants' needs as I moved the research forward in a meaningful way. I knew, for example, that I must be sensitive to the high workload demands that staff were facing, and I planned interviews at times that were convenient to them. Additionally, I maintained a non-judgmental attitude and a communication of respect.

Theoretical richness was achieved by including those experiences that were uncommon or exceptional as suggested by Morse (1991). Obtaining such experiences by seeking volunteers, recruited from the target population, who had had alternative experiences, was anticipated. Purposive sampling added to the study’s validity, for example, when I questioned participants specifically around aspects of an element of decision-making called “letting go”. This data indicated another dimension or insight to the emerging constructs, allowed presentation of all sides and experiences of the issue, even if saturation appeared to have been achieved. I also found that I had a better understanding of the scope of the feelings that the professionals described when I ensured further sampling and listened to my intuition.

**Interviews and Interview Questions**

In an interview, the researcher must initiate conversation in a respectful way to generate themes—an initial probing of concerns through “use of open questions that invite reflection” (Labonte & Robertson, 1996, p. 442). One-on-one semi-structured interviews allowed me to obtain objective, validated data and “to reveal the meanings (realities) people use to make sense of their daily lives” (Jorgensen, 1989, p.15). Since the intent of
the constructivist paradigm is to develop theory, the initial/opening interview questions for one-on-one interviews were broad and non-specific. As such, one possible opening question was, “Tell me about your experiences working in the community with clients living at risk”. The interviews occurred in a variety of locations—generally wherever the participant requested the interview to occur—and included meeting rooms at health centres as well as local parks or sports facilities. All interviews were tape-recorded. Each interview lasted 45 minutes to one and one half-hours.

As theoretical needs changed, and as categories, themes and constructs emerged, the focus of the interviews—and therefore, the target questions used in the interviews—also needed to be adjusted. The actual questions were guided by the needs that unfolded during the interview process, but the focus continued to be related to the ethical problems with clients who appear to live at risk. One example of a change in focus was demonstrated when I asked an inexperienced home care nurse to compare her experiences with ethical problems in both the hospital and the community. Interview questions are outlined in Appendices C, D, and F. I frequently accessed appropriate literature to build on developing constructs, and incorporated this literature as necessary into the interview process. One example of this was when I examined possible specific support elements for collaborative and interdisciplinary practice.

**Data Analysis**

*Data analysis* is “not a matter of data reduction, but...of induction” (Lincoln & Guba, 1985, p. 333). Lincoln and Guba have clearly outlined an analytic process, similar to ethnographic inquiry, using the dimensions of deduction/induction, generation-verification, construction-enumeration, and subjective-objective.
Data collection and data analysis have been concurrent operations in this study (Lincoln & Guba, 1985). The constructivist approaches to data analysis reflect the methods that are similar to those of grounded theory. The purpose of grounded theory is to generate explanatory theories of human behaviour (Morse & Field, 1995). Generating grounded theory requires what Glaser (1978) calls “theoretical sensitivity”—a quality that combines interpersonal perceptiveness with conceptual thinking. For the purpose of this study, the development of themes and constructs described the experiences and concerns of community health care professionals involved in ethical decision-making with clients living at risk. This process of construct development is congruent with constructivist inquiry. Chapter 4 outlines the results of this study as they unfolded throughout the process, including emerging themes and constructs, and, finally, key findings of the study.

More specifically, a dialectic process, similar to constant comparison, was used through coding, unitizing, categorization, memos etc. (Swanson, 1986). The dialectic process encourages the inquirer to clarify his/her understanding of what has been said and explore alternative explanations from the participants. In addition, dialectics can influence the sampling procedure when ensuring that alternate views are sought (Appleton & King, 1997). This aspect is illustrated in the following sections.

Starting the process of data collection and analysis— the first interview.

Sample trigger questions for the interviews are included in Appendix B and were developed prior to the first interview. It was expected that the questions would change as needed throughout the first interview, and certainly for subsequent interviews. In the first interview, the participant, a home care nurse, was initially asked “Tell me generally about your experiences when you work with clients that seem to be living at risk”.

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The first step in the process of data analysis was the task of unitizing—essentially “pulling out chunks of meaning” from the data (Lincoln & Guba, 1985). Yet, these units needed to have the following characteristics: the units should be heuristic, i.e., aimed at some understanding that the researcher needs to have, and the units should be the smallest piece of information that can stand alone and be interpretable without any additional information to support it. While I coded/unitized the data, obtained from one interview’s transcript, I continually compared it with previous units or categories and previous events from the transcripts of other interviews. This process continued throughout all the interviews.

Memo development guides the analysis and helps depict relationships between categories that emerge from the data (Lincoln & Guba, 1985). In this study, following the transcription of the first interview and a review of field notes, the complete transcript was read in its entirety. Then, as the starting point, the data were examined by scanning the transcript for codes, units or “chunks of meaning”. Possible codes, units or chunks were then noted on the margin of the transcripts or highlighted/bolded on the computerized transcripts. These chunks were then transferred and/or recorded on index cards or “post-it notes”. The index cards/notes also included the source of the data. One example of a code extracted from a transcribed sentence in the first interview stated: “frustration with the system”. Another extracted code stated: “fear for the client”. Confidentiality during the coding process was maintained by numbering the index cards or notes by participant number, for example, for interview/participant number 1, the card was labeled as P1, and matched the participant number on the transcripts.
The second step was the development of categories. Categories and their properties are conceptual codes depicting the essential relationship between data and theory (Swanson, 1986). The categories are building blocks of theory developed from initial data coding activities. Theoretical codes allow the researcher to organize the categories. Categories generated from grounded theory are reported in research findings, possibly outlining initial substantive categories, in order to identify a basic process, or multiple processes.

The essential tasks of categorizing are to gather the units/index cards together into tentative categories that relate to the content. The guiding principle for this operation is based on constant comparison. Lincoln and Guba (1985) outline specific methods for the categorization steps involved (pp. 347-351). Essentially, the most important step of categorization is to bring index cards together, then separate them into tentative categories. Each index card would be read and categorized. Once all cards have been separated, the entire category set should be reviewed, checking for miscellaneous categories, overlap, etc., then examined for all possible relationships between the categories. This process was used for data analysis in this research. At the conclusion of the categorization process, Lincoln and Guba recommend that the researcher take their "reconstructions" back to the respondents, an opportunity for a member check for trustworthiness.

At this early stage of data collection and analysis, this step involved a search for very preliminary categories. The index cards from the first interview were brought together to look for possible relationships. Each note was closely scrutinized on its own. Following examination of a few notes, it was apparent that many could be grouped
together or had possible relationships. Once I had completely reviewed all of the coded
notes and units from P#1’s transcript, and had several piles of related codes, I then
tentatively decided on names for these categories. A few notes could not be categorized
and were grouped together and labeled as “miscellaneous”. I then reviewed each of the
notes again to ensure that I had not missed anything and was careful to watch for any
possible additional categories or relationships that I might have missed. I then moved on
to consider what I needed to take forward to the second interview, searching for more
information to either substantiate or possibly refute each tentative category.

Second and third interview- coding, unitizing and categorization.

A similar question was used to open interviews #2 and #3- “Tell me generally
about your experiences when you work with clients that seem to be living at risk”. The
second participant’s health care background was occupational therapy, and the third
participant was a social worker. The data from each interview’s transcript was again
reviewed for codes, units, or “chunks of meaning”, and subsequently highlighted/bolded
on the transcript and transferred to an index card or post-it note, continuing the process of
memo development. For example, when Participant #2 was asked about feelings of guilt,
she replied, “Guilt would be if you should do something and you don’t do it”. The code
for this was left as the complete thought, an expression of a feeling experienced during
the process of making ethical decisions with her clients. Although I carefully reviewed
the categories that had been identified following the first interview, I felt comfortable
taking the same categories forward to the third interview.
Fourth, fifth, sixth and seventh interview- coding, unitizing and categorization.

As other interviews followed, these broad categories were reviewed, modified and refined. I continually searched for patterns and relationships between the categories. Could categories be merged together, for example, the two categories of “feelings” and “what caused these feelings?” If they were merged together, was something important lost? I decided to keep them separate to maintain clarity of concepts.

Information was sought to fill in gaps and strengthen the connections between any patterns. For example, I also asked myself, did the community health care professionals need support concurrently with their feelings, to actually be able to make the ethical decision? What supported them to actually make a decision? Or did they always actually make a decision? When did they not make the decision and why? Should the categories related to those things that help them deal with their “feelings” and/or help them make the decision, currently two separate categories, be merged together in to one category? Some of these questions could not be completely answered. I needed to recognize that some of these questions were beyond the scope of what this inquiry could do and may be part of a future research project.

A concept related to “knowing the community” or “understanding the community” had emerged as part of what might be supportive to staff. On reviewing transcript codes and data I noted that Participant #2 had mentioned this concept, so, in a follow up interview, late in the interview process, she was specifically asked about what this process might mean to her. I was curious to find out whether this might impact on how community health care professionals might make decisions with clients living at risk. Participant #7 was also specifically asked about this “process of decision-making”.
Participant #4 had talked about “letting go” as part of her coping strategies for dealing with her feelings and making an ethical decision. She was asked during her initial interview to further explain what she meant by “letting go”. Participant #7 was asked about the contextual aspects of interdisciplinary teams and how these teams might best be supported with ethical decision-making problems.

Use of Negative Cases

Data analysis directs inquiry. Thus, subsequent needs of the study directed the questions that I needed to ask as the interviews progressed (Morse, 1991). Following the fourth interview, I began to search for negative cases. For example, following opening questions to build on themes and categories that were emerging, I asked “I have not had anyone say that they do not experience some kind of feelings during ethical decision making with clients who are living at risk. Are there times when you do not have some strong feelings, such as guilt or anxiety, or is this something that you have experienced?

A consideration of purposive sampling, I also wanted to ensure that a “male perspective” was obtained. A male volunteer participant (social worker) provided an opportunity to obtain alternative thoughts. I also specifically searched for a less experienced community health nurse (home care nurse) volunteer to ensure that I had explored a wide range of experiences, expertise, and backgrounds and obtained “thick description”. When the feelings experienced all appeared to be “bad” or “negative” feelings, I asked participants in the last few interviews when they had “good” feelings about the decision-making process or their decisions. What did that feel like and when did that occur?
Use of Journaling and Field Notes

I had started journaling very early in my research experience, while I was still writing my research proposal and early chapters. Because I was actually working as a C.N.S. in the community practice setting, I felt it was important to note any hunches and any intuitive feelings that I had during this time prior to the actual study itself. I also recognized that because I worked closely with community health care professionals, I would need to find ways to face my own biases and assumptions, ensure that I bracketed these biases, and did not allow these to interfere with rigorous research (Ahern, 1999). I was concerned, for example, that I had a high “threshold” for risk situations and that this might somehow be conveyed to participants during the interviews. A field work journal, where I could reflect on my own biases experienced during the data collection and analysis process, worked well.

I also utilized the journaling method as an analytic journal that helped with my analysis and interpretation of the experiences of the community health care professionals as participants. As I collected data, I could use the journal to help analyze data, explore tentative categories, and construct possible themes that seem to be emerging from the data. The journal created a vehicle for creative reflection as I immersed myself in the data. The journal also provided me with an opportunity to record any feelings that I personally had throughout the process, for example, what challenges did I face and what anxieties did I experience? Any field notes from interviews were handled in the same way as the transcript data. The field note was examined for possible codes or units. For example, if my field notes indicated “a lack of resources was a cause for anxiety” or “came back again to topic of resources”, I identified that there might be a cause and effect
linkage between resources and professional anxiety, and ensured that this was noted in my category development.

**Constructs and Themes**

Categories and themes were continually formulated and reviewed throughout the process. If a possible theme or hypothesis could not be supported by the data, it was not completely discarded, but was reviewed again at the end of data analysis and placed in a category that could be considered for future research. When it appeared that I was close to stopping data collection, I reviewed all data to ensure inclusion. Subsequently, I planned that any final interviews would specifically target areas that were “thin”, or needed more substantiation or validation. During the last two interviews, all categories, themes and constructs were reviewed and modified, and relationships were more firmly refined and defined. Selective literature was once again reviewed and incorporated to support the development of these constructs.

Descriptions about specific aspects of a process of ethical decision-making and “knowing the community” appeared to be important so I interviewed Participant 2 again and specifically asked the following questions:

1. Can you explain what you mean by “understanding or knowing the community”?
2. Does “understanding/knowing the community help us deal with the ethical problems we face with clients who are living at risk.
3. A process for decision-making- what would that look like to you? What are the major elements in this process?
4. Are there times when staff don’t make an ethical decision with clients? Why?
5. I have heard a lot about “bad feelings” for people with their ethical problems?

But are there any good feelings?

The results of this interview helped in planning for the questions that were used in the last two interviews. These questions are found in Appendix F.

Stopping Data Collection and Interview Process

Knowing when to stop data collection and processing was a difficult decision for me. I had planned to complete no less than six interviews and possibly a maximum of ten interviews. After the eighth interview, including a second interview to Participant #2, it appeared that no new themes were emerging from the descriptions of the participants. Similar to grounded theory principles of analysis, I believed that sources of information were not exhausted, but regular patterns had occurred. As Lincoln & Guba (1985) describe, I felt I had witnessed “an emergence of regularities” (p.350), especially over the last few interviews. I did not experience “overextension”, nor did I sense that new information that I had been finding in the last interviews was far removed from the core of viable categories that had emerged (p. 350). Yet, I recognized that, within the limitations of what I could legitimately complete within the confines of my original research question, I believed that, at this point, I should stop one on one interviews.

I had been careful to face a personal concern that I would be pulled into “first impressions” (Lincoln & Guba, p. 354), and, therefore, I reviewed the data frequently. I was also careful not to devalue anything where I might have missing information, for example, a decision-making strategy, “having a process”, a concept that I had initially heard, but not understood completely, and had not followed up on immediately. To complete my data analysis, I once again reviewed all transcripts, all codes and memos,
and all tentative categories and constructs/themes to ensure that I had not missed anything significant.

Ensuring Rigor and Presentation of Findings

Aspects of rigor related to reflexivity have been outlined in this chapter. Rigor, in any research, is required to ensure meaningfulness and trustworthiness of the study's results. I will discuss more specific aspects of rigor for this study in Chapter 6. Morse and Field (1995) describe Lincoln and Guba's four aspects of trustworthiness in research: truth value (or credibility), applicability, consistency, and neutrality (or confirmability). These aspects of rigor are relevant for constructivist methodology and warranted consideration throughout the study. Leininger (1994) warns that adequate time in the field is required to ensure credibility. A holistic approach to data, i.e. the use of actions, events, communication, and other contextual factors can lead to saturation with emerging relevant theory.

Purposive sampling has been used to expand emerging theory and ensures the quality of resulting theory and improved reliability and validity (Morse, 1991) as it relates to the appropriateness and adequacy of the sample. Appropriateness is "the degree to which the choice of the informants and methods of selection fits the purpose of the study as is determined by the research question...Adequacy...to the sufficiency and quality of the data" (Morse, p. 154). For example, in this study, when one participant faced a particularly upsetting ethical problem, the intensity and focus of questioning and data collection changed or increased to expand developing theory. I also ensured adequacy of the data by adding a male participant.
The use of negative cases, as a special sampling strategy, has been discussed earlier in this chapter and contributed to this study by ensuring a good scope or range of experiences or understanding of the experiences. Each of these strategies consider “theoretical richness” (Morse, 1991, p.139) aiding the thick description that could target any “thin areas” and deliberately adding more information to this topic. Triangulation of data collection methods, that is, use of interviews, memoing, etc. has also been useful in this area. Furthermore, thick description assists generalizibility/trustworthiness. Transparency of data in analysis may need particular attention in reduction of possible bias; an auditable decision trail must be maintained, including use of reflexive journals (Lincoln & Guba, 1985).

