A QUALITATIVE ANALYSIS OF EIGHT HOSPITAL ETHICS COMMITTEES IN TORONTO, ONTARIO

BY

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
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ABSTRACT

Keywords: Qualitative Research; focus groups; ethics committees; ethics; research methods

The purpose of this study was to develop an in-depth understanding of HECs Role in the Greater Toronto Area and in particular to discover through written questions and focus group interviews, the experiences, perceptions and opinions HECs had about their role. The convenience sample consisted of the chairperson and members from eight HECs. This study employed an exploratory, interpretational approach to data analysis based on grounded theory and an adaptation of the constant comparative method.

HECs in the Greater Toronto Area portrayed themselves as lacking a defined role. There were three reasons for this situation. First, HECs in Toronto found themselves in various stages of development. Second, there was a lack of a clear connection between the HEC and the broader hospital community. Third, HECs in Toronto were disconnected from each other and rarely collaborated on issues.

The interpretive frameworks expert role, pair-of-hands, and powerless collaborators provided a more in-depth understanding of the HEC role.

Expert role: Consistently emerging from the study was the idea that HECs needed to acquire an expert role to avoid becoming simply another hospital committee. The perception of a lack of power and authority which HECs sometimes experienced was profoundly disturbing to some focus group participants; however, these members reconciled themselves to their role with the consideration that they had a moral authority that could not be ignored.

In this study, HECs believed the experience of ethical debate with representatives from different professional/occupational backgrounds helped to expand their understanding of problems. The principle of interdisciplinary HECs, which was experienced as broadening the individual committee member’s perspective, was specifically endorsed by members of each focus group as a valuable process.

Pair of Hands: The HEC can be seen as a pair of hands assisting the health care professional, responsible for the patient by being a resource. The HEC functions identified were: development and review of policy; providing a forum for ethical discourse; providing a listening function; assisting with ethical problem-solving and raising the ethical conscience of the hospital. Patient care consultation was not an major function of any of the participating committees.

Powerless Collaborators: The HECs in this study saw themselves as ethical guides for administration and staff rather than as decision-makers. Collaboration with other health care professionals in the provision of ethical patient care is one area that cries out for the involvement of HECs.
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CHAPTER ONE
INTRODUCTION AND PROBLEM STATEMENT

1. Introduction

Hospitals face an increasingly wide range of ethics-related challenges. This has prompted the establishment of special committees to assist and guide health care professionals, patients and their families with difficult decision-making. Indeed, a growing number of hospitals, having identified the need for ethical reflection, have allocated this responsibility to a Hospital Ethics Committee (HEC) or Clinical Ethics Committee. (Ross, Bayley, Michel & Pugh, 1986; Ross, Glaser, Rasinski-Gregory, Gibson & Bayley, 1993). The HEC has thus become the forum, in many hospitals, for the debate about ethical issues.

Clinical ethics committees have existed in Canada for thirty years, although acute care hospitals are more likely than other health care facilities, such as specialty hospitals or nursing homes, to have HECs (Bayley, 1996; Hall, 1996). Much of the growth of such committees came about in response to the Canadian Council on Hospital Accreditation’s 1986 mandate that hospitals participating in an accreditation survey have policies on several “biomedical ethical subjects” and suggested that an multidisciplinary body could address these issues (Jean, Pare & Parizeau, 1991. Meslin, Rayner, Larcher, Hope & Savulescu, 1996). HECs are primarily multidisciplinary groups composed of health care professionals and community representatives: their primary purpose is to address ethical issues and offer ethical perspectives on specific situations that occur within health care institutions (Cranford and Doudera, 1984; Glaser, 1989; Murphy, 1992). In Canada, HECs are required by the Canadian Council on Hospital Accreditation to be multidisciplinary and to include ethicists, as well as physicians and other professional staff (nurses, social workers, clergy), administrators, and hospital board members (Storch, Grieper, Marshall & Olineck, 1990; Canadian Council on Hospital Accreditation, 1986). HECs may also include members of the community and the legal profession (Avard, Grieper, Langstaff, 1985).
HECs function in several roles: in part as review mechanisms for patient care (retrospectively, prospectively or concurrently); some establish policies and standards of practice for their institution; some mediate ethical disputes; and some provide educational programs to staff and the community at large. Such additional responsibilities as research on ethical issues may also form part of the HEC mandate. In performing such functions, HECs undoubtedly benefit the health care effort, promoting an open and constructive communication of values and viewpoints and, thereby, enhancing the process of clinical-ethical decision-making.

The issues arising in hospitals which require ethical reflection often involve dimensions of emotionality, confusion, uncertainty, and subjectivity, challenging the health care providers' personal and professional values. "Formation of [hospital] ethics committees is an acknowledgement of the immensity of ethical problems facing health care providers in their daily practice" (Grundstein-Amado, 1990, p. 6). The rationale for the development of HECs is based on their ability to provide "... a more broadly based knowledge and value system on which to address difficult issues of patient care" (Storch, 1991). Although the actual resolution of individual ethical dilemmas rests with patients and health care professionals, formulating questions about what to do and providing guidance about larger systemic concerns is an important function of many HECs. For example, the HEC can help the patient care team identify and clarify issues by asking questions such as these: Who makes the decision? On what basis shall we decide? What are the limits to therapeutic intervention?

HEC members believe that their committees contribute something special to the overall health care effort (Lindfors, 1988; Ross et al. 1993). Rather than resolve "everyday" ethical dilemmas, the HEC, by virtue of its hospital mandate, addresses the special circumstances of hospitals. These include the need for the development of restraint policies, the issue of patient compliance to medication, the issue of "do not resuscitate" orders, and so on. "... [M]any, perhaps most, ethics committees play several distinct but overlapping roles" (Griener & Storch, 1992, p. 15). According to Fost and Cranford (1985), the majority of HECs, rather than adopting a decision-making
agenda, have emphasized a consultative, advisory, informational and consensus-development role.

The scholarly literature involving HECs is limited in the discussion of theory, often only describing the membership of the committee, its scope of activities and its potential contribution to the institution. From this literature, it is clear that the full implementation of the potential functions of the HEC has, thus far, been embraced by only a few hospitals, most of them in the United States (Griener & Storch, 1992; Hoffmann, 1991; Scheirton, 1993; Veatch, 1984; Wolf, 1994). Since, the first Canadian clinical ethics committee was established in 1967 at the Douglas Hospital in Montreal, Quebec. (Wilson & Steibelt, 1985), there have been only three published Canadian surveys on the role of HECs plus two Quebec studies. Since 1986, several Toronto area acute care hospitals have established their own HECs, but no published study has as yet reported on the role of these HECs. This study was designed to fill that gap.

II. Problem Statement

An important reason to pursue the current study was the question: What is the nature of the group of individuals who consider ethical problems in Toronto hospitals in the 1990's? It seemed important to explore how Toronto HECs currently fit within their institutions, what these committees contributed to patients and their families and to health care providers, and how committee members perceived the HECs' ethical expertise and competence. A review of the extant health care literature indicated the urgent need for additional research into the evolution of the HECs (Bayley, 1986; Brunetti, 1993; Day et al. 1994; Fletcher, 1992; Flynn, 1992; Hoffmann, 1991; LaPuma & Priest, 1992; Scheirton, 1993; Smith, 1990; Smith, Day, Collins & Erenberg, 1992; Storch & Griener, 1992; White, Zaher, Bilton, Hickson & Sergent, 1993; Wolf, 1992). This study describes the state of Toronto HECs approximately one decade after their institution.

The aim of the present study is to describe and develop an in-depth understanding of the current role of the Toronto HEC. The investigator decided to use focused interviews to explore the experiences, perceptions and opinions that these committees had about their
role. Specifically, the study set out to discover HEC's understanding of their own goals, their ability to implement change and their aspirations for their future. The study also sought to identify issues for further research, especially the desirability of HEC expansion into patient consultation.

III. Rationale

There are three reasons why this study of HECs in the Greater Toronto Area in the 1990's is potentially important.

The first reason is that the published literature leaves the "gold standard" for HECs relatively unclear. Their contribution thus far to the mission of the hospital has not been gauged. A review of HECs in the Toronto area is important in helping to understand how the HEC role has been implemented, what aspects of the potential role have or have not been embraced in the ten years since the initiation, why a particular role has been adopted in a given case and in what direction committees may now need to move. The first reason is, thus, to describe and situate the current HEC role.

The second reason why the study of HECs is relevant is that HECs offer a collaborative and interdisciplinary forum for patient care questions which reflects current views of health care delivery. The 1990's are a time when patients and families are insisting on a role in decision-making around their own health and when the various health care disciplines are claiming power and authority equal to those of physicians. HECs embody interdisciplinary functioning and address fundamental health care issues (Loewy, 1990; Ross, Glaser, Rasinski-Gregory, Gibson & Bayley, 1993). The second reason is, thus, to explore the impact of HEC's interdisciplinary functioning on their role and influence in the hospital.

The third reason for studying HECs is that their structure is egalitarian rather than hierarchical. This is, again, in keeping with current thinking about ethical decision-making. Egalitarian structure should allow the HEC expression of a diversity of viewpoints rendering it more responsive, more responsible and more humane (Storch, 1992). The success of such a model may offer guidelines for other areas of medical practice.
CHAPTER TWO
REVIEW OF THE HOSPITAL ETHICS COMMITTEE LITERATURE

The research topic — developing an understanding of Toronto HECs through describing members' experience, perceptions and opinions about the current HEC role involves a review of the pertinent literature on hospital ethics committees.

I. Hospital Ethics Committees

Most of the health care literature involving HECs is anecdotal in nature. There were only a few studies found which described the role of established HECs. One area identified for further research was the need for a clearer understanding of what HECs were actually doing. As one example, there is a lack of information about how HEC members address patient care consultations. This section will examine the following aspects of HECs: (a) origin and development; (b) models for considering the dimensions of HEC decision-making; (c) structure; (d) function; (e) process; (f) responsibility; (g) consensus; and (h) multidisciplinarity/interdisciplinary.

A. Origin and Development

Hospital Ethics Committees (HECs) developed out of a perceived need to address ethical problems arising in the clinical area and to help resolve such problems when they arose. Even before the formal inception of HECs, some health care institutions had hospital-based committees involved in decisions and policy-making regarding ethical issues. Today's HECs evolved to provide a formal mechanism by which said issues could be resolved.

HECs grew out of such other hospital committees as tissue and treatment (prognosis) committees. In the United States, these committees were probably the catalyst for the first HECs. The earliest of these developed in the 1920s to address the issue of sterilization of the mentally infirm. Tissue committees, which reviewed surgical specimens, assessed whether the potential benefits for patients were sufficient to justify the risks of surgical intervention (Fost & Cranford, 1985). With the advent of the
kidney dialysis shunt, treatment committees were established to select patients medically deserving of treatment for end-stage renal dialysis. Between 1962 and 1972, when there were insufficient numbers of dialysis machines, U.S. treatment committees selected patients for long-term dialysis.

In the last decade, clinical ethics committees have become the norm in most major Canadian hospitals (Storch and Griener, 1992). An impetus to their increased number has been the proliferation of sophisticated medical technology. At the same time, societal pressures demanding ethical decision-making have become increasingly pervasive.

The first Canadian ethics committee was the Committee on Ethics and Patients' Rights, established in 1967 at a psychiatric hospital in Montréal, Québec (Jean, Paré & Parizeau, 1991; Wilson and Steibelt, 1985). Subsequently, a proposal for a HEC was published in the 1971 Medical-Moral Guide of the Canadian bishops (Rosner, 1985). This Guide recommended establishing medical-moral committees in every Canadian Catholic hospital. A year later, in 1972, the Canadian Council on Hospital Accreditation Guide noted the importance of evaluating health care activities, particularly patients' rights (Storch et al.1990). The Canadian Council on Hospital Accreditation Standards and the Canadian Hospital Association both recommended that hospitals establish HECs to resolve issues in biomedical ethics (CCHA, 1986; CHA, 1986). HECs are also now endorsed by noninstitutional activists, communities, consumer organizations, and provider groups (Staff. Hospital Ethics, 1991).

In 1983, the Alberta Hospital Association surveyed 38 large Canadian hospitals. They found that 11 hospitals (29%) had ethics committees, and 13 (34%) used existing hospital committees to deal with ethical issues on a case by case basis (Levine. 1984). A Canadian survey of 196 Hospitals (with at least 300 beds), conducted by Avard, Griener and Langstaff (1985), reported that 18 per cent (n=36) of hospitals surveyed had an ethics committee. Although these committees were described as using a variety of names, they functioned basically as HECs. Also in this study, 7 (20%) respondents stated that their HECs were established before 1975, 7 (20%) between 1976 and 1980, 14 (39%) between 1981 and 1983, and 8 (22%) in the first six months of 1984.
Avard et al. (1985) also reported that hospitals with more than 700 beds were more likely to have an ethics committee than smaller hospitals. Institutions with a religious affiliation were most likely to have an ethics committee. 10 of 21 hospitals (47.6%), followed by hospitals with municipal, provincial and federal support. 20 of 95 hospitals (21.1%), while those with lay affiliations (private, non-religious) were least likely to have one. 6 of 74 hospitals (8.1%) (Avard et al., 1985). More than a quarter of university-affiliated hospitals responding to the study, 24 of 91 hospitals (26.4%) had a HEC. This survey identified physicians and administrators as the principal founders of HECs in their hospitals.

The Jean et al. (1991) study of HECs in Québec found that 94 ethics committees existed. They were divided as follows: 38 clinical ethics committees, 41 research ethics committees and 15 ethics committees concerned with both clinical practice and research protocols. Generally, the busier the hospital the more likely it was to have a HEC. There were HECs in 77% of hospitals with over 400 beds, 58% of hospitals with 300 to 400 beds, 32% of hospitals with 200 to 300 beds, 22% of hospitals with 100 to 200 beds, and 6% of hospitals with up to 100 beds. One hundred and forty four hospitals had no HEC. In addition, 26 hospitals indicated that they intended to establish a HEC in 1990.

HECs devoted to clinical practice have tended to be a more recent phenomenon than research ethics committees (Jean et al., 1991). Between 1979 and 1984, 26 research ethics committees were formed, compared with five clinical HECs during the same time period. However, between 1985 and 1989, 25 HECs with a clinical focus were formed, while only 11 research ethics committees were established.

For nearly two decades, HECs have been part of the health care system in the United States (Cohen, 1990). The 1976 case of Karen Quinlan hastened the development of such committees. In a decision permitting the father of the patient to exercise Ms. Quinlan's right to refuse treatment (and thus indirectly permit the withdrawal of life support from her), the New Jersey Supreme Court stipulated that the prognosis for a patient like Ms. Quinlan should be confirmed by a HEC or similar body. Such confirmation would permit a decision to withdraw treatment without fear of legal or criminal sanction (Quinlan, 70 NJ
10. 1976). The medical community, which embraced the rationale of the court in *Quinlan*, established HECs in many settings. In a few jurisdictions (e.g., Maryland), HECs are required by law but, in most cases, they are a product of policy rather than statute. (Hoffman, 1991a; Hollinger, 1989). Development of HECs also accelerated in response to one of the reports of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983). The report recommended that hospitals develop internal mechanisms to promote ethical decision-making in difficult areas (President's Commission, 1983).

Shortly after the President's Commission was established, interest in HECs was again highlighted by a decision not to perform corrective surgery on a baby with Down's Syndrome in Bloomington, Indiana. The so-called "Baby Doe Regulations" were issued by the United States Department of Health and Human Service to limit such decisions. Although later struck down, these regulations were probably the reason for the formation of infant bioethics committees in many institutions (Fost & Cranford, 1985; Randall, 1983).

In the United States, long-term care facilities are beginning to establish ethics committees as a way of dealing with issues related to the care of chronically ill and elderly patients (Staff, Hospital Ethics, 1988). There exist some national data on the prevalence of ethics committees in nursing homes (Glasser, Zweibel, Cassel, 1988). A national survey of administrators of 4,504 nursing homes indicated that only 29% of respondents had established ethics committees (2% of the sample). Committee formation appeared positively associated with the size of the institution and religious affiliation. In 1993, the Joint Commission of Health care Organizations published new standards for accreditation which required hospitals to have a HEC or similar body to address ethical issues (Ross et al, 1993).

HECs are clearly gaining increasing acceptance throughout the health care system in North America.
B. Models for Considering the Dimensions of HEC Decision-Making

The HEC has been criticized for its imprecision and inconsistency in the area of ethical decision-making (Smith, 1990). These problems have been attributed to the HEC's limited experience in shared decision-making. Smith (1990) has identified five appropriate frameworks for guiding HECs in this process: teleological, deontological, personalistic, integrated and utilitarian models. The Teleological Model focuses on the goals of the institution. Consequently, alternatives that offer the highest institutional value for self-realization of staff and patients are selected. The Deontological Model relies on basic principles of law, duty, and obligation. The development of alternatives focuses on the ethical principles embraced by decision-makers. The Personalistic Model focuses on the personal development of staff and patients. In other words, the enhancement of the positive development of each person becomes the goal of this model, in that staff and patients are identified as being unique, essentially being defined through relationships with others. The Integrated Model balances the goals of the institution and those of the individual against the long-term consequences of the implementation of those goals and objective moral principles, using a process of continuous evaluation. Finally, the Utilitarian Model emphasizes the effects of an action rather than the motives behind the action.

The variety of models described above is not exhaustive. A HEC's conscious use of any of these models will help members address issues more clearly, (Smith, 1990). Yet, other HECs, without adopting a formal decision-making structure, may still be able to formulate questions and determine responses.

A HEC may adopt a formal model or ask itself, "What can the ethics committee do to help in a particular case?" In either situation the question of how decision-making is perceived by parties appearing before the HECs remains important. HEC decisions may carry political, legal, or social consequences extending beyond the walls of the hospital. Nearly all HECs have adopted a formal consultative role, where the referral of a matter to the HEC is optional for staff or patients (Tong, 1991). This model allows an interested party to choose to go before the HEC, without requiring that any advice received be
followed. This approach is sometimes referred to as the optional/optional model. Models requiring mandatory consultation of a HEC or mandatory acceptance of a HEC consultation have seldom been followed. Other models involving mandatory action have largely been avoided, including optional-mandatory, mandatory-optional, and mandatory-mandatory (Tong, 1991).

Despite their formal status as optional sources of ethical guidance, the moral authority of HECs may be such that their recommendations are respected. (Brunnetti, 1993, van der Heide, 1993). The reasons for this involve the institutional role of the HEC and the inherent moral authority of a group having expertise in ethical issues. Furthermore, as these consultations are optional, it is unlikely they would occur unless requesters were prepared to abide by the decisions or recommendations of the HEC. A study cited by Brunnetti (1993), showed that only in regard to 10% of cases did doctors at Massachusetts General Hospital refuse to follow HEC recommendations.

HEC members may also seek to promote their own personal beliefs by adopting a specific type of ethical decision-making framework. For example, Downie and Sherwin (1993) proposed that members draw on a feminist ethics perspective in the HEC discussion process. They argued that the benefits of such a perspective are: the recognition of different patterns of decision-making on the basis of gender, the elimination of the oppression of women, the empowerment of women, and the involvement of oppressed women in policy development. Diversity of HEC membership protects against single issue philosophy determining HEC function.

In essence, the literature suggests that HECs possess considerable ethical authority.

C. Structure

The structure of a HEC refers to the size of the committee and the composition of its membership. In Canada, the size and membership of a HEC may vary from one hospital to another. According to Ferguson (1984), at least 10 members should be drawn from various disciplines within or outside the institution. Current American studies have found a range
of 10 to 40 committee members (Ross et al, 1993). The inclusion of representation from administration, theology, social work, law and the hospital board is often recommended. Some hospitals also have an ethicist on staff who is either a member of the committee or available as a resource to the committee.

Ethics committees seeking to shape an appropriate framework for their deliberations have developed their own structure or composition. A major challenge facing HECs is determining committee composition which, in turn, influences process and product of ethical deliberation.

The journal *Hospital Ethics* (Staff, 1990) stated that committee members should be selected for their ability to work co-operatively in a group. In both the United States and Canada, multidisciplinary ethics committees are the rule. The American Hospital Association recommends that one-third of HEC members be physicians, one-third nurses, and one-third others — including lay people, clergy and other health professionals (Loeb, 1992). As well, the regulations of the American Joint Commission on Accreditation of Health Care Organizations require that nurses participate in HECs. Curtis (1984) indicated that a "...reasonable mix of interests, expertise and sensibilities" (p.199) among multidisciplinary HEC members is a healthy trend.

Over the last 5 years, Minnesota, Maryland, the District of Columbia, Virginia and New Jersey surveyed HECs. A profile of Minnesota HECs, using responses from 155 acute care and specialty hospitals, revealed that 33 ethics committees existed (Van Allen, 1988). This survey reported that there was a relationship between the presence of a HEC and the characteristics of the hospitals that tend to sponsor them — size, urban location, and religious affiliation. For example, hospitals with more than 200 beds were more likely to have a HEC (75%). Size seemed to have had a more significant influence than urban location. Although urban location increased the likelihood of an ethics committee (78% with 200 or more beds have HECs), the religious affiliation of the hospital was important. Of the hospitals surveyed, 50% had HECs. Committee size ranged from 4 to 33 (median=14) members. The length of time the committee has operated ranged from 3 to 80 months, with half of the committees two years old or less. All committees reported multidisciplinary
membership, with an average of four to five physicians, three to four nurses, a member of the clergy, social workers, hospital representatives and one or two other hospital representatives (i.e. trustees, patient representatives, dietitians/nutritionists, staff from quality assurance, educators, discharge planners, and genetics counsellors). Two-thirds of the 33 hospitals responding reported having hospital attorneys and community representatives as members; one-third included an ethicist.

A recent study of HECs was undertaken in Maryland, the District of Columbia and Virginia (Hoffman, 1991a). The study included four phases: (1) 199 questionnaires sent to the chief executive officers of hospitals in the three jurisdictions; (2) 60 telephone interviews with chair-persons of HECs; (3) telephone interviews with 3 to 4 members of committees that had operated more than one year and had completed more than one patient care consultation (N = 124 committee members from 38 HECs); and (4) requests that hospital staff who were not HEC members describe their perceptions of HECs.

In this study, the average size of the committee was 12.5 members in Maryland, 16.2 in D.C., and 13.8 in Virginia. The smallest committee was composed of four members and the largest, 30. The study also reported that committee size changed with the size of the hospital. Maryland's typical committee (n=52) composition was 12–13 members including 5 physicians, 3 nurses, 1 social worker, the hospital CEO, 1 community representative, one-half lawyer, one-half ethicist/clergy and one-half other.

In the District of Columbia the average HEC had 16–17 members composed of 6 physicians, 3 nurses, 1 social worker, 1 lawyer, 1 ethicist, the hospital CEO, 1 community representative, 1 member of the clergy, 1 member of the hospital board and one other.

In Virginia (n=27), HECs typically had 14 members which included 5 physicians, 3 nurses, 1 social worker, 1 lawyer, the hospital CEO, 1 community member, 1 member of the clergy and one other. Other members who participated in HECs in the three states were hospital board members, representatives of administration, a health education department head, risk management personnel, a patient relations representative, a director of volunteer services, and a patient rights advisor.

The most current American survey of HECs was conducted in New Jersey (Van Allen,
1992). This study examined 53 HECs among 81 hospitals. The committees usually met monthly or quarterly and, less commonly, every other month. Physicians, nurses, hospital administrators, and clergy were most often represented on HECs. Social workers and lawyers made up the second most prominent member groups, followed by an even mix of trustees, patient representatives, lay persons, and bioethicists as occasional members.

To date, only three Canadian and one provincial survey have been reported that studied HEC characteristics. The first survey, conducted by Avard et al. (1985), supported Ferguson's (1984) observation that there was considerable variation in the composition of HECs. In the Avard et al study, 215 eligible hospitals were surveyed and 196 hospitals returned the self-administered questionnaire. Committees ranged from a minimum of four members to as many as 25 members (Avard et al. 1985). Ninety-two per cent of the committees included at least one physician on the committee, with four committees having seven physician staff members. Nurses (81%), as well as representatives from the clergy and ethicists (86%) and administrators (75%), were also usually committee members. Lawyers were included in 36 percent of the committees and lay members were reported present in 12 percent of the committees. Several committees (19%) reported that they had no nursing staff as members of the committee. Nine committees had an ethicist as a member. Within the "other" category, a geneticist, pharmacist, dentist and health record analyst served on HECs. Whereas 75% of the members of HECs were appointed, only one committee stated they had voluntary membership. More than two-thirds of respondents met on regularly scheduled dates each year. 14% meeting monthly. 30% of HECs reported meeting only when necessary. Records of deliberations were kept by most committees (92%) and 50% of hospitals surveyed clarified that anyone in the hospital such as staff, patient and families could seek recourse to a HEC.

It was the Avard et al. (1985) study's conclusion that variability in the size, membership and procedural mechanisms of HECs indicated uncertainty and confusion about committee member's roles. So far, studies of committee composition have not indicated how the different perspectives of the individual members contribute to better patient care decisions.
The second survey of Canadian hospitals was conducted in 1989 (Storch et al., 1990). A total of 120 usable questionnaires were returned from 142 large (more than 300 bed) hospitals. This survey ranked physicians (25%), administrators (20%), nurses (13%), board members (11%) and clergy (8%) as comprising the most common membership. Committee size ranged from 5 to 25 members (mean=13). Nurses, physicians and clergy were almost invariably represented on the committees, whereas social workers and board members were listed under the category of "other members" by more than 50% of the hospitals. On all committees, the number of physicians and nurses ranged from one to seven members. Six respondent hospitals had six or more physicians, and two HECs had more than six nurses. Twenty-nine respondents (41%) indicated that they had a bioethicist on the committee; two hospitals reported two.

With respect to committee membership, most of the respondents (64%) reported that HECs were selected by appointment. Seven (10%) hospitals had voluntary membership. Whereas most committees (87%) met regularly, nine hospitals stated that they met only when necessary. The mean number of committee meetings reported by all respondents was seven per year, with only a few committees (16%) convening for more than 10 meetings. Formal documentation was kept by most committees (94%). Generally referrals to the committees came from a wide range of people. Sixty-five HECs reported that the highest number of requests came from attending physicians, nurses and other health care professionals (92.9%) but, administrators and patient/family referrals were also made.

The most recent survey of HECs in Canada by Storch and Griener (1992) involved site visits to five hospitals with over 360 beds (three in eastern and two in western Canada with one in each area having a religious orientation) to assess the effectiveness of their ethics committees. With respect to the structure of the five committees, three reported to the chief executive officer and the board, and the others reported to the medical advisory committee. Two HECs reported that they functioned as an independent committee, whereas the other three committees had a parent committee with one to four subcommittees. Hospitals with a religious affiliation had formed subcommittees to deal with reproductive issues.
Jean et al. (1991) prepared an overview of HECs in the province of Québec. Questionnaires were sent to 200 hospitals irrespective of their size or purpose. The questionnaire was comprised of two sections: (1) data on the committee (origin, development, mandate, structure and administrative location), and (2) operating procedures (number of meetings, decision-making process) and activities (case consultation, guidelines, education) of the committee. A response rate of 96% (n=192) was obtained. This study revealed that the location of the HEC on the hospital's organizational chart seemed to make them responsible to a body that represented all sectors of the hospital. Earlier the tendency had been to have a HEC responsible only to a medical body. However, Jean et al (1991) found that HECs reported to various administrative authorities such as the Council of Physicians, Dentists and Pharmacists (most common), the Board of Directors, the Director General and multiple bodies (i.e., Board of Directors and Council of Physicians, Dentists and Pharmacists).

In Québec, HECs had rules governing their composition. Either these rules were part of the committee's mandate, or they were drawn up by the administration of the hospital. In order of frequency of reference in the various standards, a clinical HEC was composed of the following individuals: family physicians, administrators, nurses, clergy, lawyers, social workers, ethicists, benefactors, patient representatives, psychologists, resource persons, representatives of the community, research representatives and pharmacists. Most committees were composed of physicians, administrators, nurses, and clergy. The other professions/occupations were present in varying proportions. The duration of tenure given the members of the committees also varied, but it appeared that most people stayed for one or two years unless there was an open time frame.

