

University of Alberta

**Ethical Issues in Community Nursing**

by

Sandra A. MacPhail



A thesis

submitted to the Faculty of Graduate Studies and Research  
in partial fulfillment of the requirements for the degree of  
Master of Nursing

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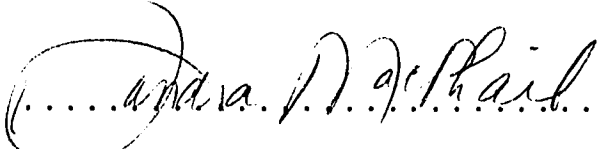
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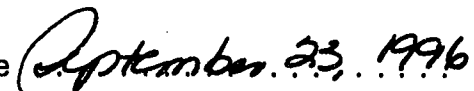
Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Ethical Issues in Community Nursing" submitted by Sandra A. MacPhail in partial fulfillment of the requirements for the degree of Master of Nursing.

  
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## **Abstract**

Very little research has been conducted to identify the ethical issues that nurses face in their practice; what has been done has been conducted in acute care. The purpose of this study was to describe the ethical issues that community-based nurses face in their practice.

An exploratory, descriptive approach was chosen to serve as a guiding framework for the research. Data were collected through unstructured interviews with five public health and five home care nurses living in or within a two-hour drive from a large western Canadian city.

Using content analysis, three major themes emerged from the data: issues of relationship, issues of resource allocation, and issues of autonomy. Previous studies have identified issues of resource allocation and autonomy, but only one other study shares the finding of a relational theme. Many of the nurses' ethical issues developed from their relationships with other professionals and their own supervisors.

Resource allocation issues figured prominently in this research, a finding which must be considered in light of the recent reduction in health care spending in Canada. The ethical issues that nurses encounter in the community may be similar to those in acute care, but the practice setting serves to increase their complexity. It is anticipated that the findings of this study can be useful to community nurses and administrators alike.

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## CHAPTER 1

### INTRODUCTION

#### Statement of the Problem

Many health care providers accept the notion that nurses working in acute care, especially those working in critical care and emergency, face ethical issues in their practice on a daily basis. But this acceptance of ethical issues occurring daily in practice does not always extend to nurses working in the community. There is a lack of knowledge about community nursing which became clear to me during a conversation with a well-respected colleague whose many years of clinical experience are in intensive care. Her reaction on hearing the proposal for this study was one of surprise: "Nurses in the community have ethical issues in their practice?" Her reaction underscored the absolute necessity for this research.

Nurses are compelled, by the very nature of nursing, to experience interactions with others (Levine, 1977). By virtue of these everyday interactions with others (which, of course, are not confined to the acute care setting), nurses are in the position of having to make daily moral choices. If Gadow (1995) was right when suggesting that "the purpose of nursing knowledge is to enhance the good in patient's lives" (p. 3), then there must be recognition that, no matter the practice setting, nursing, because it is a practice-based profession, is practiced within a moral context. Moreover, there must also be recognition that the practical knowledge of nursing is incomplete if it includes theoretical and technical knowledge without ethical knowledge (Gadow, 1995).

Rapid advances in health care technology now routinely save the lives of many individuals who until recently would have died. During the last

decade, one of the sectors that has grown and changed the most rapidly in our health care system has been home care (Haddad, 1992; le Riche, 1994). Factors influencing the growth of home care include the aging of the population and the resulting increase in the number of frail elderly receiving care in their own homes, the increasing survival rate of chronically ill children and adults, the development of sophisticated but "user friendly" medical technology that can be used in the home (Haddad, 1992), and the escalating cost of hospitalization. Clients are now receiving complex nursing care in their homes in increasing numbers (Aroskar, 1989).

Changes have also been occurring in the public health sector of community nursing. As a consequence of the World Health Organization establishing the goal of "Health for All by the Year 2000," the focus of public health has expanded to include the strategy of primary health care (Clarke, Beddome, & Whyte, 1993). Additionally, issues of health promotion, disease prevention, and communicable disease control are becoming more complicated as diseases no longer thought of as threats, such as tuberculosis, are on the rise and diseases such as human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS), and hepatitis C begin to surface in increasing numbers in the community. Client demand for maternity care that recognizes birth not as an illness but as a natural, healthy event has paved the way for early maternity discharge programs to be provided in the community by public health nurses (Capital Health Authority, 1996).

The previously mentioned factors have influenced and expanded the delivery of nursing services in the community. Nevertheless, the current political context in Alberta must also be recognized as a major factor influencing recent changes in both provincial public health and home care. It

is this political context which determined not only the speed at which the recent shift in emphasis from hospital-based to community-based health care delivery began taking place but the enormity of the shift.

In mid-1993, a newly elected Alberta government began to act on a promise to eliminate the \$3.1 billion provincial deficit. The plan was to reduce the deficit by curbing spending in the areas of education, social services, and health care. Specifically, the reduction in health care spending included budget cuts of \$734 million over a four-year period (Government of Alberta, 1993a). This singular focus on deficit reduction has led to enormous upheaval in the provincial health care system over the past three years.

Initial funding cuts resulted in massive lay offs of nurses in acute care hospitals around the province. With these institutions having to change their methods of service delivery, patients were discharged from hospital much sooner than they had been previously. Early discharge from hospital has increased for all areas of clinical practice and for all ages (Edmonton Board of Health, 1994). The delivery of increasingly complex health care services moved from the hospital into the community at an overwhelming pace. The implications for the practice of community nursing in the province have been significant.

However, prior to all the cuts to hospital budgets, the time was not taken to ensure that the required community services were put in place to receive the onslaught of clients. By June of 1994 home care staff were "stretched to the limit" as admissions to the home care program had risen sharply and the patients being admitted were sicker (Pedersen, 1994). A year later Michael Rachlis, a physician and health policy analyst, observed that appropriate community services had still not been developed to replace



hospital care, and the corresponding burden was falling to the family (Marck, 1995). The funds required to set up community programs have been slow to come from the government, causing a deficit in the home care programs around the province (Tanner, 1995a, 1995b).

The impact of funding cuts on public health has been less reported in the media. A cursory review of government documents shows that public health, which has historically received less recognition and consequently less funding than acute care, is now not only in the shadow of acute care but also in the shadow of the increasingly high-profile home care program (Alberta Health, 1994, 1995). Moreover, government cuts to other sectors such as social services and education are impacting on public health nurses who are being asked to intervene in situations where school counsellors or social workers intervened in the past.

Kalisch and Kalisch (1982; cited in Aroskar, 1987) stated that "the basic definition of politics is the authoritative allocation of resources" (p. 31). As health care budgets are reduced and more care is routed to the community, allocation of scarce health care resources becomes a larger issue in the community. Such resources generally tend to be considered in terms of dollars (Botter & Dickey, 1989). However, human resources, time, programs, equipment, and supplies are also resources in that they represent dollars.

Davis and Aroskar (1991) suggested that new technological developments and efforts at cost containment affect both the substance and the nature of the ethical problems faced by nurses today. By studying the nature of ethical problems in the community, one will also determine much about their substance.

Inevitably, concomitant with the growing complexity of health care being delivered in the community is the growing complexity of the ethical issues encountered by community-based nurses. The number and character of the ethical issues that community-based nurses face can only increase, not diminish, in this environment. It is within this context that this research was conducted. The data collection interviews took place between June 1994 and May 1995, a time that many would consider to be at the height of the changes to health care in this province.

The critical care nurse's reaction cited at the beginning of this introduction became a touchstone during the research process when doubts arose about the significance of this study in light of the drastic cuts being made to the health care system and the resulting turmoil that my nursing colleagues in Alberta were experiencing.

### **Purpose and Rationale**

Although some accept that community nurses encounter ethical issues on a daily basis, to date there has been little research conducted in the area of community nursing and ethics. Moreover, the research that has been conducted in the topic area has not used face-to-face interviews.

Although it could be anticipated that the ethical problems for community nurses will escalate as a result of providing care for increasingly complex cases, that will be impossible to determine as bench-mark information about ethical issues in community practice is lacking. There is a critical need to know more about the nature of the ethical issues facing nurses working in the community.

If we believe that nursing exists because of patients/clients and we also accept that, in order to care for these individuals, practical knowledge is

needed, then Gadow's (1995) claim that practical knowledge is made up of technical, theoretical, and ethical knowledge and that "technical without theoretical knowledge lacks foundation; technical without ethical knowledge lacks a purpose" (p. 3) must be considered. It is specifically in the area of ethical knowledge that this research is intended to make a contribution.

The purpose of this research is to identify and describe the ethical issues encountered by nurses in a community setting.

#### **Research Question**

The research question guiding this study, therefore, is **What ethical issues do community nurses describe in their practice?**

#### **Significance of the Study**

The findings of the study will do two things. First, they will contribute to an increasing awareness of the ethical issues in community practice. Second, they will assist public health and home care administrators to determine what kind of ethical problems confront their staffs and accordingly how they can be responsive to the needs of their staffs in terms of consultation and educational inservice.

## CHAPTER 2

### LITERATURE REVIEW

Prior to beginning this research study, the literature about ethics in the context of community nursing was reviewed. There were two purposes for this review: first, to become familiar with the research that currently exists in this area; and second, to identify the gaps in the research and thus establish the need for this study. The results of the initial literature review and the subsequent review that continued throughout the research process have been organized into four major sections: definition of terms, review of relevant research, the role of the nurse in the community, and gaps identified in the literature. The final section is a brief chapter summary. Chapter 5 will consider the findings of this study in relation to the research dealing with ethical issue identification as well as additional pertinent literature.

#### Definition of Terms

What is *nursing ethics*? Ethics is a branch of philosophy (also called moral philosophy) that deals with significant questions of human conduct that have relevance to us, not only as individuals but also as health care providers (Davis & Aroskar, 1991). Normative ethics asks what ought to be done or what is right in a situation where there is a moral decision to be made. Normative ethics examines individual obligations and rights and the common good. Descriptive ethics attends to what individuals think, believe, or do in a given situation (Ketefian, 1989); or as Fowler (1989a) pointed out, what "is." This research addresses descriptive nursing ethics, because

it is a beginning attempt to uncover what community-based nurses identify as ethical issues in their practice, what they describe as what "is."

In this study, the term *community nurse* is used collectively, encompassing both public health nurses and home care nurses. Public health and home care nurses both practice in the same geographical setting, the community, although they may provide differing services. Public health nurses focus on health promotion and illness prevention while working with individuals, families, groups, and communities; home care nurses focus generally on the individual and family while delivering nursing services aimed at assisting clients "incapacitated in whole or in part" (Health and Welfare Canada, 1989; cited in Alberta Health, 1992, p. 2). Nevertheless, whether they are public health or home care nurses, (a) they provide health care for clients in their homes; (b) their clients include individuals and families; and (c) they collaborate with other professionals, informal health care providers, and the private sector.

The assumption has been made, for the purposes of this research, that, by virtue of their location of practice, the two groups of nurses will experience similar ethical issues. An additional assumption is that their differing roles and philosophies will not change the ethical issues substantially. However, they may offer different descriptions of a similar ethical issue.

It is important to locate the term *ethical issues* in a framework. Most authors in the literature reviewed used the words *moral* and *ethics* interchangeably, and the terms will be used here in like fashion. Jameton (1984, cited in Fowler, 1989a; Fry, 1989a; Trudel Dowd, 1989) categorized ethical problems in a way that they appear to be on a continuum beginning with *moral uncertainty* and moving on to *moral dilemmas* and finally *moral*

*distress*. He defined *moral uncertainty* as ambiguity about moral rules or principles that may apply, or the nature of the ethical problem itself. *Moral dilemmas* are defined as conflicts of ethical principles that suggest different courses of action. He defined *moral distress* as arising in a situation where one knows the right thing to do but is prevented from doing so by institutional or legal constraints.

Fry (1992a) clarified Jameton's (1984) definitions by stating that the precursor to a moral situation is moral uncertainty, which can be described as a feeling of unease, with information lacking. The significance of moral uncertainty is that many moral situations begin at the level of moral uncertainty and there is clearly a need for additional information. Often, once the necessary information is ascertained, the situation can be resolved.

Beauchamp and Childress (1989) provided further clarification. A moral dilemma occurs if and only if there are moral reasons for taking each of two or more opposing courses of action. Moral arguments can be established for and against each alternative; and although one alternative must be chosen, neither appears decisively right (Mitchell, 1990). Aroskar (1989), in the first study that looked exclusively at community nurses, used a less restrictive term when asking about ethical problems rather than dilemmas; and by doing so, this may have captured a richer data base. Davis (1981), in a random survey of the members of a nursing organization that included acute care and community nurses, used the term *ethical dilemma* but did not define it for the participants in an attempt to encourage them to indicate their most troublesome issues. In the present study the term *ethical issue* is used (as opposed to the term ethical dilemma) in an effort to capture the full range of ethical conflicts that community nurses face rather than confine the description to ethical dilemmas. It is argued that ethically uncertain

situations may cause as much difficulty for nurses in the community as actual dilemmas and thus be important to document. For the purposes of this research, the definition of *ethical issues* will be a paraphrased version of the definition used by Aroskar (1989) in her initial study of ethical problems. *Ethical issues*, then, are those issues in community nursing practice in which there is uncertainty about the morally right thing to do or in which the obligations and duties of health care professionals are not clear.

### **Relevant Research**

Much of the research done to date has focused on moral reasoning and development; far fewer studies have focused on the identification of nurses' ethical issues (Omery, Henneman, Billet, Luna-Raines, & Brown-Saltzman, 1995). Furthermore, most of that research has been conducted in acute care settings (Aroskar, 1989; Davis, 1991). The paucity of research in the area of community-based nursing ethics necessitates that a wider scope of comparison be undertaken—one that includes research conducted to identify the ethical issues encountered by nurses in other care settings. For ease of discussion, the literature has been grouped under the following headings: (a) research conducted solely with community nurses, (b) research where community nurses have been included in the sample, and (c) research in other settings.

#### **Research Conducted With Community Nurses**

Community nurses regularly face ethical challenges in their practice (Andrews, 1988; Aroskar, 1989; Duncan, 1989, 1992). However, descriptive studies documenting the ethical issues experienced in community nursing practice have only recently become evident in the literature (Aroskar,

1989; Duncan, 1989; Duncan, 1992). The first descriptive study focusing solely on ethical *problems* in community nursing was conducted in the United States by Aroskar in 1987-88 (1989). One thousand questionnaires were mailed to nurses employed in community health (home care and public health), with a resulting response rate of just over 30 percent. Aroskar did not distinguish between home care and public health nurses' responses in the discussion of her study results. She found that although nurses in the community may encounter ethical *problems* that appeal to the same principles as do nurses in acute care and long-term care, the circumstances in which the conflicts occur differ. The categories of the most significant ethical problems that emerged from her data were designated by ethical principles and conflicts. These were identified as conflicts about the principle of distributive justice, conflicts between autonomy and beneficence, and conflicts between truth-telling and nonmaleficence. A fourth category was labelled "other significant ethical concerns."

Duncan (1989), a Master of Nursing student at the University of British Columbia, studied ethical *dilemmas* and response in community-based nursing practice for her thesis research. Duncan also chose to gather her data by way of a questionnaire approaching two groups of community-based nurses to obtain her sample. Her sample was comprised of public health nurses. The first was a group of 28 nurses working in a preventive program of an urban health department; the second was a provincial community health nurses' interest group composed of urban and rural nurses. Duncan approached the first group by speaking at a monthly meeting inviting participation. The members of the interest group were made aware of the research by way of an advertisement in the bi-monthly newsletter. This was followed by a questionnaire mailed out to 110 members. A disappointing 2



out of 28 questionnaires were returned from the urban group. She received an overall total response rate of 21 percent out of a total of 138 questionnaires sent out. Of the 30 returned questionnaires, five nurses reported no experience with ethical dilemmas despite the use of a broad definition of ethical dilemma. Duncan's findings supported Aroskar's (1989) statements that the ethical dilemmas experienced by community-based nurses were not much different from those experienced by nurses in other settings. Rather, it was the unique features of the community nurse's role that influenced the way the ethical dilemma was experienced. The three categories that emerged from the nurses' situations according to the primary ethical theme were clients' rights, nurses' rights, and system interaction (resource allocation and health care team interaction). Duncan suggested that if interviewing (which would have allowed for the opportunity to clarify responses) rather than written responses had been used, the categories might have been mutually exclusive.

Chubon (1994) conducted two ethnographic studies of home care nurses. The purpose of the first study was to learn about the job stress of home care nurses. Participant observation and interviews were used to collect the data. During this research it became apparent that the nurses were having great ethical difficulty working with people with AIDS, and this finding led to a second study with a new group of home care nurses. The aim of the second study was to learn more about home care nurses' experience caring for persons with AIDS and the *dilemmas* or *issues* they encountered. Little detail was supplied about the sample other than to indicate that the nurses (number of participants was unspecified) worked with a home care agency. The nurses' stories were analyzed using the ethical principles of confidentiality, veracity, autonomy versus paternalism,

and justice and autonomy. Chubon concluded that the language of ethics was not used when describing problems encountered in practice, leading her to believe that nurses do not always recognize the ethical implications inherent in practice situations. It may be argued, however, that the nurses agreed to be interviewed because they recognized that they had ethical situations in their practice. They just did not discuss those issues using traditional bioethical language.

### **Community Nurses Included in the Sample**

Several investigators have included community nurses among the care providers in their sample. Haddad (1992) conducted a pilot study with the dual purpose of describing ethical *problems* from the home care providers' perspective and refining a survey instrument. The 30 participants included a range of providers such as home health aides, physiotherapists, administrators, and nurses. Besides answering the multiple-choice questionnaire, 18 of the respondents responded to the request to share written narratives of practice situations. The ethical problems described by her respondents fell into three categories: difficulty with regulations (examples provided had to do with U.S. Medicare requirements), incompetence of co-workers (marginal care from a full range of co-workers from physicians to aides), and other (elder abuse, client noncompliance, truth telling, and competence of caregivers and clients). The narratives identified ethical situations that "take on different meanings in the home care setting" (p. 49). Haddad holds that the implications of some of the ethical situations can be more profound in the community than in an institutional setting. For example, the issue of co-worker incompetence is

more problematic in the community because most of the care delivered by a home care worker is not seen by others.

For purposes of comparison, Forchuk (1991) included generalist public health nurses in her sample of community and in-patient mental health nurses. Her study sought to identify the ethical *problems* encountered by mental health nurses. When the 57 written case situations had been analyzed, she found that the types of ethical problems varied with the setting. Numerous issues and ethical principles were involved in each case situation. Her findings revealed that beneficence was the principle used most commonly in all three settings. The principle of autonomy was the second most frequent problem for inpatient mental health nurses and the third concern for nurses in the community. Among the nurses in the community, confidentiality rated second as an ethical concern. Of interest is the fact that the mental health nurses' concerns varied by setting, but there was consistency in ethical concerns between the community mental health nurses and the public health nurses. This finding supports the notion put forth by Aroskar (1989), Duncan (1992), and Haddad (1992) that geographical setting or practice location is a substantial factor in community nurses' experience of ethical conflicts.

Davis (1981, 1988) surveyed nurses in the United States and eastern Canada to determine the types of ethical *dilemmas* that faced nurses in practice, what factors influenced the dilemmas, and the understanding that nurses had of the concept of ethical dilemma. The U.S. sample of 205 nurses included 61 community nurses. It is not clear how many of the sample of 100 Canadian nurses were community nurses. Nurses in the United States named prolonging life with heroic measures and unethical activity of colleagues as their most frequently faced dilemmas. In neither

study were the dilemmas discussed by practice setting. Canadian nurses cited their four most common dilemmas as sustaining life without regard for the quality, participation in abortions, following doctors orders with which they did not agree, and confidentiality. Davis (1981) suggested that nurses need the opportunity for dialogue in ethics in order to increase their awareness and ability to present a well-thought-out ethical point of view. This observation was supported by the number and length of the comments that were added to the questionnaires. The nurses' comments varied from being grateful for the opportunity to participate in research they considered important to indicating that ethical problems were becoming so troublesome that the only moral option they saw for themselves was to leave nursing. In the Canadian study, Davis (1988) found discrepancies in the definitions and understanding of the concept ethical dilemma as well as the number of ethical conflicts and their significance. Davis believed that among the factors influencing these discrepancies was the lack of ethics education in nursing. The Canadian nurses themselves indicated that they wanted better education in ethics.

A stratified random sample was used by Robillard et al. (1989) to survey 702 physicians, physiotherapists, physician assistants, and nurses regarding the frequency of ethical *issues* in their practice. The nurses in the study were either members of a primary health care specialty group or registered as primary health care specialists with the state licensing board. The ethical issues encountered most frequently by these providers of primary care centred on adequacy of care, patient determination, distribution of resources, and professional responsibilities. The most commonly occurring ethical issues indicated in this study represented the practical concerns of day-to-day clinical practice as opposed to the dramatic

situations addressed more frequently in the health care ethics literature. Ordinary, everyday encounters become ethical dilemmas because of influencing factors such as geographical location that affect the way ethical decisions are made (Aroskar, 1989; Burger, Erlen, & Tesone, 1992; Duncan, 1989, 1992).

Similarly, Viens (1993) interviewed 14 nurse practitioners and found that their *dilemmas* were not extraordinary events, a finding that she interpreted as "morality as [being] imbedded in everyday life" (p. 9). Viens' (1993) primary research question was to describe the moral reasoning of nurse practitioners but she also sought to define the dilemmas experienced in practice. The majority of the dilemmas described were around issues of patient safety and advocacy, although access to care and being able to meet the psychosocial needs of patients within the limited time available were ongoing issues inherent in the health care system.

Andrews (1988) conducted a study aimed at identifying the most frequently encountered *dilemmas* by three groups of nurses—hospital, school, and community. Using the Delphi technique, a survey tool was generated containing 55 ethical dilemmas. Andrews received responses from 247 of the 621 community nurses who received the survey, a response rate of 39.8 percent. In her findings, Andrews listed the most commonly experienced ethical dilemmas encountered by each group out of the 55 contained in the tool. Among the 10 most commonly encountered dilemmas experienced by community nurses were (a) dilemmas of resource allocation nature: emphasis on cost-effective care at the expense of quality patient care, denying care to some by cutting back on client load when staff is limited, and the problem faced by the nurse when asked to work overtime when already exhausted; (b) providing enough information so that informed

choices can be made regarding available treatment; and (c) the nurses' role in reporting suspected child abuse. Examples from her list of the 10 most important (as distinct from most common) community health dilemmas were medical and nursing colleagues providing inadequate care, child abuse, issues of working overtime, and problems encountered when expected to support a physician not responding honestly to clients. One limitation of this study was that the survey tool included many dilemmas that were never or rarely encountered by community nurses, and the author herself questioned what other dilemmas might be encountered by nurses in the community that were not on the list.

In both the research and descriptive literature on community nursing, several ethical concerns are frequently cited: high-risk parenting (Andrews, 1988; Aroskar, 1989; Duncan, 1989; Taylor & Tilley, 1989; Zerwekh, 1991, 1992), abuse of the elderly (Clark-Daniels, Daniels, & Baumhover, 1990; Saveman, Norberg, & Hallberg, 1992), patients' "right to risk" (Aroskar, 1989; Klimas, 1990; Sherry, 1990), and allocation of scarce resources (Andrews, 1988; Aroskar, 1989; Duncan, 1989; Fry, 1986; Jenkins, 1989; MacMillan-Scattergood, 1986; Silva, 1984).

### **Research in Other Settings**

Although few studies have identified the ethical issues in nursing practice, the majority of what has been done has been conducted in settings other than the community. Studies have been conducted in acute care settings including medical/surgical, emergency, neonatal intensive care, critical care, and oncology. For instance, Berger, Severson, and Chvatal (1991) used a questionnaire to study the frequency with which ethical *issues* occurred in an acute care setting and how disturbed the nurses were

by these encounters. Fifty-two nurses from medical, surgical, and intensive care units responded to the list of 32 problems and issues. A broad definition of ethical problems was used. The five most frequently encountered issues were inadequate staffing, which the authors rated as an administrative concern as opposed to a resource allocation issue or even an issue of providing inadequate care; prolonging life with heroic measures; allocation of resources inappropriately; inappropriate discussion of patients; and nursing colleagues' irresponsible activity. Based on the reported frequencies, the authors concluded that their results did not support the suggestion that ethical issues in practice are increasing. However, they conceded that failure to recognize ethical issues might account for that finding.

Ersek, Scanlon, Glass, Ferrell, and Steeves (1995) brought together the results of several recently conducted studies of oncology nurses (citing those by Ferrell & Rivera, 1995; Glass, 1994; Winters, Glass, & Sakuri, 1993) and discussion with the Ethics Advisory Council of the Oncology Nursing Society to develop a list of nine priority ethical *issues* in oncology nursing. Among the top seven ethical issues on the list were (a) assisted suicide (subtopics: importance of palliative care, exceptional cases), (b) end-of-life decisions (subtopics: hydration and nutrition, aggressive treatment of the terminally ill), (c) pain management (subtopics: undertreatment due to lack of education, fear of hastening death, fear of addiction, fear of drug diversion, regulatory and legal constraints, and cultural and family issues), (d) health care reform (subtopics: downsizing—compromising patient care and professional integrity, use of unlicensed assistive personnel, ethics of political decision making related to health care issues), (5) access to care (subtopics: rationing, access to the full range of health care services; i.e.,

prevention as well as treatment), (6) truth-telling and informed choice (subtopics: subtle forms of coercion, "degrees" of truth telling), and (7) confidentiality. The authors considered the fundamental element in determining the ethical nature of clinical practice to be the nurse-patient relationship. Trust and intimacy, necessary to foster and maintain this relationship, are the moral basis of oncology nursing.

The ethical *issues* faced by neonatal intensive care nurses were described by Miya, Boardman, Harr, and Keene (1991). The Demographic Data Form and the Moral Conflict Questionnaire, both developed and tested for content validity by Fry (1987; cited in Miya et al., 1991), were used to collect the demographic and research data from 37 registered nurses. Analysis yielded three major categories of issues: treatment, conflict, and communication. Ethical dimensions were identified including autonomy, beneficence, nonmaleficence, justice and rights of the infant and families, and rights of the professionals. Issues involving treatment had to do with the concerns nurses had about nursing and medical care of infants. Most frequently identified were issues of humane treatment, pain, and suffering. Issues in the category of conflicts involved intrapersonal, interpersonal, and role conflicts. Conflicts between physicians or nurses and parents and between nurses and physicians were most commonly described. Role conflict was related to issues of following physician's orders and patient or family advocacy. Communications issues had to do with problems with information exchange, with the focus of concern being information content and *how* the information was exchanged being the focus of concern. Of primary concern to the NICU nurses were the ethical principles of beneficence and nonmaleficence.



Omery et al. (1995) sought not only to identify the ethical *issues* in acute care but to determine whether the issues changed over time or according to the nurses' age, years of practice, education, position, or specialty practice. Surveys were conducted on five separate occasions over a period of nine years with different groups of nurses (n = 794), some of whom had just completed an ethics seminar and some of whom had received the questionnaire at a staff meeting. The instrument, which was developed for the study, consists of a list of 29 ethical problems which are then checked either yes or no to indicate if the problem has been encountered during the past year. The definition of ethical issue that was used was that of a moral problem addressed by nurses. Unexpectedly, pain relief/management was the issue indicated as occurring most frequently with nurses, whereas the second most frequent issue was related to caring for difficult patients (confused, combative, or helpless). Not unexpectedly, patient-physician-nurse relationships (i.e., hierarchical versus collegial decision making) was rated as the third most frequent issue.

When looking at the issues expressed over time, the use of morphine drips was the only issue where a trend of increasing concern was seen with each survey. As expected, nurses experienced issues depending on their specialty area. For instance, NICU nurses reported fewer problems with living wills than did other critical area nurses but more problems related to fetal surgery and child abuse. Issues of durable power of attorney increased with the nurses' age and issues of cost containment increased with each educational level. Nurses having practiced for 10 or more years reported fewer issues associated with pain relief and patient-physician-nurse relationships. The researchers concluded that as health care changes,

additional surveys will be required to chart the changing ethical issues in various practice areas.

The ethical *quandaries* of acute care were the subject of an investigation by Holly (1993). Written descriptions of personally encountered ethical situations were obtained from 65 nurses employed in critical care and medical-surgical units at four institutions. Content analysis of the written narratives revealed three recurrent categories: exploitation, exclusion, and anguish. Exploitation occurred when the particularity of the individual was not considered and there was a lack of regard for the personhood of patients or families. The category of exclusion encompassed disregard for patient choice including failure to acknowledge patient's wishes as well as failure to provide information to support decision making. Holly's third category, anguish, refers to the personal feelings of the nurses who "felt powerless to assist patients or to practice in a fully professional manner" (p. 113). Holly concluded, as did Miya et al. (1991), that despite the fact that nurses bring their unique perspective of the patient to ethical decision making, they are relegated to narrowly defined roles which limits their ability to advocate on behalf of their patients.

Several investigators initially began to study nursing ethics with other foci in mind such as nurses' participation in ethical decision making (Holly, 1993) or moral decision making (Viens, 1993) and then seemed to realize that the ethical issues that nurses experience may be unique to nursing and that these issues need to be described from the nurses' perspective prior to exploring other dimensions of ethical decision making. In other words, a fundamental piece of nursing knowledge might be to discover what nurses consider to be ethical issues in their practice.

### **Role of the Community Nurse**

The unique role of the community-based nurses may influence the nature of ethical issues. It has been suggested that community nurses practice in an autonomous fashion, often isolated from co-workers, supervisors, and physicians; this may influence their experience and the ethical situations they encounter (Duncan, 1989, 1992). Additionally, these nurses, by delivering care in the client's home and coming to know the context, are more likely to understand the client's point of view (Duncan, 1989). Further, the definition of *client* (individual, family, aggregate, and community) in community nursing may result in conflicts in obligation. Nevertheless, these ethical conflicts, not unlike those experienced by nurses in institutions, are associated with concerns for caring for vulnerable populations, client autonomy, confidentiality, and allocation of scarce resources (Aroskar, 1989; Duncan, 1989, 1992). The conflicts are often not as noteworthy or dramatic as those faced by nurses in hospitals (Aroskar, 1989; Bigler, 1990; Duncan, 1989; Robillard et al., 1989), and perhaps that explains, in part, why until recently these issues have not received much attention in the literature.

Yeo (1989) pointed out that nursing has tended to operate from a broader perspective of health than have most other health professionals, and this perspective has implications for the kinds of ethical issues that occur and the way they are framed. The focus on the client in the community has implications for the ethical challenges experienced. Schultz (1987) held that despite many years of community nursing literature advocating a reconceptualization in client focus from individual to aggregate, ethical decision-making from an aggregate or community perspective has not

Furthermore, Schultz argued, the implicit notion that ethical decisions made about individual cases do not impact on the community is false. For instance, decisions to treat severely deformed newborns or to provide more funding to decrease the cardiac surgery waiting list may eventually result in decisions not to treat others in the community because of scarcity of resources.

Fry (1983, 1985) maintained that because public health nursing is a synthesis of both the science of public health and the science of nursing, moral accountability may mean being accountable for how the health of aggregates have been promoted or protected rather than how the health of individuals has been promoted or protected. For the public health nurse to be morally accountable for promoting one good over the other means that the nurse must be able to articulate reasons for limiting either the individual or aggregate good in specific situations (Fry, 1985). Public health nurses then are guided not only by the professional ethic but by the "public health ethic" (Fry, 1992b, p. 82) which in itself can be an obvious source of ethical conflict.

Nurses are often ill-prepared to participate in the ethical decision-making process because of role constraints, lack of familiarity with the ethical decision-making process, or inability to recognize the dilemma (Fry, 1985). Burger et al. (1992) pointed out the necessity for community nurses to be knowledgeable about ethical principles and decision-making so that they may systematically resolve ethical dilemmas in their practice. Although ethicists are often available to nurses in institutions, these resources are currently not often available to nurses in the community. Fry (1989b) stressed that all nurses must be self-aware and willing to enter the actual

literature was the importance of nurses reflecting on issues and consciously choosing an ethical perspective or position (Cunningham & Hutchinson, 1990; Jenkins, 1989; Kelley, 1992; Schultz & Schultz, 1987), which might be translated into heightening their ethical sensitivity.

In an interview, Aroskar (1979b; cited in Schultz & Schultz, 1987) stated that she considered issues of distributive justice to be the most pressing ethical issues in community nursing today. Inherent in community nursing agencies is the allocation of scarce resources: "What kinds of nursing care should be given to whom and in what order?" (p. 41). This question is confronted both at the level of individual care and at the aggregate level related to policy matters. Explicit rationing of resources occurs when allocation decisions are made by the organizational administrators; implicit rationing occurs at the level of the health centre when, due to budget constraints, there is no longer a full complement of community nurses (LaRochelle, 1989). It is implicit rationing that creates serious ethical issues for the community nurse who is unable to achieve the objectives for nursing care, who must provide incomplete nursing care, and whose standards of nursing care are compromised. The descriptive literature is replete with articles discussing the allocation of scarce resources in the community by both the nurse in the community and the administrator (Fry, 1986; Jenkins, 1989; MacMillan-Scattergood, 1986; Silva, 1984).

### **Gaps in the Literature**

Although the amount of descriptive literature discussing ethics in community nursing practice is increasing, there continues to be a paucity of research in the area of community nursing and ethics. The major thrust of

institutions and has tended to fall under the rubrics of (a) relationship between moral reasoning and ethical decision making, (b) relationship between education and moral reasoning, and (c) ethical practice (Gortner, 1985; Ketefian, 1989). Oberle's (1993, 1995) study is an example of research exploring the teaching of nursing ethics. She found that ethical issues in nursing are context bound and questioned the feasibility of examining nurses' moral thinking out of context.

A preponderance of the research in nursing ethics conducted between 1970 and 1987 was at the exploratory or descriptive level with an emphasis on quantitative approaches (Cassidy, 1991). The research done since that time continues to be at the exploratory, descriptive level; however, qualitative approaches are becoming more evident. Yet, much of the data continue to be collected by open-ended questionnaires (Aroskar, 1989; Davis, 1981; Duncan, 1989; Miya et al., 1991), written narratives (Forchuk, 1991; Holly, 1993), or a combination of written narratives and forced-choice questions (Haddad, 1992). More recently, investigators have been employing the use of interviews as a method of data collection (Chubon, 1994; Millette, 1994; Viens, 1993). Of these studies using interviews, Chubon focused on home care nurses working only with people with AIDS, Millette looked at moral decision making in acute care nursing, and Viens looked at nurse practitioners' moral reasoning and identification of ethical issues.

Many nursing studies have also used hypothetical dilemmas or case studies as the basis for data collection (Cassidy, 1991; Jameton & Fowler, 1989) or forced-choice surveys (Andrews, 1988; Berger et al. 1991; Omery et al, 1995; Robillard et al., 1989). Responses to preordained, closed-ended

*ethical issues, problems, and dilemmas* often without defining these terms and frequently using them interchangeably.

It was Cassidy's (1991) and is my contention that the use of qualitative approaches, specifically interviews employing open-ended questions, would (a) provide an opportunity for nurses to identify and describe their everyday encounters with ethical issues, (b) better represent the complex nature of the topic, and (c) open up the possibility of identifying a more appropriate orientation for investigation of ethical responsibility than the existing orientations. Qualitative data, according to Miles and Huberman (1984), are a source of well-grounded, rich explanations and descriptions. These authors went on to say that when words are organized into incidents and stories, they provide a vivid, concrete, and meaningful flavor that can prove far more convincing to the reader than pages of numbers.

Both Aroskar (1989) and Duncan (1989, 1992) suggested the need for further studies in the ethical dimensions of community nursing practice. Whereas Aroskar recommended research be carried out in other geographic locations, Duncan (1989) asserted that face-to-face interviews as opposed to survey questionnaires may yield a greater "specificity of data" (p. 57). Interviews would give the researcher the ability to clarify and obtain richer descriptions of the issues.

Are the ethical issues in the community unique to the setting or are they the same as those identified in acute care but tempered by factors of role and geographical setting? Are the ethical issues in the community changing, becoming more frequent, more complex as a result of the radical and rapid changes in the delivery of health care? What do the nurses themselves identify as ethical issues and how do they talk about these

issues? These questions contributed to the need to begin to document the ethical issues encountered in community practice.