Morse (1998) emphasizes: “In qualitative research, both the factual and interpretive content are not verified at the end of the study...the content is verified step by step, piece by piece, during the research process” (p.444). The nature of constructivist methodology allows the researcher to validate any emerging themes with all participants as data is collected—“the interpretation of the study findings occurs through the researcher’s familiarity with the data” (Appleton & King, 1997, p.20). Simultaneously, qualitative interpretations are created or constructed; a working interpretation of the researcher’s results. Appleton and King recommend that the results of a study are presented to individuals or groups of individuals in similar contextual situations. “The concept of generalizability is altered to that of transferability in which the burden rests on the [researcher] who seeks to make an application of the findings to [other] contextual situations” (Appleton & King, 1997, p. 21). Within this study’s limitations, testing and
validation of emerging themes and constructs occurred by purposive/theoretical sampling and questioning, and seeking of negative cases, as the interviews proceeded.

One of the principles of constructivist inquiry ensures that the findings will have no surprises since all content aspects have been reviewed by participants and have included “negotiated outcomes.” Member checking is a process related to the validation of constructions (Lincoln & Guba, 1985). According to Lincoln and Guba, the member check is the most crucial technique for establishing credibility; a “reasonably valid way to establish the meaningfulness of the findings and interpretations” (p. 315). I completed the “trustworthiness” technique of member check by taking the constructs and themes back to three of the participants, working within the concept of “negotiated outcomes”. All constructs seemed to be valid and acceptable to the participants of the last three interviews. These participants responded very positively to the constructs that I had developed, and did not disagree with any of them.

Dissemination

Complete research findings will be written and presented to various groups within the organization (via focus groups, case conferences, and education sessions), management, regional ethics committees and quality improvement and education committees. Recommendations to certain groups, such as those in management/leadership positions, and field staff, have been included in Chapter six. Implications for professional practice, education, and support, and future research direction are the cornerstones of these reports. I will request that I have an opportunity to present my recommendations in person to the management of appropriate programs. As
mentioned, I also intend to publish findings in appropriate health care journals, and will also include the findings of this study in other conference presentations as appropriate.

**Summary of Chapter Three**

Constructivist methodology had been chosen as an appropriate methodology for examining the research question. Examining the experiences and concerns of community health care professionals in ethical decision-making processes with clients who live at risk required a methodology that allowed the emergence of theory from the data, rather than an examination of a hypothesis. This methodology, utilizing a framework called the "flow of constructivist inquiry" ensured purposive sampling, informational adequacy, and theoretical richness through concurrent data collection and analysis. To obtain credible results that give direction for health care practice, careful consideration was given to ensure that the research process was confidential, non-biased, and ethical.

In constructivism, "truth is not absolute or immutable, but...understood as the best informed and most sophisticated truth we might construct at any given moment" (Labonte & Robertson, 1996, p. 434-435). The single most important element in constructing a research design is the consistency of the method with the research questions being asked (Dreher, 1994). I believe that there is more than one reality for community health care professionals who make ethical decisions with clients who appear to live at risk, therefore more than one way of understanding and explaining their experiences was needed in this study. I believe that this methodology has been appropriate for the research question and has given me an opportunity to capture the breadth and scope of these many realities.
CHAPTER FOUR- "BALANCING OUR EMOTIONS AND STRUGGLING TO COPE WITH CLIENTS WHO LIVE AT RISK"

Powerful descriptions of the emotions and concerns of community health care professionals who work with clients who live at risk formed the basis for findings in this study. In Chapter 3, I have described constructivist methodology, including the application and methods for this study, in Chapter 3. This chapter summarizes, as "constructed meanings", those experiences described by community health care professionals engaged in ethical decision making with clients who live at risk. Major themes and constructs were developed throughout the research process, emerging from my observations and interviews. Constructivist data collection and analysis methods allowed me to purposively build on any categories that were emerging from the participants’ descriptions. From these categories, I could then identify those themes that were my interpretations of the participants’ descriptions. This chapter specifically discusses the following:

- Overview of research and descriptions of participants
- Theme #1- "Our clients who are living at risk."
- Theme #2- "Worrying about our clients."
- Theme #3- "Finding a better way- how we cope."
- Theme #4- "Frustrated by the system- hitting the brick wall."

Overview of Research and Descriptions of Participants

The primary goal of this study was to explore the experiences and concerns of community health care nurses and other professionals who participate in ethical decision-making with clients who live at risk. Eight one-on-one interviews were completed with
seven community health care professionals. One participant was interviewed twice. All participants were professional staff who, at the time of the interviews, were employees of the organization. Four of these participants were Registered Nurses, two were social workers, and one was an occupational therapist. Six of the participants were female and one was male. Three worked as home care nurses, two were involved in case management, and the others were involved in other professional support or direct client care roles. The average number of years of experience in health care practice for each participant was slightly over 18 years, and the average number of years in community practice was approximately ten years. The range of years of experience in community practice for these participants was from one year to 25 years. The median number of years in community practice was six years.

<table>
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<tr>
<th>Participant #</th>
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<td>P6</td>
<td>R.N.</td>
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<tr>
<td>P7</td>
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Average number of years in discipline: 18 years
Average number of years in community practice: 10 years
Median number of years in community practice: 6 years
Range of years in discipline: 7-31 years
Range of years in community practice: 1-25 years

*Please note: Specific information about the participant such as years in discipline, years in current position, years in community, or their current position or role has not been included to ensure confidentiality of the participant. Participant #2 was interviewed twice. All participants are quoted throughout this chapter, but specific participant information is not included with the quote to ensure confidentiality.
Introduction to Themes and Constructs

The following sections describe the main themes induced from the data as outlined at the beginning of this chapter. The themes were induced from what the community health care professionals described to me during their interviews about their experiences with ethical decision-making and clients who live at risk. A summary of these themes is provided in Table two, and is found on page 101.

Theme #1- "Our Clients Who are Living at Risk"

Participants told me many stories about the risk situations they encountered with their clients and how they felt about these experiences. These stories are significant because they describe the complexity of client situations encountered. The stories also reflect some of the professional’s emotions, including anxiety, about their clients. While all of these stories described clients who live at risk, some participants also described these clients as “overwhelming” or “having a lot of issues”. The participants also occasionally described a sense of discomfort with clients who live at risk, by saying, for example, “I’ve tried to realize that this is the way it’s going to be with her—it has to be—or else you could drive yourself nuts.”

To illustrate some of the complexity of the clients that community health care professionals encounter, I have included four examples based on the actual clients that were described to me by some participants of the study. Some information has been changed to protect the client’s identity. The situations include elements of cognitive or capability concerns or concerns regarding the client’s safety in basic activities of daily living, such as cooking. The following example shows the complexities of community clients often living with profound physical disabilities, limited family support, behaviour
and cognitive or decision-making problems, leading to multiple areas that the professional must deal with.

"This is a lady who is in her 50's with a progressive and severe M.S....she has a cat...and a family that's not really helpful...she has become more debilitated and less independent...falling all the time...with a considerable amount of dementia. We were all waiting for bones to break and...her behaviour was so bizarre...yelling and swearing...the caregivers wouldn't want to be near her or would have to leave..."

Often elderly, these clients were living in what appeared to be less than ideal situations. Community health professionals were often trying to balance the care needs of more than one individual in the home, each of whom may have exhibited significant, yet different, risk factors. One participant described the following:

"I received a call from the family physician (about) a 80 year old woman at home...she had been the primary caregiver for her mentally disabled daughter, and the G.P. found the older woman in absolutely deplorable circumstances. She had been the decision-maker...and now she was unable to look after herself...ill with pneumonia...incontinent."

Family situations, such as abuse, often contributed to the concerns for the participants. They described, for example, fears that the client may die before he agrees to get help. This third story came from an experienced nurse case manager:

"Mr. J. was in his early 70’s, living with his son who was a drug user...stealing his money, leaving needles in the chairs for the home support worker to clean up, left a gun on top of the refrigerator, a biker gang guy...Everyone begged Mr. J. to go into care, his daughter, his lawyer, and he refused. Until the son beat him up...bashed him with a telephone, then he went into care..."

Concerns for the safety of the client were often related to his/her ability to care for himself/herself or the client’s physical safety. However, concerns about another person’s safety were also a challenge in these situations. A fourth story was told in these words:

"She’s 96...completely unsafe...not wanting to leave...she has the control...no one to say she should move out of her home...her son is elderly too...on Sunday..."
when she doesn't get home support, she took three Digoxin. Her toast was stuck in the toaster and the fire alarm was going off... she didn't hear it..."

Community health care professionals work with these types of complex client situations every day, attempting to make decisions related to care needs and service provision. According to the participants, their clients exhibit a variety of characteristics, all of which contribute to the picture of clients who appear to live at risk. In other situations, families are involved in the context of the client’s life in varying ways, perhaps adding to the client's risk as might be found in abuse situations. Some clients refuse help from professionals or home support agencies. The following theme discusses the feelings experienced by these participants when working with these types of client situations.

Theme #2- "Worrying about Our Clients"

Anxiety

The participants described many emotions that they experienced when they spoke about their clients’ situations. Without exception, all participants who were interviewed described a feeling of anxiety when making ethical decisions with clients who are living at risk. Participants described some of their emotions in these ways:

“I hope I’m making a good decision...critical thinking...hope it doesn’t cause a crisis... I’m a little more anxious coming from a hospital background...I had so much more control...in our hospital. I feel I don’t have as much control.”

“Some people seem to deal better than me with these things...they don’t get as upset...I didn’t sleep very well...”

Anxiety often appeared to be related to questions such as “I might make things worse.”, “Do I have the skills and abilities?”, “What if I am wrong?”, “Can I cope?” and "Will I have to pick up the pieces?". Another participant commented: "There’s a lot
of emotion...you’re not focused when you’re anxious”. One participant’s description of her anxiety was:

“Because it’s really complicated and it’s got a lot of people involved, and it’s not a usual one. Am I going to screw this up?...if you can believe...yes, I can cope with this...it might not be perfect in the end...I have the skills...”

Anxiety increased with the perception that the participants did not have “the same control” in community settings as they had in hospital settings, and that this was “different from the hospital”.

Participants became anxious when they heard their “own clinical intuition” and believed that “this is a bad situation”. They said that they became more anxious if they believed their own presence or interventions actually increased the risk to their clients by “upsetting a fragile balance or equilibrium”. One participant was concerned that, for example, her own actions of questioning a client about her bruises, in a suspected elder abuse situation, might escalate the family’s violence.

Participants often felt that their anxiety about their clients or the client situations was increased by other people. They experienced anxiety related to perceived pressure from their team, those in management/leadership roles, or the client’s family or doctor. They talked about different perspectives and different values in the team members, for example, related to the client’s potential for risk outcomes, believing that this also increased their anxiety.

What are some of the common characteristics that the participants saw in their clients who appeared to live at risk; characteristics that increased their feelings of anxiety? A major source of anxiety was related to the participants' perceptions that many clients do not appreciate the level of the risk that they live with. When the client’s
actions, inactions, or risks sometimes put themselves or others at risk, the participants
described their clients as "not understanding their risks". Client situations were
sometimes described as “high risk”, for example, in certain situations:

“He has oxygen, he has a concentrator, he smokes, there was a fire concern...he’d
had a fire on his kitchen table...so I struggle with, what then is my intervention? I
have to realize that the oxygen may be pulled, and how will that affect him?”

The participants often described their anxiety when they felt that the client had
“too many risks”, and when they left a client alone in situation that did not seem safe:

“We’re not doing our job properly. If her house started a fire (next door) then I
would feel completely terrible because I knew that she was living at risk, so then
you have lots on your shoulders.”

Without exception, all participants mentioned the presence of questionable client
capability or cognitive issues as a client characteristic that increased their anxiety. This
appeared to be the most significant client characteristic that participants described when
they spoke about their anxiety. Sometimes they were not sure if the client had “capability
problems” or was not able to make some decisions, for example, about living alone or
refusing treatments. Furthermore, some participants stated they did not understand
applicable legislation related to capability or specific definitions of capability found
within the Adult Guardianship Act (A.G.A.) or the Mental Health Act. They believed that
were less able to cope with problems and felt more anxious with their clients because they
did not understand these acts. Participants described their marked lack of knowledge
regarding specific definitions of capability, the impact of capability on informed consent,
and the actual impact of capability decisions on the outcomes of "poor client decisions".
Participants appeared to be confused by the different definitions of capability or
competency and often mixed these definitions up with legislation from different sources,
such as mixing mental health definitions of when a person could be committed to a psychiatric facility with when a client could not make health care decisions, or when a client might be protected under the A.G.A. The participants often described their lack of experience in this area, especially related to an ability to cope with clients who were described as in the “grey area”:

"Some clients are in the grey area. They didn’t become incapable just like that!"

Participants spoke about a sense of anxiety about accepting the risks and feeling unsure of “which way to go”. When the client who was living at risk did not seem to be making "good decisions", participants tried to use various legislative acts to support their need to provide interventions for the clients; for example, the Mental Health Act was mentioned by five participants, and the A.G.A. was also mentioned five times.

One participant described her thoughts on how this anxiety about the client's capability affected her decision-making, and the decision-making of others:

"With capability...people confuse...they don’t think it through that even if the client isn’t capable how would that change the decision I would make...just because this client is not capable, I’m not going to pick them up and forcibly stick them in a taxi and send them to a facility!"

This participant voiced the ambivalent feelings that some professionals feel around issues of client capability, and how these professionals might experience this feeling of ambivalence when decision-making with clients who are living at risk.

Other Emotions Associated with Anxiety

Other emotions, including anger, were also described. The participants described anger when dealing with clients who were seen as "manipulative", “difficult”,

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8 The A.G.A. is described in Chapter 5.
“noncompliant”, or “clients we don’t like”. Participants told me about their anger at the client’s choices: “I feel a bit angry that they want to live that way”.

They also described fear combined with the emotion of anxiety. One nurse case manager described her emotions when a client had refused to go to hospital:

“My big fear was that this man would be sitting...this mentally disabled man, would be sitting with a dead body...I didn’t know if he had eaten...no family contact or friends...this could turn out to be such a crisis...a disaster.”

The participants told me about a fear that they associated with their lack of experience with clients who live at risk, and that they would “be picking up the pieces”, or:

“Fear only in the sense that things might go dramatically awry and you may make things much worse for the client inadvertently.”

Some described a type of fear and anxiety arising from professional liability concerns:

“I’m afraid if something goes wrong, and he takes all his pills, could I lose my registration?”

The participants also described a sense of personal fear, in high risk situations such as in elder abuse, substance abuse, with dysfunctional families, when they visited clients in their homes at night, or when clients lived in unsafe areas.

Several participants also identified that they experienced guilt. One participant described the emotion of guilt in the following way:

“We had to do letters for withdrawing service because her behaviour was so bad...but nobody wanted to leave her on her own...it was difficult for people ...to follow through with...consequences of (her) behaviour.”