HECs in the Quebec study varied in the frequency of their meetings. Within the last 12 month period preceding the study, 10 HECs met 11 times or more, 31 respondents between 6 and 10 times, and 40 up to 5 times, and 8 HECs had never met. Two HECs reported giving members remuneration for their participation but did not specify amounts. HECs may be large or small but they appear to be usually multidisciplinary in composition.
Ali (1996) in the journal HEC Forum reviewed an in-depth study conducted in Quebec by Parizeau and her colleagues. This study extended the work of Jean et al, 1991. The study involved an in-depth review of 6 HECs, a research ethics committee and 4 joint clinical and research ethics committees. The study concluded that HECs in Quebec have two main functions: patient case analysis and policy development. A third, intermediate function was that of self education. Parizeau concludes that the HECs placed too much emphasis on professional standards of practice in assessing matters referred to the committee. This emphasis failed to take into account ethical principles sufficiently. She also believes that the HECs need to develop their own expertise. Of particular interest to the present study is her conclusion that HECs need to define their structure and constitution more clearly although the very "vagueness" of the HEC role makes these committees more acceptable to the hospital community.

D. Function

Function refers to the major activities of HECs. HECs are involved in three types of activities — education, case consultation and the development of policy guidelines (Jean et al., 1991; Murphy, 1989; Storch & Grien, 1992). Levine (1984) reported that the functions of HECs were to educate staff and develop hospital policies on ethical issues. This author also suggested that HECs offered a forum for airing and resolving disagreements among staff, patients and families about issues of clinical care. HECs also review patient care consultations both prospectively and retrospectively. Murphy (1989) identified the "big three" (p.53) functions of HECs as education, policy development and case consultation. Siegler, Pellegrino, and Singer (1990) observed that ethics committees performed four functions. These included educating staff, setting institutional policy, influencing (directly) patient care decisions, and providing a non-judicial mechanism for reviewing and resolving cases involving conflicts. In contrast. Freedman (1996) indicated that clinical ethics committees had no role in patient care consultation.

To prepare members for their role in ethical reflection, HECs educate themselves
about ethical issues facing patients, hospitals and the community. This process of self education can involve mock consultations, educational sessions led by committee members or outside speakers, self study sessions, meetings with other HECs and formal training in bioethics. (Ross et al, 1993). Committees are thus in a position to educate other hospital staff and the community they serve. The hospital may rely on the HEC to develop policies regarding ethical issues in the clinical area. Many of these ethical issues derive from individual health care providers or from patient consultation. Some researchers have identified three principal functions for the HEC, while others view the HEC as having four functions. The function that appears to vary between the various HEC studies is the consultative role of the committee. Different researchers have tried to express this function in a variety of ways (Jean et al., 1991; Murphy, 1989; Siegler, Pellegrino & Singer, 1990; Storch and Griener, 1992). The consultation role can be summarized as involving a review process for ethical dilemmas arising in clinical practice, sometimes related to specific cases and sometimes, to broader systemic concerns. The consultative role is often viewed as involving several aspects. In particular, the HECs involvement in direct consultation on issues regarding specific patients is often distinguished from the HEC's role as a non-judgmental forum for the discussion of ethical dilemmas.

HECs implement their functions in a context defined by decisions made by social, legal, medical, and nursing forces. The religious and spiritual tenets of the patients and/or hospital (Avard et al., 1995) may preclude HECs from considering certain medications, treatment modalities or other issues. In their infancy, HECs needed to equip themselves with the knowledge and experience to engage in patient care issues. As everyday patient care problems continue to increase and more complex issues face patients, HECs will be impelled to move closer to the patient's bedside, as well as develop more sophisticated responses to patient care consultation. Although HECs originally developed to meet the needs of individual health care institutions, their function or role in maintaining patients' interests remains unclear.

Canadian researchers, Avard et al. (1985), indicated that in their survey, HECs functioned in a predominately consultative or advisory role. Only three committees out of
196 hospitals (with more than 300 beds) claimed to have primarily a decision-making role. The great majority of HECs (78%) reported that they reviewed and recommended policies that govern ethical choices within the organization. Seventy-two per cent of HECs stated that educating the staff or patients on medical matters and counselling physicians were important aspects of their role. Many HECs (56%) also stated that they spent time counselling other health professionals. The data from this study suggested that education and consultation were the committees' primary functions.

Storch et al.'s Canadian survey in 1989 of 142 hospitals (with more than 300 beds) indicated that HECs served a primarily advisory or consultative capacity (compared with 83% in the Avard et al. 1985 survey). Only one hospital reported that their HEC functioned in a decision-making capacity. Some HECs perceived their role as one of policy review and formulation, education, together with the identification of significant trends in bioethics. The two most frequently identified activities of HECs were: (1) reviewing ethical issues in patient care in order to recommend policies and procedure to the hospital board (85%), and (2) providing for continuing education (77%). Other activities included counselling and support activities for physicians (60%) and other members of the health care team (63%). As well, HECs functioned as educators to the hospital community, staff and board members. Reviewing restricted practices and encouraging research were also part of committee activities. Upon request, HECs reviewed treatment decisions on behalf of incompetent and terminally ill patients.

Storch and Griener's 1992 study of five hospital sites found that these HECs were involved in the functions of case consultation, policy formulation, and education. All but one HEC visited had begun to provide case consultation to physicians and other health care providers. One HEC referred to case consultation as "ethics discussions" to avoid any unpleasant connotation (Storch & Griener, 1992, p.20). Three HECs provided consultation using the entire committee, whereas the remaining two HECs delegated the task to two or three members.

One aspect of the work of HECs is the consideration of individual patient care cases. The goal of such a consultation is to assist health care providers in resolving
ethical dilemmas that may arise for patients. Originally, such questions would have been the exclusive territory of the treating physician, but gradually more and more HECs have chosen to become involved in patient care issues when consulted. Some physicians, primarily responsible for the care of the patient, have come to see HECs as offering valuable perspective on patient care (Ross et al., 1993).

The way patient consultations are carried out is one of the most discussed aspects of HECs today (Cohen 1992; Fletcher, 1992; LaPuma & Priest, 1992; Storch, 1991). Although there are many viewpoints, the debate centres on a conflict between those who believe the HEC is too unwieldy and too ill-informed to provide such a service (LaPuma & Priest, 1992) and those who believe that there is inherent value in the HEC consultation process (Cohen, 1992; Fletcher, 1992; Storch, 1991).

Regarding patient consultation, two major areas of concern are co-ordination and access. The first involves how such consultations can be effectively carried out by a large committee. HECs are frequently comprised of several members from a wide variety of stakeholder groups from both inside and outside the hospital (Storch & Griener, 1992). These committees which are difficult to co-ordinate, may well be unable to respond in a timely way to patient care needs. To deal with this problem, some committees have formed small subgroups consisting of a few members who can investigate a case, deal with it or, if necessary, present it to the HEC as a whole. Alternatively, patient consultation may be carried out by a single ethicist. Some commentators have proposed that HECs should not become involved in the patient care consultation field, leaving this area to specially qualified physician/ethicists (LaPuma & Priest, 1992). These specialists would function in much the same way as any other medical specialist, i.e., providing consultation to the treating physician on request.

The second issue, access, involves initiating patient care consultations. Generally speaking, it is accepted that doctors may request such a consultation. The question remains: who else may avail themselves of the process? Some HECs take the position that nurses should not have direct access to the HEC, but should deal with ethical concerns through nursing administration (Fost & Cranford, 1989; Murohy, 1986). Even more
controversial is the question of patient or patient advocate access to HECs. Policies relating to these issues remain in flux.

HECs have three ways of approaching clinical consultations — as a whole, as a small subcommittee of the HEC, or using a single member of the HEC. There are advantages to each approach. The small committees or specialized ethicists can be more responsive to urgent needs. They may be less intimidating to users, and they may develop specialized skills relatively quickly (Cohen, 1992). The use of the whole HEC, although being less responsive to the time constraints of acute patient situations, has been argued by some as more likely to maintain core HEC values (Cohen, 1992; Storch, 1991). Supporters of the HEC in its clinical deliberations criticize the use of a specialized ethicist as an extension of the wrongs which the HEC was established to correct — specifically, the domination of ethical thinking in health care by one closed group (Storch, 1991). Cohen (1992) has considered this situation and has proposed a framework within which all three types of ethical consultation would function within the HEC, depending on the type of problem faced. Her proposal is that a small screening group should review each request for assistance. The screening process is intended to define the scope of the ethical question and determine to whom it should be addressed. Issues that require broad policy-making initiatives should be the responsibility of the whole HEC. Application of policy questions may well be appropriate for individual consultants. Small sub-committees are appropriate where broader experience levels are required in the application of policy.

Little work has been conducted to assess the contributions of HECs. In one study, Day et al. (1994) reviewed the satisfaction of family members involved in patient care consultations at the Cleveland Clinic Foundation's HEC. Although the study sample was small and the findings are not generalizable to every HEC, patients' responses to consultation were used as an outcome measure of HEC effectiveness.

Most HECs reported that they devoted substantial attention to the development of institutional policy. Policies developed, or in process, involved early induction of labour for fetal anomaly, selection of criteria for artificial insemination by donor, eligibility for liver transplant, guidelines for nourishment and hydration of the
terminally ill, and application of the durable power of attorney.

According to Storch and Griener's report (1992), physicians generally supported the idea of HECs, but most never consulted such a committee. These physicians viewed the patient as "my patient" and "my responsibility" (Storch & Griener, 1992, p. 22). Nurses in this study and others were generally more receptive, perceiving HECs as providing a voice for their perspective regarding ethical decisions. Nurses however, were sometimes not aware of the committees' existence. Storch and Griener also concurred with Murphy's (1989) observation that nurses, because of their position in the hospital hierarchy, experienced difficulty initiating an ethics consultation.

Storch and Griener (1992) also discussed the perspectives of other health professionals (social workers, chaplains/theologians, psychologists, in-service educators) and hospital board members. Many in this group commented that the HEC's unique spectrum of viewpoints served to broaden information. As well, hospital administrators unanimously supported HECs. They described HECs as being a valuable resource and providing a "sensitizing influence" (Storch & Griener, 1992, p.24). According to hospital administrators, HECs increased the institution's awareness of ethical issues. Administrators in hospitals with a religious affiliation indicated that the HEC helped to maintain the religious character of the institution.

Hoffman's study (1991a), like Storch and Griener's (1992) survey, reported on the perspectives of hospital personnel who were not HEC members. Contrary to the findings of Storch and Griener's survey, physicians were most likely to consult HECs. Nurses, on the other hand, were least likely to consult a HEC. Social workers stated they would take an ethical dilemma in the first place to the HEC.

Educational offerings ranged widely within the Hoffman (1991a) findings. Newly formed HECs focused on the education of the committee itself. More established HECs concentrated on hospital-wide ethics education programs. Participants at the five hospital sites reported that education also included learning to understand and respect each other's values and perspectives. Staff not holding membership on a HEC often perceived the members' individual learning as directed towards forming their own insular,
and often unapproachable, group.

The functions of HECs in the Jean et al. (1991) study involved case analysis, preparation of guidelines, and education. Researchers found that 34 HECs undertook case analysis. Patient care discussions primarily addressed decisions to treat or not to treat. The next most frequently discussed topics included truth-telling, the dangerous patient, and patients' informed consent. In order of frequency, cases were referred to a HEC by physicians, patients, nursing staff, patients' families and hospital administrators.

Of the 53 hospitals with HECs, 33 of these committees had drawn up guidelines or policy Jean et al. (1991). The policies developed corresponded to the problems encountered in case analysis (i.e., termination of treatment, telling patients the truth, resuscitation policy, treating pain, the issue of informed consent and specific topics such as AIDS, artificial insemination and surrogacy). In this study, 37 HECs wanted to educate hospital staff in ethical matters. The themes discussed were broad and often theoretical — pain, death, informed consent, and major ethical issues.

HECs may also wish to participate in community ethics education. The social influence of hospital policies may even require such education. Clearly, HECs are well suited to lead community examination and discussion of such issues (Slomka, 1994; Weber, 1994).

Generally then the core functions of HECs appear to be development and review of policy, education of committee members and hospital staff, case consultation, and the provision of a forum for airing and resolving disagreements among staff, patients and families.

E. Process.

The unique quality of current HECs that distinguishes them from their precursors, like the dialysis committees or the medical-moral committees is that they are not decision-making bodies. HECs offer the process of discussion as a vehicle to support health care providers and families with support. The HEC is not tied to producing a
decision but rather to the process of ethical consideration.

HECs may provide an outlet for venting opposing views on emotionally charged ethical dilemmas. Such dilemmas inevitably arise, given that HECs are driven by the decision-making of social, legal, medical, nursing and religious forces. These committees, therefore, bring a number of otherwise independent disciplines into a close working relationship for mutual problem-solving. HECs can also be viewed as preserving the humane view in health care. The central functions of a HEC involve aspects of patient care. As sensitivity toward patient care problems continues to grow, more and more HECs may be involved in ethical discussions regarding the everyday care of individual patients. The issues may be simple or complex. Some have criticized the HEC as being too bureaucratic to be helpful (LaPuma & Priest, 1992). While this may be true in some cases, it is unlikely that HECs would continue to be so widely accepted if this were actually the case. The HEC is a grassroots committee concerned with day-to-day issues that need attention, and not just the dramatic, "big ticket", life sustaining issues discussed in textbooks (Staff. Hospital Ethics. 1990). As one HEC member stated, "the ethics committee is the place you go if you want to remember why it is that you went into health care in the first place" (Staff. Hospital Ethics. 1990. p.99).

An interdisciplinary approach is thought to constitute the best balance of perspectives for dealing with ethical problems (Murphy. 1989). However, such committees may not function as intended and may be diverted to other ends. Since HECs function within a rigidly structured hospital environment, power relationships in the hospital may also influence the work of the HEC (Ross et al., 1993). The patient's needs should be the ultimate determinant of the distribution of power for decision-making in a HEC. In other words, all members of a HEC must believe they have the power to improve patient care. HECs have to be aware of the substance of their decisions, and their implications for both the patient and the hospital concerned. Perhaps HEC decisions should address substance and outcome, rather than process and procedural issues.

According to Flynn (1992) the many diverse perspectives within HECs are primarily an illusion. Her study of 40 HEC decisions indicated that the traditional biomedical
viewpoint so endemic to hospital staff, particularly physicians, has dominated HEC considerations, despite the committees' interdisciplinary nature (Flynn, 1992).

In the American Medical Association Judicial Counsel Guidelines (1985) for HECs, it was suggested that members should be "temperamentally suited to making recommendations affecting the welfare of patients" (p. 2698). Members of HECs are equally qualified to discuss ethical concerns, the medical viewpoint necessarily being no more suited to ethical analysis than that of the nurse or the dietician. Bayley (1986) observed that people were attracted to HECs for a variety of reasons. Some members preferred to deal with questions of relationships and personal values. Other members wanted to understand issues, thereby better managing their own feelings and uncertainties. Still others required a place to test new ideas and insights. Overall, HEC members had to distinguish emotional/psychological problems arising from the committee's group dynamics, from substantive, ethical issues.

The recent development of HECs has generated considerable debate regarding both the issue of committee process and the question of whether the HEC can reduce biases that interfere with rational decision-making (Griener & Storch, 1992b; Wolf, 1992). Also, some members may dominate the committee, particularly members from professional backgrounds which tend to intimidate others. Generally, critics of HECs contend that they exist primarily to ease the legal liability problems of physicians and government policy-makers (Staff, Hospital Ethics, 1990).

Wolf (1992) has criticized HECs for repeatedly avowing a commitment to patient-centred values and principles, but failing to pursue such a process. She referred to HECs as a "due process wasteland" (p. 84), claiming they do not honour the values underlying a participative process when they engage in case consultation. For example, patients were seldom alerted to the existence of a HEC as a resource in their institution, or given the tools for direct (or substitute) participation. In particular, Wolf focused on the lack of patient involvement in the central activity of HECs. She criticized HECs for falling into a pattern which the principles underlying modern bioethics will no longer tolerate — expert decision-making without direct patient involvement.
Perhaps the lack of commitment by HECs to a patient-centred process reflects a confusion of the goals of the HEC. Wolf (1992) referred to HECs as having "a kind of double identity" (p.85). HECs were established as a resource for patients, yet in reality, are perceived as existing to serve the health care providers. Furthermore, it seems likely that HECs dominated by physicians and other health care personnel will, inevitably, fail to always place patient needs at the centre of their deliberations (Bayley, 1986; Flynn, 1992; Wolf, 1992).

According to Wolf (1992), any established committee is powerful. A HEC functioning in an advisory position may wield significant power. In Canada, existing HECs have been supported by the Guide to Accreditation of Canadian Health Care Facilities 1986 and the Ontario Hospital Association. As well, ethics committees in individual hospitals may follow a mandated or defined course approved by the hospital administration. At present, Canadian HECs do not have a legal obligation to involve the patient in their considerations.

HECs in Wolf's opinion can lead the way in attending to patients' rights and interests and, at the same time, their needs for care giving. "Ethics committees now wield sufficient influence over the fate of real patients that they must do so responsibly, accountably, and with some guiding rules" (p.94). As an example of this, one of particular interest to the investigator, a HEC could serve as a reliable resource for treatment/management decisions for the agitated elderly, where competence and substitute decision-making are fundamental issues.

Myers concurred with Wolf (1992) in maintaining that HECs should be designed primarily to assist the patient. However, whereas Wolf took a middle position, Myers indicated that a HEC's role was to assist patients, rather than the health care team or institutions. "The HEC must be preserved to be devoted to the needs of patients, only collaterally benefitting their surrogates and health caretakers insofar as they faithfully serve them." (Myers, 1992, p.20). Health care providers and institutions, according to Myers, have their own interests. As health care providers' roles change within hospitals, this will mean changes in the role of HECs. Myers (1992) recommended
that the HEC view itself as an independent agency, often working at odds with the hospital's overall viewpoint, but with a patient-centred focus.

In general it seems clear that while the advocacy of patients' rights and interests has been accepted as one of the main functions of HECs, it is far from clear that this function has been implemented to date.

E. Responsibility

HECs are not a replacement for the courts. These committees can assist the patient, family, and health care provider in reaching a clinical decision. HECs must be cautious, however, not to bring inappropriate pressure on competent adults (or substitute decision-makers) to make particular decisions. As well, HECs cannot infringe the rights and responsibilities of the health care provider in the care of its patients. Some HECs were criticized for protecting the institution's interests and not those of the patient (Wolf, 1992; Myers, 1992; Levine, 1984). Clearly, as studies and position papers reported, physicians — and in effect the medical model of decision-making — have dominated HECs (Storch & Griener, 1992b; Wolf, 1992; Flynn, 1992). Ideological or religious beliefs may also dominate in some ethics committees. Overall, a HEC is a resource that should be used to contribute significantly to patient health care (Levine, 1984), not merely to expand existing hospital bureaucracy.

It is clear that the desire to avoid medical malpractice claims drives much of the administrative process of the modern American hospital (Annas, 1991). The basic principle behind liability is that a health care provider will be liable where s/he fails to meet the standard of conduct of a reasonable professional in a similar situation. The establishment of HECs has been criticized by some as a way to avoid personal responsibility for questionable health care practices (Annas, 1991). The composition of a HEC, both in terms of size and variety of membership, appears inherently reasonable because committee decisions are formed through consensus. A decision made by a HEC is therefore more likely to be accepted by a court as being appropriate. An obvious concern is that this consensual process not shield a health care provider from ultimate liability for
his/her conduct.

In 1986, an American HEC was named a defendant in a lawsuit brought by a patient who had been force-fed by hospital staff following a patient care consultation. Staff physicians had consulted the HEC when the patient refused to eat and also refused to consent to alternate methods of feeding. The plaintiff indicated that the HEC was named in order to ensure that all parties potentially responsible for the involuntary feeding of the patient would face a civil lawsuit (Rust, 1986).

The potential liability of hospitals and health care practitioners is likely to be reduced in cases where an action was supported by a HEC consultation.

G. Consensus

Roughly parallelling the interest in HECs, has been the rise in commitment to consensual decision-making in health care institutions (Caws. 1991). Consensus may be defined as the agreement of a number of individuals that the decision they have reached constitutes the best outcome among a number of alternatives (Tong, 1991). In clinical patient consultations, consensus represents what clinicians can agree is best for the patients. Clearly, "consensus or agreement of opinion on the part of all concerned, is categorically distinct from compromise or agreement by mutual concession" (Braaten, 1987. p.347). Consensus can refer either to the process involved in reaching a decision or the decision itself (Caws. 1991; Tong, 1991). Until recently, the concept of consensus was found more in economics and politics rather than philosophy or health care. (Caws. 1991). Since 1970, however, consensus has been increasingly viewed by health care providers as an essential goal in the decision-making process (Veatch. 1991).

The schedules of physicians today and the complexity of patient needs are such that many patients are treated not by individual physicians, but by teams of health care providers (Caws, 1991). These teams must develop consistent plans for treating patients, a process which leads naturally to consensus-seeking. Liability for medical malpractice is a major concern for all health care providers. The cost of liability is such that it enters into nearly every decision in the modern hospital. Decisions that are
controversial or that have a liability risk may cause hospital administrators and the
decision-makers themselves to seek the comfort of consensus (Caws, 1991). In some
American states, protocols of clinical conduct approved by HECs are exempt from liability
by law. Finally, the technology surrounding modern health care may require the
participation of a number of individuals; again, consensus is seen as the most successful
way to operate in such an environment (Caws, 1991).

That experts in clinical medicine can, by consensus, determine the correct
clinical intervention, has been widely accepted (Veatch, 1991). Such experts have been
identified on the basis of ability to develop particularly reliable approximations of what
is clinically right. Yet a number of flaws have been identified within this assumption.
Although decisions can be reached by health care providers in many ways, it is seldom that
consensus is really achieved. Decisions may arise from a vote among the decision-makers;
by tacit or express agreement to accept another's views; by intimidation of or domination
by a member or members of the group; by mutual exhaustion of the ability to debate; by the
failure of disadvantaged decision-makers to participate because of profession, sex, age,
experience or other factors. Decisions arrived at in such a manner may superficially
resemble consensus but, in reality, they distort the consensus model of decision-making.
To believe that in such cases consensus has really been achieved, is to be greatly mistaken
(Veatch, 1991).

Additional factors affecting the validity of consensus are the personal qualities
of the decision-makers and the questionable issue of handing over decision-making
authority to others. Over the last twenty years, Veatch (1991) has developed a theory to
explain his scepticism about committees of expert decision-makers. His theory refers to
the process as the "generalization of expertise", which he describes as, "the phenomenon
of presuming that because one was an expert in the science of a particular condition, one
was also an expert in the clinical, valuative judgements about what ought to be done with
that condition." (p.430)

Veatch (1991) sees no logical link between medical training and value judgments.
Physicians or other experts are as likely as anyone else to make ethical mistakes.
Consensus cannot, even when it truly exists, transform a group of experts into a group of moral authorities (Tong, 1991). Furthermore, moral questions are not the exclusive domain of experts in health care. Depending on the individual's philosophical or religious orientation, moral issues may remain personal or the responsibility of spiritual leaders. Similarly, morality only has validity when it is personally endorsed. "Secondhand ethics is no substitute for firsthand ethics in a community of equally autonomous and moral agents." (Tong, 1991, p.415). Tong (1991) and Veatch (1991) support the primacy of the individual in making ethical choices, insisting such choices not be delegated to others.

H. Multidisciplinarity/Interdisciplinary

The multidisciplinary composition of HECs is cited as an essential quality of such committees (Ross et al. 1993). HEC members are portrayed as human beings who realize that the diversity of the conversation is a crucial aspect of ethical analysis.

Michel (1993) describes HEC members as a multidisciplinary "group of thoughtful people who read a lot about bioethics and continually struggle within themselves with the dilemmas of individual health care decisions, and with the larger injustices of the health care system as well" (p.246). The literature related to HECs reveals an almost universal acceptance that HECs should be multidisciplinary in composition and interdisciplinary in nature (Miedema, 1993). The reasons for this are seldom fully considered beyond an observation that different disciplines will bring different points of view to ethical issues and will be able to negotiate these differences in an interdisciplinary way (Stadler, 1994; Miedema, 1993). Deliberations involve discussions among equals, relating to a shared sense of moral accountability (Miedema, 1993). This shared responsibility can provide the basis for equal moral authority and suasion in ethical discussion.

While there is disagreement over what perspectives are brought to HECs by members of various disciplines, opinions concur that members with a background in diverse disciplines will bring different perspectives to the discussion (Miedema, 1993; Ross et al, 1993). For example, Meidema argues that nurses hold the concept of caring as a defining quality of their profession and that no other profession has the same
perspective. He argues that different self-definitions lead to different values, which in turn lead to value conflicts which need to be resolved in the HEC. Miedema (1993) identifies nurses as being both advocates for patients, families and nursing staff, as well as experienced communicators with patients, families and educators. By contrast, Ross et al. (1993) indicate that nurses see HECs as forums for technical expertise. These views, although they are very different, are not incompatible.

Another reason identified for having multidisciplinary HECs is that this gives the HEC credibility among those groups represented in the membership. The presence of HEC members from one's own discipline increases the acceptance of the HEC by all staff (McCardy, 1994). It is clear from the literature, that the concept of an HEC composed of members from a variety of professional backgrounds appears to enjoy wide acceptance at this time.

I. Summary and Critique

Generally, the studies reported used survey methods which have a number of limitations (Polit & Hungler, 1991). The information tends to be somewhat superficial. Complexities relating to the origin, functions and processes of HECs were not probed in depth. The studies were more extensive regarding the provision of an overview of the role and functions of HECs, than they were in providing intensive analysis. As well, survey methods do not permit the researcher to infer cause-and-effect relationships or to manipulate variables.

HECs have been well established in the US for several years (Cohen, 1990). In Canada, they are a more recent arrival but are growing quickly (Avard et al., 1985; Storch et al., 1990; Storch & Grienier, 1992a; Storch & Grienier 1992b; Jean et al., 1992). Committee composition alone does not tell us whether these committees serve any useful purpose in patient care (Avard et al., 1985; Wolf, 1992; Flynn, 1992). However, a few studies have made efforts to assess HEC success and effectiveness (Day et al., 1994; Griener & Storch, 1992; Smith et al, 1992; White et al, 1993; Scheirton, 1993). The following groups appear to be invariable members of HECs: physicians, nurses, clergy,
ethicists and/or health administrators. Many of these committees are no longer in their infancy, but their effectiveness as a resource for patient-centred care still remains unknown.

There is little information about how the different perspectives of the members of HECs contribute to better patient care clinical decisions. Some studies indicated that HECs spent most of their time on policy issues, closely followed by educational activities (Avard et al., 1985; Storch et al., 1990). As Storch and Griener (1992b) indicated, there has been no evaluation of HECs with respect to their patient consultation activities although there is a trend toward greater involvement in this area. Research into the interdisciplinary interaction of HEC members is also lacking.
CHAPTER THREE
PROCEDURE AND METHODS

I. Study Design

In order to describe Toronto-area HECs 10 years after their inception, an exploratory descriptive study design was undertaken. It combined two methods: a questionnaire which was delivered to every HEC member prior to the focus group interview and a subsequent focus group interview with every participating HEC. Using focus group interviews, the investigator collected qualitative data on the perceived role and functions of each HEC. A clinical scenario served as a starting point of focus group discussion. Before describing the methodology, I will outline the basic assumptions of the study, the protection of subjects and the pre-testing procedures.

II. Assumptions

The following assumptions informed the background to this study.

- The unique role of a HEC is to articulate ethical issues and provide a multidisciplinary approach for the analysis of such issues.

- HECs address clinical situations as they arise, in order to identify values appropriate to health care decision-making and to indicate possible solutions (Newton, 1990).

- HECs have a strong sense of inter-professional ethics; members respect one another as professionals and as persons and they respect the moral sensitivities of each member of the committee (Linfors, 1988).

