# Everyday Ethics in Case Management:

# Experiences of Moral Distress by Professionals in a Community Health Care Setting

by

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Abstract

Academic research has recognized and explored ethical issues and experiences of moral distress in acute care settings for many years now. The same cannot be said for ethical issues in the community care setting. Perhaps more than ever, as treatments and care are shifted out of institutions and into the home, today's health care professionals face unique and difficult ethical issues. The purpose of this study was to examine experiences of moral distress related to everyday ethical issues by analyzing data collected from a cohort of professional case managers working in a community health care setting in northern Ontario, Canada. The objectives of the study were to investigate the nature of ethical issues in the community health care setting; explore experiences of everyday ethical issues and moral distress; identify barriers to ethical practice and evaluate the available resources.

Quantitative and qualitative data were gathered using an original, self-administered questionnaire developed by the researcher. This questionnaire was distributed to case managers employed at North West (Thunder Bay and region) and North East (Sudbury and region) Community Care Access Centres. The response rate to the questionnaire was 31%, representing 66 participants from a pool of 215 potential participants. The results showed that everyday ethical issues were prevalent in this professional setting, often encountered on a weekly basis. Participants described a moderate to high level of confidence to identify, address, and resolve everyday ethical issues in their practice. Ethical issues were described as a combination of the theoretical categories of autonomy, beneficence, nonmaleficence, and justice, therefore representing complex, multi-factorial scenarios.

Experiences of moral distress were described as occurring with moderate to high frequency and intensity, most commonly expressed with emotional symptoms. The most influential coping strategies were identified as 'talking to colleagues' and utilizing 'supportive leaders'. Barriers to ethical practice included the lack of resources, restrictions based on policy and regulations, and issues related to conflict and communication. Experiences of moral distress were closely related to a lack of resources and time constraints.

Recommendations for further research include the need to identify interventions to increase ethical competence and to provide opportunities to encourage healing from experiences of moral distress. The researcher recommends that community agencies adopt strategies which foster opportunities to identify and discuss experiences of everyday ethical issues and moral distress. Avenues which may increase capacity for ethical competence may include: formal educational opportunities; agency commitment to the ongoing development of an active ethics committee; informal collaboration among colleagues, supervisors, and organizational leaders; and attention to maintaining or improving the work environment to encourage successful coping, enhanced confidence and empowerment. While issues of increased workload, lack of time, and inadequate resources are unlikely to ever be resolved in the near future, opportunities to problem solve and share strategies provide much needed support for health care professionals working in the community care setting. Further studies using qualitative methodologies of storytelling and reflection will provide further insight into experiences of moral distress and its unique manifestation in the community care setting in northern Ontario.

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# CHAPTER 1: INTRODUCTION TO THE STUDY

## Statement of the Problem

Experiences of everyday ethical issues and the impact of moral distress have an unknown effect on the professionals involved and the patients in their care (Fry, Harvey, Hurley & Foley, 2002). Everyday ethical issues often involve the challenges of meeting the client's needs while still respecting organizational demands. It is this tension between competing loyalties that often contributes to experiences of moral distress. "The literature supports the position that nurses experience moral distress in their day to day practice lives" (Zuzelo, 2007, p. 348). Therefore, opportunities to more fully define ethical issues and the resulting phenomenon of moral distress provide much needed insight into the positive strategies that demonstrate strength and hope in community-based health care.

Due to the fact that the prevalence, frequency, and intensity of moral distress experiences have not been fully explored in the community health care setting, this study provided an opportunity to identify issues which may be unique to this dynamic setting. Additionally, the researcher sought to investigate the impact of the available resources and barriers which influence the ability of these professionals to conduct ethically sound practice. The purpose of this study was to explore and examine experiences of moral distress related to everyday ethical issues with professional case managers working in community health care settings in northern Ontario, Canada

## Objectives of the Study

This study sought to…

- Investigate, through the development and implementation of a quantitative descriptive research study, the nature of some of the key ethical issues faced by health professionals in a community health care setting.
- Explore and examine the scope of experiences of everyday ethical issues and moral distress, and the perceived level of confidence to recognize, address, and resolve these issues in professional practice.
- Identify barriers to ethical practice and evaluate the resources which are available to these professionals to assist them in resolving everyday ethical issues and experiences of moral distress.

# CHAPTER 2: LITERATURE REVIEW

It is important to undertake a thorough review of the literature to understand the academic progress that has been made and identify the gaps in knowledge which are related to ethical issues and experiences of moral distress in the community care setting. In this literature review, ethical issues in both acute and community care are explored. Also, the phenomenon of moral distress is discussed as it relates to the perceived prevalence (whether or not it occurs), frequency (how often it occurs) and intensity (level of emotional, physical, or psychological impact) of these experiences. Finally, the author explored the potential role of resources and barriers during ethical decision making and moral distress experiences. To begin, it is often helpful to gain a historical perspective before moving on to more current trends and issues.

## Historical Overview of Nursing Ethics

"Historically, nurses were expected to accept authority and not participate in patient care decision making" (Austin, Lemermeyer, Goldberg, Bergum & Johnson, 2005, p. 35). In the tradition of the military and religious underpinnings of the profession, nurses were expected to follow direction without question. "In 1968, the first of several revisions (to professional codes of ethics for nursing) sought to eliminate the rules of etiquette and finally emphasize the ethical responsibilities of the nurse" (Levine, 1999, p. 213). A more detailed review of ethics literature specific to nursing is provided by Pence (1983), and Storch, Rodney, and Starzomski (2004).

The expanded professional role of the nurse has led to more detailed codes of nursing ethics that guide decision-making, behaviour, and ethical action. In 1980 the Canadian Nurses Association adopted its own code of ethics which has undergone a

number of revisions in order to encompass the complexities of ethics in professional nursing practice in Canada (Canadian Nurses Association, 2002). The latest revision has actually just been released (Canadian Nurses Association, 2008). Unfortunately, this increased professional responsibility has not necessarily been accompanied by an increase in participatory power. "Nurses often have more responsibility than authority" (Corley, Elswick, Gorman & Clor, 2001, p. 251). This sense of professional and moral responsibility extends not only to the patient and family, but also to colleagues, the organization, and indirectly, to the health care system as a whole. However, without the power and authority to fully utilize professional judgement to influence decisions and outcomes, nurses are often left feeling responsible for outcomes that are not within their power to control. Therefore, the author proposes that nursing ethics is still in the early stages of growth and development.

## Ethics

The more general topic of 'ethics' itself is also a work in progress. A solid, comprehensive definition of this concept remains elusive. "Ethics may be defined as the application of moral philosophy in an attempt to deal with questions of right and wrong" (Sellman, 1996, p. 44). However simple this may seem on the surface, questions about what constitutes a right or wrong action, and who is entitled to determine this, makes ethics a formidable discussion arena. Ethics in professional practice is "not the display of one's moral rectitude in times of crisis...but the day-to-day expression of one's commitment to other persons and the ways in which human beings relate to one another in their daily interactions" (Levine, 1999, p. 846).

"Ethics should help clarify and present the alternatives when you are faced with a difficult decision" (Hebert, 1995, p. 2). There are many theories and ethical frameworks available to professionals to facilitate decision making, however a single correct course of action is rarely determined. "There is no one 'ethics' that can be applied to any professional dilemma" (Shotton, 1997, p. 260). Professional ethics are interwoven with the profoundly held values of the group. Principles and ethical guidelines have developed over time within regulatory bodies and professional associations to guide the actions of professionals, inform judgement, and assist with decision making. "Knowing what is best is essentially unpredictable within a complex unique human encounter, presenting the practitioner with uncertainty and dilemmas about the most appropriate way to proceed" (Johns, 1999, p. 288).

Nursing has traditionally been closely tied to virtue ethics (Hursthouse, 2008). Feminist ethical perspectives have also been a topic of debate in regards to their application to nursing ethics (Liaschenko, 1993). While there are many ethical schools of thought, the application of these theories to the community health care setting remains a challenge that may look good on paper but remains stunningly difficult in practice. This is not to say the ethical issues in the acute care setting do not provide significant challenges.

*Ethical Issues in Acute Care Settings*

Ethical issues in acute health care have been recognized and researched in a number of areas. These include critical care (Elpern, Covert & Kleinpell, 2005; Meltzer & Huckabay, 2004; Erlen, & Sereika, 1997; Corley, 1995; Rodney, 1988), palliative care (Schwarz, 2003; Soloman, O'Donnell, Jennings, Guilfoy, Wolf, et al., 1993), neonatal

intensive care (Penticuff & Walden, 2000; Hefferman & Heilig, 1999), pediatric intensive care (Perkin, Young, Freier, Allen & Orr, 1997; Davies, Clarke, Connaughty, Cook, MacKenzie, et al, 1996), maternal-infant care (Jameton, 1993), and among newly graduated nurses (Kelly, 1998).

Ethical issues are often categorized using the well accepted terms of autonomy, nonmaleficence, beneficence, and justice (Beauchamp & Childress, 2001). These authors define the concept of autonomy as based on the belief that an individual has the right to make an informed choice on issues that impact their life and their health. The individual is encouraged and supported by professionals and never forced or fooled into choosing a predetermined outcome. As well, the concepts of nonmaleficence and beneficence involve weighing the options to determine the 'best' course of action. Certainly issues such as informed consent and decision making capacity become more complex when the client is affected by mental or emotional disorders which may diminish his or her capacity to fully process information and comprehend the resulting consequences. Finally, the concept of justice relates not only to fairness to the individual but also to fairness to society. Justice incorporates issues of resource availability and budget constraints, which have become a powerful decision-making factor in many health care agencies.

These key concepts are often considered a starting point for ethical decision making. However, it is well recognized that theory cannot possibly encompass all of the complex factors of a real life scenario. "Ethical issues occur that are embedded in the context of relationships, and issues that revolve around the manner, time and place in which they happen" (Austin et al., 2005, p. 33). "The bioethical emphasis on

intermittently occurring and dramatic problems tends to divert attention from the acute ethical pressures of daily nursing practice" (Corley, 2002, p. 637).

*Everyday Ethical Issues in Community Health Care Settings*

Everyday ethical issues that occur in the community setting may appear similar to acute care scenerios but "are made more complex because of the influence of the setting (isolation from nursing colleagues, role ambiguity, the shift in control, family dynamics, and the increased need to collaborate)" (MacPhail, 2001, p. 2). "The nurse may be the deliverer of care, but the setting is borrowed and every interaction is negotiated with respect to this" (Stulginski, 1993, p. 405).

In an article written by Burger, Erlen, and Tesone (1992), key factors which impact on ethical decision making in the community setting were identified as: a shortage of time to holistically assess the client's needs, increased client autonomy in the home setting versus an institutional setting, the presence or absence of a support system for the client, difficulty with communication among the interdisciplinary team members, and lack of ethics resources and supports. The authors noted "the potential for clashes between the overall goals of the agency and the ethical and professional responsibility nurses have to their patient" (Burger et al., p. 17). Many recommendations have been made to encourage the effective management of ethical issues in the community setting. As is usually the case, education was recommended as the number one strategy. Education may be delivered using one day seminars, ongoing staff-development programs, agency support groups, ethics forums, journal clubs, or establishing a formal ethics committee. The focus of these educational forums should be on raising awareness of ethical issues and providing the staff access to resources for support. Although this

article was written over 15 years ago, the authors reported, "Ethics committees in home healthcare agencies are an idea whose time has come because ethical dilemmas in home care will only increase" (Burger et al., p. 20).

As home-care services increase and expand, so must the roles and responsibilities of the professionals in these areas. In a qualitative, grounded theory study conducted by Schoot, Proot, Legius, ter Meulen, and de Witte (2006), ten Dutch nurses were interviewed about their perceptions of their role in home care nursing. The authors recognize that "little is known about home care nurses' perceptions regarding their realization of everyday client-centred care in the actual context" (Schoot et al., p. 233).The participants identified various competing roles and responsibilities related to everyday care. Firstly, the role of the responsive professional was identified as competing with being a critical professional and a developer of client competencies. This was linked to the challenges of respecting the client's wishes and autonomy versus choosing effective treatment options and promoting beneficence. Secondly, the role of the responsive professional often conflicted with the individual nurse's needs and role as an employee. Issues such as working hours above and beyond scheduled shifts and not charging for services were identified. This often occurred after a strong professional relationship had been established with clients over time. Efficiency, time management, and financial responsibility to both the client and the organization presented as significant concerns for the nurses in this study. The participants recognized the constant challenge between meeting client needs and respecting organizational demands. The authors suggest that in order to effectively balance these competing responsibilities nurses must be aware of the dynamic roles involved.

*Precipitating Factors*

Due to a strong professional relationship with clients, nurses often assume the weighty responsibility of ethical decision making in spite of the complex nature of many ethical issues. "Actions occurring as part of the therapeutic encounter are constrained by beliefs and practices of both patients and providers which are related to research and available technologies, ideas of medical uncertainty and futility, and economic and educational interests that extend far beyond the individuals involved, as well as constraints set by reimbursement and accrediting agencies" (Liaschenko, 1995, p. 186). The fact that caring relationships occur in spite of so many challenges speaks to the commitment of the professionals involved, both to their clients and to their vocation.

*Impact of Setting*

Work done by Penticuff and Walden (2000) also echoed these same issues related to the impact of setting on ethical practice. The impact of setting was found to be mitigated by ethics education and increased number of years in professional practice. The competing responsibilities related to agency needs versus client needs continues to provide a difficult tension in ethical professional practice (Gunther & Thomas, 2006). The concept of 'multiple masters' as described by Meaney (2002), highlights the difficulties that nurses face when trying to make decisions which impact various stakeholders with very different needs.

For community health care professionals in northern and rural communities, there are some significant issues which impact on their practice and on their experiences which relate to setting. Conflicts and tensions often arise for professionals practicing in these types of settings in the following areas: insufficient health care service resources, health

care provider shortages, compromised accessibility related to distance and travel requirements, financial stress in rural health care agencies, and professional isolation (MacLeod, Browne, & Leipert, 2008).

*Relationships and Ethical Practice*

The connection between relationships and ethical practice was explored in a qualitative meta-analysis of three studies done by Varcoe, Rodney, and McCormick (2003).The studies chosen were ethnographies exploring relationships in health care. They discovered that "relationships in health care practice are shaped in complex ways by the interplay between individuals acting in concert within a specific cultural context awash with taken-for-granted assumptions and unchallenged power structures" (Varcoe et al., p. 968). In essence, health care relationships are more complicated and complex than previously known. The authors direct attention to the need to further explore the concept of moral distress and the impact of these experiences on professionals. They describe how much of the literature focuses on the constraints of the working environment. However, the influence of interconnected networks of relationships may also have a significant impact on moral actions. "The relational nature of nursing practice should not be ignored. If change is to occur, we cannot expect nurses to enact their practice in isolation" (Varcoe et al., p. 970). Implications of this study suggest that change will require the development of a moral community for professional practice, "a place where values are made explicit and shared, where values direct action, and where individuals feel safe to be heard" (Varcoe et al., p. 970).

"Respect for coworkers in nursing derives from the fact that nurses and their co-workers who contribute to nursing goals are interconnected, interdependent members of

nursing as a specialized moral community and members of the wider health services and human communities" (Aroskar, 1995, p. 136). These professional relationships impact on how ethical decisions are made and the prevalence and intensity of moral distress among multidisciplinary team members. However, it has been suggested in the literature that "...the interdisciplinary team is both a source of moral distress and a significant resource for addressing and resolving it" (Austin et al, 2005, p. 45).

*Barriers to Ethical Action*

In a qualitative descriptive study by Millette (1994), the process of moral decision making and barriers to ethical action were explored. This study utilized semi-structured interviews to help the participants describe a moral choice event. Two perspectives were identified when making a moral choice: caring based on relational factors and justice based on rights. The data highlighted the difficulty that many nurses experience between acting on their personal morals and recognizing the reality of institutional constraints. Key issues were power dynamics and the importance of supervisory support and action. "In this small sample, 50% of the subjects (n=12) left nursing or changed their practice site, most reporting that they were unable to provide the care that they knew their patients required" (Millette, p. 670). Nurses who tended to utilize the 'justice' approach were more likely to choose to remain in their employment setting. One interesting finding was the impact of the nurses' financial status in relation to their capacity for decision making. Many interviews referred to situations where nurses were in 'no position' to act freely on their ideals due to fear of job loss or pay cuts. Millette observed that nurses often perceive a sense of powerlessness in the face of institutional forces and this negatively impacts their ability to act on their beliefs to create positive change in their professional

work environment. One strategy for increasing power in practice was noted to be strength in numbers: the importance of working collaboratively with multidisciplinary colleagues.