Guilt was associated with care being withdrawn from a client as, for example, in unsafe or abusive situations. Participants also described feelings of guilt when they were not doing something that they felt should have been done or that the clients or families felt should have been done:
“Guilt would be if you think you should do something and you don’t do it...you think you should be more client-directed and support the client...and you don’t do that. The guilt would be where there is conflict, either conflicting internally or conflicting externally.”

Sometimes the professional felt guilty that he/she wanted to be seen as pleasant and helpful, but the client didn’t perceive the professional in that way. Guilt feelings were also described by the professional as a feeling associated with questioning themselves and their role:

“What right do I have to intervene? Who am I to be mucking around in this guy’s life?”

Guilt was also mentioned in this way: “I was feeling guilty, but obliged to talk to someone else about the client.” An example of this was when a client was putting others at risk and the community health care professional decided to speak to the manager of an apartment building about a client’s safety and risk.

Participants also identified feelings of frustration that increased with specific client factors, situations, or actions, for example, if the client lacked personal resources, was living in poverty, or had “caregivers that were old themselves”. Participants explained that their frustration seemed to increase with the perception of not being able to “reach the client” or have a therapeutic relationship with the client, or “not being client-directed”. Sometimes they felt frustrated and unsure of the impact of their care on their clients. One commented:

“T I question if we weren’t even in there, what would it be? Sometimes I question, what difference are we making...if we weren’t in there, she’d be doing the same thing. I’m sure.” [a participant describing a client who was taking too many pills and was unsafe with cooking]
Another stated: "It's frustrating. We don't make a huge impact in their lives sometimes."

Participants also described their frustration with their clients as, for example, when the client refused help or suggestions such as home-support or facility placement. One participant described it in this way: "She doesn't want to be placed...our hands are tied".

Another stated:

"With this guy, it is frustrating. You strive to reach the individual, and develop a therapeutic relationship with him...what you are really just left with is sort of work around him."

One participant commented on her overall feelings of frustration:

"Part of the at risk thing is we are getting more people...sort of falling through the cracks...they're going into hospital sicker...coming home sicker...nobody to pick up the slack...to go that extra little bit..."

Summary

This section, associated with the theme “Worrying about our clients”, has outlined the emotions that community health care professionals described in their stories about their experiences with clients who live at risk. These emotions included descriptions of anxiety or worry, and other emotions such as anger, fear, and frustration, and are heard in the following statement from an experienced nurse:

"I felt discouraged, demoralized, not valued professionally, not very effective...my distress was multipronged...I was struggling."

Participants expressed anxiety related to their perceptions that their clients did not understand their risks. This often became interlinked with concerns about the client’s cognitive capability, stating their concerns about the client’s autonomous decisions when they thought the client was "not capable of making decisions". Clients often had multiple diagnoses and family issues that added to the complications of the risk situations and
increased their feelings of anxiety. The participants also expressed anxiety about their ability to cope with the situation, and that they did not have adequate knowledge to cope or make appropriate decisions.

Anger, fear, and guilt sometimes became part of the overall emotion of anxiety creating a cumulative effect on the participants' perceptions of coping. Participants felt afraid that "something bad would happen to the client", and they felt guilty if they did not find desirable options for the client. Other people, including their own team members or the client's family, added to the feelings of anxiety and anger. Frustration was expressed when the participants spoke about finding resources for their clients or when the client refused professional suggestions. Regardless of what the emotion was, however, participants described how they looked for ways to cope with their emotions.

Theme #3- "Finding a Better Way-How We Cope"

Participants described strategies that were helpful to them when dealing with their emotions and making ethical decisions. These strategies included personal coping strategies; accessing team members for support; utilizing people "who knew the community"; finding "a process of decision-making", including client directed care; and "letting go".

**Personal Coping Strategies**

Personal coping strategies for dealing with emotions and feelings included, for example, taking deep breaths, personal counseling, exercise, "getting hugs from others, and "internalizing it". Participants often talked to other people, including their own families or close friends, about their concerns with their clients. They described other personal strategies such as reflecting on the situation when driving to work and
"letting things percolate", trying to learn from the situation, going over the details on their own, using humour, and going out for coffee or lunch with their colleagues. The following are two participants’ descriptions of their personal coping strategies:

“I think personally what I do is analyze it a lot and try to learn from it...figure out something that I can take out of it...like maybe one sleepless night.”

“I go to lunch. I have a group of colleagues...we support each other and we use humour...we ventilate and we problem solve. That’s the best way...to share the burden”

Most commonly, the participants described how they accessed other people to help them personally deal with their anxiety and other feelings. This included friends, family, and colleagues for personal support- finding someone who listened to them. Most also spoke about how they tried to deal with their emotions on their own, in private ways, such as crying or listening to music. However, how all of these personal strategies actually helped these professionals is not entirely clear.

Accessing Team Members for Support

“Pulling together is important to a team...they all create a plan... (they) balance off each others weaknesses, and pull together their strengths...they all own that plan.”

Participants frequently mentioned that having supportive team members and supportive others within their organizational structure helped them actually make an ethical decision with their clients who are living at risk. They spoke about their interdisciplinary teams, “using the team for problem solving support”, a “collegial system” and “having a strong, functional, interdisciplinary team”. They talked about sharing feelings and turning to their colleagues within their own disciplines, such as home care nurses talking to each other about their client situations, as well as the importance of
personal relationships and friendships at work. They found support in "being listened to and being heard", those opportunities to "vent and be validated", and the times when they felt "valued as a team member".

Participants worked with others in problem solving situations, and reassured each other in stressful times as, for example, when a less experienced home care nurse talked to an experienced case-manager about their shared client. How did these strategies help them cope? One participant described the following:

"...(It's) reassurance with each other that we have done everything...that makes me feel a little bit better. That I'm not being stranded. Knowing that we have had people like this before."

Why did they go to others? One participant believed it was as follows:

"I think the most functional people probably talk to other people, come up with a plan, figure out they've done the best they can, and live with it...Because if people identify an ethical problem they usually look for somewhere to go check it out...they go to the manager or the consultant or to other team members or they find someone within the situation that they think might understand..."

Case conferences to improve communication, team building, and care coordination issues were also described as helpful. One participant stated the following about case conferences:

"I don't think we could deal with these situations without them."

Sometimes the manager was described as being "part of the team". Three professionals suggested that specific support such as knowing that the manager will "back them up", or provide critical incident debriefings, was very helpful.

Experiences with team members and working on interdisciplinary teams were not without problems. Conflicts and disagreements between team members were also frequently described:
"People are all very stressed...in high risk situations where two professionals may have different opinions about how high the risk is...how much intervention should occur because...ethics is all about where do you draw the line in the sand? And people's lines are all in different places."

As participants described the conflict, they also described what they believed would help their teams be better equipped to manage their ethical problems and decision-making issues with their clients who live at risk. They believed that there was a significant need to develop improved, "high functioning" and mature interdisciplinary teams. They suggested more team building methods to address "poor team dynamics" and ways of dealing with poor communication between team members, such as staff who "block the process", or who have "their own agenda", or who do not ask for help when they should, or who avoid confronting or dealing with the issues (either with client or each other), or are seen as "loners". One participant described this "divisive feeling" on a team:

"It becomes a vicious circle...it uses up a lot of energy that should be going to client care."

Participants asked for better ways to deal with conflict, for example, external and internal conflicts, help to deal with team problems, and someone to support and facilitate the teams when issues need sorting out. They talked about having regular neighbourhood team meetings for client review, discussion and effective case conferencing, and "more time to meet as a group". It was felt that some of these strategies would ensure a "flow to care" with good care coordination for the clients.

The professionals also noticed differences in professional values and cultures at different work-sites, for example, how staff communicate and work together, "everyone being too independent", and others listening only to emotion, not facts. They also described conflict with their own values and beliefs, and other's values and beliefs, for
example, with team members, clients, families. Professional boundary issues and conflicts associated with professional roles (for example, a difference in discipline roles and beliefs, such as might be found between nurses and social workers) were also mentioned. One participant described her observations:

"I've seen bitter feuds...in one example, it was actually between two nurses, and the client was elderly, a drinker, in low income housing. One nurse wanted more home support ...and they could not resolve the issue...they were each coming from different perspectives and different values."

Conflict with values and beliefs also appeared to be related to cultural values in certain ethnic backgrounds such as expectations by clients and families for certain levels of care. Participants described their conflict or anxiety when a family member expected extra hours of home support for cleaning because of religious beliefs, when a client needed to have special meals cooked that were more suitable for his/her cultural preferences, or when male sons in some families refused to look after their mothers.

The team and the ability to access other people appeared to play a significant support role for how participants were able to deal with their emotions and decision-making. However, conflict was also experienced on teams and when working with other disciplines.

"Knowing the Community"

The strategy of “knowing the community” was described by several participants as helpful in coping. For some participants, this was described as the participant’s own comfort (or discomfort) when dealing with risk situations, or their own experience levels with clients who live at risk. This was also described as: “getting to the place where we
are comfortable with the risk”. One participant commented on other professionals' comfort levels with risk and community practice settings:

"Staff are uncomfortable with risk...comfort would be a combination of experience and philosophy. It's a blend of a few things. People will be at risk and that may be the outcome."

One participant described the importance of “knowing the community”:

'Understanding cultural differences of going into people's homes, knowing its 'their turf', not 'our turf', they're in control. Staff who know the community know that the client is in control, know the resources, understand how people cope in their own environments, know the context and understand the power differential...''

This knowledge also appeared to be related to the following:

"an understanding of the resources, systems as a whole, and (the implications of) a breakdown in system's support...to understand the context and that they (the client) are at risk."

Another participant also described the following differences when working in the community setting compared to working in the acute care hospital setting. She described how this influences a professional’s feeling that he/she knows the community:

"Just even how people live in the homes...it's a lot bigger than someone in a hospital bed...interacting with their family...it's huge in the community."

For other participants, part of “knowing the community”, and what helped them cope, was also knowing who they should seek out they needed assistance. All of the participants spoke about accessing experienced support people as those who “knew the community”. Professionals who believed that they needed support for their feelings and concerns about their clients who live at risk often sought those who they perceived had experience or knowledge with such clients. Who did they go to for this knowledge, and who helped them with their decision-making? These people were found within the
organization itself, in management roles, or other leadership positions such as practice consultant roles, educators, or clinical nurse specialists, or as members of the interdisciplinary team—essentially "someone who was safe, trusted, and knowledgeable", and "someone who was visible".

The participants also turned to experts such as physicians with specialties such as geriatrics and palliative care, and home support agency supervisors. Other trusted professionals and contacts throughout the health care system were also supports for these professionals. Participants told me how they accessed those people who had the "right experience" to help deal with clients living at risk. They "picked others' brains" and "others' body of knowledge" to help them make their clinical judgments. One participant outlined what she looked for in these experienced staff:

"as long as they're knowledgeable of the community... really good critical thinkers... great experiences in the past with problem solving... connecting... knowing community resources and the bigger community..."

"Finding a Process"

Many participants spoke about "a process" helping them make their decisions. This construct was identified later in the data collection and analysis, and, admittedly, has not been well clarified in this study. One participant summed up how a process might work in this way: "People learn through the process." How does this process help the professionals? One participant stated:

"When staff start to spiral, you can take them back... they can keep on track... they don't end up going tangentially here, there, and everywhere which tends to happen in complex situations. It (the process) pulls people back and helps them to conclusions."
This process appeared to mean something different to each participant. Many participants did not specifically call it a process, and when three participants were specifically questioned regarding what elements this process might contain, each one gave different elements as examples to this process. One participant was specifically asked about the process and its elements and described the following:

"The process varies with every individual (staff), but it would include some things that are the same. I would see some of it being: the staff’s insight into their own practice, their knowledge, and their problem solving, how they learn and how they cope, an emotional or analytical approach...if the client is competent and if the staff is comfortable coping with that part..."

The participants described a number of elements of this process, including “thinking it through”, “analyzing”, “separating the real issues”, and “acknowledging what it is that we can change”. They also talked about “learning from it”, “getting used to it”, and “knowing this is all we can do at this point”. Having clinical guidelines and resources available for the client also helped them, as well as knowing that they had documented well. Four participants specifically mentioned using a risk assessment and ethical decision-making framework, as described by this participant:

"I use a combination of everything (risk assessment, nursing framework, nursing process, and documentation)...that’s just integrated into my practice."

The process seemed to be helped if the participants understood applicable legislation, for example, the A.G.A. They also found alot of value in case conferences and “getting together to discuss case” or “opportunities to debate things”, and having someone (for example, a facilitator) work with the team to sort out difficulties in complex client cases.
Although they sometimes used different words, some participants described trying to use a client-directed approach as part of the process to help them make their ethical decisions:

"So always you start with the client and what their perceptions are...to understand what they are thinking...they may be doing something that you think is very high risk...why are they doing it?"

This approach included strategies described as "trying to understand where the client is coming from", "creating a plan with them", "bringing our goals together", and "going back to check things out with the client." Two participants mentioned client autonomy when they spoke about respecting their client's rights, and trying to be client-directed. The concept of client-directed care is discussed in more detail in Chapter 5 and 6.

"Letting Go"

Some staff spoke specifically about an experience of "letting go" to help them cope with their feelings and experiences. "Letting go" was loosely defined by one participant as:

"to realize that there are situations where mistakes are going to be made and there is nothing I can do about it. There are situations that you're not going to be able to fix...not even fix, not even be able to assist..."

Another participant described this aspect of the coping or decision-making process as:

"getting used to it, nothing surprises me now...patting it down", not as alarming."

"Patting it down", similar to "letting go", included coping with the lack of resources, knowing that they were not always able to provide the best care, yet trying to provide the safest care, and sometimes lowering standards and expectations, and: "coming to terms
with the situation". It also included dealing with aspects of client capability, for example, as described by one participant:

"I say it like a mantra to myself...they are capable to live at risk. People at risk who are competent can make poor choices. If they end up...in a bigger stew, then I'm not responsible for that...that's part of the choice they've made."

Some of the more experienced professionals described that having past experience in ethical decision making with clients who live at risk helped them make these decisions, and was part of "letting go", a concept perhaps related to "knowing the community". They had learned to "live with the risk". An experienced home care nurse said:

"We sort of came to a conclusion that she (the client) was willing to live with this risk, she was with it enough to know that, and that we have to accept what her wishes are...It sort of felt better when we came to the conclusion...but it still didn’t feel good...leaving her like that."

Dealing with beliefs and biases was also described by some participants as part of the "letting go", and part of "finding the process" themes. With some prompting, a few participants spoke about dealing with their own values, biases, or assumptions. Some aspects of the process were related to attempts to reflect on their own beliefs and values, for example, by using a "filter" to deal with conflicting aspects of the issue. One participant described how she had to deal with her personal and professional values:

"...she could manipulate people and play people off...she would say 'What kind of nurse are you?...you couldn't take it personally...she would almost get pleasure in getting you riled up...you had to overcome some of that emotional impact that she had on you."

One participant described how she had coped with her values and beliefs:

"I've come a long way...it's definitely broadened my thought process...you always bring in your own belief system and your own values, but I put them aside and I
look at the individual as who they are...you're always going to have that with you...the most important thing is realizing that you have these values."

A few participants also mentioned "reflecting" on values and beliefs when they talked about coping with ethical problems:

"I think we need to be much more accepting of some staff saying 'I can't take this client on because I'm not doing a good job with them'. We think that everyone should be able to do everything...if we're going to screw it up for clients because our own value judgments are going to get in the way, they need to recognize that..."