- Ethical decision-making is influenced in part, by a member’s professional/occupational or lay disciplinary background as well as his or her life experience.
HECs engage in careful and reasoned analysis of policy and practice issues, using the forum for discussion, clarification, dialogue, education, and advice, in order to increase individual, departmental, and institutional sensitivity to clinical-ethical decisions. HEC members do not have to decide the ultimate rightness or wrongness of an issue, but members strive to reach consensus in areas of conflict or question (Linfors, 1988).

HECs have some familiarity with ethical issues relating to the care of the elderly patient (the subject of the clinical vignette).

III. Protection of Rights of Human Subjects

A. Procedure for Obtaining Informed Consent

While approval was sought for the research protocol from the University of Toronto Human Research Services office (UTRS), a letter was sent to participating hospitals (Appendix A) and the Chairs of HECs at selected hospitals, requesting approval to conduct the investigation, obtain lists of potential participants, or the opportunity to speak to relevant HEC members and the committee as a whole (see Appendix B). HEC chairpersons were asked to make available a copy of their committees' terms of reference and any historical or developmental information regarding their committees' inception, composition, function and reporting relationship in the hospital (see Appendix C).

The investigator met individually with the Chairpersons of potential HECs and Committee members to explain the study and ask for participation from all HEC members (see Appendix D). Potential HECs were asked to propose possible dates for focus group meetings. A confirmation letter concerning the topic for discussion, as well as the date of the HEC focus group, was circulated to committee members who had agreed to participate (see Appendix E). One week prior to the meeting, the chair of the HEC was contacted by telephone to confirm the participation of the HEC (see Appendix F). Written consent was obtained from those subjects who attended the focus group interview and agreed to
participate and have their remarks recorded, using the participant's consent form (see Appendix G).

After approval to conduct the study was obtained from UTRS and participating hospitals, the focus group interview was pretested. The investigator assessed the completeness and comprehensiveness of the focus group interview in terms of the group's ability to understand and indicate responses. This included the group's emerging perceptions. As well, the investigator sought some common way to represent areas in which participants both agreed and disagreed. It was also necessary to determine how group members came to some of their realizations about the sources of their various levels of agreement (Morgan, 1988). One pretest was conducted with Hospital A with satisfactory results. The pretest focus group members were advised that they were participating in a pretest, and that their interview would form part of the useable data in the study.

B. Safeguards to Preserve Confidentiality

Before data collection commenced, all required ethical approvals were obtained. To ensure informed consent, the investigator discussed the study's objectives and participation requirements with potential focus group participants, and a written consent was obtained. The focus group interviews were recorded verbatim by a professional reporter using audio tape recording and/or a dicta typing machine. A copy of the participant's consent form (Appendix G) with the investigator's name, thesis supervisor, and telephone number, was given to each participant for his/her future reference. Consents will be retained for the required five years by the investigator.

To ensure confidentiality and privacy, the hospital location and the participants' names were coded; and only the code names appear on the group's transcript for that focus group discussion or on the sociodemographic profile sheets. A code book with subjects' names, hospital location and code numbers was kept in the investigator's home, only accessible to the investigator during the data collection period. Upon completion of the study, the code book was destroyed. Names of the subjects and participating hospitals will not appear in any verbal or written report of the study.
C. Risks and Benefits

Participation or non-participation in the study was entirely voluntary. If a subject wished, they could leave the focus group discussion. Some participants did leave the discussion due to other commitments. If, for any reason, a subject was unable or unwilling to complete the interview, the subject was asked to provide the reason for termination. One subject refused to complete the HEC Profile questionnaire and declined to give a reason for doing so. Subjects were not paid to attend the focus groups and could not benefit directly from participation in the study; however, the results obtained may contribute to a better understanding of the role of HECs.

IV. Pretesting

The pretest focused on the nature of the questions, characteristics of the participants, their interactions, and the moderator’s procedures (Krueger, 1988). In the first instance, experts in the field of geriatric/psychogeriatric care and HECs were asked to review the focus group topic guide. It was anticipated that such experts would have had some experience with focus groups, and would be familiar with the purpose of the study (Krueger, 1988). The second pretesting procedure involved conducting the first focus group interview. The investigator/moderator once again reviewed not only the questions and probes but also the environment of the interviewing room, seating arrangements, composition of the participants, and moderator procedures. As well, the investigator determined the ease of the process and assessed the CEDDG’s sensitivity and meaningfulness. Upon completion of the focus group interview, questions were evaluated for clarity and completeness, appropriateness, and adequacy; consideration was given to the need for additions or deletions. A final procedure sought comments and concerns from the participants themselves. All participants were advised that they were participating in a pretest, and that the data obtained could be excluded from the final study.

Refinements and alterations were not required. The data from the pretest group were included in the analysis. Minor revisions, were suggested by the pretest subjects, and these did not require further UTRS approval.
V. Focus Group Interviews

The study was mainly based on focus group interviews using the modified constant comparative method from Glaser and Strauss’ Grounded Theory (1967). Focus group interviews were selected for this study because they provided a familiar group forum for HEC participation. The goal of the focus group was to conduct an interactive discussion thus eliciting from HECs multiple points of view about their role, perceptions, beliefs, attitudes and experiences. (Glaser & Strauss, 1967).

A. A Brief Background About Qualitative Research

Qualitative research is a broad term referring to a variety of research methods originating in philosophy, anthropology, psychology and sociology. These share a common emphasis on a holistic understanding of the context or situation within which experience arises (Brockopp & Hastings-Tolsma, 1995). Researchers from the social and behavioural sciences use qualitative research to understand issues related to human behaviour and functioning (Strauss & Corbin, 1990).

Quantitative and qualitative methods share a number of similar features, such as problem identification, sampling design, data collection, data management and analysis (Crabtree & Miller, 1992). However, qualitative research methods involve some unique factors that include (a) personal involvement with informants in their natural setting; (b) in-depth interviewing and detailed descriptions of observations and conversations; (c) self-reflection and introspection in order to bring forward one’s own inner feelings and intuitive responses to the data; (d) openness to the discovery of the unexpected or un hypothesized; (e) willingness to redirect research as new insights and understandings emerge from the simultaneous process of data collection and analysis; and (f) management of often large volumes of descriptive data using a variety of approaches to interpret the data. Pope and Mays (1995) describe the goal of qualitative research as the development of concepts to understand social phenomena in natural settings, thus providing a balanced perspective to the meaning, experiences and views of the participants in those settings (Powers & Knapp, 1995).
Quantitative research is based on assumptions of prediction, manipulation and control of data, (Brockopp and Hastings-Tolsma, 1995). Hypothesis testing underlies quantitative methods.

Qualitative research is another way of knowing. “Unlike quantitative methods of conducting research, qualitative strategies are useful for developing facts and concepts about an area of interest that has received little research attention, or to explore an area that has not yet been explored from a qualitative perspective” Brockopp & Hastings-Tolsma. 1995, p. 235). Morse (1986) defines qualitative research as largely an inductive method, which means bringing the reality of the phenomena under study into context. In other words, qualitative research involves a process of trying to develop an understanding of human behaviour and functioning by studying specific instances of behaviour and trying to deduce general truths. According to Morse and Field, (1995) qualitative research “...enriches one’s life, it captures one’s soul and intellect” (p. 1). Qualitative inquiry is further described as a process that strives to make sense of this reality by documenting, describing, identifying patterns and concepts, recognizing the linkage or relationship between concepts, and creating theoretical explanations.

Qualitative research may, but need not, have as its product the development of theory. “Qualitative researchers do not usually test a priori conceptual frameworks but rather inductively develop strong and resilient theory” Morse & Field, 1995, p.7). Cobb and Hagenmaster (1987) characterize qualitative research as inductive, allowing the researcher to penetrate the social context where events occur, so that the meaning of these events can be understood from the participants’ view.

Eisner (1981) makes a distinction between quantitative and qualitative research by calling the former the scientific mode and the latter the artistic mode. The quantitative research approach has been criticized for being reductionistic because of its limited “laboratory-bound view of reality” (Haase & Myers, 1988). Krenz and Sax (1986) were concerned that quantitative research was unable to produce "whole" truths. The research problem may be described objectively, analyzed statistically and presented without bias. However, in quantitative research, the relationship of results to reality
is only assumed, and is not investigated any more systematically than in the qualitative approach (Borman, Lecompte and Goetz, 1986; Krenz and Sax, 1986). Shepard (1987) referred to the quantitative approach as the traditional or scientific research method. The scientific method she describes involves rigorous hypothesis testing in a laboratory setting. Even if a laboratory setting is not used, the researcher remains a neutral observer (Morgan & Smircich, 1980). Quantitative research is, consequently, minimally involved with research participants (Borman et al., 1986).

Qualitative research has begun to emerge recently as an important methodology (Bockman & Rieman, 1987). A major criticism of qualitative research, however, is that the parameters of a study are defined and altered as the study progresses, making replication impossible and findings overly subjective (Borman et al., 1986; Haase and Myers, 1988).

The combining of quantitative and qualitative strategies has been suggested as a way to define a body of knowledge unique to clinical practice in health care (Shepard, 1987; Bockman and Riemen, 1988). As Haase and Myers (1988) state, since nurses deal with clinical reality on a day-to-day basis, nurse researchers have found a combination of quantitative and qualitative approaches to be compatible with what they observe. The use of both quantitative and qualitative research broadens the view of reality by taking into consideration the experience of both the investigator and the research subjects (Wilson, 1985).

B. A Brief Background About Focus Group Interviews

1. Definition. Focus groups are used in qualitative research, variously referred to as focus group interviews, focused interviews, and group depth interviews (Vaughn, Schumm & Sinagub, 1996). A focus group is both a self-contained research method and a data collection technique (Morgan, 1988).

The use of the focus group interview method constitutes one specific technique within the broader category of group interviewing for purposes of collecting qualitative data. The hallmark of the focus group method is the explicit use of group interaction to generate data and insights relatively inaccessible in the absence of interpersonal
interaction (Morgan, 1988). A focus group interview can yield data about the feelings, perceptions and opinions of small groups of participants regarding a specific problem (Basch, 1987). Krueger (1988) defined the focus group interview as a "carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive non-threatening environment" (p.18).

The focus group interview permitted access to several HEC members at the same time allowing the investigator to verify data as it was being generated. Meeting together in a focus group was ideal because the HEC habitually meets as a committee to discuss ethical issues, even though the group process in a focus group is not the same as the group process that takes place during an HEC meeting.

2. History of Focus Groups. The focused interview method was principally developed by Lazarsfeld and his colleague Merton, who used the method extensively in the evaluation of war time radio propaganda, using groups of civilians and military personnel (Merton, Fiske & Kendall, 1990). In 1946 Merton, a sociologist, wrote about the focus group interview as a research method and substantially refined the model (Merton & Kendall, 1946). Merton and Lazarsfeld continued to refine the method over the next ten years and developed a standard method and established standards of scientific validity (Merton, Fiske & Kendall, 1956).

Despite the maturation of the Focus Group Interview method, the direction of social science research had shifted to quantitative research methods, and for a period of approximately fifteen years, the focus group method was only used in a limited way in academic settings. The social sciences, and in particular sociology and psychology, began demonstrating a deepening interest in the focus group interview as a research method from approximately 1975 onward (Rhyne, 1995). Focus groups permit the improvement and testing of other research methods such as questionnaires and surveys and often are confirmatory of other methods or, alternatively, used in the pilot or early stages of research development. Gradually, more disciplines have turned to the qualitative information available through focus groups.
In the health sciences, focus groups have been used for a number of purposes. The synergy of the group process often produces in-depth responses that can be used to explain or clarify data generated by surveys, to generate hypotheses, and to establish items for interviews and questionnaires (Reisken, 1992). See for example, Howard, Hubelbark and Moore, 1989; DesRosier and Zellers, 1989. In addition, focus group studies have been conducted in nursing and in the areas of health education and teaching (Bryant and Gulitz, 1993; Mallis and Lansing, 1986; Nyamathi, 1990; Heiman-Rutain, 1985; McIntosh, 1981; Lakshear, 1980; Conrad et al, 1994; Alexander & McCullough, 1981, Flexner. McLoughlin & Littlefield, 1977, Heimann-Raatin, Hanson, Perego, 1985, Richter, Bottenberg, Roberto. 1991).

3. Utility. The need to explain and clarify data provided the basis of the focus group research approach adopted in this study. The focus groups were expected to yield information, impressions and/or perceptions on HEC role, to generate new hypotheses, to stimulate new ideas and concepts, and to determine how participants talk about their role and what potential problems they identify (Bellenger, Bernhardt & Goldstucker, 1976).

4. Determining the Size of the Group. Focus groups are planned in a series in order to detect patterns and trends across groups (Krueger, 1994). Ideal group size varies depending on the source. For example, Stewart and Shamdasani (1990) suggest 6 to 12 focus group participants. According to these investigators, a group of fewer than 6 people makes the discussion dull and boring, while a group of more than 12 participants is too large for the moderator to manage. Morgan (1988) recommended a focus group size ranging between 6 and 10 participants. "The traditionally recommended size of the focus group has ranged from 6 to 12 participants" (Krueger, 1994, p.78). A group size of 10 to 15 individuals was reported by Polit & Hungler (1991). Some focus groups have been conducted with as few as four participants and as many as 30, but Krueger (1994) recommends between 6 and 9 as ideal. Groups with 4 to 6 participants are referred to as "mini-focus groups" and demand a greater contribution from each member (Krueger, 1994; Morgan, 1988; Stewart &
Shamdasani, 1990). The opposite, of course, occurs in a larger focus group, where individuals participate to a lesser degree, believing the group as a whole can carry the discussion (Morgan, 1988).

5. Determining the Number of Focus Groups. One focus group is never enough (Morgan, 1988). In practical terms, unexpected situations may occur. For example, one may encounter the "cold" group, in which participants are quiet or reluctant to share information (Krueger, 1994). As well, as a result of internal or external factors, a single focus group may produce idiosyncratic results. For example, one participant may dominate the group, influencing or limiting other participants, or an external event may divert the group's attention, or an inflammatory comment from a group member might create unrest among other participants (Krueger, 1994).

The specific goal of the research, determines the number of groups to be conducted. An exploratory study which imposes a structured questioning strategy will require fewer focus group interviews than an unstructured group (Morgan, 1988; Crabtree & Miller, 1992). If the aim of the study, for example, is to obtain a perspective on a given topic, only 3 or 4 groups will be required if the moderator facilitates with a high degree of stimulation. However, if detailed content analysis on a broader range of topics is required, and the moderator's style is relatively unstructured, then 6 to 8 (or more) groups will have to be conducted (Morgan, 1988; Krueger, 1994; Crabtree & Miller, 1992).

Although the issue of structured or unstructured strategies for focus groups is a consideration, theoretical saturation determines the number of groups needed (Krueger, 1994). Theoretical saturation is a qualitative research concept and is defined as the point at which the moderator of the group can anticipate what information will next emerge (Glaser & Strauss, 1967; Krueger, 1994; Calder, 1977). In other words, the point at which further discussion among the focus group participants does not produce or yield any new ideas. Generally, the first two groups produce a considerable amount of new information, but at the stage of the third or fourth group, emerging themes are beginning to recur (Krueger, 1994; Morgan, 1988). If new information continues to be produced, focus group
interviews should continue. However, if no new data is emerging, saturation has been achieved and no further focus groups are required. Krueger (1994) suggests evaluating the situation after three focus groups, keeping in mind the nature of the study, the topic, and the homogeneity of the group participants.

6. Group Homogeneity vs. Heterogeneity. Traditionally, the guiding principle in forming a focus group is homogeneity (Kingry, Tiedge & Friedman, 1990). The goal of the study determines the characteristics or specifications of the population of interest. People who participate in a focus group discussion should have something to say about the topic and be comfortable saying it to each other. Focus groups are intended to draw on variations and differences among the content of participants' talk, not on conflict. Homogeneity is desirable but sufficient variation among participants is needed to promote contrasting debate and discussion on topics (Krueger, 1994). According to Morgan (1988), "... the more homogenous the groups are in terms of both background and role-based perspectives, the fewer you need" (p.42).

Important to the present study, is the following quote: "People who regularly interact, either socially or at work, present special difficulties for the focus group discussion because they may be responding more on past experience, events, and discussions than on the immediate topic of concern" (Krueger, 1994, p.18). Using pre-established groups of individuals, however, may be the only method to collect focus group data when a limited number of potential subjects exist as is the case in the present study.

7. Moderator's Role. The role of the moderator is central to any focus group discussions. Although the moderator usually prepares advance questions, in practice the moderator is the research instrument actively directing discussion, encouraging participation, and probing participants, without biasing responses (Basch, 1987; Nyamathi & Schuler, 1990). The moderator is responsible for creating a non-threatening, supportive atmosphere for participants. Moderators facilitate interaction among group members, interject probing comments, use transitional questions and periodical summary
statements. They avoid interfering with the group's discussions. "Focus group interviews must be conducted with the assumption that individuals do not necessarily come to the interviews with well-defined, unalterable opinions on topics, that participants may actually shape their opinions during the interview, and that the primary intent of the interviews must not be to coerce or intimate participants into espousing a particular point of view" (Vaughn, Schumm & Sinagub, 1996, p. 153). Moderators are sensitive to participants' non-verbal responses, drawing out shy participants and directing attention away from those dominating group discussion.

The moderator's role in this study was to control the set of questions and facilitate the dynamics of the group. She did not enter into the discussion in any substantive way, but kept the discussion focused on topic (Flexner, McLaughlin & Littlefield, 1977). As per Basch (1987), she was responsible for maintaining the psychological climate throughout the group's discussion. She strove to be non-judgmental, responsive to each participant's contributions and ready to explain to the group the purposes of the interview. "The moderator must... attend to the psychological and interpersonal aspects of group process, as well as being task oriented" (Basch, 1987, p. 416).

The moderator ensured that the desired set of questions was covered, but that this did not occur at the expense of participants expressing their own opinions (Morgan, 1988). She was flexible in adjusting the order of questions from group to group. She was prepared for those moments when participants brought up controversial topics, or went off track in their discussions. She emphasized that she wanted to hear as many different stories and points of view as possible. She advised participants that there were no right or wrong answers. She established the "ground rules" for discussion and gave all members of the focus group an opportunity to contribute to the discussion (Stewart & Shamdasani, 1990). This sometimes required encouragement to specific individuals to participate, and limit-setting on particularly assertive members.

The moderator was consistent from group to group with respect to the degree of structure she provided (Rhyne, 1995). Generally, she: (a) covered a maximum range of
relevant topics, (b) explored participants' feelings in some depth, and (c) analyzed the personal context that participants assume in their responses (Morgan, 1988).

The moderator was aware of the possibility of personal bias (Kennedy, 1976). Personal bias arises when the moderator welcomes opinions consonant with his/her own views and discourages those which are opposed (Rhyne, 1995). Moderators can unknowingly introduce bias by reinforcing and particularly welcoming points of view which are similar to the study's objectives. In this study, bias was countered by the presence of an observer and a transcriptionist and the detailed review of each focus group transcript.

C. Analysis of Focus Group Data

The precise objectives to be achieved by the use of focus groups need to be clear from the outset. This determines how the inductive method makes use of the qualitative data which the groups produce. "Focus groups are not intended to develop consensus, to arrive at an agreeable plan, or to make decisions about which course of action to take" (Krueger, 1994, p.19). The focus group presents a natural environment, whereby the members of the group are enabled to influence and be influenced by each other. Although the use of focus groups precludes some forms of analysis, such as quantitative approaches using statistical techniques, this method does not specify the data analysis procedure to be used as long as it is systematic and verifiable (Kingry, Tiedje & Friedman, 1990).

In this study, focus group interviews were tape recorded and transcriptions prepared, forming the raw data for the study. The investigator/moderator took written notes during and after each group interview. According to Morgan (1988), these notes are not part of the data collection but rather form part of the analysis.

Carey and Smith (1994) have clarified the way in which the focus group functions as the unit of analysis. They disagree with qualitative researchers who examine focus groups only at the group level. These nurse researchers also include the "... consideration of the data at the individual level as well as the comparison of the individual data at the group level." (Carey & Smith, 1994, p.125). Analysis at the group level includes interactional and sequential interpretation. At the individual level, participant
responses and behaviours are examined within the context of the group. For example, one participant's response may be affected by a comment from another participant in the group who answers, adds to, or clarifies a question asked of all focus group participants.

1. Process

The smallest unit of text containing themes or properties is given various names by different researchers (Rhyne, 1995). Kirby and McKenna (1989) referred to these units of text as "bibbits". Patton (1980) and Agar (1986) as "slices". "stripes" or "scraps" and Tesch (1990) as "data segments". Conceptually, these terms all relate to brief extracts of text from any source capable of conveying a concept of interest to the study. Depending on the type of analysis intended, any of these terms may refer to segments of data as brief as a word or as lengthy as several pages. The investigator must decide based on the nature of the study, what size of data segment is most useful. By breaking down the text, the investigator begins a conceptualizing process which involves "... taking apart an observation, a sentence, a paragraph and giving each discreet incident, idea or event something that stands for or represents a phenomenon" (Strauss & Corbin, 1990. p. 63). Data segments usually involve several lines of text as this length helps the investigator to maintain the group context of the focus group. In this study, data segments of several lines were usually used.

A grounded theory based analysis is useful for understanding focus group data. In classic grounded theory analysis, the researcher does not impose any preconceived notions on the data analysis. Data segments are coded to identify related ideas and reviewed repeatedly to determine possible relationships. Where groupings of related ideas can be identified, these data segments are organized into "categories". The categories are further analyzed to determine if patterns of relationship exist between the categories. Where links and relationships can be established for all of the data, substantive theory will emerge (Kirby & McKenna, 1989). The advantage of developing theory this way is that the theory will be consistent with all of the data and is easily understandable by both laymen and experts (Glaser & Strauss, 1967). The method is consequently reliable given
the close link between the data and theory. Although the theory may be modified or reformulated, it is "destined to last" (Glaser & Strauss. 1967, pp.3-6).

The main modification introduced into grounded theory in this study was the use of categories derived from some source other than the original data (Rhyne. 1995; Kirby & McKenna, 1989). Other sources included the pre-group questionnaire, the moderator's guide, and the clinical scenario. This has been advocated by Rhyne.(1995). The advantage of this method is that, while the validity of grounded theory is maintained, the development of categories is facilitated by the use of coding derived from the research goals of the study.

2. Quality of Focus Group Findings The concept of validity is determined by the degree to which a selected procedure measures what it is supposed to measure. "Focus groups are valid if they are used carefully for a problem that is suitable for focus group inquiry." (Krueger. 1994, p.31). Researchers are expected to follow agreed upon procedures in focus group interviews in order to establish validity of the findings. More specifically, focus group validity derives from the use of valid procedures and also from a careful consideration of the context of the problem.

Generally, focus groups have a high face validity, which can be assessed by the credibility of the comments of the participants to a target audience (Krueger. 1994).

3. Advantages/Disadvantages The advantages of focus groups are that they provide a flexible process and rich source of easily understandable data at a reasonably low cost (Krueger. 1994; Morgan. 1993; Gray-Vickery. 1993). In addition, the investigator can interact directly with participants and, later, review responses through tapes and transcripts. This is particularly important when dealing with such sensitive topics as will be reported in this study. Referring to focus groups. Basch (1987) discussed the sometimes synergistic and serendipitous benefits of this research method. Synergism refers to the phenomenon of producing a wide range of linked information and thereby serendipitously uncovering important findings that would be more difficult to obtain in an
individual interview.

However, the moderator has less control in a group interview than they do in an individual interview. As a result, focus group members are able to influence the course of discussion with the possibility of detours, and the raising of irrelevant issues. The moderator requires the skill to respond to such situations. Focus group data are difficult to analyze because there is no preordained protocol for analysis. Qualitative data analysis is responsive to the data itself. That is, the researcher has to make decisions and refine the analysis process while the analysis is ongoing. The whole structure of a qualitative study needs to be adjusted and fine-tuned during the data collection and analysis to accommodate data emerging from the research (Krueger, 1994). Participants' comments must be interpreted within the context of the social environment or setting of the group. Caution is required in determining that participants' comments are reported in sequence and within the natural context of the focus group setting.

Each focus group has its own personality and unique characteristics. It is important to balance the "idiosyncrasy" of individual groups with the ideas and opinions of other groups.

Focus groups can be difficult to assemble. Participants must arrive at a designated location at a specific time. The logistical problems of scheduling and coordinating the meeting of participants can be one of the most frustrating parts of a focus group study. This is particularly true when the subjects are drawn from working professionals. Another consideration in focus group methodology is the time and cost involved in subject recruitment (Krueger, 1994; Morgan, 1993; Kingry, Tiedje & Friedman, 1990). Access to such segments of the population as political leaders, physicians and executives can be difficult and financially costly.

Focus group discussions are generally not appropriate for experimental designs or for drawing inferences about larger populations. One obvious drawback reported by Basch (1987) is that participants must be able and willing to express their views. Nyamathi and Shubert (1990) discussed the argument that focus groups force participants to comply with the norms of the group. Explaining to participants that one statement or behaviour is not
more desirable than another protects subjects from forced compliance (McQuarrie & McIntyre, 1987). Clearly, the verbal agility required for focus group participation would disqualify certain population groups such as those with any type of verbal or hearing impairments, or those not comfortable with the spoken language of the group. Also of importance is a trusting, comfortable and secure setting for conducting the interviews. White and Thomson (1995) recently proposed an "anonymized telephone" based focus group methodology for sensitive topics whereby participants can express their true feelings and beliefs confidentially. Because so much of the responsibility falls on the moderator to set the tone of the discussion, well-developed skills in group dynamics and data organization are essential. Finally, the live and credible nature of focus groups may lead to greater faith in the findings than is actually warranted (Rhyne, 1995). Carey and Smith (1994) are critical of researchers who analyze data only at the group level without considering individual responses and comparing them with the group data.

VI. Sample and Setting

Convenience sampling was employed in this study. Sample size, based on the purposes governing the research, was determined using established criteria for sample selection, and continued until saturation was achieved.

The sample was recruited in one phase. The goal of this phase was to determine the number of hospitals which have HECs and provide care or long-term care to the elderly adult, (the subject of the clinical scenario) and to obtain the names of individuals chairing these committees. HEC members were contacted through the Chairs of their committees to elicit their participation in a focus group interview. Focus group interviews were audio-taped and written records kept. Written transcripts from these interviews provided the raw data for this study. HEC interviews took place in their regular meeting locations.

Participants were recruited from six University of Toronto affiliated teaching hospitals and two selected community hospitals, all of which had established HECs and also provided care or long-term care to the elderly adult. Focus group method for sample
procurement suggested that interviews be over-recruited if possible by 20 percent to cover for unpreventable contingencies (Morgan, 1988). Actual committee membership and the discipline composition of membership were both predetermined by each HEC's Terms of Reference. All members of participating HECs were asked to attend a focus group interview. Some HECs exceeded the recommended 12 members. Focus groups were not conducted if membership fell below 4 people.

The final sample consisted of the chairpersons and members from eight HECs in the Greater Toronto Area. In all, 67 HEC members participated. Participation in the study was voluntary.

The criteria for any individual's inclusion in a focus group interview were as follows:

- Was s/he a member of a HEC at the time of the focus group; and
- Was s/he able and willing to participate in a group discussion.

HEC participation also involved approval of the study by the University of Toronto Human Research Services office. The description of potential data collection sites is outlined in Table 1. The investigator first contacted seven teaching hospitals affiliated with the University of Toronto and 9 community hospitals likely to have HECs. Eleven of the 16 hospitals had HECs but, for reasons outlined in Table 1, only eight hospitals volunteered to participate in the study. The original 16 hospitals contacted were selected following discussions between the researcher and her thesis advisors. Not all hospitals in the Greater Toronto Area were contacted, nor were nursing homes, convalescent hospitals, specialized psychiatric hospitals or other medical facilities. The institutions contacted were all large hospitals with geriatric programmes.