### **Summary**

A review of the literature provided evidence, first, that there is a lack of research in the area of community-based nursing and ethics. Of the studies located, only three researchers studied exclusively either public health nurses, home care nurses, or both. Other studies either included home care and/or public health nurses in the samples or the sample consisted of nurses employed in acute care. Two investigations included another group of nurses often based in the community, nurse practitioners.

Second, the literature review revealed the need for a qualitative approach using interviews as a data collection method. No qualitative study focusing exclusively on the ethical issues facing community-based nurses has used interviews to gather the data.



## **CHAPTER 3**

### **METHODS**

In this chapter, the methods used to answer the research question will be addressed. First, the study design will be discussed, after which sampling will be explained and a description of the participants included. Next, the collection and analysis of the data will be outlined, followed by the strategies to enhance trustworthiness. Finally, the ethical considerations particular to this research will be described.

#### **Study Design**

An exploratory, descriptive approach using qualitative methods provided the framework for this research study. Qualitative methods are used when there is little known about a topic and when the researcher wishes to describe a phenomenon from the participant's perspective (Field & Morse, 1985). Both a review of the literature, which revealed that little is known about the ethical issues confronting community-based nurses in their practice, and my intent to describe ethical issues from the perspective of the community nurses supported the choice of qualitative methods to study the phenomenon. These methods consisted primarily of unstructured interviews augmented by the use of field notes.

Brink and Wood (1988) advised that when there is a lack of knowledge about a topic, level 1 research questions result and that these level 1 questions lead to exploratory, descriptive research designs. Descriptive studies yield knowledge about a concept that has not been studied in a particular population, whereas the purpose of exploratory studies is to

suggested that descriptive research has value on its own and therefore is an end in itself. Descriptive research provides rich detail about what is happening in a particular setting or with a particular group of participants so that their point of view may be understood (Artinian, 1988).

## **Sample**

### **The Target Participants**

The notion of representativeness of a sample when using a qualitative approach to study a phenomenon differs from representativeness in the quantitative sense. In the qualitative sense, any participant belonging to a particular group is thought to represent that group (Sandelowski, 1986). Because the intent of this study was to capture the perspective of the research participants by way of face-to-face unstructured interviews, this research approach required first and foremost "that the participants be able to meet the informational needs of the study" (Morse, 1991, p. 127). That is, the participants must be willing and able to discuss the ethical issues that had occurred in their practice.

Sampling for this study involved recruiting a volunteer sample and purposefully choosing the participants that best met the study criteria (Field & Morse, 1985). Potential participants included community nurses willing and able to articulate their experiences and thoughts about ethical issues in practice and living within a two-hour drive of a major city in Alberta. Because the aim was to gather personal experiences from practice, a decision was made not to include in the sample nurses working in administration.

The inclusion of the geographical criteria was an attempt to include the rural community nurses' experience. Consideration was initially given to

whether the variation in educational levels of the participants would influence the study results. Home care nurses' education within the province may range from RN to MN, whereas public health nurses must have at least an RN and a diploma in public health nursing, although most have a BScN. Davis (1981) found that the nurses in her study, regardless of their educational background, described the same ethical issues and seemed to have a good understanding of the concept of ethical dilemma. Accordingly, a decision was made to record educational level but not to make it a criteria for inclusion in the study.

An attempt was made to ensure that an equal number of nurses with public health and home-care experience were included in the study in order to be able to comment on possible similarities and differences in their experiences. This endeavour, of recruiting equal numbers of home care and public health nurses into the study, although important, served to lengthen the recruitment phase of the research.

Purposeful selection of participants occurred simultaneously with data collection and analysis. Initially it had also been proposed that the selection of participants would continue until no new insights or dimensions casting light on the research question were identified (Germain, 1986; Morse, 1991). The rationale was that a comprehensive, full description relevant to the research question would thus be obtained. However, after enrolment of the tenth participant had occurred, it was decided that recruitment would cease due to financial and time constraints even though new insights continued to be identified. It had originally been estimated that between 7 and 10 participants would be required to attain informational adequacy, keeping in mind that it is not the number of participants but the amount and quality of information that determine adequacy (Morse, 1991; Patton,

1990). During an 11-month period, 12 nurses responded to a variety of sampling strategies, 10 of whom indicated that they had experienced ethical issues in their practice. All 10 were included in the study.

### **Sampling Strategies**

Sampling strategies included placing advertisements in the Alberta Community Health Nurses Society (ACHNS) Newsletter and the Alberta Association of Registered Nurses Association (AARN) Newsletter (see Appendix A). The method of recruitment by way of newsletter was chosen because it afforded access to the largest number of community nurses in the targeted geographical area. All of the community nurses in the targeted geographical area receive the AARN Newsletter. Moreover, the lengthy process of obtaining ethical approval at the many regional health units in the targeted area made this strategy less appealing. Advertising in the smaller ACHNS Newsletter was also used, because members of nursing interest groups tend to be committed to professional issues, thus heightening the possibility of member participation (S. Duncan, personal communication, November 20, 1993). The membership of this community nursing interest group (and thus recipients of its newsletter) is comprised largely of public health nurses.

When it became apparent that recruitment via newsletter alone would not be sufficient, several additional recruitment tactics were employed. The Director of Home Care at an urban regional Health Unit was approached about the possibility of attending a meeting of the home care nurses to outline the study and to elicit their participation. The home care nurses employed at this health unit had been identified as being particularly interested in health care ethics and thus likely to participate in the research.

As with the other sampling strategies, approval for this recruiting measure consisted of obtaining ethical clearance from the Faculty of Nursing's Ethics Review Committee as well as permission from the Director of Home Care for the Health Unit. There was no ethics review committee in place at this particular regional health unit at the time of recruitment.

When this strategy also proved to be somewhat less successful than anticipated, plans were made to attend an ACHNS general meeting where flyers using the newsletter advertisement were prominently displayed.

The third strategy was to modify the advertisement that was to appear in the Fall ACHNS Newsletter (see Appendix B). Due to unforeseen circumstances, that issue of the newsletter, which had been scheduled to be mailed out to the membership in October of 1994, did not go out until January of 1995.

### **Sampling Strategy Result**

Eleven home care nurses attended the Regional Home Care meeting, and of that number at least two nurses were employed in management and thus ineligible to participate in the study. Approximately 40 public health nurses attended the ACHNS general meeting, although this number included administrators and nurses outside of the study geographical area.

A total of 10 community-based nurses responded to the recruitment strategies, indicating that they had ethical issues in their practice and that they were willing to discuss them. All 10 were accepted into the study.

Of the 10 nurses who participated in the study, three telephoned me in response to the AARN newsletter advertisement, one nurse responded to the advertisement in the ACHNS Newsletter, one nurse enrolled in the study as a result of the home care meeting that I attended, three approached me after

hearing discussion of the research proposal in a social setting, and the last two nurses came into the study at the suggestion of a colleague who was also in the study. No response was received from the ACHNS general meeting.

The participant selection process raised some interesting questions. First, I was contacted by 12 community nurses who expressed an interest in learning more about the proposed research. Of that number, two indicated that, although they whole-heartedly supported the research, they themselves had not experienced ethical issues in their practice. Another nurse employed simultaneously in public health and acute care settings said upon hearing of the study, "I don't need to be part of a study because I don't have ethical problems. I'm not stealing from little old ladies!" Of note was the fact that the nurse who gave this response had recently graduated from a post-basic BScN program, where ethics would have been part of the course content.

An assumption held at the outset of this research was that nurses, by virtue of their daily contact with clients and colleagues, would experience ethical issues in their practice. This assumption came out of the belief that ethics is about, as Levine (1977) so clearly put it, "the ways that human beings relate to one another in their daily interactions" (p. 846). However, encountering ethical issues does not mean that they are recognized as such.

The second surprising observation was the overall lack of response to the recruitment strategies. My assumption was that there would be an adequate, if not huge, response to the research. This assumption, although obviously not valid, came from witnessing and hearing the turmoil that nurses were feeling as a result of the cutbacks in health care.

I am uncertain how to interpret this lack of response but will put forth several possible explanations. The first may have to do with the rapid and

numerous changes that were occurring in community nursing. The overwhelming changes certainly meant, in some cases, huge increases in workload along with daily changes in policies and guidelines. That, combined with the uncertainty that these changes were bringing about, may have contributed to nurses not having the energy to be involved in 'one more thing.' They may have been just too busy at work (working overtime) to consider becoming involved in something that may have held little value for them. A second explanation is that the language of ethics is one that is not used in practice—the nurses are therefore uncertain as to what the study is about or how they can be involved. This does not mean that their practice is unethical, just that they do not use the words *moral* or *ethical* to talk about the troubling things that are occurring in their practice; thus they do not see the connection between what I am studying and what they are experiencing. A third explanation is that the nurses were concerned that I would in some way judge them and their stories. Because most of the recruitment was done through newsletters, I did not have the opportunity to meet potential participants face-to-face to discuss the study. This might have been a study limitation.

### **Process of Participant Enrolment**

Community nurses responded to the advertisements in the AARN newsletter by telephoning me directly, at which time I explained the study in detail. If after verbal explanation the nurses indicated a continued willingness to consider enrolment in the study, an information letter and consent form were mailed to their homes, and a follow-up call was made once the potential participant had had an opportunity to read and reflect on both (see Appendices C and D). The same process of enrolment as above

occurred for those nurses with whom I came into contact in social settings or by way of referral from another nurse.

Home care nurses attending the regional health unit meeting had an opportunity to discuss the study with me. Those interested in participating were asked to complete a tear off-portion of the consent form (see Appendix D) and deposit it in the box dedicated to this purpose during the following several days. To allow nurses attending the meeting time to decide whether to participate in the study, the tear-off portions were not collected from the box and mailed to me until 3 days after the meeting. Upon receipt of the name and address of the potential participant, contact was made by phone and an information letter mailed out.

### **Description of the Sample**

Purposeful selection was used to include an equal representation of both home care and public health nurses. All of the nurses who (a) made contact with me, (b) indicated that they had had ethical issues in their practice, (c) were willing to discuss them, and (d) lived within a two-hour drive of the major city were included in the sample.

**Gender, age, and ethnic origin.** All 10 of the nurses in the study were female, ranging in age from 25 to 52 years. Seven of the nurses were between the ages of 40 and 48. The sample included nine Caucasian and one Asian participant.

**Years of experience and education.** All were registered nurses with 2 to 25 years' experience, but as community nurses, their experience ranged from 8 months to 21 years. Four of the nurses had between 15 and 21 years of community experience, and four had between 6 and 10 years. The



mean community nursing experience was 10 years. Five of the nurses were employed as public health nurses and five as home care nurses.

At the time of the first interviews, five of the nurses were working full time, four were employed part time, and one nurse was working casual. The one nurse identified as working casual had changed her employment status from part time to casual just prior to the first interview.

The educational level of the nurses also varied: All were registered nurses; seven had obtained a BScN, and one had earned a Master of Nursing. Five of the nurses were enrolled in course work at the time of the first interviews: one was completing a BScN, three had completed some coursework towards a Master of Nursing, and one had completed some coursework at the Ph.D. level.

Four of the nurses had taken courses in ethics either at the undergraduate or graduate level; four had attended employer-sponsored courses which although not entitled ethics course work addressed in some detail how values and attitudes might influence practice. Ethical conflict often results when there is a conflict in values; thus I considered course work aimed at values clarification as course work that might heighten awareness of ethical issues. Two nurses had taken no specific courses in ethics and one nurse had participated in an intensive summer course the year before on her own initiative.

The nurses in the study came from a large geographical area that includes a major city in the province of Alberta and an area of up to two hours drive in any direction from that city. Seven of the nurses resided and worked in a major city; three lived within two hours drive of the city, two of whom had rural caseloads. In all, four regional health authorities were represented by the participants.

In summary, this was a well-educated and highly experienced group of participants with 8 out of 10 having at least a baccalaureate degree. They had a mean of 16 years of nursing practice and a mean of 10 years of community nursing experience. Because all the nurses interviewed were women, feminine pronouns will be used throughout this thesis to refer to the participants.

The nurses were given pseudonyms prior to the second interview. In recognition of the contribution of the participants to this study, the pseudonyms chosen are names of nurses who have made significant contributions to public health or home care. Indeed, as I got to "know" some of the participants, I became convinced that the pseudonyms in some ways were very accurate and symbolized the qualities that these participants possess. Just as the women whose names I used or "adopted" were or are women of great courage, who helped to make nursing what it is today, so are these participants women of courage, for they tell their stories exposing their own flaws as well as their concerns to me and to the reader. Some of the names "adopted" are of nurses who are locally known in that they are nurses who have made major contributions to nursing in Alberta, whereas others are names of nurses familiar to many of us. The pseudonyms I have adopted are Florence, Margaret, Clara, Lillian, Kathleen, Charlotte, Mary, Helen, Christine, and Sara (see Appendix G for brief information about the nurses whose names were "adopted" as pseudonyms for the participants).

### **Data Collection**

Data for this study were collected primarily through the use of audiotaped unstructured interviews that were then transcribed. The interview data were augmented by the documentation of field notes

following each interview as well as keeping a research journal. Biographic information was collected at the beginning of the initial interview and provided an additional data source (see Appendix E).

The interview times and dates were scheduled at the convenience of the participants. Interviews ranged in length from 1 to 3 hours. The time length between the first and second interviews varied from 1 to 9 months. Seven of the interviews took place in the nurses' homes, five at their place of work, and eight on the university campus. It was necessary to conclude two of the second interviews in a follow-up telephone conversation which was not taped. Extensive notes were made during and following each telephone interview. Another second interview had to be accomplished in two separate interviews 1 week apart due to the time constraints of the work place.

The first interviews began with prechosen broad questions that were intended to serve as a point of departure while providing the interviewer with a general understanding of the participants' experiences (see Appendix F). The participants' stories of ethical issues in their practice served to guide the interview as it unfolded. Thus, as the interviews progressed, the questions became more specific as increased depth of information was required (Field & Morse, 1985). Each nurse was interviewed twice during the research process, with the second interview being informed by and in response to beginning analysis of the stories of ethical issues (May 1991).

At the outset of the second interview, each participant was given a written summary of the initial interview. The participants' stories of ethical issues had been summarized or retold in my own words. The participants were given an opportunity to read the summaries and make any margin

notes that might help them provide additional clarity. The stories were then verbally discussed, providing me with a way of ensuring that important points or nuances of the stories had not been missed or misunderstood. This format allowed for verification, clarification, and expansion of the ethical issues in each story from the participants' perspectives. The intent was not to gain new data, although several participants did share additional stories during that interview.

### **Data Analysis**

Content analysis of the transcripts was accomplished using coding similar to the first two levels of coding used in the grounded theory method (open and axial coding). The first step in the analysis process was to gain a thorough familiarity with the data collected during the first interview by reading the transcript carefully while listening to the tape. At this point, the focus of the analysis was on the line-by-line examination of the data with a view to naming the phenomena. This involved breaking the data down into discrete parts and closely examining them. Descriptive labels and impressions were recorded in the right hand margin of the transcript. Persistent words, phrases, or concepts used to describe ethical issues were also recorded for each participant. In an attempt to remain open to insights, I constantly asked the question "What is this?" of the data during the first step of analysis. The process of naming and categorizing phenomena is called *open coding* (Strauss & Corbin, 1990).

Through this process, I was able to develop insights into the similarities and differences in community nurses' experiences of ethical issues. Similar concepts were grouped together as coding evolved. This grouping of similar concepts, known as categorization, is a process whereby each category is

given a conceptual name reflective of the concepts grouped within it. The initial groupings were considered provisional and changed as the analysis advanced. Strauss and Corbin (1990) asserted that "categories have conceptual power because they are able to pull together around them other groups of concepts or subcategories" (p. 65). These initial categories were used to develop three central themes of ethical issues. These themes are not mutually exclusive. The process of looking for patterns in the data is called *axial coding*.

The process of data collection and analysis can be described as cyclical in that data analysis occurred throughout the data collection process (Germain, 1986). Using the coding process outlined in Strauss and Corbin (1990), the data were analyzed inductively.

Interviews became more focused and the questions became more specific as categories began to emerge and notions about how the phenomena may be related to each other developed. As the interviews progressed, questions were designed to elicit information related to the emerging categories. Throughout the data analysis process, I consulted my field notes and journal.

### **Trustworthiness**

Trustworthiness in qualitative studies can be determined using a four-factor framework. The four factors or criteria are credibility, fittingness, auditability, and confirmability (Sandelowski, 1986). For each criterion, there are strategies that can be used to achieve rigor in the study.

Credibility depends on the researcher's abilities to describe faithfully and interpret the participant's experiences (Sandelowski, 1986). As with all qualitative research, the data in this study were obtained from the

participants directly and as a consequence were grounded in the participants' perceptions of their experiences rather than being obtained by way of an instrument. Strategies used to maximize credibility included (a) regular discussions with the thesis supervisor throughout the entirety of the research process as a way of maintaining awareness of the possible areas of researcher bias, (b) recording subjective feelings and initial reactions in a research journal which served as an aid in recognition of assumptions and bias, and (c) an evaluation of the skills of the researcher to elicit the experiences of the participants by conducting a pilot interview prior to commencement of data collection.

A pilot interview using the guiding questions was conducted primarily as a way of evaluating my interviewing skills. The pilot interview accomplished a great deal. It provided an opportunity for feedback as to the adequacy or the need for refinement of the guiding questions. The opportunity to rehearse interviewing using the guiding questions and collecting information for the biographical data form was invaluable, but just as important was the chance to practice using the tape recorder. Following this interview, it was determined that the internal microphone was unsatisfactory for interviewing. The participant graciously offered to reschedule the interview and as a result the data obtained in the repeat pilot interview was included in the research with the consent of the thesis supervisor.

Other strategies that were employed to enhance credibility of this research were triangulation of data collection sources and member checks. Triangulation of data collection sources included going back to both the descriptive literature and the research once several interviews had taken place and again during the writing of the final report. These reviews of the

literature were used to help me to reflect on the study findings. Second interviews were held with all of the participants which offered a form of member check (Hoffart, 1991). The participants responded to the summary of their stories and identification of issues. Once the findings had been summarized, four participants were asked to determine the extent to which these findings demonstrated their experiences with the phenomena. As an additional means of attaining credibility, one interview was independently coded by the thesis supervisor, and the results were compared with mine.

The criterion of fittingness has been achieved, according to Sandelowski (1986), when the findings fit into contexts other than the study situation, the audience and others see the findings as relevant to their own experiences, and when the findings fit the data from which they were derived. Two individuals who met the study inclusion criteria but were not part of the sample were asked to review the findings to determine relevancy to their own experiences with the phenomena. Additionally, the presentation of early findings at a national home care conference elicited feedback from conference members that the findings fit well with their own experience.

Sandelowski (1986) held that auditability is the criterion for determining reliability. Auditability is evidenced when another researcher can follow the progression of events or "decision trail" of the researcher and reach conclusions that are similar. Several strategies were taken to ensure auditability in this study. First, regular meetings with the thesis supervisor occurred during the course of the research. Second, I conscientiously documented the methods of data collection and analysis in field notes, memos, and a method log. Significant decisions made during the course of the study were recorded in the method log.

Confirmability of this research will have been attained if credibility, auditability, and fittingness have been established. Confirmability refers to the findings themselves, which are dependent on (a) triangulation of data collection methods, (b) an audit trail that can be easily conducted, and (c) whether the findings have "fit and grab" for the readers.

### **Ethical Considerations**

Ethical approval was obtained from the Faculty of Nursing Ethics Review Committee prior to beginning this study. Permission to speak with the home care nurses in one regional health unit was obtained as well. The following sections outline the measures taken to ensure that the consent obtained was informed, that the participant's anonymity and confidentiality were protected, and that any possible risk to the participants was reduced.

#### **Informed Consent**

When potential participants initiated contact with me, a detailed verbal explanation of the study was provided along with an opportunity to ask questions. All of the potential participants were given time to read and reflect on the information letter and consent form prior to being recontacted by me to determine their continued interest in the research (see Appendixes C and D). Once verbal consent was obtained, an appointment was made for a time and place that was convenient to the participant, and the written consent was obtained.

Participants who agreed to take part in this study were asked to sign two copies of the informed consent; one copy was provided to the participant, and the other was filed in a locked cabinet to which only I have access. The participants were made aware that they might withdraw from



the study at any time by telling me or my supervisor. The participants were provided with both the thesis supervisor's and my telephone numbers in the event of questions or concerns throughout the course of the study.

#### **Confidentiality/Anonymity/Storage of Data**

Measures to protect confidentiality of individual information as well as individual anonymity included storing all data (audio tapes, transcripts, and consent forms) obtained in this study in a locked filing cabinet to which only I have access. Consent forms have been stored separately from the data and will be destroyed five years following study completion. The audiotapes and transcripts will be retained in a locked container for seven years following study completion, at which time they will be destroyed. Should secondary analysis be considered, appropriate ethical clearance will first be obtained.

The participants' anonymity has been protected using the following precautions. Code numbers were assigned to all the participants and interview sessions and a master sheet with the names and code numbers has been stored in a locked drawer separate from the raw data. Pseudonyms have also been assigned to the participants and used in this final research report. Any exemplars which might identify the participants have been altered. A generalized description of the participants has been provided in this research report as a way of protecting anonymity. A copy of the findings will be sent to all of the participants who signed the findings request portion of the consent form.

### **Risk versus Benefit**

Although there were no obvious risks to the participants in this study, there was the possibility that the discussion of troubling ethical issues during the interview process might elicit disquieting or distressing feelings for the participants. Because of this, the names and phone numbers of a mental health therapist and a practice consultant with the AARN were available should debriefing be necessary.

Several of the participants commented that being able to discuss their stories of ethical issues was of benefit to them in that they were able to talk about very troubling incidents with a "nonjudgemental" individual. This telling and retelling of the story, sometimes in great detail, seemed to help them to sort out the issues. As Brody (1987; cited in Hutchinson, Wilson, & Skodol Wilson, 1994) argued, this telling of their stories may have helped them to make sense of a troubling experience.

## CHAPTER 4

### FINDINGS

In this chapter, the results of the data analysis are presented. The chapter is organized into two sections. The first section helps to put the ethical issues into a context. Data are presented about the way the nurses in this study spoke of their ethical issues (in the form of stories), the contexts in which the nurses practice, and the influencing factor of geographical setting on the ethical issues that the nurses experienced. Some observations are provided about the nurses' characteristics and the language that they used to talk about the ethical issues in their practice. In the second section, the three central themes are discussed: relationship, resource allocation, and autonomy. The chapter ends with discussion of additional findings. Data analysis to obtain themes was accomplished using the first two coding levels of the grounded theory method (Strauss & Corbin, 1990).

The purpose of this research was to begin to document the ethical issues that community-based nurses face in their practice. The participants were asked to "Tell me about an ethical issue from your practice." Of the 10 nurses, nine talked about the issues in their practice using stories. One nurse, wanting to safeguard the anonymity of those in her specialty practice, preferred to talk about the issues from a more general perspective and so posed many questions and in some cases spoke to these questions.

### Storied Talk

The nurses in this study used stories to talk about the ethical problems in their practice. Stories provided a way to convey the rich detail and complexity surrounding the issue or issues. That the nurses would speak in stories was not altogether surprising, given that this is the way that we, as humans, talk in everyday life about our lives. We tell our friends and colleagues about important day-to-day happenings in our lives, and these happenings have a storyline with a beginning and a middle and usually an end. It is also the way some of us "make sense" of things. We tell the story of happenings in our lives and the telling often helps the "teller" to make sense of the story, to understand that particular happening in his or her life—Why is the happening so important? Why is it so troubling? What about this story makes me angry? When we hear ourselves talk about a situation, we often also hear ourselves say things that we did not know we even thought about that particular situation.

The troubling issues in practice, just as in our personal lives, are almost always about particular individuals with particular sets of circumstances or contexts. For the most part, the nurses told stories about particular individuals (clients and/or other health care providers). Some of the nurses, besides telling particular stories, told general ones as a way to protect the confidentiality of the individuals involved. Many of the stories I heard were more troubling and more complex than anything that I had imagined I would hear.

No limit was put on the number of stories that each participant could tell nor did the issue have to have occurred within a particular time frame. As a result, with the exception of the nurse who spoke exclusively in generalities and questions, the participants told between 3 and 11 stories

each, for a total of 53 stories. Some of the stories occurred as long ago as 11 years prior to the interview, whereas other stories were still unfolding.

Several of the nurses seemed to be "sorting things out" as they were telling specific stories. They seemed to be trying to make sense of what had happened or what was happening or even deciding what to do as they spoke. Liaschenko (1993) called this "deliberative narrative" in that the nurses were struggling sometimes on several levels with what to do in the particular situation.

Some of the stories, as troubling as they were, acted as critical incidents serving to enhance the nurses' ethical sensitivity. Helen, a public health (PH) nurse, tells of the young woman asking her to adopt her child, which she says caused her to think more seriously about the ethical issues in her practice. "It's just made me realize at times that no, this is more than a practice decision. This is an ethical decision." Similarly, Mary (PH) says that prior to her experience with child welfare, whose actions destroyed her relationship with a family, she had been involved in ethics but in a more removed way. She had not had the "same commitment to [ethics]." That particular situation heightened her awareness of ethical issues in a way that other experiences had not. Perhaps it is as Gilligan (1988) suggested: The moral self becomes known through the experience of engagement with others. Particular relationships raised these nurses' ethical sensitivity and enhanced their sense of themselves as moral beings.

A kind of "moral maturing" resulting from their reflectiveness and questioning nature was evident in the talk of "Ethics is a growing thing," "I probably would do it differently now," and "I would try to work around it somehow" (Florence, a home care [HC] nurse); and "If it happened to me again, I would know" (Charlotte, HC); and "I've learned from that" (Mary, PH).

### Practice Contexts

The nurses in this study do not provide care for the same age groups or have the same kind of clients on their case loads. For instance, the practice of several of the public health and home care nurses includes children, whereas others have caseloads comprised mostly of seniors. Thus the study includes stories about individuals across the life span and families of different composition: families with infants, families with children, and families with elderly members. A full spectrum of community nursing care is evident in stories about newborns, palliative care, clients with chronic/acute illnesses or post surgery, and mental health clients.

Program changes occurred in both public health and home care either just prior to this research getting under way or during the process of interviews. For example, in public health, the Healthy Beginnings Postpartum program, community follow-up of early discharge post partum women, began during the time that interviews were taking place, whereas the earlier expansion of home care programs to include all individuals who require support services in the community (Alberta Health, 1992) had already resulted in a huge influx of clients. Home care in this province had previously provided professional and supportive care to elderly persons to help them remain in the community as well as professional services to those under 65 years of age. However, with the expanded mandate (i.e., support to all), home care clients soon became an even more diverse group which included earlier medical and surgical discharges, children with complex health needs, and mental health. Moreover, just as public health has provided health care for clients across the life span, home care provides care for clients of all ages. The majority of home care clients have been seniors until recently, making up 93% of the home care nurses' case load in 1990

(Trojan, 1992). As such, the stories from home care nurses are not primarily about the elderly in the community as they might have been a few years ago. The stories then are reflective of the huge changes that have taken place in both of these areas of community care.

### **Practice Setting**

The most obvious and significant factor influencing ethical issues in community-based practice is the setting, the location or environment in which the nurses practice. Practice setting influences the nurse's access to the client and family, the nurse-client relationship, and the "control" that the nurse has. The geographical location may even dictate *whether* a client will receive care or not. Because care is provided in the client's home, colleagues and supervisors are not all under the same roof, which also influences the timing of their support.

### **Image**

Home care nurses talked about being conscious of their image in the community—as Florence (HC) said, being "under scrutiny" in the community. Some of her concern about image had to do with how patients died at home. Was it a good death, as good a death as would have occurred in hospital? "In people's homes there's always that thought that maybe there's more that we could have done." The home care nurses were concerned about how the community viewed them. For a second nurse, Charlotte (HC), image had to do with protecting home care's reputation and responding to family requests for services. It was important that the public not get the impression "that we are not doing our job properly. . . . We are concerned with what the community thinks about us." This concern about

image might be connected with the fact that home care is a relatively recent program in Alberta which has undergone a rapid expansion of services, gaining a higher profile in the community and the media.

### Control Shift

Delivering care in the community means that there is a "control shift" between the nurse and the family. Once entrance to the home is granted, the nurse realizes that she is on the client's "turf" and thus respects that the client holds control: The nurse is a guest in the home. Control is experienced very differently in acute care where access and control are assumed by the nurse and other professionals. Clients "give up so many rights when [they] are in an institution, whereas [they] have all the rights at home" (Christine, PH). What Christine is talking about in that excerpt is the consent that is assumed when a client is in hospital. That same level of consent cannot be assumed in the community. Because self-care is encouraged in community care, the nurse does not want to be in control. She must "work collaboratively with the clients" (Florence, HC) once entrance to the home is gained.

A public health nurse or a home care nurse may be the only health care provider the client or family sees, so maintaining access is very important. The nurses are careful to protect their relationships with the clients and families. "They can kick you out anytime they want, so you really have to be careful what you say" (Margaret, HC) and then "nobody will see them" (Florence, HC). The ethical issue here is, how does one tackle unsafe or unhealthy or questionable client practices while maintaining access? Often the answer to that question is that the nurse tackles these issues "at a slower rate" and with a great deal of tact, but "my eyes are always open



when I'm there" (Florence, HC). For instance, Margaret (HC) talks about the sensitivity needed when talking with a parent about a necessary but overdue appointment with the child's specialist: "The best that you can do is say, 'Have you talked to the doctor about this?'"

### **Visible Family Dynamics**

Family functioning and family relationships are more visible in the home, where clients are in their own element. Nurses become aware of how families deal with issues, make choices, and interact with each other. Issues that would not have been visible or needed to be considered in an acute care setting become highlighted in the home.

The story that Florence (HC) tells about a female palliative care client, who wished to stay at home but whose son's drug of choice, as a drug abuser, was morphine would not have presented as an issue in an acute care setting. In the home setting, the drug abuse problem and the implications for this woman's care were highlighted.

### **Isolation**

Nurses working in the community are isolated from the support of their colleagues and supervisors: "You [feel] so alone out there in the field" (Lillian, HC). This sentiment was expressed mainly by the home care nurses. The isolation extended to an ethical isolation for some of the nurses, particularly when supervisory support or ethical awareness was lacking. "I really felt I was alone there, that I was the only one who had these concerns" (Clara, HC).

Florence (HC) talks about a 95-year-old man who had repeatedly spoken with her about wanting to die at home but who did not have a Do

Not Resuscitate order. During a home visit, the man suffered a minor stroke and stopped breathing briefly. As she was assessing his status, Florence experienced tremendous anxiety about whether she should carry out cardiopulmonary resuscitation (CPR). Her comment about ethical decision making about providing CPR in the case of a code during her home visit points to the ethical isolation that some of the nurses described: "I'm not sure that I should have been thinking about making that decision myself as a nurse on my own in the community." Contributing to this sense of ethical isolation is the fact that support in the form of clear policies addressing issues such as CPR and advanced directives is often lacking. As Margaret (HC) emphasizes, "There isn't a procedure manual in the home."

There is also an uncertainty associated with providing care in clients' homes which may heighten the sense of isolation. Even if clients are known to the nurse, she is often not sure what she will find at the next home so planning care is difficult. The sense of uncertainty is heightened by the fact that the nurses are dealing with diverse practices which include a wide variety of age groups and a concomitant variety of clinical issues. Although uncertainty is not an ethical issue in itself, it is a contributing factor.

### **Equal Access**

Clients located in the inner city are not provided with the same health care as clients in other parts of the city. The downtown core is seen as an obstacle to the level of care that can be accessed through home care, social services, and physicians who make house calls, as "People don't want to go there and stay very long" (Charlotte, HC). Both private agencies providing personal care attendants and regional health authorities now have guidelines about travelling into the inner city. Although these guidelines are aimed at

staff protection, they also make apparent the fact that clients living in this area will receive care only during certain hours of the day if at all. This sets up questions of equity of health care.

### Role Issues

Role issues seem to be linked to geography as well. Questions of role uncertainty such as "What is my role here?" were most frequently asked by the public health nurses. The questions most often concerned budget cuts to social services. The changes resulted in overworked, inexperienced social workers with increasing case loads affecting the public health nurses and the safety of their clients. For example, Kathleen (PH) asks about monitoring unsafe home environments: "Is that really our job or is that child protection's job? What do you do?" Home care nurses seemed to have more clarity about their role as health care providers in the community, although one home care nurse stated that "roles are much clearer in PICU" (Pediatric Intensive Care Unit) (Margaret, HC). This seems to suggest a role clarity continuum: The more technical the clinical area, the more clarity there is in roles. Perhaps this role confusion reflects the health care environment at the time the interviews took place, although the literature supports the need for role clarity (Clark, Beddome, & Whyte, 1993; Stewart & Arklie, 1994).

### **Characteristics of the Nurses**

#### Reflective Practice and Ethical Sensitivity

In order for nurses to be able to talk about ethical issues, they must first be able to recognize (and identify) that they have ethical issues in their practice. Being ethically sensitive or aware is linked with being reflective.

Sensitivity and reflectiveness go hand in hand. The notion of ethical sensitivity is one that cannot be overstated, for if we are not morally sensitive we will not recognize or label an issue as an ethical one and thus not deal with it as such. Moreover, ethical reflectiveness helps to increase that awareness. Reflectiveness requires that we have frequent internal dialogue, asking such questions as Have I done the right thing in this situation? What can I learn from this situation? How would I do things differently next time? Bergum talked about seeing or living "ethics as question" (personal communication, April 25, 1996). With each new situation, whether it is an encounter with a colleague or time spent with a client, one asks oneself, What is the right thing to do in this particular situation? How should I be in this particular situation? The purpose of reflection is to achieve the best possible outcome in a particular set of circumstances. With reflection about practice comes learning and perhaps even "moral maturing," both of which contribute to one becoming a more ethically sensitive nurse.

The participants in this study displayed ethical sensitivity by virtue of the fact that they recognized ethical issues in their practice, issues that they wanted to share with me. This ethical sensitivity seemed to have come about as a result of two things: (a) reflection on specific experiences and/or (b) education.

Evidence of the nurses' reflectivity was provided in many ways: the way they chose to tell the stories, their thoughtfulness (as in being full of thought), the questions that they asked themselves, the length of time that they had been thinking about the experience, and the words or phrases that they used when telling their stories. For instance, several of the nurses used phrases such as "looking back" or they would "wonder" about a particular

situation. Helen (PH) said, "I was having really conflicting thoughts," "I gave it a lot of thought," and "I started to then rethink perhaps I had been wrong about this woman." Margaret (HC) used the phrases "You are never sure" and "There is always another way of doing things." Charlotte (HC) told me that she had "never forgotten him" when she talked about a particularly troubling situation with an elderly man which had occurred some eight months prior, and Mary (PH) observed that an equally troubling situation which had occurred a year before the first interview "really affected me." All of these phrases, although devoid of context, illustrate the nurses' reflective nature. In fact, some of the participants admitted that they were known for their reflective habits:

I told [my boss] about [the situation] and she said, "You did the best you could Florence." They know sometimes that I think too hard. They say, "you think too hard, Florence" [laughs].

and

In terms of my situation, I have been pegged as the one that is always saying, "Why are we doing this?" and they will say, "Oh well, of course, Lillian will [ask] why, why are we doing this?" and that is just my nature, I guess.

### Persistence and Integrity

In addition to the qualities of ethical sensitivity and reflectiveness, the nurses exhibited qualities of persistence and integrity. By persistence I mean staying true to a course of action, not being easily dissuaded. For instance, Sara (PH) became "the pest on the phone" when dealing with social services and trying to get children in an unsafe environment apprehended. Or Kathleen (PH) tried to "wear down" the physician in the hope that he would change his mind. Lillian (HC) showed evidence of persistence or perseverance when she said, "We need to continue to raise the issues and

continue to be there and make our little bit of difference . . . and to preserve some of the values that we want to hold onto." Although their persistence is not always rewarded, instances were cited where it was only as a result of their persistence that changes occurred. They were willing to go the extra mile to make sure the same problem did not happen again. They were not willing to accept that nothing could be done about a situation.

A sense of integrity and resistance to mediocre practice were both visible. Integrity means for these nurses being able to live with oneself at the end of the day. An inability to turn away from need was repeatedly illustrated. Sara (PH), in explaining her need to go the extra mile especially in the case of children, talked about being unable to "turn a blind eye." That term captures what the other nurses talk about in describing their responses to seeing need. When clients or families were in crisis or had no care alternatives, the nurses spent unpaid time with them or worked overtime, sometimes even when they were exhausted. It may be that as Nelson (1986) stated, "One's relationship with others has everything to do with one's relationship with the self" (p. 92). Turning a blind eye or not responding to a need meant that their practice had become mediocre; mediocre practice would impact their relationship with themselves—it would not allow them to live with themselves at the end of the day.