In a qualitative descriptive study by Storch, Rodney, Pauly, Brown, and Starzomski (2002), focus groups were utilized to identify chief concerns that nurses had related to their ability to participate in ethical action. These issues included the organizational climate towards ethics, ambiguous or rigid policies, resource availability and utilization, conflicting loyalties, and finally, not enough time. The authors noted that, "Nurses' abilities to practice ethically are inseparable from practice realities that can create a climate for ethical or moral distress" (Storch et al., p. 8).

## Moral Distress

A philosopher by the name of Jameton (1984) was the first to conceptually define moral distress and distinguish it from the concepts of moral uncertainty and moral dilemma. "Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton, 1984, p. 6). In further work done by Jameton (1993) this phenomenon was described in terms of initial and reactive moral distress. "Initial distress involves the feelings of frustration, anger, and anxiety people experience when faced with institutional obstacles and conflict with others about values. Reactive distress is the distress that people feel when they do not act upon their initial distress" (Jameton, 1993, p. 544). This work is now considered quite limited, and further research has sought to develop a better understanding and more comprehensive explanation (Hanna, 2004).

Wilkinson (1987/88) further empirically defined the concept of moral distress "as the psychological disequilibrium and negative feeling state experienced when a person

makes a moral decision but does not follow through by performing the moral behaviour indicated by that decision" (p. 16). Wilkinson's contribution to nursing theory on moral distress resulted in the development of the first theoretical model of the experience of moral distress, and explored its impact on staff nurses in hospitals and its relationship to quality of patient care. Initially, the author used a survey approach to collect data on the properties and concepts that categorized the phenomenon of moral distress. Then, 24 present and former hospital staff nurses were randomly selected to participate in one hour, face-to-face interviews which were taped and transcribed. Approximately half of the participants (n=12) had experience in intensive care nursing, and half of those nurses (n=6) no longer worked in that area. The most common moral issues identified involved situations causing undue harm to the patient and dehumanizing patients. The predominant strong, negative feelings were reported to be anger, guilt, and frustration. "Nearly all the subjects believed that ongoing moral distress had been detrimental to their personal or professional wholeness" (Wilkinson, p. 22). Participants described the effects of their experiences as negatively impacting on their sense of self-worth, personal relationships, psychological well-being, physical health, and behaviour. Wilkinson speculates that the effects of this phenomenon on patient care may have been underestimated by the nurses and therefore requires further investigation.

### *Prevalence*

The prevalence of moral distress among nurses has been found to vary in the academic literature. For example, Redman and Fry (2000) found that one third of nurses in their study (n=470) experienced moral distress. In another study by Solomon, O'Donnell, Jennings, Guilfoy, Wolf et al. (1993), almost 50% of the nurses (n=760)

reported acting against their conscience. Finally in qualitative studies by both Wilkinson (1987/1988) and Millette (1994), at least 45% or more of the nurses reported that moral distress was a key factor in their decisions to leaving an area of professional practice or the nursing profession entirely.

An American study done by Corley (1995) explored experiences of moral distress in 111 critical care nurses with a questionnaire sent out in the mail. The response rate for this study was 61%.The mean scores on the questionnaire showed a low level of moral distress. However the range of scores indicated that some of the nurses experienced high levels of moral distress. Demographic factors of age, experience, and education did not significantly affect levels of moral distress in this study.

Sometimes key ethical issues are strongly tied to the resources and barriers associated with a particular area of nursing practice. Redman and Fry (2000) reviewed five studies which explored ethical conflicts experienced by nurses working in four different specialties (diabetes education, rehabilitation, nephrology, and paediatrics). This study found that each nursing specialty described a different type of main ethical issue encountered in their professional practice. In these five studies, approximately 33% of the nurses reported experiencing moral distress related to their professional practice.

Finally, an American study by Corley, Elswick, Gorman, and Clor (2001), surveyed 214 nurses who reported a moderately high level of moral distress in their hospital practice. One very interesting finding was that none of the professional or demographic variables appeared to be related to experiences of moral distress. In this study, 15% of the participants reported that they had quit a nursing position due to

experiencing moral distress. However, current levels of moral distress were not predicted by a previous resignation due to this phenomenon.

*Frequency and Intensity*

Corley, Minick, Elswick, and Jacobs (2005) conducted descriptive correlational research on ethical nursing work environments and experiences of reactive moral distress. They explored the frequency and intensity of relationships of moral distress to work environment, and examined moral distress in relation to the demographic data. The impact of moral distress experiences on nurse attrition was a sub-purpose of this work. The authors utilized two self reporting instruments to collect the data. With a sample of 106 medical and surgical nurses from two medical centres in a mid-Atlantic American city, factors which influenced experiences of moral distress were identified. These factors included the presence of an ethically supportive environment and degree of conflict with policies. Many of the ethical concerns described were related to everyday ethical issues. The item with the highest frequency and highest intensity score was related to unsafe staffing levels. The mean intensity score reflected a perception of moderately intense moral distress experienced with a low frequency by the nurses in these work environments. The interpretation of these findings was that although moral distress intensity was described as moderate, situations related to these experiences did not occur frequently. Intensity was negatively correlated with age, meaning that lower intensity scores were found in older nurses. This gives credence to the role of experience. Although the correlation of the relationship between age and intensity were low, they were significant. Finally, nurse attrition from past employment due to moral distress was found to be higher than previous studies have indicated.

*Coping Strategies*

"Moral distress can include situational, cognitive, active, and emotional dimensions" (Austin, Lemermeyer, Goldberg, Bergum & Johnson, 2005, p. 34). It is a complex phenomenon; however to begin to understand it one must seek a basic understanding of what moral distress actually consists of. The psychological impact of experiences of moral distress can include: alienation, sense of grief, self-criticism, decreased self-esteem, self-doubt, self-blame, sense of powerlessness, and self-disappointment (Kelly, 1998).

"Moral distress brings about coping behaviors, influenced by the frequency of cases nurses encounter, and affects nurses' wholeness and patient care" (Wolf & Zuzelo, 2006, p. 1194). Academic work done by Raines (2000) identifies positive coping behaviours which include planned problem solving with colleagues and accessing supports and resources. The development of positive strategies to cope with moral distress can facilitate both personal and professional growth and development (Rushton, 1992).

"Although stress can be a motivating influence for change, moral distress reflects a negative response to problems in the work environment" (Corley, et al, 2005, p. 382). Work related stress may result in the development of negative coping strategies (see Table 1), which have physical, emotional, and behavioural signs and symptoms.

**Table 1- Signs and Symptoms of Moral Distress**

| Physical | Emotional | Behavioural |
|---|---|---|
| Crying | Anger, outrage, frustration, confusion | Distancing, lack of emotional engagement |
| Insomnia/loss of sleep | Guilt, resentment, regret, sense of failure | Escape-avoidance, detachment |
| Changes in appetite | Powerlessness, shame, disappointment, loss of trust in self and system | Trivialization |
| Headache | Anxiety, confusion, grief, misery | Unreflective acceptance |
| Heart palpitations | Depression, sorrow/sadness | Denial |
| Changes in body functions | Job dissatisfaction, sense of unease with decisions | Pleasing, dialoguing |
| Stomach problems, stomach-ache | Feeling 'stupid', embarrassment, worthlessness, loss of confidence | Directing care |

Authors Schoot et al. (2006) identified four strategies for coping in their study of home-care nurses. These included: pleasing, dialoguing, directing care, and detaching. Similar findings were described by Kelly (1998) in a study of newly graduated nurses. Coping skills identified in this study were: avoiding interaction with clients, leaving the workplace or the profession, working less hours, blaming administration, rationalizing one's actions, and finally blaming the health care system. If positive coping skills are not developed, "the professional simply stops identifying ethical problems because one can no longer cope with all the ethical problems encountered" (Severinsson, 2003, p. 61).

*Bending the Rules*

One means of coping with moral distress that has been identified in the nursing literature is termed 'bending the rules' (Storch et al., 2002). When 'bending the rules' results in a positive outcome, it is often considered acceptable on some level. This 'end justifies the means' type of thinking has not been fully explored in the nursing literature. Nathaniel (2006) describes this behaviour as 'making a stand', "when they step beyond

the customary boundaries of the profession to do what, to them, seems morally correct" (p. 431).

Obviously this type of action involves personal and professional risk for the nurse. In the event that a negative outcome results, nurses may be subjected to being "ostracized and subjected to hearings, firings, legal proceedings, and harassment" (Nathaniel, 2006, p. 431). Certainly the strategy of 'bending the rules' would never be officially and professionally condoned. However, since it has been identified in the ethics literature, it deserves some discussion.

*Storytelling*

Opportunities to share stories of ethical issues and reflect on their meaning often provides nurses with the emotional space to address difficult circumstances and generate strategies to sustain ethically sound practice (Storch et al., 2002; Schoot et al., 2006). The concept of story telling and reflection can be seen in studies that utilize interviews to explore ethical encounters.

Gunther and Thomas (2006) conducted a descriptive phenomenological study using interviews to explore unforgettable patient stories of 46 American hospital nurses. The sample represented various specialties including: medical-surgical, emergency, intensive care, oncology, pediatrics, and obstetric-gynecology. The nurses shared stories about loss and powerlessness. They noted that reflecting on these events and identifying meaning was an important way of coping. Many stories had the concept of isolation as a prominent theme, and they noted that the camaraderie of a good team of coworkers made a world of difference. Some of the stories asked key questions such as: "Could I have done anything else?" and "How do you do your best and it not work?" (Gunther &

Thomas, p. 374). This iterative state of constant questioning is described by the authors as 'moral residue'. They describe that the "participants were still trying to make sense of distressing aspects of their world that diminished their efficacy, such as lack of resources and collegial support" (Gunther and Thomas, p. 375).

## Resources and Support Systems

"Ethical dilemmas are evident in health care, and it is necessary to have methods or support systems that can facilitate ethical decision-making when they arise" (Kalvemark Sporrong, 2007, p. 32). Resources may include: support from nurse managers and chaplaincy (Zuzelo, 2007); ethics education, professional standards and ethical guidelines (Rodney, Varcoe, Storch, McPherson, Mahoney et al., 2002); support from colleagues, significant others, education programs, and ethics committees (Raines, 2000). "The presence of well-functioning clinical ethics committees can also be a significant resource to nurses in their quest for constructive interdisciplinary dialogue on ethical problems" (Storch et al., 2002, p. 13).

The role of supports for ethical practice was explored in a British study conducted by Holloway (2004). In this study a questionnaire was used to survey 171 nurses working in the community to explore ethical dilemmas and the supports available to the nurses. It should be noted that the response rate to the questionnaire was quite low, with a return rate of only 16.7%. The author identified that the study participants were mostly senior nurses. Six types of support were identified in the study. These included organizational polices and procedures, ethical training, reflective practice, multidisciplinary team meetings, ethical committees, and colleague support. The support of colleagues through dialogue was ranked as the number one source of support. Unfortunately, the respondents

indicated that their access to colleagues was often limited by the reality of community work in rural, isolated settings with time constraints on accessing members of their multidisciplinary team. The least helpful supports were found to be policies and procedures, and surprisingly, ethics committees. Holloway notes that the structure of ethics committees likely varies across organizations, and further study would be required to evaluate and determine unhelpful components and issues. Also, an important comment was made about the fact that resources are not mutually exclusive, and that they may be used in varying combinations to enhance effectiveness.

In a recent study by Zuzelo (2007), a convenience sample of 100 nurses in an urban medical centre in the north eastern region of the United States were surveyed about moral distress. A variety of resources were listed, including managers and supervisors, ethics committees, chaplain services, nurse colleagues, and physicians. A small number (n = 8) indicated that no resources were available to them, and even fewer (n =6) recognized that they were unfamiliar with what resources were offered. Barriers to accessing available resources were noted to be time (weekends and off-hours) and fear of confrontation.

The importance of resources such as dialogue with colleagues and professional associations, and utilizing ethics literature to raise awareness and foster a greater understanding of ethical issues is echoed in other sources of academic literature (Storch et al., 2002; Liaschenko, 1995). The role modelling of strong nursing leaders appears to be a powerful resource to draw from.

Ethical issues and moral distress are closely linked by the fact that successful ethical decision making strategies and the presence of adequate resources and support

systems, often mitigate experiences of moral distress for professionals in their everyday practice. In a discussion paper issued by the Canadian Nurses Association (2000), sources of everyday ethical issues which may cause moral distress are often related to working in situations with limited resources. Work completed by Varcoe and Rodney (2002) discusses how the 'ideology of scarcity', meaning fear that there is not enough money, resources, staff, etc, limits the 'moral agency' of nurses. The lack of availability of these resources may occur on three different levels. These levels include societal, institutional, and individual.

Resources at the societal level can be limited by access to and availability of government funding. The degree of control that a health professional has over these limitations is varied and often minimal. At the institutional or organizational level, resources may be allocated according to internal budgets, policies, and procedures. "It is the nurse's inability to affect these sources of distress that is most problematic" (Canadian Nurses Association, 2003, p. 4). Finally, resources at the individual level depend on one's confidence and competence to make ethical decisions and successfully resolve issues. Sometimes personal internal constraints, like fear of being fired, previous negative experiences, professional socialization to strictly follow protocol, or self doubt, affect an individual's personal and professional resources (Austin et al., 2005, p. 36).

## Gaps in Knowledge

There is little research available on everyday ethical issues and moral distress in the community care setting. In particular there is a paucity of research on the potentially positive impacts of everyday ethical encounters which might highlight excellence, opportunities for finding balance, discussions about the rewards of being a client

advocate, opportunities to celebrate creativity, and ways of recognizing heroes and mentors. This angle could be further explored by focusing on the link between ethics and power dynamics. "Power is a positive force and can be used wisely to effect change throughout the health care system and to enhance ethical practice" (Storch et al., 2002, p. 13).

## Conclusion

"Morality and ethics are not only relevant, they are central to nursing practice" (Wilkinson, 1987/88, p. 17). "Being a nurse is, in itself, a moral endeavor. Almost every decision a nurse makes has a moral dimension. This applies not just to life or death situations, but also to the mundane issues encountered on a daily basis" (Neville, 2004, p. 128). Moral distress can impact the patient, the nurse, and the health care organization. A clear understanding of this phenomenon has not yet been discovered. For the patient, increased suffering or discomfort may result. The impact of suffering for the nurse may lead to resignation, burn-out, and nurse attrition (Corley, 2002). The organizational impact may result in high staff turnover rates, difficulty in recruiting, decreased quality of care, low patient satisfaction, and ultimately a poor reputation for accreditation (Corley, 2002).

For over two decades, researchers and scholars have tried to accurately define moral distress. The difficulties encountered with ethical decision making can lead to experiences of moral distress related to the process itself, and/or the final outcome of the situation. Determining how moral distress is defined and therefore made identifiable, can be a difficult exploration. "For nurses and others who inhabit "the trenches" of healthcare, the *ordinariness* of everyday ethical issues can mean that their moral

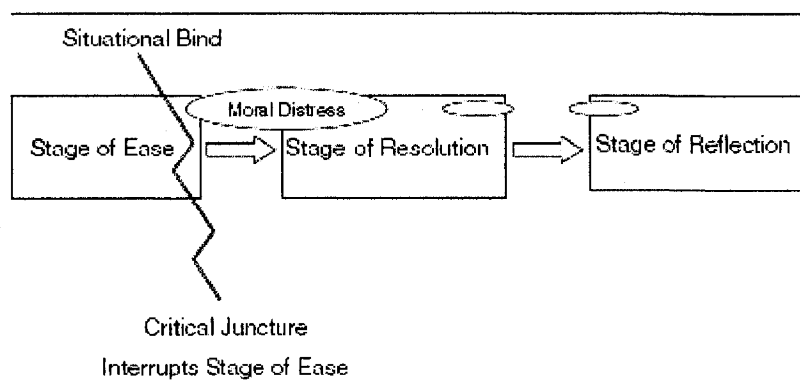
significance goes unrecognized" (Austin, 2007, p. 82). The academic literature uses many different, yet similar definitions to describe experiences of ethical decision making and moral distress (see Appendix C). "Without an adequate definition, moral distress can be unrecognized, yet have a silent, clinically significant impact on health" (Hanna, 2004, p.73). This study will evaluate experiences of everyday ethical issues and related experiences of moral distress in the community care setting using a quantitative descriptive research design.

# CHAPTER 3: CONCEPTUAL FRAMEWORK

## Grounded Theory of Moral Reckoning

The conceptual framework of this study is largely based on a relatively new grounded theory known as moral reckoning in nursing (Nathaniel, 2006). The purpose of the initial research in this area was "to formulate a logical, systematic, and explanatory theory of moral distress and its consequences" (Nathaniel, p. 421). The theory of moral reckoning was developed through the analysis of qualitative research data and an extensive literature review on the concept of moral distress. "Moral reckoning is much broader, both in temporal and in psychosocial spheres, and more explanatory and predictive than is the extant concept of moral distress" (Nathaniel, p. 423). This theory describes the currently accepted definitions of moral distress as not having 'a good fit' to real life situations as discovered through qualitative interviews. Therefore, Nathaniel proposed to elaborate on this concept to create a three step process which encompasses moral distress as a core feature.