Six of the seven teaching hospitals participated in the study. The HECs in two of the sites included members of the researcher's thesis committee but neither thesis committee member participated in the focus group sessions. The teaching hospital which did not participate was unable to do so because its HEC was in abeyance during the data collection period.
Two of the nine community hospitals contacted participated in the study. The remaining hospitals did not participate for a variety of reasons. One institution had no HEC of its own but relied on the HEC of one of the teaching hospitals. Two hospitals had no HEC, or their HEC was in abeyance during the period of data collection. A major suburban hospital approved the study for research but was then unable to schedule a date for the focus group within the data collection period. Two smaller community hospitals declined to participate in the study; one hospital, whose HEC was recently reorganized did not respond to any communications from the researcher over the entire recruitment and data collection period from December, 1993 to June, 1995.

A. Recruiting Focus Group Participants

Potential subjects were identified by the investigator who then contacted the Chairs of the identified HECs in December, 1993. Approval of the study was obtained from the University of Toronto Human Research Services office in June, 1994 and a pretest focus group was held in July 1994. The pretest data and analysis was completed by September, 1994 and the study was approved to proceed by the researcher's Thesis Committee late in the same month.

New sites were contacted throughout the data gathering period. In some institutions, additional approval of the study by the Research Ethics Committee of the hospital was required before the HEC would consider participating in the study. In all cases where such approval was required, the study was approved. In some cases, very minor amendments were requested to the form of the participant's consent (Appendix G).

Following the agreement of a HEC to participate in the study, a mutually convenient date for the focus group interview was scheduled. Approximately two weeks prior to the focus group interview, copies of the HEC questionnaire, the Participant's Consent Form and the Information for Participants for each HEC member were provided to the HEC Chairs (see Appendices A-G). HECs preferred that the investigator not contact HEC members directly, but communicate through the HEC Chairs or their designates. Consequently, the investigator could not anticipate precisely the number of HEC members
attending focus group interviews. The investigator advised the HEC Chairs or their designates of the importance of sufficient group size and of the need to have at least four HEC members — and preferably as many as 8 HEC members — attend the focus group interview. One HEC was on two occasions unable to produce enough members to proceed with a focus group. The support of HEC chairs and their designates proved invaluable to the study. Where HEC Chairs were not supportive of the study, it was not possible to proceed. Although all the hospital HEC Chairs co-operated fully with the investigator, group sizes and composition varied substantially for each focus group interview. The size and composition of HECs reported in this study appeared to be consistent with the HEC literature. It should be noted that, as in this study, physicians, nurses, clergy, ethicists, and health administrators were identified in Canadian studies as the most common members of HECs (Storch et al., 1990; Storch & Griener, 1992). Data collection occurred over a one year period commencing in July, 1994 and concluding in July, 1995. The smallest focus group size was five participants (Groups A and F). The largest number of participants was 14 in Group B. Mean group size was 8.5 people.

As noted in the review of the focus group literature, sample size in focus group research is also determined by saturation of the qualitative information, as well as adherence to the requirements of the specific study. By these criteria, the sample of eight HECs, which consisted of 67 individuals out of a possible 144, constituted a significant sample. The researcher was satisfied that saturation occurred in the sample and that increasingly smaller amounts of additional information would have been obtained through further focus group interviews.

In all, 67 individuals returned useable HEC Profiles from the eight focus groups. HEC profiles were not completed by a number of observers who, while attending the focus group interviews, did not participate in the discussion. One subject refused, without explanation to return the HEC Profile.
### Table 1 - Hospitals approached to participate in the study.

<table>
<thead>
<tr>
<th>Hospital Designation: University (U) or Community (C)</th>
<th>Participated in Study: Yes/No</th>
<th>Status of HEC: Meeting (M) Meeting In abeyance (A) Non existent (N)</th>
<th>Date of Focus Group Interview</th>
<th>HEC Reasons for not participating</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (U)</td>
<td>yes</td>
<td>M</td>
<td>July 1994</td>
<td></td>
</tr>
<tr>
<td>B (C)</td>
<td>yes</td>
<td>M</td>
<td>October 1994</td>
<td></td>
</tr>
<tr>
<td>C (U)</td>
<td>yes</td>
<td>M</td>
<td>January 1995</td>
<td></td>
</tr>
<tr>
<td>D (U)</td>
<td>yes</td>
<td>M</td>
<td>January 1995</td>
<td></td>
</tr>
<tr>
<td>E (U)</td>
<td>yes</td>
<td>M</td>
<td>February 1995</td>
<td></td>
</tr>
<tr>
<td>F (C)</td>
<td>yes</td>
<td>M</td>
<td>February 1995</td>
<td></td>
</tr>
<tr>
<td>G (U)</td>
<td>yes</td>
<td>M</td>
<td>May 1995</td>
<td></td>
</tr>
<tr>
<td>H (U)</td>
<td>yes</td>
<td>M</td>
<td>July 1995</td>
<td></td>
</tr>
<tr>
<td>I (U)</td>
<td>no</td>
<td>A</td>
<td></td>
<td>Individual members advised that the HEC was not meeting</td>
</tr>
<tr>
<td>J (C)</td>
<td>no</td>
<td>N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>K (C)</td>
<td>no</td>
<td>A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>L (C)</td>
<td>no</td>
<td>M</td>
<td></td>
<td>HEC was not able to commit the time required</td>
</tr>
<tr>
<td>M (C)</td>
<td>no</td>
<td>M</td>
<td></td>
<td>HEC was not able to commit the time required</td>
</tr>
<tr>
<td>N (C)</td>
<td>no</td>
<td>M</td>
<td></td>
<td>Agreed to participate but was unable to schedule a date</td>
</tr>
<tr>
<td>O (C)</td>
<td>no</td>
<td>A</td>
<td></td>
<td>Never responded</td>
</tr>
<tr>
<td>P (C)</td>
<td></td>
<td>Uses HEC of Hospital G</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
VII. Instrument Development

The Clinical-Ethical Dimensions Discussion Guide (CEDDG) used in the focus group
terviews was developed by the investigator based on the existing literature and on the
investigator's clinical experience (see Appendix H). The CEDDG used a clinical scenario
developed by the investigator to stimulate and focus HEC members' discussions. The HEC
Profile questionnaire also obtained qualitative data about HEC members' individual
perspectives on the issues raised during the focus group interviews, as well as
sociodemographic information. Definitions provided to the focus groups are set out in
Appendix I.

A. Clinical-Ethical Dimensions Discussion Guide (CEDDG)

1. Development of Discussion Guide. In the development of the CEDDG, the
investigator organized relevant questions under specific topics. These topics included
the nature and quality of the HEC role, the identification of ethical issues, and the
making of ethical recommendations. Krueger (1988) noted that an ideal focused interview
includes fewer than ten questions and often around five or six in total. The CEDDG
included six questions guided by numerous prompts.

The CEDDG arranged a logical, sequence of questions which progress from the
general to the specific question. As a result of the guide, discussions were focused as
participants were asked to identify ethical issues and make specific recommendations
about the patient in the clinical scenario. Questions contained in the CEDDG were open-
ended, and were worded to stimulate discussion. Whenever the investigator/moderator
discovered, through group discussion, that an additional question seemed relevant, such
new questions were left for the final five to ten minutes of the group. Unanticipated
questions included discussions of HEC roles in resource allocation.

Since the CEDDG organized each group's interview around the same set of questions,
this facilitated the comparison of HECs using HEC members' questionnaires to substantiate
and support analysis made at the group level. The investigator was aware that the CEDDG
should not be rigid and that questions could be re-ordered, depending on the evolution of the group's discussion. Although questions varied from group to group, the general format of the guide was maintained. As previously mentioned, the moderator sought to involve all members in the discussion ensuring that strong, persuasive speakers did not dominate the group and that quiet members were encouraged to participate (Schalter, Shmerling, Murphy, 1943).

"Participants in focus groups do not always say everything they wish to say, nor do they necessarily readily articulate what they think" (Stewart & Shamdasani, 1990, p.951). Mindful of this, verbal cues or prompts were used to guide participants through the interview which, in turn, helped HEC members bring forward their own subjective views. Examples of prompts include the phrases "Tell me more", "Can you explain what you mean?", or "Is this anyone else's experience?" Participants were not asked directly if they agreed or disagreed with any other participant's statement. "Good probes ask for more information without suggesting specific answers and without making the respondents defensive" (Stewart & Shamdasani, 1990, p.96).

B. Clinical Scenario

The topic of the scenario was selected based on the investigators clinical experience. Formulating the scenario involved obtaining recent clinical challenges from experienced nurses caring for elderly patients, from the geriatric health care literature, and from the investigator's own clinical experience. In general, scenarios or vignettes used in research are brief concrete descriptions of realistic situations, so constructed that reactions to them will yield information about respondents' perceptions, opinions, or knowledge concerning the phenomenon under study (Kerlinger, 1986; Polit & Hungler, 1991). Scenarios need to have a "narrative, story-like structure that preserves chronological flow and that normally is limited to a brief time span, to one or a few key actions, to a bounded space, or to all three" (Miles & Huberman, 1994, p.81). In this study, the scenario is a focused description of a series of events concerning a hypothetical patient called Mr. O. The patient's actions in the scenario are taken to be a
representative, typical or valid portrayal of the behaviour of an agitated elderly person with a dementing illness within the context of a specific event in his everyday life (Erickson, 1986; Miles & Huberman, 1994).

Because patient agitation elicits ethical decision-making on the part of health care professionals, the scenario combined the following dimensions of agitation: (1) restlessness; (2) resistance; (3) shouting; (4) swearing; and (5) aggression. Each dimension can range in severity from non-existent to mild, moderate or severe behavioural disturbance. When considering a patient's agitated state, a diverse number of behavioural combinations are possible, although it was impractical to try to capture every dimension. The scenario describing a moderately agitated patient state was incorporated into both the questionnaire and focus group interview (see Appendix I). The questions asked of participants following the scenario were framed in an open-ended way and provided the opportunity to engage participants in a patient consultation — by having them reflect on ethical issues and make recommendations for the patient's care.

This scenario was reviewed by experts in geriatric psychiatry and gerontology and considered representative of this group of patients. As well, two doctoral students in bioethics from the University of Toronto reviewed the scenario to determine whether ethical issues and recommendations could be elicited, given the open-ended nature of the narrative story. They concurred that, although this was a clinical scenario, it did raise ethical issues appropriate for reflective deliberation in determining recommendations for the patient's care.

C. HEC Members' Sociodemographic Profile

The HEC Profile asked some factual, sociodemographic information about HEC members in relation to the clinical scenario and to their role on the committee (see Appendix I). Sending out the questionnaire in advance served two purposes. One was to minimize disruption caused by late comers who could join the focus group already possessing the questions and an explanation of the format of the focus group. The other was to allow participants to first think individually about the questions, thus deterring
"group think" or yielding to the dominant voice in the group (Janis, 1972).

1. Validity. The HEC Profile was developed from the investigator's knowledge of the relevant literature. The questions were clearly written so that the intent of the question and the nature of the information sought were self-evident to the participants. Closed-ended questions asked direct information from participants concerning their HEC role. Open-ended questions asked the participants to respond in their own words to items concerning the clinical scenario and to their HEC role. The content validity of the HEC Profile was assessed by two individuals with expertise in bioethics who were members of a HEC. After the focus group, the subjects were asked to complete the last question of the HEC Profile before the investigator collected the completed questionnaires.

D. HEC Profile Data Analysis

As noted earlier, the HEC Profile semi-structured questionnaire included both qualitative and quantitative questions. Qualitative answers were transcribed and entered into the Ethnograph software. Then this material was analyzed in the same way as the Focus Group interviews. Qualitative data from the HEC Profile was also entered into the Statistical Package for the Social Sciences. Version 6.1 (SPSS 6.1) to determine whether there were any associations or relationships between these categories and the quantitative questions on the HEC Profile. Despite the fact that this procedure failed to produce significant findings, this analysis was beneficial in providing an overview of individual HEC members.

The quantitative questions from the HEC Profile were also analysed using SPSS 6.1. This process involved statistical analysis of each quantitative question, as well as performing cross tabulations among questions based on the formulated research questions. Since the inferential statistical analysis produced limited information, descriptive statistics were used to analyze the quantitative questions contained in the HEC Profile.
The design of the research provided for focus group participants to receive and complete the HEC Profile questionnaire before attending the focus group interviews. Most participants did so, although some completed the HEC Profile after having participated in the study. In these cases each subject was asked to approach the questionnaire as an individual health care provider and as though the focus group interview had not occurred. Although individual HEC Profile responses obtained after the group interview were naturally influenced by the prior discussion, the HEC profile questionnaires returned by these subjects, however, were consistent with the rest of the data in that broad ranges of opinion were expressed.

VII. Data Collection Procedures

The investigator met with HEC chairs/delegates and members to explain the purpose of the research and enlist their voluntary participation in the study. HECs agreeing to participate were provided with information about the study, as well as a copy of the HEC Profile. Focus group participants were asked by the investigator to complete all questions on the HEC Profile except the final question (which referred to their evaluation of the focus group interview), and bring it with them to the interview. The focus group interview was then scheduled on a date convenient to the participating HEC. After explaining the study and obtaining the HEC members' consent, the investigator conducted focus group interviews using the CEDDG (see Appendix H). Data were collected from each group in a single interview lasting approximately 1 - 2½ hours. The questions, as delineated in the CEDDG, were asked of all focus groups at a pace comfortable for the subjects. After obtaining consent to tape-record responses were audio recorded and recorded in writing by the investigator/moderator and an observer.

A. Role of Moderator/Investigator

The investigator/moderator guided the focus group interviews and was aware of the research question. Previous experience in interviewing and counselling skills, and formal training in conducting focus groups and qualitative analysis, assisted the
investigator/moderator. As the research tool, the investigator/moderator was the contact person for all HECs. set up the environment for transcribing focus group interviews, conducted the group interviews and made observations during as well as at the end of each focus group. The investigator/moderator was intimately involved with the data from beginning to end, listening to audio tapes, reading transcripts and preparing summaries.

1. Moderator Biases  The investigator/moderator was aware that her own bias, which was that of a health care professional who valued highly the moral necessity of providing clinical consultation. Self-monitoring was mandatory, particularly since the investigator acted in the role of focus group leader. At the same time, "such directive work on the part of the moderator is necessary if the focus group is to yield desired data" (Vaughn, Schumm & Sinagub, 1996, p. 90). Using an external group moderator was not possible given the financial and time constraints on the project. When the investigator offered information to the group, she made it clear that it came from the literature and not from her personal views. As well, the investigator/moderator used her thesis committee to examine transcripts at the beginning of the study to assess her questioning route and the latitude given to participants to express their own views. The investigator/moderator had never been a member of a HEC in the Greater Toronto Area, and did not know any of the participating HEC members personally. All focus groups were conducted in the presence of an observer and discussions with him following the group interview did not reveal any inadvertent or purposeful statements made to influence the outcome of the study. Focus groups were asked for their confidential comments at the end of the interview and no one suggested any particular bias on the part of the investigator.

B. Role of Observer

The investigator was assisted throughout all of the focus group interviews by an observer as recommended by Dilorio, Hockenberry, Eaton, Maibach & Rivero, 1994. The observer was trained by the investigator to assist in setting up audio recording equipment for the verbatim transcription, organizing group discussion materials, and minimizing
interruptions throughout the interview. As well, the observer received formal training on focus group interviews at the Institute for Social Research, York University, and from the investigator. The observer maintained notes on each group session to record such contextual information as the verbal or nonverbal behaviour of individual HEC members in relation to the group discussion. Additionally, the observer and the moderator reviewed each focus group after it was completed and prepared a memorandum summarizing their observations.

C. Quality of Focus Group Findings

In distinction to quantitative findings, qualitative studies are not evaluated on the basis of reliability and validity but rather on the basis of credibility, auditability, fittingness, and confirmability (Lobindo-Wood & Haber, 1994).

1. Credibility refers to the accuracy of findings as judged by participants and others within the discipline. It is a concept similar to face validity. The focus group data was generated in the context of a discussion among peers who meet frequently and, thus, had substantial credibility. Furthermore focus group volunteers must have been strongly motivated to participate in the study and were thus unlikely to distort the reporting of their views.

2. Auditability refers to the method and ease with which the study can be repeated. It is a concept analogous to test-retest reliability. The study's use of a moderately structured questionnaire and topic guide, together with the comprehensive written thesis proposal, provides substantial warranties of auditability. The investigator maintained a comprehensive documentary record of memos on data analysis and conduct of the groups to make possible retracing the course of the analysis. Furthermore, eight focus groups were completed and the data appeared to be saturated; this also indicated that the study can be easily replicated.

3. Fittingness refers to the study's meaningfulness to the everyday reality of focus group participants and to those outside the study. It is analogous to the inclusion/exclusion criteria for sample recruitment. The study utilized meetings of HECs
in their usual meeting rooms, discussing issues with which they were familiar. Beyond that, however, focus group data included analyzing participant's opinions, as well as the group dynamic. Such an approach permitted the investigator to identify common issues, broad differences, and collective impressions of the HECs involved. Part of the study required HECs to put aside their terms of reference and consider a patient care problem. However, this deviation from their standard role was modest and did not undermine the applicability of the study.

4. **Confirmability** refers to the degree to which the above standards have been satisfactorily met. The study design was narrow in scope and the standards of confirmability have been maintained throughout; such intended limitations recognize that focus group data is not generalizable to other groups because opinions and attitudes respond to changing environments.

**VII. Analysis of Qualitative Data**

**A. Grounded Theory**

The major intent underlying this study is to express the results in words rather than in numbers. "Words especially organized into incidents or stories, have [more] concrete, vivid, meaningful flavour ... than pages of summarized data" (Miles & Huberman, 1994, p.1).

This study employed an exploratory, interpretational approach to data analysis which was strongly influenced by grounded theory. The level of analysis elaborated in this approach derives from an adaptation of the constant comparative method introduced by Glazer and Strauss, (1967) in their *The Discovery of Grounded Theory*, to manage and analyze data.

Grounded theory is a method of qualitative analysis that was developed within the Department of Sociology at the University of Chicago. The theory sought to establish methods for the explanation of human behaviour. Based on them knowledge that relationship constantly changed. Consequently, the process of observing behaviour, developing a theory to explain the behaviour and verifying the theory, all needed to be done simultaneously.
Data collection for analysis consists mainly of unstructured interviews, observation of subjects, and fieldwork. Fieldwork refers to the direct presence of an observer in the natural habitat of the group under study (Munhall & Oiler, 1986). The process of analysis is holistic in that it seeks to interpret all of the available data and integrate them into a unified theory. The name "grounded theory" refers to theory development that is grounded in data.

In grounded theory analysis using focus group methods, the verbatim data are coded for ideas as identified by researchers in their review of the text. The term "code" the elemental building block of grounded theory, refers to a concept or thought stimulated in the mind of the researcher by the words, content and dynamic generated within the focus groups. Each code is reviewed by the investigator "over and over" in order to identify patterns and linkages between the codes and the verbatim text.

In grounded theory, codes are considered fluid and will change as the analysis proceeds. Kirby and McKenna (1989) describe this process as "living with the data" as the researcher becomes submerged in the analysis process and is constantly comparing new codes against existing codes in search of patterns and relationships. This method is described as the constant comparative method and, in focus group research, comparisons would be made both within and across groups. Generally, grounded theory researchers eschew predetermined codes in favour of codes which emerge directly from the data. The identified codes are then reviewed to determine their characteristics, patterns and relationships. It is possible for identified codes and categories to shift and even change substantially through the course of the data analysis, as the ideas of the researcher evolve.

The patterns and relationships identified by the researcher are identified and defined through a cyclical process which involves a method of non-linear analysis. The research is conducted by collecting data, assigning the data to categories that occur to the researcher as possible ways to understand the data. All the while, the researchers maintain a written record of the process of analysis, contained in informal memos by the researchers to themselves. This process is often referred to as memoing. Through
reviewing and re-reviewing the data, the categories, as well as the research notes about the analysis process, core categories or relationships are identified. Although the term "category" is commonly used in this field of research, other terms may be used, such as themes, concepts or ideas.

Memoing involves spontaneous recordings of the investigator, which vary in written length and style and are intended to capture connections among the data (Munhall & Oiler, 1986). Such a process of recording is both inductive and deductive in that the investigator must conceptualize his/her ideas upon observing certain patterns, trends or associations among phenomena and then, through deductive reasoning, attempt to derive valid conclusions (Munhall & Oiler, 1986; Holm & Llewellyn, 1986). A memoing process helps the researcher to: a) identify assumptions, b) foster thinking about multiple incidents, links and connections, c) capture the developmental process and d) identify directions for future research. In other words, memoing is the written record of analysis developed by the investigator, describing the evolving process from raw data to the formulation of theory.

Categories are then further considered in order to develop an explanation about observed behaviour that is comprehensive and inductively tied to the data leading to emerging hypotheses that are both appropriate and plausible. During the coding process, each part of the data is coded in as many ways as possible to ensure full coverage of all possible explanatory theories. Emerging theory must fit the data and be able to explain behavioural variations.

Grounded theory dictated that, in order for the emerging theory to have validity, it is essential that the researcher conduct the research in an appropriate setting, with an adequate range of subjects; accurately record the data; and obtain comments on the research from the participants involved in the study. The researcher must be aware of his/her own biases and preconceived theories and be true to the evolutionary process of the method. Consequences include the fact that the research question may change as the study progresses.
B. Grounded Middle Range versus Grand Theory

As was the case in this study, a considerable body of information is often generated during focus group research. Such information needs to be presented in a structured way, to be comprehensive and to accurately reflect the views of study participants. Modified grounded theory has been identified as a method for analyzing selected focus group data (Kirby & McKenna, 1989; Rhyne, 1995).

In this study, modified grounded theory was used to bring forward selected theoretical propositions relating to the dimensions of HECs' role, and the issue of how HECs would approach a patient consultation as depicted in the clinical scenario.

This process involved the construction of hierarchies of ideas, moving from the original data to a refined theory. The constant comparative method also facilitated the process of data analysis by permitting the investigator to move from focus group to individual. Grounded theory as used in this study is best thought of as "middle range" rather than "grand" theory. Middle range theory focuses on selected elements of a phenomenon and encompasses a limited range of concepts (Polit & Hungler, 1991). Grand theory, also called macro theory, seeks to explain a far broader reach of human experience. Focus group research, because it cannot be generalized to other times and places, is unsuited to the development of grand theory although it may well form part of a research process leading to such theory.

C. Transcription and Review

Each focus group interview was transcribed with an audio-tape backup by a professional verbatim transcriber. A transcript-based analysis as proposed by Krueger (1994) was used to analyze these data. The analytic process included the following steps to help conceptualize the data:

- The transcriptionist prepared a verbatim transcription of each focus group with backup tape recording;
- The transcriptionist reviewed the original tapes against verbatim transcripts and
corrected any errors;

- The investigator listened to tapes, added pseudonyms, completed missing data (if possible), and entered data into the Ethnograph program;
- The investigator filed tapes, transcripts, notes for future analysis according to focus groups;
- The investigator reviewed the raw data and identified segments of data that captured potentially interesting ideas or comments;
- The investigator labelled data segments with brief code words that captured the meaning of data segments.

D. The Ethnograph

For the process of data analysis, the investigator made use of a much-used computer programme for qualitative research. the Ethnograph (Seidel, Kjolseth and Seymour. 1988). "The Ethnograph is a set of interactive, menu driven computer programmes designed to assist the ethnographic/qualitative researcher in some of the mechanical aspects of data analysis" (p.1-1. Seidel).

E. Coding and Categories

As the process of labelling continued, some codes emerged which seemed to capture similar ideas. A code that applied to more than a few data segments and referred to a specific idea or concept of some importance or interest was called a “category”. (Rhyne. 1995).

Multiple reviews of the raw data provided a way to validate the reasonableness of the original coding and, during such reviews, categories developed. The data were reviewed three times, twice by the investigator and once by the observer. The observer was aware of the research questions and had participated in all of the focus groups. Data segments were initially coded according to categories which became apparent from the focus group transcripts and the pre-defined categories described below. Categories were presented as they emerged from the data, the investigator did not attempt to organize or conceptualize
the data according to some predetermined scheme (Kirby & McKenna, 1989, Rhyne, 1995).

Each focus group was coded immediately after a transcript was received and as the new data were completed, the coding and categories were revised to include all of the data.

Contemporaneously with coding and developing categories, the investigator considered the linkages and interconnections between categories. This process permitted the researcher to consider links between categories, plus possible relationships or hierarchies which facilitated understanding of the data.

F. Adaptation of the Constant Comparative Method

Describing these linkages and interconnections was the next stage of developing modified grounded theory. These links are intended to be fluid and to be constantly refined to encompass all dimensions of the raw data. The links and interrelationships between categories were expressed in a variety of ways. "Themes" was the term used to capture these relationships in this study. In addition, the investigator considered any data that raised new categories and revised the existing categories or formed additional categories in accordance with the data. Finally, the investigator prepared the draft report.

G. Process of Category Negotiation

Negotiating categories was a crucial component to the study, intended to minimize the influence of the moderator/investigator's biases or subjective tendencies (Vaughn, Schumm & Sinagub, 1996). The same coding process was performed by the focus group observer independently of the investigator. The investigator then coded the data a second time and compared the first coding review with the second to determine the accuracy of the selected code terms. When the investigator was satisfied with the coding, she and the observer compared their coding and categories for each transcript and negotiated the limits of the codes and categories. For example, the observer identified a category called "HEC Barriers" that represented data segments relating to the perceived lack of acceptance of HECs by the larger hospital community and to the lack of resources for the HEC in carrying
out its role. The investigator had no "HEC Barrier" category. Instead, the investigator had an "HEC resources" category that included many of the data segments relating to the "HECs lack of resources", as well as segments relating to the "lack of acceptance" of the HEC in the "HEC framework - structure" subcategory. The reasons for establishing the different categories were discussed by the investigator and the observer and a consensus was reached that the data segments relating to lack of acceptance of the HEC were best categorized with the data segments relating to the HEC's relationship with the hospital gathered in the category "HEC Authority and Power". The data segments from HEC barriers that related to financial support were merged with the HEC resources category. This process continued until all of the data had been reviewed. The process was always one of consensus and both observer and investigator had to reach an agreement on the categories and coding.

The HEC Profile, which obtained opinions from individual HEC members, had been designed to be compatible with the CEDDG. The same kind of information that was elicited from HECs using focus group methods was also requested from individual members completing the questionnaire. The investigator needed to bring together information collected from the focus groups and HEC Profiles allowing significant overlapping patterns and linkages to emerge from the data.

While this process of dynamic conceptualization proceeded, the investigator began to develop a number of theoretical propositions based on the evidence available from the literature review, the HEC Profile, and the focus group interviews, with the aim of eventually confirming or disconfirming these theories. As the analysis proceeded, evolving theoretical propositions were reviewed and refined in order to establish justifiable conclusions.

Focus group reporting requires that the experiences and voices of focus group participants be integrated within the investigator's perspective. This integration of the subjects' voices together within the investigator's view produced several hundred data segments. Since it was impossible to refer to all of the data segments in the presentation of the results, only representative statements have been chosen to
illustrate the opinions of HEC members in each category. The quotations chosen by the investigator were selected because they reflected brief conceptualizations of the core issues for that category. Lofland and Lofland (1984) describe the process of selection as the “agony of omitting”; the investigator must, unfortunately, exclude important data segments to make the report readable.

Theoretical dimensions derived from the data represent the outcome of a process of refinement and elimination.

H. Data Management

Identifying patterns in the focus group data involved examining the data that emerged from the interviews, and further substantiating this information with responses from individual research participants who completed HEC Profiles.

Original source materials as focus group transcripts, observation notes, analysis memoranda were printed by the Ethnograph programme with a wide margin on the right and numbered lines of text (see Appendix K). The investigator reviewed the text and noted possible categories on the print-out. The initial reading of data was done rapidly and followed with a more detailed review of the same data. A comparison of the categories identified in each review was used to prepare a preliminary coded version of the data from the Ethnograph programme. The Ethnograph was used to retrieve codes, count codes, or count segments of text (i.e., line, paragraph, page) which comprised that category.

I. Preliminary Categories

Six categories were identified by the investigator as initially emerging from the focus group data: Recognition of the Scenario, Initial Approach to the Scenario, Issue Identification, Recommendations, Multidisciplinarity and the Role of HECs. These categories were used to code the preliminary review of the focus group interviews and qualitative data from the HEC Profile. Since these were only preliminary categories, it was expected that they would be revised, expanded, altered or abandoned, depending on the verbatim material. The attributes assigned to each pre-defined category are set out in
the following paragraphs.