The participants also noted their own personal values, for example, related to self-reliance, independent practice, and use of scarce resources. Some participants also recognized that clients have personal values, for example, related to self-care, privacy, cleanliness, and personal risk. This example describes how a participant recalls her earlier professional experiences, and how it impacted her decision-making:

"The value that I was taking ...as a new (professional)....(values like) independence, getting people home, not looking at other parts...what was going on in their heads...what we can do to people, by just going on our own assumptions, our own value set, and just riding right over them..."

To summarize, community health care professionals described a wide variety of coping strategies for dealing with their feelings of anxiety, anger, fear, guilt and frustration. Many of these strategies involved other people, such as accessing team members for emotional support or problem solving. They spoke about finding people in the system who "knew the community" and could assist them in making their decisions. They also utilized personal strategies including exercise or personal reflection.

Some believed that they were more comfortable with coping with clients who live at risk once they had had more community experience, and that this aspect of "knowing the community" helped them through the more difficult situations and enabled them to
help other professionals on their teams. They described elements of client-directed approaches. Some type of process of decision making was mentioned by many participants with specific elements such as using risk assessments, "letting go", or having a case conference to discuss the client situations. They tried to deal with their concerns about the client's risks and capability issues in this process, and found ways to deal with their personal feelings or emotions about these elements. At many times, however, these participants experienced difficulties in making decisions, and felt that the process of decision-making was "a constant struggle".

Theme #4 — "Frustrated by 'The System'- Hitting the Brick Wall"

Community health care professionals identified barriers or hindrances to making ethical decisions for clients who live at risk. As one participant reflected:

"This person really needs help. My professional assessment and judgment says that they need help and I can't get the help that I think they need...I have experience, education, training, clinical intuition, and I can't get (the help)...(I'm) hitting the brick wall"

Many professionals described a sense of frustration with elements of "the organization" or "the system". This frustration was linked to several areas such as inadequate resources and a lack of professional time/heavy workload issues. Participants also described frustrations with conflict between team members; this area has been discussed in the previous theme.

"The Gaps in Between"

The participants talked about a sense that they did not have accessible resources
that are effective or equitable, that is, a sense of having to "beg for resources".

Sometimes they felt that they did not know what the resources were. Some of these frustrations are described in the following statements:

"What is it that I have to do to get help for a person? ...We can't give people what they need"

"We got to the point where we were just going to let her make the decision to be at risk, being powerless to do anything further...because there wasn't any good options."

They felt that they could not provide "what the client wanted", or what they, as professionals, wanted to provide. They described not having enough options for the client, "having to argue within our own system", and that "special interest groups are getting a bigger piece of the pie". An experienced social worker summarized this concern by saying: "The greatest challenge that I have is finding options and resources for our clients." Lack of options was mentioned especially with marginalized groups, such as the frail elderly population, where some participants felt there was a need for transitional places for clients who were at risk when discharged from hospital to home.

"This poor woman...there wasn't the resources in the community that would take her and her dog...she wouldn't give up the dog...she was trying to get into (long term care facility) but they wouldn't take her because of her behaviour...her mental health...she wouldn't go into a facility where there were (only) seniors."

The professionals described resource allocation problems, including the lack of resources for direct support of staff, and feelings of frustration that they did not have "control over the system". They experienced barriers to service from other agencies as, for example, when they lacked referral options to specialized services, access to mental health services, and client advocates. One participant described her frustration in this way:
"We had clearly determined what the client wanted...he was competent...we were hitting up against barriers from other agencies...the frustration of advocating for a client...the lack of communication, inability to get everyone together...to have a care conference...and mixed in with this is what if we are wrong? The rest of the world is saying he can't cope at home...we're really believing that he can or at least he deserves a chance...but what if we're wrong?"

Participants described feelings of helplessness, powerlessness, and impotence, related to their sense that resources in the community were inadequate. A nurse with many years of experience defined her feelings in this area as:

"It's a helpless feeling...I am a person with a lot of skills, education...life experience, and none of these (are) helpful...with a scarcity of resources."

Participants described a sense that the professional cannot do anything about some risk situations or has to wait for a crisis to occur, "the final straw". The following quotation summed up a home care nurse's feeling of helplessness as she looked for options for her clients: "I felt like a failure...if I didn't fix things."

Lack of resources in the form of effective guidelines or support for people who are living at risk were also described. The A.G.A., believed by many to be a good support for professional decision-making with clients who live at risk, was frequently described as not widely known. Some participants felt that more education was needed about the A.G.A. The A.G.A. is discussed in Chapter Five.

"Not Enough Time, Not Enough People, Nobody's Listening"

Associated with the general lack of resources, every participant mentioned a lack of time to deal with client issues or complex issues. This added to their frustration, and was summarized as: "Workload is a huge issue for us." This frustration was also seen in comments such as:
"We’re expected to do this along with the rest of our workload... everyone too busy to problem solve."

"Clients who are living at risk should get the same priority (time, resources, etc.) as we give to other clients, for example, pediatric palliative clients."

Some also felt that inadequate time was available for proactive work with clients who were still at “lower risk” for problem solving before a crisis occurred; for example, they talked about a sense that “everyone’s too busy.” Another participant stated:

"I think the shortage of time with difficult cases is absolutely affecting the quality of our decision-making...and a shortage of time to support new staff."

Participants also described a sense of "isolation" in their decision-making with their clients since they were often alone in the client’s home, and some felt too inexperienced to handle risk situations. Related to a sub-theme of “knowing the community”, many participants spoke about the need to have “someone to help support us”, someone who was available to them to assist their decision-making and problem solving. This is how one participant, a home care nurse, described the need:

"We seem to be missing that middle link...We need someone who knows the system...some people don’t know what their job is (C.N.S., educator)...if the manager’s not experienced... there’s not that person you can go to...a lot of our senior nurses are retiring...(we need) someone who can bounce things off of...a person who could help with talking to and problem solving, like a charge nurse."

Similarly, some participants also cited problems with the “decentralized structure with no head nurse, no neighbourhood team leaders”, stating “those people who have experience are missing”. One participant stated:

"We don’t have a care coordinator...we don’t have anybody (who) checks or...monitors that everything is in place for this one person (the client)...people say we don’t have time to do it."
A need to improve mentoring for new staff was mentioned by three participants. This included a need to have people who could better support those inexperienced or anxious staff who didn’t have much clinical or community experience. This person could be a team member, a manager, a practice consultant, or others. However, the key factors, according to some participants, were to ensure a “quiet, focussed, supportive environment” with someone who “understands” and “has something to offer” to these staff; someone who, in other words, was both “experienced and available”.

Four participants also asked for specific resources of support. These included the following (each suggestion was requested by at least one participant):

- Help to work “smarter”, ie. make work easier with, for example, computerized records, hand held computers, cell phones, and transportation for clients.

- Better emergency response when a client is in crisis, an ability to deploy resources in urgent situations, for example, a “flying squad” for clients who are at risk.

- Better support system and identification of strategies for dealing with staff safety issues, and supporting new and experienced staff in their safety concerns and practice, was also considered important.

- Improved clinical guidelines, for example, algorithms, checklists, etc. for clients who live at risk, for example, similar to what the hospice program provides, was also mentioned.

- More knowledge about cultural sensitivity or diversity issues.

To summarize this section, many specific elements of the organization and its structure or system frustrated these community health care professionals. Participants
expressed feelings of frustration when dealing with a scarcity of resources, a lack of
time, and a need for improved support. They often described a lack of available resources
or options for certain client populations, for example, frail elderly or brain injured
younger adults.

They felt frustrated that, at times, they could not do anything about a risk
situation until it had deteriorated into a crisis. They asked for more opportunities to have
case conferences, and for experienced professionals to support their practice. They
struggled with dealing with personal and professional values and beliefs as they made
their ethical decisions.

Summary of Chapter Four

“It is a whole complex of frustration, tiredness, working overtime, having too
many situations that were awful, and not being able to resolve them, and not
having the support to resolve them...those things accumulate. I talk about the
moral distress and it becomes moral anguish.”

This chapter has described those themes and sub-themes that emerged from the
experiences of community health care professionals who are making ethical decisions
with clients who live at risk. The participants in this study described variable levels of “at
risk” factors when they discussed their client situations, and often described the
complexities of these clients. Their clients may or may not have been actually living at
risk, as defined in Chapter 1 and 2. The important point was that the community health
professional perceived the client as living at risk, and felt that the situations were
complex in nature. This is part of the context for their experiences and decision-making.
This distinction is explicitly made due to possible values, biases, or assumptions that a
community health care professional may have about risk and clients who live at risk. This aspect is discussed in Chapter 5 and 6.

Significantly, in all interviews, many clients were described by the participants as "incapable of making decisions", "incompetent", or "demented", especially related to the client's insight into their risk situations or their potential for risk outcomes. The concept of capability/incapability, or incompetence, appears to be the single most concerning client characteristic for professional staff coping with making ethical decisions with clients who are living at risk. Its impact on how community health care professionals cope with their ethical problems and/or make ethical decisions with clients living at risk is discussed in Chapter 5.

The participants described many emotions and concerns that they experienced in their ethical decision making with clients who are living at risk. These included anxiety, anger, fear, guilt, anger, and frustration. The participants, when facing ethical problems in stressful situations with their clients who live at risk, coped with these emotions in many ways. They used personal coping strategies, and they talked to others, including team members. They tried to be client directed in their practice, and to deal with their values and beliefs. Participants spoke about the amount of experience that they had, or others had, in the community practice, and its impact on how they coped with their feelings and their decision-making. This concept is described as "knowing the community" or "understanding the community". They talked about using some type of process, including "letting go" to deal with their feelings and make their decisions.

Support for interdisciplinary teamwork was also cited as a critical need to enhance this decision-making by ensuring good communication and care planning. Issues
associated with resource allocation, including both "people" and "time" resources,
appeared to be one of the more significant issues that community health care
professionals' described when coping with and making ethical decisions with clients who
live at risk. One participant stated: "Resource allocation is a political voice that's played
out at a much higher level." Chapter 5 will discuss these findings, focusing on specific
areas that have significance for clinical practice in community settings.
Table Two

Descriptions of Community Health Care Professionals’ Experiences with Ethical Decision-making with Clients who Live at Risk

“Our clients who are living at risk”
- Complex
- Intolerable risk
- Lives alone
- Capable of making decisions?
- Puts others at risk
- “The client doesn’t understand their risk”

“Finding a better way- how we cope”
- Talking to others
- Interdisciplinary teamwork
- Personal strategies
- “Knowing the community”
- A process
- “Letting go”
- Dealing with our values

Feelings and emotions
- Anxiety
- Worry
- Frustration
- Guilt
- Helplessness
- Fear
- Anger

“Worrying about our clients”
- Lack of skills and knowledge
- “Can I cope?”
- Not having the same control as in the hospital

“Frustrated by the system-Hitting the brick wall”
- Not enough time
- Not enough people
- Nobody is listening
- “The gaps in between”
- Struggling for resources
CHAPTER FIVE- DISCUSSION AND INTERPRETATION OF FINDINGS

In Chapter 4, I presented four themes that were identified during data collection and analysis phases of this study: “Our clients who are living at risk”; “Worrying about our clients”; “Finding a better way”; and, “Frustrated by the system”. The participants in this study, with their powerful stories, described the complex issues associated with their experiences of ethical decision-making with clients who live at risk. They spoke about strong emotions that they experienced as they tried to deal with their client’s risks, and reflected on their ethical problems. From these stories and themes, there are many areas that could be discussed in this chapter, however, I will only address a few select topics or concepts that are related to the findings. Many of these concepts are closely connected, and, therefore, I will present them in the following order. First, I will provide an overview of moral distress as a concept within healthcare ethics, and as a finding of this study. Next, I will define moral distress, in light of this study’s findings, and I will discuss specific areas that complicate moral distress for community health care professionals as described by the participants in this study. Personal and professional values and beliefs, characteristics of “at risk” clients, especially those with capability concerns, use of legislation (for example, the A.G.A. and the Mental Health Act), allocation of scarce resources, and ethical climates in organizations can all impact on feelings of moral distress, and are discussed in this section. Finally, I will address two concepts that seem to be related to what can help healthcare professionals cope with moral distress and make ethical decisions. Client directed care delivery— an approach that is based on principles of autonomy and respect and collaborative practice within interdisciplinary teams, are outlined in this section. Chapter 6 will discuss specific
clinical practice, research, education and system implications (recommendations for
leadership) arising from the discussion of these concepts.

Moral Distress in Community Practice Settings

Community health care professionals who participated in this study described
many emotions that they experienced as part of their overall experience of ethical
decision-making with clients who are living at risk. These emotions included anxiety,
fear, anger, guilt, and frustration. The participants described their experiences with
complex clients as "worrying about our clients" and also spoke about how they coped
with their emotions and feelings as they attempted "to find a better way". Their stories
outlined many details about the complexities of clients who live at risk, including their
health and social issues, and how these complexities impacted the participants' anxiety
and other emotions as they tried to make ethical decisions. Participants told me that they
experienced anxiety when their clients refused their suggestions, such as home support or
meal programs, or when they were not sure how to deal with the client's complex care
issues. The described their feelings of fear when their clients fell or remained in abusive
family situations. They felt guilty when the clients caused fires on their stoves, and anger
and frustration when they could not find appropriate resources to support their clients.
They worried that other people might also be left at risk if the client made poor decisions.
Feelings of frustration were expressed with clients who seemed incapable of making
decisions related to their risk. From their descriptions, I believe that these emotions are
descriptions of moral distress. While only two participants actually mentioned "moral
distress" in specific terms, the language or words do not seem to matter; the overall
experience seems to be congruent with experiences of moral distress that have been previously described in the literature.

Defining Moral Distress

What is moral distress? Moral distress is frequently mentioned in ethics literature and is defined as occurring when a moral choice cannot be translated into a moral action (Jameton, 1984), or "what nurses experience when they are unable to fulfill their moral intentions" (Rodney & Varcoe, 2001). Moral distress has also been defined as an inability to face the concerning issues and deal effectively with them (Keatings & Smith, 1998) and "occurs when a person is prevented from acting on their individual conscience to exercise their moral choice" (Wociol, 1996, p. 152). Moral distress may include "the creation of feelings such as "I know what I want to do, but I feel as though I can't do it" (Dossetor & Cain, 1997, p. 21). For example, an individual may know the right thing to do, but situational constraints such as organizational policies prevent them from acting (Jameton, 1984; Wociol). Moral distress, according to Wociol (1996), may also cause feelings of "burnout", and can cause nurses and physicians to give up on their profession, move to other areas of practice, and “intentionally shield themselves from situations where ethical dilemmas arise, or practice in a fog” (p. 153).

When a health care professional feels unable to do what he/she thinks is best, moral distress may lead to feelings of guilt, anger, frustration, discomfort, powerlessness and dissatisfaction (Keatings & Smith, 1998; Rodney, 1997). Furthermore, nurses appear to experience anger, frustration, guilt, and powerlessness when they encounter constraints in moving from their moral choice to moral action (Rodney & Varcoe, 2001). The participants in this study expressed anxiety when they were unsure of how much control
they had in community settings, or when they were concerned about leaving clients alone in risk situations. They described their fear and frustration when service options for the client were not available, as, for example, when a nurse was not available to make a home visit.