**Figure 1**
**The Relationship Between Moral Distress and Moral Reckoning**




<u>Source</u>: Nathaniel, 2006, p. 424 (permission from the author obtained)

As described by Nathaniel (2006), the three stages of moral reckoning include ease, resolution, and reflection. The stage of ease is the process in which a professional becomes comfortable and confident in their role within the agency they work in, with their colleagues, and with their clients/patients. This includes a sense of becoming (defining one's values/beliefs, developing a sense of moral integrity, gaining experience), professionalizing (accepting principles and professional values/norms), institutionalizing (learning the structure of the organization, working within the mission/mandate of the agency, recognizing the power/authority structures and deciding how all of these items fit into one's own value system), and working (finding one's own role within the profession). The stage of ease can be described as sense of balance between personal and professional values.

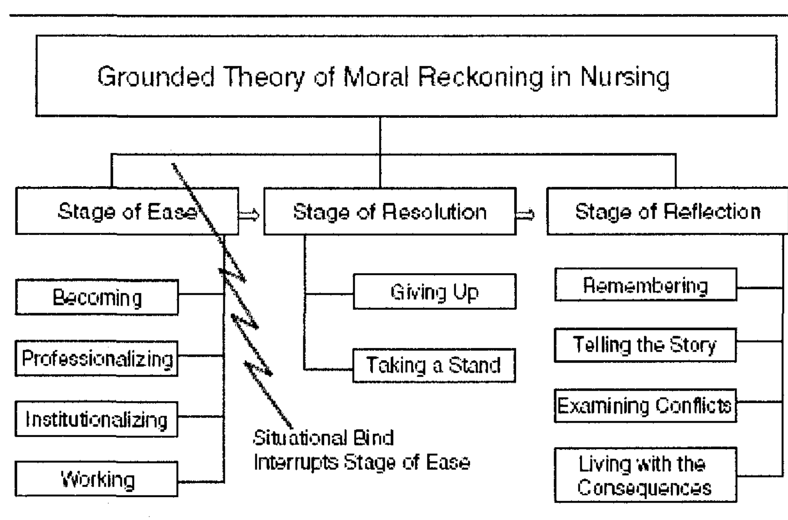
At some point a situational bind occurs, an ethical dilemma where a decision must be made. It will involve an internal conflict between professional values and situational forces, which may involve a disagreement between decision makers. Often these situations have a power imbalance or sense of powerlessness for one or more of the key players. Frequently it may be linked to agency barriers to adequate patient care such as staffing shortages, heavy workloads, lack of resources, or unsafe work environments.

The second stage, the stage of resolution can include 'giving up', when barriers either organizational or personal, do not allow the professional to take action, or 'going along' with a decision that they do not feel is right. Sometimes professionals choose not to act due to the implications of speaking up such as job loss. Many professionals choose 'taking a stand', utilizing resources and peer support to assist them to move forward

toward resolution. Finally, 'bending the rules' has been noted as a little-discussed option in achieving what the professional believes ethically must be done.

In the third stage, the stage of reflection, the professional is emotionally impacted by whether or not they feel that they were successful or unsuccessful in dealing with the situation. This stage includes remembering (recalling details and emotions, placing blame, 'if only' type of thinking), telling the story (searching for meaning with others, trying to make sense of it, learning from the experience), examining the conflicts (reflecting on what could have been done differently, reflecting on one's values, setting rules), and living with the consequences (which may be insignificant if it was well resolved or significant if it was a very negative experience with an unsuccessful outcome). Reflection can have a positive impact such as leading the professional to seek further advice, further education, or further action. However the negative sequelae can result in professionals leaving their place of employment or seeking other professional endeavours entirely. The stage of reflection is not a single point in time occurrence. The author notes that this stage is likely to be ongoing and "may last a lifetime" (Nathaniel, p. 432).

Figure 2
Model of the Grounded Theory of Moral Reckoning in Nursing




Source: Nathaniel, 2006, p. 426. (permission from the author obtained)

This theory of moral reckoning was chosen due to its broad definition of this dynamic concept. As recommended by Webster and Baylis (2000), the concept of moral distress requires a broader definition, including not only organizational factors but also personal factors which may influence this complex human experience. It is hoped that this conceptual framework will guide the researcher to thoroughly examine the qualitative data using the stages of resolution and reflection to identify common themes.

# CHAPTER 4: METHODOLOGY

This study was created with a quantitative descriptive research design, which would be most appropriate to potentially capture the lived human experiences of the participants (Creswell, 2002). "Rules derived from the principle of beneficence remind the researcher of the requirement to use the best possible research design to maximize benefits and minimize harm" (Milton, 2006, p. 307)

## Research Design

In this study, a questionnaire was issued to a purposive sample of registered nurses and registered social workers who were employed as case managers/community care coordinators in Community Care Access Centres (CCAC's) across northern Ontario. The purpose was to investigate the extent to which these professionals experience everyday ethical issues and moral distress using an inter-professional focus. Both quantitative and qualitative data were gathered, which is a strategy supported by recent academic literature. "A real enrichment of ethics by an empirical understanding [...] can only be achieved by the use of both qualitative and quantitative research approaches. Their integration leads to enhanced theoretical insights into the multidimensional nature of reality" (Dierckx de Casterle, Grypdonck, Cannaerts & Steeman, 2004, p. 38).

### *Setting*

Community Care Access Centres (CCAC's) were established by the Ontario Ministry of Health and Long Term Care (MOHLTC) in 1996, for the purpose of providing and enhancing access to government funded home care services in the community and streamlining the application process for long-term care facilities. Under

the Long Term Care Act, 1994, CCAC's purchases a variety of health related services from local agencies.

CCAC's employ case managers (community care coordinators) who are regulated health professionals (registered nurses and registered social workers). The case managers assess the needs of the client and create a service plan if the client is eligible under government guidelines. The case manager then coordinates and monitors the delivery of the services which are provided by contracted agencies. These services may include nursing, convalescent care, physiotherapy, personal support, occupational therapy, social work, speech and language services, dietary support, and respite. If the client is ineligible for services, CCAC provides a liaison to local community agencies that may offer support. There are currently14 CCAC's in the province of Ontario. The bulk of these agencies are located in southern Ontario, with only two CCAC's to cover the northern regions which constitute approximately 75% of the province's geography (Statistics Canada, 2006).

From a population perspective, the northern region of Ontario constitutes 75% of the land mass of the province, but is home to only approximately 6% of the province's population (see Table 2).

**Table 2. – Geographic and Population Comparisons for Northern Ontario**

| | Area (km2) | Area of land for the Region/Province | Population | Population of the Region/Province |
|---|---|---|---|---|
| Ontario | 1,076,395 | | 12,160,282 | |
| Northern Ontario Region | 802,378.67 | 75% | 745,372 | 6% |
| Northwestern Ontario Region | 526,371.87 | 49% | 235,046 | 2% |
| Northeastern Ontario Region | 276,006.80 | 26% | 510,326 | 4% |

**Source**: Information adapted from Statistics Canada (2006), Community Profiles, 2001.

*North West Community Care Access Centre (NW CCAC)*

NW CCAC has their head office in Thunder Bay, Ontario with nine satellite offices in the region. The northwest region includes the following communities: Kenora, Dryden, Rainy River, Fort Frances, Red Lake/Ear Falls, Sioux Lookout, Atikokan, Marathon, and Geraldton.

NW CCAC serves the largest geographical area of any CCAC in Ontario, covering about 47% of the land mass of the province. However the population in the northwest region accounts for only 2% of the province's total, with communities scattered throughout this large geographical area (see Table 3).

**Table 3. – Populations of Communities in Northwestern Ontario**

| Northwestern Ontario Region | Population |
|---|---|
| Thunder Bay (district) | 109, 140 (149,063) |
| Kenora (district) | 15,177 (64,419) |
| Dryden | 8,195 |
| Rainy River (district) | 909 (21,564) |
| Fort Frances | 8,103 |
| Red Lake/Ear Falls | 4,526/1,153 |
| Sioux Lookout | 5,183 |
| Atikokan | 3,293 |
| Marathon | 3,863 |
| Geralton | 4,906 |

Source: Information adapted from Statistics Canada (2006), Community Profiles, 2001.

*North East Community Care Access Centre (NE CCAC)*

NE CCAC has their head office in Sudbury, Ontario with 20 satellite offices in the region. The north east region includes the following communities: Kirkland Lake, Englehart, Haileybury, North Bay, Burk's Falls, Sturgeon Falls, Sault Ste. Marie, Blind River, Hornepayne, Elliot Lake, Wawa, Espanola, Timmins, Cochrane, Matheson, Hearst, Moosonee, Iroquois Falls, Smooth Rock Falls, and Kapuskasing. Again, cities

and small communities are dispersed throughout the region (see Table 4). The north east region has a strong francophone population.

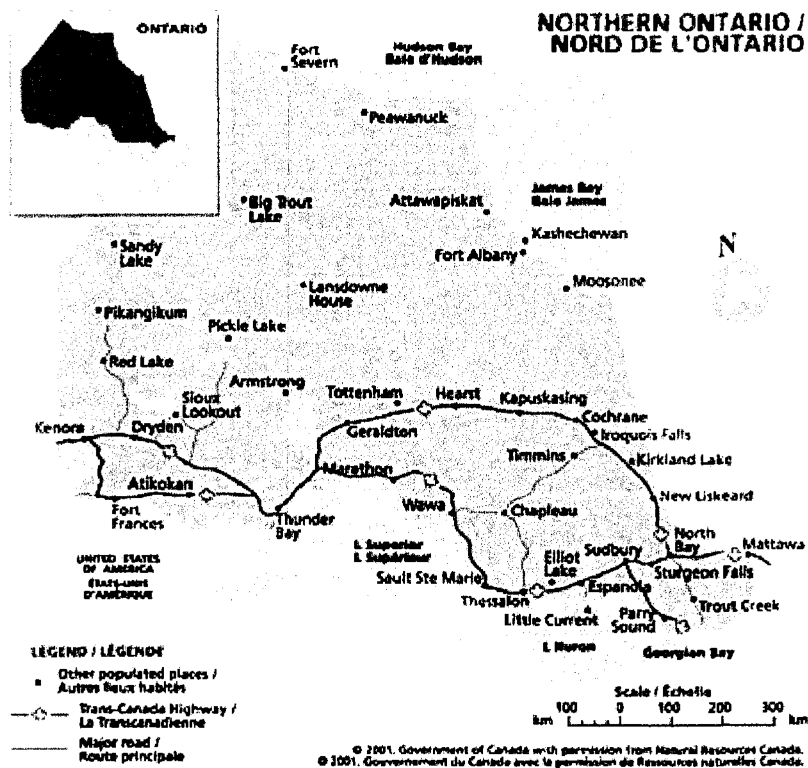
**Table 4. - Populations of Communities in Northeastern Ontario**

| Northeastern Ontario Region | Population |
|---|---|
| Sudbury (district) | 157,857 (21,392) |
| Moosonee | 2,006 |
| Iroquois Falls | 4,729 |
| Smooth Rock Falls | 1,473 |
| Kapuskasing | 8,509 |
| Kirkland Lake | 8,248 |
| Englehart | 1,494 |
| Haileybury | 10,732 |
| North Bay | 53,966 |
| Burk's Falls | 893 |
| Sturgeon Falls | 13,410 |
| Sault Ste. Marie | 74,948 |
| Blind River | 3,780 |
| Hornepayne | 1,209 |
| Elliot Lake | 11,549 |
| Wawa | 3,204 |
| Espanola | 5,314 |
| Timmins | 42,997 |
| Cochrane | 5,487 |
| Matheson | 2,619 |
| Hearst | 5,620 |

Source: Information adapted from Statistics Canada (2006), Community Profiles, 2001.

It is important to note that many of these small communities in northern Ontario have limited access to urban centres where resources and services might be more readily available. See Figure 3. for a visual representation of the geographical area described in this study.

**Figure 3- Map of Northern Ontario Region**




Source: Government of Canada website (2001).

*Sample Selection*

The sample for this study included 74 and 141 regulated health professionals from NW CCAC and NE CCAC respectively, specifically registered social workers and registered nurses working in the capacity of case managers (community care coordinators). The researcher utilized a purposive sampling strategy. Participants were recruited from the community health care agencies through the agency managers either via email or at a regularly scheduled staff meeting to introduce the upcoming study and then through a detailed cover letter which further discussed the nature of the study and what would be required should participation be considered.

Inclusion criteria allowed for the participation of all registered nurses and registered social workers employed by CCAC in northern Ontario, on a full time, part time or casual basis in any area of case management.

### *Ethical Considerations*

The study was examined by the Lakehead University Research Ethics Board and wholly accepted for approval before any part of the research was begun. Ethics approval of this study was officially granted by Lakehead University on December 4, 2007. Internal ethics approval from the NE CCAC Ethics Committee was granted on January 9, 2008. Further internal ethics approval from NW CCAC was not required, as at the time of the study they did not have an internal ethics committee in place.

Participation in this study was voluntary and consent was implied with the completion and return of the questionnaire. Anonymity and protection of the participant's confidentiality were ensured within the research process. No name identification or coding methods were used on the individual questionnaires. The raw data was entered into the computer program by the researcher as the questionnaires were received. "The ethical dimension of the qualitative research process ensures the protection of participants by taking extra care in preserving confidentiality, anonymity, safety, and the right to withdraw from the research at any time" (Milton, 2006, p. 307).

## Instrumentation

"In an attempt better to understand moral distress and thus better support the nurses who experience it, some researchers have chosen to illustrate the phenomenon by using models and measure it using questionnaire-based measurement tools" (Austin et al., 2005, p. 36). The researcher found no previously developed instruments that would

sufficiently meet the needs of this study, specifically due to the setting being a community care organization. The questionnaire used in this study was developed by the researcher after identifying key elements from published academic literature. The questionnaire (Appendix B) was reviewed by the thesis chairperson and second reader for clarity of content, and approved by the Lakehead University Ethics Committee.

Using a five-point response scale, experiences of ethical issues and moral distress were explored. The questions investigated prevalence, frequency, and intensity issues. Participants were asked to identify key ethical issues in their practice, rank their level of confidence to recognize, address, and resolve ethical issues, rank effective resources and support systems, and identify perceived barriers to ethical practice. Basic demographic information was also collected. The final two pages of the questionnaire gave the participants an opportunity to share an ethical experience and provide comments. The open-ended final section was added to gain an "...understanding of meaning in human thought and behaviour, not explanations of causal associations" (Ohman, 2005, p. 275).

## Data Collection Procedure

Data were collected via a questionnaire (Appendix B). Each potential participant was provided with the research cover letter (Appendix A) which provided detailed information about the study, and the research questionnaire. The researcher was available via phone and email to respond to any questions or concerns. None of the participants contacted the researcher for further information. The participants were requested to return the questionnaire within two weeks of receiving it, at their earliest convenience. The questionnaire was returned directly to the researcher via mail, and a return-addressed,

stamped envelope was provided. The agency did not note individual participation or have any contact with the data on the completed questionnaires.

At NW CCAC the study was introduced at a regular weekly staff meeting on January 16, 2008 by the senior director of client services (manager). The cover letters and questionnaires were then distributed to those present, given to team assistants (secretaries) to distribute and mailed out to those in the regional sites. The details of the distribution of the study to the regional employees was graciously undertaken by the agencies. The senior director of client services provided an email each week over a four week period to remind the staff about the study. The final email contained an attachment from the researcher which indicated that the study deadline had been extended and to encourage further participation. On February 25, 2008 the senior director of client services at NW CCAC held an informal coffee break for all staff and distributed additional questionnaires to staff who may have misplaced their original copy.

At NE CCAC the senior director of client services introduced the study via an email to all eligible staff about the study, using the research cover letter. The executive assistant then sent out the questionnaires to each case manager in Sudbury and the region during the week of January 28, 2008. Again reminder emails were sent out weekly, with a personal email from the researcher attached in the fourth week.

The time frame for the data collection was originally planned over a two week period. Due to a slow response rate the deadline date was extended. By February 11, 2008 the researcher had only a 20% response rate (42 questionnaires). By February 29, 2008 the researcher had achieved a 26% response rate (55 questionnaires). The last questionnaire included in the study was received by the researcher on March 4, 2008,

which represented a 31% response rate (66 questionnaires). Therefore, data was collected over approximately a seven week period of time. In general, response rates to questionnaires as reported in the academic literature have been found to be quite poor. Therefore, the researcher was satisfied with this response rate. Unfortunately, two additional questionnaires were received in late March/early April 2008, and these data could not be included in the final analysis or discussion.