Another quality of many of the nurses was their ability to remain "open to the possibility" when they approached situations in their practice (Bergum & Dossetor, 1994). There was no preconceived notion about the outcome of the ethical situation:

There's an element of [pause] what is the word I'm looking for? Hope, or something . . . that you go into some of these situations and you don't automatically think, "Oh forget it, this lady's a

total write off" or something like that. You sort of have a little bit of faith in the possibility, or something like that. And I think that's kind of good. (Helen, PH)

### Language

Only one nurse consistently used the language of ethical principles to talk about the ethical issues in her practice, although she also mentioned "contextual ethics" and spoke frequently about relational issues. The terms *informed consent*, *resource allocation*, and *confidentiality* were used by several of the nurses, although for the most part the issues were not described using these terms. When talking about the issues, the nurses said things such as "It doesn't seem right," "This really bothers me," "That is not good," "I don't know what is right," "That's not fair," or "Was it right?" The phrase "It's not black and white" was used by five out of ten nurses when talking about ethical issues in general.

Some nurses talked about the fact that they do not use the term *ethical* much in their practice. They talked about ethical issues using different language, although they still had the same concerns. Perhaps it is because the language of ethics is not known or understood by them or perhaps, as Liaschenko (1993) and Yeo (1989) observed, that by borrowing theories of ethics from other disciplines such as medicine and philosophy, nursing has neglected developing its own theories of ethics. A serious consequence of this borrowing has been to see ethical issues as only those that correspond to the ethical principles, which has led nursing to understand ethical issues from a very narrow framework. *What* nurses consider to be an ethical issue has been influenced by the strict adherence to principled ethical thinking (if one were even familiar with the principles at all). That perspective has crept into nurses' thinking about ethics even without a working knowledge of the

ethical principles and can be heard in the language of rights and duties. It is only recently that scholars in nursing have considered ethics as broader than the principles. The influence of principle-based ethics has tended to encourage nurses to think that ethical issues have to do with the dramatic "life and death" cases that are frequently used in educational sessions. Such discussions tend to be theoretical in nature, do not involve nurses, and have limited relevance to daily practice.

When nurses talk about "not being able to do what they felt that they ought to do" or "not being able to do what is right for the patient" (Clara, HC), or talk about something as not being "fair" or "not right" (Charlotte, HC), or "I don't know what to do" or I have a "conflict" (Kathleen, PH), what they are often talking about are ethical issues, but they do not have the language to speak more clearly than that.

There was another element to the nurses' talk and that was the way that they spoke about their clients. They did not speak about clients in a neutral fashion but tended to use what Bishop and Scudder (1990, 1991) described as integral language. They integrated the language of relationship, or expressive and evocative language, with a more detached and scientific way of speaking, or propositional language. For example, when talking about diagnoses and treatment, propositional language would be used; but when talking about their feelings, expressive language would be used. Evocative language is said to bring about action or change on the part of the client and is evident when the client is encouraged through either touch or word to believe "You can do it." Evocative language was not as often evident in the transcripts as clients are often encouraged indirectly through word and action that they are worthwhile and therefore "can do it."



Florence (HC) showed the use of integral language when she talked about a client:

"He's about 68 [years old] and has been fighting terminal cancer for about 4 years. He has cancer of the bowel and has had two or three or four surgeries. When he obstructs this time, that's it; . . . and all he wants to do is be at home.

When the man started to show some signs of a bowel obstruction, Florence asked him "Do you want to stay at home? You can stay at home."

[I didn't like] the idea of putting him in hospital when he doesn't want to go and there's a son that's unemployed right there sleeping his days away in the house, waiting for his dad to die. It makes me angry. I'm trying to put in as much home care as possible to allow him to have his wishes.

In the excerpt above, Florence starts off in a propositional manner talking about diagnosis and surgery but becomes expressive when she identifies feelings of anger. Evocative language is used indirectly both when she asked the man if he wants to remain at home and then through her actions of putting in as much home care as she can. Florence is saying to the man that his wishes are important, that he can do it—he can die well. This way of speaking about clients is the language of connection, involvement, and concern (Bishop & Scudder, 1991).

Sara (PH) expressed concern about the recent trend in public health, toward talking about clients as *consumers* or *customers*. "I don't like [the word] 'patient' in terms of public health. But 'client' seemed okay to me. It's pretty equitable: I have things to offer, you have things you can tell me about. But now it's 'consumer.'" Sara questions what the use of the word does to the relationship between the nurse and client. "It's very business oriented and dollars are placed on it. It's not very personal." Both Gadow (1994) and Levine (1989) supported Sara's concern that language defines relationships. It was Levine's contention that the language of the

marketplace is replacing the language of compassion. Implicit in the individual as a consumer/customer is the notion that every individual is autonomous to the same extent and the nurse is merely a provider of information (Gadow, 1994). But then what of other influences of the use of the word *customer*? For example, how does the choice of the word subtly influence the nurse's role as advocate?

### Three Central Themes

The issues expressed in the stories were viewed through the lens of relationship. That lens was not immediately apparent; but as the interviews progressed and more issues came forth, relationship began to emerge as the way that the nurses themselves viewed their practice. Thus the ethical issues that occurred for them tended to reflect that view. The following three excerpts illustrate how the nurses viewed their practice:

I think nurses probably have a different [definition of ethical issues], and that is because of the relationships that we develop with clients. It's so unique, and so I think our ethical perspective reflects that caring relationship that we develop. Other disciplines which don't have the opportunity to be so intimately involved with clients or to be able to develop this relationship have a different ethical framework, maybe? Physicians are more rule and principle oriented. And so that's basically why perhaps we get into some of the ethical situations I've described. It's become clearer for me that's why I felt so uncomfortable in these situations . . . because that [relationship aspect] was so important for me with these clients. But it wasn't for the people, the administrators [pause] who are making their decisions from a sort of different ethical background. (Clara, HC)

and

We have a real personal relationship with our clients and our community. We have a community of our own that we foster a relationship with and then in that community there are certain families that we deal with. . . . I mean we have a real area of practice ourselves, a private practice in a way and because of that I think we develop a long-term relationship with our clients that is very complex, that has all of the good parts of a long-term relationship and the bad parts too. (Helen, PH)

and

I think that it has a lot to do with what your opinion of nursing is—a lot of nurses think that nursing is *doing things* like taking blood pressures and things like that. *How* I do it [the task] and the communication is way more important than the task. (Florence, HC)

Everything that nurses do is centred around relationship. Nurses are in relationship with clients, colleagues, other health care providers and administrators of the agency or institution where they work. Even the nurse's interactions with those who are not her clients are connected to the relationship with the individual who is in her care, although sometimes that connection is very distant and not so obvious. These relationships and interactions are not always positive, but the nursing world exists because of and is centred on the relationship with the "other," the client. Ethical issues are inextricably linked to the people nurses connect with (or don't connect with) in their practice. Ethical issues arise through or out of our relationships with others. It is *because* of relationships that there are ethical issues. Ethical issues arise out of conflicts and questions of values. Whose values? Nurses' values, clients', colleagues', and other team members' values. If nurses worked in isolation from their clients and colleagues, there would be few (or very different) ethical issues in their practice. Would there be the same questions about "How should I be in this situation?" if nurses worked alone? Nurses work with others and in doing so try to do "the right thing."

The word *relationship* is used in this study to denote the nurse and client connecting during a shared experience. Relationships are not always positive but can be good, bad, or indifferent; long- or short-term (Bergum & Dossetor, 1994). Levine (1977) suggested that ethical responsibility is inherent in every nursing relationship. Gadow (1990a), among others,

pointed out that the primary focus of nursing is the client and thus the nurse-client relationship. The commitment to nurturing and preserving the nurse-client relationship may be the *reason* for the ethical issue, but the *source* of the issue may also lie in the network of relationships with other team members (Bergum, 1994). Gadow (1985) talked about the caring relationship as one where the client is protected from being reduced to an object. Levine observed that "the very nature of nursing makes it impossible for an individual to stand aside from the experience of interacting with other human beings" (1977, p. 849) or being in relationship. Thus, Levine reminded nurses that in carrying out their responsibility to their clients they inevitably encounter other care providers whom they must also engage in an ethical manner. Ethical issues and dilemmas that nurses face, stated Aroskar (1979a), "involve relationships where there is conflict over what should be done in a given situation" (p. 89).

Has viewing the transcripts through the lens of nursing relationship shaped the findings? As I began to see the significance of relationship for the participants, I also began to see that the issues could be "sorted" into three major themes for the purpose of discussion: clear issues of relationship; issues of resource allocation and relationship; and finally, issues of autonomy and relationship.

For example, the theme of resource allocation is not only about how we decide to distribute scarce resources but underlying that theme is how we as a society (or a government or a health authority) see our relationship with others. Who and what is important? Our decisions will be based on whether we think people and relationships are important or whether the economic "bottom line" is the most important.

Themes do not have the rigid boundaries or mutual exclusivity that categories might. Whereas categories are like boxes from which the concept, once placed in them, does not stray, themes are a way to describe an experience. An experience, situation, issue, or story may show several themes—the challenge then is to choose which theme is "best" illustrated by the excerpt. Because ethics is complex, the stories are frequently not confined to one issue. That is, the stories often contain issues pertaining to at least two of the major themes and sometimes all three. I have attempted to use excerpts from the stories that illustrate most clearly the theme that is predominant within the story.

There are several reasons for choosing to use large excerpts and sometimes whole stories. The first is to avoid decontextualizing the actual situation and as a result distorting the issue. The second is as a way to convey the richness as well as the complexity of the situations with which the nurses have to deal in day-to-day practice. The third is as a way to hear the concrete experience of the nurses and resist becoming so abstract that their voices and experiences are lost. In short, it is necessary to use the nurses' own words as much as possible. Finally, the use of large excerpts provides evidence of analytic interpretation. Editing of the excerpts has taken place to enhance readability (such interruptions such as "er," "uh," "you know," and false starts have been deleted).

There may be, at times, a question about why a situation presented is an ethical issue rather than strictly a clinical one. The answer is that ethical problems are embedded in clinical practice. I believe that this is what Gadow (1979) was saying when she suggested "that there can be no division in nursing between ethical and nonethical issues. Because the principal elements in the nursing process are persons" (p. 93).

In health care ethics there is a sense of movement away from using the terms *client*, *patient*, and *resident* in favor of the terms *person* or *individual* receiving care. The terms client, patient, and resident are used in this research because these are the terms used by the participants. Use of the term client throughout this chapter is not limited to the individual but may refer to families and groups or communities.

### **The Theme of Relationship**

Talk of relationship pervaded the nurses' stories, because to do the work of nursing means that nurses must be in relationship with clients. Ethical issues arising out of relationship are related to trust as fundamental to relationships with clients, functioning from the perspective of relationship versus the perspective of rules, advocacy and relationship, preserving relationships between the vulnerable client and the other health care providers, collaborative working relationships, support for the nurse as relationship, and abusive relationships.

The ethical issues the nurses spoke of were generally not the dramatic issues portrayed in the literature but were found in the ordinariness of life:

Despite the fact that some of those [hospital] situations are very life and death and [pause] very dramatic, I think that some of the community health ethical issues are . . . not the headline stuff; it's what happens before the headline starts and after the headline ends. And in fact, after the headline ends is even more touching for us. (Helen, PH)

Relational ethics considers the nurse-client relationship as central while not discounting the significance of the other relationships that the client has including the family relationships, physician-client relationship, and so on (Bergum & Dossetor, 1994; Gadow, 1990a). This ethical perspective takes into consideration the particularities of the individual as well as the context

of the situation. When particularities are considered, the uniqueness of the individual is taken into account, that is, the characteristics which differentiate one particular person from another (Gadow, 1995). The client may be a young mother, a sister, a daughter, and a wife. She may also be a student who enjoys classical music. Practicing nursing from a relational point of view means that the nurse uses all of that knowledge in the provision of care. For instance, the nurse might use the knowledge that the young woman likes classical music to help her to relax during a painful treatment.

When considering the context or circumstances of the particular situation, the history and background and even the physical environment are taken into account. Context was a large influencing factor for both public health and home care nurses. They talked about "looking at the whole situation" (Sara, PH), "every situation is so very different" (Florence, HC), "It's really important in my practice not to take [the ethical issue] out of the context and lose the peopleness in it" (Helen, PH), and "I think in anyone's life there are so many factors you have to be aware of and take into consideration and mull over" (Kathleen, PH). In talking about considering the particular client or family, Lillian (HC) said "If we can't look at individuals, I would hate to see where our health care is going." Not taking particularities and context into account "interferes with your ability to practice good nursing. . . . Our clinical knowledge may be of generalities but we have to learn the context of the situation that the family is in" (Margaret, HC).

The setting was a factor in the development of the kind of relationship that ensued. As Lillian (HC) indicates, "One of the advantages of being in home care is that you can develop a bit of a relationship of trust with the family in the home setting." Visiting the clients face-to-face in their homes

and being familiar with the particulars of their situation influenced what the nurses saw as ethical conflicts and how they saw them being resolved. Providing nursing care in the home and community put the nurses in the privileged position of having knowledge and insight into the family that other caregivers did not always have:

We see the impact of caring for a [sick] child on the family situation, the family dynamics, and we get the day-to-day input from the families. (Margaret, HC)

### **Relationship: The Root of Ethics**

In some cases, it was only as the nurses' knowledge of the client and the family grew that they were able to see ethical concerns in a particular situation. The ethical concern may not be immediately evident until the nurse and individual patient get to know one another. Many of the ethical issues that the community-based nurses identified in this study came out of the very fact that they were the most constant health care contact that the client had. Once the client trusted the nurse, the ethical question might be revealed in all its complexity or dimensions. Kathleen (PH) talked about ethical concerns in her practice as being something that "grow" or evolve out of being in relationship. She said, "Ethical concerns are something that seem to develop and that aren't right there initially in black and white."

Conversely, ethical issues arose for the nurses when the individual nature of situations was not considered, such as the way scarce health resources were being allocated, and/or when other care providers' perspectives differed from their own. When the particularities of an individual were not considered, the nurses saw this as a callous disregard for the personhood of the patient. Nurses accordingly perceived ethical issues where other health care providers might not have.



Helen (PH) illustrated how ethical issues came out of being in relationship with her clients through an unusual story of an event which occurred early in her practice. She was providing one-to-one prenatal teaching to a very young woman who was planning to place her baby in an open adoption:

I'm quite an open person, and I felt that one of the things that would be a facilitating factor in this relationship that I had with this client was to reveal that I was going to be an adoptive mother. So she knew that I was involved with a private adoption agency.

About a month into the prenatal teaching, the pregnant woman was distressed to find out that the family who had agreed to adopt her unborn child would no longer be able to do so. Helen describes her continued involvement with this woman:

I comforted her and we talked about beginnings and endings and things like that and I went away. About three days later she called me again and she said, "I'd like you to come over again." I thought it was going to be more of the support function. When I went over, she said, "Well I've been doing a lot of thinking about it, and I'm wondering if you and your husband could adopt my baby?"

This request prompted immediate feelings of elation from Helen who desperately wanted a child. Shortly after, though, questions such as "But is it ethical?" started to "niggle" her and she began an extensive investigation into the professional ramifications of such an adoption as well as intensive self-questioning and reflection.

How would I feel about it, if 5 years down the road I had adopted [this] child, would I ever wonder had I done the right thing? I didn't want anything to taint my relationship with my child. I wanted it to be pure, and so I had to feel good about it myself.

Would she be doing anything unethical or illegal by adopting this young woman's baby? Her investigation included discussions with not only her

employer and her professional association but with the city police, the provincial law society, social services, her colleagues, and her family.

This story shows the importance that Helen places on the nurse-client relationship as well as how important it is to her to conduct her relationships with moral integrity. Had Helen not disclosed personal information about herself to this young woman in an effort to facilitate a connection between them, the moral question would not have arisen.

### Trust

Relationships built on trust are essential to do the work of nursing. Without a trusting relationship, the nurse will not have credibility with the patient and any advice, information, and teaching that the nurse provides will not be heeded: "You can't help anyone unless they trust you" (Christine, PH). Most of the nurses spoke of the need for their relationships with clients and families to be built on trust. Without trust, access to the family home might be denied and little could be accomplished in the way of health care, teaching, or even monitoring progress. Often the nurse is the only health care provider going into the home on a regular basis and is thus the only person who can monitor and influence the family.

Christine (PH) recounted a situation where, although many issues are evident, the most significant issue for her was the one of trust. She talked about a young woman who is HIV positive and lives as a prostitute. This woman came into Christine's public health practice because of her HIV status and the fact that she wanted to regain custody of her infant. Some time later, Christine was contacted by a public health regulatory person who wanted her help in locating this woman. A complaint had been lodged with the Medical Officer of Health about unsafe sex practice. Although HIV is

not yet a reportable disease in Alberta, Christine's understanding was that if a person is HIV positive and does not take precautions in preventing the disease, that person is in violation of the Public Health Act by putting the public at risk and may be detained in a health care facility. Because Christine had "built up trust with [the woman and her mother]," she was thought to be the logical person to help the public health regulatory person locate her. Having not had previous contact with this regulatory person, Christine wanted to "make sure that she could be trusted. I did not want to lie to the client about trusting someone who was going to do something that would be viewed as not being trusting."

The situation got "messier" when Christine found out that the young woman had been jailed for assaulting a police officer and subsequently broken her parole. Christine was in a quandary. She had developed what she had experienced as a trusting relationship with the woman. She wondered about her role. If the young woman contacted her or came into the public health centre, would she, as a public health nurse, need to contact not only the regulatory person but the police? This would have been in direct conflict with everything that she believed about maintaining a trust relationship in order to get the work of nursing done.

One of the hardest things for us to do is to establish trust with people [who] live these type of lifestyles, to be able to help them get out of the lifestyle or to change the behavior or whatever. To violate that in their eyes puts the whole process back and makes it worse. What is my professional role here? We as nurses generally act as advocates for the person. Well, I don't see this as advocating for the person. Maybe the public, yes, but not the person.

What Christine makes evident is also the role uncertainty she experienced in this very complex situation. This was her first encounter with someone with HIV and the issues that surround the disease. Christine believed that the

young woman needed an advocate, but being her advocate put her in conflict with the public health ethic of the greatest good for the greatest number. How could she maintain trust with the woman when the public's health could be at risk? Many conflicts emerged for her out of her relationship with this woman:

How I would want to act as a person probably differs from what is expected of me as a professional, . . . and it has to do with outcome too. I have the feeling that by following through the way that I should act as a professional will in the long run be detrimental for the public.

She makes a very astute observation about the long-term effects of not supporting this young woman. Her observation suggests that the role of trust and relationship in the treatment of clients with HIV and AIDS is different than the treatment of clients with tuberculosis. Unlike tuberculosis, HIV and AIDS as we know them today do not become less infectious with treatment. If this young woman goes to jail because she has broken her parole or is "detained" under the Public Health Act, eventually she will be released. If she has not had supportive relationships or has experienced less than trusting relationships during this time, what are the long-term consequences of that lack of support once she is discharged? "Is she going to act out and infect as many people as she can?" asked Christine, who went on to question how successful we are when we enforce rules such as the Public Health Act without the added element of support (as in supportive relationship). How do we help people to make lifestyle changes in a way that is supportive of the individual as well as ensuring the protection of others? She asked whether the "method that we have in place to address this problem is a good one for these complex situations."

This story is also about trust and disease prevention in a relational sense in that "the way that you are treating one affects many" (Christine). Trust that is maintained can influence disease prevention in the long term.

Another ethical concern raised by this situation is the ethics of making the woman the vector of disease. Should the woman be the only one responsible for practicing safe sex? Christine wondered, "Shouldn't the 'john's' activities fall under the Public Health Act?" The john seems to have no responsibility in this situation. Does it make a difference that this woman is a prostitute? "If the john was infected and the prostitute found out, I suppose she could complain, but I wonder how that would be viewed."

### **Advocacy**

A majority of the nurses spoke of client advocacy as an important part of their nursing role. Advocacy for these nurses meant speaking out for the client on significant matters. In most cases, acting as advocates came from coming to know the clients and through their ongoing relationship with them knowing what the client wanted, not only in terms of care but what would fit into the context of their lives. "You stand up for them" (Florence, HC).

In choosing to advocate for their clients, the nurses were often placed in situations where they were in conflict with other health care providers. Persistence and fortitude, or having the courage of their convictions, were required. In the next examples, with different contexts, the underlying notion of advocacy and being in relationship with the client stands out.

Florence, a home care nurse, tells of a woman receiving palliative care who appeared to be in denial of her terminal condition. The team of specialists at the pain clinic were intent on making sure that she understood the terminal nature of her illness. Florence, knowing the family dynamics

and recognizing the stabilizing role that this woman played in her family, observed that whenever the woman was put into a position where she was forced to talk about her impending death, her pain became unmanageable. Florence believed that the woman needed a strong advocate, so she communicated with the pain clinic specialists, by telephone and letter, her recognition that this woman's emotional pain influenced her physical pain. An angry response was received from the pain clinic, but Florence persisted in her attempts to convince them and in the end,

They wrote me back the nicest letter saying, "You must really understand this lady," because after awhile they understood that I was right. I don't think that they'd ever thought that that was an option, although I don't know why 'cause I'm sure there must be other people out there [who react the same way].

Florence realized that talking about death was taking away this woman's hope and causing more emotional turmoil than she could handle. The woman's family recognized the relationship that had developed between the nurse and patient as well as the nurse and family by asking her to give the eulogy at her funeral.

They were so impressed with her last couple of months of life that they had more peace and more togetherness. By making her dying comfortable, they were able to deal with some issues [as a family].

Another story, where the ethical issues regarding advocacy came out of the nurse-client relationship, was with a young mother who had just been diagnosed as being HIV positive. Shortly after receiving the diagnosis, the young woman's baby was admitted to hospital and diagnosed as being in a full-blown AIDS crisis. The mother was in a fragile state emotionally and had a great need for support. She requested that Helen (PH) act in an advocacy capacity with the public health regulatory representatives who had repeatedly requested that she identify any sexual contacts she might have

had. The mother did not feel that she could cope with the ostracism and the loss of the few remaining supports that would surely occur once her positive HIV status was made public through the contacting of her partners. The mother knew she had to stay healthy in order to be there for her ill baby. Helen described what the issues were for her:

My first concern, very honestly, was for my client. . . . She was stressed out to the max. . . . She could just barely deal with getting herself together and caring for her sick child with all the resources we still had in place. But on the other hand, my whole public health philosophy is for the better of the community versus the good of the one.

Fry (1992b) identified this conflict between the professional nursing ethic of the care of the individual client and the public health ethic of the care of the community as a very thorny one. Her suggestion was that many of the ethical issues that arise for public health nurses arise out of that dissonance. The role of advocate is one that is often cited as a major part of a nurse's role (Canadian Nurses Association, 1991), yet in public health nursing advocacy for the individual and community is in conflict. Helen admits that the advocacy role is tricky:

The times that you're advocating for these clients is nearly always in a situation where it's against the system. It's a vulnerable individual and it's in a situation where somebody's not giving her what she wants. Why aren't they giving her what she wants? Because often it's something that they've decided is "better for the system." Not better for this client, but "better for the system."

What is defined as the *system* may vary as the situation or the individual's case varies—it may be administrative rules, or the organization, or the political structure or 'society.' Helen's story shows how these nurses, rather than standing back from a moral situation, "seem to enter the problem" (Pike, 1991, p. 360).

Helen's colleagues disagreed with her plan to act in an advocacy capacity for the individual client, but she explained that they did not have the advantage of a face-to-face relationship with the mother. Helen had the advantage of seeing this young mother's vulnerability and her pain at having her child suffer because of her own actions.

They're not in the intimate relationship that I am with my client. . . . I think that it was pretty easy for them to say that [they disagreed]. This is the only HIV or AIDS family that we have in [our] clinic, and I think that each of us needs to go through this.

Helen's point was that this story was about strictly applying the rules without looking at the situation and taking the context into account. To Helen, the mother and the child were concrete and real, whereas to her colleagues they were just as faceless as the public on whose behalf they believed she ought to act.

Helen's story is very much about advocacy and relationship. She agreed to the request to advocate for this young woman not only out of the relationship that they had developed but in order to support the relationship between the mother and her infant. Helen also identified that this situation was about trust, too. The young woman was confident ~~that Helen would~~ not use her position of trust to convince her to do the ~~right thing.~~ As Helen pointed out, "She trusted me so much that she never questioned that I was going to [advocate for her]." That is not to say that Helen and the woman did not discuss practicing safe sex and the need to make sure that no one else would be hurt as she had been.

All three of the nurses who spoke of having HIV positive clients talked about the emotional reaction that they and/or their colleagues had to their clients' situations. "It hits people's feeling level," said Christine (PH) when explaining that her colleagues' responses came out of the fact that "we



really have had very little to do with people who are HIV positive." Limited exposure to clients with HIV means limited exposure to and understanding of the myriad social and ethical issues that accompany the virus.

Helen (PH) suggested that her colleagues' reaction to her story came out of a personal fear: "I think it's more like [HIV] scares the heck out of me! What if it was me [who had it or who found out that I had been exposed to it]?" Lillian (HC) spoke of her own reaction when dealing with a young woman with HIV whom she suspected of having unprotected sex—her fear came from her own experience as a mother of young sons who might become infected from a woman who was HIV positive. The emotional reaction and initial fear appeared to be related primarily to the nurses' lack of knowledge about and experience with the disease (Reutter & Northcott, 1994). Although the nurses attempted to become more knowledgeable about the virus and AIDS and had more knowledge than their colleagues, they admitted that this disease was new to their practice.

### The Place of Rules

Trust and honesty are valued highly and deemed necessary for relationship. They are even more important in community nursing in order to gain or maintain access. The community-based nurses in this study tended to function from a perspective of relationship with their clients rather than from a perspective of the rules of the organization. Problems arose when other members of the team involved with the family did not function from the same perspective. Sometimes it was felt that functioning from the perspective of rules rather than relationship jeopardized not only the nurse's relationship with the family but also access to the family by other health care providers.

Mary (PH) tells about working with a family with multiple problems in which two of the four children had health problems: One of the twin babies had cerebral palsy and an older boy has a genetic condition which had required psychiatric care. Other family problems included drug and alcohol abuse, poor parenting skills, and marital problems. The family's experience with health care providers in the past had not been positive and they were initially very guarded in their interactions with Mary. They only let Mary, a public health nurse with a speciality in genetics, into their home because of the disabilities of the two children. Over several months, Mary worked hard at developing a good rapport with the family and began to see positive results from her efforts. However, a home support aide working with the baby with cerebral palsy noticed some problems which she interpreted as neglect and which she believed needed to be reported to social services (child welfare). Mary said,

I was really concerned about that because I knew what that would mean for that family. I knew that if we reported [pause] our relationship would be finished. By this time, the report had been made by the aide to social services and so they called us for a case conference. . . . I had said to the social worker when she called me that I felt she should invite the mother. . . . I felt that these were issues that we should be talking to the family about and asking how we can help them. But that wasn't the issue for them. The issue was protection for the children. So I did say to the social worker at that time, I have real concerns about what this is going to do to this family. Do we worry about the kids' protection or do we worry about the service in that home *after* this report is made because I felt the consequence would be they would never let anybody step foot on their property again. . . . [The parents] were doing their best under the circumstances. They really were.

Building on positive lifestyle changes and encouraging parenting skills cannot happen without trust. The conflict for Mary was one of child protection versus that of long-term access to the family home where she could continue to be in a helping relationship and assist them to access the

resources their children would clearly continue to need. Mary's assessment of the situation was that she and perhaps all health care providers would be seen as untrustworthy after social services had entered the home with a complaint of possible neglect. Her concerns were very real in light of the family's initial guardedness (and the outcome).

Mary was assured that the social worker going into the home would "proceed with care." At this point, there was little that Mary could do given child welfare's legal mandate once there has been a complaint of possible neglect. The mother came away from the initial interview with child welfare with inaccurate information about how the decision making to investigate the claim of neglect had occurred and who had initiated the complaint:

I can remember the day that she came into the clinic to see me and it was this look of betrayal. . . . Of all the professionals involved, I was the one that was so concerned about what the ramifications of this reporting would be, and she was so angry and betrayed . . . and said, "I trusted you. How could you have done this?"

The mother forbade Mary to set foot on her property again. It was not the mother's words that affected Mary the most but the look on her face that "wounded me." The more that Mary tried to explain that she had not made the complaint, the angrier the woman became. Mary continued:

The ethics of it for me now is that if I was faced with another situation like that, I wouldn't report to Social Services and that is an ethical dilemma for me because I know by law you have to, but I also know by the situation what the ramifications are and just to follow through with it. Well, once Social Services had been involved, their mandate is that they can only be involved for 21 days. If they don't see any blatant abuse in that time, they close the file. So here was a family that was accessing service, they were making changes in a positive way. They now have had no service [for a year].

In the end, the children were not apprehended and remained in the home receiving limited health care because Mary was not allowed to visit. The relationship between Mary and the mother, which had been supportive, was

replaced by hurt and anger. As Mary indicated, "I had probably been the first person that she trusted for a long time." It may be said that support and follow-up are not the mandate of child protection. Does that lack of mandate, however, absolve the social worker from interacting with the family in a compassionate and sensitive way? As Mary indicated when she followed this up with a social services supervisor, "But it was the *way* it was handled that I have problems with." The family has now had their distrust of the health care community confirmed. Had Mary and the social worker met with the mother to discuss the observations that had been made, asking the mother for her perspective (Hughes, 1995) as Mary had requested, the situation might have been resolved differently.

Mary was functioning from a perspective of relationship and trying to build on this particular family's strengths for the long-term physical and mental health of all of the family members. She was responding to this family's very high needs as well as her perception of their vulnerability—a lack of trust of health care providers. The social worker, on the other hand, was operating from a perspective of rules with little regard for how her entry into the home would influence long-term family functioning once the assessment had been completed. The rules for the child welfare worker were applied to every family in the same universal way; there could be no exception. Mary believed that what was best was to support the family in every way possible, to foster positive change through relationship.

Functioning from a perspective of relationship, as Mary was, meant that unsuccessful resolution of differences of opinion constituted a moral issue.

This belief in supporting the vulnerable family and trying to encourage them to help themselves was supported by the work of Zerwekh (1990), whose research documented the competencies of expert public health

nurses. The nurses in Zerwekh's study also hesitated to involve child welfare unless risk to the children became unacceptable.

Another relational issue is the lack of collaboration between social services (and the rest of the team) and public health. "I was the one who was saying, 'Let's not go in there and do this to this family,' because I know what the repercussions [will be] and I felt that I wasn't heard as a professional." Mary's professional opinion about how this family might best be approached was not valued by her counterparts in social services. The lack of cooperation or willingness of professionals to work together toward a goal of child safety and family health was an issue that was echoed by four of the five public health nurses (and five out of the seven nurses in the study who have children on their case loads).

### Preserving Relationship

Among the ethical situations where other providers were involved were issues of preserving relationship between the physician and the patient and family. The next excerpt shows how far the nurse was willing to go to preserve relationships. Clara (HC) spoke of an elderly man being cared for by his niece. The elderly man had multiple decubitus ulcers which were not responding to the agency's research-based protocol:

The niece has a very good relationship with his physician. The physician makes home visits. So that relationship is really important [between] the niece and his physician.

[The consulting dermatologist] debrided and ordered hygeol soaks which is contrary to our protocol, but I knew what we had been doing hadn't worked so I informed my clinical coordinator. I said this is what the physician has ordered, but let's try it because even if research says it doesn't work, what we are doing isn't working either and I didn't want to jeopardize the client's relationship with the physician. And I had a good relationship as well with the physician.

So, you have to make these decisions which sort of put you in an awkward dilemma. Do you follow what you're supposed to be doing, or do you go with your gut feeling and follow [pause]? I did that [followed my gut feeling].

And I'm sure if I had not gone along with [the doctor], it would have jeopardized our relationship.

This excerpt plainly illustrates the importance this home care nurse places on preserving the relationships between all involved: the elderly man, his niece, and the doctor; and her own relationship with the family and with the physician. The high value placed on relationship meant that resolving the conflict between agency policy and physician's order was a moral concern. Clara says of the niece, "She had such a good relationship with that physician. It would have been devastating for her to be put in a position to have to choose between our protocol and what his physician wanted done." Because Clara made the decision to follow the order to use hygeol soaks, the niece did not have to make that choice. Clara believes that going against agency policy in order to be able to continue to work effectively with the physician and preserving relationship put her at risk for her own job. This excerpt also raises the issue of particularity: How do health care (home care) policies allow for the particularities of the clients and families to be dealt with?

The nurses talked about how relationships in their practice were influenced by face-to-face contact; in fact, this direct contact was seen to promote relationship with clients and with co-workers:

The hospital social workers I've worked with are quite different, because some of them I've seen in face-to-face contact, so I'm a person. They can relate to me. (Sara, PH)

Sara's experience as hospital liaison nurse was that social workers became comfortable working with her as a colleague as they got to know her. She has not had the same collegial relationship with social workers in the

community as she communicates with them by telephone, rarely meeting with them personally. The group of nurses that she works with have recently talked about interacting with social workers in person as a way of promoting better working relationships in a time of shrinking resources, when working together will be even more important.

### Collaboration

Collaborative practice, or interdependent relationships (Fagin, 1992) occur when professions respect each other's unique professional qualities (Coluccio & Maguire, 1983) and communicate effectively. Collaborative relationships between nurses and other health care providers are necessary to provide care that meets the needs of and ensures the safety of the client. Community-based nurses may work closely with a host of different providers including hospital nurses, physiotherapists, early childhood interventionists, physicians, teachers, personal care attendants, and social services providers. Just as nurses in acute care settings experience ethical issues which arise from a lack of collaborative relationships, so too community-based nurses experience lack of collaborative relationships.

The nurses spoke about not being able to count on other providers (social workers, physicians, and personal care attendants) to have the expertise, resources, sensitivity (as in the story from Mary above), or the will/determination necessary to do the job required of them. For instance, social workers who were overworked, under-experienced, and under-educated for the complex cases they were assigned, handled cases inconsistently, particularly where apprehension of children was concerned. Thus the public health nurse was left to do ongoing monitoring, information gathering and follow-up which ought to have been done by those in social

services who had the authority and legal mandate to deal with unsafe home conditions.

The two groups of professionals most frequently mentioned as sources of ethical conflict were physicians and social workers, specifically child welfare workers. Not surprisingly, the public health nurses spoke more of issues with social services; home care nurses spoke more of physician-nurse conflicts. Nurses working in acute care, supervisory staff, and personnel from contracting agencies were also cited as sources of conflict. What makes lack of collaboration an ethical issue is that the patient's needs were not met and in some cases patient safety was compromised.

Ethical problems resulted primarily when nurses' assessments of unsafe home situations and pain management were not respected or valued by other professionals. Lack of collaboration, lack of respect for nursing knowledge and expertise, team members not supporting and not consulting one another, all made the nurses' job more difficult.

How does one work with a team member who does not value or respect one's skills? What happens to patient care when one provider does not accord the other respect? In the following two excerpts, the nurses talk about a lack of collaboration in that their nursing assessments were not valued. Lillian (HC) spoke of a physician who did not value her knowledge in pain control:

We're looking after the symptom control and trying to work with physicians who, a lot of them, are not yet informed in terms of pain control. And then having the family who worship their physician, particularly in a small town. They're so loyal to their doctor. He or she must know everything that ever was. For us to then watch these people writhing in pain and to suggest, "well, there are other options for you," they have difficulty pursuing that with the physician and when we try to pursue it with the physician, we're looked upon as "who do you think you are? How do you [as a nurse] know?" . . . The key would be to work as a team, and that so often doesn't happen.



Despite the fact that nurses in the community function more autonomously than nurses in acute care settings, the hierarchal relationship and power imbalance between some doctors and nurses continues.

Christine (PH) recounts a situation where she suspended public health services to a home because of concern for her own personal safety. She recommended apprehension to social services, stating that if the home was not safe for the nurse then it might not be safe for the newborn. Yet she found that child welfare was not going to take any action. She said:

I don't think child welfare views our assessments of social situations in the same way that they did the [assessments of the] social worker in the hospital. Now I don't know what the reason for that is, but even though we don't use a formal method, we have good assessment skills on what it takes to be a good parent. That's part of our job to be able to assess that. . . . So if we say that this child shouldn't be in the home, the child shouldn't be in the home . . . and it's very frustrating when people [social worker] don't act on that. And we don't have the authority to do anything about it.