Many have written about the experience of moral distress (Rodney, 1997; Storch, 1999). Moral distress has also been linked in the literature to moral uncertainty or moral anguish. Moral uncertainty is defined as: “When one is unsure of what principles or values to apply to resolve moral distress or even what the moral problem is (Wociol, 1996). Rodney (1997) has written about a kind of anguish that emergency nurses described upon discharging of seriously ill patients from hospital when they believed that there was not enough resources in place to support the patient and family. Rodney also attributed this anguish to situational constraints such as lack of leadership and lack of time to make thoughtful ethical decisions. Of interest, feelings of anguish and uncertainty might be part of the emotions that community health care professionals experience. While only one participant in this study used the words “moral anguish” (with a client who was living at risk during an episode of scarce community resources and communication problems on the interdisciplinary team), several participants mentioned their feelings of anxiety and uncertainty when a lack of leadership support or time to cope with the ethical problems of their clients who live at risk was encountered.

As I listened to the participants’ stories and reflected on their experiences and emotions, I was struck that these professionals, for the most part, desperately wanted to provide the best care that they could, but could not provide this level of care for many reasons. They struggled with how to actually deal with the ethical problems and how to
provide adequate care. These participants appear to demonstrate that their moral choice-the care that they wanted to provide for their clients- could not be translated into a moral action due to certain constraints; this is the essence of moral distress (Jameton, 1984).

Many factors that contribute to moral distress are cited in the literature (Jameton, 1984; Rodney, 1997; Storch, 1999). There are some similarities and some differences in the factors associated with the moral distress of community health care professionals when caring for clients who live at risk. The next section will discuss these.

**What Contributes to Moral Distress in Community Practice Settings?**

This section describes some of the areas that community health care professionals mentioned when they described their emotions- emotions that, in my view, sound like moral distress. The first area that I discuss is the effect of personal and professional belief systems, including biases and values, on feelings of moral distress and on decision-making. The next area relates to participants' sense of uncertainty regarding the concept of client capability, and associated legislation, as a factor contributing to their distress. The impact of scarce resources in community health care settings on moral distress is then discussed. This section ends by discussing the impact of ethical climates within organizations on moral distress and ethical decision-making.

**Values and Belief Systems**

Participants in this study described the impact of their personal belief system (such as biases, values and assumptions) on their process of dealing with their ethical problems with clients who are living at risk. They described to me the impact of their own belief systems when they asked themselves questions such as "What is risk?" and "What client situations are intolerable risk?" The participants in this study described
feelings of conflict between their own beliefs and those of the client as, for example, when a client stayed in an abusive home situation despite the availability of safer alternatives. Some participants in this study stated that they may have difficulty accepting a client’s goals and may not be able to accept client choices when the client’s goals and values do not match their own values. One participant, for example, described her frustration with a client’s use of alcohol and medications. Turner, Marquis, and Burman (1996) describe how, in situations where clients do not agree with the professional’s risk assessment, or do not agree with the family’s risk assessment, non-consensus about risk with all participants may occur with accompanying high potential for conflict in care-planning with the clients (Turner, Marquis, & Burman, 1996).

Participants also mentioned the impact on their distress of family members’ belief systems, as when a client’s family believed that government services should “take care” of their family member. Participants also described the biases and value judgments of their colleagues who disagreed with their care plans as, for example, when one professional wanted to discharge a client and another did not agree. Uncertainty about one’s own values and conflicting values between people in a given client situation seem to contribute to community professionals’ distress.

The concept of ethical knowing includes the role of values, beliefs and biases on ethical decision-making and has been introduced in Chapter 2. Moral distress may be increased or complicated by a professional’s personal belief systems, including his/her biases and values. The participants in this study, for example, spoke about the importance of a social and professional value related of client autonomy and acknowledged the significance of respecting this value. Respect for autonomy and the consumer’s right to
choice must now be considered by health care professionals but may cause internal value
conflicts when the professional disagrees with the client’s choices.

As ethical problems increase in complex settings, an examination of values for
professional decision-making becomes more important (Weis & Schank, 1997). Knowing
ones’ values (professional and personal) and being able to confidently use them in ethical
decision-making can be an important tool for avoiding moral distress. Grundstein-
Amado (1995) comments: “If each of us will engage in research activity and a
clarification process with respect to his or her own values system, we will be open to
others’ perspective and an effective dialogue can take place” (p. 177-178).

Furthermore, Glen (1999) believes that effective interpersonal collaboration
depends upon respect for differences in values and beliefs. Participants in this study
frequently mentioned that talking to others helped their reflective and decision-making
process, for example, with clients who were “non compliant” with care plans. Further
implications for practice associated with this concept are outlined in Chapter 6.

Capability concerns about their clients was one area that was frequently mentioned when
the participants talked about their biases and assumptions.

**Capability and Legislation with Clients who are Living at Risk**

Capability concerns were one of the main client factors that increased feelings of
anxiety, frustration, fear, anger, and guilt in the community health care professionals who
were interviewed in this study. Professionals used two terms (capability and competency)
to describe this state and also used “not able to direct their own care” or “demented” to
describe clients. They also talked about various legislative acts such as the Adult
Guardianship Act (A.G.A). or the Mental Health Act, and what they believed capability
meant within those acts. Overall, the participants seemed to feel anxious and uncomfortable about how to apply the concept of capability in their decisions with their clients who live at risk. Furthermore, they struggled with how legislation, such as the A.G.A., could impact decisions about capability, and, therefore, impact ethical decision-making with clients who live at risk. Generally, there appeared to be a lack of clarity about how to best use the definitions of capability and how to apply appropriate legislation. Several legislative acts differentiate between varying interpretations of capability and an examination of these acts demonstrates why health care professionals may become anxious and confused when making ethical decisions with their clients who have cognitive issues (Public Guardian and Trustee of B.C., 2001). The A.G.A. and the Mental Health Act were the two acts that were most likely to be mentioned by the participants. Definitions of capability in these two acts are briefly outlined in the following sections.

The Adult Guardianship Act, proclaimed as of February 2000, may have a significant impact and influence on clinical decision-making for professionals with clients who are living at risk and may offer support to clients, families, legal and health care professionals in decision-making (Public Guardian and Trustee of B.C., 2001). Ethical principles have been integrated into these principles and approaches, and include:

- All adults are entitled to live in the manner they wish and to accept or refuse support, assistance or protection as long as they do not cause harm to others and they are capable of making decisions about those matters.

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9 Section 44 of the A.G.A. specifically defines those clients who may be considered under the A.G.A.
• All adults should receive the most effective, but the least restrictive and intrusive form of support, assistance or protection when they are unable to care for themselves or their assets (Public Guardian and Trustee of B.C., 2001).

The act enshrines the principle of autonomy with use of the least intrusive and most effective intervention and use of court orders as a last resort. Within this act, if the client fits within the definition under Section 44 of the act, the test of incapability includes the following questions: Does the adult understand the services described in the support and assistance plan? Does the adult understand the reason the services are being offered? Does the adult understand the consequences of not accepting the services? This legislation was intended to standardize and formalize the assessment of capability, however, as described by the participants in this study, much confusion remains regarding the use of A.G.A., who the A.G.A. applies to, and how an adult is defined as incapable within the A.G.A. Large health care organizations are often designated to follow-up on reports of abuse, neglect, and self-neglect under the A.G.A. Adults who are reported to these designated agencies may be abused or neglected, are often perceived to be living at risk, and may be perceived as incapable of making some decisions. Health care professionals, such as those who participated in this study, seem to struggle with their decision-making with these clients and the use of the A.G.A. legislation for guiding decision-making.

The Mental Health Act allows for voluntary or involuntary psychiatric treatment of persons with mental disorders. It sets out the procedures for voluntary and involuntary admission, treatment and detention in psychiatric facilities and ensures that a seriously mentally ill person has immediate access to psychiatric treatment. For admission of
involuntary clients, the test of incapability includes: Is the person capable of appreciating the nature of treatment and/or his/her need for it, and is he/she therefore incapable of giving consent? In my professional experience, community health care professionals often believe that clients who are living at risk (for example, a client with dementia who refuses care) should be deemed incapable of making their own decisions under the Mental Health Act. Participants in this study described how they wanted to use the Mental Health Act to ensure that a client received care. Yet this idea created feelings of anxiety and fear, and the participants often recognized that such an action could have a long-term impact on the client’s right to autonomy.

To summarize this section, community health care professionals in this study appeared to feel anxious, confused and uncomfortable with issues of capability and were often seeking ways to clarify capability. A few participants in the study questioned: Does it matter if the client isn’t capable? Does it make a difference if we don’t know what they are capable of doing? Can we still make ethical decisions with our clients when they don’t seem to be capable of making decisions about risk in some areas? Furthermore, the participants also described that they often had few places where they could access adequate direction with their concerns about capability, and, therefore, struggled with how to provide ethical care to their clients who seemed to have cognitive problems.

With several different definitions of capability to deal with, it is little wonder that community health care professionals experience many emotions-emotions that sound to me like moral distress-when they are coping with decision-making with clients who are living at risk. It is even possible that the A.G.A, still relatively new, unknown, and not well-tested, as well as other legislation, has created more anxiety. Specific practice
recommendations and implications associated with capability and legislation are outlined in Chapter 6.

Moral Distress, Resource Allocation, and Social Responsibility

When community health care professionals described their experiences, some of their concerns were specifically about the constraints to moral action posed by the complexities of resource allocation and their perceptions of apparently scarce resources. They told me about their frustrations when they could not offer an adequate range of services for their clients, especially for those clients who had few personal resources. Many participants questioned how decisions were made about resources and how fair health care policies that impact resource allocation were developed in health care organizations. They felt frustrated by a sense that they could not personally or professionally impact how resources were allocated to health care services.

Associated with this issue, constraints also arose related to an overall lack of social or community supports for some clients and their families, as well as concerns about social inequities within the bigger picture of health care and broad definitions of health (Chafey, 1996; Kenny, 1999; Saul, 1999; Sherwin, 1998). Participants wondered if the health care system could provide adequate care for their clients whose risks included poverty or abuse. As Sherwin aptly recommends: “If we are truly to respect patient autonomy, we, as a society, need to develop a health care system that is more attentive to the actual needs of the diverse variety of citizens who depend on its services” (p. 44).

Overall, how do we deal with the resource implications and ethical issues with clients who are living at risk? Resource allocation is "the distribution of goods and services to programs and people" (C. N A, 2000). To participants working in the
community, these resources appeared to be in scarce supply. Macdonald (1999) suggests that the potential for difficulties among conflicting forces, such as those found when allocating health care resources, is never far removed. According to the C.N.A. (2000), there are three kinds of scarcity: supply scarcity (the shortage of a finite resource because of natural limits to the resource's availability); fiscal scarcity (resulting from a shortage of funds); and crisis scarcity (when, in a crisis situation, such as an earthquake, there is not enough medical care for the casualties). Community health care professionals, like many health care providers, face a competition for two of these scarcities, supply scarcity and fiscal scarcity, often on a daily basis. The participants in this study, when they described "being frustrated with the system", and as they worked on the front lines, certainly expressed many concerns related to the scarcity of resources, and some expressed feelings of frustration and anger over their lack of impact on the decision making for the allocation of these resources. Although not a word used by all of these professionals, rationing is the term that implies that there will be guidelines for the use of resources when there are not enough to meet the demands for those resources as, for example, when there is a shortage of nurses. Rationing of resources in the community seemed to lead to emotions such as frustration and anger in the participants of this study. Similar feelings are also described by Rodney and Varcoe (2001) with nurses practicing in emergency and acute medical units.

Overall, this is a problematic area that cannot be fully addressed in this thesis; however, some recommendations regarding implications for practice and recommendations for leadership are included in Chapter 6. This study only starts to "scratch the surface" of these concerns and further investigation into this area is needed to
explore this concept within community practice. Yet, within the limitations of this thesis, some type of "meaningfulness" about the impact of values on decisions about resources may be found.

Decisions about utilizing resources are based on values. While some authors have suggested that corporate values are becoming too important in resource decisions (Varcoe & Rodney, in press), many decisions about the utilization of resources as seen, for example, with allocation of home support in health care, originated with those values that were established historically by levels of administration or governments (Saul, 1999). Eligibility criteria for receiving home support services originated with provincial governments’ health ministries and are based on provincial government values. Yet, within the ethical principle of distributive justice is an underlying value that fairness must be based on the equal worth of all individuals. Perhaps, community health care professionals and their leaders can be assisted in their struggles around this issue by considering the following: “There are several criteria that must be applied to determine fairness, for example, to each according to worth, to each according to need, to each according to contribution...a value commonly held in Canada is...equity is fairness according to need” (Storch, 1999, p. 359). The principles of equality and equity are also considered in the allocation of scarce resources. Equality is a main element of justice and includes equal access to resources, and also a distribution of resources that favours those who need more than an equal share (Williams, Yeo, & Hooper, 1996). Equity is not the same as equality. According to Rodney and Varcoe (2001), equality has been interpreted as treating everyone the same and could result in unfair allocation decisions while equity would consider the circumstances of people's lives when making fair allocation decisions.
Since participants in this study frequently mentioned their concerns about the inadequacy of resources for supporting clients who live at risk, considering resource allocation and defending resource allocation according to a needs-based allocation approach may be a way to help community health care professionals cope with their feelings and their decision-making process. This approach might be possible within the environment of an ethical health care organization.

**Organizational Ethics**

This concept of organizational ethics, including an organization's ethical climate, was discussed in Chapter 2 and relates to all of the themes identified in this study. However, the concept of organizational ethics specifically relates to theme #4 ("Frustrated by the system- hitting the brick wall"). The participants frequently talked about their feelings about the "system", and, while most participants did not specifically define their organizational system as an "ethical climate", it is known that the organization and its ethical climate impacts on moral distress and, therefore, on ethical decision-making (Olson, 1995). Community health care professionals mentioned problems associated with support for their decision-making. These included barriers to their ability to provide care, such as a lack of support or resources (as mentioned in the previous section), a lack of "people resources", such as adequate staffing and support people, and enough time to provide safe, effective care.

Organizations have responsibilities for micro, meso, and macro levels of decisions made by their staff. The concept of organizational cultures has emerged as a critical concept relevant to organizational life, influencing organizational behaviour and organizational performance (Silverman, 2000). Silverman defines organizational culture...
as "the shared values that have been reflected on and articulated by the members...accepted by them as normative for the culture of that organization" (p. 205). The concept of organizational culture incorporates the idea of shared assumptions of the way things are done within that organization. Similarly, an organization’s ethical climate can be assessed by measuring an employee’s perceptions of organizational practice that reflect how decisions that have ethical content are solved, or by the presence of organizational conditions that allow employees to engage in ethical reflection (Olson, 1998). Therefore, an organizational ethical climate is "the shared set of understandings about what is correct ethical behaviour and how ethical issues will be handled" (Silverman, p. 208). Related to this topic, Storch (1999) has written about “moral communities” where information is shared and ideals are translated into conduct within an environment of thoughtful reflection. When participants in this study spoke about having opportunities to talk about their ethical concerns and time to develop better care plans with their team members, I believe that they were trying to think of ways to develop a moral community in their workplaces.

The development of ethical climates in organizations is challenging. Murphy (2001) writes: "Participating in and supporting such decision-making processes requires vulnerability and trust to voice underlying concerns, a willingness to listen and clarify perceptions and confusion, courage to dialogue and decide" (p. 160). If staff are to engage in ethical reflection, conditions of power, trust, inclusion, role flexibility, and inquiry, should be present (Olson, 1998). For organizations such as large health care regional boards, it is also worthwhile to look at specific elements of organizational ethics such as being value-based, proactive, practical, accountable, measurable, sustainable, and
cost effective (Potter, 1999). Many participants in the study talked about being cost-effective and utilizing limited resources, yet struggled with determining ways to improve access to a wider range of resources and options for their clients.