## Data Analysis

All data analysis was completed by the researcher. The quantitative data was analyzed using SPSS, version 15. The qualitative data was first reviewed by the researcher to gain a general understanding of the experiences. "Data analysis was approached from the phenomenological perspective of granting authenticity to lived experience" (Wilkinson, 1987/88, p. 19). Subsequent readings of the data were done to apply the conceptual framework of Nathaniel (2006), identify common themes, and extract direct quotes to be placed in the final report. Categories were then formed from the themes that emerged from these statements. The researcher utilized a thesis committee, internal examiner, and external examiner to review the accuracy and reliability of the qualitative analysis.

# CHAPTER 5: RESULTS

The quantitative data were analyzed with SPSS software (version 15). It is presented here in the following order: descriptive information related to participants and setting and application of findings to the study's objectives. Following that, the qualitative data are organized according to Nathaniel's (2006) theory and categorized by common themes. As not all of the participants' direct quotes could be used in the body of this report, please see Appendix D for additional comments.

## Preliminary Analysis of Demographic Information

The sample for this study consisted of 66 registered health professionals employed as a case manager/community care coordinator at a CCAC in northern Ontario, who were recruited using a purposive sampling method. The participants practiced in a variety of specialty areas in the agency including: palliative care, schools, hospital discharges, adults, children, short stay/post operative, long term care placement, and intake. The average profile of a participant in this study was: female, degree prepared registered nurse, working in a full time position. The mean age was 45 years (standard deviation 9.11) with a range from 28 to 63 years of age. The number of years in professional practice ranged from 2 to 42 years (mean 19.24, standard deviation 11.13). Further details of the specifics of the demographic data can be found in Table 5.

**Table 5.** Demographic Characteristics of Study Participants and Setting

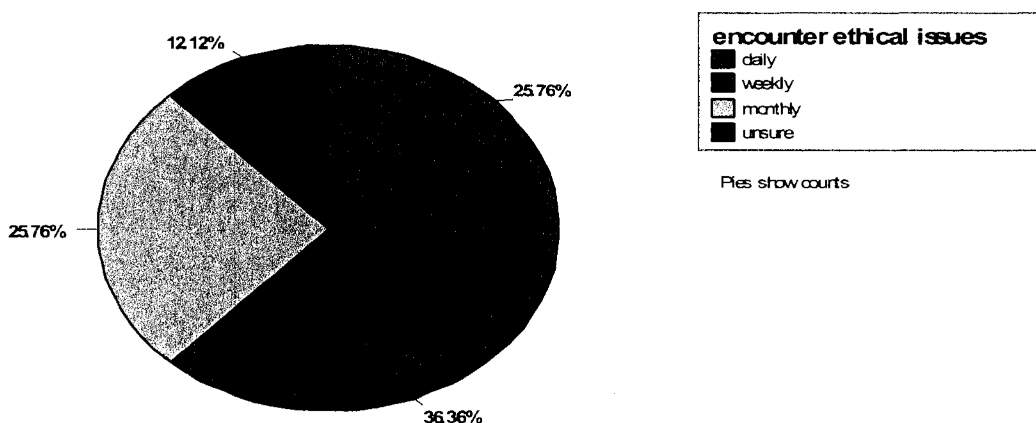
| **Characteristics** | **n** | **%** |
|---|---|---|
| **Age** | **63** | |
| 20-30 | 4 | 6.3% |
| 31-40 | 15 | 23.8% |
| 41-50 | 26 | 41.3% |
| 51-60 | 16 | 25.4% |
| 61+ | 2 | 3.2% |
| **Gender** | **65** | |
| Female | 63 | 96.9% |
| Male | 2 | 3.1% |
| **Employment Status** | **66** | |
| Full time | 56 | 84.8% |
| Part time | 8 | 12.1% |
| Casual | 2 | 3.0% |
| **Location of Practice** | **66** | |
| Thunder Bay | 22 | 33.3% |
| NW Region | 12 | 18.2% |
| Sudbury | 7 | 10.6% |
| NE Region | 25 | 37.9% |
| **Area of Specialty** | **66** | |
| Palliative | 2 | 3.0% |
| School | 2 | 3.0% |
| Hospital Discharge | 4 | 6.1% |
| Adult Community | 20 | 30.3% |
| Many Areas | 24 | 36.4% |
| Children | 1 | 1.5% |
| Short Stay | 3 | 4.5% |
| Long Term Care | 5 | 7.6% |
| Intake | 5 | 7.6% |
| **Professional Affiliation** | **65** | |
| Registered Nurse | 56 | 86.2% |
| Registered Social Worker | 9 | 13.8% |
| **Years in Practice** | **66** | |
| 0-5 | 13 | 19.7% |
| 6-10 | 4 | 6.1% |
| 11-15 | 6 | 9.1% |
| 16-20 | 13 | 19.7% |
| 21-25 | 12 | 18.2% |
| 25+ | 18 | 27.3% |
| **Education** | **66** | |
| College Diploma | 31 | 47.0% |
| Bachelor's Degree | 33 | 50.0% |
| Master's Degree | 2 | 3.0% |

## Application of Findings to Study Objectives

### *Everyday Ethical Issues*

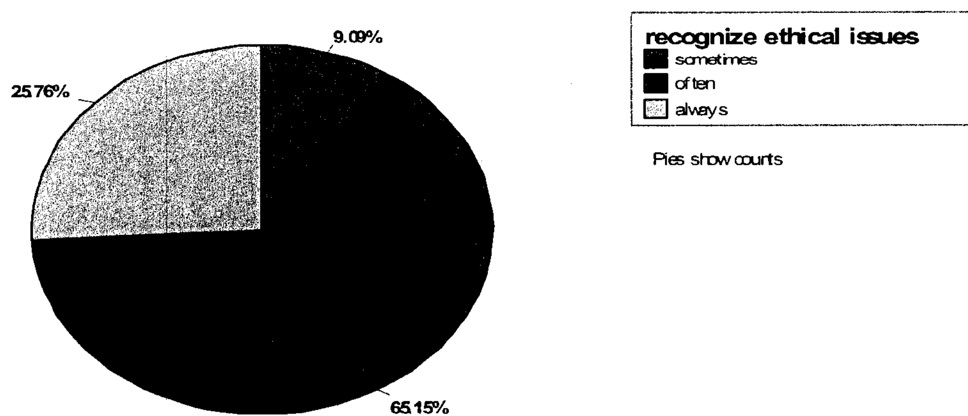
On the questionnaire, an ethical issue was defined as 'a situation involving values, interests, rights or duties where the choices between right and wrong, good and bad, are not always clear'. The majority of participants reported that they encounter ethical issues on a weekly basis (17/66, 36.4%), see Figure 4 below. None of the participants indicated that they 'never' encounter ethical issues. This finding indicates that ethical issues are prevalent in the professional practice of case manager/community care coordinators working in the community care setting of CCAC in the northern regions.

**Figure 4- Frequency of Encountering Ethical Issues (n=66)**



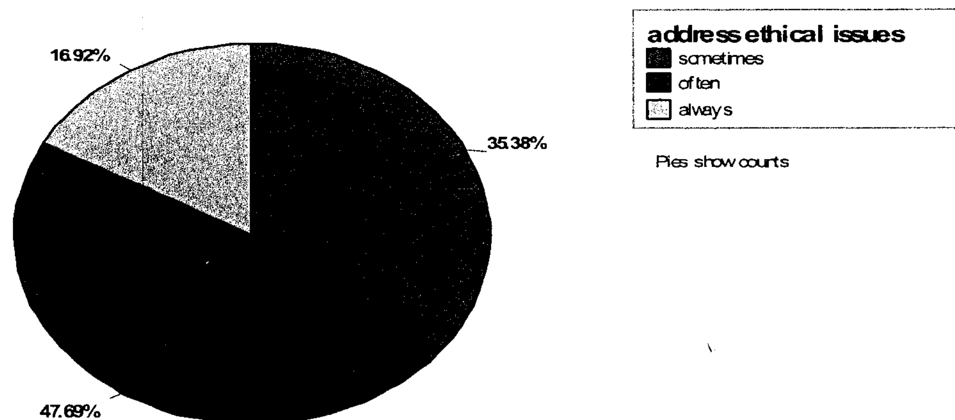

Study participants reported that they 'often' (65.2%) felt confident to recognize ethical issues in their professional practice. None of the participants chose the options of 'never' or 'unsure' when reporting their perceptions of their confidence to recognize ethical issues in their practice, see Figure 5. This finding indicates a moderate to high level of confidence to identify ethical issues in their practice.

**Figure 5- Frequency of Confidence to Recognize Ethical Issues (n=66)**



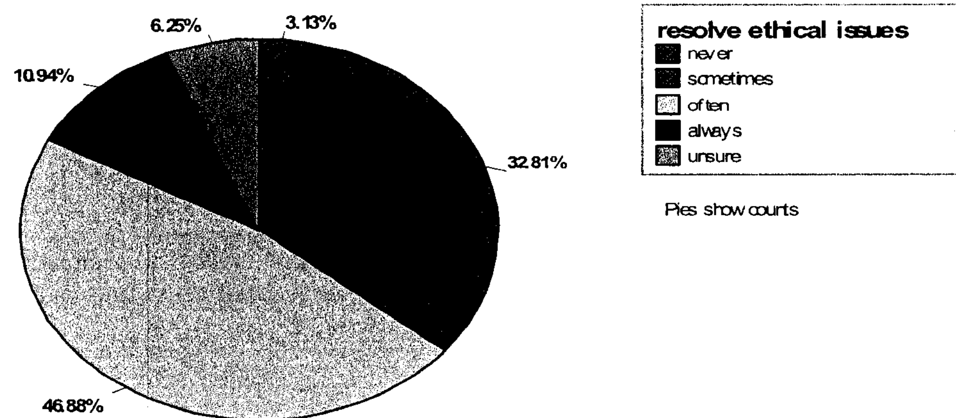

Similarly, participants reported that they 'often' (47.7%) felt confident to address ethical issues in their practice. One participant chose not to respond to this question. Again, none of the participants chose 'never' or 'unsure', see Figure 6. This finding indicates a moderate to high level of confidence to address ethical issues in their practice and should be reflected in the qualitative data with a moderate to low level of frequency and intensity of experiences of moral distress.

**Figure 6- Frequency of Confidence to Address Ethical Issues (n=65)**



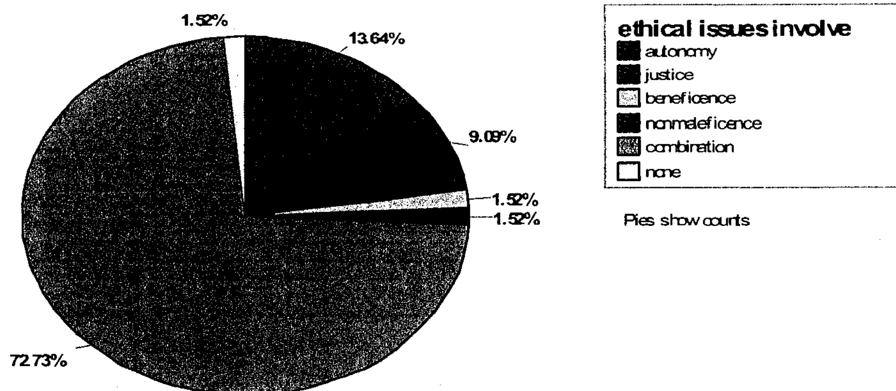

Finally, approximately 47% of participants reported that they 'often' felt confident to resolve ethical issues in their practice, see Figure 7. Two participants chose not to respond to this question. Also, 2 participants (3.1%) chose 'never' and 4 participants (6.3%) chose 'unsure' to describe their level of confidence to resolve ethical issues. Again, this indicates a moderate to high level of confidence to resolve ethical issues which should be reflected in the qualitative data by a moderate to low level of frequency and intensity of experiences of moral distress.

**Figure 7- Frequency of Confidence to Resolve Ethical Issues (n=64)**




Key ethical issues found in this professional practice setting were categorized on the questionnaire under the headings of 'autonomy', 'justice', 'beneficence', 'nonmaleficence', 'a combination of the previously mentioned categories', or 'applicable to none of the categories'. The majority of ethical issues encountered by the participants were described as a combination of the identified categories, see Figure 8. Only one participant (1.5%) reported that these categories were not applicable to the majority of ethical issues encountered in their practice. One participant wrote a comment beside this question, *"I feel beneficence overrides all in very difficult situations"*.

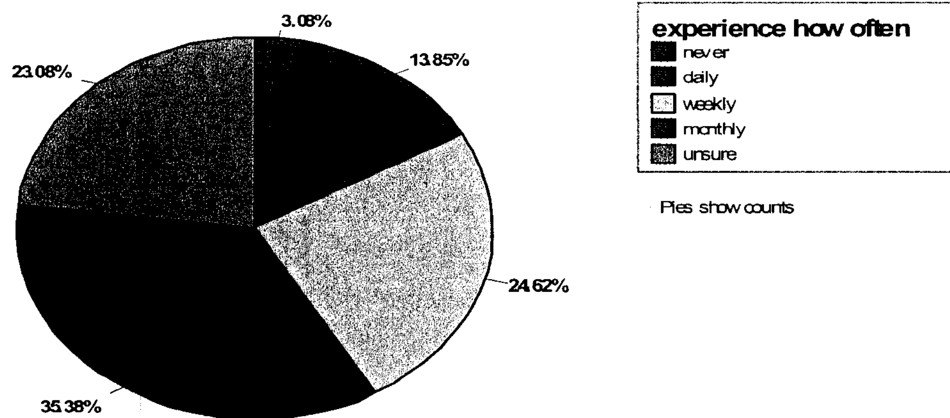
**Figure 8- Main Category of Ethical Issues in Professional Practice (n=66)**




## *Moral Distress*

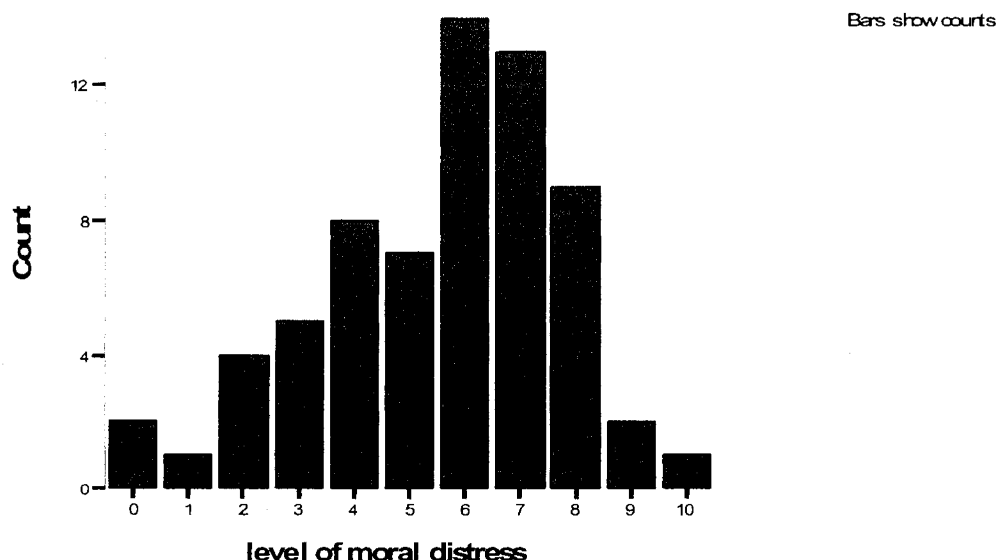
On the questionnaire, moral distress was defined as occurring when 'a person believes they know what they should do, however they are unable to do so'. The results indicate a moderate to high prevalence of moral distress, with 16 participants (24.6%) reporting experiencing moral distress 'weekly', and 23 participants (35.4%) reporting it 'monthly'. Two participants (3.1%) reported that they 'never' experience moral distress, and one participant chose not to answer the question. It is interesting to note that approximately 23% of participants were 'unsure' how often (or if) they experience moral distress. This may be related to the fact that there is not a clear understanding of the concept of moral distress experiences among health care professionals. See Figure 9 for further details.

**Figure 9- Frequency of Experiencing Moral Distress (n=65)**




The participants were asked to rate the level of moral distress that they experience in their role as a case manager/community care coordinator at CCAC on a scale from 0 (none) to 10 (most). The results showed a mean of 5.5 (standard deviation 2.19). This represents a moderate to high level of intensity. See Figure 10. All 66 participants responded to this question, even though 23% previously reported that they were 'unsure' if they had experienced moral distress. The 3% of participants who reported that they 'never' experience moral distress, chose an intensity level of 0 on the questionnaire.