1. Recognition of the Scenario. The first category referred to the evaluation of the scenario by the focus groups as being realistic and consistent with their experience. Although several previous steps had been taken to ensure the authentic characterization of the clinical vignette, this category validated this part of the study design and established a common discussion basis for HEC participants.

2. Initial Approach to the Scenario. This category referred to the initial response of the HEC members to the scenario. The subjects' assessment of the scenario as raising ethical, clinical, moral, policy or administrative problems was of particular interest. This category became an omnibus or catch-all category for subjects' statements in response to the scenario.

3. Issue Identification. The third preliminary category referred to the identification of ethical issues by the focus groups. The investigator had anticipated that the focus groups would identify ethical issues in the scenario and discuss these in some detail. It was anticipated that the identification of nonethical issues might occur although their nature was unpredicted. Initially, this preliminary category was conceived of as a grouping of the variety of ethical issues which might emerge from discussion. Issue identification, in the final analysis, became a grouping of both ethical and nonethical emerging issues.

4. Recommendations. Preliminary category number four referred to members' choices regarding their view of a reasonable next step in the care, treatment and management of the agitated elderly person described in the clinical scenario. Most HECs have experience in education, policy and, in some cases, patient consultation issues. In this study, the investigator was more interested in obtaining possible recommendations than in decision-making as such. The term "recommendation" was selected since it appeared
to be a flexible and comprehensive to describe HECs' recommendations, suggestions, comments, opinions and experiences. Any recommendation can be viewed as having both moral content and power. The clinical vignette encouraged HEC participants to make recommendations which could, for example, involve them in making a prognosis, seeking legal guidance, educating hospital personnel, or suggesting patient-focused solutions. It could also elicit the recommending of hospital policies.

In the analysis of the focus group transcripts, it was sometimes difficult to distinguish statements which were recommendations from statements which related to the committee's initial consideration of the scenario. Since the CEDDG specifically addressed the topic of recommendations, it was possible to clearly distinguish between the recommendations made by focus group participants and the CEDDG prompts used during the focus group. The issue of when data segments could be coded as "recommendation" was resolved by observing the context in which the statement was made, then coding as recommendations those words which appeared to be intended by the subjects as conclusions to their consideration of the scenario. Thus, responses suggested in the early part of the interview were usually not coded in the form of "recommendations" but as "initial responses to the scenario". The intention was that recommendations could only be said to exist once the review of the scenario and its ethical ramifications had been completed. As well, the study design made it possible to compare the data coded as "responses" in the preliminary phase of the focus group interview with the words coded as "recommendations". thus permitting some insight into the development of participants' ideas. Categories were not conceived of as exclusive however, and where the categorisation of the data segment was ambiguous, it was included in both categories.

5. Discipline Diversity. This preliminary category referred to the professional/occupational or background of HEC members, and how this may have affected their discussions in the focus group interview. Focus groups were asked to identify their profession/occupation in the HEC Profile and again in the focus group interview in order to provide the investigator with specific information about the professional disciplines
of HEC members. The review of discipline-specific information occurred as part of the data review process. Questions asked during the focus group interview were intended to explore how subjects saw the multidisciplinary/interdisciplinary nature of the HEC.

6. HEC Role. This preliminary category refers to the variety of ways in which the HEC conceives its role, and how the HEC was seen by others within its institution. The functioning and internal processes of the HEC were also part of this theme.

VIII. Coding

In the analysis of the focus groups, the investigator completed memoranda immediately following each focus group interview and again after completing a review of the transcript of the original focus group interview. These memoranda suggested further categories to be used as part of the coding process. As well, categories unanticipated by the investigator emerged. For example, Focus Group A had an extensive debate about whether the scenario illustrated any ethical issues at all, or only raised only clinical issues. The investigator had to consider whether a new category might be justified.

Preliminary coding for each focus group was refined using the preliminary categories defined above. These categories appeared to be significant to the research focus from the prepared memoranda. As each focus group had its own special identity, specific categories were found to vary from group to group. The development and evolution of the analysis proceeded by reviewing each group in turn until no new insights or information were generated; in other words, no new categories were identified and saturation of categories was achieved. Discussions involving the first three focus groups who participated in the study were more comprehensive than were the later focus groups because identification of categories and the development of categories were mostly crafted using the earlier groups (Focus Groups A to C). The review of the later focus groups was then limited to the identification of new themes arising from the analysis. Of course, the identification of new categories meant that earlier focus group transcripts had to be reexamined and refined.

Preliminary coding of the focus group transcripts based on these categories, plus
additional categories developed by the investigator during the course of the review of the transcripts, generated a list of nearly 300 different words. (See Appendix L). While such a large list was considered unwieldy for purely coding purposes, the detail of the list permitted the original coding to be used for indexing the transcripts as well. Next, every data segment coded according to the word list was generated. A large number of multiple codes existed and the process produced several repeated data segments. However, no effort was made to limit any data segment to an exclusive category, and some data segments represented multiple categories. Only 34 code words had 10 or more data segments. The remainder appeared less frequently, with more than 200 appearing only once. As the analysis proceeded, data segments were excluded or reclassified as appeared appropriate.

The most commonly occurring of the pre-defined categories was that of “HEC Role”. As the process of analysis proceeded, data segments were recorded and categories were organized into themes or discarded, as appeared appropriate to the investigator and the observer. Categories with a large number of data segments were accepted as constituting possible themes and were treated on that basis. Subsequently, the data segments were reviewed again and the report on the data prepared, using verbatim quotes from the focus groups.
CHAPTER FOUR
ORGANIZATION OF RESULTS

This chapter will provide a brief review of data collection process and outline the study’s procedures for data analysis. It will also describe the sample of focus group participants. Finally, the codes identified prior to the review of the data and the codes emerging from the data will be briefly identified.

This study obtained qualitative data from the focus group interviews and from selected qualitative questions which formed part of the HEC Profile. The procedure used to review and analyze the qualitative data was an adaptation of the constant comparative method (Glaser and Strauss, 1967).

As a result of this analysis the investigator identified two main themes in the data, (a) data segments that illustrated the breadth and depth of the HEC Role, and (b) data segments related to the discussion of the scenario. The present chapter describes the conduct of the focus groups. The discussion of the analysis of the data segments related to the HEC Role appears in Chapter Five. The analysis of the data segments related to the discussion of the scenario are contained in Chapter Six. The data related to the quantitative questions in the HEC Profile are described in Chapter Seven.

I. Sample

Sixty-seven HEC members, men and women, from eight HECs in the Greater Toronto Area participated in this study. HEC members were predominantly female (female 71.6%, male 28.4%) in the context of the total population of the research study. As mentioned in Chapter Three, the sample was recruited according to a set of aims which were partially fulfilled. as such, it fits into the context of a convenience sample. All of the participants voluntarily agreed to participate in the study, and written informed consent was obtained. Figure 1 illustrates the size of each focus group and the professional/occupational backgrounds of HEC members. The most frequently represented professions/occupations in the sample were: physicians, nurses, hospital administrators and ethicists/clergy. The group designated as “psychosocial health professionals” (n=7)
included social workers (n=3), psychologists (n=3) and a psychotherapist (n=1). The group designated as "other" included various professions/occupations who were represented rarely in the focus groups, such as students, patient representatives and scientists. The "ethicist" group also included members of the clergy. Participants' ages ranged from 29 to 72 years with a mean age of 46.06 years. Figure 2 shows a box plot of the ages of HEC members according to their reported professions/occupations. The youngest and oldest participants are represented at the data points above and below each box. The shaded area of the box indicates the range within which 50% of focus group participants are found, and the solid dark line within each block indicates the mean age of participants.

II. Overview of Focus Group Interviews

A total of eight HECs from various metropolitan, university-affiliated, teaching and community hospitals participated in the study. Table 2 provides an overview of the written Terms of Reference of each participating HEC. The Terms of Reference were not strictly followed by any HEC. In fact, in individual members' responses to the HEC Profile frequently indicated that the committee was not involved in all the activities identified in their Terms of Reference. As well, some HECs were engaged in activities that exceeded the activities set out in the committee's Terms of Reference. One committee was unique in its avowal of an interest in research and promotion of ethical issues in a broader academic sense. This HEC, unlike 6 of the other 8, had never consulted with other HECs on such issues of common interest as "do not resuscitate" policies.

The smallest focus group consisted of five HEC members and the largest consisted of 14 participants. The mean group size was 8.5 subjects. Group size did not appear to affect the amount of data produced during the course of the focus group interview. The investigator requested that HEC members complete the HEC Profile, sent in advance, even if they would be unable to attend the focus group interview. In fact, only those who attended completed the HEC Profile.
Figure 1
Distribution of professions by focus group
Figure 2
Age at Last Birthday by Professional / Occupational Background

- Physician: 14
- Nurse: 12
- Ethicist: 9
- Health Admin: 8
- Social Worker: 7
- All Others: 14

Age at last birthday

N = 12 9 8 14
<table>
<thead>
<tr>
<th>Name of Hospital (date of origin of HEC)</th>
<th>University or Community Hospital</th>
<th>Education of Members, Staff and Hospital Community</th>
<th>Policy Development</th>
<th>Policy Review</th>
<th>Patient Care Consultation</th>
<th>Retrospective Review of Patient Care Issues</th>
<th>Ethical Resource for Hospitals</th>
<th>Forum for resolving ethical issues</th>
<th>Research in ethics</th>
<th>Self education and Development of Committee members</th>
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<tbody>
<tr>
<td>A (1985)</td>
<td>University</td>
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<td>B (pre1988)</td>
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<td>C (pre1989)</td>
<td>University</td>
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<td>D (1990)</td>
<td>University</td>
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<td>E (1988)</td>
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<td>F (1992)</td>
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<td>H (1987)</td>
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The first focus group interview was held in early July, 1994 and five HEC members participated. Although a larger group was expected, several individuals were unable to participate at the last moment. For all HECs that scheduled focus group interviews, enough members participated for the interview to be included in the study.

HEC Chairs were supportive of the study and accommodated the focus group interview during regularly scheduled committee meetings or at a specially convened meeting of the HEC. Each focus group included members from several professions/occupations who quickly embraced the focus group interview format. During the focus group interview, HEC members told the investigator that they relied on such factors as disciplinary background, legal implications, clinical experience, acquired understanding of how hospitals work, informal/formal education, values and personal limitations when discussing their views about the clinical scenario.

The Clinical Ethical Dimensions Discussion Guide (CEDDG) included some warm up questions designed to set the tone for the remainder of the interview. These questions elicited the thoughts and feelings of HEC members about the clinical scenario. The patient in the scenario was described by focus groups as “common,” “extremely common,” in that HECs agreed they “see a lot of [these patients]” in their hospitals. One HEC member stated: “In this hospital at any given point, about 3 or 4 times a day” [the events described in the scenario occur].

The scenario appeared to achieve its desired purpose in providing a common ground and instantaneous starting point for the focus group interviews. Participants overwhelmingly agreed they knew people like Mr. O. Focus groups willingly expanded on their statements with little probing from the investigator. Their responses verified the quality of the clinical scenario as a description of a patient situation prevalent in today’s hospital. In addition, HECs indicated they had experience, professionally and/or personally with individuals similar to Mr. O. HEC members who recounted personal experiences described family members such as parents, grandparents and others like Mr. O.

Although the HEC body of literature stated that the purpose of these committees
was to improve patient care, few of the HECs in this study directly communicated with patients. Patient access to these committees seemed to be almost an afterthought. The HECs in the present study discussed — education, primarily their own and that of other hospital staff. — and providing a forum for staff to discuss and review ethical issues. The impetus for the review of ethical issues was frequently prompted by the committees' involvement in policy development and less frequently by discussions initiated by health care providers. Community education initiatives appeared only in the Terms of Reference of a few hospitals participating in the study. Only one HEC appeared to actively encourage patients or their families to access the ethical forum of the HEC. A detailed description of each HEC based on the HEC Profile is set out in Appendix M.

A. Review of Preliminary Codes and Naming of Categories

This section discusses the breadth and depth of the HEC Role as reflected in the focus group interviews. The data from the focus groups were reviewed as soon as possible after the interview. As a first step, members were asked about their perceptions of the HEC role and what others in the hospital thought of their committee. The investigator read first through the transcripts and then coded them using preliminary categories that had been identified and explored through the questions contained in the Clinical Ethical Dimensions Discussion Guide (CEDDG). The pre-identified categories were: recognition of the clinical scenario, initial approach to the scenario, ethical issue identification, recommendations, multidisciplinarity and role of HECs. In this study, the HEC Role was further defined by the several successor categories: HEC Framework, HEC Administration, HEC Barriers to Success HEC Ethical Conscience, HEC Clinical Contribution, HEC Role Redefinition, HEC Resources and HEC Multidisciplinarity.

After reviewing the coded data segments, the investigator used the constant comparative method to compare each data segment to determine whether it fit within one of the preliminary categories or fell within some other new category. Table 3 presents the words used by the investigator to identify data segments that formed aspects of the HEC Role category. Forty-two different code words were used to define the HEC Role.
The computer program used by the investigator to manage the data, "The Ethnograph" could only accommodate labels for codes of eight or fewer characters in length. Consequently, the codes used are sometimes cryptic. All opinions expressed by participants, even when unexpected or rare, were considered as part of the analysis process. Whenever the data added a new aspect to the category or contributed to the understanding of the category, this information was discussed in the report on that category. Where these opinions appeared to lie outside the main body of the participants' experience, this was indicated.

An evaluation question had also been included in the HEC Profile. This question was completed by respondents following the focus group interview. The purpose of the question was to obtain some baseline data about the focus group process, and to identify potential failings of the study. Most respondents identified their experience as focus group participants as "interesting" and "fun".

The written comments of participants were of additional interest. Some respondents commented that they had enjoyed or appreciated the opportunity to participate in the study, since it had caused them to review the role of their HEC and consider its current direction. For example, one respondent noted that the study "widened knowledge of [my] HEC. very worthwhile exercise". Another HEC member stated that the study was an "extension of our ongoing discussions about who we are as a committee and what we do."

These written comments were reflective of statements made to the investigator and the observer by HEC members after the focus group interviews.

An extensive analysis was required by the amount of information and breadth of views expressed by HECs. Assessment of the study data involved continuously re-reviewing the raw data to verify codes, identify possible categories or sub categories, and to seek linkages between data, sub-categories, categories and themes. Categories and sub-categories are described by interesting or illustrative quotes. Since this process was fluid and changed continuously, only the last stages of the transcript-based analysis appears in this study.

Once the preliminary review and recording of data was completed, all data segments
were reviewed again to determine if additional categories and subcategories needed to be developed. At the same time, categories were being evaluated to determine if they could be regrouped or consolidated in any way. Defining the categories/sub-categories of the data permitted the investigator to understand and refine the workable data.

B. Collapsed Categories Reframed and Restated from the Data

Once the investigator identified several categories derived from coded data, it was necessary to move to the next level of data conceptualization. This level involved collapsing categories, where possible, and reframing/restating them as new categories more accurately reflective of the data.

The pre-identified category *HEC Role* produced a large quantity of data. The importance of this category, *HEC Role*, and its component categories was evident from the large number of data segments coded in these categories. As the process of analysis proceeded, it became apparent that *HEC Role* was not suitable as a category because it included too many concepts. Thus the investigator concluded that *HEC Role* constituted a theme or higher level of conceptualization. The data coded as part of the category *HEC Role* had to be expanded into a new group of categories, which described more accurately the scope of the *HEC Role* theme. The data segments began to shape an emerging vision of HEC ethical involvement represented by such new categories as: *HEC Framework, Authority and Power, Barriers to the HEC Role, HEC Clinical Contribution, Ethical Conscience, Role Redefinition, HEC Resources*, and *Multidisciplinarity*. 
Table 3
Codes relating to the HEC ROLE

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<td>CLINICAL VS ETHICAL</td>
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<td>LEADERSHIP</td>
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<td>EDUCATION</td>
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<td>POLICING</td>
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<td>CONSTRAINT</td>
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<td>HEC IMPEDIMENT</td>
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<td>REVIEW</td>
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<td>BARRIERS</td>
<td>40.</td>
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<td>17.</td>
<td>CLINICAL/ETHICAL ISSUES</td>
<td>41.</td>
<td>EMPOWERMENT</td>
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<td>ETHICS VS LAW</td>
<td>42.</td>
<td>SUPPORT HEALTH CARE</td>
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<td>19.</td>
<td>HEALTH CARE PRACTITIONERS AND</td>
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<td>HECS</td>
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<td>20.</td>
<td>HEC CHANGE</td>
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<td>21.</td>
<td>PATIENT CONSULTATION</td>
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<td>22.</td>
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<td>23.</td>
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<td>24.</td>
<td>CASE CONSULTATION</td>
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CHAPTER FIVE
DISCUSSION OF HEC ROLE THEME RELATED CATEGORIES

This chapter describes the experiences, opinions and perceptions of HECs about their role. Focus group interviews provided the context for HEC members' discussions, and a qualitative analysis facilitated the discovery of information about their role. The focus group results relating to the scenario, the identification of ethical issues, and the recommendations proposed by HECs appear in Chapter Six.

I. Analysis of the Category HEC Framework:

The *HEC Framework* category referred to HECs' perceptions of the committee, and how they viewed their role and obligations. This category also included several data segments about the responsibilities of HECs. Data segments, which were coded as part of the *HEC Role* but did not fit into other categories, were included in this category. Data collected as part of the category *HEC Framework* were further organized into sub-categories titled *Structure, Function, Ethical Leadership* and *Obligations*, in order to make the data understandable and manageable. These sub-categories define in more detail the category *HEC Framework*.

A. Structure (Sub-category). During the course of the structured focus group interview, HECs appeared eager to discuss issues about the framework of the HEC. A number of interesting points emerged from their comments. The majority of these data segments described the administrative structure of the HEC and, in particular, the authority and power of the committee. Data relating to the feelings of focus group participants about their influence within the hospital were re-categorized and incorporated into the category *HEC Authority and Power*. However, data segments discussing the formal reporting relationship of the HEC remained in this category.
In one group, an ethicist member screened all issues which came before the HEC, and directed all patient care issues to himself or the other staff ethicist. While this structure effectively removed some of the responsibility from the committee, the committee was supportive of this practice. Other committees did not report a screening process.

One aspect of subcategory structure raised by several focus groups was their influence on decision-making in the hospital. Some HECs commented specifically on their limited power to make or even influence hospital decisions. When suggestions or opinions of HECs were put forward to persons in authority, HECs saw their power as only one of moral persuasion capable, but not guaranteed to influence the Board of the hospital, the Chief Executive Officer or the Medical Advisory Committee. HECs were acutely aware of limits to their authority because the power to implement their suggestions usually rested with individuals or groups other than themselves. One nurse participant spoke about the distant relationship her HEC had with the hospital administration:

*But even so, if [Mr. X.] or the board of this hospital was forever in their meetings thinking of ethical issues and felt that this was the conscience of the hospital and was constantly referencing and referring ethical issues here, then there would be more a sense of this committee being involved on a more pervasive level. but it doesn't seem to me that that's at all what happens.*

**B. Function (Sub-category).** When specifically asked about the role of the HEC, some focus groups responded with amusement and others with ambiguity. "I still haven't figured out what this committee does!" (A225-6), or "we are trying to figure that out" (A228-9) were some statements made by members in one HEC.

Although the investigator encountered HECs with specific Terms of Reference, some committees appeared to be only vaguely aware of what they were empowered to do. The latter HECs identified the following functions as being within their jurisdiction: development and review of policy; providing a forum for ethical discourse; providing a listening function; assisting with ethical problem-solving and raising the ethical consciousness of the hospital through education of staff and the hospital community.
The issue of policy development was a well-recognized function of the HEC Framework category. In some cases, HECs took on the development of policy themselves. In other circumstances, HECs responded to requests for the development of policy usually originating from the hospital administration. Other HECs functioned in the role of reviewers for policies forwarded to them by the administration. As one HEC Chair commented:

...We respon[d] to others trying to develop policies, like recently these restraint policies, the policy we are trying to develop in long-term care relating to levels of medical intervention when someone becomes terminal or whatever... (A741-747).

The scope of review for specific policies was sometimes limited to clinical issues by hospital administration. On other occasions, explicit direction was given to HECs regarding the development of policy and the issues to be addressed. One HEC was routinely asked to review all the major policy developments in that hospital. This committee appeared to have a more influential consultation role in their hospital than was seen in the other participating HECs. However, HEC members in this hospital, accustomed to an inclusive management approach by their administration, placed little importance on this policy aspect of their role.

The data segments in the "Function" sub-category reflected a range of HEC responsibility. Policy development and review were recognized by most HECs as forming part of their function. Policies regarding patient issues — in particular, physical and chemical restraints and Do Not Resuscitate (DNR) policies — were also mentioned. Other policies discussed included violence, discrimination, policies on resource allocation and education. An ethicist HEC member stated:

... I remember the discussion we had about the guidelines for violent patients and that nursing had brought some concerns about what to do, particularly from an ethical perspective as well as a management perspective, and we gave some feedback on that... (D628-635)

HECs described their role in policy-making using a passive voice. That is, most issues
brought before the HEC were for discussion, rather than having been generated by the HEC itself. Some HECs raised the issue of self-initiating policy or policy review, but most members indicated their committee did not have this function.

The issue of the HEC as a forum or sounding board was also a recurrent image, as an ethicist member of a HEC indicated:

*But I think it is an alternate forum, it's hopefully a dispassionate forum, it's a forum where there is no major, I think -- I hope-- vested interest or access...you know, we're trying to be dispassionate about it. So it's somewhere where people can go to reflect on issues in hopefully a non-threatening, very supportive way.* (F868-877)

The chairperson of another committee said:

*I like to think we offer a venue for individuals who have encountered a difficult clinical situation to come discuss it, or to broach it with a representative on the committee so it can be discussed here. That is one of our roles.* (B1156-1162).

Although the emphasis varied from HEC to HEC, the central vision of members was that the committee offered a forum for health care providers to address ethical issues, as well as obtain impressions and/or recommendations from HECs. All groups were insistent that the process was a voluntary one. Some HECs observed, however, that individuals not interested in the committee's insights were unlikely to refer any issues to the group. In some settings, the HEC appeared to function solely as a sounding board for health care professionals' ideas and concerns. Others, in particular Focus Group C, saw the HEC as having a more proactive role, supporting staff by providing a resource for conflict resolution and ameliorating stress in the hospital. The idea conveyed was, "[you] are not alone, in making these difficult decisions". This sentiment was clearly stated by a physician participant:

*I cannot say that I would predict that the people in the hospital here would agree with me, but I have always felt, in the bottom of my heart, that one of the roles of a committee like this should be perceived as achieving an element of stress reduction, because these are always conflictual situations, where there is more than one party involved, debating about the right action. And if, you know, if that*
kind of opportunity exists, where the ethics committee can help mediate or facilitate or resolve in some other mechanism, any dispute, that cannot help but reduce stress in the environment. (C997-1014).

This desire to ameliorate difficult situations may have explained the lack of formality adopted by most committees. Few committees prepared any written materials about their deliberations. One group preferred that staff resolve ethical issues within their own clinical areas and not involve the HEC. In this hospital, HEC members were assigned responsibility within various areas of the hospital to respond and resolve ethical dilemmas. The appearance of ethical problems at the HEC level was perceived by this committee as a failure of their committee’s organization. This model of ethical intervention on the unit level was unique compared to the other HECs participating in the study and may provide some scope for further study. The Chair commented on her HEC’s role as follows:

...we hope that issues don’t come to the committee, because when there are problems on the unit, it is only if they can’t be addressed there with perhaps the help of an Ethics Committee member or the representative for that particular program that it would need to come further. So in a way, outside the policy and the hospital wide issues...we hope [it] wouldn’t come this far, because in a way it doesn’t work and we have a failure of our system. (D678-694).

HECs indicated a need for having experienced individuals with ethics training available in the general hospital setting to assist staff, patients, and their families with the resolution of issues. The need to debate ethical issues at several levels and, in particular, the right of persons to explore ethical issues in a broader setting is crucial.

HECs functioned as educators and “consciousness-raisers” within their institutions. As one physician participant observed:

I do not think that everybody in the institution thinks about ethical issues when they are dealing with clinical decisions, and it is something that is a learned thing. It is something that this committee, I think, has a responsibility to try and just raise the awareness of those issues when they are dealing with clinical decisions. (B1143-1154).
A community representative noted one of the limits to this role:

One of the things this group has done extremely well is education, and I know that in the last couple of years they have had to reduce the frequency of educational events, and it has been because of lack of resources. (C1164-1170)

Several HECs inferred that because heightened awareness of ethical issues and the mere presence of the committee in the hospital, staff would bring issues of ethical concern to the HEC. Furthermore, in many settings the HECs arranged for or taught education and information sessions for the benefit of other staff. While participating HECs indicated that they were dedicated to the education of hospital staff and patients, not all of them were equally active in this endeavour. At least one HEC indicated that funding had limited its ability to conduct educational programs.

C. Ethical Leadership (Sub-category). In addition to the functions already described, some HECs saw themselves as having a leadership role in ethical matters. This was described in two ways. First, ethical models were developed to permit hospital staff to analyze and resolve ethical dilemmas. The process in one group was described as developing an ethical template. Practically speaking, no HEC appeared to have chosen this kind of leadership role. Second, the ability of HECs to devise solutions to ethical problems frequently resulted in the committee being seen in a leadership role. The multidisciplinary nature of the HEC made it particularly suited to this task. This view was captured by one participant, a psychologist, who stated:

I think leadership [comes] from most of the people in this room. They are on the staff here, and it's the way they approach issues of the day that will be sort of the model that other staff might follow.

Investigator: It is role modeling and knowing that people on the committee are approachable so that if you want to talk to an individual committee member and bounce things off of them, you know they are available?

Participant: Yes (D640-652).
D. Obligations (Sub-category). Several areas of interest were raised by HECs about the committee's obligations within their various areas of responsibility. The HECs' comments included such sentiments as: (a) the HECs' role as the "ethical cops", (b) the HECs' role to ensure respect for the dignity of patients and staff, (c) the HECs' role in mediation of cultural issues and (d) the HECs' ability to alleviate moral distress. For example, in one focus group the following comments were made:

*Nurse:* ...we want to be able to help people reflect and come to some conclusion or some reasonable adjustment to their thinking as compared to being ethical cops and saying "This is what you have to do". And I think that has to be written into our process. *(F1352-1358).*

*Health care administrator:* ...and there certainly are some people out there who see us as a threatening group; i.e. the cop approach that is going to go in and tell people what to do. And it is like anything: you just have to work with people so that they are reassured *(F1409-1416).*

The investigator was successful in stimulating considerable discussion by asking if HECs saw themselves or were seen by others in the hospital as the "ethical cops". A related issue was whether the committee saw itself as the "ethical conscience" of the hospital. This latter question justified its own category and was addressed separately. Every focus group denied playing the role of the "ethical cops" for its respective hospital. In fact, many HECs seemed distinctly uncomfortable with any kind of overt ethical role outside the scope of the committee. One nurse member commented:

*The only thing that I would not want out there is that we would have any role insofar...[as] policing of [ethics] ...I would just not want that kind of thing.* *(C1061-1066).*

Although HECs were on occasion approached by other staff in the hospital, few members wanted to take any active role in seeking out ethical issues within the hospital. Focus Group D, a HEC with patient consultation responsibilities, was the exception: they had a model of triage intended to manage ethical issues. Members wanted their colleagues to approach them and willingly brought their issues forward to the HEC.
II. Analysis of the Category HEC Authority and Power

It appeared the HECs in the present study were at various stages in their development and evolution. This became particularly clear when analyzing HECs' relationships with the administration of their respective hospitals. The administrative structure of each HEC was different, but usually involved a reporting relationship to either the senior administration of the hospital, the hospital board, the chief executive officer or the Medical Advisory Committee. Some focus groups were more comfortable in an advisory role while others "chafed" against it. Originally, "Administration" and "Authority" were used as code terms to represent data segments which disclosed aspects of the formal relationship between the hospital and the HEC, as well as the feelings of the HEC about that relationship. On further examination, the investigator concluded that these concepts were actually related in content and combined them together to form a new category "HEC Authority and Power".