Christine cited "lack of authority with child welfare" as the most common ethical issue in public health practice, meaning that the relationship with social services was not an equal one and that if they decided not to act on her recommendation, she had no recourse.

When the professionals holding the authority to apprehend or make decisions about guardianship or competence do not value or respect nurses' knowledge, the ethical issue that arises is often one of patient safety. In spite of the fact that nurses are educated to work with families, assessing needs, providing support, and teaching, these skills are not always valued by other health professionals. Public health nurses spoke of how, along with the aforementioned skills, they were the health care workers "connected" with the schools and agencies in their communities. They were the ones who had the opportunity to see the family in a wider context, in more

settings, and so could gain information about how a family was functioning in the community, how the children managed in school, and so on. There is almost a puzzled quality when Sara (PH) talks about other professionals not valuing or "using" her knowledge:

I'm the person who can kind of fit the pieces together because I'm not isolated in one setting. . . . I can be out in the community. [I should have the] social worker phoning me [saying], "you're the public health nurse. You have a lot of community insight. Please tell me everything that you know. Tell me who are the people I can contact."

Kathleen told about another situation when nurses' assessment about safety was ignored by another professional. Her story is about an elderly man for whom safety was a definite issue due to diminished competence.

I have been visiting him for a couple of years; he still doesn't know who I am and why I'm there, although I tell him every time. I tell him during my visit why I'm there and who I am and what my first name is and I can see my card, my calling card sitting at various spots around the house—by the telephone, on the fridge, above the sink—but he has no connection that that is who I am and why I'm there. The whole issue boils down to his safety. How safe is he? Can he make a decision about his own safety? And I see evidence of fires on his stove; he has a gas stove and he smokes and he lights his cigarettes on the gas stove. I have come into the house on occasion and smelled gas and gone over to the stove and turned it off. The physician doesn't see this as a problem.

How is it that this man has remained in the community when he was assessed by the nurse as being clearly unsafe? Kathleen went on:

The nurses' opinion and assessment of the situation was totally ignored by a physician who hadn't known him as long as we had and hadn't seen the deterioration in him or, regardless of the deterioration, the fact that he was in the state he was in now. And to say that how he was living was not a danger to his health when we so clearly, myself and the nurse before me, saw it as a danger to his health. Especially with the fires. The fires were the big thing there. If he ever got out of the house, I don't think he would ever know where he lived and be able to come back again.

And I think maybe that was the issue [for me], my feelings of impotence, not having any power to say, "Fine that's your opinion. I want a second opinion here" and not being able to get one at that point. I think that's what it is. Because I think that

man could have died in a house fire. I think it was just God watching over him that prevented that.

The elderly man could not make a meal for himself, his home was filthy and he would forget to change his clothes—but those things did not put him at risk. What put him at risk was the fact that he was no longer "marginally functional." This was not a case of fluctuating competence. The elderly man was unsafe because, when evaluated, his cognitive functioning was so poor that he was no longer able to understand the consequences of his actions, the risks, and thus was not capable of making a decision about his own safety.

There has been an ignoring of and a lack of respect for the nurses' assessment over the years, as Kathleen was not the first nurse concerned about this man's safety. How is it that several nurses could visit a home regularly for years and all consider the situation unsafe, whereas another team member visits the same home but does not agree? Although Kathleen agreed that there was a lack of respect for her opinion about safety, she also said that she and the doctor "did not have a common agreement on what were safety issues." On each visit, Kathleen "used to do a mental assessment to see how he was." This mini mental status would be relayed to the physician, but action to place this man did not occur. Would a respectful attitude toward the public health nurse from the physician have meant that a second opinion or a cognitive assessment would have been carried out? Kathleen's frustration over her powerlessness to get a second opinion when the physician did not agree with her about the man's safety is plainly stated. Both Kathleen and Chris talk about the lack of control or powerlessness they felt when they saw unsafe situations and could not effect a change because they lacked authority. This imbalance of power

between the two providers is a relational issue (Erlen & Frost, 1991). Talk of powerlessness in terms of ethical decision making was a common thread throughout the stories.

One of the reasons that other professionals may not value the nurses' assessments is that there is limited understanding of the breadth of knowledge and skill level that nurses practicing in the community have attained both by education and experience. The following excerpt illustrates how undervalued and misunderstood nurses feel:

Something blew up and we ended up bringing in a facilitator, . . . a PhD in psychology, [who] told us that we weren't prepared academically or clinically to be doing the job that we've been doing in the home—the psychological work and the social work. [All of this falls] under the gamut of nursing care, but it comes down to people not understanding what nurses do and how prepared we are. (Margaret, HC)

It is not only other disciplines which do not value the knowledge and expertise of community-based nurses. Hospital nurses are also in conflict with community nurses:

I think that there is a conflict between what nurses do in the hospital and what nurses do in the community. [One reason may be that] nurses in the hospital are in total control of what goes on with their client, and they don't understand why the nurses in the community don't have that control and [that] if they are not real careful, [they] will be ostracized from the person's home because they've pushed too hard or they've dug too deep. . . . [Then] nobody will see the [family]. (Florence, HC)

If cooperative relationships are required to ensure that patient care needs are met, if team members are to understand the moral commitments of each other, and if cooperative relationships are necessary to ensure safe and humane care, then it could be argued that *not* functioning from a collaborative perspective is unethical. Further, if we agree that respect for persons is a fundamental ethical principle, then we must also consider that

this principle applies to all persons—colleagues within nursing and outside the discipline—not just clients.

Of course many relationships between professionals are positive. Florence makes a comment that, with the exception of one physician, she generally has a good working relationship with all the physicians in her small rural community. She says that collaboration may have to do with getting to know each other:

I can always get around [the physicians]. It's not fun sometimes, but I can usually. I only phone them when I absolutely have to. And they know when I call that they have to talk to me. They have to do something. . . . They know that I'm really independent, and they ask my opinion . . . 'cause they all know me and I've been around here long enough. They get mad at some of the other people, but they don't often get mad at me. I don't know why.  
(Florence, HC)

Florence and the physicians in her community not only know each other but they know how they work together because they have had many clients in common. They have been team members together on many clients' health care teams. They are in a cooperative relationship that works because they know each other and have proven themselves to each other. By extension, then, besides the many other elements that influence collaboration, community setting can also be a barrier to collaboration, especially in larger communities where the many providers do not get to know one another. Unlike hospital care where the team members remain relatively constant, the nurse in the community may work with different team members with each client.

Another major barrier to relationship with other team members is power imbalance. This imbalance does not promote working with each other as equals and sharing information about a mutual client. Instead it promotes one team member "lording" it over the other. As Sara (PH) said:

I think that varies from social worker to social worker in the child welfare system. Some are very open about the information and some [say], "By the way, you know I [have] the power to tell you nothing, and if I don't want to tell you [anything], I'm not going to. And I have that power too." That doesn't make for a good working relationship. It causes a lot of barriers.

In fact at times there seems to be no desire to work as a team by some professionals. Even though their goal of child safety may be the same, how the goal is achieved, the method, is very different. Conflicting methods of goal attainment may also explain lack of cooperation. For example, nurses teach parenting skills to prevent child abuse, whereas social workers react to abuse once it occurs. Conflicting methods become a "huge barrier" to good collaboration, says Sara. Mary (PH) identified this as a difference in approach:

Community health nurses have traditionally been enablers of the family, whereas my feeling about social workers, and you can't group them all in the same category, but that generally it's a power and control issue for social workers. It seems to me, "we're the power. We have the control. This is what you're going to do." Community health is very different in that we try to look at what the best outcome is for that family.

### Support as Relationship

Not only did nurses talk about other providers not valuing nurses' opinion but more distressing was the talk of not being valued or supported by their own supervisors. During a period of immense change, management may have to make decisions that will not sit well with all staff as there may not be time to discuss with all staff the decisions that have to be made. However, providing support and creating an ethical environment for front-line nurses are among the responsibilities accorded to management (Levine-Aruff & Groh, 1990).

A common statement made by the nurses about supervisory support was that due to restructuring and organizational changes, supervisors were not available a great deal of the time; support was not available to the nurses when they needed it. Further, several of the nurses spoke of their supervisors' lack of knowledge and thus their ability to provide support when for example, they faced issues around HIV and abuse. Some nurses expressed concern that not only did supervisors lack knowledge of ethics but they lacked sensitivity in recognizing ethical issues. This lack of sensitivity at times compounded the ethical issue.

Clara (HC) tells of a situation that created ethical concerns about her own safety which her supervisor minimized. A young man had been hospitalized for a gunshot wound as a result of a hostage-taking incident where he shot a police officer. While in hospital, he was under 24-hour guard. He attempted to assault a nurse while in hospital. Due to a lack of communication, he managed to discharge himself from hospital while there was a warrant for his arrest; Clara was asked to provide wound care for him in the community. Even though she was accompanied into the home by a police escort, Clara had a real fear for her own safety in light of this man's history of violent behavior. However, on taking this concern to her supervisor, the supervisor said:

"We do not discriminate against criminals." So I was quite shocked really that she would not value her staff more than that. . . . When I [told] her how risky it was, she still felt that she would send staff out there. So I mean that was really unethical to me, that she would expect her staff to go into situations like that.

Clara was most troubled by her supervisor's lack of recognition of the potential of risk even after it was pointed out. She wondered about the "ethical responsibility that my supervisor had for her staff." Having her concerns minimized while having her responsibility to the patient pointed out

is suggestive of a degree of insensitivity, especially when the supervisor did not recognize her own responsibility. There was no reflection on the situation as to how this could be dealt with in the future because it was not seen as a problem.

Lack of agency support is also an issue that was presented in the earlier excerpt (p. 80) where Clara (HC) went against agency policy to preserve relationship. She said that even after she had documented that the agency wound care protocol was not working and had discussions with her supervisor, if the woman had experienced problems using the physician-recommended treatment, "I wouldn't have got any support from [agency name]. I would have been standing on my own because I had not followed their policies."

Colleagues for the most part were seen as providing support, although several nurses spoke of situations where they were not heard by their colleagues and thus experienced a devaluation of their moral experience.

### Abusive Relationships

Both home care and public health nurses spoke of issues having to do with abusive relationships of children and elders. One nurse, when asked what was the most common ethical issue in public health practice, answered, "The abuse issues: child, wife, or elder abuse."

Elder abuse issues ran the gamut from financial to emotional and physical abuse. Predictably child abuse issues had to do with physical violence and neglect. There was a great deal of uncertainty around the issue of abuse. The province has yet to introduce legislation aimed at providing protection for the elderly. Even though there is a legal mandate to report child abuse, the questions of what constitutes abuse and what



evidence is needed to ensure apprehension remain largely unanswered for these nurses. Some examples of issues/questions regarding what constitutes abuse are listed as follows: If a woman is addicted to drugs and is breast feeding her infant, refusing to bottle feed because that costs money, does that constitute abuse? Kathleen (PH) cited lack of policy in this area as a consequence of the lack of research but this also results in a lack of legal support for a charge of child abuse. If a parent continually "forgets" to give his/her child a cardiac drug or withholds treatment from a chronically ill child, does that constitute abuse? If a child is not being stimulated developmentally and is being deprived of vital parent-child interactions, does that constitute abuse? If a child is locked in a closet for a weekend as a form of punishment, does that constitute abuse or neglect? If a child with spina bifida has open sores on her genitalia because she is not catheterized regularly and is left in a urine-soaked diaper for extended periods of time, does that constitute child abuse or at least neglect? Ambiguity characterized the nurses' discussions of abuse issues even after opinions from social services and lawyers had been obtained.

In some cases, reporting of what appeared to be blatant neglect issues did not even result in an investigation of the family by social services. In other cases, where there was a suspicion that a child might come to harm but there was no evidence to sustain that suspicion, the child was swiftly apprehended. Underscoring these questions is an implicit question: Does our definition of child abuse change with the number of social workers or child welfare workers available?

In cases where there is a great deal of uncertainty about what constitutes abuse, such as Kathleen's question about the drug-addicted mother breast feeding her infant, child safety is recognized as the ultimate

goal. Given that goal, maintaining access to the family home may be as important or more important than reporting a specific incident. The nurse is likely to be the only health provider monitoring the family. The nurses were concerned for the long-term care of the family.

### **Summary**

Ethical issues for the nurses arose out of their relationships with individuals. Relational issues were evident in narratives about the value and necessity of client trust, advocating for the client, preserving relationship between the client and other professionals, and having to make choices between supporting the client or the rules of the organization. Other narratives showed the difficulty in attaining collaborative relationships with other professionals and even how lack of supervisory support is a relational issue. The high degree of uncertainty in defining abusive relationships was evident in the questions posed by the nurses.

### **The Theme of Resource Allocation**

Resource allocation issues were a major concern to the nurses. Three of the participants cited resource allocation as being the most common issue in practice today.

I guess the one that we deal most commonly with in home care is recognizing our limited resources. When we become quite involved with the families, often it's so visible to us that they need so much and we recognize that our resources are so limited, so almost daily, really, we find ourselves having to make choices and trying to explain and justify. We work within an agency so we have to go with their priorities and with how they have chosen to allocate the funding, and often it isn't how we would necessarily like it to have been done. (Clara, HC)

As the nurses got to know the clients on their case load, they became sensitive to their individual contexts, their particular situations, history,

background, and environment. As Clara (HC) said, they "feel in tune" with their clients, indicating that the relationships that were developed helped them to see the client's needs. Her frustration was evident, as she assessed needs she was not able to meet. The nurses in this study felt strongly about responding to the needs they saw (Gilligan, 1988); these needs were not just physical needs (Liaschenko, 1993a), but psychosocial needs as well. Not being able to address recognized needs created ethical tensions for the nurses.

Charlotte's (HC) perspective on resource allocation was echoed by other participants. The principle she wanted to be able to use for making resource allocation decisions was an equitable principle of giving preferential option to those persons most in need:

In the case of [scarce] resources, it's okay if you provide the needy with more, because you can't really have one standard to cover all. There should be flexibility, but that flexibility should be applied to the ones who really need it instead of the people who do not necessarily need it or could use less but want or know how to get more.

There is a dissonance or incongruence between what the nurses saw was needed at the micro level and how resource allocation decisions were being made at the macro level. The principle being used at the macro level is a utilitarian one, or "the greatest good for the greatest number" (personal communication, Shirley McLellan, Alberta Health Minister, May 24, 1996). Making the egalitarian perspective even more difficult to practice was the fact that at the time of the interviews, Home Care had a funding limit of \$3000 per month per person as set by provincial legislation. Charlotte recognized that although people may all be of equal moral and social worth, the reality is that they do not all come to a given situation with the same advantages. They are not all coming from a place of equality. In a way, she

was pointing out that making decisions about the distribution of resources as if people are all equally advantaged is a questionable practice in itself as it often serves to perpetuate those inequalities. Moreover, she noted that it is the people with a "voice" or the "squeaky wheel," those who are often advantaged, who know how to get what they want and who use resources that they might not truly need. Others who are disadvantaged by way of poverty, education, or background do not:

There are some people who know how to get extras in services. They say, "This is coming to me and I want it," and because they say it loud enough [they get it]. Usually it's people that have a certain education and that have a certain background and that have certain money. Those three things go [together]. Then they know "this is mine to take and I will have it." I have problems with that. I mean you can't provide resources equally, but is that unequalness applied [in favor of] the one who needs it, so that the [one in most need] gets [what he/she needs] rather than the one that can speak the loudest [getting what he/she wants].

[The disadvantaged] don't know that they can ask for [what they need], or they don't know that they can have more.

Charlotte's worry about the vulnerable being inadequately served was also a concern for the future. It is her belief that as more care moves into the community and resources become even scarcer, it will again be the vulnerable or disadvantaged who will suffer:

I'm sure down the road we will have to cut back, because they are already talking about [the admissions to home care being] doubled, and also more and more people with symptoms have increased need [and are being admitted], so we eventually are going to have to cut back and say we cannot afford so much. But it's going to be the ones that can't afford to hire privately that [will] suffer because the ones that can, that's okay. It's the ones that can't [afford to hire private care]. It will be a problem for them.

Similarly Sara, a public health nurse, expressed her concern about the message of social worth that was being implied by the recent provincial resource allocation decisions at the macro level. It is her belief that the decisions having to do with reducing spending in the areas of health,

education, and social service, send the message to all, including inner city residents, that inner city people don't matter:

[The needs in the inner city community are] just phenomenal, and a lot of people don't understand unless they've worked the area, the inner city, unless they've actually been really in touch with the people. I don't mean just walk through the area. I mean actually work there for several months or years. . . .

I feel that the people that are going to hurt the most are the kids and the kids who are in those families that are high risk. They will suffer.

Both Sara (PH) and Charlotte (HC) talk about the long-term ramifications of the resource allocation decisions that are being made now. Charlotte's concerns centred around what she terms as "drying up the well." She recognized the need to have some flexibility in deciding what kind of service to authorize and that this flexibility may result in "unevenness" in authorization of home care service. However, she also sees that some coordinators:

do not go back and recheck [the level of service authorized], because perhaps [the client has] improved and the service could be decreased. . . . So what will happen is eventually we are not going to be able to provide support service any more. . . . We may be drying up our well too quickly.

Once again Charlotte's concern was for the vulnerable in the long term, because if we "dry up our well" it will be those who can not afford to pay for service who will suffer. Sara agreed and suggested that the long-term consequences need to be considered:

If we don't look after these people, 20 years from now their children will be in your backyard breaking into your house, looking for food.

Her observation suggests a cyclical nature to the provision of resources (not only health care but the determinants of health, including education, food, shelter, and so on) to the most vulnerable, in that if we provide the vulnerable with what they need, as children, we will all reap the benefit of

them growing up to be productive members of society. On the other hand, neglecting their needs can only result in negative consequences for all.

### **Levels of Issues: Micro, Meso, Macro**

The actual resource allocation issues fell into two subthemes: issues that were at the micro or individual nurse or team level, and macro issues or resource allocation decisions that were made at the regional health authority or government level. There is overlap in the subthemes of micro and macro, as decisions at both the macro and meso levels influence the practice of those nurses working at the grassroots level of practice. Meso level issues have been included in the discussion of micro issues as they are decisions made within the organization where the nurses work, within the proximity of the nurse. There is a relational aspect to them (between the nurse and the manager—they know each other and talk). This relational aspect is missing from the macro issues.

### **Micro Issues**

Resource allocation issues occur daily at the micro level or at the level of the individual "grassroots" or front-line nurse. The decisions at this level are generally about immediate care: who will get what kind of care today; when; and, perhaps in the case of home care coordinators, by what *level* of caregiver. The nurses in this study speak of the following micro allocation issues: day-to-day decisions of who gets what when, consistency of care, coordination between hospital and home, fragmentation of care, and commitment.

**Who gets what when.** The nurses appreciated the difficulty of making resource allocation decisions, especially because of the restructuring of

health care that has been occurring. Their thoughtfulness is evident in the many questions and suggestions about what ought to be taken into account in considering who gets what. As with relationship issues, context and particularity of the individual or family continue to be important factors in making resource allocation decisions. Yet how can we adequately recognize context and particularity in making resource allocation decisions? What is fairness? Fairness to whom? What rules are present to make these decisions fair? There is a recognition that what might be fair to one family might result in unfairness to another. For instance Margaret (HC), wondered:

Should single parents [caring for a family member] get more hours [of respite care] than foster families, as opposed to a two-parent family with only one child, compared to a two-parent family with six kids?

But that's an ethical decision because sometimes it's not based on fairness, and how are you going to say what's fair? To try to tie in all the factors like, maybe this couple is really struggling in their marriage. There's so much we don't know that is it the fairest thing to say, "Look, we have this many hours; divide them up," or should we give all the resources to this family here and let the others struggle, or [pause] how, how are you going to do it?

Margaret, although recognizing the necessity of budgetary constraints, remains open to thinking about how the decisions to divide scarce resources may affect the individuals and the families involved, but "the bottom line is always funding and there's never enough of it!"

Charlotte (HC) discusses how the realities of the resource allocation process are bound up in the relationship with the client.

[When] you establish rapport with the client and if you have a good relationship with the client, it's hard to pull service out. Once you've started a service and have to pull back and say we can't give you any more, nobody likes that. So you have to start with a low minimum because if you go high and then you decrease, the decrease is always difficult.

Clara (HC) told of a fragile elderly woman who wanted to remain living with her daughter rather than move to a nursing home. She was alone all day because her daughter was at work, and getting out of bed alone was a problem. She had fallen often. Although Clara had arranged for services (such as Meals on Wheels, a commode next to the bed, as much home making service as the budget would allow), she felt that the woman needed to have someone with her all day but did not have the budget to provide that kind of support.

The situation was made more difficult because the physician felt the woman ought to be in a nursing home in spite of her desire to remain with her daughter. This example shows the kind of overlap in themes (in this case autonomy and resource allocation) evident in many of the stories. In helping the woman to maintain her autonomy and risk falling and injuring herself, the issue of resource allocation arose. This is the kind of situation that the home care coordinators are faced with daily. Although not dramatic, nurses recognize that there have to be rules to make these decisions, yet there is also the question of what the best solution would be for this woman:

It's just very difficult for case coordinators not to be able to provide what the client needs and what the client is willing to accept.

(Interviewer: It sounds like you do a lot of saying no.)

Yeah [laughs]. You do. And it's tough, because there isn't any place we can take [these concerns]. Well, we always bring them back to our supervisor and discuss them at team, but it's not from an ethical perspective. There isn't a forum to address these issues from an ethical perspective.

You're the one that has to tell them, "I can't put somebody in when you need them." (Clara, HC)



This example shows how resource allocation is not separable from connection with the client. The importance to the nurses of identifying their concerns as ethical, having others support that perspective, and then being able to discuss the concerns in that context is also clearly evident in the above excerpt.

One difference between the resource allocation issues for home care nurses and public health nurses is that the public health programs are determined by legislation, the Public Health Act. In fact, the only mandated program is the communicable disease program. Clients whose health care needs fall under that mandated program become the priority for the public health nurse while, as Kathleen stated, "Everything else takes a back seat." Programs concerned with the health of young families are thus of secondary importance. Home care nurses are more constrained by individual client budget limitations. The case coordinator provides services to a client within a monthly budget amount that is legislated. However, he/she is often encouraged to keep costs below this amount. Both pieces of legislation create resource allocation issues for nurses.

The resource allocation issues described by public health nurses were for the most part linked to recent program changes as well as macro changes in education and social services over which they had no control (to be discussed in more detail in the macro issues section).

One micro issue that was represented as a public health resource allocation issue was the one of resources available for high-risk families. Many "at risk" families live in Sara's district. As a result she has to make decisions about which families to work with in the limited time available. Families with multiple and complex problems require a great deal of time and there may be many obstacles to success (including the nurse's own personal

safety). Because of the complex nature of many of the problems, Sara's decision regarding her depth of involvement hinges on the safety of the children in the home. If there is a danger then involvement or not is no longer a question.

**Consistency of care issues.** Consistency of care means having the same person delivering care to a client over a number of days. Consistency of care is used instead of continuity of care because it is the term used most often by the nurses. Consistency of care is voiced more frequently by, but is not limited to, home care nurses. Some of the nurses talk about a decrease in the consistency of care as being a recent development, concomitant with the move to early discharge of patients from hospital.

As a result of huge case loads, case coordinators have associate nurses and casual nurses working as part of the team, which often means that many different nurses work with one client. Clara (HC) said this lack of consistency results in the "poor service we offer our clients." She recounted a story of a man with bilateral leg amputations who required twice daily dressing changes for a large draining ulcer. He called a supervisor to complain that:

"In the last 10 days I've had 20 different nurses." And so the supervisor came to me and said, "We've had this complaint." And I said, "well, I completely agree with him." I mean I can't see all of my clients consistently so I ask other nurses to see them and then in the evening it's a different nurse too.

We should have smaller caseloads so that we are able to manage [them]. It's just getting worse.

You know that this kind of thing shouldn't happen but you have no power to do anything about it.

Several issues are evident in Clara's statements. Underlying her concern is the knowledge that consistency of care is important to her clients; they want to "know their nurse." It is also believed that having the same nurse

for a period of time is likely to improve the care. Clara expresses a sense of powerlessness—that there is little that will change unless case loads are reduced.

Some might suggest that Clara, as case coordinator, ought to have acted in advance to ensure that this kind of inconsistency did not occur. Clara herself even suggests that this ought not to occur. What this situation shows is that there are often constraints preventing the nurse from acting in the manner that she would like to; the situation is not as straight forward as it first appears. The sense of powerlessness evident in the excerpt supports the idea that there may be constraints that have not been made explicit.

Besides the large caseloads, consistency of care is further influenced by the use of casual staff. Charlotte (HC) described the care as "scratching the surface" when there is the regular/frequent use of casual staff:

Continuity is poor because of that. They are always using casuals to fill in. This is another big problem, [because] your clients are [always] different faces. You start working with [a client], then you're gone. Someone [new] comes in and has to do all the groundwork again, then she's gone. So, I think things are missed because of that.

Quite often when you are casual, all you are doing is the task. You don't have time to get to the core of things.

Charlotte's concern is that as a casual nurse who sees new clients every day, symptoms are missed because only the obvious is treated. Further, the clients are not happy having a new nurse every day, to whom they have to explain, again, where they store their supplies and how they like the dressing done.

Clara (HC) went a step further and identified that inconsistent care leads to nursing errors:

I have been concerned for a long time about the lack of consistency, and I can think of a couple of errors that were made which I felt were related to the inconsistency of care. So I have

brought it forward to my supervisor that this is an area that we need to improve on, but I have always felt that at this agency it hasn't been a concern of supervisors.

What makes this lack of consistency of care an ethical issue for these nurses is that it jeopardizes the care that their clients receive and in some cases creates unsafe practice conditions. Nurses have an obligation to provide a certain level of care to their clients, and anything preventing the provision of that level of care creates ethical tensions, issues, and in some cases ethical dilemmas. Compounding this issue is the lack of recognition on the part of management that moving/changing staff from one area to another or using casual staff on a regular basis has a huge impact on clients. There is also an implication in the excerpt that although the resource allocation decisions are occurring at the micro level, there is a situational constraint in place preventing ethical practice. A situational constraint, according to Rodney and Starzomski (1993), is some aspect of the nurses' interpersonal and structural work environment that jeopardizes nursing care by preventing the implementation of professional standards of nursing.

Consistency of care issues are not limited to home care nursing. The new post partum early discharge program, called Healthy Beginnings, has created consistency of care issues for some public health nurses. At the time of the interviews (June 1994-May 1995), public health nurses worked in assigned geographical areas or districts and were responsible for the care of the clients in a certain district; yet, not all public health nurses were trained to do Healthy Beginnings visits. The nurses trained in Healthy Beginnings made the first visit, which was followed by subsequent visits by the district nurse. It was possible then for the new mother to be visited by two different nurses within a brief period of time; one nurse who would attend to the woman's physical exam and one who would not. At a time

when the new mother may have questions about the changes occurring to her body and about the care of her infant, consistent information, teaching, and support are required and can best be provided by one nurse doing all of the visits. The Healthy Beginnings nurse can build on her initial assessment to provide efficient and consistent care, taking into account the concerns expressed during the first visit.

She has to almost do a reassessment of an assessment that I've already done. Let's talk about efficiency here. And let's talk about health care dollars here. Is this effective?

Why not train everybody for Healthy Beginnings and I think everything will run a lot smoother.

The same nurse should be seeing the same mom for X number of days. Not this nurse on day one, this nurse on day two, and this nurse on day three.

**Coordination between hospital and home.** Kathleen (PH) provides another portion of a story discussed earlier (p. 85) about an incompetent elderly man who was unsafe living alone:

He burned one of his shoes on the stove. I had been in on numerous occasions and seen burned plastic dishes on the [gas] stove, burned shoes, burned bits of paper, cigarette packages that have been burned up, just ashes sitting on the stove there. Anyway, apparently he had caused a fire and that was enough that the neighbours saw smoke coming out the window and called the Fire Department. The Fire Department was able to get him admitted to the hospital where the physician and the gerontologist didn't, wouldn't, take action because they felt that it was not necessary. . . . He was only kept for about a day or two and then sent back home again. When he was sent home, he came home by taxi and he had no idea where he was or where he was coming from, or how he got into the taxi. The social worker at the hospital had some concerns, although physicians who saw him and discharged him had no concern about him coming home.

The man had been unable to provide the hospital staff with any information about himself or his address. The fire fighters provided the hospital with identification they had found in his home. Kathleen could not understand how the man could have been discharged from the hospital back to his home

without alternate care in place. What is the health care provider's ethical responsibility to clients once they are deemed ready for discharge? As health care providers is there an obligation to ensure client safety in the community?

Kathleen, the public health nurse, found out about the hospital admission when she telephoned the elderly man to remind him of her regular visit. When there was no answer, knowing that the man never left the house, she rushed directly over to his home. Kathleen was standing on the front step when the taxi pulled up to the house, bringing the client home from the hospital. The taxi driver told Kathleen where the man had been as he was unable to do so. After a phone call to the hospital revealed that a referral had been made to home care, Kathleen contacted home care and expedited the assessment which was completed that day. In the end, the man was admitted to a long-term care institution that same day.

This story shows the need for increased communication *between* providers and coordination of care and resources *between* hospital and the community as the provision of care moves more extensively into the community. When there is a lack of coordination of resources, tragic results can occur as might have happened here had the public health nurse not arrived at the home of this elderly confused man when she did.

**Fragmentation of care.** Fragmentation of care is defined as care that is provided by many kinds or levels of care providers (several different agencies or community services) which serves to fragment the patient:

There's so many people involved and often the focus will be moved from the family to the roles of the team members as opposed to focusing on the family and what they want. (Margaret, HC)

When the relationships between the providers become the focus of attention, the client's needs get lost. Providing fragmented care is seen as "uncaring," in that clients are not viewed as individuals with particular contexts; they may not be viewed as a whole person at all. Each provider may be only dealing with the little piece of the client that is within that provider's domain without taking into account how this "little piece" might affect the rest of the client's life socially, physically, and so on.

For example, when the home care agency does not have the "people resources" to provide the full range of services that a client may require, the services are contracted from another agency. The question then becomes how is that service monitored and who does the monitoring? Geography exerts a critical influence in this example. When care is being provided in the community, monitoring that care becomes a more difficult matter and cannot be accomplished in the same way as in an institution. In institutional or acute care, the mere presence of other providers serves as a monitoring mechanism. The caregiver, whether it be a registered nurse, a licensed practical nurse, or a home support aide, is frequently alone with the client in the home. If questions arise about the care, there is no one on site to be consulted. Home care coordinators may make home visits to monitor the care, but for the most part each caregiver is on his/her honor to provide competent, humane, and safe care.

Charlotte (HC) spoke about an experience that she had had where an elderly man was left lying in his own excrement over a weekend because an aide working for an agency did not let anyone know that the elderly man had told him to "Go away." The point of her concern was not to blame the aide, who was just following the agency mandate of not providing care when it was refused, but to suggest that one of the results of fragmentation

of services between agencies can be poor communication. The aide had neglected to notify anyone that the man had refused care. Had the service been delivered through the home care agency, the aide might have had an assigned person to report to at the end of the shift. A home care coordinator then could have followed up with the man as to why, when he was so ill that he could not get out of bed, he would refuse care.

We have little control really when it comes to [care being provided by a contracting agency]. We really can't do very much because too many things are assigned out. You are hoping that it will be done and that it will be done the way that you want. But it doesn't always work because everything is so indirect. (Charlotte)

Lillian (HC) has also had several experiences that make her wary of contracting services from private agencies. She would prefer to use staff that she knows and can supervise herself. She questions how to monitor the standard of private agency care when "we can't keep tabs on all the staff out there." She spoke of an elderly woman whose caregiver wanted to leave the home early. The caregiver told the senior that if the company called, she was to tell them that she had just stepped out the door when in fact she had been gone for some time. The elderly woman was frightened into agreeing to this request, perhaps fearing that she might lose the services that she was receiving. For Lillian the issue was one of resource allocation and accountability; having to contract services from outside agencies meant losing control over the standard of care. She recognizes her moral accountability for the care that her clients receive as she is the one who is contracting the services. Yet, she has no control over the care that is being provided as she is at arms length from the actual provider. She would like to be able to consider the capabilities and education of the people to whom she is delegating, but the agency makes the determination about who is best suited to the assignment. Lillian said:



You establish a relationship with the client and the family when you've worked through what their needs are and you have said, "Well, I can provide some service for you. We'll contract it from an agency." They have developed a trust relationship with you and then you're having to bring in these people and you don't know the kind of care they're going to give.

Lillian's clients have entrusted her with the responsibility of ensuring that they are provided with competent care and that they will not be at risk. How can competent care be ensured when services are fragmented by contracting them out? Lillian's concern about accountability and fragmentation is even more pronounced when private agency caregivers are going into homes where the client is cognitively impaired. Providing care in the privacy of the home may put clients at increased risk for abuse and exploitation (Ruddick, 1994). As health care continues to move into the community, this problem of supervision and accountability will become more significant for home care.

Charlotte (HC) told a general story of fragmentation of care. She received a new assignment to provide nursing care in a seniors lodge for a period of months. Although home care nurses provide care in client's homes, they also go into lodges when asked to provide care for the residents there. Some lodges also have their own nurses and herein lie the ethical predicaments. When two different organizations (one not-for-profit and one for profit) are providing the same nursing care for the same clients in the same institution and this is combined with a lack of communication between the two groups, fragmentation of care is the result.

Charlotte was requested to see a lodge resident who needed care for a skin rash. Although the referral had been made to home care from the doctor, the client was also seen by the lodge nurses. Charlotte was unprepared for the territoriality exhibited by the lodge nurses:

The manager in the lodge . . . caught me one day and asked me why I was there, and I said, "Well, I'm just looking after his skin rash. This guy has pustules." And she said, "We're supposed to be doing that because you shouldn't be here." I said, "This is a referral to home care so I'm [pause]." "But the referral," she said, "is only for a bath assist." Home care had authorised a bath assist, so he gets a phiso hex bath once a day, then I go in and put the ointment on and she said, "Well, why are you doing that? We just need a bath assist." And I said "All I know is I'm supposed to look after his skin rash and I authorized the bath assist, so someone else bathes him and I will come and put the cream on and monitor this rash and phone the doctor if it needs to be [pause]." "Oh," she said, "we do that." I found out later that there was a little bit of fighting over territory. I perhaps was stepping in sort of their territory by my doing that, because you see they charge them for nursing service.

[The lodge nurses] look at [home care] nurses that go in there as sort of taking something from them. They don't look at OTs the same. Occupational therapists can go in there, and it's different because they are not nurses, they are OTs, so then they don't have a conflict of interest.

Charging clients a fee for each nursing service performed is something that makes Charlotte feel very uneasy, as she perceives it as an unfair distribution of resources when the client could receive the nursing care from home care at no direct cost. Her understanding is that there is no regulation to prevent privately run lodges from charging for nursing services. In some cases paying for nursing services makes the difference as to whether a resident can afford to continue living in the lodge:

[The residents] are not always rich. Some of them, their children pay for [the lodge] so they can live there. So then it becomes a financial burden for some. One lady said, "I can't afford to live here any more because they charge me for everything." If [the residents] wander out in the hall and [the nurses] direct them back, then they charge them \$1.50 or something like that.

To Charlotte's further dismay, when residents or families started to ask about the nursing costs:

Sometimes they don't always get an answer as to why they are paying that extra money.

The elderly residents and their families may be told when they are admitted to the lodge that there will be a charge for nursing services, but it seems that they may not understand or remember. It also seems that the information is not made explicit enough that there are two kinds of nursing available. Compounding Charlotte's concern for the residents who seemed to be unknowingly paying for nursing services is the fact that her own colleagues do not see an ethical predicament. She described their response to her concerns this way:

When you are new you can say "Hey something [is wrong here]," and then they will listen to you; but after a while they just say "Well, it's been going on. You can't change it." So I wasn't very happy working in that situation.

This story, although at first appearing somewhat benign, highlights some very troubling ethical issues as it unravels, issues that have not been evident previously but that may be seen in health care in the near future as our system of health care delivery changes. Underlying the story is a kind of objectification of the client that can occur when that person is thought of as "owned by one group" and is a source of revenue.