**Figure 10- Level of Intensity of Moral Distress (n=66)**




Participants were asked about how they experienced moral distress using the categories of physical, emotional, and behavioural symptoms. Two participants chose not to answer this question (n=64). The most common experience was of emotional symptoms, which was chosen by 25 participants (39.1%). Some participants chose to underline the symptoms that they have personally experienced. The ones that were highlighted included frustration, sense of unease with decisions, anger, guilt, disappointment, anxiety, powerlessness, job dissatisfaction, heartsick, outrage, sense of failure, avoidance, guilt, resentment, sorrow/sadness, shame, depression, distress, confusion, embarrassment, and regret.

The second most common way of experiencing moral distress involved a combination of physical and emotional symptoms, as described by 15 participants (23.4%). A small number of participants (7.8%) described experiencing moral distress most often with physical symptoms only. Again, certain symptoms were underlined in the

questionnaire. These included loss of sleep, headache, loss of appetite, nightmares, and stomach problems.

A small number of participants (10.9%) felt that they experienced moral distress through emotional and behavioural symptoms. Only two participants (3.1%) experienced only behavioural symptoms, mainly distancing, escape-avoidance, and trivialization.

Finally, ten participants (15.6%) indicated that they experienced moral distress with physical, emotional and behavioural symptoms. This question was followed by a question which asked about recognizing moral distress in co-workers. All 66 participants answered this question. Most participants chose 'sometimes' (48.5%), with 'often' as a close second with 34.8%. The numbers for the other options were quite low; 4.5% chose 'never', 4.5% chose 'always', and 7.6% were 'unsure'. These findings indicate that the study participants recognize experiences of moral distress in themselves as well as in their colleagues.

The last question on moral distress asked the participants if they believed that experiencing moral distress as a case manager/community care coordinator should be accepted as part of the job description. The intention of this particular question was to assess the perceived locus of control. For example if the participants chose 'always', perhaps they felt that external forces determined their experiences of moral distress. Alternatively, if they selected 'never', perhaps they felt in control and were more internally focused. Whether or not this question was fully understood by the participants is debatable. The academic literature supports the view that experiences of moral distress among health care professionals are a common occurrence. "However, even though nurses are often in environments ripe for situations of moral distress, it should not be

considered inevitable or predetermined in any moral situation" (Austin et al., 2005, p.35). One participant chose not to answer this question (n=65). The results were; ten participants (15.4%) believed that one should 'never' accept experiences of moral distress as just part of the job, ten participants (15.4%) chose 'often', three participants (4.6%) chose 'always', and three participants (4.6%) chose 'unsure'. Most participants, 39 responses (60%), believed that it is 'sometimes' necessary to accept moral distress as part of the job description of a case manager/community care coordinator in a community health care setting. These results may indicate that the locus of control is determined by situational factors. However, in the literature one author did comment on whether or not moral distress should be expected in professional practice. "Health care professionals should anticipate experiencing moral stress in clinical practice" (Zuzelo, 2007, p. 344). One participant commented:

> *Regarding accepting moral distress as part of the job. Part of me believes that we should not have to accept distress, that more equality of resources needs to be made available especially between southern and northern Ont. But the reality of working in the government sector is that there is no fairness/equality. So we need to accept that this occurs in order to maintain your health. You need to find effective ways to problem solve or come up with solutions to problems ie. with the long waiting lists- we look into all sorts of possible resources available for families to access while waiting.*

*Resources and Support Systems*

Study participants were asked to rank the top three resources and support systems available to them to assist with ethical issues. Only 60 participants (six missing)

responded to this question using the ranking format for their first and second preferred resource. Some participants did not chose a third preferred resource (n=57). Those who did not rank their choices were excluded (ie if they chose three selections, but did not rank them). The number one resource (60%) selected was 'talking to colleagues'. However one comment that was written beside the question stated, *"can't find colleagues when you need them, when it would be most helpful"*.

The resource which was rated as second in the ranking was 'supportive leaders', chosen by 24 participants (40%). Again comments were added beside the question which noted that leaders and managers are not always available as a resource. It is interesting to note that 'supportive leaders' were also chosen as the top selection (21.1%) for the third most important resource. The fact that the support of leaders and managers is highlighted twice in this research speaks to the value of the support system that these individuals can provide.

Additional data on resources and support systems were written in beside the question and noted in the comments section of the questionnaire. Study participants also noted that they seek support through reflection and prayer, journaling, reading scripture, and talking to family or spouse. These areas were not considered in the development of this questionnaire. These findings deserve further empirical investigation.

Participants were asked about their perceptions regarding the value of an ethics committee when dealing with an ethical issue. All of the participants chose to answer this question (n=66). The responses were: three participants (4.5%) chose 'never', 16 (24.2%) chose 'sometimes', 21 (31.8%) chose 'often', ten (15.2%) chose 'always', and 16 (24.2%) chose 'unsure'. Comments were added beside the question and at the end of the

questionnaire. One participant noted that an ethics committee is not particularly valuable because *"it takes too long to resolve issues"*. Another added that attending an ethics meeting is just *"one more meeting to go to when we already have too many meetings. We meet monthly to discuss complex cases and have a chance to seek input, debrief, etc. This is helpful."* It should be noted that at the time of this study, NW CCAC did not have an ethics committee, but was in the early stages of developing one. NE CCAC has an ethics committee.

*Barriers*

The next topic on the questionnaire related to workplace issues which are most often perceived as the root cause of an ethical issue. Again a ranking format was requested, and participants who made selections but did not rank them had their answers excluded from the findings. The top ranked cause of ethical issues was 'lack of resources', which was selected by 26 (41.3%) participants (n=63). The number two ranked cause of ethical issues was 'policy and regulations', which was selected by 17 (28.3%) participants (n=60). And finally, the third ranked cause of ethical issues was identified as related to 'conflict and communication', which was selected by 12 (21.4%) participants (n=56).

Following this question was a request to identify aspects of professional practice that most often create moral distress. The number one ranked cause of moral distress was 'lack of resources', which was selected by 22 (35.5%) participants (n=62). The second ranked cause of moral distress was 'lack of time', selected by 12 (20.3%) participants (n=59). And finally, the third ranked cause of moral distress was equally shared between 'lack of resources' and 'lack of time', which was selected by ten (16.9%)

participants respectively (n=59). These findings are consistent with the literature which repeatedly identifies time and resources as key issues in today's health care environment.

Additional comments about barriers to dealing with ethical issues and successful resolution of experiences of moral distress were found written beside the question and at the end of the questionnaire. One participant identified that there is *"a lack of knowledge, empathy of others involved with client care in the setting I work in."* Another participant also commented on the knowledge deficit during interaction with other community players in relation to understanding the assessment process when determining a client's eligibility for services. Also mentioned was the fact that *"people's expectations of the type and amount of help they want/need exceeds what can be provided."* Finally the issue of workload was highlighted, with further discussion seen in the qualitative data.

*Ethics Education*

Participants were asked about previous education related to ethical issues in professional practice, whether it was received during training, post training, or through independent learning and professional experiences. All participants responded to this question (n=66). Only four respondents (6.1%) indicated that they had 'never' received education of any type regarding ethical issues in professional practice.

Further to this, participants were asked whether or not they believed that further education about ethical issues in professional practice would be helpful to them personally. All participants responded to this question (n=66). The results indicated that 78.8% (n=52) stated 'yes', 6.1% (n=4) stated 'no', and 15.2% (n=10) stated 'unsure'.

These two questions together represent an interesting finding. Although the vast majority of participants already have some type of ethics education, the overwhelming

response to further ethics training was 'yes'. This finding is very positive for the agencies involved, as it provides a concrete solution and education is sure to be an outcome recommendation from this particular study.

Qualitative Data

On the second last page of the questionnaire participants were asked the following open-ended question:

> 'Most health professional have had at least one experience of an ethical issue which stays in their mind as though it happened yesterday. Please describe a troublesome ethical issue that happened to you as a case manager in a community care setting. Please note the feelings you experienced and the impact that you believe the situation had on your professional practice.'

The responses to this question were initially read for a general understanding of the story that was shared. Subsequent readings of the data were done first considering the conceptual framework of Nathaniel (2006), then categorizing the data according to common themes, and finally to extract direct quotes to be placed in the final report.

One participant wrote "*no time to answer*" the question. Another wrote, "*No time to think. Everything and everyone is rushed here and there, too much information and expectations for case managers to deal with. Gone are the days you could talk with fellow workers*." And finally, another participant commented, "*I have many of them but due to lack of time I can't complete this section. I guess the worst feeling is going home every night and wondering what you have forgot to do. Not enough time in the day.*" Although not thoughtful and reflective of the nature of the question, these brief answers do reiterate

the challenges identified in the quantitative component of the questionnaire related to resources and time.

*Utilization of Moral Reckoning Theory*

The qualitative data was reviewed and separated into the two stages of moral distress as identified by Nathaniel (2006); the 'stage of resolution' and the 'stage of reflection'. Further to this, each stage was then organized into the categories outlined by the Grounded Theory of Moral Reckoning in Nursing (Nathaniel, 2006), with one participant comment quoted for each section. Further qualitative data can be found in Appendix D: Personal Experiences of Everyday Ethical Issues and Moral Distress.

*Stage of Resolution- Giving Up*

Initially the researcher felt that there were some great examples of 'giving up' to be found in the qualitative data gathered. Upon further consideration, the researcher realized that it was only after the professionals had exhausted all resources and options that 'giving up' was even considered. Beyond that, the professionals didn't describe it as 'giving up'. This particular stage often occurred after 'taking a stand' did not result in a successful outcome. Participants described these situations as a need to accept that they had done all that they could, even if they struggled to come to terms with this. As Nathaniel (2006) describes, professionals are often the first to recognize the futility of a situation, knowing well what the final outcome is likely to provide.One participant made this point very clearly with the following comment:

***"Clients and/or caregivers who make bad choices causing increased risk and potential harm. Despite providing education and utilizing all resources***

***available to me including presenting at rounds the outcomes could not be changed."***

*Stage of Resolution- Taking a Stand*

There were many readily available examples of 'taking a stand' in the qualitative data gathered. As Nathaniel (2006) has explained, this category in the stage of resolution includes claiming one's power and often assuming some degree of professional risk in doing so. Sometimes this includes 'bending the rules' to do what one feels is the morally or ethically correct thing to do. However, assuming this risk often leads the professional to later question whether or not the end justified the means. The quote provided below from one of the study participants hints at the unexpected impact of 'taking a stand'.

***"Had an elderly lady living with her husband. Husband was primary caregiver. Wife had cognitive issues and had had a stroke. Received a report that husband was helping her transfer with a rope about her neck. Client did not want any intervention done as she did not want to leave her home- or risk losing her caregiver. When I received the report- my immediate supervisor- advised me that there was nothing we could do. I was astounded. I went above her- and went to my professional body who assured me that if I broke confidentiality- I would be protected as I would act in client's best interest. The whole episode was very stressful and emotional. It was resolved but it made me unsure of future decisions."***

*Stage of Reflection- Remembering and Telling the Story*

These two areas in the stage of reflection are combined here because the researcher found it quite difficult to differentiate between the two. Both of these areas

involve describing emotions such as guilt, self-blame, anger, sadness, or anxiety. It explores the 'if only…' type of thinking, which can change future practice in positive or negative ways. The following quote is one example of a story that was shared:

***"I had a lady in her 80's with no family support in the community with dementia, that was starting to show signs of inability to cope on her own in the community, wandering at night, not eating properly, when case manager would go and see her, the apartment was well maintained, she was always appropriate and well dressed and appeared well cared for. Therefore unable to provide any in home services as client also refused, she did not want to initiate long term care papers. Therefore I could not keep her on my caseload, but would receive numerous calls from the community with concerns which the CM shared with family physician but nothing could ever be done and I worried about her for months and would go out of my way to reassess her and hope that she would accept help. Ended by her having a fall and going into hospital then dementia increased and then was ALC till placement."***

*Stage of Reflection- Examining Conflicts*

Nathaniel (2006) defines this category as an opportunity to explore personal values versus professional ideals. It is sometimes an opportunity to gain strength and learn from experiences to improve future professional practice. The participant stories that will be shared here are organized under the following headings; conflicting sense of responsibility to client versus the agency, conflicting sense of responsibility to client versus health care system, meeting the needs of the client versus family, conflict and communication issues, and finally relationship issues.

*Conflicting Sense of Responsibility to Client versus Agency*

***"Ethical issue related to organizational polices and regulation. The needs of the clients that are outside the eligibility criteria, continue to be a challenge for the clients, and if not addressed or managed, can cause clients to either end up with multiple emerg/hospital visits or eventually LTC."***

*Conflicting Sense of Responsibility to Client versus Health Care System*

***"Ethical- working as a discharge planner (DP) and the CCAC CM Liaison at the hospital- you are put in the position of trying to free up beds in the hospital as the DP but it may not be in the best interest or the safest thing for the client. It becomes a challenge: $ vs. client wellbeing."***

*Meeting the Needs of the Client versus Family*

***"The most frequent is care of the elderly with a decline in cognitive status. They probably should not be living at home but they show at times they are capable of choosing right/wrong. Family members want their parents etc. to be put into long term care without even telling them, or they want services to be started and the client does not want service. Families wanting to know client's information and the client does not want any information divulged."***

*Conflict and Communication Issues*

***"Problem: Family does not want diagnosis or prognosis discussed in front of or with client. Requires staff to discuss in another room and not let client know 'if they know they will give up and die'. Client is capable- should be able to have a say in what treatment or care they want. There will not be closure with family and client if unable to speak openly about their wishes. Nothing is 'said'.***

***Person dies and you know unanswered questions. I feel they are aware of what is happening. Would benefit from having input into what 'care' is provide at end-of-life. May have emotions/concerns they need to discuss with family members. It creates tenseness in the environment. I have since discussed openly with my own family my wishes so there are no questions/decisions placed on others. Your children may not want to hear about death but the reality is there. Hopefully they will talk openly with their families."***

*Relationships*

The impact of relationships on ethical professional practice was highlighted by the participants of this study. One individual mentioned the hardships associated with being a case manager in a small community, where you cannot simply make a decision and walk away. You may have to face that client or family out in the community for many years to come. Also, in working with a small team of colleagues issues can become magnified.

***"Hardest part is knowing clients on a personal level then dealing with them professionally."***

Other issues related to relationships involve members of the multidisciplinary team. These issues may include miscommunication and intentional misuse of power.

***"Referrals made by hospital discharge planner that are inappropriate- she knows CCAC eligibility but continues to send inappropriate referrals to make a political statement. Frustration- waste of time for case managers and patient. Uneasiness- feel wasting patient's time, confusing for them, and uncomfortable having to tell them cannot provide service. Anxiety because d/c planners calls***

> ***repetitively and questions non-admits. Disillusionment at times as management gives services to ineligible clients when they raise a fuss or threaten to make a public complaint. D/C planner misinforms physicians/hospital staff about CCAC practices, affects working relationships with these people. These experiences make job more difficult and stressful."***

Also important are the collegial relationships that lend support and expertise to case managers who work independently, often in isolation, out in the community.

> ***"Team meetings were initially set up for the express purpose of collaboration and including a safe environment to discuss ethical issues. However, meetings became formalized with agenda/minutes and have now evolved to process/policies, therefore no where to bounce ideas, get collegial feedback."***

*Stage of Reflection- Living with the Consequences*

In a very candid and honest comment, one participant shared her story about 'living with the consequences' of everyday ethical decision making and experiences of moral distress. Portions of the quote have been removed to preserve the participant's anonymity.

> ***"...One of the contributing factors was workload (case load of 150) and lack of self-care. I was not recognizing my physical and emotional, behavioural signals as a cue to take stock in what was going on in me. I'm a person that has great empathy and the more I pushed aside my distress the greater my empathy for client situations that normally I could handle. The result was a complete break down ... I'm cautious about returning to work and don't know what lies ahead***

***- if I can continue in this position. My enthusiasm and passion is no longer with me."***

*Additional Findings*

A number of issues were highlighted in the qualitative data that had not been addressed in the questionnaire. These included spiritual resources and vulnerable client populations. Please see Appendix E for further qualitative data on these issues.