Several of the HECs in this study had experienced or were experiencing uncertainty concerning their committees' contributions to the hospital. According to their members, only a small number of HECs were aware of their own committee's Terms of Reference, or felt supported and respected by the administration of the sponsoring hospital.

The category of "HEC Authority and Power" reviewed the relationship between HECs and hospital administration and in particular, the formal reporting responsibility of the HEC, its authority and the rationale for the various structures which surrounded its operations. Focus groups reported on a variety of formal reporting structures. In this study, HECs reported to the CEO of the hospital, the Board, the Medical Advisory Committee, or one of the subcommittees of these bodies. Only one focus group was fully comfortable with its administrative structure. Many focus group members questioned the organizational structure of the HEC-hospital relationship, but there was no consensus among HECs regarding how they might address these deficiencies. As one HEC Chair noted:

*We have had some disappointments about the lines of communication with the administration here, and we have been vocal about those disappointments and have demanded more input into questions that we think are appropriate for the Ethics Committee to have more input into, and, we think -- this is a little early in the
day to be sure—but we think that the administration is responsive to those requests... 

As indicated previously, HECs thought they had a lack of influence when it came to overall decision-making within their hospital. This was a difficult area for HECs. Most committee members did not want to be a decision-making body. Yet HECs also thought they had important contributions to make to the administration of the hospital.

Not surprisingly HECs believed that their committees and the hospital administration had different goals. HECs’ lack of authority and power was made a virtue rather than a liability by many HEC members. The community representative on one committee stated:

*We are really serving the patient, not the institution. And that is what we should be doing. And from that point of view, I think that... in effect, the less structural power you have, the better you will end up doing it. You then become a patient advocate.*

HEC members perceived a difference between their approach to ethical issues and the approaches of hospital administration. Whereas HECs had to deliberate over the complexity of ethical issues, administrators had to act or react quickly and address problems immediately. HECs appeared to prefer an advisory role and having influence on decision-making rather than being the decision-makers themselves.

One HEC viewed this relationship with administration solely through policy review. Members from this HEC preferred no role in policy development, since policy development was not seen as an effective use of their skills. A senior administrator in this focus group reported that:

*...the need to define it fairly clearly was there to avoid the ethics committee being a bit of a policy dumping ground; like, oh, we need a hospital policy on...I'm going to say restraints, because it's an example of where -- it actually was written somewhere else, but -- and all of a sudden the ethics committee gets the extremely time consuming task of actually trying to develop the policy, and so we were very careful about positioning ourselves so that we would really be advising on policy or reviewing policies that were put together by other groups, recognizing that there may be some exceptions.*

*(H1430-1447).*
The authority of the HEC was accepted by most participants as advisory in nature. Focus Group A expressed frustration that it was not being consulted in major policy debates within the institution over issues which involved ethical concerns. This concern was captured by a psychologist member:

But even so if Mr [X] or the board of this hospital was forever in their meetings thinking of ethical issues and felt that this was the conscience of the hospital and was constantly referencing and referring ethical issues here, then there would be more a sense of this committee being involved on a more pervasive level, but it doesn’t seem to me that that’s at all what happens. (A1165-1176)

In particular, this focus group said they were concerned about the allocation of hospital resources. Focus Group D reported it was already involved in the debate about hospital resource allocation, and quickly pointed out that the administration of their hospital always consulted the committee about such issues.

Some HECs in this category saw their advisory role as limiting. The competing perspective was that the authority of the HEC was not based on any direct power within the committee, but resided in the subject matter of the HEC’s deliberations. The HEC had a moral authority which, given the multidisciplinary nature of the HEC, could be seen as non-partisan. A number of HECs commented that hospital staff frequently perceived their committees as having far more authority than in fact it did. HECs thought this perception might be a reflection of the moral authority accorded to them by other hospital staff. One HEC member expressed this feeling as follows:

I agree. I don’t think this committee has the formal authority. I think it has referred authority and I think that the perception out there is that the committee is much more powerful than we think it is, and I think its very interesting because it’s usually the converse, the committee is seen as being very influential so its interesting. (A950-958).

The administrative structure of the hospital seemed to play a crucial factor in assessing the authority and power, or perceived authority and power, of the HEC. One HEC served in a hospital where services were being decentralized. The focus group members in this hospital were concerned that, with the erosion of hospital-wide structures and the
development of decentralized health care teams, the ethical leadership of the HEC would be supplanted by services available within these decentralized teams. (e.g., Oncology team would address oncology related ethical issues). Members of this HEC were unable to identify solutions to their concerns. However, some members thought the role of the HEC would be preserved and enhanced by the integration of committee members into the decentralized teams. Unfortunately, members did not know where to take their concerns, but agreed on the importance of awareness of their role in the hospital’s administrative structure.

A number of HECs in the study perceived the administrative bodies they reported to as lacking understanding of the HEC and its goals. Members commented:

*I am not sure that the body we report to, which is the formal Ethics Committee, clearly appreciates that vision (F981-984).*

*Plus, I feel that the body that we report to in a sense dies there. It doesn’t seem to affect anything, wherein I think another reporting structure, it may just be in another culture (F986-990).*

As previously noted, most hospitals have only currently put into place formal mechanisms to address ethical concerns. This may be one possible explanation why hospital administrators lack understanding of the HEC role. Several HECs argued that hospital administrators need to know more about their role. Comments made by HECs indicated that the reporting relationship of the committee influenced its authority within the hospital. In other words, if a HEC was isolated from the corporate structures of the hospital, its role would be diminished. An administrator stated:

*If you look at the Ethics Committee as part of this reporting structure and the fact that it is medically oriented and goes to the MAC, it completely isolates itself from the administrative corporate side of the institution, and my personal opinion is that that is somewhat lacking in that approach. (F1042-1049)*

**III. The Analysis of the Category HEC Clinical Contribution**

This category reviewed the support HECs members believed they provided to the
clinical practice of the institution they served. Many HECs expressed the view that hospital staff were unaware or unsure of the HEC role. At the same time, several HECs expressed concern about a lack of focus in the committee itself. As one nurse commented, her HEC was "...sort of rudderless on occasion" (A778-779).

By far the most significant barrier for focus groups was the lack of awareness or understanding of HECs within their respective hospitals. HECs believed that some staff in their various hospitals would not "buy into" the idea that the HEC role could be useful for them. The following quotes were typical of the observations of participants:

[A member of the clergy noted]...there are groups of physicians, staff, et cetera, who are very appreciative of the fact that there are resources. Whether it's an individual or a group, I think there are other groups who don't have anything to do with us because it doesn't fit their world view: they don't approach us, and we don't approach them right now if the truth be known. (F1391-1401).

[A Chairperson stated:] Before things were done routinely and arbitrarily, according to clinician's judgement and I think it also has made communications better within the health care team. You know, there are islands that it is hard to penetrate... (B1194-1200).

Since participation in HEC activities is voluntary, staff in the hospital can avoid the existence of HECs almost entirely if they want to do so. Thus in some cases, hospital staff know the HEC exists, but refuse to seek its guidance.

Frequently, focus groups referred to a lack of awareness among staff, patients, and families about the existence of the HEC. In one focus group, staff believed the HEC was too disorganized within itself to provide ethical leadership. Despite recent changes, staff in the hospital continued to view this HEC with skepticism. An administrator in this focus group observed:

I don't think we've had that kind of...really very much positive profile. I think, if we've got any positive profile, it's happened in the last three or four months. But, I mean, what's happened in the last three or four months may just be bringing us up to sort of a neutral point. But prior to that, I think that there was some degree of negativity about the Ethics Committee because it was seen to be there but not really functional or doing anything. So it was a negative... (H1265-1280).
Members of another HEC indicated their committee was viewed by staff as being "different" because of their membership on the HEC.

*I think there are some subtle differences in the team in the sense that there are members who sit on [the HEC] and others who don't. So I think it creates a different impression of how you're perceived...*(F1167-74)

Some focus groups also commented on a number of interpersonal deficiencies within the organization of the HECs which, in members' opinions, reduced its effectiveness. One example was the ability of physicians to dominate any discussion where medical issues were central to the deliberations. As one committee member observed, despite the theoretical equality of all HEC members, individual members were still perceived as part of the hospital hierarchy. People with perceived authority in the hospital thus recreated their positions within HECs and were able to dominate other members.

One HEC had been asked to develop education programs and staff support materials concerning amendments to the provincial legislation regarding consent to treatment, mental incompetency, and substitute decision-making. This provided a specific focus for the committee and raised its profile considerably within the hospital. At the time of the focus group interview, this HEC was considering ways to pursue its advantage and further enhance its profile. This HEC intended to move in the direction of education and policy development.

The HEC was seen by some focus groups as representative of the moral community of the hospital. This was expressed by an ethicist HEC member:

*I think for me maybe it's on the same point that we have talked on a number of occasions about the hospital being a moral community. And, to me, the ethics committee is in some way representative of that community, and it provides a forum, or a haven, or whatever word we want to use, where people can come and get help thinking about problems. And we've just started to do more thinking about how we'll do that in the life of the organization...And it's somehow a forum where those issues are at least identified as issues, and people, I hope, would feel safe to air them.* *(G1046-1068)*

The existence of such a community was reflected and maintained through the provision of a
safe forum for discussing ethical issues. As well, the HEC fostered hospital endeavours through the education of its members and other staff, and by influencing policy. In this study, HECs advocated formal and informal approaches to staff education. The education of HEC members was effective in developing a group of experienced ethical persons within each hospital. As one nurse commented:

*There is a softer role that the ethics committee plays of developing a recognized core, if you will of the ethics enterprise in the hospital, that over the years that I have been associated with the committee there have been numerous people who have come onto the committee, or have been somehow attached to the committee through working groups, or projects, or conferences, or whatever. And I think now at the hospital there is a recognized community, if you will, of people who have an interest in, and a knowledge in, and some energy around ethics, and that gets spun into all sorts of different things. So whether we can say we’ve done five policies or not, we can say that there is a group of people who are aware of the issues and are able to converse one-to-one, and in a more broad way as well.* (G1021-1044).

HECs agreed that an experienced core group of committee members was crucial to the committees’ success in raising staff awareness to ethical issues. Comments made by HEC members indicated a preference for leading by example, such as demonstrating to hospital staff how the HEC would approach an ethical issue.

Policy initiatives by the HEC were discussed in some detail. A typical statement made by a nurse was that policy seldom changed as a result of committee discussion:

*...we talk about changing policy more than we actually -- changing or writing more than we actually do.* (G1008-1010).

Although policy discussions provided an opportunity for developing ideas within the HEC, these discussions often led to members’ frustration if the efforts of the HEC were repeatedly ignored. As one HEC member indicated, her committee had the opportunity to receive input from the “grassroots” of the hospital, but this seldom happened. On reflection, focus group participants thought HECs were a good place to develop directly applicable policy since they could create policies which met the needs of the persons appearing before them.

In this study, education (of members, staff and the hospital community), policy
development, and ethical leadership were all frequently mentioned by HECs as their major contributions. The provision of patient care consultation was relatively more limited in the present study.

IV. The Analysis of the Category "HEC Ethical Conscience"

Focus groups were responsive to any questions concerning the nature of the HEC role. Many HECs had considered their committees' structure and the ways in which it could be improved. The CEDDG asked focus groups what others thought of them within their own hospitals. In order to facilitate this discussion, focus groups were asked if they perceived themselves as either the "ethical conscience" or the "ethical cops" within their hospitals. This prompt often elicited animated opinions from HECs. As well, there was much ongoing debate about what exactly the HEC represented in their respective hospitals.

The suggestion that the HEC was seen as the ethical conscience of the hospital was vehemently rejected by all groups. A psychologist emphatically stated:

*I really don't understand the question to some extent, because I suspect it's coming from a different take on things. I don't feel like an ethical conscience. A pain in the butt at times, but not an ethical conscience. (F1359-1365)*

A more serious response from one of the HEC chairs was:

...*the hospital has its own ethical conscience in that...I mean, it is not one. It is obviously a myriad of people. I see us as a consciousness-raising, educational, policy-advising tool. (B1717-1723).*

In fact, many HECs appeared amused by the suggestion. Perhaps the ambivalent role HEC members see their committees as playing was the origin of this amusement. Focus Group participants presumed they had a certain moral authority, but no power within the hospital. In contrast, HEC members thought that their committees were viewed by hospital staff as having both power and moral authority.

The investigator did not define the term "ethical conscience" for most groups. If asked to clarify the question, the investigator referred to the HEC literature and the comments made by other focus groups. The term "ethical conscience" was interpreted by most
groups as involving two factors: a) having a leadership role in addressing ethical questions; and b) having the authority to resolve such questions. Generally, HEC members refused to consider the committee as the "ethical conscience" of the hospital because they rejected any absolute authority in ethical decision-making. However, they agreed that they did have a leadership role in ethical matters.

One HEC reported it had been approached anonymously by the Department of Nursing to review certain ethical issues arising in a patient care area. In this instance, the Nursing Department itself did not want to be identified as the instigator of the ethical review which it believed was necessary. This HEC's example appeared to support beliefs of HECs that they provide leadership in examining ethical issues yet sometimes this leadership role lacked collaborators. Such examples confirmed to the investigator that the HEC was seen by others in the hospital as an "ethical conscience".

The focus group most receptive to the idea of acting as an "ethical conscience" was a religious-based HEC. Its ethicist viewed the hospital as a moral community and the HEC as a microcosm of that community. Ethical values were seen as personal in nature in this hospital, and the HEC was not perceived as the "ethical conscience" of the community. Each person was expected to express his or her own ethical consciousness.

The question, why HECs do not want the responsibility of being perceived as the ethical conscience of their hospital elicited many responses. The notion of policing ethics within the hospital was challenged by several HEC members, since it was seen as adopting a dictatorial rather than a consultative role. For example, the HEC members from Focus Group E saw themselves as a consultative, indeed supportive, body and this role precluded exercising mandatory power. Other groups saw the adoption of the role of ethical conscience as belonging to such members of the hospital as pastoral care providers, ethicists, social workers, hospital personnel, professional organizations representing hospital members, or the individual in his or her own profession/occupation. An ethicist participant referred to the hospital community as forming a "mosaic of conscience". Each HEC was consistent in placing the responsibility for matters of ethical conscience on others; however, there was little consistency from group to group about who,
if anyone, those others were.

The literature identified HECs as playing a leadership role in maintaining the ethical principles of the hospital. Although HECs in this study accepted this characterization, they rejected the notion of mandatory authority. It was clear that HECs were uncomfortable with their leadership role and prepared to place the responsibility for this role elsewhere including, for example, on individuals, professional bodies, hospital management, clergy/ethicists, or on the general hospital community.

V. Analysis of Category: HEC Role Redefinition

During the focus group interview, participants were asked if they wanted to modify their role at all and, if so, how. This question occurred as part of the interview and attempted to determine: (a) the official position of the HEC within the hospital, (b) the divergence between the official position and the way that the HEC actually functioned, (c) the perceptions of other health care providers about the HEC, (d) the issue of deficiencies in the execution by HECs of their role and (e) areas for future change. This category captured areas where HEC members expressed a desire to adopt new practices, polices, methods and educational initiatives. In addition, members were offered the opportunity to choose a direction for change in the HEC role. This question was asked following a discussion of the HEC role and the limits experienced by individual members. These questions successfully elicited from focus groups the changes they wanted and the activities they were interested in pursuing. The responses obtained varied since focus groups interpreted this question in different ways.

A number of HECs discussed recent changes which had improved their committees, as well as future positive benefits HECs expected to gain. The following comment of an administrator was reflective of this sentiment:

*I think probably now more than ever, given this has become a culture of change. Our last three or four years of experience in the institution has taught us to sort of be ready for anything. So if there was ever a time you could do something new this would be the time.* (G1194-1201).
Many HECs did not provide specific examples about how they wanted their committee to change, and this question was of limited success even with the investigator using probes to identify more specific opinions from participants. When asked to elicit possible directions for change, HECs were often unwilling to countenance any change and were prepared to continue doing the same thing, only more so. Among the responses received were suggestions that the HEC foster its role as a non-judgmental forum for the discussion and review of ethical issues. An ethicist made this comment:

...my kind of dream about this would be that we would be a true forum, or think tank. I don't mean that we're in the stratosphere, but it's a safe, a truly safe environment in which people can air very serious and profound moral differences, or ethical differences about decisions that have been taken or that are proposed within the context of patient care, for example, or management about resources. And by that I mean a safe environment, that people would hang their job titles and positions outside the door, and there would be a condition of entry that we all come and be on a level playing field...(G1209-1227).

Other identified future directions included: (a) additional patient care consultation, (b) the development of small HEC teams involving ethicists and non-ethicists for direct patient care interventions, (c) additional education for staff, patient families and the community, and (d) an expanded role in policy consultation.

Some HECs were pessimistic about the possibility of change. Reasons identified by members arose from the HECs’ poor relationships with the authorities they reported to within the hospital hierarchy. The following comments from two chairpersons expressed these concerns:

The other element of the education is the communication. Certainly we have done a lot of writing and sometimes it really does not get from...it gets from here to the major board roles, but it really does not get communicated back down to the health care team in a way that it should, and that is supposed to have been done traditionally through the clinical areas...(B1345-1355).

We have had some disappointments about the lines of communication with the administration here, and we have been vocal about those disappointments and have demanded more input into questions that we think are appropriate for the ethics committee to have more input into, and to, we think -- this is a little early in the day to be sure-- but we think that the administration is responsive to those
requests that we have, or demands maybe that we have made, and we are in anticipation of even more...the lines of communication opening up even more. (E669-684).

Furthermore, some HEC members thought their committees were perceived by hospital administrators as being an adjunct to clinical practice. All HECs in this study accepted a responsibility to assist health care providers in resolving ethical dilemmas. Yet some HECs thought they had been slotted into a limited role because the hospital administration failed to recognize the important contributions of the HEC beyond the clinical setting. It was the view of these focus groups that such limitations would be overcome by: (a) having staff ethicists, (b) increasing the funding to the HEC, or (c) helping the hospital administration respond to external challenges. Stable HEC membership and strong leadership were also identified as essential to implementing changes within the HEC.

VI. Analysis of HEC Resources/Barriers Category

A shortage of resources was identified as a limitation governing the role of the HEC. This category identified the limitations in resources experienced by HEC members in carrying out their role. The reference to limited resources, which appeared more frequently in the data than the investigator expected, was coded separately to determine if it would constitute a separate category. The quantity of the data and the ideas involved qualified this as a separate category.

The following exchange captured the sense of this category:

Physician "That's really just a dollars and cents issue, that's not an ethical issue."

Administrator "Well, it is an ethical issue... I think it's a very large ethical issue that we did not identify when we were talking about ethical issues, and I think it is an ethical issue of how we spend our resources in the hospital and, in fact, all our health care system." (H830-842)

The issue of resource allocation was a concern raised by all focus groups; however, the direct impact this would have on their committees appeared to be of fairly
limited interest to them. A recurring idea in the focus group interviews was that a holistic approach was necessary to adequately respond to patient needs. As one subject said, "...the ability to bring an elderly client through a very serious health crisis is of little or no value if we are not prepared to care for them afterwards." G999-1010.

Hospital staff required several sources of ongoing support to implement their clinical work. HECs identified the following supports for patient care: a) having enough staff to provide patient care, b) written hospital policies, c) contributions by patients' families and/or volunteers, d) staff education, e) administrative supports, f) cooperation of clinical teams, and g) the HEC itself. Many of these patient supports relied on funding which could be reduced or eliminated at any time. HECs did not know what role they would have in evaluating existing hospital resources.

It was apparent some HEC functions had already been disrupted by a lack of hospital resources. One example provided was that of the HECs' role in education. A number of focus groups reported that their ability educate staff about ethical issues was limited by a lack of financial support. Resources were not always expressed in monetary terms. One focus group thought the lack of an ethicist had impaired the efforts of their committee to move forward and provided details about the negotiations with the hospital administration for hiring an ethicist.

A lack of resources for HECs was an issue for several of the focus groups. However, in comparison to other challenges faced by the participating HECs, this problem appeared peripheral.

**VII. Analysis of the Category Multidisciplinarity/Interdisciplinarity**

The HECs in this study were all multidisciplinary in composition (see Appendix O). Although the value of the multidisciplinary HEC has been challenged in the literature, none of the HECs in this study indicated any reservations about the multidisciplinary composition of their HEC. The investigator suggested that alternate models, such as those discussed in the literature review, might be of interest to committees. None of the HECs expressed any desire to change the multidisciplinary composition of their committees.
HECs in the present study adopted an egalitarian approach to the idea of ethical expertise. Ethicists and members of the clergy were expected to have some level of expertise; yet this was more closely related to the analysis of ethical problems, than to an ability to resolve such problems. The expertise existed not in claiming to know what was ethical, but rather in helping to elicit ethical principles and in facilitating ethical decision-making. In other words, clergy/ethicists have expertise in how to think ethically. A psychologist participant expressed this opinion:

...rather than taking the kind of expert approach to ethics, we have taken the practitioner approach, I think. And what I mean by that is, emphasizing that ethics is what we all do every day of the week. and rather than kind of...like, we could have employed or encouraged the hospital to employ an ethics expert who was kind of flown in when there was a problem, something like that.

We’ve consciously tried to stay away from that. We’ve utilized experts in terms of helping us develop where we’re going and stuff like that, but we haven’t defined our approach to ethics in that way. So if you’re going to go at it in that kind of practitioner mode, I’m calling it, you do need a balanced multi-disciplinary approach, because none of us are in quotes “true ethics experts” in any sense. And I think some of the comments here about expertise and level of expert, that’s where that comes from, that dynamic we’re struggling with. (F1227-1252).

All HECs in the study had either ethicists or clergy members, most of whom were able to participate in a focus group interview. One focus group was chaired by an ethicist; all of the other professionals in ethics (clergy and ethicists) served as HEC members. Focus groups were asked for their reaction to a suggestion that the HEC not be involved in clinical ethics consultations. A clinical ethics consultation service would be staffed by specialists in ethics. This suggestion was unanimously rejected by HECs in the study. Even the ethicists and clergy members of the focus groups were not supportive of a separate clinical ethics consultation service.

HECs broadly accepted other underlying characteristics of an interdisciplinary HEC. In particular, the existence of a relationship between one’s professional/occupational background and approaches to patient care was acknowledged by
most HECs. A psychologist said:

"...one of the reasons we have a group is that we don't get caught up with our initial priorities to some extent, but one of the benefits of working in a group is that we do try and see it from as many different angles as possible.

So I think maybe the answer to your question is not what I bring to the situation from my personal background, but what I try and not bring from my personal background. (F263-279).

HECs were enthusiastic about the interdisciplinary dimensions they contributed to their committees. Examples of the value of interdisciplinarity focused on the sharing of knowledge about each other's professional experience and obligations.

The personal experiences of HEC members were identified as important to the self-development of the HEC as a whole. It was also true that HEC members had much in common, such as similar life experiences, a basic professional education and standards, religious tenets, and so forth. As well, the personal experiences of HEC members appeared to influence their responses to the concerns raised by the clinical scenario. An interesting expression of this situation was contained in the following quotation from one of the physician participants:

Well, it's just in coming from my own background as a physician. I mean, your perspective has definitely got limits to it, it's got some boxes around it. And you know, "I come to this group and state what my opinion is or what my point of view is, and then to be challenged with a point of view that doesn't even necessarily fit into the boxes that I live in, and to sort of look at it, you know. From a completely different perspective, and I guess the way I look at it is, it's kind of like getting perspectives from the world at large, that a physician... I mean, the medical community tends to put its perspective at the top of the pyramid. If all else fails, we'll look at things from a medical model and then everything will be okay.

And then you start to realize: Gee, you know, the rest of the world doesn't always operate that way. (F1188-1210).

As well, there existed specific differences in the areas of life experience, education and other aspects of the individual HEC member. While these differences among individual committee members were small, they benefited committee initiatives. This was well expressed by a nurse member of a HEC:
I think that saying that it is a richness. I mean we gain from each other. And social work, right beside me. I hear from her perspective and how she views situations. And she looks at it and she deals with it from a slightly different perspective, although there are certain -- obviously there are similarities and things that we share, but because of where she works and how she works then it brings you a broader view of the situation. For me it's been very good in helping me to identify and understand ethical issues within the unit where I work. And I think it's helped me to work better in that environment. (G1281-1299).

The chair of one group indicated that when a hospital chose to rely on non-experts for ethical guidance, a balanced interdisciplinary approach was required. Furthermore, he suggested, rigour in ethical analysis would only be achieved by developing consensus among HEC members. The discussion of possible solutions in a multidisciplinary forum permitted HECs members to assess the flaws in proposed solutions and to understand the impact that such solutions would have for other groups or individuals within the hospital. For example, in one focus group the following discussion occurred:

(Community Representative): Is it any easier to make the chemical restraint decision?

(Nurse.): No, no it is not. It is not. I still have trouble with it every time I go... you know, to give some more, to get some more, and then finally, think, "Where do you stop, and when is it going to start working". And you are sitting there, on edge of the patient, just as much as with the anxiety, and maybe not the agitation, but the anxiety, is when is this going to... when is this medication going to kick in, and help them be able to control. and get back into a realm where they can control themselves.

In this extract the nurse indicated an aspect of the use of restraints that might be unknown to non-nurses. In the opinion of the investigator, this quotation clearly demonstrates the shared benefits of interdisciplinary knowledge. Such comprehensive information can be used in designing a policy or providing guidelines which will respect the concerns of nursing staff, non nurses and patients. It was clear from this extract that, because of their multidisciplinary backgrounds, HECs were able to function as non-expert consensus builders on ethical issues. At a minimum, all of the groups involved in the care of the patient should be represented on the HEC. In this way multidisciplinarity
adds understanding, richness, diversity and authority to the HEC process and benefits the patient.

The focus groups in the study routinely referred to the multidisciplinary HEC as constituting a safe and trusted setting for the discussion and review of ethical issues. The observation of the investigator was that the most self-confident HECs came from committees where the chairperson was very dedicated and supportive of the efforts of the HEC. In reviewing the history and origin of one participating HEC, it became clear that lack of dedicated leadership had caused major problems for this committee. Participants in the focus groups made the point that a highly skilled facilitator was required to develop consensus among committee members. In fact, HEC members can hold such divergent views that reaching a resolution would seem almost impossible. The chairperson's facilitation skills were crucial at such times in order to resolve the impasse.

Multidisciplinarity offers HECs an opportunity to bring a diversity of backgrounds, and a range of responses, to bear on a particular issue. Only one participant commented that, where multidisciplinary representation was absent, this may have undermined the effectiveness of the HEC. One focus group observed that their HEC was formerly dominated by physician members, who had been reluctant to admit any need for consensus building. However, the physician members had since left the committee or stopped attending, and the HEC was currently experiencing a loss because of the absence of these opinions.
ORGANIZATION OF CATEGORIES/SUBCATEGORY TO DESCRIBE
THE THEME HEC ROLE

→ HEC Framework - HECs perceptions of their role and obligations
  - Structure - formal relationship of HEC in relation to the rest of the hospital
  - Function - scope of activities HECs see themselves as performing
  - Ethical leadership
  - Obligations - duties performed by HECs

→ Multidisciplinarity - multidisciplinary composition of the HEC Role

→ HEC Role Redefinition - modifications or changes HECs wanted to make to their role. For example HEC members expressed a desire to adapt new practices, policies, methods and educational materials

→ HEC Barriers and Resources - financial barriers to the HEC role.

→ HEC Authority and Power - Authority of the HEC and the formal reporting relationship of the HEC

→ HEC Ethical Conscience - HEC as the ethical conscience of the hospital

→ HEC Clinical Contribution - Contributions HECs believe they made to the clinical practice of their hospitals
CHAPTER SIX
ETHICAL ISSUES AND RECOMMENDATIONS

This chapter describes the categories identified in the focus group data related to the clinical scenario involving an agitated elderly patient – Mr. O. In particular, the categories *Reaction to the Scenario, Identification of Ethical Issues* and *Recommendations* are explored.