The resource allocation issues in this story include fragmented care and charging clients for nursing services that they could receive without cost to them through home care. However, there is also the way that Charlotte experienced a devaluation of her moral experience by her colleagues as shown by their lack of willingness to recognize the issues. Charlotte's concern for the autonomy of the elderly residents in not being given the choice to decide whether they want home care services or lodge nursing services is also apparent.

The most disturbing issues were the dangerous aspects of nurses from two different agencies providing fragmented care. Clients receive care from

various and different providers all the time. What makes this an ethical issue of fragmentation is that the patient is lost in the process and there appears to be a lack of communication with home care when care is being provided (taken over) by the lodge staff. This lack of communication can lead to potentially dangerous situations:

Sometimes I would go in and [the client] would say, "Oh, that nurse already put the ointment on." And I would say, "Which nurse?" And she says, "Oh, the nurse in the lodge." So the nurses in the lodge really see us as infringing their territory because it's in a way a money-making thing for them. But they would let us do things that they can't provide or if it's too much for them, then they would refer.

This practice sets the stage for the possibility of duplication of medication administration. A less obvious resource allocation concern is the home care nurse using valuable time to travel to the lodge only to find that the nursing function had been performed by someone else. Duplication of ointment administration is one thing, but ignoring the results of chem-strips could be deadly. Charlotte continued:

For example, I go to do chem-strips four times a day on a client. But [the lodge nurses] give the insulin, first. So I asked them, "Why are you giving insulin when I'm doing the chem-strip? Aren't you interested in what my chem-strip says?" And she said, "You can leave the result at the front desk." They're not interested. I said "how could you give insulin without knowing the chem-strip? I am here to do chem-strip four times a day for a reason because she's not stable, so why are you going around giving [pause]?"

It is hard to understand how this fragmentation of diabetic care might be justified given the possible severity of the consequences. The concern of fragmentation of care leading to dangerous practice clearly also contains an issue of questionable professional competence about the administration of insulin. It is my understanding that this issue among others was looked into shortly after this occurrence. Some might say that this kind of situation ought not to happen, but the story shows that it does and illustrates

problems within the system—the need for better communication and even support.

Fragmented care does not only occur in home care. Sara (PH) told an equally frightening story about fragmented care when she talked about a family receiving services from many agencies in the community but lacking a coordinator of that care. Sara attempted to perform the coordinator function but encountered many obstacles. Only through her persistence was safety finally achieved for the children in this family. Her story was of a baby girl born to a woman who openly admitted to frequent drug use and who was often seen intoxicated in the community. At the time of Sara's initial involvement, the woman was pregnant with the infant of the story, her 11th child. Her three youngest children lived with her and her current partner. A number of this woman's other children had been apprehended by social services in the past. As Sara learned more about this family, her concerns for the safety of the unborn child and the children still in the home grew. She contacted social services outlining her concerns. The social worker at the hospital knew the woman, was aware of her drug use, and had "definite concerns." Sara then called the social worker at child welfare. Child welfare, however, was reluctant to investigate the home despite Sara's reported concern and calls from the Head Start teacher about the neglect and suspected abuse of the 5-year-old. This excerpt hints at the fragmentation of the family by social services. Sara had to call two different sets of social workers (hospital and child welfare) to register her concern for the children in this clearly unsafe home environment. She believed apprehension should occur at birth as the mother, incapacitated much of the time, would be unable to care for the newborn.

Contributing to the family fragmentation was the number of providers involved and the lack of communication among them. There were already at least five other providers involved with this family that Sara knew of (the Head Start teacher, child welfare worker, hospital social worker, community outreach worker, and nurse practitioner). Each had only small pieces of the family's story.

Sara became increasingly concerned when the mother and her baby girl were discharged the day after the birth despite admitted cocaine use the day of delivery. Sara continued,

She had used all through the pregnancy some form of drug or alcohol, and right before she delivered she had used. But she went home with the baby. When I talked to the social worker I was, of course, really upset. "How could you let that baby go?"

Well, what they said was we called crisis unit. Of course crisis unit is very short staffed. So I phoned the crisis unit. They said, "Well, we did our observation for two days." So they went to the home twice, and I believe she was escorted by a police officer if that gives you any indication about what goes on at home. Lots of family violence. The mom is violent.

Despite the fact that the woman was known for her violent outbursts and drug and alcohol use, neither the social worker nor the crisis worker believed that there was a concern for the safety of the infant or the other children. Sara, in talking about her reaction to constantly dealing with at-risk families, said "It worries me because I have become numb now," when past similar situations would have caused her to say, "Isn't that obvious?" Is it possible that continuously dealing with situations of abuse and at-risk situations results in a kind of "numbness" that sets in with all situations but the most blatant and violent? How else can drug use and violence be seen and not be considered unsafe except if more blatant or violent abuse have been seen elsewhere?

One of the issues here is that there are very different perceptions held by the many providers. A contributing factor may be that, although Sara sent documentation of her concerns to the social workers, neither of these social workers had all of the family information at their disposal because the two social services departments operate independently.

By this point in the story, there were several more providers who had come into the family's life, including the hospital staff of nurses and physicians (for a total of at least nine providers). Care was being provided by many caregivers who were not communicating with each other, leading to an incomplete picture of the family and ultimately fragmentation of the care.

When the infant was about 8 weeks old, Sara heard from the Head Start teacher that she was in hospital (not the hospital of her birth) on life support:

Now we have another social worker at the [new hospital] involved who doesn't know the history of what happened at the [other hospital] or any of that history that's happened in the community. She knows nothing. Other than that, this baby is on life support in the hospital. This baby is now blind, deaf, has cerebral palsy, has just recently had a gastrostomy tube put in [for feeding].

And the [social worker] is getting lots of reports from the staff about how the parents are reacting to the baby. Actually the nurses said that the mom didn't even want to hold the baby, had showed no affection towards the baby.

Plans for discharge began at a case conference to which Sara was not invited. The community outreach worker, knowing the family, told the providers that "this child cannot go home with these parents."

Following the case conference, the community outreach worker, puzzled by Sara's absence, contacted her. From the report of the case conference discussion, the child continued to be separated from her context during the discussion—there was talk of the child's diagnosis but no talk

about how that would affect her need to be parented in whatever home setting she would be in. There was no talk of how she would need to be stimulated now that she was blind and deaf; no talk about the task of teaching this child to suck again for nourishment or for oral gratification or how that might be accomplished in a home where violence and drug abuse were common. Although the plan continued to be to return the infant to her mother's home, the infant had been apprehended for a 30-day period during which the foster parents would teach a licensed practical nurse to care for the infant. On the infant's return to her home, the LPN would teach her mother how to care for her.

One of the main issues for Sara, among the many evident, was the fragmentation of services as a result of the number of care providers and their varied perceptions of the family and infant. It was her belief that this fragmentation contributed to the tragic outcome for this infant. By the time that the infant was readmitted to hospital, there were many providers involved who only knew a part of the story. What was lacking was a clear coordinator with the authority to bring all the providers together and to make decisions.

Upon hearing that the plan was to return the infant to his home, Sara and her supervisor scheduled a meeting with management of social services. Consequently, all four of the children were placed in foster care. For Sara the story continues.

When telling this story, Sara's anguish mixed with anger was readily apparent. She had seen a crisis waiting to happen but was unable to obtain the cooperation to prevent it. She believes that the infant's permanent condition of blindness, deafness, and cerebral palsy are the result of the lack of interdisciplinary cooperation.



Nurses believe that there needs to be some other mechanism in place to appeal to if social services doesn't agree with the public health nurse that the child needs to be apprehended. The situation as it stands is that if a nurse goes into a home and feels personal safety is an issue, as in Sara's story, she withdraws services. A letter is written to social services advising that the home has been assessed as unsafe for the nurse and the child and apprehension is recommended. If social services assesses the situation differently, the public health nurse has no recourse, no other body to whom she can appeal regarding the safety of this child.

If child welfare doesn't take [the case], then who has it?

We're not visiting because it is not a safe place and child welfare is not doing anything either. The family is just left with absolutely no one. That doesn't seem right. (Christine, PH)

When does commitment end? The nurses in this study clearly felt strong obligations to their clients and were conscious of the fact that in some cases they were overstepping some professional boundaries. Nevertheless, they had trouble walking away from families in crisis and sometimes that meant they crossed boundaries and either volunteered their time (unpaid) or worked overtime even when exhausted. The following excerpts speak to that commitment to the clients:

Another situation I'm sensing now with the whole cutbacks and people being asked to stay at home or "Well, there isn't a bed right now. You can stay at home" are families who are feeling I can't handle any more. Home care is being asked to provide some more care, but I'm finding some situations where there's clients and families who are to the breaking point. They need a break [by having the ill family member] admitted to the hospital, even for a few days, but there isn't a hospital bed and so the families are having to push even harder.

Again, with the whole issue of allocation of resources, home care is supposed to be the be-all and end-all for so many things now. [laugh] And yet in reality the funding has not come through for us so that we can provide the resources for this to happen for people when a family member is exhausted. We provide a token kind of

program . . . still, and it's not a 24-hour program, so if you can look after mom for 24 hours a day, 7 days a week, we will *drop in* and we will provide 4 hours of respite or whatever. But 4 hours is not a heck of a lot of respite when you are, in fact, physically and emotionally exhausted. (Lillian, HC)

Despite the move of client care into the community, funding has not followed the client into the community at the same rate. It is that lack of funding that contributed to the nurses volunteering unpaid time. It is not always nursing time that is needed by the family. The need may be for respite or personal care which can be provided by another level of caregiver. The point is that the nurses see families exhausted by the need to care for someone 24 hours a day, families in crisis, and they cannot turn away.

This situation of volunteering to provide care has several consequences. The most evident consequence is staff burn out; but the less obvious one is that, in the long run, volunteering will maintain the status quo and not bring attention to the fact that there is not enough funding to support the resources that are needed in the community:

We've recognized the need and the distress that the family are in, so you pull out all your own stops and your friend's stops and [you help out by volunteering]. . . . Some people would say, "Well what's wrong with that?" What I say is that's fine for a period of time, but you're going to burn out your resources, you're going to burn out your staff. It's also dishonest. It's dishonest because if you're saying that a program is supposed to be offering this and yet then we don't provide it, and we're not able to provide it and yet nobody is hearing that we're not, then it's assumed that it's happening.

I guess it's so difficult, particularly I think for us older nurses, because we can't leave people stranded as easily. I'm not criticizing the younger nurses, but they're able to sort of say, "Hey, I'm sorry but I can't do this." And they're much more able to recognize themselves as being important too and being able to care for themselves and their health. So they won't do it.

But they also recognize that if they back off and have the family then rise up and scream for help, then something might change. Those of us who sort of say, "Ah, we can't bear to have this

happen!" we jump in with both feet and we're probably going to burn ourselves out as well as not change the situation. (Lillian, HC)

This story sharply outlines how resource allocation is influenced by the relationship that the nurse has with the family. She is not able to ignore the needs of the family. Although the nurse recognizes that the situation is not good for either her health or the issue of long-term resource allocation, she is unable to leave a family with limited emotional and physical resources.

Overtime is also an issue in home care, especially when the family is well known to the nurse. Several of the nurses spoke of their feelings of obligation to the families and how they were prepared to make sacrifices in order that families' needs be met:

I've had days where my priority is these families and if they need care, I will drop everything I have to do, including cancelling a casual shift at the hospital, because they can always get a float in. They can work short-staffed and still deliver some level of care, whereas in Home Care, it's one-on-one and if they don't have you, they don't have anybody. Where I personally feel that I will go in under just about any circumstance unless I am sick. (Margaret, HC)

Both unpaid time and overtime are examples of very personal resource allocation decisions that the nurse has to make because she has to consider her ethical responsibility to herself in a different way than if she were making an ethical decision about how she would spend regular paid work time. In that case, she would only have to consider how her decision might affect her other clients, whereas the decisions where she is giving of her free time or is fatigued require her to consider her obligation to herself to remain healthy (and whether fatigue has altered her competence to provide care).

Both of these excerpts speak to resource allocation issues at the level of the individual nurse, but in both cases the issues only arise because of perceived resource allocation decisions at a macro level.

**Meso issues: Influence on micro issues.** Additional ethical questions and issues about client care in the community, at the micro level, pertained to such concerns as the orientation of new staff, determining the appropriate level of caregiver, lack of "grassroots" input into agency policy, and the lack of recognition by administrations/management of the impact that their decisions have on nurses and clients. These ethical issues were voiced for the most part by home care nurses.

In order to provide quality care, the suggestion was made that home care ought to hire only experienced nurses. This suggestion was based on a recognition of the major difference in care setting or "geography" between home care and institutional care. Home care nurses make visits alone and so cannot quickly or easily consult with other (more experienced) staff as they might in an institutional setting. An ethical problem was created when nurses perceived that client assessments (for the purposes of determining home care services) were not being adequately done by new and inexperienced staff. Inadequate assessing meant that inadequate services were put in and the client thus did not receive appropriate treatment. The moral problem for the nurses was not only that the clients were not getting all of the care that they required but that the new staff were not getting the orientation and the support that they needed.

The level of caregiver assigned also became an issue for some nurses, as care that had previously been provided by registered nurses was being reassigned to Licensed Practical Nurses (LPNs) and personal care attendants (PCAs) as a cost-saving measure. Some families wanted registered nurses

only, yet were identified as needing only LPN or Nursing Attendant (NA) level of care. There were questions of *when* and *how* the determination would be made that a family could safely be cared for by a lower level of caregiver. In light of the lack of supervision and access to other health care providers, is client safety being jeopardized by downgrading the level of care provider? Additional resource allocation questions also included decisions about giving the families the number of respite hours of care that they required. Some of the concern voiced here had to do with the fact that the families had little say in these resource allocation decisions. Although client safety was the foremost issue, valuing nursing's unique skills and knowledge base was also part of the resource allocation decision that one nurse thought ought to be given consideration:

It comes down to valuing what nurses are and the difference that nurses make to the healthy outcomes for families. (Margaret, HC)

Do families "miss out on something" by having a LPN deliver care that had been previously delivered by a nurse, asked Margaret (HC)? How safe will the level of care be when health care providers who do not have the same level of physical assessment skill as registered nurses, especially in the care of very ill clients and technologically dependent or chronically ill children, are hired? Will care be compromised?

Several of the stories contained examples of decisions being made at the management level where their impact on clients and staff seemed not to be an important consideration. The issues in these stories are about the allocation of nursing resources and the relationships that clients develop with their providers. For example, moving staff from one program area to another or using casual staff on a regular basis has a huge impact on the clients. Often the impact of staffing patterns and changes on clients was

not acknowledged as a problem, and "the [importance of] patients being served gets lost" (Clara, HC). At issue is the decision makers not understanding or valuing the ethical implications of their actions. This kind of decision making does not allow for exceptions, for people to be treated individually, or for the particularities of the situation to be taken into account. Clara explained her concern about not being asked for input about how resources should be distributed:

We're expected to fulfil the policies and to do as the policies say, and there is no structure to even discuss the ethical dilemmas that we deal with. I have brought it to the [agency's] attention on several occasions, the need for an ethics committee.

Nurses felt that those making decisions:

do not understand the ethical implications. So, they are just not aware and don't value it or understand. . . . They lose touch, I think, with how difficult that is and do not have an appreciation for the impact of their decisions.

### **Macro Issues**

Macro level resource allocation decisions are those decisions that are made at the government and the regional health authority (RHA) levels with respect to the community's health care resources. Generally these decisions are of a health policy nature. Most decisions are made at arm's length from the health care situation. They influence both the levels of care and the programs that will be implemented and the actual provider of health care service in many ways. Macro and micro resource allocation decisions are interrelated. How decisions made at the government or RHA level impact on the delivery of health care in the community was by far the largest concern voiced by the participants about the allocation of health care resources.

**Restructuring: Change and community care.** Changes to community care programs have come about as a result of budget cuts in acute care,

education, and social services. Acute care delivery with early discharge, outpatient surgery, and consolidation of hospital beds has had the largest impact on community care. Budget cuts in the areas of social services and education have impacted public health predominantly, as has the early post partum discharge program.

An example of how cuts to education have impacted public health is Sara's comment that some schools have deleted counselling positions and expect to be able to "fill in with the public health nurse."

The short-stay maternity program has "mushroomed" and has tended to push aside other programs. Healthy Beginnings, the public health program, ensures that mothers are visited by a public health nurse within 24 hours of discharge from hospital for physical exams of the mother and infant, blood tests for PKU and bilirubin levels, and so on. The demands of this new program, combined with the cuts to social services, caused added ethical issues for public health nurses.

Because of the short-stay program, mothers are leaving the hospital before nurses and social workers have a chance to do referral assessments. The public health hospital liaison program has also ended. Social workers no longer routinely check with mothers being discharged to any home where there might have been inadequate preparation for the infant to ensure that all was in place in the home for the baby to go home (clothing, diapers, and formula if necessary). The result is that the good communication between hospital social workers and postpartum and public health nurses is no longer happening.

I find that it ends up in the community. That's where all the problems are happening now. (Sara, PH)

During that Healthy Beginnings visit, the nurse may find a crisis situation (such as a mother without money and without milk for the baby) which could have been averted had a social worker intervened in the hospital. The public health nurse handles the crisis situation in an appropriate way, usually by dealing with social services on behalf of the mother. Dealing with these crisis situations impacts on the public health nurse's ability to deal with the rest of her caseload. The Healthy Beginnings program shows us, rather rapidly, how decisions made in one area impact on another.

Equally troubling for Sara (PH) was the response that she received from her supervisor when she asked how to handle these kinds of emergency situations. She was told "Just do the basics—that's all you can do," which caused her more conflict and did nothing to alleviate her concern for the client's unmet needs. The response also made her question her role in all this restructuring:

Whatever "just the basics" means is questionable. We're not told what to do exactly. We're not given any clear direction on how or what will be our role. For instance, the social workers have basically dropped off. They're not doing the assessments and they're not providing the resources that these families need before they get home.

Frustration can be heard in Sara's excerpt about the practicality of dealing with families with complex problems. Not having the support of social services and then not getting management support and direction regarding role change compounds that frustration.

An implicit issue here has to do with the nurses' ethical obligations to client care as their role change and they can no longer count on the same supports and resources. Role confusion/uncertainty is contributing to some distress about how ethical obligations might be met or managed with less



support. The client's needs may not change as roles change but who will take the responsibility for these clients if public health will not?

I'm just so confused about how our roles are going to shape up because everything's just kind of falling out. People are trying to juggle and pick up these pieces here and there and try and resort them or repiece them to make some sense.

Everybody just goes to work saying we just do what we have to do to get through that day. You know you deal with a crisis when it comes up. And [you do] what you can live with, what you can go home and live with.

. . . these are *people* you're dealing with and it's just not a function. (Sara, PH)

The one group that will be negatively affected more than any other is the most vulnerable of the populations, the at-risk or disadvantaged family. Sara questions who will be following these families now that social services has been restructured and downsized and public health nurses no longer have the time to work with at-risk families—who's going to look after them? Priorities are being re-created as new programs such as the early post partum discharge program are gaining in size (effect).

We used to do [visits to high-risk families] when I first started on a weekly basis. Then it went to maybe once in three weeks. Then it went to once in four weeks to once in six weeks. Now they're just a sheet sitting on your desk that you never get to, and the only reason why we were told to put them on high risk is to show that we do have high risk clients that we really can't get to—which is really scary. The only way I would attend to them is if I know that there's a life-threatening concern here. (Sara, PH)

Certain unmandated programs are priorities, such as the well-baby clinic and the new Healthy Beginnings program, but Sara indicates, "No additional funding came with this new program," even though it has just "mushroomed." What Sara is identifying (helping us to see) is that money has been cut from the hospital budgets by discharging new mothers and their infants within 24 hours. The care of those early discharge patients has been

Because this new Healthy Beginnings program is a mandated one, it takes precedence over the at-risk families. One group of vulnerable clients has displaced another group of clients. When public health nurses see that programs tend to favor a particular segment of the population (in this case middle class mothers) over another group (in this case, the at-risk family), confusion and ethical problems arise (Fry, 1994).

The restructuring that has occurred in social services at the same time as the commencement of the Healthy Beginnings program has contributed to a kind of role uncertainty. This role uncertainty can be thought of as a consequence of the resource allocation decisions.

With everything dismantling and coming apart, nobody knows who's doing what any more. (Sara, PH)

Christine (PH) believes that the early discharge program is not in the best interests of all mothers and infants, especially when there are complicating health, and social, or other problems which might impact on the safety of the infant in the home. The brief period that the mother and infant are now in hospital is an inadequate period of time to alert the hospital staff (nurses, physicians, and social workers) to behavior that might signal problems with parenting or mental illness.

*Before*, all these women were seen in the hospital by the social worker and then the baby was apprehended in the hospital before the mother was even discharged from hospital. [If there was a history of IV drug abuse, the social worker automatically saw this woman] and did an assessment as to whether this was a safe place for this infant to go home to. *Now* that's not the case. While there's communication between hospital and public health, there isn't that social services link. It's so much more difficult to apprehend in the community. (Christine)

Early discharge may not be the best way to deal with women who have complicated social and health problems such as IV drug abuse, as it does not

allow for the appropriate assessment in terms of the woman's condition and the safety of the infant:

Because Health and Social Services are restructuring, everything is chaotic at the moment, okay. So in September things weren't as bad as they are in January. Or in January they're not as bad as they are in March. So things have become more and more chaotic. Plus more women are being discharged early from hospital so there's not the chance for an assessment even being done in hospital any more. So they're out in the community already before an assessment has been done. So we're the people that go out and we do basically the job of the nurse in the hospital and the job of the social worker in the hospital, as far as the assessment is concerned [regarding] lifestyle situation. Right. And then when we refer to child welfare, child welfare doesn't have enough people to be able to act on the referrals that they're getting. And so.

(Interviewer: Right. But this is not a new problem though. It's escalated, but it's not a new problem. Is it?)

No. But it's worse. We're seeing more of this type of thing, and we're seeing bad outcomes because of it, and it's frustrating [laughs]. (Christine. PH)

Budget cuts to acute care have had an enormous impact on home care. The cuts to acute care have included the number of beds available for medical investigation, length of hospital stay following surgery, or admission for chronic illness and investigation. The nurses identified that the transition period between the decision to cut beds or shorten stays and the implementation of the decision was too short. Consequently, the home care programs were not up and running when clients that needed care started to be discharged to the community. The lack of planning included funding not being in place, not having sufficient care providers for the number of admissions, and not providing the caregivers with the knowledge to deal with the new client programs. Huge shifts in how patient care is being delivered require time to plan so that safe, competent, and ethical care can be provided. That clearly has not happened.

Lack of planning as to [pause]. I mean there seems to be a decision that yes, home care will take on the mentally ill. Home care will take on the handicapped children as of, I think it's early this year, part of this year we will be doing it. We will take all that on but there isn't the planning that's been put into place to then provide the funding and the resources and the knowledge base for the staff as well. We've received all these mentally ill clients and none of us have a knowledge base to how to care for them in the community. All that bigger picture should have been in place before it's dumped on us.

So it's an ethical issue in terms of are we giving adequate care and have the adequate knowledge to provide the care. (Lillian, HC)

The funding issue seems to be a pivotal point, as staff can not be hired or provided with continuing education if the dollars are not there in the budget.

However, there is also an issue of evaluation of the cuts to health care:

There are ethical questions in the job that we're doing, and I think one of the big things in home care is evaluation. We've got to start doing systematic evaluation of what is going on, and evaluation from all of the stakeholders' points of view, because we are a new program and things are changing so rapidly. (Margaret, HC)

The larger issue seems to be one of government support or lack of it and the timing of the process. The nurses' comments were consistent—that the process was done too rapidly without thought to the ramifications. A more sensible approach would have been to make sure that one program was up and running with adequate levels of funding and staff and then move onto instituting another program. Charlotte said:

Suddenly, there is this great deal of change and an influx of patients because they opened up this short-term intervention. I think that they weren't ready as far as manpower, I mean training [new staff] to the point that they can be independent. So as long as you have a body to go out, that was sufficient.

The closing of hospital beds has impacted on home care in more than one way. Not only have early discharges swelled the number of people receiving complex care in the community, but when home care providers have clients who are very ill and whom they believe ought to undergo a more thorough

investigation than can be provided quickly in the community, the providers are told not to have the person come to emergency as there are no beds available. The changes to admitting policies have also impacted on the community in that only the sickest patients are being admitted.

I see it more and more now. I phone emergency and say "Look you should be seeing [this person]." [And they say] "Well, don't send her. Whatever you do, don't send her, because we have people lined up in the hall way in emergency. She would just have to wait. So whatever you do try not to send her." That is what you get from emergency at the hospital. Can you imagine that? (Charlotte, HC)

**Lack of community alternatives.** Several nurses spoke of the lack of community alternatives for care. There are families who have no choice but to take or keep their ill family member home because an alternate level of care required is not available. These are families who need support in the long term. What do families who have a chronically ill family member or child with medically complex needs do when they need a break? The question of long-term planning with respect to how best to support families to keep their chronically ill or technologically dependent family member in the home was raised. What happens when family circumstances change and the family can no longer care for the ill child or family member? Several nurses spoke of the failure of the system to provide intermediate care alternatives between hospital and home. From a relational perspective, the moral question is one of moral support (how do we support these families) rather than one of moral obligation (what is our moral duty or obligation)?

Charlotte (HC) speaks of the lack of community alternatives and provides the example of an early cardiac discharge program. Home care nurses have guidelines about when to send cardiac clients to emergency for medical attention. However, the guidelines include only physiological concerns; they do not provide for the client's need for emotional support

which may not occur during business hours. Either the nurse or the client feels that there is a need to see a physician for emotional support. The "rules" or guidelines don't allow for a particular client's needs. There is no provision for emotional support and reassurance. Admittedly cardiac clients requiring emotional support may not be appropriately seen in emergency, but whether the concerns are emotional or physical they need to be addressed.

Cardiac patients are now discharged home earlier. In the past they would have had hospital staff available 24 hours per day to deal with their concerns. There was a period spent adjusting to this new health problem and new lifestyle. Patients learned to recognize changes in how they felt and what they could expect of themselves and their bodies. That adjustment period is now spent in the community. What Charlotte identifies is that there are some early discharge programs where the support for client's special needs are not being met in the community (during evenings and weekends) causing increased client stress. There are some concerns about lack of options to emergency on the weekend:

We're seeing community needs and we're seeing hospitals closing the doors on these needs, where before it was never a question.  
(Charlotte, HC)

Lack of community alternatives is also an issue for public health nurses. If the social worker agrees with the public health nurse that apprehension of a child is warranted, the next problem is often where to place the child. There are too few foster homes for the number of children who, in the public health nurses' opinion, need to be apprehended. This lack of foster homes also shows a larger or macro resource allocation issue of lack of community support or lack of community alternative.

So you apprehend them. What do you do with them? Who wants them? Where do you place them? How do you put all of the kids into one home, if that's the ideal situation? I know that's a big thing. Then, you've got to get ready to present this in front of the court. How do you do that? Do you have the information you needed? Are you experienced in going in front of a judge to present your case? Are experienced enough? All those kinds of questions.

It is a lot easier to keep them in the home in terms of the paper work, the headache. (Sara, PH)

We see from this excerpt that community alternatives or resources, or the lack of them, influence the issues that the public health nurse has to deal with. The lack of this kind of alternative, that is safe foster homes that social services can move a child or children to, can have tragic results for the child.

Assuming access to family caregiving. Several of the home care nurses talked about the shift in assumptions about caregiving that have been made recently. The move from hospital to community has assumed that the family will take care of individuals requiring care following early discharge, palliative or chronic care, the elderly mother living alone in her own home, or the ill child. The recent new emphasis on "family values" espoused by decision makers at the macro level has filtered down to the health care providers so that there may be little consultation with the family members about their capability or willingness to take on the care. The family becomes a previously "underused resource" and is now seen as the answer to a resource allocation problem:

I struggle with this because in home care we do very much focus on the client who's admitted to our program. . . . It's becoming clearer to me that we need to assess not only the family relation to the client but the whole family and the impact of the client's illness or whatever, on all the family members who are involved.

Clara (HC) sees the need to involve the family caregiver in the planning:

Half of our assessment is the client, and then for every need that we identify we have to check off [whether] the support person, or persons, is willing and able to meet this need. I would suggest that probably in 99% of the cases we don't ask the caregiver. We make the assumption from what the client tells us whether the caregiver is able to do that.

We need to be clearer about who our client is. It's much broader than the person who is admitted to our program. I mean we have a responsibility to, we should be supporting, supplementing the care that the caregivers are providing, so we need to assess them as well as we do the client.

Assumed access to family caregiving becomes an ethical issue for the nurses when family caregiving is used as a way of dealing with problems of scarce resources. We need to determine the particular circumstances of the family or person who will be the caregiver.

Often financial pressures require that both partners work outside of the home, so that providing care in the home setting may be problematic for some families:

If they have chosen to have mom or dad at home that's one thing, but some of them are being forced to and that's not a comfortable situation either for them or for us. . . . The underlying story is you will be considered a failure if you can't keep mom at home. This is the sense that I'm getting, that people are feeling pressured into doing something that they don't really want to do, but "Well, Mrs Jones down the street did it, so I guess I have to do it as well."

I guess it's again the whole issue of being fair to everybody, and not putting people into a situation that they can't handle. That's going to be so frightening for them that who knows the repercussions down the line. (Lillian, HC)

and

We always try and encourage [caregiving]. I don't know if that's fair either, because it always ends up it's the female person that ends up with that job. It's not fair, I guess. (Florence, HC)

What is the family's responsibility to the ill family member? Noddings (1994) suggested that we ought to ask the client and the family caregiver what they mean to each other as a way of determining how they see their moral obligation to one another. When nothing is known about family



relationships, health care providers ought not to be making assumptions about caregiving. To demand that family members be morally obligated to act as caregivers for their ill relatives, whether child, parent, or partner, means that there ought also to be discussion about the limits of these obligations and how fairness among those obligated is envisioned.

By implying that the caregiving role is "forced" on the family, we understand clearly that the needs of the individual family are not taken into account in the decision making. Once again there is an overlap here, in that this excerpt also shows the theme of the autonomy of the caregiver and the caregiving role being "forced" on the family member by using shame or implying that the caregiver is inadequate in some way (Bartky, 1990; cited in Held, 1993), not a good daughter or wife or mother if there are "problems" with taking the ill family member home. This shame of which Bartky wrote is more than a deeply disempowering feeling of personal inadequacy. It is a reaction to the patriarchal social structures and relations within which women live. Shame is experienced because the woman believes that she has shortcomings and comes to see herself as someone of diminished importance. The lift of an eyebrow by someone in authority can bring forth this feeling of shame. There seems to be little "justice" in this process of distributive justice.

Just as women are "shamed" into taking their ill or elderly relatives home to care for them, parents of ill children are in an untenable position—to hesitate, or worse, to say no when asked if they want their child at home—is to risk being labelled a bad parent, with all of the ramifications entailed by that labelling.

Does the family have the financial resources to be able to commit to the care (supplies, medication, etc.) of this individual? Will the caregiver be

able to continue to contribute to his/her own family life in the same way? Considering the extent of what was being asked, how would the caregiver continue to work outside the home to meet basic financial needs or even be able to care for other family members (such as children)? Is there community support for these families? Several nurses identified this as a women's issue in that it is women who frequently give the care, give up the job, and do the extra work. Excessive burdens are placed on the primary caregiver who in most cases is the woman. As Warren (1989) pointed out, this solution to a moral problem of resource allocation "ignores the interests of women" (p. 74).

I guess the issue that I see also is that the brunt of that care ends up with women. I guess as a woman and recognizing that it's the woman, whether it's the daughter or the daughter-in-law or the [pause], that it's women that are being put to that task again. And that the break down of relationships again that happens because the family constellation that was whole breaks down. It's because the caregivers are so exhausted. So the relationships are [pause]. There isn't an ideal relationship any more because, particularly if it's a daughter-in-law, they are, you know, supposedly to be caring for this father-in-law or mother-in-law and really don't have the bonding perhaps that a daughter might have. But they're having to do it regardless. As I say, I guess it's the issue that women get caught up into again because it's mostly women that do the care providing. (Lillian, HC)

and

It's a women's issue. . . . I think it's coming back to that and do we as a society want to, can we afford to be putting care in the home so that the women can work. . . . Time and time again it is the female partner that gives up her job to look after the [sick family member].

If we're insisting that these [individuals] be looked after in their home, as a society we're going to have to value that. We have to value and put resources into supporting these families. (Margaret, HC)

**Time.** When talking about the issues, the nurses continually made reference to the notion of time. They spoke about time as a precious

resource, that good ethical decision making takes time, and reflective time is needed for dealing with ethical issues.

The fact that the nurses talk about time as a precious resource and not having enough of it is not very surprising. It would be more surprising if they did not talk about time in that way. For example, Charlotte (HC) said:

I do what I can with the time that I have and that's how you work all the time—you are just scratching the surface.

and

Sometimes you go in and one case, one person, takes up the whole morning and then you are completely backed up. . . . Yet what are you going to do with your other clients? I hear this all the time.

In the excerpts above, time is referred to in several different ways.

Charlotte says that time is required to provide "good" care; time is a precious resource and it is difficult to distribute it fairly among her clients and that lack of time is a frequent issue.

Clara (HC) talked about an elderly woman who wanted to stay in her own home. Her daughter, who was her guardian, believed that a lodge or nursing home would be safer. To support the client's choice to remain in her own home takes time: to meet with the mother and the daughter, to hear everyone's thoughts, and to help everyone understand what might be at stake and to determine the context. The notion that good decision making takes time underlies it all.

Well, it just takes time and working with all the family and trying to be [supportive].

It would be much quicker [laughs] for me to phone the daughter and say, "You know, I agree with you. You should make your mother go [move to a lodge]. And just do it. Book a place in the lodge and say, 'mom we're going today.'" But I know and the daughter knows, that the client would really be upset with that and probably wouldn't stay in the lodge. She'd wander away. Would refuse. So it would be a matter of going to court. Within

our mandate, within our mission statement and our guidelines, it does say that we respect that clients may choose to be at risk. (Clara, HC)

As Kathleen (PH) observes:

I think in anyone's life there's so many factors you have to be aware of and take into consideration and mull over, that [ethical issues] are not something that you can come to a decision quickly on.

When working with families, nurses need the time to get to know the individuals involved in the care, to develop trusting relationships, to talk with them, and to understand what is important to them in their lives. It is only when the nurse has taken time to get to know the client as a particular individual that she can work to protect the client's autonomy. It also takes time to get to know the community that the clients live in because, as Florence (HC) suggested:

If you know the politics in a community you can work around a lot of difficult things, [but] it all takes time to learn and understand.

Implied here is that knowing the community participants and forming collaborative relationships takes time, but in the end this knowledge is necessary to be able to advocate for the client. Fostering processes which support thinking and acting collaboratively can take awhile. Lillian (HC) states:

I would love to be able to work as a team more. It's coming with a few people.

Reflective time is required to deal with ethical issues. In order to give important moral decisions the merit that they are due, Helen (PH) noted that

it takes time that is sometimes reflective, quiet, alone time . . . and thinking about and talking about these issues. . . . To think about this far away from everything.

The nurses made clear the need for time and space for ethical reflection when faced with difficult moral questions. In fact, however, although there

is much talk about the importance of ethical practice, time for ethical decision making is seen as a luxury:

I think [time for ethical reflection] is not something that we acknowledge as part of our job as public health nurses. Part of the reason is maybe that there's not always even an acknowledgement that there are ethical issues in public health. Secondly then, [if we do acknowledge] that there are some ethical issues, [we're told to] "just deal with it sort of. And it'll come out as you're working or something."

And that's not always the case. Sometimes you need to sit back and say now what am I really thinking about here. Why am I troubled by this situation? What is it that's troubling and why is it making me feel the way that I am? What do I do about it now? What are the real issues and what are my values under here that are making me feel this way? Is it my values or is it something [else] or are there rules, whether they're ethical rules or legal rules, whatever, that are actually making, that should have an influence on this? But I don't think that we're given that kind of time to think about that. (Helen, PH)

### Summary

Resource allocation issues were evident in stories about daily decisions made about how much care could be provided to each client and when. Concerns were expressed about providing consistent care amid the challenges of large caseloads, the use of casual staff, and major program changes. Commitment to client care was shown in examples of nurses working overtime and without pay and nurses questioning if they had done enough. Troublesome issues were raised about how care becomes fragmented as the number of providers involved with one client/family increases and communication decreases. Fragmentation of care leads to compromised care and confusion of care. Restructuring of the provincial health care system produced the largest impact influencing programs in all sectors of health care.