The concept of "organizational integrity" should also be considered for "value-driven organizations". This integrity is demonstrated in a commitment to achieve a strong alignment between stated mission/values statements, and decision-making and behaviours at all levels within the organization (Silverman, 2000). Yet, if integrity is important to organizations, where does an organization start in developing an ethical climate? I believe that they start with their leadership. If one definition of organizational ethics is "the discernment of values for guiding management decisions that affect patient care" (Potter, 1999, p. 174), and clinical ethics "is the discernment of values for guiding clinical decisions that affect patient care" (Potter, p. 174), and "the starting point for organizational ethics" (Rorty, 2000, p. 64), then one must assume that field staff and those in management positions should not be working in isolated and separate philosophical worlds. Many clinical ethics issues have organizational causes (Rorty), and can best be cured by organizational change. The participants in this study felt that the organization could provide much more support for them. Their suggestions included having access to practice consultants and others "who know the community". They asked for education about capability and legislative acts. They mentioned the need for improved safety standards when they visited their clients at risk, and they asked for more opportunities to sit down and deal with their anxiety and other emotions. Specific recommendations for leadership are included in Chapter Six.
Coping with Moral Distress

Community health care professionals coped with their emotions in many ways and often described a lack of support or variable support for this. There seemed to be almost an imperative for them to deal with their feelings in some way. However, they also mentioned specific strategies that they did use to cope with their distress. At a micro and meso level, there are some things that support or help professionals to make ethical decisions with clients who live at risk. First, the participants described using client-directed care delivery approaches as a strategy for coping with their moral distress. Second, the participants identified that collaborative practice within interdisciplinary teams also helped them cope. The following sections describe these two areas.

Client Directed Care Delivery -Respecting Client Autonomy

Many of the community health care professionals in this study talked about how they coped with decision-making with clients who live at risk. This process was described in several ways such as “Trying to reach the client”, “being where the client is”, “going back to the client”, or “looking at the client’s goals first”. They spoke about “acknowledging the client’s rights”, “knowing this is how they choose to live life”, and “it’s how we should be talking to people”. Some participants, in mentioning ethical principles such as autonomy and respect, wanted to ensure that they had included the client in their decision-making, but struggled with how to actually do this. Three participants specifically called their approach “being client-directed”.

These descriptions are consistent with the philosophy of client-directed care delivery, “an approach to service that embraces a philosophy of respect for, and partnership with people receiving service. It recognizes the autonomy of individuals, the
need for client choice in making decisions about their needs, client abilities, and the need to ensure that the service fits the context in which the client lives” (Law, Baptiste & Mills, 1995, p. 252). This process is based on client-focused values and beliefs of care/case management (Berg, 1998). Principles of client-directed care include: a client/provider relationship based on respect and trust; flexibility in providing client support; adaptability to changing needs in client's situation; recognizing the client's present strengths and resources; and shaping resources to meet client-identified needs (Berg, 1998).

One of the principles of client-directed care delivery ensures that the evaluation of, and planning for, community clients cannot be done in isolation from those who will be affected. Many of the participants in the study described how they tried to include their clients in their decision-making processes. Porter writes: “Home care clients should participate not only in defining their risks but also in determining their needs related to those risks. Home care professionals must develop mechanisms to ensure that their agencies solicit clients’ perspectives, incorporate knowledge of clients’ lived experience in the system of care, and enable clients’ voices to be heard within the policy-making arena” (1994, p.64).

Considering the client’s autonomy would be integral to the concept of client-directed care delivery, but the concept of autonomy and its application in practice may confuse professionals who are dealing with clients who live at risk. Valimaki et al. (2001) state that autonomy is based on equal respect of all persons recognizing that individuals have “unconditional worth with the capacity to determine his or her own destiny” (p. 8). Autonomy also, according to Valimaki et al., does not mean that clients can do whatever
they want without limits. Limitations to autonomy would be imposed when one
individual's autonomy interferes with another's rights or well-being (Valimaki et al., p.
9). This perception of autonomy appears to fit the feelings that participants had when
they felt that they could not respect the client's autonomy because the client was putting
others at risk (for example, creating fire risks in apartment buildings), or if the client
appeared incapable of making some decisions.

Furthermore, within client-directed approaches, recognizing the importance of
client autonomy in ethical decision-making underlies the practice of case-management, an
organizational process in the community. In a qualitative interview study, however,
Clemens, Wetle, Feltes, Crabtree, and Dubitzky (1994) addressed the question: “To what
extent is client-centered theory reflected in case management practice?” (p. 72).
Significant differences were discovered between reported client-centered theory and
directive practice (p. 70,77), and such contradictions were more likely to occur with
clients described as “difficult”. Five themes, pertaining to the differences, were
identified: client wishes versus system constraints, the paradox of working to keep clients
at home versus possible nursing home placement, the case manager's care plan versus
client-centeredness, self determination versus levels of paternalism, and informing the
client about case management versus the reality of practice. These themes seem to be
similar to those experiences described by the community health care professionals in this
study, for example, as seen with clients who refused services, such as home support or
facility placement, to decrease their risks. Clemens and Hayes (1997) also found that
health care practice is often inconsistent with the ideal of client autonomy set out in
professional ethical codes. Additionally, ethical decision-making may increase the
difficulties associated with case management and professional autonomy when professionals attempt to balance between the needs of self, patient, family, employers, and society (Keffer, 1997).

Community health care professionals who participated in this study appeared to be attempting to use the philosophy of client directed care as a strategy for approaching their care delivery and ethical decision-making with clients who live at risk. This does not mean that this strategy was consistently implemented or that the participants always felt comfortable about being client-directed. One participant in this study commented:

*For some reason, people are really scared to say...being honest...to a client- ‘I'm very concerned that you are in this situation, living at risk...I'm feeling very uncomfortable.’ There’s nothing wrong with that as long as you are checking out and hearing what they’re saying.*

The literature seems to clearly support health care professionals who, in trying to be client-directed, have recognized that the client must be an active participant in the assessment and planning aspects of their own care. Implications for supporting client-directed care delivery approaches are discussed in Chapter 6.

**Collaborative Practice Within Interdisciplinary Teams**

Community health care professionals in this study identified that one way of coping with their feelings included “*using the team*”; they described experiences and decision-making practices that were influenced by their team members. At a micro level, the interdisciplinary and/or neighbourhood -based teams, of which the participants were part of, appear to play a significant role in how these participants both coped with their feelings and made decisions with their clients who live at risk. Participants wanted teams that were supportive, had experienced members, respected their knowledge, valued each
other as team members, and were reassuring during stressful times. Such ideals are consistent with what is termed “collaborative practice”.

According to Wells, Johnson, and Salyer (1998), collaboration is defined as “working together toward a common goal” and “involves shared responsibilities, decision-making and rewards” (p. 161). Each individual brings a specific set of skills and knowledge to a collaborative interaction that will contribute to the decision-making, planning, implementation, and outcomes of this interaction. Participants in this study often mentioned the value of their team member’s experience and knowledge as they coped with their ethical problems.

In community practice settings, the collaborating team has become critical to developing care-plans for clients. Many disciplines, for example, home care nurses, have been accustomed to working within their own disciplines or services. However, the current trend in health care delivery involves collaboration between interdisciplinary professionals (Howard, 1994; Yaffe, Dulka, & Kosberg, 2001) and a transition from a discipline-based to a program-based model (Howard, 1994). A single type of health care discipline may be insufficient to enable clients with increasingly complex medical and social problems to achieve optimum well-being (Yaffe, Dulka, & Kosberg). Elsner, Quinn, Fanning, Gueldner, and Poon (1999) also advocate a multidisciplinary approach to the challenge of caring for vulnerable older adults as a way to refocus away from the medical model toward a framework of maximizing function. Similarly, McClaren, Lan, Snell, and Franco (1998) describe evidence that unidisciplinary approaches to case management—a key concept in community practice—may be too limiting.

In community practice, an interdisciplinary health care team is a team composed
of the client, family, nurses, social workers, physiotherapists, occupational therapists, nutritionists, speech language pathologists, physicians, and other professionals. This team collectively and cooperatively shares the responsibility for formulation, implementation, review and evaluation of a service or a care plan (Howard, 1994); they respect and rely on each other's competence (Yaffe, Dulka, & Kosberg, 2001).

There are significant benefits obtained from ensuring that team building strategies have been integrated and are supporting collaborative practice. Teekman's work (2000) identified that collegial support and previous experiences were the most important factors for professionals “making sense of the situation” (p. 1130). Being able to communicate well, identify what others are saying, interpret it, and reflect it back to team members objectively and systematically when making decisions, have been mentioned as important communication skills for team members. Gage (1998) suggests that, for success, participants within teams must: “feel heard”, “feel valued”, “believe in each others competence and nurture each others’ knowledge", and therefore will “establish a listening environment, foster innovation, (and) develop team spirit, including a common vision” (p. 20-21). Certain characteristics of team composition, structure, and function may affect team performance such as the stability in the team's composition, regularity of ethical discussions, and availability of conflict resolution mechanisms (Yaffe, Dulka, & Kosberg, 2001). These authors also describe certain aspects of the organizational structure and function as influences, both positive and negative, on team performance. They recommend that organizations ensure the stability of team functions, for example,
by finding ways to maintain staff. Teams of professionals who are working together need to balance their responsibilities, opinions, client, individual and team goals, values, and decisions when participating as a member of a decision-making team (Sharp, 1994).

As the participants in this study described, there are major barriers to interdisciplinary practice and teamwork. Interdisciplinary teams are relatively new in community practice settings; the participants in this study recognized that they did not get many opportunities to develop their team building skills or work on client problems as groups. Furthermore, these teams are not static; frequent changes of staff within a team of professionals may lead to a lack of trust relationships within the team.

Historical factors such as different philosophies of practice and professional training (such as might be found between nurses, rehabilitation therapists, and others), logistics of team implementation, and resource implications (Glen, 1999) may also be evident. Participants in this study described times when team members did not agree on the interventions for their client, and when some team members did not take the time to attend case conferences. Wociol (1996) has written that collaboration in resolving ethical problems is hindered by uncontrolled emotion, poor communication, time, and conflict—all elements that were also identified by the study’s participants as problematic within their environments.

There is evidence in the literature that groups of professionals who work together as a team make decisions differently than do individuals (Sharp, 1994). The research of Clemens & Hayes (1997) suggest that "the professional skills of nurses and social workers working in tandem can help minimize the biased effects of socialization in decision-making practices" (p. 19). Clemens and Hayes also articulated differences in
practice and decision-making for nurses and social workers who are working with clients who are living at risk, demonstrating variable thresholds for risk tolerance among diverse professionals. Participants in this study spoke about the positive aspects of the differences in discipline backgrounds on a team. However, they also mentioned conflict between two disciplines, such as was seen between a social worker and a nurse who did not agree on how much help the client really needed.

In summary, the participants in this study identified that teamwork and individual team members had both positive and negative impacts on decision-making processes. Although many participants believed that they obtained a great deal of support from working collaboratively on interdisciplinary teams, they also mentioned that these teams were not yet fully functional enough to cope with complex decision-making and care coordination. Improving care coordination for the client by having regular case conferences and “building up teams” were both mentioned frequently by the professionals.

Teams within this organization are not all the same, but appear to need significant support to enhance their decision-making roles. Given that in the setting in which this study was conducted, it is still early in the development of interdisciplinary teams, specific strategies to support collaborative clinical practice should be considered by practice leaders throughout the organization. These strategies will be outlined in Chapter 6 as an implication for practice.
Summary of Chapter Five- Moral Decisions and Risk in Community Settings

This chapter has discussed several concepts related to findings that emerged in this study. Moral distress is believed to be part of the experience that community health care professionals described when discussing their ethical decision-making with clients living at risk. Personal and professional beliefs and values will impact moral distress and decision-making processes. Confusion over definitions of capability and legislation may contribute to anxiety and other emotions as well. Respecting autonomy within an environment of scarce resources or unethical organizational climate may also increase moral distress. The professionals in this study felt they were not always able to offer or provide adequate community resources to clients and families, did not always know how to proceed in an ethical way, and did not consistently feel that the organization was supporting their decision-making. While community health care professionals may cope with their distress in many ways, two significant strategies are related to planning care for clients who live at risk- client directed care delivery and collaborative practice within an interdisciplinary team. Chapter 6 outlines implications for clinical practice, education, research and leadership that have arisen from the discussion of the findings in this chapter.
CHAPTER SIX- IMPLICATIONS AND CONCLUSIONS

The articulation of the voices of the nurses and other professionals who cope with ethical problems with clients who live at risk has demonstrated the experiences of these professionals as they try to provide care in ethical ways. In this study, four major themes were identified. These themes include “Our clients who live at risk”, “Worrying about our clients”, “Finding a better way”, and, “Frustrated by the system- hitting the brick wall”. In Chapter 5, I discussed some of the concepts that relate to those themes: moral distress, values and beliefs, client capability and legislative acts, resource allocation, organizational ethics, interdisciplinary collaborative teamwork, and client directed care delivery, including respect for autonomy. This chapter will address both methodological and substantive conclusions. The methodological conclusions will include a summary of the study, limitations of this study, including researcher biases, and trustworthiness considerations. The substantive conclusions include implications for clinical practice, implications for education, and recommendations/implications for leadership. Implications and considerations for future research in ethical decision-making in community settings and final conclusions complete this chapter.

Methodological Conclusions

Summary of Research

The purpose of this study was to explore the experiences of community health care professionals in ethical decision making with clients who live at risk. A constructivist inquiry approach was used to explore this area. One on one interviews were completed, using purposive sampling techniques. Inductive data analysis was used consistent with methods of qualitative content analysis and constant comparison. The
descriptions of community health care professionals' experiences with ethical decision-making led to the identification of four major themes. Thesethemes were: "Our clients who are living at risk", "Worrying about our clients", "Finding a better way-how we cope", and "Frustrated by the system-hitting the brick wall".

Trustworthiness Considerations, Audit Trail, and Limitations of Study

This research was concerned with the ethical decision-making experiences of a specific professional population (community health care professionals) in a specific setting (a large metropolitan health care organization) with a specific client population (clients living at risk). These experiences may or may not be similar for professionals working in other community practice settings. Some of the findings may be similar to what might be found among professionals working in a residential care facility setting (long term care) or home support agency, or with professionals who work with clients in community based mental health services. However, the experiences of health care professionals in acute care settings could be expected to be different, at least in some aspects.

Auditability of research is important to ensure rigor and trustworthiness. According to Peter (2000), “auditability is achieved when researchers describe and justify their research process” (p. 113). The following audit trail is available to ensure this study’s trustworthiness considerations:

- Computerized transcripts of all interviews
- Computerized transcripts of all field notes and journal entries
- Computerized and hand written codes and units from each transcript
- Tentative, preliminary, and final categories as determined during data analysis
There are a number of limitations to this study that need to be acknowledged in this concluding chapter. Bias and aspects of rigor have also been discussed in Chapter 3. The most important limitation that I must acknowledge was that doing research in my own organization certainly challenged my abilities to remain unbiased. Within itself, the fact that I completed research within my own practice setting is a limitation of the study. I will describe specific researcher biases in the next section. I must also acknowledge that my sample size was quite small, although not uncommon for qualitative research within constructivist methodology (Morse, 1991). However, I would have liked to have been able to interview a less experienced social worker, another professional in rehabilitation services such as a physiotherapist, and a nurse who worked in mental health.