I. Analysis of the Category Reaction to the Scenario

There were varied preliminary responses by HECs to the scenario. This category comprised HECs’ initial reactions to Mr. O’s agitated behaviour. In the HEC Profile, members frequently raised the need for Mr. O to be assessed, either medically or psychiatrically. Assessment was often suggested by focus group members as the first step in the analysis of Mr. O’s clinical problems. One area of assessment agreed on by HECs was the need for a capacity assessment to determine Mr. O’s mental competency. Also of interest was the division of reactions HEC members based on their professional/occupational backgrounds.

*Reactions* to the scenario described in Table 3 were categorized in two ways: (1) reactions that involved participants having direct contact with Mr. O, either through some intervention or by placing themselves in Mr. O’s position; and (2) reactions that involved an indirect connection between HEC members and Mr. O, whereby a further assessment or analysis of the patient situation was required.

The *Reactions* to the scenario identified by the investigator as *direct or interventionist* included: (a) frustration about the difficulty of communicating with Mr. O.; (b) fear of not being compassionate when dealing with Mr. O; (c) concern about imposing on Mr. O traditional practices convenient to the nursing staff, but not to the patient; (d) risks for Mr. O associated with physical restraints; (e) the need for Mr O to have a calm, attentive listening interaction; and (f) the benefits for Mr. O of a caring nursing interaction. *Indirect and/or analytical* reactions included: (a) the need to know or investigate the cause of the agitation to find appropriate treatment options; (b) staff
anxiety over Mr. O’s loss of control; (c) the need to understand the meaning underlying Mr. O’s agitated behaviour; (d) the concern about Mr. O’s mental competency; (e) the responsibility of Mr. O’s family or friends to intervene; (f) concern about cultural issues being respected by any intervention planned for Mr. O; (g) a concern over the management plans and hospital policies established to manage patients like Mr. O; (h) the need to educate staff to respond to situations like Mr. O; and (i) management strategies that would avert this kind of patient situation.

Direct reactions were suggested by HEC members with nursing or community backgrounds (Registered Nurses, patient ombudsmen, community representatives). Perhaps health care providers who have direct contact with patients approach clinical problems by using themselves therapeutically, and intervening personally in a face-to-face manner with patients. The indirect reactions were mainly from physicians, health care administrations, ethicists and other representatives of professions not directly involved in providing care to patients like Mr. O. The shaded area in the Table 4 explains that reactions by patient representatives and respiratory therapists appear in the indirect group and by health care administrators in the direct group. However, reactions to the scenario by health care administrators in the direct group also reflected some of their personal experiences with patients like Mr. O. Other health care providers in this study preferred seeking additional information about Mr. O; and therefore, these individuals would only be remotely involved in the patient’s care. The investigator’s observations of this category appeared to provide some evidence for a link between professional/occupational background and HEC members’ reactions to the clinical scenario. Individuals with direct patient contact as part of their professional/occupational background appear to favour interventions with which they are familiar.
<table>
<thead>
<tr>
<th>Direct or intervening reactions</th>
<th>Indirect or Analytical reactions</th>
<th>Professional/Occupational background of HEC members</th>
<th>Quotations representative of the Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>Administrator</td>
<td>You think of the patient who is not able to communicate, the frustration that you feel</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Nurse</td>
<td>Very difficult to know that you are going to have to deal with it and have compassion</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Clergy</td>
<td>the shift change, which is enforcing some other kind of stricture on him</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Community Rep</td>
<td>a patient would be terribly frightened with being restrained somewhere, I mean it is very frightening...</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Patient Rep</td>
<td>I would try to pull up from within me the ability to be able to stay calm and be attentive and listen to them</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Nurse</td>
<td>benefits of a caring interaction</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Physician</td>
<td>I hope that you already had a plan in place as you should have covered how to react to the patient with the family</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Student</td>
<td>staff anxiety about danger of Mr. O</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Student</td>
<td>an understanding what the underlying agitation is</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Physician</td>
<td>he is the facility for a reason it should be done already...there should be a plan to respond...</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Ethicist</td>
<td>I would like to draw on family connections ...the staff might have recourse to knowing who the family member is on call who could come in or suggest strategies.</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Patient Rep</td>
<td>I recognize there are different cultures...we have to respond in a culturally appropriate way</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Physician</td>
<td>Plans and strategies to manage such patients</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Student</td>
<td>education of staff</td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>Respiratory Therapist</td>
<td>planning in terms of when patients are admitted, as to where they are placed...can help prevent these problems.</td>
<td></td>
</tr>
</tbody>
</table>
II. Analysis of the Category Ethical Issues

This category was defined as the ethical issues arising from the hypothetical clinical scenario. The investigator had devised the scenario to raise ethical issues. In this study, the category *Ethical Issues* referred to any suggestions by a HEC member that an issue had ethical dimensions. The investigator did not question whether an issue was ethical or not ethical, but relied on the statements of HEC members.

The HEC Profile asked participants, before coming to the focus group interviews, to review the scenario and identify any ethical issues. The CEDDG also sought identical information from participants in the focus group interviews. During the first focus group interview (pilot), one HEC member was adamant that the scenario raised no ethical issues. One HEC member, a psychiatrist, took the view that ethical considerations were irrelevant to good clinical care.

*We are assuming that good clinical care is ethical care, but again that's stretching it. I still say if one is going to do this man justice we are going to have to provide him with good clinical care. (A567-572)*

*... if we want to make everything an ethical issue, we can, but I just don't know how you can start getting into that every single time you have a patient encounter on every single level. Of course, one hopes that as a clinician one is guided by certain ethical principles. (A611-619)*

This participant modified her position to some extent during the focus group interview, as she openly discussed her experiences with other HEC members:

*Psychiatrist: It seem to me part of what we are discussing, Bob and I, is whether you can be a good clinician without being an ethical clinician and I'm saying yes. I guess you can. (A651-655).*

*Psychologist: I don't think you can. (A657)*

*Psychiatrist: But if I'm going to go around looking at ethical principles of every single encounter, I'll drive myself crazy. I certainly guide my work as a clinician on very basic principles, but good clinical care is good clinical care. And, you are right, it probably has ethical qualities to it, grounded in research and grounded in skill and attitudes, education and experience and working with colleagues and working things out. Yes it's probably ethical but I wouldn't put*
This psychiatrist recognized ethical practice as a concern for the hospital, but would not contemplate good clinical practice existing separately from good ethical practice. HEC members in this focus group discussed some limits to ethical practice. One nurse stated:

Nurse: I think it comes back to the scenario that's been given and I think from my point of view at 11:00 o'clock at night you tend to be less ethically thinking. I mean, I'll be honest with you, you are more pragmatic you have got to get this guy to sleep. (A679-684)

The investigator identified data segments and organized them into two subcategories Patient-oriented Ethical Issues and Other Ethical Issues to help clarify the scope of Ethical Issues. The subcategory Patient-oriented Ethical Issues was limited to data segments that discussed the ethical issues related to Mr. O. A few data segments did not relate to Mr. O. yet still raised ethical issues. As these data segments did not have any connection to the Patient-oriented Ethical Issues category, they were grouped in the subcategory Other Ethical Issues. The data in this subcategory are limited and provide little insight into the issue of ethical issues beyond Mr. O. The subcategory Other Ethical Issues contained such limited data that it will not be discussed further.

A. Patient-Oriented Ethical Issues and Limitations

Several data segments were found in the focus group data related to ethical issues. Various expressions were used by HECs in describing these issues. The following subcategories were developed by the investigator: Competency/Incompetency, Dignity, Safety of the Patient and Balancing.

1. Competency/Incompetency (Subcategory). This subcategory referred to the mental capacity of Mr. O to manage his behaviour. All HECs recognized that Mr. O's mental competency had to be considered in any response to the clinical scenario. HECs indicated that Mr. O's autonomy had to be respected, whether he was competent or not to make his own
decisions. Again, HECs had to ask themselves if Mr. O was not competent, for example, to refuse medication or other forms of treatment. Could he be medicated or treated? Furthermore, if Mr. O was partially competent, would it be possible to alleviate his agitation or calm him by communicating, reasoning or humouring him? This question of competency raised such additional issues as substituted decision-making, respect for incompetent persons, and the management of patients in a situation where physical and/or other chemical restraints are required. Many of these issues (competency, consent) are controlled by legislation, and the powers of the HEC and hospital are specifically circumscribed.

2. Dignity (Subcategory). This subcategory collected data segments that involved comments on the need to respect the dignity of Mr. O. The data collected indicated the concerns HECs had about these issues.

... I have heard some consensus, feel free to disagree, that a beginning place was really trying to think about Mr. O as the individual... (C1529-1533)

Another. I guess if you could call it an ethical issue, comes down to the essential dignity of the patient and what interventions are used. And this actually does take me back to my father, where his agitation, I guess, was becoming a concern to the nursing staff and so one of the answers was to have him sitting in a chair, you know, somewhat restrained outside of his room; of course, in these wonderful hospital gowns that are provided. I mean, my mother and I came up to the unit and went into major tantrums about the fact that this was the intervention that had been selected to deal with it.

Respect for Mr. O as a person was identified as an important element in any ethical analysis, particularly this kind of situation. The scenario provoked a reaction from many HEC members who became concerned that the facts of the scenario might result in a loss of manifest respect for Mr. O. This concern was expressed by a nurse manager who stated:

... it’s just my concern that at eleven o’clock at night, a busy unit, when staff are changing, I think dignity and stuff like that can get lost. (F470-474)
Dignity included a recognition by HECs that Mr. O was a person with rights and these should not be ignored to help staff overcome their own difficulties. HECs agreed this would sometimes involve a balancing process between staff and patients' rights.

In the scenario, Mr. O is repeatedly referring to the loss of his wallet. An effort to determine the validity of what concerns Mr. O might help de-escalate the situation. In addition, it might explain the lack of any real grounds for Mr. O’s concerns and assist clinical staff in assessing his mental state. HECs treated Mr. O's complaints seriously, demonstrating a respect for him. Others in the focus group interviews commented that Mr. O. should not necessarily be considered incompetent. Another point raised by one HEC member was that an inquiry into Mr. O’s financial affairs might be interpreted as a lack of respect for him.

Another aspect of dignity was the need, in Mr. O’s care, to involve individuals important to him such as family, a spouse or friends. Ensuring the cooperation and support of family for any steps contemplated by health care providers was not difficult when significant others felt their family member was treated respectfully. The efforts of staff to settle a patient's agitated state may prove of little value if the patient’s family and friends are unhappy about his or her care. A pharmacist and administrator expressed her personal reaction to such an occurrence:

... my mother and I came up to the unit and went into major tantrums about the fact that this was the intervention that had been selected to deal with [my father’s agitation]... (H723-727)

... the issue of respecting this patient’s choice, or autonomy, seems to be the main one, in how to deal with it. I mean, his behaviour is posing a problem, but if he is ... if he understands and can rationalize why he is doing what he is doing, then it is going to be hard to stop him. (C331-339)

Mr. O, while competent, could refuse medical treatment; should he be found to be incompetent, limits would be imposed on Mr. O's autonomy. If Mr. O were incompetent, his ability to make choices independently would be legally diminished.
3. Safety of the Patient. This subcategory was derived from HECs' comments about Mr. O's safety. The scenario described Mr. O as having moderate agitation that raised in most focus groups, a concern for his safety. If Mr. O's behaviour escalated, he would pose a threat to his own safety and possibly to the safety of others. Committee members considered the possibility of having to restrain Mr. O, in some way, - physically or chemically. Some focus groups identified their right to be safe and not subjected to unreasonable risks. These HEC members saw Mr. O's behaviour as disruptive to staff, other patients and possibly their families. As one HEC member stated, "peace is an ethical issue," since the disruption caused by Mr. O affected other patients and prevented staff from having enough time to care for them. HECs' discussions about protecting Mr. O recognized the need to balance possible harms with potential benefits in the treatment of the patient. The scenario posed a dilemma for HEC participants because they did not know when and how they could intervene. The investigator believed this balancing of ethical issues was at the heart of the HEC's function.

I think we also have to consider two other things, and something I came up with as an ethical issue, and that is the safety both for the patient, the caregivers and the other patients involved (A162-167)

4. Balancing (Subcategory). Data segments in this subcategory involved HECs' comments on the balancing of the rights and needs of Mr O with the rights and needs of other patients and staff. Identifying ethical issues, for all but one focus group, was largely straightforward. A HEC member who rejected ethical analysis in a patient care context, conceded that ethical principles were sometimes difficult for staff to integrate with clinical concerns. Focus groups concurred that HECs were useful in carrying out this balancing process involving the patient and other patients or staff. Most ethical concerns arise when conflict emerges with competing and similarly valid ethical concerns. On a basic level, the ethical principle of dignity is limited by the right of other persons to their own physical and mental integrity. Some examples of the discussion of the balancing process follow:
Physician... the issue of justice in terms of balancing the rights and needs of this individual against those of the staff and other patients on the unit ...
(F604-607)

A member of the clergy... So I found myself balancing the two: the autonomy of the patient versus beneficence. And in a sense, too, you know beneficence says not doing harm to the patient. If this is a non-competent patient, then I think you have to set guidelines that are for the benefit of the patient, to protect the good and the welfare of the patient, that they don't hurt themselves. And so then I thought ... the question I asked verbally was, is this a situation where you can apply the principle of double-effect; that you do, you know, restrain the patient. So maybe you are compromising the autonomy of the patient, but the overall ... your first ... that is the side-effect of trying to protect the patient so that the patient doesn't do harm to themselves. And so that even though you're compromising overall the autonomy separately, but that's the side-effect of it.
(F508-532)

An extension of this category was the recognition by some HECs that the patient’s values may conflict with those of the hospital.

Nurse... you need to find out what the patient’s values are. And it’s very much. I think going to be in contrast to the organizational values in which patients have got to be good, they have to be neat, they have to be in bed by eleven o'clock. You know, it's nice to have a slightly confused elderly patient, but not too confused that they don't disrupt the other patients on the floor, that kind of clash. And there may be something really important for Mr. O here that I don't know, and I think that is really important to find out. (H597-613)

In the present study, most focus groups saw Mr. O as a threat to the integrity of the hospital (danger to staff and other patients, disruption of the other patients, risk of self-injury). As a result, focus groups discussed balancing conflicting ethical concerns such as: (a) justice for all versus justice for one; (b) patients’ needs and available resources; (c) patient care solutions and available funding; and (d) Mr. O’s needs balanced against the needs of the unit. Several focus groups mentioned physical and chemical restraints and the problems arising from a lack of resources. These two areas, considered subcategories, are discussed next.
5. **Restraints** (Subcategory) HECs’ responses were explored to describe the subcategory “restraints”. The investigator defined restraints as physical and chemical interventions intended to modify Mr. O’s behaviour without his cooperation. As one psychologist noted:

> Well, yes, I do. As I say, I see this, the philosophy of choosing these restrictive alternatives as being ethically driven. I don’t think they are clinically driven. (A418-422)

All participating HECs were aware of the complexity of restraints and had recently discussed restraint policies. Focus groups indicated reluctance to rely on restraints except where exceptional circumstances existed. HEC members used such words as: “absolutely necessary,” “out of control,” “banging and hitting” to describe conduct of Mr. O that might require restraint.

6. **Resources** This subcategory of the category *Patient Oriented Ethical Issues and Limitations* collected data segments that involved comments on the allocation of limited hospital resources. The issues were captured in the following statement by a physician:

> We are now caught into a tug-o-war between cost-effectiveness and the ethics of the situation. In other words, if we have just two staff on, we should be able to phone someone immediately to take care of the patient, rather than shoving pharmaceuticals into them, have an extra person there. I think that that is a very important ethical issue, the dollar and cents that comes down from above on our heads. It has to be challenged, because otherwise you end up in court. (B776-789)

Mr O’s presence on the unit diminishes the available resources for other patients. When asked, which patients nurses attend first, a HEC member indicated that “... health care providers will respond to the loudest and most demanding patients first and get to the rest when time permits” (A1110-1120). This HEC member went on to say that the disruption caused by patients like Mr. O is so great that the care of other patients will suffer. Focus group participants thought the limited resources of the hospital would be inequitably distributed because of the demands Mr. O placed on the health care team.
7. Summary. Several focus groups provided examples of ethical issues from the clinical scenario. Since the purpose of the scenario was to stimulate discussion, ethical issues were obvious and many ethical issues identified by focus groups were similar. The data arising from the subcategories Competency/Incompetency, Dignity, Autonomy and Safety of the Patient reflected aspects of the individual patient’s rights. The properties of the subcategories were interrelated in that developments in each will affect the others. However, each subcategory also had sufficient data to be examined and reviewed separately. This process allowed the investigator to further identify and define the dimensions of the ethical issues under study. For example, the competency of Mr. O affected his ability to exercise his rights of self determination. HEC members acknowledged that respecting Mr. O became more difficult as his behaviour escalated and he began to pose a threat to his own well-being. This interrelationship between respecting Mr. O and protecting others (staff and patients) also imposed limits, described in the Balancing subcategory. The positive balancing of the patient’s own rights overlaps with the balancing of patients’ rights against the individual and group rights of others. As expressed above, health care providers may be unable to perform this balancing adequately within the confines of everyday concerns.

III. The Analysis of the Category HEC Recommendations

The number of recommendations in this category was extensive and the process of analyzing and evaluating these data proved difficult. As stated previously, grounded theory analysis characteristically adopts an evolving approach to the understanding of the original data. The focus groups made a variety of recommendations, and identifying categories of recommendations proved challenging. For example, a subcategory for HEC recommendations "Restrains" was considered. The definition of this category could have grouped together all recommendations that Mr. O be restrained whether verbally, chemically or physically. However the intervention of staff talking to a patient and trying to calm or distract him/her was referred to by many HEC participants. In these circumstances, the investigator chose to include in the restraint subcategory only those
data segments that revealed the use of physical or chemical restraints. Verbal interventions were coded as part of the subcategory Individual Interaction. As well, the investigator chose not to group all recommendations for interventions by staff together. Only certain types of staff interventions that appeared consistent to the investigator were grouped together.

The investigator identified seven subcategories of recommendations: 1) non-interventionist, 2) individual interaction, 3) assessment, 4) staff education, 5) restraint oriented intervention, and 6) use of family intervention. These groups of reactions are discussed in greater detail in the following sections.

A. Non-interventionist Only some focus groups accepted that the problem in the scenario could be assisted by the HEC. A participating ethicist strongly opposed the HEC considering a patient care consultation like that of Mr. O's. He believed the purpose of the HEC was considered reflection on issues of ethical concern. No consideration of questions requiring an urgent or immediate reaction (as he perceived the scenario to be) was appropriate for the HEC. The HEC could develop policies to help address the type of problem identified, but should not comment on specific problems. The chair, along with other HEC members, did not accept this position and was interested in challenging it. The Chair of the committee felt the scenario “cried out” for HEC involvement. In another focus group, a HEC member objected to even discussing the scenario, since he did not understand how it had been brought before the committee. “Whose problem is it? And did the right person bring it before the HEC?” Underlying this reaction may be a challenge to the validity of the HEC as a forum to discuss the scenario or a recognition that the HEC consults to someone and not in a vacuum.

The second approach taken by some focus groups was that other individuals, groups or committees in the hospital were better qualified than HECs to respond to this kind of patient problem. One physician participant had numerous patients like Mr. O in her clinic. Both she and other members of her focus group concluded that this physician's clinic would meet the needs of Mr. O better than the HEC (or by implication, the general
hospital unit). According to this physician, there was no role for the HEC in resolving issues raised by the scenario. Generally, other committee members were supportive of this physician's position. A second focus group had an organizational model where HEC members were identified for each department of the hospital. Any matters of patient care would be resolved at the unit level through the intervention of the HEC member. Patient situations like this one raised in the clinical scenario were addressed by the HEC, but the presence of these issues represented a failure for this committee.

B. Individual Interaction. This subcategory summarizes focus group data relating to recommendations for direct interaction with Mr. O. Several focus groups expressed the view that interventions by nursing staff or family members were the best ways of approaching Mr. O's situation. In fact, focus groups suggested that understanding Mr. O as a person was important. Some focus groups considered such questions as: What was he going through? Was he angry? Terrified? Some HEC members thought the conduct of Mr. O disclosed some significant information that would assist staff in responding to his difficulties. For example, one HEC member suggested giving Mr. O a small amount of money to see if this alleviated his agitation, or showing him his wallet. The need to listen to Mr O. despite his behaviour and to determine the truthfulness of his statements was the impetus for HEC members suggestions. "It is not a matter of not being bad, it has to do with how do we do things better."

One HEC member directly articulated the approach underlying many of the HECs' recommendations. She saw reacting to Mr. O's situation as a two-phase process. Phase one made it necessary for staff immediately to involve themselves with Mr. O to decrease his agitation. In the second phase, an assessment of Mr. O was required. The purpose of the assessment was to develop a more specialized plan of treatment/care that would assist staff in responding to Mr. O's behaviour. Focus groups suggested several methods for reducing Mr. O's agitation: (a) segregation of the patient in a quiet area either on his own or with someone, (b) trying to deflect Mr. O's anxiety by giving him an object such as a doll or his wallet, (c) talking to Mr. O directly, and (d) calling in persons trusted by
Mr. O or able to reach him through his confusion to establish a secure relationship. If these approaches were not successful, a number of HEC members were prepared to consider the use of chemical or physical restraints. These committee members preferred the use of sedatives to other medications or physical restraints.

C. Assessment Certainly, many focus groups wanted additional information before making suggestions in relation to Mr. O’s care. One HEC member captured the concerns of several focus groups when she said “Why is he here? If there are serious health concerns an aggressive approach to the scenario may be justified. Conversely, if there is no serious health risk there may be a totally different response that is appropriate.”(A911-926). HECs in this study assumed that a comprehensive physical assessment was completed by Mr. O’s clinicians. Focus groups were not given any further information than what appeared in the scenario during the focus group interview by the investigator. Originally, the investigator tried to distinguish recommendations that required some “further information” and those that contemplated a “comprehensive physical and mental assessment” of the patient. Upon further review, the investigator determined that it was not possible to separate the numerous recommendations and further analysis of the data were required to develop meaningful categories.

Several focus groups wanted Mr. O to be assessed. Their reasons included: (a) identifying a cause for Mr. O’s difficult behaviour, (b) determining Mr. O’s mental competency, and (c) identifying the degree of risk posed by Mr. O’s behaviour. Other reasons for an assessment of Mr. O included the need to understand the scope of Mr. O’s difficulties necessary for developing an effective care plan. As well, some participants indicated that an assessment would establish events that triggered Mr. O’s conduct. Such information could be used to manage his care and avoid a similar problem. Focus group participants agreed that a comprehensive ongoing assessment might reveal: (a) potentially effective treatments and care plans, (b) whether there had been a deviation from Mr. O’s normal pattern of living, and (c) the origin of Mr. O’s agitation. The investigator tried to encourage focus groups to move beyond an identification of information deficiencies and
to speculate on other recommendations. Several focus groups refused to make detailed recommendations for Mr. O because of limited knowledge about him. The investigator validated that their committee practice was to provide patient care recommendations. In other words, some HECs provided patient consultations but may not have provided formal recommendations. As well, the investigator considered the possibility that HECs were reluctant to give a recommendation in the clinical scenario but acted differently when actually performing a patient care consultation. Unfortunately, this question could not be answered from the focus group data and must be left to a further study.

The range of assessment recommended by focus groups varied from minor to detailed investigations of Mr. O’s medical and personal background. Specifically, families and hospital staff were identified by HECs as important sources of information to provide insight about Mr. O’s medical history or advance directives. As well, HEC members raised the need to consider whether Mr. O’s difficulties required invoking hospital policy. In the present study, HECs devoted considerable time to policy development and review, but only infrequently mentioned consulting policy to clarify or support patient/staff concerns. Sometimes where an issue before the HEC appeared to have policy consequences, a draft policy would be drafted and reviewed, circulated to other areas, and reported on in writing.

D. Staff Education. The need for staff education to assist Mr. O was identified by several focus groups as an important recommendation. One administrator stated:

A program in place of ongoing education... How do we identify these individuals? How do we work with individuals when they become agitated? And things like that. Strategies around working with individuals and looking at where is this person coming from? How can we best respond to that individual at that point in time when they are agitated? Those might be some recommendations (G1627-41).

A nurse from one HEC and a psychologist from another HEC also supported an approach involving education:

Nurse: I was going to say, more staff education, certainly around this issue. I think that’s a big issue. And obviously I think resources need to be looked at, but
primarily staff education (H1999-2004).

Psychologist: We mentioned it right at the beginning, staff education (A1321-2).

However, a specific education program or strategy was never discussed in much detail by focus group participants. When validating HECs' opinions, it became evident to the investigator that members recommending staff education thought patient situations like Mr. O's might have been prevented if staff training had been anticipated. A concern raised by some focus groups was whether the committee should be commenting on the education and training of staff. According to focus groups, there was the real possibility of conflict of interest between staff departments and HECs making these kinds of recommendations. On further deliberation, HECs thought patients or families would use their recommendations to establish the legal liability of the hospital and its staff, if some contradictory patient issue was involved.

E. Restraint Oriented Interventions. One aspect of this assessment process was to determine if Mr. O posed any threat of violence or injury to himself or others. Focus groups thought the threat posed by Mr. O should be proportional and commensurate with the dangerousness of his behaviour. On the issue of restraints, there was no consensus among focus groups. More recently, several focus groups had been involved in the review and/or development of restraint policies in their own hospitals and seemed to be aware of the patient issues. Focus groups provided two approaches. In the first approach, focus groups rejected restraints as inappropriate except in most extreme circumstances. Only infrequently did focus groups think the scenario suggested anything. Several HECs considered a second approach wherein restraints had a place in assisting staff to defuse an aggressive or violent situation. A nurse said:

There is a spectrum of treatment. I mean, there is sort of listening at one point, but also you often have to have sort of fairly firm reassurance to help shape, so that's a kind of restraint that is not a physical or chemical restraint, and then you go along the spectrum, sort of get into some of the more medical interventions and more intervening interventions (H692-702).
Another nurse commented:

...there is lots of patients that I've seen who, as soon as you restrain them and help them feel some control, they settle fast, and they don't need to be restrained very long...So I don't think we can say no to those treatments or managements simply because they might feel uncomfortable to be restrained. (H669-679)

An administrator observed:

...So holding off on a restraint policy until it becomes absolutely necessary is an important ethical imperative in this situation, because this is a person with rights. (C1620-1624).

Restraints, in this study, were a sensitive topic. Generally, focus groups seemed cautious about restraints for patients. If restraints had any place at all in patient care, they had to be a limited, short-term intervention.

F. Family Intervention. Several focus groups recommended that patients' families be involved in their day-to-day care. For example, HECs considered family members to have additional knowledge about patients that would assist staff in providing patient care. As well, family members were seen as beneficial to patients in calming his/her agitated condition. Most important, family members may have insight into how patients wish to be treated if they are unable to express his their own will.

A minister stated:

I think any of the recommendations would have to have the family as an ally. We'd probably hope from the very beginning, if this person has family that they've already been involved, but you're dealing with situations where they could be very angry about certain things that are being done. So it would sort of decrease the we/they stance and it would probably help us understand that person more as a person if we could have the benefit of their knowledge about them, and maybe tap into whatever that person does have in their control. They might have some ideas. I think that -- if there were consultation where we would, as a team, we would obviously ask the family members to attend. I could see that as being very valuable (G1794-1815).
CHAPTER SEVEN
QUANTITATIVE ANALYSIS OF THE HEC PROFILE QUESTIONNAIRE

I. Data Analysis

The HEC Profile was completed by most focus group participants before the focus group interview and returned to the investigator. Following the data collection phase, the HEC Profile was reviewed to obtain only sociodemographic data about focus group participants. Descriptive statistics were used to report on the percentage of participants responding to a given question on the HEC Profile, excluding non respondents about whose potential responses nothing was known. The results of questions quantitatively analyzed were set out on a focus group by focus group basis (see Appendix M).