### The Theme of Autonomy

Autonomy is the third of the three central themes into which the stories/data clustered. Just as with the other two major themes, a relational aspect can be seen in the issues surrounding autonomy.

Recently there has been much controversy about the notion of autonomy (Liaschenko, 1993a). Some of the controversy is captured in the question, Can truly autonomous decisions ever be made? This question acknowledges the fact that health care workers provide information to patients from a different position of knowledge than the patient and, further, that this information is inevitably value laden. The information comes from a health care provider who likely values the system she works in and thus the information is never value free.

Additional controversy surrounding the word *autonomy* comes from the fact that there is no broad agreement in the literature about the definition of autonomy. Instead, there is an extensive range of understandings (Sherwin, 1992). The common definition of autonomy in the bioethics literature was the Kantian one, "rational, individual self-rule" (Sherwin, 1992, p. 256). This notion carries with it the implicit assumptions of independence and isolation. As a result of this controversy, some scholars have chosen to use the word *agency* (Liaschenko, 1993a) in the place of autonomy to talk about decision making. Despite the controversy, I chose to use the word *autonomy* because it was the term used by the nurses.

I have defined autonomy here as the recognition of individuals' "rights" to make their own choices about their lives and what they value. Underlying that definition is how health care providers respect others and thus their choices. It is not enough to say that autonomy is about respect for persons; the relational aspects of autonomy must also be recognized. People are

interdependent, social individuals, and relationships are a large part of who and what we are (Held, 1993). The interdependent nature of decision making means that decision making does not occur separate from those who are important to the decision maker. As Hardwig (1990) correctly stated, "There is no way to detach the lives of patients from the lives of those who are close to them" (p. 5). Depending on the circumstances and significance of the decision making, the people important to the decision maker may include family and friends as well as the nurse and other health care providers. Indeed, all of our choices affect those we are in relationship with just as their choices affect us.

Using the word "rights" may conjure up, for some, a more traditional view of ethics rather than ethics from a relational perspective. But rights do not stand alone. Rights always mean that we are involved with others, although in some cases a more adversarial relationship may be suggested.

The role of the nurse is to assist clients and families in autonomous choice making. In order to do this, the nurse must have some knowledge of them as people, not just clients. The relevant social context within which the decision making is to take place is often available to the community-based nurse. The nurse knows where and how the client lives and often knows who in the client's social world ought to be included in the decision making. The nurse may be aware of who, from the range of family and friends, will have the client's best interests in mind and who might have their own interests at heart. Being in relationship with a client and/or family provides the nurse with the opportunity to assist with autonomous decision making. The nurse can help clients to determine what is important to them and to be clear about what their values are.

### Issues of Autonomy

Four of the nurses spoke of issues of autonomy as being the most common issues in their practice. These were concerns based on confidentiality, informed consent, and of health care providers imposing their values on others. The stated issue of autonomy was more often a problem for home care nurses in this study, perhaps because of the acuity of care that is provided by home care nurses. The timing of this research might have influenced whether issues of autonomy were raised or not raised. The recent expansion of home care programs to include the care of children with complex health needs, combined with the increase in the number of persons referred to home care rather than admitted to hospital and the earlier discharge of acutely ill individuals, served to influence the variety and number of issues of autonomy raised by the home care nurses. The early postpartum discharge program Healthy Beginnings came on stream in public health during the time that the interviews were taking place. Now that the Healthy Beginnings program has been running for some time, there may be more issues of personal autonomy for public health nurses and their clients because early discharge is no longer a matter of choice.

Margaret (HC) used the metaphor of a tree to describe how she sees issues of family autonomy being dealt with in the community. She imposed the example of parental decisions about their children's resuscitation status (resuscitation versus no resuscitation) in the community on the picture of a tree. The visible part of the tree, the leaves and branches, were depicted as the ethical issues that could be seen in the community. In Margaret's case what she saw was the lack of code status as well as the lack of information that parents receive in order to make decisions about code status for their chronically ill children. The part of the tree not visible, the roots, were all



related to deeper societal problems such as lack of community support for care that is centred on the individual and family (family centred care). This metaphor may be quite useful as a way to keep reminding ourselves that although ethical issues may be the visible problem, there are usually underlying social problems at the root, so to speak, of the ethical issues.

Within the theme of autonomy, issues of respecting choice, fostering and supporting choice, informed consent or client and family decision making, balancing the bests, imposing values, dying well, confidentiality, and incompetence were described by the nurses.

### **Respecting Choice**

Respecting choice has to do with whether the health care provider perceives the client and family as passive recipients of health care or active participants in their own health care. The attitude toward client and family choice making influences how and what information is shared with the client and family and whether choice making is encouraged, supported, or even whether the provider sees that information ought to be provided at all.

The word choice implies, first, that the individuals involved *know* that there is a choice to be made; that is, that the options to make a selection from are provided and, second, that those involved will have the *power* to choose. The nurses in this study considered client and family involvement essential in any and all decision making about their health care. In some cases there was even stated agency support for that position. Yet some nurses felt that was not enough. They thought that the agency had to legitimize a philosophy which espouses family-centred care, care that not only involves but is directed by the family. This means that there has to be

support for the care providers to ensure congruence between the agency philosophy and what actually is supported in practice:

We can't pay lip service to, "Oh yes, we'll listen to the families," and then not do anything about it. think it's even worse to pretend that you are involving families and then not. It's even worse than saying you can't be involved in this decision, we're making it. (Margaret, HC)

In practice, operationalizing client and family involvement in decision making is often challenging and may even be beyond the nurse's control. The decision maker may be the physician, supervisor, or another team member who does not see the need for the same level of client and family involvement in decision making.

Margaret (HC) practices from the belief that the "family is the expert in the child's care and is to be making all the decisions." She finds respecting choice a particular challenge ethically in situations where parents withhold treatment or medication from their children. She wonders "where to draw the line." When do you stop calling this respecting family decision making and when do you start calling this potential child abuse? How do you support both the parents' choices and the well being of the child?

Lillian (HC) told of a situation where she struggled with whether to respect the client's choice not to accept additional home care assistance. The woman refusing the care had been diagnosed with AIDS and had become depressed after her husband died of the disease. She had three young children. Lillian asked:

Do you step in and sort of take over for her and say we'll do this for you? How do we protect her as a person and her personhood?

Lillian's ethical concern was not only for the woman, who is almost incapacitated by grief and depression, but for her children and their relationship with her. Also at issue, then, is "Who is the client?"

**No Information: No Choice**

Charlotte (HC) spoke of caring for residents in a lodge (presented in some detail earlier on p. 108), where information about the two types of care available was not being given to patients. The two types of care included: care provided by the lodge nurse, in which case the resident paid for each service provided, or by the home care nurses at no charge to the client. Because many of the lodge residents were unaware of this information, they did not *know* that there was a choice. Clearly at issue was the lack of respect for the client's right to information and so the right to choose. The issue was not whether the elderly person and his/her family knew that there was a charge for each nursing service the lodge nurse provided but whether they knew that nursing services were also available at no direct charge and could be received while the resident was in the lodge.

The perspective of the lodge nurses cannot be called paternalistic, because the basis for calling an act paternalistic is that the best interest of the patient is thought to be served by the action or inaction, in this case, not giving information. In this situation it was the best interests of the lodge, not the client, that were being considered by not giving the information.

**Inadequate Informing: Poor Choice**

Margaret (HC) observed that families often seemed ill prepared to take on the care of a child with technological dependence or chronic illness. In some cases, parents were even ambivalent about taking on this care. Inadequate informing prior to hospital discharge about the "benefits and burdens" of caregiving was of great concern to her. Caregiving can be overwhelming to a family (physically, emotionally, and financially), no matter what the duration. There is also the toll that that caregiving might exact on

the rest of the family. Margaret's questions, although specific to the home care of children with chronic illness, ought to be discussed with any family that is taking home a sick relative. She wonders "whether the family is well enough emotionally or financially to be able to maintain this child at home," and how the family will live with the changes that will occur when the sick child is being cared for in the home. She also had other questions including:

When does the child become too much? When is it too disruptive to have this child at home? Who decides that? How well do we support family decision making?

Several other nurses talked about being in the difficult position of knowing that the family did not have enough information to make a well thought out decision. A natural response on hearing that concern might be that the nurse has an obligation to send the patient and family back to the doctor to get more information or, in some cases, to provide the information herself. For the nurses in this study, the first concern was to protect the relationship between the family and the physician. Each nurse realized that the family, vulnerable due to the gravity of the family member's illness, needed to be confident in their relationship with the physician. That realization, along with knowing that the family also needed her support, meant that questioning of the physician or encouraging the family to question was done very carefully. The nurse did not want to be seen as contradicting the physician. She also did not wish to jeopardize her own relationship with the family or the doctor. She talked carefully about other points of view or other ways of providing care:

Ethical decisions are not up to the physician. I know better than that, but it's so hard when it gets down to practice. I would say that this was a physician-nurse ethical issue influencing the [client and family]; and if you can imagine the family of a [very ill patient], they are going to need to look to somebody for all the answers. Some physicians are very good about really involving

the parents in the decision making, whereas others aren't so good. They say, "Well, this is the way it is and that's all there is to it." (Margaret, HC)

### **How Information Is Provided: Accessing Choice**

Just as not providing information inhibits choice making, how the information is provided influences the choice. Two competing models or perspectives of information giving are evident in Charlotte's (HC) account of an elderly man who refused the care offered by a personal care aide discussed more fully on p. 106. The personal care aide had visited the previous Friday and left the rooming house because the man refused care. The aide did not question the ill man as to why he was refusing care or provide him with more information about what care he could give. This is an example of providing information from the consumerism perspective. The client is provided with information and then makes a choice without assistance from the caregiver (Gadow, 1990b), although in this case the information provided was minimal. Charlotte's perspective can best be described as one of nurturance (Bergum, 1993). The nurturance perspective allows for relationship between the caregiver and client as well as consideration of the client's context. For Charlotte, the big ethical question was whether this man had enough information to make a choice. They needed to talk about what was happening for him and through the talk she might find out why he had refused care. He needed to be helped to make a decision about what care he would accept, given his very weakened state. The longer that Charlotte spent with the elderly man, the more care he allowed her to provide.

### **Fostering and Supporting Choice**

Fostering choice making has to do with helping the client or family to make the choice (or in some cases helping them to recognize that they have choices). Once the family or client choice had been made, the nurse must work to support that choice.

Fostering activity is centred around talking with families to help them to understand that they ought to have a voice in the decision making or that there are other options than the ones that were presented to them. Encouraging families to question physicians was often a very difficult thing to do but, as Margaret (HC) indicates, "The impetus has to come from the nursing staff to allow [for] family decision making." Most families are willing and able to be involved in the decision making process.

Family involvement, if not happening, was seen by the nurses as something to be fostered and encouraged. The challenge became how to encourage the client and/or family to question a physician about alternative treatments or even question the physician's expertise in a special area without destroying the family-physician relationship as well as the relationship between the nurse and the physician. The physician is often placed on a pedestal:

[Parents] do put a lot of trust in their physicians. In most situations, that trust is earned. The physician is not the expert in child care or in parent-child interaction or in education. Yet they may profess to be, and the parents may take the advice of the physician over the advice or the information given to them from an early interventionist. (Margaret, HC)

Supporting family choice has very much to do with knowing the family particulars and context. Taking the family particulars into account may lead the nurse to ask different questions about the choice and the process than the caregiver who is operating from a more distant, less "family

knowledgeable" perspective. The notion of generalizing services to families without taking their wishes and circumstances into account was unthinkable for these front-line nurses. The use of care mapping, such as levels of care, in home care was seen as particularly dangerous in terms of not considering family context as well as eroding family choice making:

Forget that they're a single parent. They have very few social support resources, their child may be more cognitively impaired than we think, there's problems with parent/child interaction, they can't access early intervention services, or they don't know how. Instead we're trying to put them into little boxes. (Margaret, HC)

Team conferences were seen as a way to encourage patient and family decision making, but often clients and families are not invited to team conferences—a concern acknowledged by Lillian (HC):

What right do we have to be talking about their care and they are not involved in it [the team conference] at all [laughs]? That to me is a very major ethical issue. They have a right to be making the decisions.

Lillian's experience with palliative care was positive in that patients were always involved in the team conferences. Margaret's experience with families with ill children was quite different, in that she had "not often been to a team conference where the family's been there." Because team conferences are where the plan of care is discussed and decisions are made, this exclusion of the family was an ethical issue for Margaret.

Several of the home care nurses who were working as respite or casual staff in home care talked about not being included in the team conferences. These team members, because of their particular knowledge of the client and family context, would bring valuable information to the team's discussion, information that may have a great bearing on the decision making.

In some cases the nurses became ethical mediators (Leavitt, 1996). They sought to mediate among the physicians, clients, and families or between the clients and their families such as in the cases of the elderly individuals wanting to remain in their own homes.

Several of the nurses (both public health and home care) had long-term clients, clients that they had visited for years and were very clear about what they wanted or did not want in terms of care. As Florence (HC) said about one client, "I knew him better than most of his kids [did]," indicating that elderly clients often share things with the nurse that they do not share with their own families. One example of an ethical problem was when the elderly individual began to develop symptoms of fluctuating competence, resulting in his/her family wanting placement in a lodge or nursing home. Although the desire for protection is important, the nurse acts as an advocate, knowing the wishes of the elder and believing that he/she can still safely remain in the home with some help. One nurse wondered, "Who knows what's best for these people?"

The thing is if I, as a home care nurse, say this person can be kept out in the community and something terrible happens to this person because they're in the community, how responsible am I to the family member that wants this person wrapped up in cellophane and put into a long-term care facility? (Florence, HC)

Safety is always at the heart of the family concerns, and Florence saw the issue as one of autonomy versus beneficence. But she also said, "You can make the whole world safe by putting them into long term care facilities." The question of accountability in supporting the client's choice, their legal liability in "at-risk" situations or "How responsible am I?" was one that was voiced by several of the nurses. Supporting the client who is cognitively intact was not a problem—it became an issue when signs of cognitive impairment became evident.



### **Informed Consent**

*Informed consent* is used here to talk about explicit consent issues as opposed to treatments for which consent is implied (Veatch, 1995).

Examples of explicit consent issues are code status in the community and courses of chemotherapy treatment as opposed to dressing changes which might be done without explicit consent. The client might indicate consent implicitly to the dressing change by showing the nurse where the supplies are kept.

In some cases, the nurses' ethical issues about family decision making were "influenced" by geographical area and specialty area of practice. Informed consent might be influenced by the physician caring for all of the patients of a practice speciality in a geographic area, such as palliative care or pediatrics, and whose perspective might be considered paternalistic. The physician may believe that he/she knows what is best for the clients and families in his/her care and presents information accordingly.

Informed consent with respect to code status was an equally relevant ethical issue for the elderly and families with young children and infants. Specifically, individuals and families needed more information about the possible outcomes of treatment and/or resuscitation. In situations where the family members were not given enough information about the alternatives and potential outcomes of a resuscitative event on the patient, questions such as Who does the informing of the clients and families? What information are they given? What resources are the family given to make their decisions? and Do the families know that they can change their minds about code status at a later date? were posed.

In Margaret's home care practice, the issue of informed consent with respect to code status is her most troubling issue. Her concern has to do

with the way that the physician presents information about resuscitation to these "very vulnerable" parents. She believes that the way the information is presented is predictive of their decision making. The parents need enough information to make a decision but ought not to be told what they "should do." In some cases, the parents are told, "If you don't do this, this is going to happen."

Parents have no choice because what is "going to happen," as expressed by the physician, is always detrimental to the child. There are always other alternatives as this nurse sees it and perhaps much less certainty about outcome than the physician is willing to discuss. What Margaret is calling attention to is the fact that the parents, in being subjected to what some might call "overbearing persuasion" (Dossetor & Cain, in press), are in fact not giving a valid consent. That being said, what is happening is that the physician is imposing his/her values on the family. Although the physician values life above all else, she/he may have done no exploring of what the parents' values are.

The nurse sees the situation from a relational perspective, believing that there is much to be considered in making this decision of code status. The physician sees the situation from a more impersonal perspective, where the "patient's best interests" have been determined with little knowledge of the family's context or values.

Florence (HC), on the other hand, talked about the potential for abuse of informed consent by nurses. In the home care agency where she works, the client is required to sign a consent before treatment begins. Her worry is that the signed consent will contribute to nurses being less thoughtful about their work and that there will be less teaching and discussion about the treatments. Capron (1974; cited in Davis, 1989) identified the

"encouragement of self scrutiny" (p. 64) as among the important functions of informed consent. Florence wondered whether obtaining informed consent might do just the opposite in the long term. She was worried about the signed consent becoming so familiar that it becomes a taken-for-granted reality. As Dossetor and Cain (in press) cautioned, familiarity should not lead to laziness about observing consent. Because the client has signed the consent, the nurses may "think that because they are a nurse, they might be able to go in there and do what ever they have to do without explaining it" (Florence, HC).

Florence was awed by the trust that her clients have in her and the potential that that presents for abuse. She said of some of her clients, "If I asked them to sign it, they would sign it. They wouldn't even ask me what it was about. They trust me that much." The problem with this level of trust is that it can be exploited and used paternalistically. Childress (1982; cited in Sherwin, 1992) rightly stated that "paternalism presupposes trust" (p. 256). Even if the health care provider knows that the client does not want the treatment or hospitalization, if it is believed to be in the client's best interests the nurse might be "tempted to allow that to happen." This is especially true for situations where the client and/or family is vulnerable by way of severe or chronic illness (or by the fear that accompanies illness). The trust relationship that clients have with nurses and other health care providers necessitates careful honoring of that trust.

### Balancing the Bests

Questions of "whose best interests" were being served become highlighted for community-based nurses, given the visibility of the family context, the environment, and attendant conditions (i.e., diagnosis). For

home care nurses, it may be balancing the interests of the family versus the sick relative; for public health nurses it is often the best interest of the mother versus the best interests of the child or the elderly parent versus the grown children. For home care nurses, the client is vulnerable and in need of complex care; for public health nurses, the client is vulnerable due to age (old or young) or social condition. As Helen (PH) expressed so well, when working with clients in the community "we see the ordinariness of their life." The home setting, being more comfortable, offers a conducive environment for the clients and family to express themselves and behave more naturally than they would in a hospital. The changes to the family household that result when a member of the family is being cared for in the home become apparent. Unhealthy family dynamics or living conditions become visible.

For public health nurses, the situations of "balancing the bests" were evident in cases such as the young woman whose capabilities had been diminished by a brain injury but who wanted to keep her newborn baby. Whose best interests do we consider?

Is this client's autonomy more important than the issue of beneficence for the child? . . . It's my feelings about it, my observations about it, which are also based on, well, some experience . . . also, some rather other complex feelings. I mean don't forget that years of practice are tempered by getting into a personal relationship with her, and I feel sorry for her and compassion for her, as well as saying, no, the more I know her, the more that I know about her diminished capacity. (Helen, PH)

Helen explores the kinds of information she uses to reach a decision: objective knowledge of observation, clinical experience, and subjective knowledge of the young mother's experience gained through relationship with her.

Kathleen (PH), too, asked about drug-abusing young women who want to breast feed their infants:

**"Where do you stand? Do you say to the mother, you are damaging your baby by nursing? Or does the amount of drug in the breast milk, how does it weigh in relation to the nutrients, to all the benefit that the baby is getting out of nursing?"**

When taking an ill family member home, the family has to think about what is best for the family as a whole and what is best for the ill adult or child. How will the family cope with the changes that will take place in the family functioning once a person requiring ongoing care is living in the home? Whose needs does one put first and how does one weigh those needs? Margaret (HC) has had families say to her, "We feel like we are living in a fishbowl. Everyone knows the intricacies of our lives." Part of the frustration that the family is voicing has to do with the regular "invasion" of the home by caregivers and equipment. Compound that problem with a new respite caregiver each night in their home. Commonly, new caregivers introduce themselves using first names only. In hospital, when the caregiver introduces him or herself using a first name only, no problem is posed; but when a person is going to be in the family's home when they are asleep, a whole new set of questions is raised about parents' choice about their child being cared for in their home and the assumptions caregivers make about invading clients' personal space. Families are asked to assume a level of trust about caregivers that wouldn't be assumed about other "guests" in their homes.

### **Imposing Values: Right to Risk**

Physicians and nurses can be equally culpable in not respecting clients' rights to make choices. One explanation for the imposition of one's values on another may be that the health care provider wants to protect the client

despite the fact that the client may be fully aware of the risks taken. This need to protect the client is evident in the following narrative:

It's come to my attention that people are unaware that they are on the wait list for long-term care. The home care nurses put them on the wait list because they feel strongly that the people are at risk and not safe in their homes, so the nurses feel they are doing the right thing by putting the paperwork in place and getting things moving to get them into a long-term care facility. But to me it's so unethical because if the person is cognitively aware and making those choices, then you have to accept them even though it's not what you would want.

It's sort of balancing, informing the client. You have to feel that you have informed the client but at the same time you have to appreciate where they are coming from and accept that they choose to remain in pretty awful situations sometimes, abusive even. (Clara, HC)

Helen (PH) spoke about situations where the provider has "truly different values than" the clients. She gave the example of breast feeding and how public health nurses "really believe in breast feeding" but wonders if that belief results in not supporting the non-breast-feeding woman.

The nurses in the study recognized that it was very easy to impose their values on others given their position as "expert" on health care and that "as a nurse you can make things happen" (Florence, HC). A rhetorical question similar to "Maybe it's my value system I want to impose on them?" (Charlotte, HC) was asked by several nurses. The questioning was most evident when the client did not live in the same middle-class setting as the nurse and when safety was a factor.

Florence (HC) tells of an elderly man whom she visited many years ago, very early on in her home care career. This man lived alone on a farm,

in the most appalling conditions I'd ever seen. But he was happy there. There were no doors, no windows. The animals would wander in and out of the house. He was in severe congestive heart failure and he just wanted to stay at home and die.

After she had examined the man, she telephoned the doctor who talked the elderly man into coming into his office. Florence broke company policy by driving him into the doctor's office in her vehicle,

because I was sure that if I left him there the next person that went there wouldn't find him alive.

The elderly man was admitted to the hospital and died several months later "in the sterile hospital" that he did not want.

I guess the dilemma would have been to leave him until his family would bring him in, but I didn't think that they would. I'd only seen this guy three times, so I didn't have a relationship with him as such. But afterwards I thought about it a lot and I thought you know we couldn't find his glasses. He was upset about that. But I had to get back. There were other people I had to see. I couldn't look for his glasses for hours on end. I don't think he ever did get his glasses. He never did go back to his home, so I think that he would have died [at home if I had left him]. He might have called the ambulance himself had I left him there, but it would have been his choice. This way it was the doctor's and my choice to coerce him into coming to the hospital to die. In hindsight, I think it might not have been the right thing to do.

We can almost feel Florence's angst. The vulnerability of the sick old man is made real by the talk of his being in the "sterile" hospital without his glasses. The nurse was in a situation where she felt that whatever she did was wrong because leaving him to die alone would not have been "right" either. She went on to say that she felt that she imposed her values on him when she phoned the doctor. Her values were shown by the statements that "he needed to get treated" and that "nobody should even live in a place like that, let alone die there by himself." Years of experience and reflection about this man have convinced her that she would not do the same thing again.

This story not only gives a view into the anguish that the nurses felt about some of the ethical situations that occurred for them in practice but it also shows the length of time that some of them reflected on the situations.

Florence's experience with this elderly man occurred about 11 years prior to the interview.

Right-to-risk issues concerning the elderly were important for both home care nurses and public health nurses. The conflict for the nurses was between wanting to protect their clients and respecting the clients' right to make decisions about the amount of risk that they were willing to take to remain in their homes. When clients were fully competent, the issue was a matter of recognizing that they were experts on their own lives, and had the ability to make their own decisions.

I have clients who do live in really slum conditions. But they are competent. They have made decisions on their choice of lifestyle. I believe that they know that there's an alternative to how they're living, because they manage well in the community. They manage their own affairs. They do very well in every other aspect of their life except their living conditions and some of their personal habits. But they're not life threatening. There's no issue of safety there. And in that situation yes, you say fine. You've made a choice and I have to respect that, because you've done it in a knowledgeable way.

And as long as safety is not an issue. I think when safety is an issue then, in my experience anyways, you really have to assess the situation in such detail to make sure that they are aware of all the ramifications of their behaviours. (Kathleen, PH)

A particularly difficult aspect of the right-to-risk issue was that of elder abuse. The nurses, both home care and public health, spoke of abuse that was financial, psychological, and physical. The issue is likely to be one that affects mostly women clients, given the demographics of the elderly population. Married women live longer than their partners and at some point require assistance to remain in their own homes. A family member living outside the home may provide support as needed or the elderly person may be cared for in his/her own home, as in the following case.

Kathleen, a public health nurse, was visiting an 80 year old woman with her health concerns. As the nurse-client relationship developed, the



ethical issues emerged. The woman shared with Kathleen the fact that her 50-year-old alcoholic son, who was living with her, was stealing her pension money as well as physically abusing her. Actual physical abuse was rare; but threats of it were not, especially when he was on one of his frequent drinking binges. As soon as Kathleen became aware of the abuse, she made sure that the son knew her visits were going to be regular and that there were things that she was concerned about. Any prolonged absence by Kathleen spelled trouble.

I went away for a vacation for about 6 weeks and during that time [the elderly woman's son] robbed her, took all her money from her pension cheque. She used to keep the money under her pillow in the bed, so when she was up he went in apparently and took it. When I came back, she told me what had occurred and that he had hit her also. I said this was an issue that we should involve the police, and she said, "No," she didn't want to because of the fear of being more physically abused or being left on her own. I wanted to address the issue with the son, but she really didn't want me to and so at that time I just left it. It was a difficult decision on my part because I thought he should be called on it, especially for the physical abuse—but we just let it go.

The theft was repeated the next time that Kathleen went on vacation, but the woman remained firm in not wanting police involvement. Kathleen, respecting the woman's wishes, did not press the point. She did, however, let the son know that she was aware of the missing money and that she would press charges against him the next time anything happened. Kathleen continued her regular contact with the woman:

No other theft occurred until one time when he phoned me to say that she was very ill. When I went to the house, the woman was quite ill and she had had a stroke. She had been bed-ridden. The son had told me she had been sick for about 5 days. He was giving her one can of Ensure a day. He had taken her down to the hospital to the emergency department where they had said she had a chest infection and gave her some antibiotics. When I saw the woman, there was no way she could swallow any medication. I'm not even sure how she got to swallow one can of Ensure, but she was in a terrible neglected state. As I say, he had been drinking for 5 days and giving her one can of Ensure a day and her money was gone and so we got an ambulance and she ended up

dying in the hospital in the next couple of days. So the dilemma for me is would that 5 days of near starvation and illness at home have been prevented if I had gotten the son barred from the home, or would she have been at greater risk because he was the one who used to buy her groceries for her and actually have daily contact with and give her some support in that respect?

Kathleen continued to reflect on the issue of how to respect a client's choice when there is a great deal of risk attached to the choice yet the client is willing to take the risk. She had a great many unanswered questions about whether at the time of this woman's death she ought to have filed a complaint with the police because of the neglect that she knew had taken place in the days prior to the son's call. Discussion with colleagues and supervisor yielded few answers for Kathleen and this remains a concern for her, especially as policy support on the issue of elder abuse in the community is lacking.

Less common is the issue of being forced to risk. Nurses struggle with respecting choice and right to risk issues, but now that resources are becoming more scarce there is a danger of leaning in the other direction. The danger is of forcing people to take risks and live in situations which would have resulted in institutionalization only months prior. This issue is sure to become more common as the population ages and there are fewer spaces in seniors' facilities. Lillian (HC) spoke of a client and family who were convinced that an elderly man required more assistance and supervision than the daughter and home care could provide in a lodge, and so a nursing home became the choice. However, he did not qualify for admission to a nursing home according to the "number crunch":

He was borderline and he was very at risk to be in the community, and the family and the client knew he was at risk. They didn't want to take that risk, but they were being forced to.

So he was going to go back into a lodge setting. She [the daughter] was part of the care for him. We would be putting in more [home care] supports. The lodge had to put in more help or assist a little more, and she was having to do part of it. She said, "I know it's not going to work. I know my dad will not comply. He will not take the medications he needs in the community, and I can't do it physically. I don't think I can do it." And she wasn't heard, or she was heard but because he didn't qualify by the figures, I'm sorry we can't take your father.

The [admissions] committee said, "But it hasn't been trialled enough in the community to see if all the supports out there can't be there to help him." We don't have enough supports out there. I mean, we can't give him 24-hour coverage. We can't be there at night time, and when he gets mixed up and confused and takes off his oxygen—and he does; he was having to take that risk again because he didn't qualify for the nursing home.

The most recognizable and certainly the most important ethical issue to the family and to Lillian was the fact that the family's choice was not being respected and they were being forced to take risks that until recently they would not have been asked to take.

Also visible is a "woman's issue" in that the woman/daughter is saying that she can not physically provide the care that her father needs in the community, yet this is not acknowledged. The committee of decision makers attaches no significance to the knowledge. The daughter is silenced.

### Dying Well

Several of the home care nurses work with palliative care patients as well as other clients. Fostering and preserving choice in palliative care is very important. Examples of the issues significant to these nurses are ensuring that the patient has a good death, pain management, and how and where the patient dies.

Lillian (HC) spoke of a child with advanced cancer whose parents want him to die at home. The problem was that the pediatrician was not adequately familiar with pain control for children. Lillian had worked in

palliative care for many years, and although pediatrics was not her speciality she knew that there were different options that could be explored:

I'm thinking of a young 6-year-old who is just writhing with pain at home and the mum and dad just pleading and saying, "Isn't there something [that can be done]?" and I said, "Yes, there is." They pleaded with the paediatrician and he admitted the little boy to a hospital with this scenario of saying well, they need to have the child away from them, that those cries of pain are much too much for them. But he said, "There's really nothing more. He's on the optimal amount of medication that he can be on." [I had] to try to convince the family, "There are other options and I would encourage you to ask him to check with [large city]." Actually they became so frustrated that they just yelled at him and said, "If you do not find a solution within the next two hours, we are getting an ambulance and we are taking our child to [city]."

The physician, in fact, did call somebody in [name of city]. But to have to watch families who have had, naturally, a close rapport with their physician and having them [the family] feeling that [the physician] knows everything. . . . It's been tough to work with them [the physicians].

The ethical issues for Lillian were that this child's pain was not managed well and that the physician, by not exploring other pain management options, was not going to honor the family's wish to have the child at home as long as possible. Lillian continued:

I didn't have the very specifics of what needed to happen, but I valued the family's request which was to have the child at home. I valued the importance of having it become a good death and the importance of the relationships with the other children that were in the home, that they needed to not be so frightened of death because of hearing the screams and the cries and the turmoil and the fear that they saw in their parents' eyes.

Clearly Lillian did not want the death of this child to be remembered with horror. The relational component is highly visible in Lillian's talk about the importance of the relationships among the family members, herself, and the doctor.

Florence (HC) was concerned about "dying well" issues in her practice as well. Earlier she talked of the elderly man living alone in a farm house that lacked doors and windows. Her reference to the man dying in the

"sterile hospital" that was so alien to the way that he lived gives us a sense that she does not think that he "died well."

Her questions around dying well also have to do with a patient with bowel cancer who did not die of the disease, per se, but because she was no longer able to take nutrition. Parenteral nutrition was not the answer because it would have meant hospitalization, something the patient did not want. The woman was where she wanted to die, at home. Nevertheless she asked, "Was that the right way to die?"

Lillian (HC) cited an example of a physician who was unable to tell a patient dying of cancer that there was nothing more that medicine could offer in terms of cure. Instead of offering symptom control, the physician offered another course of chemotherapy:

I think it's another case of the physician knows best that the families are not given all the information. They are just given what he deems that they can handle, . . . and the family then doesn't have the whole picture.

The patient and the family, looking for any "ray of hope," consented to the chemo when in fact what was needed was perhaps better pain control:

They can be at home and be cared for by the family and be allowed to die with some dignity instead of going through all the symptoms of the chemo.

Clearly this scenario shows paternalism; but there is also an issue of the patient not being defined as palliative, meaning that issues of dying do not become a priority and thus are not dealt with by the patient or family. The question of what a good death means to this patient and family were not discussed because the client believed that there would be time to deal with that later. Lillian suggests that when the patient and family are told that "there isn't anything further that can be done," the realization that they have limited time together helps them to "move into being able to have a close

kind of relationship for the last days or weeks." In a sense, not sharing the information about the patient's condition combined with the side effects of the chemotherapy serves to rob the patient and the family. They are robbed not only of the opportunity to make choices but also of what is morally important about family relationships (Lindemann Nelson, 1992). They are robbed of the possibility of sharing final intimacies of family life where people who care deeply for one another spend the time that they have left together in meaningful ways.

### Confidentiality

Clients and families disclose information to their care provider that is not generally known to the community. Clients have the right to expect that any information that has been disclosed to their provider will be held in confidence and shared with other members of the team only if it is pertinent to the treatment plan or care being provided. This notion of keeping information about the individual or family private stems from the basic principle of respect for persons.

The nurses in the study spoke about breeches of confidentiality among and between providers; disclosure of information to other family members; the use of confidentiality by other care providers as a source of power, even when another provider's safety may be comprised; and the need for those in positions of authority to be ethically sensitive and to model ethical behavior not only in patient care but also in research activities and in education. The thorny issue of documenting cases for educational purposes using actual experiences was put forward as an example of a breach of patient confidentiality. This nurse was troubled by the fact that despite raising the

concern of client confidentiality, a lack of recognition of its importance when using clients' stories remained.

Several nurses were especially concerned about confidentiality given their respective specialty areas. One public health nurse, who had a speciality area of practice, suggested that confidentiality was a major issue in her practice. Another nurse spoke only in generalities, wanting to safeguard the confidentiality of the small population with whom she works.

Lillian's (HC) experience with an HIV-positive mother highlights a situation that is becoming more common as people with HIV and AIDS are cared for in their homes. This woman required child care while she spent time with her husband who was hospitalized with full-blown AIDS. Lillian, when checking out day cares for this client's baby who's HIV status has not yet been determined, queried day care personnel as to whether universal precautions were used. She did not use identifying names or information when she contacted the daycares, but the woman became angry at her for asking the question about universal precautions for fear that in some way her anonymity would be jeopardized. The woman's fear was that should Lillian find an opening in a day care not using universal precautions, the day care workers would be alerted that there was cause for concern by being told that they needed to follow universal precautions.

This situation resolved itself once a daycare that consistently used universal precautions was located. Throughout this scenario, Lillian was keenly aware of the need to safeguard her relationship with the mother so that she would continue to accept home care's help as her needs increased. This story illustrates not only the issue of keeping information private but also the issue of the individual good versus the common good. Lillian was very concerned that she not put unsuspecting day care workers or others at

risk, even if the possibilities of that risk were "infinitesimal." She struggled with how to deal with this ethical conflict without jeopardizing her relationship with the woman. The concern was that the woman and her family would require home care

down the road, when we will probably be carrying her for some time when she develops full-blown AIDS.

Lillian did not want this experience to influence negatively the woman's use of home care when she would inevitably need it "down the road."

### Incompetence

Both home care and public health nurses told stories of working with clients where competence was an issue. How valid is a signature for treatment from a client whose cognitive status fluctuates? Several ethical situations occur with some regularity with elderly clients whose competence fluctuates as indicated by data obtained and documented on the Alberta Assessment and Placement Instrument (AAPI).

An elderly client wishes to remain in his/her home, but the children fear for their parent's safety and so coerce him/her into signing the consent for placement or sign the consent themselves. Florence found this issue particularly troubling, especially when she had a relationship established with the client prior to the fluctuating competence and was well aware that the individual did not want to go anywhere. How would she support her client's choice?

**Kathleen (PH) asked:**

When the client is starting to decline mentally and their ability to make their own health decisions is slowly declining, where is the cut off? Where is the cut off where [on one side] you respect their wishes and where you say, "No, you don't realize what's going on here and we have to do something against your wishes."



This question of "where is the cut off" is a complex and important one to the nurses. The thought of forcing elderly clients into giving up their homes and all their familiar possessions (the familiar things that give their lives meaning and keep them rooted in the here and now) to move into institutional care was one that deeply concerned them.