*Spiritual Perspective*

The researcher did not consider religious or spiritual aspects as a means of support and as a resource system for professionals. Also, barriers to utilizing this resource may result in professionals experiencing a decreased sense of fulfillment in their practice. The spiritual perspective was noted by two participants in their comments. One of the quotes is presented here:

> ***"Knowing what is right and wrong is very clear in light of God's word- there are NO grey areas in the bible. Doing what is right is not easy at times. I think one of my most difficult situations that caused me 'moral distress' was assessing a very intelligent, active woman my own age who had terminal CA for in-home service. The conversation turned to spiritual matters and she expressed great distress related to her time in eternity. She was obviously afraid to die and looking for answers in strange and deceitful writings. I knew the right thing to do was to share God's promises with her but as an RN Case Manager it would be seen as 'imposing my beliefs' on her. Unable to give her the answers she so desperately needed (and I knew) I offered her counselling from a local pastor-***

***which she declined- and left her in spiritual anguish. As a result I hardened my heart a little more."***

*Northern Perspective*

***"Case loads are too large to be able to do proper case management with clients and communities. No supports, work in small branch office of the CCAC and I do all areas of case management, ie. community, hospital, palliative, pediatric, school health, intake and long term care placement papers, and travel 100km one way in 3 different directions to cover the area. Most times unable to do it all properly, stressed ++ all the time, when start running wait lists for services, complaints ++ and very challenging, no peer support as everybody is bombarded and everyone trying to pass their work to others and moral is very negative. Difficult to cope most times. Managers do the best they can, but are all also too busy, when I have a dilemma most times have to deal with it myself as managers are not available."***

*Vulnerable Populations*

Participants described experiencing moral distress related to everyday ethical decision making with vulnerable populations. This was often due to a lack of resources and service availability to meet the clients' special needs. Vulnerable populations who were identified by the professionals included: children, the elderly and in particular elderly caregivers, those with mental illness and/or substance abuse issues, and homeless clients.

***"When applying health care services such as we do in our isolated area, often clients are left to feel vulnerable and that we don't care. For example, elderly***

***people are regularly asked if family can help with their care- this question is often perceived by clients as a way for our agency to offset costs. Many find it cold and uncaring. I know, I've heard about it in my practice. As well, we give one bath per week to clients who have no one else often to perform this task. If it were me, I would feel awful not only not having a bath every day, but not having the choice is even worse. I believe that the way we apply our services can often contribute to making already vulnerable people feel they are not worth much in society. I do not find the explanation for the way we operate in our business as 'client focused' nor do I see any type of connection between policy and client that satisfies the needs that exist out there. While we may apply physical services, we often step over and on peoples' rights to choose and their feeling of worth to satisfy government ideals."***

Dissemination of Results

All summaries of the research findings from this study will be made available upon request to the participants, the participating agencies, and the academic community. The final draft of the study findings will be disseminated to health professionals and submitted for publication in a scholarly, peer-reviewed journal.

# CHAPTER 6: DISCUSSION

This study was designed to explore experiences of everyday ethical issues and moral distress among case managers/ community care coordinators employed with CCAC in northern Ontario. "If all the findings are very much like the literature, then nothing new has been added and the literature can be affirmed. If the findings are not like the literature, either new knowledge has been discovered or some part of the literature has been disconfirmed" (Hanna, 2004, p. 82).

## Everyday Ethical Issues

The nature of some of the everyday ethical issues faced by health professionals in this community health care setting were found to be mostly a combination of the theoretical categories of autonomy, beneficence, nonmaleficence, and justice, therefore representing complex, multi-factorial scenarios. Key issues identified in the qualitative data were identified to be: a conflicting sense of responsibility to the client versus the agency, a conflicting sense of responsibility to the client versus the health care system, challenges related to meeting the needs of the client versus the family, conflict and communication issues, and relationship issues. Similar findings related to competing roles were echoed in work done by Burger et al (1992), Meaney (2002), Gunther and Thomas (2006), and Schoot et al (2006).

It is interesting to note that similar everyday ethical issues have been identified in the community care literature for almost two decades. Therefore it is important to look at the frequency and intensity of these professionals' experiences. In this study, the frequency of encountering ethical issues in professional practice was found to be moderate to high, most likely to be encountered on a 'weekly' basis. The participants

described a moderate to high level of confidence to recognize, address, and resolve ethical issues in their practice. One might propose that if a professional feels a lot of confidence to recognize, address, and resolve these issues, then that professional would be likely to experience low levels of moral distress. However, the data gathered in this study did not support that theory.

## Moral Distress

"The literature supports the position that nurses experience moral distress in their day to day practice lives" (Zuzelo, 2007, p. 348). The prevalence of moral distress experiences among the participants in this study was found to be moderate to high, most likely to be experienced on a 'monthly' basis. Similar findings were discovered by Corley et al (2001), who also reported moderately high levels of moral distress among nurses in hospital-based practice.

Approximately 60% (n= 39) of this study's participants reported experiencing moral distress in their professional practice in the community care setting. In contrast to this, Redman and Fry (2000) found that nearly one third of the 470 nurses in their study experienced moral distress. However in both studies, moral distress experiences were closely linked with issues related to a lack of resources and time constraints.

Experiences of moral distress were described as occurring with moderate to high frequency and intensity, most commonly expressed with emotional symptoms. In contrast to these findings, Corley's (1995) work with critical care nurses found a low level of moral distress among the majority of the study's respondents. Due to the fact that Corley's work was done approximately 13 years ago, it is unrealistic to directly compare such large gaps in time and settings, as well as very different populations (critical care

versus community care). These data highlight that there may be many additional issues and dynamics involved in the phenomenon of moral distress, especially in the community setting.

## Resources and Support Systems

The findings related to resources and support systems closely mirrored the academic literature (Raines, 2000), with 'talking to colleagues' and 'supportive leaders' ranked at the top. The frequent inaccessibility of these preferred resources and support systems were identified as a challenge. Issues of access to these types of support systems was also seen in work done by Holloway (2004), which was also done in a rural, isolated setting. Therefore, the researcher proposes that issues related to access to resources and support systems is a significant factor in successful ethical practice for professionals in rural communities.

## Barriers to Ethical Practice

Barriers to ethical practice were found to be: 'lack of resources'; 'policy and regulations'; 'conflict and communication' issues. Millette (1994), and Storch et al., (2002) found similar results regarding power dynamics. In the current study, the participants did not refer to power or powerlessness directly, however it was a theme that was threaded throughout much of the qualitative data. Zuzelo (2007) also identified time as a key barrier to ethical practice. However, Zuzelo's work also identified 'fear of confrontation' as a barrier, which was not an issue revealed by the participants in this study.

## Ethics Education

In this study, only 6.1 % of the participants responded that they would not be interested in further education about ethics and ethical decision making. This information is encouraging, as the literature strongly supports the use of ethics education to mitigate the difficulties faced in rural and isolated settings (Penticuff & Walden, 2000). The further development and strengthening of the role of ethics committees in these organizations will provide an excellent venue for a variety of educational opportunities and potentially initiate the use of ethical decision making frameworks which would build on core ethical competency development from an inter-professional perspective. However as described by one participant, it will be important for the agencies to fully define the role of the ethics committee to decrease the sense that "it is just another meeting".

Training opportunities may have to be structured in a significantly different way than traditionally offered in acute care settings, to truly meet the needs of professionals working in the community care setting. Discussions about the fundamental differences between traditional clinical ethics frameworks and the newer arena of public health ethics may prove to be a starting point. Also in ongoing development is the area of community based ethical frameworks (Anstey & Wagner, 2008). Because communities and agencies living in rural and northern communities face unique challenges when compared to their urban counterparts, beginning with theory to develop procedure and practice guidelines is another good place to begin.

## Limitations and Delimitations

Limitations of this study include the lack of validation by participants as to the accuracy of the interpretation of the data, and the fact that the researcher can only provide a nursing perspective in relation to the review of the academic literature, analysis and discussion of the findings. In hindsight, the researcher might have included on the questionnaire additional demographic information on race, marital status (ie. single parents and the financial implications of job loss as a result of actions), perceived support systems of family or spouse and spiritual perspectives. Also, only two of the study participants were male. A stronger male perspective on this topic may have provided interesting comparative data.

Internal validity issues relates to the truth value of the study. The researcher developed the questionnaire to closely match the currently accepted knowledge gained from previous academic literature. The purpose of this strategy was to attempt to maintain reliability and consistency of the data, which relates to the issue of dependability. The questionnaire was then reviewed, adjusted, and then approved by members of the researcher's thesis committee. As well, the study was reviewed in its entirety by the thesis committee, an internal examiner, and an external examiner for critical appraisal and feedback prior to the final submission.

Also the presentation of direct quotes from the study participants contributes to maintaining the truthfulness and credibility of the concepts and experiences. "Rigor, credibility, and critical appraisal are essential to clarifying meaning, refining ideas, building knowledge, and bringing forth scholarly work for the purpose of determining its value and contribution to nursing science" (Milton, 2006, p. 309). The confirmability of

the findings was enhanced due to the anonymity of the participants and the neutrality of the researcher to the agencies and to the data collected which provided for the opportunity to objectively evaluate the results.

According to Creswell (2002), "reliability and generalizability play a minor role in qualitative inquiry" (p. 195). Therefore, delimitation issues, such as external validity, will not be a significant concern for this study. The utilization of this study and its findings by the participating agencies is the primary goal of this endeavour. Obviously the appropriateness of transferability of these findings to CCAC's or beyond case managers in non-northern geographic locations would require further investigation.

The application of an exclusively principle-based ethical approach may also have limited the findings of the research data in this study. The use of a variety of ethical frameworks may have provided further insight into the complexities of the everyday ethical issues and experiences of moral distress for the professionals in this setting.

Finally, the breadth, complexity, richness, and depth of the qualitative data gathered certainly cannot compare to data gathered in using an interview process. However, the researcher does believe that due to the anonymity and confidentiality ensured by this particular research design, participants may have felt safe to share information more freely than they otherwise would have. Exploring personal experiences should promote "a sharing which belongs to each alone but speaks in a voice heard and understood by many" (Levine, 1999, p. 213).

## Significance

Moral distress can lead to professional frustration, reduced moral integrity, loss of job satisfaction, burn-out, job resignation, and nurse attrition. The current nursing

shortage is impacted by this phenomenon and the shortage itself fosters an increase in morally distressing situations (Corley, 2002). Therefore, experiences of moral distress are more profound than just an individual problem. Collective experiences of moral distress make this issue a key component of recruitment and retention challenges and have an unknown effect on the quality of patient care and ultimately, on health outcomes especially in the community care setting.

## Recommendations

Opportunities for the recognition, identification, and open discussion of experiences of moral distress are key strategies found in the academic literature related to successful coping, enhanced confidence and empowerment (Hamric, 2000; Peter, Lunardi & Macfarlane, 2004, Kalvemark Sporrong, 2007). The researcher recommends adopting agency appropriate strategies to facilitate discussions and learning related to everyday ethical issues and moral distress.

### *Education*

- Increasing capacity for informal collaboration among inter-professional colleagues, supervisors, and leaders.
- Increasing capacity for formal educational opportunities to discuss strategies which support the development of ethical decision-making competencies and successful coping strategies for experiences of moral distress.
- Identification of agency resources and best practice guidelines for ethical decision making for all staff members

Opportunities for reflection are also recommended in the literature. "Through reflection, ethical principles are transcended and assimilated into knowing in practice,

enabling the practitioner to become more ethically sensitive in responding to future situations" (Johns, 1999, p. 287). From the overwhelming response that the researcher received in the form of qualitative data, it is clear that these professionals have many valuable stories to share.

*Reflection*

- Identification and recognition of staff members (leaders and role models) who have developed successful professional skills to identify, address, and resolve ethical issues in their professional practice.
- Encouraging opportunities for team building and collegial support within the agency.

Finally, recommendations have been identified in the literature which relate to the quality of the professional environment. "When nurses have appropriate autonomy, support and opportunities for professional growth in their workplace, there will be fewer barriers to ethical practice and less ethical distress" (Canadian Nurses Association, 2003, p. 4).

*Environment*

- Identification of agency barriers to ethical practice and a collaborative approach to problem solving at various levels to address these challenges. Key barriers noted in this study were a lack of resources, policy issues, and conflict and communication difficulties. These same issues were also perceived to be linked to experiences of moral distress.

- Implementation of early identification and support strategies for staff members who display the signs and symptoms of moral distress. This may include the use of interventions such as the Employee Assistance Program (EAP).
- Ongoing agency commitment to the development of a strong ethics committee which may be used for problem solving, planning, and potentially policy changes which meet the changing needs of the community health care environment.

While issues of workload, lack of time, and inadequate resources are unlikely to be resolved in the near future, opportunities to problem solve and share strategies may provide much needed support for health care professionals working in the community care setting in the northern Ontario region.

## Opportunities for Further Research

As would be expected in any research endeavour, attempting to find answers usually successfully generates even more questions and hypotheses. It is this iterative cycle of learning that creates a knowledge base for health care professionals to turn to for best practice guidelines and guidance. The current literature on everyday ethical issues and moral distress provides the following suggestions for opportunities for future research.

First and foremost, Hanna (2004) highlights the need to move from descriptive to interventional studies to explore opportunities for healing and transformational growth. "Research is needed on interventions that health care organizations can use to enhance the ethical environment and provide a possible approach to reducing nurse moral distress" (Corley, Minick & Jacobs, 2005, p. 388).

However, much work can still be done using descriptive exploratory research to more clearly define the terms and concepts related to everyday ethical issues and moral distress. “Illustrating the conceptual processes and measuring the occurrence of moral distress may contribute to an initial understanding of the phenomenon” (Austin et al, 2005, p. 38). One successful avenue for qualitative research is the use of story telling, as both a method of data gathering and as a therapeutic intervention (Yarling & McElmurry, 1986; Benner, 1991; Fairbain & Mead, 1993).

Finally, as suggested by Kalvemark Sporrong (2007), little is known about the differences between professional groups when it comes to perceptions of ethical issues and moral distress. Corley (2002) suggests the need for research on: experiences of moral distress for nurse educators and students, the effects of moral distress on patients, the role of an ethics committee’s impact on nurses’ moral distress, and lastly, comparisons between the benefits and the harms of moral distress. Aroskar’s (1995) work echoes this suggestion, encouraging the value of opportunities “to identify with other co-caregivers the ways in which nursing as a moral community is or can be implemented in one’s own health care setting, recognizing the realities of power, politics, and economics that may inhibit or enhance nursing as a moral community” (p. 138).

Opportunities for further research identified in this study included the need to further explore and define the role of spiritual resources in professional practice, to research everyday ethical issues and experiences of moral distress as they relate to northern issues, and to focus on the unique challenges associated with caring for vulnerable populations in the community care setting.

Issues specific to practice in northern and rural settings included isolation from collegial support and limited access to resources. Participants in this study iterated an increased sense of responsibility to their clients because they saw themselves as the only link to the care that their clients so desperately needed and were entitled to. Feelings of guilt, frustration, and desperation contributed to experiences of moral distress in situations where options were limited by policy and agency regulations. Opportunities to explore avenues for increasing a sense of professional autonomy and decision making capacity should be focused on in future research endeavours. As well, comparative studies between larger urban-centred agencies and northern or rural agencies might provide valuable insight into the unique and varied challenges presented by the different settings.

Finally, issues specific to vulnerable populations deserve the attention of academic investigation. Participants in this study felt that they had often 'failed' their clients in the respect that they could not adequately preserve the autonomy and dignity that their clients deserved. This led to feelings of powerlessness for the case managers when clients fell between the gaps in services and suffered due to time constraints and workload obligations. The impact of 'not doing my job the way I know it needs to be done' must be further explored through qualitative methodologies and the use of more holistic, shared theories and ethical frameworks.

## Conclusion

The purpose of this study was to explore and examine experiences of moral distress related to everyday ethical issues with professional case managers working in community health care settings in northern Ontario, Canada. The three objectives of this

work included a desire to: investigate the nature of ethical issues in the community care setting; explore and examine the scope of experiences of everyday ethical issues and moral distress, as well as the perceived level of confidence to recognize, address, and resolve these issues in professional practice; identify barriers to ethical practice and evaluate the efficacy of available resources. A questionnaire was developed by the researcher to gather both quantitative and qualitative data to more fully define the ethical issues and resulting phenomenon of moral distress. The grounded theory of moral reckoning was the theoretical framework which guided this research. From a cohort of 215 registered health professionals, a 31% response rate was obtained. The ultimate goal of this research was to seek insight into the positive strategies that demonstrate strength and hope in community-based health care.

As identified by MacPhail (2001) and Stulginski (1993), ethical issues in the community care setting are often more complex than those found in acute care settings. Due to the fact that the prevalence, frequency, and intensity of moral distress experiences have not been fully explored in the community health care setting, this study provided an opportunity to identify issues which may be unique to this dynamic setting.