Concurrent education in ethics and ethical decision-making for the participants occurred during the data collection and analysis phases; it is not clear how this education might have changed how the participants described their experiences in this study. However, the purpose of this study was to describe the professionals' experiences at a
particular point in time.

Finally, I must acknowledge that because I completed research in my own practice setting, I must be cognizant of possible limitations associated with participant voluntariness. I have discussed this aspect in Chapter 3, but I do not believe that this has had a negative impact on the research study.

Possible Researcher Bias

In this section, I outline those biases that I have had to face as a researcher. As discussed earlier in this thesis, much of these biases are related to my role as a Clinical Nurse Specialist within the organization where I did the research. Because I work closely with many community health care professionals, and have worked with multiple client situations where the clients are “living at risk”, I did feel that, at times, “I knew it all” or “I had seen it all”, so I did not feel very surprised by many of the participants' stories, or by the scope of feelings that they described in their experiences.

I often reflected on how much I might have assumed about the outcomes of this study before I started the research. I also wondered if I had become so immersed in many risk experiences over years of community practice that I could not completely separate out the specific experiences that were described in this study from those experiences described to me in the past. Reflecting on these areas, speaking to trusted colleagues, and bracketing my biases, assisted me to better handle these areas of concern. This also helped me to be less judgmental about the effectiveness of those decisions that participants described to me as part of their decision-making. Furthermore, I realized that I was surprised by the strength and depth of the feelings and emotions of which the participants spoke. Therefore, I believe that I was successful in dealing with many of my
biases in this area.

Associated with this area of bias, I must also acknowledge that I needed to be careful that I did not appear to be “protecting” my own position within the organization and, therefore, slanting my interpretations of the participants’ descriptions to reflect their need for a practice consultant or clinical nurse specialist support. I believe that I did take adequate care to remain unbiased towards these support roles and I was extremely careful to separate my roles during the interviews.

I often reminded myself that I could not assume that all community health care professionals have had previous experience in ethical decision making or that they always recognized ethical problems or issues. I also could not assume that all professionals understood concepts of respect or autonomy and applied them into practice. This was initially of some surprise to me, but, with reflection, this assumption was set aside quite quickly.

I also needed to recognize that I have strong personal values about individuals being autonomous, independent, and being involved in decisions that affect their lives. This is a personal value as well as a professional one. Do I help or hinder ethical decision-making with this strong bias? Since I acknowledge that this value influences my practice, did this impact my research? Was I able to bracket this from coming through in my interviews? To assist me in this area, I reflected on the following statement “We don’t see things as they are, we see things as we are” (Epstein, 1999, p. 834). In this area, I am not entirely certain that I was able to be totally unbiased, although I believe that by acknowledging my bias that I may have diminished its impact during data collection.

I also acknowledged that I am willing to accept quite a high level of client risk
and that others may have different levels of risk tolerance. Similar to the previous value, I had clarified this well before I started data collection and recognized that this must be managed carefully. Therefore, I feel I was successful in bracketing this bias.

Finally, I must acknowledge that, at times, I may have a personal bias in being critical of health care organizations and their support and encouragement of ethical climates during stressful times of change. Did this bias cloud my vision during data collection? Did I bracket these biases during the interviews with the participants as well as during data analysis? Once again, I discussed this issue with trusted colleagues and reflected on how our personal experiences with organizations can impact ethical qualitative research. I believe that I did as much as I could do to possibly diminish the impact of this bias. I always tried hard to truly hear the experiences of the participants.

Substantive Conclusions

Implications for Clinical Practice

The findings from this study give a clearer picture of how community health care professionals experience ethical decision-making with clients who are living at risk. The descriptions of these experiences have implications for nursing and other professionals practicing in community settings. Overall, there is a critical need to ensure that professionals have opportunities to deal with their emotions and concerns when dealing with all ethical problems, including those associated with clients who are living at risk in community settings. This can occur in a number of settings and may also set the stage for using a process of ethical decision-making.
Values clarification and reflective practice.

There are a number of strategies that should be incorporated into practice to address the need for professionals to clarify their own beliefs and values and to reflect on their practice. The literature supports the following directions for all health care professionals, not only those in community health care practice.

Grundstein-Amado (1995) emphasizes the need for a personal value system as a solid ground for a sound decision-making process while Wociol (1996) claims that “Developing a sense of self-awareness is the best tool to use in harnessing emotions and using reason to resolve dilemmas” (p. 154). Use of reflective practice has been described as part of an overall process to assist professionals to deal with the moral distress they experience and may help them make decisions with ethical problems for clients who live at risk. According to Teekman (2000), reflective thinking, when used in practice settings, transforms a situation of doubt or conflict into a situation that is clear and coherent. This process contains significant learning components as well as elements of critical inquiry. Reflective thinking for learning is “an effective strategy to make sense of, and learn from” (Teekman, p. 1127). Teekman also writes that specific situations in practice require reflective thinking as critical inquiry, and must go beyond questions of technical proficiency to levels of thoughtful reflection. Reflective thinking may be used, for example, when professionals take opportunities to discuss their biases and assumptions about clients who live at risk with other team members or practice leaders, or when they review their overall practice with a more critical eye.

Requisite to making clinical decisions is critical thinking— a concept associated with values clarification and reflective practice for assisting ethical decision-making.
Critical thinking is careful, deliberate, goal-directed and encompasses attitudes, knowledge, and skills (Lipman & Deatrick, 1997), and is further defined as "a unique type of purposeful thinking using assumptions, knowledge, and competence to identify and challenge personal beliefs as one explores and creates alternatives" (Sandor, Clark, Campbell, Rains, & Cascio, 1998, p. 21.) Critical thinking may be crucial in complex decision-making situations, such as those found with clients living at risk, where solutions to problems are not readily available (Girot, 2000). Identifying and challenging assumptions is central to critical thinking (Duchscher, 1999), with use of strategies such as found with reflective thinking (Bittner & Tobin, 1998). Various methods such as use of case studies, group discussions, clinical journaling, and use of decision trees and algorithms can also advance the skills of individuals and teams. These strategies are very similar to those that were mentioned as helpful by participants in this study.

Articulating one’s personal “philosophy of practice” can also be an opportunity to reflect on and identify what is meaningful within one’s own professional practice (Kinsella, 2001). This philosophy includes a platform of aims of professional work, goals for clients, goals for self, preferred client/practitioner relationships, and preferred work climate. This approach could also be used within team building strategies, for example, with community based interdisciplinary teams.

Supporting collaborative teamwork.

According to Wociol (1996), utilizing an ethical decision-making process that focuses on collaboration is the best way to prevent moral distress and its consequences. Working together to achieve collaborative solutions to ethical problems takes effort, time, and commitment. Within this study, the importance for staff who are dealing with
ethical problems to have an interdisciplinary team environment for collaborative
decision-making emerged as a vital aspect. Within the overall support system for
professionals who make ethical decisions, the development of highly functioning
interdisciplinary neighbourhood based teams appears to be a priority for community
practice. These teams, in order to become effective must have a high level of support
from the organization. However, individual team members must also be willing to engage
in “collaborative moral reflection” (Wociol).

Within their team environments, community health care professionals talked
about the importance of those "who know the community". Experienced support persons
and practice leaders must be available to facilitate decision making processes, support
staff through clinical problem solving, and assist professionals to deal with the discomfort
of client risk. Managers, clinical nurse specialists, practice consultants, educators and
clinicians must be readily available to provide this support and mentor all staff.
Individual team members should also be encouraged to assume leadership roles for this
support.

Coping with capability in ethical care planning for clients who live at risk.

Will it help community professionals if they believe that they can better use
capability assessments? Many of the complex clients that community health care
professionals described in their interviews appeared to have capability issues; the
presence of these issues increased the professionals’ anxiety and fear. Ethical practice
and respect for autonomy will be complicated when professionals view autonomy as
appropriate only when their clients are competent to exercise it. Professionals who
support and respect autonomy “allow” their clients to think independently, use their
judgments, and pursue their own goals, within possible limitations of capability. Perhaps, it would help to support community practice if we can understand that professionals may be able to adequately support the partially capable client without a formal competency assessment. The Baycrest Competency Clinic (Toronto, Ontario) screens all referrals for competency assessments by requesting explicit information about the necessity of the examination and outlining benefits of the assessment (Silberfeld, 1992). Donelly (1996) suggests that “the best standard of care that physicians can follow in considering competency is to do a thorough assessment focusing on the patient’s ability to function and addressing the patient’s unique needs” (1996, p. 484).

In assessing capability/competency in community clients, according to Browne, Blake and Donelly (1997), three specific areas will need to be considered:

1. Whether the person is competent to live alone,
2. Whether the person can make health care decisions,
3. Whether he/she can handle finances.

An incapability/competency assessment should examine the specific decision being questioned about the client. Furthermore, in order to be credible, competency statements must also specify the extent of the incompetence, and must include information regarding a client’s ability to make choices, give directives, and do for themself (Silberfeld, 1992). Silberfeld and Kane (1998) also recommend that different criteria be examined related to what is the particular decision that needs to be made at a particular time. Ideally, examination should look at task-specific competencies, since clients will have different abilities to make different kinds of choices and may be competent to make some decisions but not others. A client who is not capable of making
some decisions, but is living with tolerable risk, for example related to finances, may be able to continue to live at risk, with support and resources. Capability assessments, similar to risk assessments, can be used as a tool to aid clinical decision-making. A failure, for example on a memory test, may imply a risk only for specific areas of decision-making, such as those decisions involving finances.

The literature (and legislation in British Columbia) suggests that it is our responsibility as health care professionals to maintain as much autonomy as possible even when the client living at risk may not be able to make decisions in some areas. A nurse or other professional’s advocacy role involves providing the client with an opportunity to make autonomous decisions and promoting the respect for that person “as a moral agent to act on his or her own behalf” (Valimaki et al., 2000, p. 10). While some aspects of decision-making must be delegated, being allowed to make small day to day decisions can still have an impact on a person’s sense of control. As client advocates, nurses and others, aware of the client’s values and beliefs, can foster the best interests of their clients (Davies, Laker, & Ellis, 1997). Other interventions that can directly support a client’s autonomy include supporting informed consent procedures, assisting clients and families to increase their knowledge about rights in health care and social care, and offering options to the client even if the health care professional does not personally like the options, such as when the client could remain at home and live at risk.

Community health care professionals in this study described a process that assisted and supported their decision-making with their clients. Kuhl and Wilensky (1999) write: "The moral quality of a clinical decision is dependent on the process of that decision and is not only the outcome. We are accountable and responsible for the way in
which our decisions are made” (p. 75). Does this process include carefully setting aside personal and professional biases? Is part of the professional's process an acceptance that clients can take responsibility for their own actions? Could part of this process be ensuring that their client care plans reflect the rights of their clients to be independent, make choices about risk, and to direct their own care? These are areas for further research; however, participants did describe “finding a process” as an effective strategy. Perhaps being able to articulate and use this process, if clearly supported by the organization, could help them feel better about their ethical decisions.

Client-directed care delivery.

Participants in this study often mentioned client-directed approaches as helpful for decision-making. Active participation in such caring, client directed relationships provides both clients and health care professionals with a voice in decision-making, promotes a shared sense of responsibility, and holds participants responsible for consequences (Koloroutis & Thorstenson, 1999).

In a positive professional/client-directed relationship, professionals can assist the client to review the consequences of their actions and be accountable for their own decisions/behaviour. Yet it must be acknowledged that health care professionals can not always assess how much responsibility a client may want to accept. I propose that a philosophy such as client directed care delivery can be part of this process that supports professionals involved in ethical decision-making and may give support and guidance to staff when making ethical decisions with clients who are living at risk.

Within a client-directed care approach, a health care professional’s approach to risk may include a number of steps (Berg, 1998). The first step is the necessity of the
professional to reflect on, and set aside his/her own personal and professional values, beliefs, and biases (V/RHB, 2000a). This would be followed by assisting the client to articulate his/her values, goals, and needs, identifying the client’s actual or potential risks as well as their strengths, and establishing how the client perceives, identifies and assesses his/her risks. The outcomes of the identified risks, including both the benefits and harms, would be discussed, as well as what value or meaning the client has attached to an action/inaction. Establishing realistic goals with the client and ensuring that the client has made decisions with full information would follow.

Ongoing support for a client who is living at risk would include continuing to support the client, building and maintaining trust and communication, appreciating the need for the client to maintain control of their situation, and ensuring that the client is informed about risks and outcomes/consequences of these risks throughout the process. Maintaining objective documentation, including capability information, and reviewing the client’s care plan regularly, would also be important. Finally, it would be critical to ensure that community health care professionals are dealing with personal and team feelings and emotions, and are using colleagues and resource people for support (Huston, Allen, & Roy, 1993).

Within this overall conceptual framework of client-directed care delivery, future research may substantiate theories on how community health care professionals are best supported to participate with the client in sound ethical decision-making in situations that may involve a high degree of risk.
Implications for Education

Education needs related to ethical decision making for professional staff were mentioned several times by the participants in this study. Many of these education needs could also be built into concurrent team building strategies. These needs included the establishment of an integrated comprehensive education program that would include the following concepts: values clarification and reflective practice; interdisciplinary team building strategies to create “trust environments” for collaborative care-planning; and, case conferencing supported through education and role modeling. Understanding the principles of conflict management, cultural competence, and risk assessments along with basic ethical principles and ethical decision-making strategies or frameworks would be helpful for community professionals. Professionals also need education about specific legislative acts, including the Adult Guardianship Act. They also need working definitions of capability and how to assess for capability in their clients.

Implications for Leadership

The creation of supportive environments for ethical decision-making must be one of the aims of effective organizational leaders. Rodney & Varcoe (2001) agree in describing how nurses (and, surely, other professionals) need access to a supportive network of well-prepared colleagues and practice leaders. I believe that community health care professionals, like most professionals, want to provide the highest standard of ethical care possible, but that they need support to do this. The participants in this study spoke about trying to be client directed and asked for support in making ethical decisions. Participants in this study often mentioned that those in leadership positions were
important to them as they attempted to make ethical decisions with their clients who live at risk.

A critical element in ethical leadership is the way that an organization’s key values are communicated to staff. Strong, visible, and consistent support for organizational values from senior management needs to be present to encourage staff to see ethical problems in their workplaces. Organizational leaders must commit to “living” the organization’s values and principles; they must model and demonstrate these principles, since “articulated values have no meaning or use if they are not demonstrated in the lives of organization members” (Koloroutis & Thorstenson, 1999).

A policy statement alone will not create a strong ethical climate. Integrity— the intentional use of values to guide decisions (Potter, 1999)— in health care environments can occur when there is courage to do the right thing in difficult situations (Kerfoot, 1999). I have chosen to include the following recommendations to leadership in health care organizations in order to support professional staff, primarily at micro and meso levels, in ethical decision-making with clients who live at risk. I have also related these recommendations to the themes that I identified in the study.

The first five recommendations relate to the theme “Finding a better way—how we cope” and are as follows:

1. Ensure reliable, consistent access to clinical expertise and support, for example, experts/resource people such as managers, practice consultants, educators, and others who “know the community”.