#### Summary

These nurses strongly believe that clients and families ought to be making their own decisions about their care and this was evident in their narratives about clients having adequate and appropriate information, free of coercive influence. They struggled with balancing the best interests of family members, protecting clients and respecting their right to make choices that they considered unsafe, and how to help people die well in the community. Issues of client incompetence were most evident when talking about elderly clients; however, stories of clients who had had brain injuries or who were mentally ill also showed issues of incompetence. Stories about the right to keep information private or confidential were varied and included clients' rights to expect confidentiality from all levels of providers, from the personal care attendant to management; as well as the conflicts that might be provoked when working with persons with HIV; and how nurse safety can be compromised when other professionals do not make violent home situations known.

### **Additional Findings**

Additional findings that have emerged from the data will now be presented. These findings are of interest in that they identify factors which influence the ethical issues and tell us more about the ethical issues that the nurses described and the resources they used.

### **Outcomes**

There were both positive and negative outcomes resulting from the ethical issues found in the nurses' practice. The positive outcomes were varied, including a client and children finally being safe, gaining knowledge and confidence so as to be able to handle a similar situation in future, and increased knowledge of other professionals about the skills and research-based practice of home care nurses.

Florence (HC) talked about a situation which had positive ramifications. A woman with cancer was being cared for in her home. The woman's son, a drug abuser whose drug of choice was intravenous morphine, lived with her. The potential ethical issue was how to honor the woman's choice of remaining at home and managing her pain without using a morphine pump. The physician wanted to admit her to hospital as soon as she required IV morphine. Florence convinced him to try complementary forms of pain control (massage, TENS, and oral morphine). This worked so successfully that Florence believes that this physician will be open to using complementary pain medicine again.

Another positive outcome of Mary's (PH) persistence in exploring the ethical perspective of her experience of working with other professionals (e.g., child welfare, p. 77) is the establishment of an ethics committee.

Mary and several colleagues put together a proposal for an ethics committee which is currently being reviewed by the regional health authority.

Some outcomes resulting from lack of cooperation between professionals contributed to tragic results. Sara (PH) considered the infant she spoke about earlier—who at birth was apparently healthy but at the time of the interview had developed cerebral palsy, was blind and deaf, and required feeding by gastrostomy tube—to be an example of a tragic result.

### Situational Constraints

Some of the findings were not examples of ethical issues in themselves but were influences or constraints on how the nurses experienced or dealt with issues. These influences or situational constraints, according to Rodney and Starzomski (1993), can be described as "aspects of the structural and interpersonal work environment that impede the implementation of professional standards of nursing" (p. 24). For instance, several of the nurses made reference to the fact that some supervisors seem to think that ethical issues do not occur in community nursing, suggesting that these supervisors do not recognize problems as ethical or as having an ethical component. Helen (PH) suggested that "there is not always acknowledgment that there are ethical issues in public health" and thus there is no time needed for discussion of issues that don't exist. Sara (PH) found that, when she suggested at meetings that a problem might be an ethical one, she got a reaction that implied that "that's a really scary word for management. . . . It's like it shouldn't be associated with public health. [It's] like how does ethics and Public Health fit?" Margaret (HC) observed that issues that she believes are ethical in nature are called "human resource issues" by management. Clara (HC) stated that "management, people who

are making decisions, are unaware of ethics and clients' rights. They have no appreciation." These excerpts raise the question of how nurses function in an ethical way in an environment that does not recognize that there are ethical issues.

Lillian (HC) suggested that if questions about the ethics of practice are continually devalued, there is a predictable outcome—ethical discussion will be stifled: "You ask a couple of times and you are put down, or you're called the 'shit disturber' all the time. Soon you don't ask any more. You soon don't question."

This finding raises some concern in light of the consistent talk about needing support for ethical decision making. Besides needing supervisory and agency support, the nurses frequently referred to the need to discuss issues with colleagues: "I should have talked with one of my co-workers before I . . ." (Florence, HC). Support was also lacking in the areas of policy, legal recourse, and research. Community policy is largely lacking in areas such as advance directives. A need for legal recourse was cited for those situations where there are safety issues and support is lacking from other professionals. Program evaluation and abuse issues are areas which would benefit from research support. Kathleen (PH) went so far as to suggest that what was needed was wider policy making in the area of ethics. Ethical policy, if it is to be effective, must encompass more than one institution or agency; it must be inter-agency to ensure support:

We may have a fine policy in place, but if the other agencies or government don't support some of the issues around what is abuse, what is neglect, what things our society is going to let go on and what things they are willing to take action on, then our policies are really not as effective as they could be or our program around ethics would not be as complete as it should be. How helpful is it going to be for staff?

Nurses also indicated that they felt vulnerable with respect to job security, rehiring and personal safety. This vulnerability influenced not only their decision making regarding resource allocation but heightened their concern about confidentiality in terms of participation in this research project.

Personal safety was seen as both a situational constraint and an ethical issue in and of itself. Safety was a situational constraint when the nurse was personally unsafe and so removed herself from the home but remained concerned for the client (in most cases a child). Personal safety became an ethical issue when the nurse did not feel supported in her concern for her own safety.

In some of the stories, ethical concerns collided with legal concerns. Examples of those situations included ones where the nurse knew the client wanted to die at home without medical intervention, yet there was no advance directive; there was a request to disclose information about a child to a parent no longer living in the family home; and where clients whose competence fluctuated signed consents. In some cases, the nurses sought legal opinion.

### **Forum for Discussion**

Being a professional means understanding, discussing, and analyzing problems of professional morality (Brown, Kitson, & McKnight, 1992). Thinking about moral concerns means finding ways of putting these concerns into words so that they can be discussed. The nurses felt that they did not presently have, to use Clara's (HC) words, "a forum for discussion" for ethical issues. Discussion of ethics occurs informally with colleagues.

The nurses clearly saw a need for regular meetings dedicated to the discussion of ethics, time set aside at staff meetings where ethical issues can be brought up, or an ethics committee which they may access. At the very least, they wanted recognition that ethics is an important and relevant topic for nurses to discuss on an ongoing basis.

Having a forum to discuss the ethical issues in practice would have several benefits. It would promote more confidence and responsibility in ethical decision making. The nurses see a forum as a place to discuss difficult situations and as a way to increase the moral competence of all involved. More importantly, it would maintain what Urban Walker calls a kind of "reflective space" (p. 33) that the nurses are asking for when they ask for the "forum," a place where moral discussion is acceptable and encouraged, a place where discussion and competence might be facilitated rather than having ethics reduced to a formula or negated. A place for discussion where the term *ethics* can be demystified is needed. An ethics review committee might make moral discussion professionally acceptable and encourage thinking about ethics.

The fact that some of the nurses had stories from 11 years ago in their practice lends credibility to the need for some form of forum. The need to discuss their stories was also evidenced by the nurses thanking me for listening in a nonjudgemental way; some said that they had had few opportunities to talk about their stories. The deliberative or sorting out nature of the story telling supports the need for something less formal than an ethics committee.

### **Powerlessness**

A majority of the nurses spoke of having experienced a sense of being powerless when it came to their role in ethical issues. They said things such as "What can I do when a physician is unwilling to take a course of action which is obvious" (Kathleen, PH). "Sometimes you feel like you're knocking your head against the wall because you see something that needs to be done and you don't have the power to carry it through" (Christine, PH). "I had no influence, no input into the policies that I had to implement. . . ." (Clara, HC). "As a [nurse] you're at the bottom of the bureaucracy" (Margaret, HC). "What are we doing? I have no control in this, even though I screamed, shouted, yelled, jumped up and down don't let this baby go home" (Sara, PH). "I can't do anything about it" (Charlotte, HC). A sense of powerlessness was indicated in such phrases as "what can I do," "I can't do anything," "feelings of impotence," "out of my control," "having no authority," "power imbalance," "not making any impression at all," "she's my supervisor and I'm an employee."

### **Resources**

The nurses were not asked specifically to name the resources they used to assist in dealing with the ethical issues they encountered, although in the process of discussion they mentioned a variety of resources. Most frequently, colleagues acted as resources or sounding boards. Also mentioned were clinical coordinators, supervisors, professional associations such as the Alberta Association of Registered Nurses (AARN), the Canadian Nurses Association (CNA) Code of Ethics, police, and the Alberta Law Society. Several nurses were aware that the AARN has published guidelines for ethical decision making; however, only one nurse stated that she used

this booklet to assist her. Only one nurse mentioned the CNA Code of Ethics as a source of information in ethical decision making.



## **CHAPTER 5**

### **DISCUSSION**

This chapter is divided into five sections. First, brief attention is paid to the topics—lack of ethical issues, practice setting, role issues, and language. Second, the relevant literature is discussed in relation to the findings. Third, the implications of this study for nursing education, practice, and research are dealt with. The limitations of the study are discussed in the fourth section. Finally, a summary and conclusion are presented.

Little thought has been spent upon our ethical culture. . . . There is a mystery surrounding the term "ethics" which causes the average nurse to turn away and wait for another to ask the first questions or to make the first demand. (Riddle, 1903; cited in Levine-Ariff & Groh, 1990, p. 13)

The significance of this quotation is that it was written 93 years ago, yet it remains true today. As the nurses in this study indicate, ethics remains a "scary" and mysterious word for many. Although the study participants show themselves to be ethically sensitive, it seems that they are sometimes in a minority, being more sensitive than colleagues or supervisors.

#### **Lack of Ethical Issues**

The participant selection process raised some puzzling questions. Two nurses called me about the research but denied having ethical issues; another nurse claimed not to be stealing from little old ladies and therefore had no ethical problems. My experience is supported by Davis (1988) and Duncan (1989), both of whom had surprisingly high numbers of nurses responding to their questionnaires who indicated that they had not experienced ethical dilemmas. Five out of 30 of Duncan's respondents

indicated no ethical dilemmas; 9 out of 100 of Davis' respondents said the same thing. Davis offered no explanation for this finding, but Duncan offered several. The first was that one nurse was likely not sensitized to ethical issues in the community as she was new to the practice setting. Her second explanation was that nurses who had been in practice for many years might be unfamiliar with the concept of ethical dilemmas if they had not had recent continuing education or they might see ethical dilemmas as dramatic occurrences as opposed to ones that happened every day. Finally, she suggested that nurses who have been in practice for some time may have become desensitized to the issues.

Duncan's second explanation may fit one caller who had been in practice for some time; but the other two nurses had recently finished post basic BScN degrees through the local university, where an ethics component is contained in the required nursing courses. This could mean a couple of things. One is that the principle-based approach to ethics is difficult to relate to everyday practice because of its focus on dilemmas and crises. The second explanation is that the ethics course work is not grounded in actual clinical situations, again making it harder to relate to practice.

An additional but unlikely explanation is that not recognizing troublesome ethical issues saves the nurse the problem of dealing with them. This does not seem a likely explanation, because I was contacted by the nurse to express interest in the study. Whatever the explanation, these nurses seemed not to have a good understanding of ethical issues and confusion between ethical and legal problems was evident in the one response of having no ethical issues because there was no theft taking place. What this experience points out is that research to identify the factors that raise ethical awareness requires further study.

### **Practice Setting**

Prior to a discussion of the three central themes, a brief mention must be made of the literature which supports the influence that practice setting has on ethical issues in community-based practice. Aroskar (1989), Duncan (1989), Forchuk (1991), and Haddad (1992) all contended that practice location is a substantial factor in community nurses' experience of ethical issues. Additional studies, although not focused on ethics, made reference to the importance of recognizing the autonomy of the client in relation to the home setting. Research by Luker and Chalmers (1990), Stulginski (1993), and Zerwekh (1990) has contributed to the understanding of the many factors involved in gaining access to the client home and "entering into the client situation more fully" (Luker & Chalmers, 1990, p. 75). Among the interrelated factors is the ever-present awareness that the power and control to grant entrance rests with the client and that the nurse is an invited guest in the home. Behaving like a guest serves two purposes: to reinforce the client's role as decision maker and to build trust necessary to the nurse-client relationship (Zerwekh, 1991). Stulginski added that this differing power and control is one of the greatest adjustments that a nurse must make when working in the community.

Various studies commented on the additional influences of community practice setting. Studies by Stulginski (1993) and Zerwekh (1990) supported the notion that family dynamics are more visible when working in the community. Several investigators spoke of the sense of isolation that can accompany nurses working in the clients' homes (Haddad, 1993; Stulginski, 1993). Liaschenko (1993a) explained that a client's home or "personal geography can show you their life" (p. 149). Robillard et al. (1989) cited geographical influences on access to medical and nursing care,

which I interpreted as being a more traditional view of geography entailing distance from services. Liaschenko, in talking of "social space" having an influencing effect on access to health care, highlighted how poverty and thus where the client lives dictate the kind of health care received.

Discussion of nurses' concern for their image was not found in any of the research reviewed, although role issues for public health nurses were very evident in the literature.

### **Role Issues**

Some of the nurses in this study experienced conflict and uncertainty with respect to their roles when confronted with ethical questions. This role questioning was more apparent for public health nurses than for home care nurses. Feldman, Olberding, Shortridge, Toole, and Zappin (1993) determined from their study with public health nurses acting as case managers for home care clients that there is "role conflict and blurring of responsibilities between public health nurses and social workers" (p. 36). They concluded that in the absence of role clarity, public health nurses have tended to take on many of the responsibilities and duties of social workers, especially in the areas of child protection. Their suggestion of the essential need for role clarification for public health nurses relative to other members of the health care team is supportive of the findings of this study. Erickson (1987) suggested that fragmented delivery of services and role confusion have contributed to the undervaluing and the frequent invisibility of the role of the public health nurse. Some have suggested that lack of role definition has resulted in underfunding of public health (Duncan, 1989; Zerwekh, 1992).

The public health nurses interviewed for a study conducted by Reutter and Ford (1996) stated that public health nursing is not well understood by either the general public or other professionals, including other nurses. This is due in part to the difficulty in understanding the generalist public health nurse's role, as well as to other factors.

Although the expert home care nurses in Stulginski's (1993) qualitative research evidenced a clarity of roles, role confusion in public health has been attributed to the question of who is the client—community or individual (Zerwekh, 1990); to intense change being experienced in the health care system and community nursing (Duncan, 1989); and as a cause of decreased job satisfaction and increased stress (Stewart & Arklie, 1994). Clarke et al. (1993), in their initial work on conceptual framework development for public health nursing, identified the urgent need for direction in regard to the changing role of the public health nurse.

Giovinco (1979) saw role definition as one of the most pressing problems in nursing today, attributing role ambiguity to a lack of definition of the constituents of nursing specialties such as public health nursing. It was her contention that the way that roles are defined determines the nurse-client relationship.

### **Language**

That the nurse participants in this study did not use the language of biomedical ethical principles is not a new finding. Chubon (1994) noted that nurses did not use the language of ethics and believed that this meant that they did not recognize ethical issues in their practice. She commented that they needed to learn the language of ethics to be able to reframe the difficult situations in practice as dilemmas. Liaschenko (1993a) found that nurses do

not use either language of care or principles. Viens (1993), on the other hand, found that nurse practitioners used language more indicative of the ethics of care than of principles. The nurse practitioners in Viens' study did not "relate to bioethics or rule and principle ethics in any way, except to mention that it was content that they'd had in the past" (p. 13).

### Ethical Perspective

Many of the research studies aimed at identifying ethical issues in practice did not state the ethical perspective from which the investigators viewed the findings (e.g., Andrews, 1988; Berger et al., 1991; Haddad, 1992; Omery et al., 1995; Robillard et al., 1989). Not known, then, is whether the researchers' perspective was limited to knowledge of bioethical theory (rule-oriented ethics or the justice perspective) or whether the researchers had a broader knowledge of ethics, one that included relational ethics or feminist ethics. The reason that it is important to be aware of the investigators' orientation is that ethical orientation influences which features of a situation are given attention and which are not (Oberle, 1995) and thus what might be considered to constitute an ethical issue. Holly (1993), Liaschenko (1993a), Millette (1994), and Viens (1993), for instance, viewed their findings from a perspective wider than the traditional principle-based orientation. Their perspectives included either the relational ethic of care or feminist ethics. Only one study with the *single* purpose of identifying ethical *issues* in a specific area of nursing practice had a stated perspective wider than the traditional justice perspective (Holly, 1993). Further, no other study with the same purpose identified the theme of relationship as being central to the data. Some investigators stressed the importance of relationship to the work of nursing (Aroskar, 1989; Duncan, 1992; Ersek

et al., 1995; Viens, 1993), but only one saw it thematically (Liaschenko, 1993a); this research was philosophical in nature and had not set out to identify ethical issues in practice. That is not to say that some of the issues identified and described in these other studies did not reflect issues of relationship; it is to say that although the themes of autonomy and resource allocation were stated and easily located in all studies, no other study besides the present one stated a theme of relationship.

From the perspective of relational ethics, the relationship between the health care provider and the client assumes primary importance. Gilligan (1982) first identified an alternative approach to ethics in her landmark book *In a Different Voice*. Her research challenged Kohlberg's (1958, 1981; cited in Gilligan, 1982) theory of moral development, which is built on longitudinal research conducted exclusively on male children. Kohlberg's stages of moral development were based on a Kantian model of moral agency (Cooper, 1990). From this model, ethical decision making is guided by rules and principles and individual autonomy is prized. Gilligan's research, which included adolescents of both genders, showed an alternate set of moral concerns that centred on responsiveness to others, preventing harm, and maintaining relationships (Kittay & Meyers, 1987; Sherwin, 1992). Gilligan's female participants spoke not of hierarchical ordering of rules and principles, but of "a network of connections, a web of relationships that is sustained by the process of communication" (Gilligan, 1982, p. 33). Importance was placed on the particularities of the individual and the situation as well as context, connection, and recognizing competing needs and corresponding responsibilities (Cooper, 1990). Gilligan contended that "theorizing connection as primary and fundamental in human life directs attention to a growing body of evidence that cannot be incorporated within

the old paradigm" (1995, p. 123). For Gilligan, considerations of relationship, emotions, and particularity became moral ones, unlike for Kant (cited in Sherwin, 1992), who disallowed these responses from the moral domain. As Held (1993) pointed out:

Most moral theory has hardly noticed as morally significant the intermediate realm of family relations and relations of friendship, of group ties and neighborhood concerns. . . . Standard ethics has ignored the moral aspects of concern and sympathy that people actually feel for one another and what moral experience in this intermediate realm means for an adequate morality. (p. 57)

A feminist ethic, like traditional principle-based ethics, is characterized by variety and disagreement (Jagger, 1991). Some feminists accept Gilligan's (1982) ethic of care, whereas others do not. However, most agree that a feminist ethic recognizes that women's moral experience and practice are worthy of respect and that subordination of women is morally wrong. Further, it also recognizes and questions the social structures which have served to oppress women and other groups, viewing all forms of oppression as immoral (James, 1995; Liaschenko, 1993b; Sherwin, 1992).

Principle-based ethics have been viewed primarily as an ethic of crisis and quandary (Cooper, 1989a; Liaschenko, 1993a) that relies on objective rules and principles to guide decision making. Viewing health care practice from this ethic narrows or limits what might be considered an ethical issue (Liaschenko, 1993a) and ignores the variety of ethical problems which are either unique to nursing or are modified by it (Omery, 1985; cited in Cooper, 1989a). This ethic of crises and dilemma may not seem to have much relevance to everyday nursing practice. As Levine (1977), Robillard et al. (1989), and Vlens (1993) noted, it is the everyday practice encounters with others that hold moral significance. When the relational concerns that inform nursing moral judgments are not acknowledged as moral, this leads to



issues being identified as communication problems, human resources or personnel problems rather than ethical ones (Cooper, 1989a). For instance, studies by Aroskar (1989) and Forchuk (1991) described either ethical problems that did not fit traditional ethical principled analysis or problems put forth by nurses where no principles could be identified. The data were being analyzed from a principle perspective which might account for the difficulty in categorizing the problems. Aroskar outlined her data using four categories, three of which are principles or conflicts in principles and the fourth "the significant ethical concerns." One of the examples that she provided as not fitting traditional ethical principles, and therefore falling under the category of other significant ethical concerns, was "how we behave toward each other" (p. 973), which is clearly relational in nature. A wider view of ethics, a relational view, does not relegate issues of human interaction to a kind of catch-all category but rather views relationship as central to morality.

The purpose of this explanation of ethical orientations is to highlight the fact that depending on the investigators' approach to ethics, what is seen to be an ethical problem may vary. This orientation will influence the construction of the data collection instrument (or even whether an instrument is used to collect the data) and then how the data is finally analyzed.

The nurses in this study saw that there were ethical implications to much of what they were doing—in other words they identified ethical issues from a much wider perspective. Not only did the moral questions come out of relationship but, as one nurse put it:

If you are looking for ethical answers by going to principle based ethics, you are not going to find them there. . . . It's only through the use of feminine ethics and contextual ethics that you can really find your answers. (Helen, PHN)

### Discussion of Findings and Relevant Literature

The three central themes that emerged from the data will now be discussed relative to the relevant nursing research literature. Those studies dealing exclusively with community-based nurses will be discussed first, followed by studies where public health and/or home care nurses have been included in the sample. Finally, I include a discussion of several studies seeking to identify ethical issues in other settings. Because the theme of relationship is unique to this investigation, the findings will also be discussed by theme in order to show the links between this and other research.

Aroskar (1989) reported the results of the first descriptive research focusing solely on ethical *problems* experienced by community-based nurses (public health and home care). The *problems* that she has identified were similar to those in this study, but the categorization she has chosen differs from this study's themes; for instance, she addressed the significance of trust and relationship to the work of nursing in the "truth-telling" category. As in my study, issues of distributive justice or resource allocation were most frequently encountered. Aroskar talked about "creative charting" to meet short-term goals, just as the nurses in this study talked about overtime and unpaid volunteering as having long-term consequences of supporting a system that leaves clients' nursing care needs unmet. Many of the randomly chosen examples Aroskar presented under the principle categories are similar to the findings of this study, such as deciding what to do about a client who is physically deteriorating but still mentally capable of refusing

help, patients who are not fully informed about their health status, rights of patients to make their own decisions about living and dying and refusing treatment, and negligence of a child with not enough evidence to do anything about it.

Several of the nurses' stories Chubon (1994) used to illustrate the categories of *dilemmas* clearly show relational aspects such as issues emerging out of the relationship between the nurse and client, although this aspect was not discussed.

Many of the stories and issues found in the present study are similar to Duncan's (1989, 1992) but were captured differently, perhaps in part due to the complexity of the issues and situations. For example, both the current study and Duncan's include discussions of issues of safety risks for the frail elderly and high-risk parenting. Duncan also found *dilemmas* related to lack of community resources and collegial relations.

Viens' (1993) research on nurse practitioners' moral reasoning also sought to define the moral *dilemmas* experienced in their practice. Most of the nurse practitioners' dilemmas in her study were around issues of advocacy and patient safety. Viens and Liaschenko (1993a) were the only two researchers to speak of issues of advocacy as ethical or, in the words of Fowler (1989b) as a "morally based concept" (p. 97). Viens' study was also one of the few studies that acknowledged the inherent power that the nurse has in the nurse-patient relationship.

The most striking similarities between the study by Robillard et al. (1989) and this current study are issues of relational aspects and resource allocation. Among the 12 most frequent issues encountered by Robillard's primary care providers was the relational issue of professionals treating patients disrespectfully and the resource allocation issues of time for patient

care, lack of service continuity, and lack of patient funds (which contributes to a host of problems including noncompliance, reduction in quality of care and not receiving referrals).

The purpose of Liaschenko's (1993a) research, "to provide an account of an actual morality of nursing" (p. 3), was more philosophical in nature while identifying ethical *concerns* of the two practice groups examined. She synthesized her data in a unique way suggestive of a theory of nursing ethics and philosophy of nursing practice. Nevertheless, the three themes central to her findings—having a life, advocacy, and relationship—are remarkably similar to those in this current work. Liaschenko was also clear in saying that these themes overlap and are not mutually exclusive. Having a life, a theme broader than but including patient agency, bears some similarity to this study's theme of autonomy. The moral aim of the 19 nurses (10 home care and 9 psychiatric nurses) in Liaschenko's study was to help the patients "have a life." Her theme of relationship between the nurse and the patient was revealed as the "vehicle for the work of nursing" (p. 222) and not an end in itself. This relationship requires time and knowing the patient. Liaschenko's third theme of advocacy, another kind of work, is the work of speaking for patients. Resource allocation issues were not raised in this study.

Haddad (1992) found, as did Forchuk (1991), that the "multifaceted nature of the cases" (p. 48) about which respondents wrote made it difficult to choose which of the ethical issues identified took priority. Haddad's categories of findings (difficulty with regulations, incompetence of co-workers, and others) bear no resemblance to the themes identified in my research—although some of the problems she identified within these categories resonated with findings of elder abuse, questions of client

competence, and most notably the role of two agencies providing care to the same client.

Holly's (1993) research explored the ethical *quandaries* of acute care nurses. She identified categories of exploitation, exclusion, and anguish which are vaguely similar to the themes in the present study. Exploitation, similar to the theme of relationship, occurred when the particularity of the individual was not considered. Exclusion parallels the theme of autonomy (or lack of it), because patient choice is disregarded. Holly's third category, anguish, refers to the personal feelings of the nurses who "felt powerless to assist patients or to practice in a fully professional manner" (p. 113). Feelings of powerlessness and frustration resulting from lack of time to provide adequate care, lack of supervisory support, hierarchical forces, and concern for personal safety led to anguish. Similar subthemes are evident in the current study under relationship and resource allocation. Notably absent in Holly's work were explicit references to interprofessional conflict.

### The Theme of Relationship

The nurses in this study tended to interpret their ethical responsibilities in terms of their relationship with others, and thus their ethical issues came out of that interpretation. Studies exploring nurses' moral reasoning have now begun to consider Gilligan's (1982) theory of moral development as an alternate framework to Kohlberg's (1958, 1981; cited in Gilligan) theory, which has historically been used (Millette, 1994; Nokes, 1989; Oberle, 1995; Parker, 1990; Viens, 1993). Only one other study exclusively seeking to identify ethical issues facing nurses explicitly considered ethical issues from a relational perspective (Holly, 1993). However, much of the research reviewed cited issues that are relational in nature, such as issues of

advocacy, abuse, collaboration, and support. Even though these issues were not stated as relational, they have been considered supportive of the present findings. For example, Allen (1974), in the first Canadian study seeking to identify the ethical *problems* facing nurses, identified conflict between knowing what to do and doing it as one of three kinds of ethical problems that nurses encounter in practice. She included within that theme conflicts of what to do about abusive relationships involving children and the elderly. From the perspective of this present study, the conflicts that she presented were relational in nature.

#### **Trust, Advocacy, and the Place of Rules**

Under the theme of relationship, no study specifically addressed issues of trust, although Duncan (1989) frequently referred to the value that nurses place in establishing trusting relationships with their clients. Forchuk (1991) and Aroskar (1989) both found problems with truth telling. Aroskar observed that critical to establishing relationships is honesty or truth telling. Without truthfulness in communication, a lack of trust ensues and relationship is damaged. Viens (1993) found that most of the issues encountered by the nurse practitioners in her study were around issues of advocacy, although specifics of the issues or examples were not provided. Liaschenko (1993a) found advocacy to be part of the work of nurses, which she looked at through the language of testimony. Advocacy was possible only through knowing the client as a person.

The research literature did not address the conflict between rules and relationship with the client and family, nor did it address issues of preserving relationship in these terms. However, Duncan (1989, 1992) reported on

nurses acting from their own professional/personal values rather than the rules of the organization and, as in this research, risking their jobs to do so.

### Collaboration

Fry (1994) revealed that the earliest research in nursing ethics consisting of content analysis of nurses' diaries occurred in 1935, and the biggest ethical problem cited was conflict between physicians and nurses. Ethical conflicts related to interprofessional collaboration, usually between nurse and physician or nurse and social worker, have continued to be reported as common (Aroskar, 1989; Chubon, 1994; Duncan, 1992; Erlen & Frost, 1991; Forchuk, 1991; Holly, 1993; Miya et al., 1995). Field (1988) argued that community care is multidisciplinary rather than interdisciplinary, leading to lack of communication and fragmented care. Like the nurses in my study, she suggested face-to-face communication among nurses, social workers, and physicians as one method to deal with the problem.

Liaschenko (1993a) used the word *competence* when she discussed how nurses' input is discounted by other professionals, thus leading to a lack of collaboration. Competence for her was concerned with "questions of what counts as reliable evidence and who is competent to give it" (p. 260). She held that nurses collect evidence but then are not allowed to act on it, having no authority.

Several recent studies, including one by a group of physicians (Gramelspacher, Howell, & Young, 1986) supported the claim that nurses view relational conflicts as ethical (Grundstein-Amado, 1992; Uden, Norberg, Lindseth, & Marhaug, 1992). Pike (1991) reported that in a supportive environment collaboration can occur between nurses and other care providers.

Storch and Griener (1992) suggested that the attitude of some physicians is that they "own" the client, and as owners are then responsible for making decisions about the treatment and care. This attitude was supported by the fact that there is generally only one physician attending the client. If a referral is made, the client remains the "property" of the referring physician. A discussion of how this attitude objectifies the client is beyond the scope of this work. If that perspective of "ownership" holds true for many physicians, it might provide a clue as to some of the reluctance to collaborate with other team members. Somewhat in support of that theory was the suggestion by Gramelspacher et al. (1986) that physicians do not see themselves as accountable to other health care team members or the family. I suggest that a similar perspective may be held by some social services providers who also have case loads of clients for whom they are solely responsible. This client perspective may be very different than the one held by nurses, where even in the community there is frequently more than one nurse providing care to a client and family.

### Support as Relationship

Several studies, although not looking at ethical issues specifically, discussed perceived lack of supervisory support for community-based nurses. Stewart and Arklie (1994) identified sources of stress for community nurses as including a lack of value placed on their work, perceived lack of support from supervisors, heavy workload, and conflict with other service providers. Although they did not identify these issues as ethical in nature, the similarity between their findings and what the nurses in this study identified as sources of ethical issues is striking. Traynor's (1994) work strongly reflected many of these findings as well. The



community nurses in his research described themselves as "strongly oriented towards delivering personal care" and made comments about management being out of touch with reality (p. 102). They believed that the best interests of the patient are not the central focus of administration. Relationship with the patient gave validity and meaning to their work, yet the nurses felt that management lacked understanding of the amount of work being accomplished as well as its complexity. They believed their work to be undervalued and misunderstood. Traynor's findings also show the nurses expressing feelings of powerlessness both in their written responses and during the many meetings he attended as an observer. This powerlessness is in response to budgetary restraints and values espoused by government and managers. Millette's (1994) examination of nurses' moral decision-making processes found lack of confidence and trust in nursing supervisors to be a common theme. The nurses in her study felt betrayed and even abandoned by their supervisors. Holly (1993) suggested that lack of supervisory support or poorly defined mechanisms of support set up barriers to ethical practice. In her discussion of resources used by the nurses in the study, Aroskar (1989) noted that over one half of the respondents indicated a lack of administrative support for working toward the goal of enhancing or maintaining quality of client care.

### **Abusive Relationships**

Issues of abusive relationships were reported in the research as early as 1974 (Allen, 1974). Young, Pignatello, and Taylor (1988; cited in Haddad, 1992) reported situations of client neglect or abuse as one of the four key ethical concerns in home care of the elderly. Haddad (1992) also reported elder abuse among the ethical problems identified by her study. Issues of

elder abuse have become the focus of research over the past decade (Clark-Daniels et al., 1990; Gilbert, 1986; Saveman, Hallberg, & Norberg, 1993; Saveman, Norberg, & Hallberg, 1992). For instance, Saveman et al. (1992) interviewed 23 Swedish district nurses to discover how elder abuse was handled and found that nurses experienced overwhelming feelings of powerlessness in dealing with these conflicts. These authors recommended that not only do district nurses require education and support, but they also require counselling when dealing with an abusive family. Despite mandatory reporting in the majority of the United States, clear guidelines of what constitutes abuse are lacking; and there is a belief that when abuse is reported, it is poorly handled (Clark-Daniels et al., 1990; Gilbert, 1986).

Similar to the issue of elder abuse, the guidelines of what constitutes child abuse continue to be open to interpretation. Andrews (1988) noted that issues of child abuse are among the 10 most frequently experienced ethical dilemmas community nurses face. Omery et al. (1995) ranked child abuse/neglect as number 27. That low ranking might be explained because child neglect and abuse may be recognized more frequently in the community than in acute care, and in acute care, the nurse may not take sole responsibility for reporting. Duncan (1989, 1992), Taylor and Tilley (1989), and Zerwekh (1990) all addressed the difficulty that community nurses have in deciding when and whether to notify authorities about suspicions that child safety is at risk. Consistent with this present study were the concerns of damaging the working relationship with the family and the corresponding long-term consequences of diminished access to the family home.

Taylor and Tilley (1989) also commented on the frustration felt by the health visitors as a result of their lack of power and influence. Their referrals, skills, and opinions were not valued by other professionals.

### **The Theme of Resource Allocation**

It appears that despite the call to spend less on health care—and at the same time shifting financial support to community care, health promotion, and disease prevention—available health care dollars continue to be spent on the "heroic and costly measures" (Gillis, 1992, p. 21) of acute care and cure rather than in the area of health promotion and disease prevention. The demand for home care and public health programming costs continues to exceed funding, but acute care issues are the ones consistently making the headlines.

The initial research looking to identify ethical issues did not report resource allocation as a major ethical concern issue (Allen, 1974; Davis, 1981; Nursing Ethics, 1974). Issues of resource allocation were not discussed by either Allen or the *Nursing '74* study and were rated as occurring infrequently by Davis. However, as health care resources diminish, questions of "just" allocation of resources are now receiving the attention that they deserve, and justice may no longer be regarded as the "poor cousin" (Hoffmaster, 1995, p. 2) of the ethical principles.

### **Micro Issues**

**Who gets what when.** Several more recent studies which included community-based nurses in the sample cited resource allocation issues as being among the most frequently encountered (Andrews, 1988; Robillard et al., 1989). In both studies, at least one half of the most frequently

encountered issues were of a resource allocation nature. For instance, Robillard et al. gave this as one of their most frequently occurring issues—quality of care reduced by lack of patient funds. Other findings supportive of this current investigation included the resource allocation issues of time, access to health care, and quality of health care (Viens, 1993). Studies seeking to identify ethical issues in acute care also found resource allocation issues to be prominent (Berger et al., 1991; Omery et al., 1995; Rodney, 1994b).

None of the research reviewed showed similarities on the subtheme coordination between hospital and home. Similarities might be expected in the case of Forchuk's (1991) work with mental health nurses, given the frequent hospitalization of many patients with mental illness.

**Fragmentation of care.** With respect to fragmentation of care, as mentioned previously, Haddad's (1992) study revealed a similar story to the one of the lodge nurses and home care nurses both delivering care to the same group of clients. Robillard et al. (1989) found "lack of service continuity compromising care" to be among the top 12 most frequently occurring issues (p. 12). Because the investigators did not elaborate on this particular finding, it is difficult to know whether to interpret it as supporting either fragmentation of care or consistency of care subthemes in this study. Fragmentation of care was a subtheme reported in Liaschenko's (1993a) work. She defined *fragmentation* as preventing "the smooth movement of the patient and/or resources" (p. 154; as opposed to care being provided by many different agencies and levels of care provider). The examples provided were more about conflicts between client needs and institutional requirements than conflicts that occur between agencies; however, the results were similar in that the client did not receive the needed care.

**When does commitment end?** Stulginski (1993) spoke to the difficulty that community nurses have when they know that clients have no one else, no other option for care, and how that might lead to visiting or phoning the client on personal unpaid time. Among the 10 most frequently encountered ethical problems by nurses working in the community was the problem of deciding whether to work overtime when exhausted (Andrews, 1988). Overtime and volunteering unpaid time were issues raised by the nurses in this study but were not among the most frequently encountered. In fact, one participant observed that by the time of the second interview (February 1995), overtime had become less of an issue.

### **Macro Issues**

**Restructuring: Changes to community care.** Rodney (1994a, 1994b) spoke of resource allocation decisions made in one sector of health care impacting on other areas of the system. Like Rodney, we found that resource allocation decisions made in one area of health care delivery (such as acute care) directly and rapidly influenced resource allocation decisions in community care. In the current study, the issue was identified by 6 of the 10 community nurses (4 home care and 2 public health nurses). This issue of change in one sector impacting another area was expected to be prevalent in the literature but was surprisingly absent.