The results of this study confirmed the prevalence of ethical issues in the community care setting. These ethical issues were most often described as a complex, multi-factorial scenerios often complicated by a conflicting sense of obligation to the client, the agency, and the health care system in general. Other complications were identified as being related to conflict and communication issues, and inter-relational dynamics. This study uncovered everyday ethical issues which reflect themes that have been identified in the home care literature over the past two decades. The frequency of

encountering ethical issues in this setting was identified as moderate to high. It is difficult to directly compare these results to acute care, institutional studies as the statistics vary among specialty areas.

Experiences of moral distress in the community care setting indicated moderate to high levels of prevalence, frequency, and intensity. As would be expected, these experiences were related to issues of lack of time and resources. Further research should be conducted to gain a wider perspective of the dynamic phenomenon of moral distress experiences in the community care setting. Resources for mitigating moral distress among professionals included discussions with colleagues and supportive leaders.

"It has been argued that moral distress has a pervasive quality and is intrinsically connected to health care practice" (Austin et al., 2005, p. 39). "Nurses are likely to continue to face a wide range of ethical situations leading to the experience of moral distress. An organizational commitment to addressing the issue of moral distress could reap benefits with greater employee job satisfaction, decreased turnover, and ultimately improved patient care" (Pendry, 2007, p. 220).

Additional findings in this study highlighted three topics which had not been previously considered by the researcher and have not been fully explored in the community or acute care settings. These included: the role of spiritual aspects as a means of professional support; unique challenges related to practice in a northern, rural environment; the political and economic limitations which particularly impact vulnerable populations.

The main recommendation from this study involves increasing educational opportunities related to ethical decision making and discussion. As identified by the

participants, additional training opportunities would be welcomed at this time. "What is necessary is a climate of openness to ethics and ethical discussion, which must be considered an integral part of the provision of care" (Canadian Nurses Association, 2000, p. 4). "Given the inherent unpredictability of the future, medical ethics needs to be flexible and open to change and adjustment, as indeed it has been for some time now. However, we can hope that its basic principles will remain in place, especially the values of compassion, competence and autonomy, along with its concern for fundamental human rights and its devotion to professionalism" (Williams, 2005, p. 118). In conclusion, the researcher would like to end this thesis work with a quote to encourage the reader to reflect on the many reasons why discussions and research on the topic of ethics is so very important.

> We must constantly remind ourselves of what it
> is that we wish humanly to defend and
> preserve, always keeping in view the defining
> and worthy features of human life.
> Nothing less deserves to be called 'bioethics',
> the ethics of human life as it is humanly lived.
> (Kass, 2002, p. 76)

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## APPENDIX A

### Research Cover Letter

***"Everyday Ethics in Case Management:***

***Experiences of Moral Distress by Professionals in a Community Health Care Setting"***

Dear Potential Participant,

I am a registered nurse and a Master's of Public Health graduate student at Lakehead University. I would like to invite you to participate in a research study. The purpose of this study is to examine and explore everyday ethical issues in a community health care setting and the relationships to experiences of moral distress. It is hoped that the results of this study will influence professional awareness of everyday ethical issues, identify the education and support which would be helpful to case managers to deal with ethical issues, and promote further research studies on the impact of moral distress on professional practice.

The study consists of a 6 page questionnaire which should take less than half an hour of your time to complete. It includes questions about your area of professional practice, age, education, and your personal experiences of everyday ethical issues and moral distress. Also, there are questions which refer to potential barriers to successful resolution of ethical issues and the resources available to you as a health care professional.

Your name will not be requested in this study as all the participants will remain anonymous to ensure the privacy of the responses. The information that you provide will be kept confidential, securely locked in storage for seven years at the researcher's office, and then shredded. The information gained from this study will be analyzed and

written up in a formal article, which will be available to health professionals. You can also request to receive a copy of the final results of the study.

This study has been reviewed by the Lakehead University Research Ethics Review Board. It is anticipated that there is a minimal risk of harm and no direct benefits for participants in this study. You may ask to be removed from the study at any time or choose not to answer any questions. All answers are acceptable, with no right or wrong responses. Your participation is absolutely voluntary and very much appreciated.

Thank you for considering taking part in this research study. If you have any questions or concerns, please do not hesitate to contact me. You may also contact the chairperson of my thesis committee, Dr. Jaro Kotalik at (807) 343-8126. If you have any ethical concerns regarding this study please contact the Lakehead University Research Ethics Review Board at (807) 343-8283. I look forward to your participation in this important study.

Should you agree to participate in this study, please complete the questionnaire at your earliest convenience and return it in the postage paid envelope provided. I thank you in advance for your time and commitment to the opportunity for research to improve professional practice.

Most Sincerely,

Kristen Jessiman BScN, RN, MPH (cand)
Phone: 807-683-8739
E-mail: kristenjessiman@shaw.ca

APPENDIX B

***"Everyday Ethics in Case Management: Experiences of Moral Distress by Professionals in a Community Health Care Setting"***

**Questionnaire- page 1 of 6**

***Everyday Ethical Issues in the Community Care Setting:***
Definition of an ethical issue: A situation involving values, interests, rights or duties where the choices between right and wrong, good and bad, are not always clear.

1. As a community care coordinator/case manager in a community health care agency, how often do you feel that you encounter ethical issues?

   ☐ Never ☐ Daily ☐ Weekly ☐ Monthly ☐ Unsure

2. Do you feel confident to ***recognize*** ethical issues or dilemmas in your professional practice?

   ☐ Never ☐ Sometimes ☐ Often ☐ Always ☐ Unsure

3. Do you feel confident to ***address*** ethical issues in your professional practice?

   ☐ Never ☐ Sometimes ☐ Often ☐ Always ☐ Unsure

4. Do you feel confident to ***resolve*** ethical issues in your professional practice?

   ☐ Never ☐ Sometimes ☐ Often ☐ Always ☐ Unsure

5. Most of the ethical issues in my professional practice involve (choose one):

   ☐ Autonomy- respecting the client's right to make decisions and choices.

   ☐ Justice- providing the most appropriate services and options for the client, service providers, and/or the organization.

   ☐ Beneficence- making decisions in the best interest of the client.

   ☐ Nonmaleficence- making decisions that will result in the least amount of harm.

   ☐ Combination of the above categories.

   ☐ None of these categories apply to the ethical issues that I encounter.

***"Everyday Ethics in Case Management: Experiences of Moral Distress by Professionals in a Community Health Care Setting"***



***Experiences of Moral Distress:***

Definition of moral distress: Moral distress occurs when a person believes they know what they 'should' do, however they are unable to do so. Unresolved moral distress may result in a variety of physical, emotional, and/or behavioural symptoms.

6. As a community care coordinator/case manager in a community health care agency, how often do you feel that you experience moral distress?

   ☐ Never ☐ Daily ☐ Weekly ☐ Monthly ☐ Unsure

7. How would you describe the level of moral distress that you feel as a case manager on a scale of 1-10? Please circle the number which applies to you.

   0 (none) 1 2 3 4 5 6 7 8 9 10 (most)

8. How do you experience moral distress? Choose all that apply to you.

   ☐ Physical symptoms (crying, insomnia/loss of sleep, nightmares, loss of appetite, headache, stomach problems, heart palpitations, changes in body functions).

   ☐ Emotional symptoms (anger, frustration, guilt, resentment, sorrow/sadness, powerlessness, shame, disappointment, anxiety, depression, job dissatisfaction, sense of unease with decisions, avoidance, outrage, distress, stress, confusion, regret, sense of failure, feeling 'stupid', embarrassment, heartsick/heartache, grief, misery, worthlessness, loss of confidence, robot-like attitude).

   ☐ Behavioural Coping Strategies (distancing, escape-avoidance, trivialization, unreflective acceptance, denial).

9. Do you recognize experiences of moral distress in fellow co-workers?

   ☐ Never ☐ Sometimes ☐ Often ☐ Always ☐ Unsure

10. Do you believe that experiencing moral distress is something that one should accept as part of the job description of a community care coordinator/case manager in a community health care setting?

    ☐ Never ☐ Sometimes ☐ Often ☐ Always ☐ Unsure

*"Everyday Ethics in Case Management: Experiences of Moral Distress by Professionals in a Community Health Care Setting"*



***Resources and Support Systems:***

11. Please indicate the most helpful resources that you use in your professional practice when dealing with ethical issues. Please select the top three and add the numbers 1, 2, 3 besides them according to their usefulness.

☐ Talking to colleagues, one to one
☐ Reflective practice
☐ Team meetings
☐ Referring to policy/procedures
☐ Using best practice guidelines
☐ Applying ethical frameworks
☐ Talking to supportive leaders/managers
☐ Other___________________________

12. Do you believe that having an ethics committee as part of an organization is helpful?

☐ Never ☐ Sometimes ☐ Often ☐ Always ☐ Unsure

***Barriers:***

13. What aspects of your work most often create ***ethical issues***? Please rank the top three by noting 1, 2, 3 beside the boxes.

☐ lack of time
☐ lack of resources/ inappropriate allocation of resources
☐ working independently
☐ staffing shortages
☐ organizational/institutional policies and regulations
☐ lack of supervisory support
☐ conflict and communication issues
☐ legal limits
☐ other reasons not listed here
☐ lack of knowledge of ethical principles applicable to a situation

14. What aspects of your work most often create ***moral distress***? Please rank the top three by noting 1, 2, 3 beside the boxes.

☐ lack of time
☐ lack of resources/ inappropriate allocation of resources
☐ working independently
☐ staffing shortages
☐ organizational/institutional policies and regulations
☐ lack of supervisory support
☐ conflict and communication issues
☐ legal limits
☐ other reasons not listed here
☐ lack of knowledge of ethical principles applicable to a situation

***"Everyday Ethics in Case Management: Experiences of Moral Distress by Professionals in a Community Health Care Setting"***



***<u>Demographics</u>:***

This information will be used to describe the sample of participants who responded to this questionnaire. It will not be used to identify you in any way in the final results.

15. Age:___________(years)

16. Gender: ☐ Female ☐ Male

17. Employment status: ☐ Full time ☐ Part time ☐ Casual

18. Main geographical location of professional practice:

☐ Thunder Bay ☐ North Western Region ☐ Sudbury ☐ North Eastern Region

19. Area of specialty (choose one):

☐ Palliative ☐ Adult community ☐ Long Term Care placement
☐ School ☐ Medically fragile children ☐ Intake
☐ Hospital discharge ☐ Short stay/post op ☐ Other
☐ Work many different areas of specialization

20. Professional affiliation: ☐ Registered Nurse ☐ Registered Social Worker

21. Number of years in professional practice: ___________(years)

22. Highest level of education (choose one):

☐ College diploma ☐ Bachelor's degree ☐ Master's degree ☐ Doctorate

23. I have received education about ethical issues in professional practice:
(Choose all that apply)
☐ During professional training
☐ Post professional training (ie. workshop, course)
☐ Independent learning and professional experiences
☐ Never

24. I believe that it would be helpful to me to have further education about ethical issues in professional practice.

☐ Yes ☐ No, wouldn't interest me ☐ Unsure

*"Everyday Ethics in Case Management: Experiences of Moral Distress by*

*Professionals in a Community Health Care Setting"*

**Questionnaire- page 5 of 6**

***Your Experience:***
Most health professional have had at least one experience of an ethical issue which stays in their mind as though it happened yesterday. Please describe a troublesome ethical issue that happened to you as a case manager in a community care setting. Please note the feelings you experienced and the impact that you believe the situation had on your professional practice.

*"Everyday Ethics in Case Management: Experiences of Moral Distress by*

*Professionals in a Community Health Care Setting"*



Please use this area to provide any comments or share any information that was not captured in the previous questions. Your insight and experiences are valuable.

***Thank you for completing this questionnaire. I appreciate the investment of your time and effort in sharing your thoughts, ideas, feelings, attitudes and perceptions about ethical issues. Please enclose this questionnaire in the attached, postage-paid envelope and mail it back within 2 weeks of receiving it, at your earliest convenience.***

## APPENDIX C

### Definitions

**Ethical Awareness (Moral Sensitivity)**
The ability to recognize an ethical situation, reflect on the situation, and appreciate the impact of ethical decision making on the final outcome (MacPhail, 2001).

**Ethical Comportment**
"The embodied, skilled know-how of relating to others in ways that are respectful and support their concerns" (Benner, 1991, p. 2).

**Ethical Fitness-**
"Ethical fitness is the human activity of ethical reflection and justification, requiring a certain degree of knowledge and skill in ethical problem-solving" (Canadian Nurses Association, 2000, p. 3).

**Ethics**
"Put simply, ethics is the study of morality- careful and systematic reflection on and analysis of moral decisions and behaviour, whether past, present or future. Morality is the value dimension of human decision-making and behaviour" (Williams, 2005, p. 9).

**Moral Comfort**
Polar opposite of moral distress (Corley, 2002).

**Moral Dilemmas**
Moral dilemmas occur when one must choose the 'right' course of action from a number of equally desirable options, but only one option can be pursued (Jameton, 1993).

**Moral Distress**
"Moral distress is defined as a feeling state experienced when a person makes moral judgements about a situation in which he or she is involved, but does not act on those judgements" (Fry, Harvey, Hurley & Foley, 2002, p. 374). It is typically associated with strong negative emotions related to powerlessness and a sense of responsibility for the outcome of a particular situation, thus having both short and long term effects on the individual (Fry et al., 2002).

**Moral Judgement**
"Moral judgement involves integrating numerous ethical considerations that count for or against a particular course of action" (Corley, 2002, p. 646).

**Moral Outrage**
A term coined by Wilkinson (1987/88) which describes feelings and effects which are similar to the experience of moral distress, however "the difference is that they (nurses) do not believe they, themselves, have done anything wrong, and are, therefore not likely

to experience guilt" (p. 24). It refers to an experience where someone other than the nurse was perceived as acting immorally, but the nurse was unable to stop them.

**Moral Residue**

"Moral residue is that which each of us carries with us from those times when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised" (Webster & Baylis, 2000, p. 218).

**Moral Uncertainty**

"Moral uncertainty is characterized by unease and questioning when the person is not clear about the right course of action" (Hamric, 2000, p. 199)

## APPENDIX D

### Personal Experiences of Everyday Ethical Issues and Moral Distress

Stage of Resolution- Giving Up

*"I guess as someone who has worked in the health care field- primarily home care field- I believe everything in life comes down to choices and for the most part everyone can make 'bad or poor' choices- they are the ones who have to live with the outcome. I don't let my personal feelings or opinions influence choices made as long as the choice/decision is made once all information has been given. I have to say- some of the questions asked did not have an answerable box to check that is why I have left some blanks on questions."*

Stage of Resolution- Taking a Stand

*"This is freshest in my mind, not because it was so distressing that it has 'stayed in my mind as though it happened yesterday' but because it did happen yesterday- not literally- but within the last month. I'm CM for a large retirement home, whose director/manager is an RPN whose job is largely marketing. She has constant pressure to keep her apts/suits filled (by her regional managers) especially now that they have 1. built a large new wing and 2. one block away is built a large new RH. All this to say there are not functional Ax's (assessments) done on incoming residents, so that she admits many residents who are not appropriate for RH living- rather they require LTCH level of care. I was called to do an Ax on a lady who was hailing a taxi at 4pm each evening and going to a nearby licensed restaurant and drinking (?) then until closing at 9:30pm. She was assisted every evening to her room, where she slumped onto her sofa, drunken and smoking (chain smoking). There were approximately 12 burn marks on her*

*carpet where she sat. I had 77 other residents there who are clients of mine, most of whom are hard of hearing and would* <u>*never*</u> *hear a fire alarm. This resident kept the window wide open behind her, with filmy long drapes blowing close by her (increased risk for rapidly spreading fire). The director chose not to evict this resident, even though resident's doctor begged director to do so or* <u>*something*</u> *about it. Director had carpet sprayed with a chemical fire retardant and had a plan in place for PSW staff to check on resident every 1.5 hours, but PSW staff unable to due to 2 PSW's only for 200 clients, all of whom are higher needs than belong in RH setting. As soon as I became aware of situation, I literally stopped my computer and took her (client) to ER and advocated +++ to get her* <u>*admitted*</u> *long enough to prevent/treat DT's so that LTCH's would consider her. Upon discharge back to the RT, I was advised by the 7 LTCH's I had done* <u>*Crisis*</u> *Application to, for resident, that she was declined as she was a smoker, even though she was* <u>*now*</u> *compliant with RH smoking policy.* <u>*So*</u> *I put in place a 'quit smoking' program: 2 cigarettes in am, at noon, in afternoon, and at bedtime, then 1 cigarette in am, at noon, in afternoon, and at bedtime, then 1 cigarette in am, at noon and at bedtime, then 1 in am, then none. Resident's daughter in agreement and paid for 1:1 PSW or companion aid staffing client to prevent her smoking (drinking)- private pay. Resident was on 'the patch'. Daughter lived 3 hours away so I took care of the staffing for her, communicating to the workers, the RH staff, the CM in another region, and my team manager. The outcome: client* <u>*successfully placed*</u> *in LTCH of the family's choice (client incapable for LTC decision) 1.5 weeks later. The dilemma: I pretty much put the rest of my caseload on hold as this case was so intense. I worked until 9pm most evenings, just dealing with VMM's and emails. I ended up staffing the resident myself on a Friday evening and*