2. Ensure consistent basic orientation, basic education, and ongoing/continuing
education in ethical decision making and associated concepts. Integrate ethical
decision-making into overall practice, in other words, do not just isolate it to the
bigger problems.

3. Identify a flexible process for dealing with ethical issues for clients living at risk.
Provide adequate guidelines and policies to support associated issues or variables
with the decision-making process. Involve the staff in the development of this
process. This will also assist them to have ownership of the process. Provide
leadership to assist them to use this process in one on one or small group discussions,
or case conferences. Ensure a similar process is defined for care coordination and case
conferencing to support emotional concerns and clinical decision-making.

The next six recommendations primarily relate to the themes “Finding a better way”
and “Worrying about our clients”:

1. Provide support to interdisciplinary teams for decision-making and team building.
Support and build on individual and team capacity when advancing skills and
knowledge, and when professionals are "using each other" for emotional support
and clinical decision-making support, for example, group facilitation skills. Outline
strategies for dealing with the impact of group dynamics, such as groupthink, on
decision-making. Encourage professionals to include clients and families at case
conferences.

2. Provide a flexible, transformational leadership approach and support across the
region, at local sites, and within a changing and learning organization. Essentially,
this also includes a need to “back up your staff!” especially when they have
demonstrated utilization of an appropriate process to make their clinical and ethical
decisions. Ensure that leadership values match organizational values.

3. Ensure access to timely “defusings” or critical incident debriefings by appropriate,
available and trained individuals, including team members. Encourage professionals
to find appropriate strategies for dealing with their emotions and feelings, and support
for “letting go”. Consider the role of leaders in helping professionals to understand
that they will not always feel good about their experiences with clients who live at
risk, but negative feelings may be diminished with the support of their teams and
leaders.

4. Recognize and act on the importance of equipping professionals with enhanced
communication skills and other strategies to deal with their own anxiety with families
and others who are participating in decision-making.

5. Encourage professionals to feel comfortable to be involved in decision-making
especially related to how scarce resources are rationed or allocated and how priorities
are set. Encourage professionals to identify resource allocation concerns and to
document and report them to management. Assist staff to realize that resource
decisions are made daily by professionals and "are influenced by constraints that may
have to be critiqued" (C.N.A., 2000, p. 11).

6. Support and offer opportunities for staff to participate in research into practice
issues, including ethical decision-making for clients who live at risk and others.

The following recommendations speak more specifically to the theme “Frustrated by
the system”, and might be implemented at both the macro and meso levels of
responsibility.
1. Demonstrate a commitment to being “an ethical organization” or a "moral community", essentially a safe environment where staff can share information and are supported in their decision-making with formal and informal measures. This culture can encourage staff to challenge their own practices and achieve "ethical fitness" (Storch, 1999).

2. Support the work of regional and local ethics committees. Work with other leaders and front line staff to review the roles of these committees and their redesign within the care delivery model and organizational structure.

3. Within a quality improvement framework, set up processes to monitor and evaluate the organization's ethical performance, for example, client/family and staff satisfaction surveys, and ethical climate surveys. Focus groups and semi-structured interviews may also be effective in this area.

   Teamwork, clinical decision-making, and other aspects of ethical decision-making such as conflict resolution, values clarification, and reflective thinking take time and commitment from all levels within organizations and must be acknowledged within an overall environment of support. Community health care professionals will more likely integrate ethical principles and behaviour into practice when ethical behaviour and decision-making is modeled by those in leadership positions within organizations.

Implications for Future Research

This study, as might be expected, elicited more questions than answers. More research is needed in community practice settings in a number of areas that impact ethical practice for community health care professionals. I have mentioned areas where research
may be helpful at a number of places throughout my analysis. I will now elaborate on the implications of this study for research.

More evidence is needed to determine and validate those behaviours and system supports that would positively impact ethical decisions, both with clients who live at risk and other populations of clients in the community. When education in ethical decision-making within an organization occurs at orientation and as ongoing continuing education, evaluative research centered on the impact of these programs on practice should also occur. The experiences of professionals who work with other client populations also needs study. For example, what is the difference between coping and decision-making with clients who live at risk and other populations where there are ethical issues, such as palliative care?

There are a number of other areas that could provide significant insight into the ethical decision-making of community health care professionals. Are there differences in how the organization’s leaders approach ethical problems with their staff, and does this have an impact on the decision-making process? Do these differences in approaches also impact overall stress that staff may be experiencing, therefore impacting on how staff coped with all aspects of client care, including ethical decision-making? What type of support, leadership, or facilitation do different types of teams need?

The impact of reflective, mindful practice, values clarification, and critical thinking needs to be studied. The impact of client directed care delivery as a community based care delivery philosophy should also be researched. This research could include clarifying an ethical decision making process and the integration of the process into practice.
Another area of research could focus on the feelings that the health care professionals experience. Many of the feelings described by the participants in this study might be called "bad feelings". The concept of "good feelings" did not completely come up on its own in this study. Two participants were asked about whether they could identify "good feelings" experienced during ethical decision-making with clients who live at risk. One participant responded:

"I think that people who are experienced, who have lived through the experience and have seen some good things, who have supported others in their experiences, maybe feel a lot better about ethical decision-making with these clients. Maybe it's a confidence too..."

Another respondent felt that "good feelings" or "feeling better" might be related to: "Making a difference", or "When we bring our goals together" (client and health care professional). Was decision-making impacted by the amount or type of previous experiences with clients who live at risk? When a professional, for example, has had more experiences with clients who live at risk, did they approach situations differently, or "feel better" about the experience? Associated with this, is there a need for more research to determine what will help professionals "feel better" about their decisions? Is it important that professionals "feel better" at some point in this process?

Furthermore, how did professionals really decide that clients were living at risk? Are these clients that professionals are concerned about actually "living at risk"? What might be the impact of increased knowledge regarding risk, risk assessments, or capability on decision-making for clients who live at risk? What is the impact on ethical decision making when professionals label some clients as "difficult clients" or "non compliant clients" or "clients that we don't like"? Do professionals consistently cope
with these clients in ethical ways? These are all areas for future research.

Discipline-specific differences in values and decision-making also need further research. Within this study, there arose two questions related to professional discipline that could not be clarified and should be studied further. These questions are: Did the discipline of the community health care professional make a difference in decision-making? Was there a difference in how members of different disciplines, for example, nurses and social workers, approach ethical problems with clients who are living at risk? Some research has been done in this area, but it has not provided clear direction for community practice. Research should also look at how ethical values have been incorporated into the organizational values of large regional health organizations, and therefore, the kinds of ethical climates that are being created.

Finally, I would also add that qualitative research within a constructivist feminist inquiry may be especially beneficial (Peter, 2000; Rodney, 1997) since these methods may be more sensitive to the complexities of ethical problems in community practice. As health care delivery in the community becomes more client-directed, feminist ethics may help support the view that while persons are connected to others, oppression is a fundamental moral wrong and nurses must be on guard for relationships built on power and control (Peter; Rodney). Furthermore, feminist ethics emphasize “everyday” moral struggles and would be particularly interesting in community practice settings where little research in ethical decision-making has been completed.

**Final Conclusions to Chapter Six and Thesis**

What does it feel like to be a community health care professional coping with ethical decision-making problems with clients who are living at risk? The participants in
this study told me that they often felt worried, afraid, angry, frustrated, and guilty as they worked through their clients’ issues. They told fascinating stories about their clients who lived with multiple risk factors in difficult situations—clients with significant cognitive, decision-making concerns, and family dysfunction, even abuse. The participants in this study felt frustrated by the lack of resources that they could access, trying to balance the care of these clients within workloads that did not allow them to fully participate in effective processes of ethical decision-making or supportive discussions. They coped by finding support from their team members, from those who, in "knowing the community", could contribute insight and experience, and by finding processes to assist decision-making.

These professionals appeared to describe feelings of moral distress, and, in their desire to provide better care; as such, they described needing considerably more support within the organization to ensure that their feelings were adequately supported and that their ethical decisions were made with consideration and reason. It is of interest to me that most staff did not specifically identify that they needed more training in ethical decision-making. It is also interesting to me that professionals sounded as if they believed that much of the help that they needed must come from “above”; for example, the help needed was seen as a responsibility of those at leadership and management levels, and not their responsibility. Is this perhaps an indication of their perception that they lacked power to change the support structure unless decisions came from those with direct power and leadership, from those who are perceived to have decision-making control in the organization? Are they overwhelmed by workload demands and therefore perceiving that they lack the time to initiate any of their own steps to enhance their
support systems? I am not clear on what this means and how it contributes to the overall feelings of moral distress that they described to me. Perhaps they just recognize that, with ethical problems, sometimes there are no right answers.

Much remains to be discovered about the ethical issues found in community health care practice. This study has provided some insight into the experiences of community health care professionals who are striving to make ethical decisions with their clients who live in community settings, including clients who live at risk. It is clear to me that much can be done to improve clinical and educational support for these professionals. Organizations and their leaders must take responsibility for initiating much of this change. Furthermore, a significant amount of research is still needed to further understand this practice setting and, therefore, advance practice in this area.

This chapter concludes with two quotations that I believe summarize the essence of what community health care professionals, within supportive environments, might be seeking, as they cope with ethical problems with clients who live at risk. MacMillan (1994) writes:

"To learn acceptance of risk or responsibility calls for courage. The ability to be courageous is about dealing with the anxiety which is intrinsic to thinking and listening to others' needs" (p. 255).

Lynch (2000) also speaks of courage:

"To begin to speak about ethics is to ask ourselves, 'What kind of world do I want to live in?' If we want an environment in which there is respect for others, honesty, compassion...we have already set a context for our discussion. With those values as guides, we now think about how to ensure that they endure by way
of our actions. Finally, of course, it comes down to courage—how to act when I know what to do, but when I also know that what I should do will be very difficult for me." (unpaged).

If courage is needed for community health care professionals to be ethical with clients who live at risk, then courage is also needed by ethical health care organizations. Ethical and courageous leadership within visionary health care organizations will ensure that professionals have clinical support, education, and research to make these difficult clinical decisions. Can we meet the challenge?
References


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Appendix A

THE FLOW OF CONSTRUCTIVIST INQUIRY

(Adapted from Lincoln and Guba, 1985, p.188).

Natural setting

Human as instrument/researcher as instrument

Building on Tacit knowledge

Using Qualitative methods

Purposive sampling via 1:1 interviews

Emergent design and ethical considerations

Inductive process via concurrent data collection analysis (coding, unitizing, categorization, memos)

Grounded theory principles

Development of themes/constructs

Involving

Negotiated outcomes and presentation of preliminary findings, tentatively applied

Leading to future steps

Further validation, a case study or case report, presentation of final findings, and termination of inquiry process
Appendix B

Sample Trigger Questions for Interviews

The interview is intended to be semi-structured. The actual questions that will be used in interviews must be guided by the data needs that may unfold during the interview process, or the data needs required by emerging themes/constructs. These questions, as initial trigger questions, are intended to be more general and open-ended. Actual questions will become more specific throughout the interview process for testing and validating merging data, themes and constructs.

Trigger questions

1. Tell me about your experiences of ethical problems working in the community with clients living at risk.
2. What are some of the situations with clients living at risk that you have felt might be ethical problems?
3. What kind of feelings do you experience when you make ethical decisions about your clients?
4. How do you make ethical decisions about your clients?
5. How do you feel once an ethical decision had been made?
6. How does the environment affect your decision-making process?
7. What was helpful or unhelpful or hindering for you in your decision-making process?
Appendix C

Prompt Questions for Interviews

1. Tell me about one of your clients who you believe is living at risk?
2. Tell me how you decided that your client was living at risk?
3. *(If an ethical problem is identified during the interview)*, what aspects of this situation made you believe that this was an ethical problem?
4. We all have personal values and biases that influence our decision-making. For example, *(If an ethical problem is identified during the interview)*, what kind of personal values, biases and assumptions do you see in this situation?
5. How did you make your decisions about this client?
6. Who else was involved in the decision-making process?
7. *(Specific to client or general)*, for example, are there some policies that hindered your abilities to make ethical decisions with clients who live at risk?
8. *(Or, what kind of organizational supports do you think were available to support you in your decision-making process?)*
9. The (organization) has developed a risk assessment tool and an ethical decision-making process/framework. Did you use these? How did these work for you?
10. What other strategies could be used to support you in your decision-making?
11. We hear a lot about “being ethical in our practice.” What does that mean to you?
Appendix F

Questions for Interviews 6 and 7

1. Tell me generally about your experiences with ethical problems in working in the community with clients who are living at risk. Please use examples if you wish.

2. The following are some of the feelings that have been identified by others that I have talked to. (list-anxiety, fear, frustration, powerlessness, anger, etc.) Are these some of the feelings that you have experienced when working with these clients?

3. You identified these feelings as part of the experience you have had (eg. anger, fear, etc.) (or others have had). What might cause these feelings?

4. I have heard a lot about “bad feelings” for people with their ethical problems? Are there any “good feelings”?

5. Many participants have spoken to me about how they cope with these feelings in their experience. Many use other people, eg. the team, to help them cope. How have you this worked for you? How might the team hinder your ability to cope or make a decision?

6. What else has helped you cope with or deal with those feelings? eg. having a process, “knowing the community”

7. What actually helps you make ethical decisions with clients who are living at risk? (or do any of the following things from “a process” help you?)

8. What could the organization do differently to support ethical decision-making with the living at risk client population?

9. What else is helpful or unhelpful or hindering for you in your decision-making process? Or what influences how you make the decisions? (positive and
negative influences) Or, what kind of organizational supports do you think should be available to support you in your decision-making process?

10. We all have personal values and biases that influence our decision-making. For example,.....(If an ethical problem is identified during the interview), what kind of personal values, biases and assumptions do you see in this situation? (Or refer to cultural values or professional values.)

11. One of the things that people have talked to me about with ethical problems with clients who are living at risk is capability issues. How do you think these influence decision-making? What kind of help do you think you need to deal with these issues?
Appendix G

adapted-October 2001 RISK ASSESSMENT TOOL

I. Purpose

The purpose of the risk assessment tool is to promote collaboration between clients, caregivers, and health professionals in identifying client strengths, areas of risk and the resources that are currently in use to provide safe care in their home environment. This information should provide the basis for realistic care planning.

II. Considerations

1. Prior to doing a risk assessment the health care professional should spend time with the client so that he/she can clarify his/her goals and values.

2. Consultation between client, caregivers and health care professionals is an essential part of risk assessment. The caregiver may be a spouse, family member or significant other. If consensus is not reached about client risk this should be identified.

3. Individual risk factors may be tolerable. A risk for one person may not be a risk for another due to their personal strengths, support system and environmental supports. When there are several risk factors the client's overall risk may become intolerable.

4. Client goals, strengths and supports, together with the identified risks should provide direction for the development of the care plan.

5. Levels of risk are assessed as follows:

There are three levels of risk:

- 0 No risk- no intervention required.
- 1 Tolerable risk-intervention may or may not be required.
- 2 Intolerable risk-(as determined by the six elements)-intervention required.

Intolerable risk has six elements:

- A change in the person that impairs his or her ability to protect himself/herself or others, from harm
- Evidence of current decline/severe change in condition
- The severity of the anticipated harm
- The high probability that decline/severe change will occur
- The imposition of risks on others
- The inability to choose to run a risk

(adapted from original risk appraisal work by Geriatric Clinical Practice Working Group, April 1997, and 2000. Full assessment available.)