The conflict of having to decrease service to high-risk families in favor of programs to benefit another group or population was expressed by the nurse administrators in Duncan's (1989) study. Many questions and feelings accompanied the administration of these decisions, with which the administrators and staff nurses were not always in agreement.

Ersek et al.'s (1995) topic of health care reform and downsizing (with subtopics compromising patient care and professional integrity, use of unlicensed assistive personnel, and ethics of political decision making related to healthcare issues) also reflected the findings in this research. No other report captured the resource allocation issue of health care reform as closely to this study as theirs did.

**Lack of community alternatives.** Intuitively, one might expect that the studies by Chubon (1994) and Forchuk (1991), because of their focus on AIDS and mental health respectively, would identify lack of community alternatives as issues—but that was not the case. In fact, Forchuk did not find issues of resource allocation in any of the settings she examined. That might be explained by the timing of her research, just prior to health care cost containment coming to the forefront in Canada. On the other hand, Aroskar (1989) did find problems of lack of community resources which might be linked to alternatives in care in the community.

**Assuming access to family caregiving.** Society's expectations that women will be unpaid caregivers of ill family members was not a new concept in the literature (Brakman, 1994; Dossetor & MacDonald, 1994; Kristjanson & Chalmers, 1991; Stulginski, 1993), but there was limited attention paid to the ethics of assuming access to caregiving. Moreover, none of the research aimed at identification of ethical issues in practice cited this as an ethical issue.

Rutman (1996), a social worker from British Columbia, investigated women caregivers' (paid and unpaid) experiences of powerlessness and powerfulness and found similar patterns between the paid and unpaid caregivers. Two out of the three of her emergent patterns were clearly seen in this current research of paid caregivers: lack of recognition or respect for

caregiver's competence and expertise by other providers (often compromising care), and the needs of the receiver of care not being primary in an under-resourced and overly bureaucratic system. The paid caregivers in Rutman's study also expressed concern over legal liability in "at risk" situations, as did nurses in the current study when trying to support client autonomy. Rutman makes the observation that underresourcing of caregiving in the community reinforces the limited value that society assigns to not only caregiving work but those who perform it.

**Time.** Several investigators discussed time explicitly, although not always as a resource allocation concern. One of Aroskar's (1989) randomly chosen examples under the category of resource allocation was the problem of not having enough time to deal with patient concerns in a timely fashion. Similarly Viens (1993) and Holly (1993) both spoke of not enough time to meet patients' needs. Viens (1993) noted the nurse practitioners carried over to their expanded role an appreciation for the significance of the nurse-patient relationship, recognizing that the success to therapeutic interventions was determined by this relationship. According to these nurses, time was a factor in how meaningful the nurse-patient relationship became. Robillard et al. (1989) found that spending the appropriate amount of time with each patient was the most frequent issue encountered by providers of primary care. Reutter and Ford (1996), in examining public health nurses' perceptions, found their greatest stressor to be insufficient time for planning, developing client relationships, and reflection.

In the context of finite resources and thus limited time for quality patient care, it is somewhat puzzling that other studies did not indicate larger and more frequent resource allocation findings.

### **The Theme of Autonomy**

Aroskar (1989) noted that community nurses identified several of their most significant conflicts in relation to autonomy. The largest category of responses in Duncan's (1989) study involved ethical dilemmas involving client's rights (made up of high-risk parenting, adolescents, and mental health issues). Violating patient autonomy was tied in rank with dilemmas of confidentiality in the study by Davis (1981). Forchuk (1991) revealed that autonomy was the third most frequent issue for public health nurses but did not elaborate on how the issue displayed itself. Disregard for patient choice was how Holly's (1993) category of exclusion was defined. Patient choice to accept or refuse treatment or even to have his/her wishes respected or acknowledged was disregarded.

### **Respecting Choice**

An attempt has been made to discuss the findings of other investigators under the same subthemes as this study employed, but there is much overlap between, for example, lack of information for informed consent and lack of information about treatments and health status.

**Inadequate informing: Poor choice.** The studies reviewed indicated issues for the most part of inadequate informing as opposed to a total lack of information. Miya et al. (1991) found inadequate disclosure to be the most frequently occurring situation within the category of communication. The content of the information as well as how the information was presented were also at issue. Inadequate informing interferes with the patient and/or family's ability to make informed choices (Miya et al., 1991; Robillard et al., 1989). Patient noncompliance was suggested as a result of lack of information/education (Robillard et al., 1989). Both Aroskar (1989)



and Davis (1988) provided the example of clients not being informed fully of their health status. Pervading the ethical situations in Holly's (1993) category of exclusion was a lack of information or incomplete informing.

**Informed consent.** Clients consenting to procedures with incomplete information was cited as an example of a specific dilemma faced by the nurses in the research conducted by Davis (1988) and Andrews (1988). Among the 29 issues that Omery et al. (1995) rank, issues of informed consent rank as seventeenth; Ersek et al. (1995) ranked informed choice sixth among the nine priorities listed. Although in this study the explicit consent required for an informed consent and consent to treatments such as dressings were dealt with separately, there is no way of telling whether other investigators dealt with them differently or not.

#### **Imposing Values: Right to Risk**

Duncan (1992) stated that within the category "clients' rights," nurses found the most difficult decision to be the clients' rights to be at risk. Aroskar (1989) gave several examples under the category of autonomy which would fit under the subtheme of right to risk (for example, a client who is physically deteriorating but still mentally capable and who refuses help). Holly (1993) cited examples of health care providers and family members not only imposing their values but acting in opposition to the patient's wishes.

#### **Dying Well**

A trend noted in more recent studies aimed at identification of ethical issues was that pain relief through the use of technology such as morphine pumps is becoming an issue for community and acute care nurses alike

(Omery et al., 1995). Ersek et al. (1995) found the top three priorities for oncology nurses to be assisted suicide, end-of-life decisions, and pain management; within those topics were such subtopics as fear of hastening death, regulatory and legal constraints, and the importance of palliative care. The issue of pain management and its subtopic subtle forms of coercion are consistent with several of the issues illustrated in my findings.

Many of the studies reviewed identified the following issues associated with dying well: prolonging life with heroic measures (Berger et al., 1991; Davis, 1981), keeping a dying patient alive against his or her wishes (Aroskar, 1989; Holly, 1993), and rights of patients to make decisions about living and dying and refusing treatment (Aroskar, 1989).

Both Chubon (1994) and Liaschenko (1993a) used excerpts very similar to one related by one nurse in my study where a patient is not told truthfully of the terminal nature of his prognosis. The ethical harm in both cases is that the patient receives an overly optimistic prognosis and as a result is not given the choice of what he would like to do for his last couple of months; he is not allowed to die well.

### **Confidentiality**

Duncan (1989) addressed this issue under the category of system interaction, indicating that confidentiality was one of the primary conflicts when interacting with the health care team. Similarly, Forchuk (1991) found confidentiality to be the second most common ethical concern for public health nurses. Berger et al. (1991) ranked clients being discussed inappropriately as fourth out of the five issues encountered most frequently. Confidentiality was determined to be one of the four most common ethical dilemmas facing nurses in the 1988 study by Davis, whereas both Omery

et al. (1995) and Ersek et al. (1995) found it to be among the top 10 issues. Problems of confidentiality were not discussed by Aroskar (1989); however, it is possible that she subsumed them under the principle of autonomy. In the present study, although confidentiality was an issue for many nurses, it was among the primary concerns for only two of them.

### **Incompetence**

Client competence was not as frequently mentioned an issue in the research literature reviewed for this study as expected. With the exception of Duncan (1989), Haddad (1992), and Omery et al. (1995), few of the studies reported ethical issues associated with client competence and thus capacity to make choices, although Aroskar (1989) did provide an example in her discussion of autonomy that illustrated questionable competence. This is a huge issue for home care nurses and those public health nurses who care for seniors or clients with mental illness. One might expect that this issue will become a more significant one in the research literature with the aging of the population.

## **Additional Discussion**

### **Situational Constraints**

Several of the investigators made reference to situational constraints or barriers to ethical practice (Rodney, 1994a; Rodney & Starzomski, 1993). For instance, lack of supervisory support or poorly defined mechanisms of support can set up barriers to ethical practice as was suggested by Holly (1993). Duncan (1989) made reference to the fact that some nurses make decisions to act on their own personal values at the risk of losing their jobs; Millette (1994) stated that those nurses who were financially secure to

some degree felt that they were freer to act on behalf of their clients. Moreover, Millette noted that 50% of the subjects in her sample of 12 nurses either left nursing or changed their jobs because they were unable to practice in a manner consistent with their values of quality patient care.

### **Forum for Discussion**

As in other studies, some nurses in this study discussed situations that had often occurred years prior (Crisham, 1981, cited in Duncan, 1989; Liaschenko, 1993a). Several of the nurses thanked me for providing them with an opportunity to talk about their issues, and the majority of them spoke of the lack of an organized forum for discussion of the ethical issues in their practice. Nurses clearly want to talk about the ethical issues in their practice (Davis, 1981; Liaschenko, 1993a). There is an obvious need for a space where the issues that the nurses have deemed to be ethical can be validated and recognized as such. Investigators spoke of the nurses' need to discuss clinical ethical issues and conflicts not only as a way to increase ethical sensitivity but as a way of improving their ability to put their ethical concerns into language that others can understand (Chubon, 1994; Davis, 1981; Erlen & Frost, 1991). Wocial (1996) maintained that resolution of ethical issues is dependent on nurses being able to articulate their concerns in a way that is understandable to all involved. Equally as important is being able to identify and interpret others' ethical concerns. Nurses are becoming better able to recognize ethical issues in practice (Holly, 1993), but ongoing dialogue is seen as necessary to the ability to articulate their own concerns to other team members. Researchers make varying recommendations as to how that continued ethical dialogue might occur. Recommendations include continuing education (Berger et al., 1991; Davis, 1981, 1988; Haddad,

1992), although Davis (1988) stressed that this education must be grounded in clinical experience. Other researchers suggested the use of agency/ institutional ethics committees (Berger et al., 1991; Chubon, 1994; Haddad, 1992; Miya et al., 1991), opportunities to share their experiences with other nurses (Davis, 1981), nursing ethics councils (Holly, 1993), and nursing ethics rounds (Berger et al., 1991; Haddad, 1992; Holly, 1993). Miya et al. (1991) suggested providing nurses with the opportunity to talk with nurse ethicists, a suggestion which was supported by the work of Lo and Schroeder (1981), who found that sensitivity to ethical issues increased when an ethicist began to attend rounds and take part in discussion.

### **Powerlessness**

The nurses in this study spoke of their sense of being powerless to influence ethical decision making in situations where physicians and social workers were concerned, but they also spoke of a lack of nursing administration support as contributing to this powerlessness. Seeman's (1959) definition of powerlessness was cited by Erlen and Frost (1991) as "an expectation of individuals that their actions cannot affect particular outcomes or goals that they are seeking" (p. 398). They observed that powerlessness is a relational concept in that it is dependent on the degree of imbalance in the relationship between those involved. The participants in Erlen and Frost's interviews used words or phrases similar to those used by the nurses in this research such as *helpless, frustrated, powerless, and I have no control*. In the cases where the participants felt powerless, it was because, in trying to use their legitimate, expert, or coercive power to solve an ethical problem, they met with resistance, and their clinical expertise or knowledge was not recognized (Erlen & Frost, 1991; Rutman, 1996;

Traynor, 1994). Also similar was the fact that this lack of power led some of the nurses to question their effectiveness in their practice.

Saveman et al. (1992) reported district nurses' feelings of powerlessness when dealing with situations of elder abuse. The nurses in this current study expressed feelings of powerlessness when dealing with both child and elder abuse and how and when to intervene, which was compounded by a lack of recognition of their assessments by other professionals.

Millette (1994) reported that the most common theme in her research was the nurses' sense of powerlessness about their roles in ensuring that clients received the care needed. Holly (1993) referred to this powerlessness in her anguish category. Interestingly, Traynor (1994) posited that powerlessness can also result when nurses are faced with budgetary restraints that influence client care.

### **Resources**

Many of the researchers noted that nurses consulted their nursing colleagues (co-workers) most frequently for support and guidance (Aroskar, 1989; Chubon, 1994; Berger et al., 1991; Holly, 1993). Similarly, the nurses in this study most frequently sought support from nursing colleagues within their work setting.

Although the nurses in this study were not asked specifically about the resources that they used, they primarily spoke about their colleagues as being supportive resources. Unlike what was found in the literature (Davis, 1981; Berger et al., 1991), the majority of these nurses did not cite unethical practice among their own nursing co-workers as a source of conflict (by *co-workers* I mean their own immediate health unit co-workers).

Several researchers have also observed that although nursing has a professional code of ethics, few nurses indicate using the code as a resource (Oberle, 1995; Viens, 1993). Consistent with their observations, only one nurse in this study stated that she referred to the Canadian Nurses Association Code of Ethics as a source of guidance. Perhaps lack of reference to the professional code is due in part to problems of "ethical universalism" (Gadow, 1995, p. 6). Gadow stated that in constructing professional codes of ethics, rules for professional behavior are translated from the principles, but rational principles guide ethical knowledge only if all of the situations are alike. Perhaps it is because nurses cannot abstract the particularity of the person and the context of the situation enough to be able to make a link with the generalities of the code. Perhaps it is also because they cannot see all situations as universal, that the code of ethics is referred to less frequently than are colleagues, with whom nurses can discuss particularity. Findings of recent studies show that women react to complex, stressful situations by becoming interdependent with others (Gilligan, 1982; Gilligan, Ward, Taylor, and Bardige, 1988; Holly, 1993). This need for interdependence may provide further support for the use of co-worker support as opposed to use of the professional code of ethics.

Issues of powerlessness, the resources the nurses use for ethical support, and forums for discussion are interconnected. It is likely that providing a forum for discussion would assist nurses to be able to articulate their ethical concerns more assertively and thus influence their being heard, thereby decreasing their feelings of powerlessness.

### **Mutual Exclusivity of Themes**

Davis (1981), Duncan (1989), Liaschenko, (1993a), Chubon (1994) and Miya et al. (1991) all noted that mutual exclusivity of their categories was not achieved in their findings. Duncan (1989) suggested that the use of interviews might serve to assist in attaining mutually exclusive categories by allowing the researcher to clarify with the participants. That was found not to be the case in this research, because the overlapping of themes was not due to lack of clarity about the issues but rather due to the complexity and multifaceted nature of the stories.

### **Issues for a Beginning Researcher**

One of the problems that I experienced as a beginning researcher using an overwhelming amount of interview data was trying to keep the nurses' ethical issues concrete. In working with the data, there was a tendency to try to reduce it to a level of abstraction so as to make it more manageable. Analysis proved to be very difficult because of the complexity of the stories. The challenge was to manage the data and keep it at a concrete level so that it would remain readable but not overwhelming in length. To some degree, the length of the findings remains a concern. Deciding what context or what part of these complex stories to include in the description of the ethical issues in the findings chapter was difficult.

## **Implications for Education, Research, and Practice**

### **Implications for Education**

The findings of this study may serve to sensitize nursing students to the ethical issues that may occur for them or their colleagues in community practice. The findings also support the need for raising levels of ethical



sensitivity and reducing the mystery of ethics through, among other things, continuing ethics education. Raising awareness of ethical issues or "ethical sensitivity" does have implications for the recognition of and the inclusion of an ethical component in any and all nursing education. Pellegrino (1993), among others, has correctly stated that "recognition of the good does not ensure doing the good" (p. 5); or, stated another way, recognition of the ethical issue does not automatically mean that ethical action will be taken. Given that nursing is a practice discipline, one way to raise ethical sensitivity is through ethics education, where theory is linked to practice by discussion of practical, concrete situations (Davis, 1988).

Although nurses who are currently receiving their nursing education *may* be receiving the benefit of ethics threaded through their course work, those of us who received our basic education 20 or more years ago and who have not had the benefit of continuing education may be at a disadvantage when it comes to the recognition of ethical issues in our practice.

#### Implications for Research

Nursing ethics research did not begin in earnest until the 1980s (Fry, 1994) and since has been carried out primarily in acute care settings; hence the fact that there has been little research describing ethical issues in the community.

The findings from this study of two groups of community nurses contribute valuable information to the growing body of research in the community. Because of the broad question asked of the participants, it is difficult to make substantive claims about differences between the two groups of nurses. Independent studies of these two groups of nurses with larger sample sizes are suggested to get at the issues more clearly. These

might then be followed by studies comparing the two groups to determine if there are indeed differences. More in-depth study of this population is needed to establish clearly the ethical issues in community practice, recognizing that as the role of the community nurse evolves, so will the ethical issues (Omery et al., 1995).

It is also recommended that this study be repeated in the same geographical area at another time, because this would give some sense of whether the current findings are a result of the rapid and radical changes in health care in the province. Because there is no benchmark for determining the ethical issues in community practice in this province, it is impossible to say whether the issues identified in this study represent issues that result primarily from the huge budget cuts to the health care and social services sector or are issues that have just been magnified because of the cuts. Once the budget cuts to health care and social services have ended and a level of stability is re-established in community care, further research is required to determine if, for instance, issues of resource allocation remain as significant.

Additional questions have been raised by this research. Would the results of this study have been significantly different if the respondents had included male nurses? Second, many of the nurses cited a specific incident with a client as raising their ethical awareness. Further investigation into the role that critical ethical incidents play in moral maturing and ethical sensitivity is recommended.

Several researchers have noted that the language nurses use to discuss ethical problems in practice is not one of principles (Chubon, 1994) or of the ethic of care (Liaschenko, 1993a). It would be folly to assume that because nurses do not use the language of biomedical ethics that they are any less

ethically sensitive. The 53 ethically complex stories narrated by nine nurses is evidence to the contrary, but research aimed at learning more about how nurses talk about ethical issues in their practice might contribute to how nursing education can best be structured. There continues to be a great need for research at the exploratory, descriptive level in order to answer some basic research questions.

### **Implications for Practice**

Although the results of this research are not generalizable, they raise some important questions and provide some useful information for nurses and administration to begin the dialogue about nursing ethics.

At the Health Unit and Home Care Agency level, this information would provide administrators with a base line for the kinds of issues that nurses might face in their practice and serve as an indicator of the continuing education needed. The findings of this study might help administrators and community nurses work together to identify the appropriate resources which need to be developed to address the issues in their area. Stories and excerpts may be more valuable than survey results to a supervisor or manager who can use stories from this work as concrete examples of ethical issues from an actual Alberta contemporary.

Andrews (1988) recommended that once certain ethical issues have been identified as occurring frequently, policies should be developed to assist nurses in dealing with them (i.e., personal directives). Most importantly, awareness of the problems that these community nurses identify would promote a better understanding of the problems that clients are confronted with when receiving health care in the community (Duncan, 1989).

The study findings show serious and essential concerns about the need for collaboration between professionals. It is crucial that we begin to think about how to promote interdisciplinary collaboration. Interdisciplinary education (basic and continuing) is one way to promote understanding and respect for each other's expertise.

Forums for discussion at the health clinic level could help nurses to increase their ethical sensitivity as well as their ability and confidence in presenting their ethical concerns. These forums may also have a preventive function. Establishing nursing ethics committees with some authority would serve an educational purpose and as a support system as well as a way to decrease nurses' feelings of powerlessness. Interdisciplinary ethics committees, also with authority, might appear more accessible to nurses once positive experience and support had been gained using nursing ethics committees. Because of their feelings of powerlessness, nurses also need their professional association to stand up for them and speak on their behalf regarding collaboration.

## **Limitations**

### **Design**

A qualitative approach was chosen for this research given the study purpose which was to describe ethical issues encountered in practice by community-based nurses. One of the limitations associated with using a qualitative approach is that the findings are not generalizable beyond those participants in the study (May, 1986; Sandelowski, 1986). Although the goal of exploratory, descriptive research is to learn about the phenomenon from the participant's perspective rather than to be able to generalize to other populations, the lack of generalizability remains a limitation.

The subjective nature of the analysis used in qualitative methods means that replicability is often difficult. Sandelowski (1993) used Tesch's (1990) reminder that "there is no correct way to draw a face" (p. 305) in explaining that "different qualitative representations of common phenomena [may] all be valid ones" (p. 3). Similarly, Patton (1980) suggested that qualitative research findings represented the researcher's "perspective" of patterns in the data. Having said all that, the difficulty in replicating the findings of this study remains a limitation.

### Sample

The sample for this research was not randomly chosen. Nurses chose to participate in the study by contacting me and volunteering. There is the possibility, then, that the participants perceived me as a "listener" and so chose to participate as a way to "sort out" their ethical problems. That possibility can be construed as either a limitation because the participants were self-selected or as support for the need for more opportunity for dialogue in nursing ethics.

There is also the question as to whether the stories told by the nurses were mentioned because they were typical or because they were troublesome and unresolved. Although other studies in other contexts have shown similar findings, again, the issues that the nurses spoke about might be unique to them, and there is no way of telling whether the nurses came into the study to talk about these unique issues. However, the nurses were asked if their experience with ethical issues was different from the experience of their colleagues and five of the 10 nurses indicated that their colleagues had experienced similar issues in their practice. Further, expert nurses who read the findings were supportive of these findings.

### **Research Setting**

The nurses in this study were recruited from both home care and public health in order to obtain a wide view of the ethical issues in community nursing. The assumption was that because both groups of nurses work in the same setting, the community, their ethical issues would be similar. The limitation in obtaining that wide overview is that although certain ethical issues appeared to occur more frequently for one group of nurses than the other, the broad questions did not permit an in-depth look at either group, nor did it facilitate a clear comparison between the two groups.

### **Study Timing**

This research presents a snapshot picture of home care and public health issues at a specific point in time. The interviews took place between June 1994 and May 1995, a period when services in both sectors of community care were undergoing rapid and significant change. It is conceivable that if this study were repeated with the same nurses, now 18 months later, the issues would be different. In follow-up conversations with the participants for the purpose of offering the opportunity to review the findings chapter, several of them commented on the fact that their practices have changed since the interviews. For example, public health nurses in the major regional health authority represented in the study have gone from generalist to focused nursing practice, a change that will likely influence the ethical issues. One nurse working in a rural practice commented on the increased demand for home care services even since the interviews, indicating that the caseloads are larger and becoming increasingly more complex. Omery et al. (1995) asserted that ethical issues in practice do not

evolution of the ethical issues in community practice might have been speeded up in Alberta in the last three years, given the radical changes to practice that have occurred.

### **Summary and Conclusions**

The purpose of this study was to gain an understanding from community-based nurses of the ethical issues that they encounter in practice. The research question that guided the study was **What ethical issues do community nurses describe in their practice?** It is anticipated that the resulting findings can be used to increase nurses' and administrators' awareness of the issues and to assist in developing appropriate resources to deal with these issues.

The findings of other researchers were often difficult to compare to the findings of this study because of varying ethical perspectives, research designs, and method of reporting results (i.e., listing of ethical issues). The overarching ethical perspective dictates the kind of questions that will be included in the survey instrument and thus what issues will be identified and how the findings will be viewed. This research revealed that

- nurses in the community experience ethical issues in their practice and can most often recognize them as such.
- the nurses speak about their ethical issues in the form of stories.
- three major themes emerged from the stories: issues of relationship, issues of resource allocation, and issues of autonomy.
- ethical issues in community practice frequently arise out of everyday occurrences (as opposed to crisis situations).
- the stories these nurses tell are complex, containing multiple issues that lead in many directions.

- the nurses in this study frequently identified ethical issues as emerging from their relationships with other health care providers. The findings show how crucial it is that all health care providers look at how we can work together better.
- issues of resource allocation figure predominantly in this research.
- ethical issues that arise in community practice may be similar to those in other settings; however, they are made more complex because of the influence of setting (isolation from nursing colleagues, role ambiguity, the shift in control, family dynamics, and increased need to collaborate).
- community nurses want and need support for their ethical decision making. A nursing ethics committee with authority would provide needed support.
- community nurses want and need a forum for discussion of the ethical issues in their practice. For example, regular meetings to discuss ethical issues in practice would raise awareness as well as offer the opportunity to discuss solutions and serve a preventive function.

Nursing has long had an oral tradition (Liaschenko, 1993a). All nurses have stories from practice that are shared when we get together with our nursing colleagues. It is my hope that the stories represented in this investigation will resonate for some and spark curiosity for others, but that overall they will stimulate discussion.

In universities people know through studies.  
In business and bureaucracies people know through reports.  
In communities people know by stories. (McKnight, n.d.; cited in Alberta Centre for Well-Being, 1996, p. 6)



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## **APPENDIX A ADVERTISEMENT**

**Advertisement which appeared in the ACHNS and AARN Newsletters**

### **Ethics in Community Nursing**

**A Master of Nursing student is conducting research to identify and describe the kinds of ethical issues that community-based nurses encounter in their practice. For the purposes of this study, ethical issues are defined as issues in your community nursing practice in which there is uncertainty about the morally right thing to do or in which your duties and obligation as a health care professional are unclear.**

**If as a Public Health or Home Care Nurse (a) you have experienced ethical issues in your practice and feel comfortable talking about them, and (b) you live within a two-hour drive from Edmonton, you are invited to participate in this study.**

**For more information please call 438-0681 (collect) and ask for Sandy MacPhail. To call collect - call through a live operator.**

## **APPENDIX B**

### **Modified Advertisement**

(included in the Fall 1994 ACHNS Newsletter)

#### **Ethics in Community Nursing**

**Some nurses think that ethical issues only occur in acute care. Can you help me show others that ethical issues do occur in the community?**

I am a Master of Nursing student conducting research to identify and describe the kinds of ethical issues that community based nurses encounter in their practice. For the purposes of this study, ethical issues are defined as issues in your community nursing practice in which there is uncertainty about the morally right thing to do or in which your duties and obligation as a health care professional are unclear.

If as a Public Health or Home Care Nurse (a) you have encountered ethical issues in your practice and feel comfortable talking about them, and (b) you live within a two-hour drive from Edmonton, you are invited to participate in this study.

Participation will involve face to face interviews in your home or an alternate location of your choice. Initial interviews will last approximately an hour. One or two additional interviews may be arranged to gain more information and to help me to understand your experience better.

Please call 438-0681 for more information and ask for **Sandy MacPhail**. To call collect—call through a live operator.

## **APPENDIX C**

### **LETTER OF INFORMATION**

**Project Title: Ethics in Community Nursing**

**Investigator: Sandy MacPhail**

**Dear Colleague:**

Ethical issues in community-based nursing practice have only begun to be studied recently and as a result are not well understood. Research on the issues that result in ethical conflicts in nursing practice has taken place in hospital settings, but the ethical dimensions of community practice have been largely ignored to date. As a result, research is required to begin to identify the community-based nurses' perspectives on the ethical components of their practice. As a community-based nurse in practice, you have a much-needed perspective on the ethical dimensions of your practice.

As discussed in the spring newsletter of the Alberta Community Health Nurses Association (or the May issue of the AARN Newsletter), I would like to study the clinical issues that pose ethical concerns for community nurses. I am asking those community nurses who feel comfortable talking about ethical issues that they have encountered in their practice to assist me in this research. I am defining ethical issues as those issues in community nursing practice in which there is uncertainty about the morally right thing to do or in which your obligations and duties as a health care professional are unclear.

By choosing to describe your experience with an ethical issue, you will be helping to develop our understanding of the difficult situations faced by both community nurses and clients. In learning more about these situations, we may then be able to determine how to arrive at better resolutions.

Please also read the consent form attached. I will be phoning you in several days time once you have had a chance to think about this study and to decide whether you would like to participate. If you decide to participate I will make an appointment to meet with you to sign the consent form. The interviews may start after that time. Thank you for taking the time to read this information.

Sincerely,

Sandy MacPhail, RN, BScN,  
Graduate Student

## **APPENDIX D**

### **CONSENT FORM**

**Project Title: Ethics in Community Nursing**

<p><b>Investigator: Sandy MacPhail, RN, BScN</b>  <b>Graduate Student</b>  <b>Faculty of Nursing</b>  <b>University of Alberta</b>  <b>Office Phone: 438-0681</b></p>	<p><b>Advisor: Dr. Vangie Bergum</b>  <b>Associate Professor</b>  <b>Faculty of Nursing</b>  <b>University of Alberta</b>  <b>Office Phone: 492-6676</b></p>
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**The purpose of this research is to identify and describe the ethical issues that community-based nurses encounter in their practice.**

**I would like to talk to you about the ethical issues that occur for you in your practice. You will be interviewed at least once in person at a time and place that is best for you. Should you prefer to be interviewed by telephone, arrangements would be made to do so. Initial interviews will last approximately an hour. Additional interviews may be arranged to gain more information and to help me understand your experience better. These additional interviews may be over the phone and may also be shorter. All interviews will be tape recorded and then typed word-for-word so that the information you give me can be reviewed later.**

**You do not have to be in this study if you do not wish to be. If you decide not to be in the study, you may drop out at any time by telling me. You do not have to answer any questions or discuss any subject in the interview if you do not want to.**

**While you may find some value in talking about your experience, you will not benefit directly from this study. If you agree to participate in this study, you may feel some anxiety, discomfort, and self-doubt related to reviewing and reliving the ethical situation. If this occurs, you may choose to discuss your anxiety with either a counsellor (Mardi Bernard, phone 449-5298), with a person of your choosing, or with one of the Practice Consultants with the Alberta Association of Registered Nurses (Wendy Duggleby or Patricia Marck, phone 451-0043 or 1-800-252-9392). The researcher will not be able to assist you to resolve the ethical issues brought forward. However, results from the study may help to identify the types of clinical situations which involve ethical conflict for community nurses.**

**As with all research done in an area of clinical practice, there is the potential for direct unethical practice to be uncovered. An example of this would be ongoing patient abuse. In such a case, the bounds of the researcher's own professional code of ethics will take precedence over researcher confidentiality and the unethical practice will have to be reported. You would be encouraged to discuss the practice in question with your direct supervisor.**

**Your name will not appear in this study. A typist will listen to the interview tapes in order to make typed copies of the tapes. The typed copies will be identified by code number and all names will be removed to**



protect the anonymity of the informants. All data will be kept in a locked cabinet separate from the consent forms. Consent forms will be retained for five years, and the tapes and typed interviews will be retained for seven years after the study is complete. The tapes and typed interview notes may be used for a different study in the future provided the researcher receives approval from the appropriate ethical review committees.

The tapes will only be shared with Sandy MacPhail's thesis committee from the University of Alberta. The information and findings of this study may be published or presented at conferences, but your name or any material that may identify you will not be used. If you have any questions or concerns about this study at any time, you can call the researcher or her thesis supervisor, Dr. Vangie Bergum, at the number above.

Consent: I have read this information and agree to be in the study named above. I have had a chance to ask whatever questions I have about this study and my part in it. My questions have been answered to my satisfaction. In addition, I know that I may contact the researcher or her supervisor both named above, if I have further questions either now or in the future. I have been given a copy of this form.

\_\_\_\_\_  
Signature of the Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

Request for Summary:

If you wish to receive a summary of the study when it is finished, please complete the next section:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

If you wish to talk to Sandy MacPhail, the researcher, about this study, please fill in your first name and phone number below and detach this section of the consent. To maintain anonymity you may deposit the form in the box provided during the break. The researcher will call you as soon as possible.

Your First Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

**APPENDIX E**  
**BIOGRAPHICAL DATA SHEET**

**Project Title:** Ethics in Community Nursing

**Code Number:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**1. Age:** \_\_\_\_\_

**2. Gender:** \_\_\_\_\_

**3. Employment Setting:** \_\_\_\_\_

**4. Years of Nursing Experience:** \_\_\_\_\_

**5. Length of Employment in this Setting:** \_\_\_\_\_

**6. Nursing Education:** \_\_\_\_\_

\_\_\_\_\_  
(year[s] graduated and degree)

**7. Past Experience in Nursing:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## **APPENDIX F**

### **EXAMPLES OF GUIDING QUESTIONS**

1. Tell me about an ethical issue from your practice.
2. Tell me about what makes this an ethical issue for you.
3. Describe an ethical issue in which you thought there was a positive outcome? (and one where there was a negative outcome?)
4. Tell me if your experience with ethical issues is very different from the experience of your colleagues.
5. Tell me about other kinds of ethical issues you might encounter in community nursing.
6. What kinds of issues do you believe occur most frequently?

These guiding questions were used to begin the interview process with all the participants. Given that these questions were for the purposes of guiding the interview, they may not have been asked exactly in ascending order or may not have been asked until the second interview.

## **APPENDIX G**

### **PSEUDONYMS**

The following is brief information about the nurses whose names were "adopted" as pseudonyms for the research participants. The snippets of information are arranged in the order that the nurses came into the study.

**E. Kathleen Russell** was founder and director of a 3 year nursing program at the University of Toronto. This program, based on "sound educational principles," came into being in 1933 although Russell had been working toward this since 1920 (p. 24). Russell was testing new ground for nursing, firmly believing that nurses in the future would need advanced education. The program graduated nurses who were qualified for work in either public health or hospital (Allemang, 1985).

**Florence Nightingale**, who besides all of her other well-known accomplishments, developed public health policy for India and was a foremost social reformer and sanitarian (Allemang, 1985).

**Margaret Sanger**, whose work as a visiting nurse led her to a life of championing the rights and well-being of women and by extension their families, believed in challenging the system rather than working at the individual level and included opening the first birth control clinic in 1916 in the United States (Ruffing-Rahal, 1986).

**Charlotte Macleod**, from New Brunswick, went to Massachusetts to train at the Waltham Training Home for District Nurses, and later became the superintendent of that school. In 1897 she became the first superintendent of the Victorian Order of Nurses of Canada (Allemang, 1985).

**Clara Barton** never received formal nursing education. Her nursing education took place on the battlefields during the American Civil War. She was known as the "Angel of the battlefield" (Pryor, 1987). Clara, after learning of the International Red Cross in 1870 while travelling in Europe, worked for five years to establish a branch of the organization in the United States. The Red Cross had initially been formed in Europe as a response to the disorganized and poor treatment of the wounded in wartime, something with which Clara had had much experience. However, Clara also recognized the benefit the organization might be during periods of national disaster and so promoted an expanded mandate of disaster relief. However, it was not until 1882 that the Treaty of Geneva was ratified, bringing the International Red Cross to the USA. Over 100 years later the American Red Cross stands as a monument to her courage, foresight, and perseverance.

**Lillian Wald** realized the need for secular visiting nurses in 1893 after being asked to visit a sick woman in her home. She was so moved by the experience of seeing such extreme poverty that she was challenged to do what she could for the poor. She believed that nurses should be at the "call

of people who needed them" without the intervention of a physician (Christy, 1970, p. 51) and that nurses ought to live where people who needed them lived and so moved to the lower East Side of New York and eventually to the Henry Street house. Her group of visiting nurses not only made daily rounds caring for the sick but contributed in many ways to the material comfort of their patients, often bringing food, clothing, sheets, and furniture. Over a several year period, the Henry Street nursing agency became a highly organized nursing service and she worked there until her retirement in 1933. But Miss Wald's accomplishments did not stop there. She is also credited with organizing the first system of nurses in public schools and with developing, along with Adelaid Nutting, the first advanced preparation program for public health nurses as well as with predicting the eventual formation of a state medical insurance for the sick in the United States (Medicare and Medicaid).

**Mary Black** was an early district nurse in Alberta and later became the nursing supervisor of the Vegreville Child Welfare Clinic which was established in 1926. The Vegreville Clinic was one of 5 clinics in the province, the others being in Edmonton, Calgary, Drumheller, Medicine Hat. During a winter whooping cough and smallpox epidemic she resourcefully solved the problem of how to get to the homes in the country to do immunizations. She borrowed the home-made snowmobile that had been built by an automobile company in Vegreville and used it to accomplish the essential immunizations. (Schartner, 1982; Stewart, 1979).

**Helen McArthur** graduated with a BScN in public health nursing from the University of Alberta in 1933. After working as a district nurse, she went on to become not only the director of nursing services of the Canadian Red Cross but the president of the Canadian Nurses Association (Cashman, 1966).

**Christine Smith**, a nurse with seven years of V.O.N. experience, became the first Director of Nurses of the Public Health Nursing Service which was established in Alberta in 1918 (Stewart, 1979). During her tenure, a Public Health Program was established at the University of Alberta and the Public Health Nursing Act was passed.

**Sara T. Fry** is a contemporary nurse ethicist who practiced for over 13 years in both acute care and public health settings before going on to graduate school. She has masters' degrees in both public health and philosophy as well as a Ph.D. in philosophy. She has written and lectured extensively in the area of nursing ethics. Many of our community health nursing texts contain chapters on community nursing and ethics written by her.