*Saturday afternoon when staff didn't show up. I did not report this to my team manager* *until yesterday, as I would have been reprimanded for working so many hours (I did not log these hours, nor get paid by my employer or privately) and for getting too involved. I felt I had no choice, as the acute care hospital had done all they could, the psych hospital declined client, the RH refused to do more, and I felt responsible for the safety of my client and 77 others."*

*"83 year old female lived with elderly spouse who was main caregiver. Her spouse died suddenly. She required 24 hour care however refused to go to long term care or hospital. Her wishes were to remain in the home her husband built for her. We increased our services to max and she privately paid what she could however she was alone for long periods of time during the day and all night. She was found capable of making own decisions so we tried to support her. She died in her sleep 10 months later in her home as per her wishes."*

Stage of Reflection- Remembering & Telling the Story

*"A lot of my experiences have to do with placement and deeming a client incapable of making own decisions. I know I am protecting the client but I also feel guilty when I see how this client does not want placement. It is difficult to force someone or go against their wishes."*

*"Determining capability of clients for service set up at home upon discharge from hospital setting. Often challenged re: client's actual capability and therefore ability to safely manage in community by hospital staff Frustration/self-doubt occurs."*

*"I have a case in mind but overall it involves community clients that are doing their best to stay in their home but because of whatever circumstances end up in hospital*

*more than once. Once there physicians and hospital staff call a case conference and more often than not a client is convinced through intervention to go into placement. I always feel awful and torn because I saw how much they loved their life at home and if we only had more community resources we could keep them at home. I have seen clients die soon after admission to LTC."- my previous answers are based on 5 years as case manager prior to long term sick leave.*

Stage of Reflection- Examining Conflicts

*Conflicting Sense of Responsibility to Client versus Agency*

*"Something I struggle with is getting clients to go to ambulatory care. I hear from the nurses that people are ambulatory, so I call clients and let them know I'll set them up in ACU and they tell me they can't go. Who do I believe? If I stop nursing from visiting, will they go to ACU? Our managers say finances are not our concern, but if people have to pay for a cab or parking and can't afford it, they won't go. I worry that wounds will get worse and feel guilty taking services away from people who have paid taxes all their lives."*

*"Personal support service- our criteria requires that individual must need help with ADL's in order to qualify- many seniors have the energy to bath or shower on their own but not the energy to manage their laundry and housekeeping- those who have means can purchase housekeeping services- those without means cannot afford to do so- as coordinators we must then assess the level of risk to the client in the community, seek other resources, consider wait lists. These situations require a lot of problem-solving and critical thinking especially in cases where you know the help is needed- then is it possible*

*in the assessment data to make a fit between the criteria and the data in order to deem eligibility? Then the process must pass the manager's approval..."*

*"When clients have 'too' much HON services already initiated. As a CCC, I make reassessment visits and notice that the time already allocated exceeds our criteria however clients have been receiving this level of HON for a year or years. As a CCC, I have an obligation to follow guidelines (time per task) but at the same time it is difficult to decrease services from clients who have relied on these services for quite some time. I struggle with this issue frequently."*

*"Recurring issue- An elderly person on a limited income calls to get a homemaker to assist them with household management. They have no personal care needs, they are independent with personal care (therefore they don't meet eligibility criteria for homemaking). They need help vacuuming and doing laundry. They have no family or friends who can help and say they cannot afford to hire anyone. I can hear the desperation in their voice, but have no option besides private pay options to offer them. Who will help them? I feel desperate for them. This feeling decreases my job satisfaction because I am an RN (because I wanted a caring profession) and want to help people."*

*"Budget constraints create a huge ethical challenge- the client requires the care but the budget cannot sustain the level of care required- client has a fall as a result of decreased care."*

*"To deal with moral distress- case managers need greater autonomy in service planning and allow creative problem solving rather than micro-managed by executive."*

*Conflicting Sense of Responsibility to Client versus Health Care System*

*"We are receiving pressure from hospitals and management to not have patients going to emerg and having to admit patient to await ALC- Alternate Level of Care (ie nursing home or rehabilitation hospital). However, at the community level we cannot use own judgement to set up individual plan to help caregiver, but are restricted by guidelines for service that are task/time specific (ie. 15 min. meal set up, 15 min. dressing, ½ hour bath, 3 hours respite, etc). We are challenged by managers when we put in our homemaking hours and we cannot increase as client needs change without manager approval. This is too micromanaged and puts stress on family, client, case manager as caseloads increase, workloads increase, no time to do all this."*

*Meeting the Needs of the Client versus Family*

*"Generally, situations occur around consent and capability and attempting to service the client and at the same time incorporating the family's concerns and wishes and meeting their needs of supporting the client."*

*"Elderly ...lady (age 92) who is no longer safe in own home- over last 3 years discussions with son and granddaughters ie placement. Because client does not want LTC, family reluctant to complete paper work. Client is incapable of making decisions. Supported in community by daily homemakers who constantly report unsafe conditions- recently plumbing not working, client burning pots, unsteady on feet and down basement to keep wood furnace going. Son took her to his home but stayed only one week. Feeling of pressure to do right thing- but morally can we continue to maintain in own home knowing she is not safe."*

*"Families that choose to keep elderly, often dementia seniors in home for monetary gain. Situation occurs, but unless able to prove neglect or abuse or other family members use to support, there is limited intervention as a CM. Generally, we provide as much support as is possible. Inform caregivers/family re: risks of leaving client in "unsafe" or unsupervised situation. Continually educate re: options and always be aware of any signs of neglect."*

Conflict and Communication Issues

*"Organizing a service plan for a client to return home from a Hospice Unit. The client was bedridden and having difficulty with pain control management. Client required nursing 3xday for pain and symptom management; the family was to assist client with medications and bed care. The client, his wife, son and daughter-in-law were all part of this service plan and I was debating in my mind whether or not to discuss an alternate plan of care if the client's health condition changed or began to deteriorate. I decided to bring this forward, with the recommendation of possibly returning to Hospice or to the ER or if the client and family was comfortable with a planned death at home (explaining in detail what this involved). The client was accepting of these choices and wanted to see how things would go at home and then would discuss it with the visiting nurse. The client's wife and son were visibly upset and verbally expressed their anger with this conversation and questioned my professionalism. I apologized to the client, wife and son; the client reiterated that we would have to determine his plan from home. After leaving the client's room the client's son continued to verbally express his displeasure of this meeting. I explained to him about the reasons for this discussion however he refused to listen and left the unit. The son's wife contacted me later that day and explained that he*

*was in denial and not accepting his father's condition. She explained that she will work with the visiting nurse to help her husband and mother-in-law understand the disease process. My dilemma was that I could have left this for the visiting nurse to address options when client's condition worsened but I chose to address it because his pain control was variable and his physical condition was deteriorated. The Hospice physician also reported that this client only had a short period of time at home. This conversation is not uncommon when service planning for home but the difference in this situation was that I did not have a good sense of how adjusted the family was or was not; I had only spent time with the client apart from the family and he expressed his knowledge of his prognosis and acceptance of it. Unfortunately, I did not allow time for more of family discussion however due to the client's strong desire to go home his discharge was planned quickly. After this experience I then made sure that the client and family had knowledge of client's prognosis and had a good sense of their acceptance of the disease process. I also conducted service planning meetings with the Unit's SW if the client or family was having emotional difficulties with returning home/disease process."*

*"I work as a d/c planer/CM in hospital. Elderly demented lady who had advanced directives prior to incapacity – coded, was taken to SCU revived to only die several days later (client wishes were no code, no intubation- both of which were done as family wanted this). Very proud lady died having lost dignity, felt we as caregivers failed her miserably, tried to advocate with doctor. He stated once client unconscious, family had SDM role. Felt conflicted as this was not my understanding of advanced planning and often recommend clients do this. I sought out professional advice after this incident re: client's rights by a capacity assessor. I believe physician errored and let his patient down*

*as he did not remain her advocate in death. I now work closely with physicians to communicate with their clients re: wishes and try to bring families into the decision making ie case conferences, etc."*

*"Clients need to know their 'rights'. When you have a doctor that keeps trying new drugs- trial drugs right up to the time of death. Client needs to know they can stop treatment and side effects of that treatment when they have had enough. Sometimes the doctor does not know when the person had endured enough. Doctors need to know it's not that the client is giving up and not a reflection on them."*

*Relationships*

*"Lack of productivity for multiple reasons by both coordinators and support staff that have not been addressed satisfactorily by management. My thoughts inevitably conclude that there is a definite distinction between older and newer workers re: work ethic- some exceptions to the rule of course. Cannot address personally- as no authority therefore feel powerless and dismayed and overworked as a result because I am affected inevitably re: increased workload."*

Additional Findings

*Spiritual Perspective*

*"I think our profession today is so focused on the leaves, on the branches, on the trees that we forget about the forest. Everything is overanalyzed and then sight is lost. Things that sound great on paper often do not work well in practice. People are unique and precious; applying too much policy often causes more harm than good. Bottom line- if we apply the 'love your neighbour' policy properly- it works for everyone. Of course this won't happen because the vast majority of people don't understand 'love your*

*neighbour' and won't study God's word to become wise. My challenge is to do what is right in light of God's word, within my practice and when I don't feel like it. Knowing right and wrong, good and bad is the easy part- doing right and good is the hard part. Check it out in the Bible."*

*"... On one hand, making decisions based 98% on this base (nursing) does 2 things so far in this setting for me: 1. gives me ample empathy to both community, staff and client and affects my decisions from the nursing angle- which is good. 2. no experience until now in the non-nursing aspect such as the financial decisions ie-which equipment will benefit the client or be the best financial choice? Almost always defaults to the client and their needs. I personally am 'ok' with this but will try and be broader minded in the best spent money for the tax payers. This is an ethical dilemma which often causes me stress. My other ethical dilemma causes me much more stress than the above. Short staff problems looked at by management as temporary but it never changes for the better so I am always giving up something- not doing my job the way I know it needs to be done- feels lack of control. Always juggling something but never catching up. Administration probably sits at 5 or 6 on 1-10 compared to other agencies I've worked for but they never seem to be able to 'fix' anything either so 'you cope' is the key word. And if you can't you'll likely be asked to leave or be responsible for negative outcome with virtually no support from management. In other words in my nursing experience including CM, the nurse is the one holding the burden. How she does it is very poorly supported and because she is responsible for her own practice, union or no union, the burden is 'mine'. Thank God I have personal and spiritual support from family, friends, and the God of Christianity."*

*Northern Perspective*

*"It is difficult to get the full picture of how a client is managing and I try to provide the most safe service plan ie. OT home safety assessment or SW if client expressing distress related to their circumstances or housing situation. I will then request a community co-ordinator to visit as soon as possible. The community co-ordinators' workloads are enormous and it is difficult for them to visit quickly which creates a dilemma for both of us however we prioritize visits and high needs clients are seen as soon as possible."*

*"There are many gaps in services where I work in the North. And there are decision makers who formulate how our practice is prescribed in our communities; but from the 'Southern perspective'. As well, our town has not been progressive as I believe that we are 'left alone' while our Southern policy makers are caught up with the distractions of the South. Therefore, we have few resources and people and infrastructure that is outdated to address the growing needs of our area. I do not believe the LHIN will be able to address such huge issues except in a piece meal fashion- which is reflected in how people in our area have learned to accept their health care. Thanks for letting me say my piece."*

*Vulnerable Populations*

*"Extremely long waiting lists causing children in high need of ie. speech services (ie. school teacher, peers unable to understand student as a result student withdraws, effects self-esteem). Children waiting 1+ year and always limited funds. Having to decide who would be the next student that needs to be seen (manager does that). Most needy are seen but we end up with really needy kids waiting. Frustrating as a worker- limited input*

*into who is the most needy- priority 2 clients waiting +++ as priority 1 clients are sent first. Sometimes it feels like the school program has the lowest priority for funding (ie not acute, not hospital). It helps to talk with co-workers to try to develop strategies to assist with advocating for more $ or finding creative ways to manage limited resources."*

*"Respite for parents of special needs children is an ongoing issue there is a patchwork of inadequate programs and inequity in terms of resource allocation to families- both within the region and from region to region. Studies have been funded, reports developed and forwarded to ministry staff and nothing has really changed- many families continue to barley cope at great cost to themselves (parents) and siblings (physical, mental and social health). Children's services (scattered across health, social services, education, etc) are fragmented and difficult to access (multiple points of intake, eligibility criteria, etc). I had hoped the new Ministry of Children and Youth Services would start looking at amalgamating children's services "under one roof" with a single point of access- ideally CCAC."*

*"Most of my experiences surround whether CAS or Dilico needs to be contacted. A decision is always made with my supervisor. The feelings I have are stressful. I usually feel sick and worried. 'Did we do the right thing?' I tend to go over and over the situations in my mind. I tend to err on the side of safety for the children. So far my experiences have been positive and the families have respected my decisions."*

*"Assistance with home management had to be discontinued for majority of clients, including the frail and elderly living alone in community. I felt guilty, headaches, dissatisfaction with work, thoughts of changing jobs, very difficult for many months now ok."*

*"Due to regulations, I have one almost daily, where spouses get priority over single/widowed people in respect to placement. I have to follow the regulations and they are discriminating. Also if a male spouse is in a facility and there are several female spouses waiting for that facility, I have to accept the first female on the list even if it means splitting up yet another couple. The regulations need to be changed!"*

*"Who has more rights, patient or caregiver? Deal with issues of placement regularly where caregiver can no longer care for client but they want to remain at home and there are limited or not enough services in home to provide adequate support. Takes a lot of time, negotiation and communication to resolve these issues."*

*"Client with diagnosis of Alzheimer's and behaviours- increased agitation/aggression both physical and verbal. Wife seeking increased respite, LTC. Client previously attended Alzheimer's Day Program with subsequent referral to attend (prior to onset of physical aggression).This CCC (community care coordinator) made referral to COT & GAP- who recommended LTC and Alzheimer Day Program again. This CCC unable to make client eligible for Alzheimer Day Program ie physical aggression (history of threats to wife and homemakers) re aggression, unpredictable behaviour (other clients may be at risk- remember ? CASA VERDA inquest). This decision precipitated much conflict between myself and COT team members and NP. Ethical dilemma increased awareness that wife <u>needed</u> respite and placement. This CCC processed referral to dementia unit/LPH for assessment and treatment with much conflict/resistance re: same."*

*"One client was living alone in a senior's apartment, had multiple health problems, including alcohol abuse and malnutrition. He also had behavioural issues.*

*Other residents in the building were very concerned about their own security, afraid of fire as this client was also a heavy smoker and would be forgetful. He had no family support at all and no friends. Client had to be evicted from building and was forcefully admitted to hospital for eventual placement. The case was very moving- gave me feelings of hopelessness as this client was only middle-age and could be very nice at times."*

*"Client had severe dementia, 75 years, one person assist with ambulation. Total care with ADL's/IADL's/insulin and medications, feeding. Care giver female, 73- up every night because client has hallucinations and calls for her, so she never gets full sleep, client resistant to her leaving during the day. Caregiver lost 20 lbs in 6 months. Client eligible for daily 2 hrs split (1 hour in am and 1 hour in pm) according to our criteria but wife preferring to bunch hours to get more time away for respite ie 3 days with 3 hours each respite and 2 days split 1.5 and 2.5 for bathing, feeding, dressing. Total 14 hours. Manager advised me that client only eligible for CCAC 3 hours per week respite and other hours can't be grouped. So here I have caregiver doing her best to keep spouse out of LTC and hospital and we cannot accommodate this."*

*"Referral for nursing home placement. Client living in unsafe conditions, no family or other support. Concerned neighbours. Client declines case manager visit. Declines nursing home placement. Client not competent. Very frustrated with system as client needs assistance to see family doctor but not competent enough to make own decisions. No system in place to help these people out."*

*"There is a huge mental health population who have little or no services available to them. My agency is not funded or equipped to care for these individuals. It is very difficult to not try and help them."*

*"One of the policies of eligibility are that clients must have a valid address. We have many homeless in Sudbury who do not get the care they need and end up in emerg. Not providing care to the most vulnerable is truly heart-breaking. My own moral base helps me deal with this by flexing the rules to allow as much care, or direct these people to the best resources."*