A. Quantitative Procedures

The following procedures were used to analyze the data from the HEC Profile:

1. Frequency distribution for all quantitative responses of HEC members in eight focus groups;

2. Descriptive cross-tabulation techniques for identifying the characteristics of HEC members in the eight focus groups; and

3. Univariate procedures (analysis of variance, simple linear regression) to determine the degree of relationship between the questions.

The data was analyzed using the Social Sciences Statistical Package for Windows (SPSS, release 6.1). SPSS is well-recognized as a statistical analysis program and powerful data management tool.

B. HEC Profile

HEC Profile questionnaires were returned by 67 subjects. Although HEC Profiles were given to all potential subjects (n=144), only those respondents who attended the focus group completed and returned the questionnaire. One subject declined to complete the
HEC Profile or explain the reason for this refusal. Questions 2-11 on the HEC Profile were answered by the HEC Chairs and not by the other respondents. A summary of the results of questions 2-11 answered by the HEC Chairs or their designates can be found in Appendix M.

Although data were analyzed for all sample respondents (n=67), separate analyses of data were performed for five subgroups: physicians, nurses, clergy/ethicists, health care administrators, and psychosocial health care providers (comprising social workers, psychologists and a psychotherapist).

II. Responses to HEC Profile Questions

Special Position (Question 1)

Special positions were held by 18 (27.7%) of the subjects. These positions were Chairs, Co or Vice-Chairs, Secretaries and Management Board liaisons.

Tenure (Question 12)

Subjects were asked how long they had been members of the HEC. Responses ranged from less than one year to 13 years. Only one subject had a tenure of 13 years. The next longest serving HEC members were four subjects each with seven years membership. The mean tenure for health care administrators was the highest of the selected groups with 3.56 years with a standard deviation of 1.52 years. However, the means for the other professions were not different (physicians 3.50 years, nurses 3.27 years, PHCPs 2.21 years, clergy/ethicist 3.55 years).

Affiliation with Other Hospital Committees (Question 13)

A majority of sample respondents (n=41 or, 64%) indicated that they had some affiliation with other hospital committees. The range of committees named was very broad and included all aspects of the hospital's affairs. As might have been expected, all health care administrators were involved with other hospital committees. Interestingly, clergy/ethicists had the least involvement (n=3 or 50%) of all professional occupational groups.
**Discipline (Question 14)**

As noted earlier, physicians (n=15 or 22.4% of the sample) and nurses (n=13 or 19.4% of the sample) were the most frequently represented groups in the study. Health care administrators (n=9) were the next largest group. The number of clergy/ethicists was smaller than expected (clergy n=1, ethicists n=3, clergy and ethicist n=2, total combined n=6). Social workers (n=3), psychologists (n=3) and psychotherapists (n=1), were grouped together as psychosocial health care providers or PHCPs (n=7). This later professional occupational grouping, while not found in the health care literature was felt by the researcher to be justified based on the similarities between the roles of these groups.

**HEC Role (Question 16)**

Respondents were offered a list of possible roles and asked to indicate which their HEC performed; 87.7% answered education (n=57) and 83.1% answered policy making (n=54) were both broadly accepted roles for HECs. As well, staff consultation (n=46, 70.80%) was also commonly recognized. Fewer respondents (n=32, 49.2%) identified patient care consultation as a HEC role. The only group that varied from this view was the HEC members who comprised Group F as they functioned in the role of a patient consultation team (as a subcommittee of the HEC within their institution). These individuals indicated that patient care consultation was a role of their HEC. Other HEC roles identified by individual HEC members included approval of medical research, policy review, consultation with family members and patient advocacy.

**Examination of Issues (Question 17)**

Respondents were asked how the HEC approached issues that came before them. The majority of respondents reported that issues were examined both prospectively and retrospectively (n=51, 81%), while a minority (12.7%) reported that issues were approached prospectively only (n=8).
Effectiveness of HEC (Question 18)

This question asked respondents about the effectiveness of the HEC in "helping to protect the rights and welfare of patients or providing a mechanism for ethical deliberation?" The question was phrased in this way to ensure that the focus HEC members perceived their committee as having - either in patient care or ethical deliberation - the respondents opinion of the committee's effectiveness would be obtained. Only four respondents (7.3%), two of them members of Focus Group D, indicated that they found their HEC "very effective." The majority of all sample respondents (n=46, 83.6%) reported that they considered their HECs "effective to a degree." A cross tabulation between this question and Question 16 relating to the HEC role failed to indicate any statistically significant correlation between the responses to these two questions.

Agreement in Ethical Deliberations (Question 19)

Although HECs were generally not expected to be decision-making bodies, there were occasions where agreement in ethical deliberations may have been required. This question sought data about members' understanding of how agreement was reached on their committees with respect to ethical deliberations. The responses indicated that HEC members were not aware of specific guidelines on decision-making. The most common response among participants was that "no specific proportion" of the membership was required to reach agreement in ethical deliberations (n=39, 60%). The next most common responses were "unsure" (n=9, 13.8%) and "consensus" (n=7, 10.8%). In each group, with the exception of Group C, there was a clear indication that "no specific proportion" of the HEC membership was required for the HEC to reach an agreement. Subjects' responses in Group C were evenly distributed among all possible responses. Concluding it seems reasonable, therefore, that Focus Group C members may be confused how decisions were arrived at in their HEC.

Consensus (Question 20)

Respondents were asked to agree or disagree with a statement that their HEC "strove for unanimity" when it made a recommendation. Respondents could choose to "Agree."
“Disagree” or “Neither Agree nor Disagree” in response. No focus group provided a consistent response to this question. Nearly 50% of respondents either could not agree or disagree with the statement n=25, 37.3% neither agreed nor disagreed, while, n=8, 11.9% disagreed. This would appear to indicate that the decision making processes of the HEC were probably unexplored by most HECs.

Tenure at Hospital (Question 21)
HEC members included individuals having no involvement with the hospital other than their HEC participation and other individuals who worked in a variety of capacities in the hospital sponsoring the HEC. One focus group member had 35 years of employment with the same hospital. The mean period of time with the hospital for HEC members was 11.54 years. The administrator group exceeded this with a mean of 13.78 years, while clergy/ethicists had the lowest mean of 7.88 years.

Education (Question 23)
Figure 3 describes the educational qualifications held by respondents in the study. Six percent of respondents had diplomas as their highest level of education. The remainder of the sample had university degrees at the bachelors and masters level and 20% of HEC members held MD/FRCP degrees.

Previous Experience with Ethics (Question 24)
The majority of respondents, n=58, 86.60% had experience with ethical issues before becoming involved in the HEC. Physicians (80.00%) were the professional/occupational group who had the least previous exposure to ethics.

Gender Question 27
Figure 4 describes the gender of HEC members. Overall, women participated more than twice as often as men in the Focus Groups (female=48 – male=19). This disparity may or may not reflect the true gender proportion on HECs. As only some members of each HEC
participated in the study, determining the gender of those members who were unable to attend was not possible. The investigator was not able to ascertain who would be attending each focus group before the group met and thus was not able to ensure the study was balanced in terms of gender. Nursing and administrators were disciplines in which only female subjects participated while the physician and clergy/ethicist disciplines were equally represented by both men and women.

Country of Origin (Question 28)

Most HEC members were from Canada (n=52) with the United Kingdom being the next most common country of origin. The preponderance of subjects from one country made any further analysis of this question or the use of this question as a part of further analysis of limited value.

Hypothetical Clinical Scenario Typical of Patients Referred to Committee (Question 33)

Most respondents indicated that their HEC did not conduct patient care consultations regularly and the scenario was not typical of requests made to their HEC. Only 7.5% of respondents said the scenario was typical of cases submitted to their committee, while 58.2% indicated that it was not typical, and 38.8% made additional comments explaining that case consultations involving Mr. O were unlikely.
### Highest academic degree?

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Missing: 2

Total: 67

Cum Percent: 100.0

**Figure 3 Chart of education.**
Figure 4 Chart of selected professions by gender

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CHAPTER EIGHT
RESULTS, LIMITATIONS AND FUTURE DIRECTIONS

This chapter discusses results and limitations of the study and considers possible directions for future research. It will begin with a brief overview of the study which will include consideration of the study’s qualitative methods and the issue of sampling. In addition, this chapter will discuss possible interpretive frameworks to describe the role of the Toronto HEC in the 1990's. These frameworks are drawn from the literature and from the data obtained in the study.

I. An Overview of the Study

The purpose of this study was to describe and develop an in-depth understanding of the current HEC Role in the Greater Toronto Area. The methods involved asking HECs, as committees consisting of physicians, nurses, clergy, ethicists, health administrators, social workers, lawyers, business, industry and lay persons from the community, to participate in a focus group interview and complete the HEC Profile questionnaire.

The convenience sample consisted of the chairperson and members from eight HECs who each voluntarily participated in a single focus group interview. All participating university-affiliated and community-based acute care hospitals provided care to a diverse patient population. Although HECs in the present study had different responsibilities within their respective hospitals, they each considered themselves an ethical resource and part of the overall health care team effort.

HECs, at study onset, were newly-established in Toronto. According to the American literature (reviewed on pages 5-30), HECs function within an ethical framework, are multidisciplinary in composition and have expertise in patient care consultation. Canadian HECs (see pages 5-30) are evolving in several different directions from their American counterparts and are only now beginning to address patient care issues. Because of their different compositions, numbers, turnover, experience and other factors mentioned in Chapter Three, a focus group approach and a consequent qualitative methodology was adopted in order to interview HEC members and interpret their responses.
II. The Role of HECs

At the time of this study, HECs in the Greater Toronto Area portrayed themselves as lacking a defined role. In reviewing the categories, the investigator sought a descriptive term that would capture the present context of the HEC Role. The term best describing the HEC Role was "role-less". There are primarily three reasons why participating HECs were considered role-less. First, HECs in Toronto find themselves in various stages of development independent of the sponsoring institution's maturity. Second, there is a lack of a clear connection between the HEC and the broader hospital community. Third, HECs in Toronto were disconnected from each other and rarely collaborated on common issues.

In this study, none of the focus groups appeared comfortable or completely settled in their role. Every focus group expressed a desire for additional responsibility, concern over their utilization by the hospital, or frustration over their relationship with the hospital administration. In fact, several focus groups were even unclear about the terms of reference of their committees. For example, the Terms of Reference of one HEC indicated that the committee should provide patient care consultations, while the focus group members including the Chairperson were unaware of this. At the same time, most HECs in the study have been in operation for at least five years.

A review of the relevant literature, supported by the study results, confirms that HECs had hitherto been involved in aspects of the "traditional" HEC role such as policy development and education of committee members and other hospital staff. The Focus Groups thought their HECs had been sufficiently established within their institutions to be able to take on new functions. HECs are emerging out of a period of "vagueness" and are beginning to identify areas of confusion, conflict and frustration which render them role-less both internally as a committee composed of various individuals with specialized backgrounds, and externally as an effective ethical body. HECs in this study seem to have an opportunity now to redefine their status within their institutions. HECs with a strong leadership and a good rapport with hospital administrators seem able to address internal committee issues because of the external support fostered by these positive factors.

The second reason underlying the vagueness of the role of the HEC relates to the
increasing specialization of health care, which tends to make the HEC less representative of the views or interests of health care professionals who might access the services of the committee. Moreover, the formal structures of the hospital overlap with those of the HEC in a manner that ensures the HEC reflects the views of the hospital administration. In other words, the HEC may be perceived as a repository of the hospital culture, failing to develop into a fully functioning committee representative of the interested parties in the hospital and the community it serves. Furthermore, the HEC may have originated as a formality to satisfy the requirements of accreditation and, therefore, not be fully accepted within the hospital. A good deal of time and effort is required to build and maintain a committee; role confusion will undermine its credibility and acceptance. Instead of emerging as a co-ordinating mechanism designed to assist patients, their families and health care providers and to enlarge the sphere of bioethical knowledge, the results of this study showed HECs in many ways content, to let the current situation prevail.

The third reason HECs were considered roleless involved the "separateness" or isolation each committee had from their clinical/ethical counterparts at different hospitals. Infrequently, HECs consulted each other or were cross appointed to other HECs within the Greater Toronto Area. Perhaps the above situation will change with the new direction from University of Toronto Joint Centre for Bioethics whereby clinical ethicists will be jointly appointed by the University and sponsoring hospitals to work collaboratively in planned directions.

III. Interpretive Frameworks

The interpretive framework arising from the data provided a more in-depth understanding of the theme the "Roleless role of HECs". The possible role paths of the HEC can be identified as follows: expert role, pair-of-hands, and powerless collaborators.

Theories about roles are, briefly, the study of the expectations, rights and duties attached to a person or a group's status (Kozier and Erb, 1988). Although the concept of "role" is open to different approaches and interpretations, the following are
considered representative concepts of role theory.

- Some behaviours are formed by the context and characteristics of a situation one finds oneself in.
- Sets of persons who share a common identity may also have similar roles.
- Awareness of roles both by the person and by others may influence behaviour and the response to it.
- Roles are meaningful because of the functions associated with the set of persons involved.
- Persons are socialized about their roles but may accept or reject the proposed role (Biddle, 1979, Kozier and Erb, 1988).

**A. Expert Role.**

The first interpretive framework couched within the role of the HEC is that of the *expert role*. Understanding the *expert role* is facilitated by discussing the organizational placement of the HEC within the hospital and committee membership. Troubling to the investigator was the apparent distancing of the HEC in relation to the hospital environment and the patients it serves. One of the central reasons for conducting a study of this nature was the question: Who will consider ethical problems in hospitals? Consistently emerging across categories was the notion that HECs needed to acquire an expert role to avoid becoming a committee simply existing within the hospital’s overall structure. The investigator noted that focus groups in this study rarely spoke about their committee’s influence when asked: “What do you contribute to the overall health care effort at your hospital?” Generally, focus groups responded, as reported in Chapter Five that they contributed an educational function through the dissemination of knowledge, and a policy function through policy review and development. Yet, the committees in this study did not provide a coherent expression of the role characteristics of HECs, revealing a degree of vagueness about their identity. Most focus groups believed that the hospital community assumed that the HEC had a certain moral authority. Committees who perceived themselves as not fully functional wanted an expert to guide them through the initial
periods of role uncertainty — that is, an ethicist who could provide ethical leadership. This point will be expanded on in the section addressing committee membership.

1. Organizational Placement. The direction HECs chose to set for themselves in this study appeared to depend on where the committee was placed within the overall organizational structure of the hospital. Wilson et al. (1986) addresses three different ways a HEC can fit into a hospital structure — as a medical, administrative or board committee. A medical ethics committee requires that at least half of the members be physicians (Wilson et al., 1986). An ethics committee that is administratively appointed tries to reflect the multidisciplinary composition of the hospital. Thus, it should be representative of the hospital and typically has no set membership requirements (Wilson et al.1986). In the present study, HECs appeared to be administratively-based and supported the principle of multidisciplinarity as they are presently constituted. Board committees are comprised of trustees and are less representative of all of the disciplinary backgrounds found in a hospital. None of the HECs in the study used either a medical or board committee model.

According to Wilson (1986), HECs formed by hospital administrations have two significant consequences. First they reinforce the concept that ethical questions could not appropriately be resolved on the level of clinical decision-making. The second is that an administratively appointed HEC recognizes the equal contributions of all members (Wilson, 1986). In this study, having an equal input into committee issues seemed less of a concern to focus groups than did the weight the committee carried within the hospital. In other words, several study HECs did not think they were fairly considered within the eyes of the hospital administration.

The category HEC Authority and Power further clarified the issue of the committee relationship to the hospital's administration. Although HECs in this study were administratively-driven committees, they responded to different bodies within each hospital.

HECs participating in the present study confirmed the findings of Jean et al.
that HECs reported to either the Medical Advisory Committee, the Board of Directors, or the senior administration of the hospital. Focus groups indicated their committees' relationship with administration was a consultative one and the discretion to accept, reject or modify the recommendations put forward lay with administration. The relationship between the HEC and the hospital administration has not been discussed in any detail in the literature. The tension between what is right and what is possible, responsible and affordable has never been so prominent as it is currently with respect to health care. The perception of a lack of power and authority which HECs sometimes experienced was profoundly disturbing to some focus group participants; however, these members reconciled themselves to their role with the consideration that they had a moral authority that could not be ignored. Observations about the considerable moral authority of the HEC were made by a number of participants. The HEC literature also supports the concept of the moral authority of HECs (Brunnetti, 1993; Van der Heide, 1993).

Before conducting the focus group interview, the investigator requested copies of each HEC's Terms of Reference and any written historical material relevant to the formation and experiences of the HEC. The information requested was not always available or was provided at the focus group interview or after the interview. In the HEC Profile, the investigator sought general information about the range of committee activities. When the data from the HEC Profile questionnaires and the focus group interviews were compared with the Terms of Reference, it was evident that several HEC members were not aware of their powers and areas of responsibility. Focus group participants including, most HEC Chairs, never raised the Terms of Reference when discussing their committee's authority.

Surprisingly, HECs in the study did not utilize their Terms of Reference as a means of directing their efforts. Although the literature has reported that HECs are uncertain about their role, data from this study appeared to show a substantial discrepancy between what HECs do, what they were set up to do, and what they want to do. The need to clarify the role and function of HECs is a recurring theme in the HEC literature (Ross et al, 1993).
2. Membership on the HEC. The multidisciplinary composition of the HEC was accepted by focus groups and perceived as essential in legitimizing their role. The investigator asked participants whether they thought a HEC with a specialized group of "expert" members such as physicians or nurse only members would be more effective. None of the participants endorsed any system other than that of a non-hierarchical multidisciplinary body. The presence of members having different professional/occupational backgrounds was viewed by focus groups as essential to their committee's achieving results. However, focus groups made very few connections between how their professional diversity influenced policy-making or patient care.

Every focus group agreed that the process for arriving at ethical positions should have validity in the eyes of the hospital community and resonance with the diverse background and representation of that community. This was helped by having various occupational/professional groups involved in HEC deliberations. In this study, HECs believed the experience of ethical debate with representatives from different professional/occupational backgrounds helped to expand their understanding of a problem. The principle of interdisciplinary discourse, which was experienced as broadening the individual committee member's perspective, was specifically endorsed by members of each focus group as a valuable process.

Although this was not explored in-depth in the literature, focus group participants emphasized the importance of having personal or professional experience with the issue before the committee. Some participating HEC members advised the investigator that they felt free to express their ethical opinions in committee meetings and that these opinions could well be shaped by personal experience with patients or through professional/occupational background. Several focus groups in the present study accepted the proposition expressed in the HEC literature that a relationship exists between one's professional or disciplinary background, and one's actual approach to problems arising in patient care (Miedema, 1993; Ross et al, 1993).

Although many HEC members were clinical experts within their own practice areas and brought expertise to ethical matters, most did not consider themselves ethical
experts. As noted in the discussion of HEC consensus development, ethical issues retained an element of personal conviction that remained separate from the authority of the HEC. The HEC thus presented a mixed message: While wanting to provide expertise to the hospital in ethical matters, it was by its own very definition not a collection of experts on ethics.

**B. Pair of Hands**

The second interpretive framework of the HEC is proposed by the study results as a *pair of hands* assisting the health care professional, responsible for the patient by being a resource. The term *pair of hands* is both dismissive and reflective of the true assistance the HEC can offer. The Focus Group participants indicated that they often felt used in this way. They were called on to fulfill several roles, none of which were very well defined and from which they could be summarily dismissed.

The category *HEC Framework* provided several examples of the way that HECs saw themselves as lacking effectiveness. The reporting structure of the HEC was usually to the highest levels of administration of the hospital, but this access to an influential decision-making level also represented a limit to the HEC’s access to the rest of the hospital. The supervisory body was frequently described as being a gatekeeper of the committee’s access to the rest of the hospital.

One example provided by a HEC showed that matters referred to it were screened by an ethicist. Those matters considered more appropriate for the ethical consult service were referred there and not to the HEC. This screening represented a profound expression of a lack of faith in the committee to appropriately screen its own agenda. Even the HECs own bioethicist treated the committee as though it were incapable of appropriately selecting how to respond to matters that came before it.

As noted in the review of the categories, most HEC members used a passive voice to describe their activities. Most of the functions identified by respondents were of only very limited concern to the hospital community, unless the community endorsed the involvement. The functions identified were: development and review of policy; providing a
forum for ethical discourse; providing a listening function; assisting with ethical problem-solving and raising the ethical conscience of the hospital.

The development and review of policy is a notoriously slow and time-consuming process. As HECs meet only for a few hours each month, they appear even slower as developers of policies than the usual administrative process (Avard et al. 1985, Ross et al 1993). Furthermore, the limited aspect of the role of the HEC was reinforced by the committees' not initiating policy review but only reacting to requests from administration. One HEC was trying to assert a more positive role by refusing to develop policy and offering instead only to review policies developed by others.

Policy development carries potential risks for HECs. Callahan (1995) noted that HECs addressing large social issues risk being drawn into the political struggles of the hospital. The neutral stance of the HEC may be imperiled when the HEC becomes involved in debates between institutional factions. These questions require a morally sensitive consideration that may not be available from a polemicized HEC.

The three functions of providing a forum, listening and assisting with ethical decision-making can be grouped together. The practice of many HECs was not to provide any written material relating to their consultation. While it may have encouraged some people to bring matters before the HEC, this lack of formality also reflects a lack of respect for the integrity of the HEC by its members. An expert consultation generates a note in the patient file indicating the occurrence of the consultation, the conclusions reached and the options for the patient. By not providing a written consultation note the HEC indicates that its advice is less important than a clinical consultation and that it cannot be trusted to use discretion in any consultation note, that it may provide. Some focus groups indicated that they were now providing written consultation notes or were thinking of doing so. This information suggests that they are beginning to recognize the limitations of their existing approach.

The consciousness-raising function of the HEC was usually limited to a conception of the HEC as an educator. The focus groups were very quick to deny that they constituted any kind of ethical watchdog for the hospital. The function of the HEC as a kind of ethical
conscience was denied by all focus groups but appeared to be a reasonable way to interpret the position of the HEC. The concept of a conscience, the HEC knowing the right thing to do but not compelling conformity is descriptive of the HEC role.

The category of Clinical Contribution was also indicative of the distance that most HECs perceived their committee to have from the rest of the hospital. The focus groups were also acutely aware of the lack of understanding and/or appreciation of their committee by the general hospital community. The lack of clarity about the role of the HEC must be a significant factor in the existence of such a lack of understanding.

The category Role Redefinition also clearly indicated the frustration that the vague qualities of the HEC role imposed on the committee members. Their seeking additional tasks or different administrative structures reflected this frustration. At the same time it should be noted that several focus groups thought they had improved their position and could continue to improve.

When the question of the obligations/duties of the HEC was raised, many of the committees seemed to be limited to considering issues referred to them by the administration. The very limited contact between the HECs and most hospital staff and the almost total absence of patient initiated consultation indicated that the HECs saw a very limited role for themselves. The participants appeared to accept their limitations on access because they had little or no desire to make decisions or because they perceived that their acceptance by the hospital community was a long way off.

C. Powerless Collaborators

This was the third interpretive framework used to help understand the HEC role. As indicated in the study, most HECs did not provide any kind of supporting role for specific patients. Instead, although the HEC was ideally placed to address the issues of holistic care for the patient, this path was not open to them or was seldom accessed. While many respondents were anxious to gain a more effective role for their committee within the hospital, not all endorsed the importance of patient care consultation. In the category HEC Role Redefinition, patient care consultation was identified by only some respondents
as a useful development. Ironically, as noted by Ross et al (1993), patient care consultation is often much more satisfying for HECs because it permits them to act decisively, quickly and with direct effects, something that is relatively unknown in the other HEC functions.

Most of the focus groups did not appear committed to seeking patient care consultation as part of the HEC role. They had the ability to be effective collaborators for the patients of the hospital but were powerless to achieve this collaboration without both their own will to do so and clear direction from the hospital administration, neither of which appeared likely to occur.

IV. Theoretical Implications. In their recent study, Parizeau et al (Ali, 1997) notes that there is considerable "vagueness" about the role of ethics committees in the province of Quebec. Yet this vagueness can be a source of power for the HEC, as this situation gives it considerable flexibility. Conversely, the vagueness of the HEC role may limit the ability of the HEC to modify the scope of its activities or challenge other members of the hospital. The ambiguity or rolessness of the HEC role may thus either be a source of weakness or of strength. Determining which could provide an hypothesis for further research into HECs.

IV. Limitations of the Study

Several limitations of the proposed study are acknowledged by the investigator. This study does not purport to generate data that is generalizable beyond the focus groups participating in the study. Each focus group represents a single observation (Stewart & Shamdasani, 1990). Although 67 subjects in eight focus group interviews participated in this study this represents only eight observations. For this reason, statistical estimation is not possible, or is it appropriate to generalize to the whole target population. However, a small number of group participants can provide rich in-depth descriptive data.

Qualitative methods such as focus groups are by definition subjective. Within
this subjective involvement, the investigator selected excerpts from focus group interviews to illustrate dominant themes arising from the research. Focus group research is subjective in that the investigator evaluates the data for the purpose of developing an understanding of the scope of the issue under review. At the same time, the investigator follows a rigorous process of analysis intended to ensure that the perspectives of participants are heard and integrated within the research report (DeRaeve, 1996).

Another challenge in the reporting of a study of this type is the issue of presenting the data fairly. The role of the investigator is to evaluate available data without silencing the voices of the subjects. The data in Chapter Five was presented so as to describe the scope of each category. The breadth and depth of discussion was reported with little comment from the investigator other than observations about the scope of the discussion. One disadvantage of this approach was the emergence of diverse opinions about issues that sometimes formed the description of the categories. However, the analysis was not compromised, since the purpose of the focus group interview was to describe the category, not to limit or define it narrowly.

The presentation of a clinical scenario raised the issue, first, that the contextual probe — used in the Clinical Ethical Dimensions Discussion Guide (CEDDG) and the HEC Profile — was hypothetical, and second, that the focus group interviews were artificial. Furthermore, the participants may have been influenced by the group interaction and the opinions of others and may have responded in ways which did not convey their true opinions.

As the investigator acted as the moderator for all groups, her conscious or unconscious biases may have had an effect on the interpretation of the study's results. Group participation may also be compromised by the composition of the group, the presence of a particularly dominant group member, or some other group-related factor (Stewart & Shamdasani, 1990).

The scenario selected for use during the Focus Groups was chosen by the investigator after consultations with experienced staff in psycho-geriatric facilities as representative of a type of patient problem that raised both clinical and ethical
issues. In selecting the subject, the investigator may have unconsciously chosen an elderly male subject in the expectation that although the described behaviour was only moderately agitated, the focus groups would assume that his behaviour would continue to escalate. The focus groups often made this assumption and, as a result, discussed the need for physical/chemical restraints. If a female subject had been selected, the same assumptions may not have been made. In retrospect, the discussions about restraints were interesting and contributed to the range of responses.

A second area of possible bias is the acceptance of the investigator that the interdisciplinary dialogue offered by HECs is valuable and needs to be realized.

The HECs participating in these focus groups did not fully attend (i.e. some members were absent) and the group process may have been altered as a result. It is therefore not possible to say unequivocally that the data speak fully even for the HECs that participated. At the same time, most available Toronto HECs were invited to participate and themes were pursued until they were saturated, which suggests that, overall, the focus groups elicited the major themes likely to be central to HECs.

V. Recommendations

Several recommendations arise from the data and might provide a launching point for further HEC development. Specifically, the following questions are offered for consideration and refinement:

1. Do HECs want to move closer to the patient’s bedside? Answers to this question will require that HECs and hospitals collaboratively examine the committee’s role in patient care consultation and how HECs can be easily accessed by patients and their families.

2. The HEC role as policy-makers begs more investigation particularly in light of the reluctance to assume ethical decision-making. Were HECs to pursue policy as their primary role, they would be asked to defend their reasoning in broader political forums especially where institutional, patient, and family interests come into
conflict.

3. How HECs respond to current ethical issues in Health Care will say much about the future of these committees (Callahan, 1994). HECs will be required to respond to a broad range of ethical issues that can give HECs credibility within their hospitals and within the larger health care system. Perhaps HECs have to move away from process and procedural issues and address the broader public agenda.

4. What specifically does a multidisciplinary HEC bring to ethical consideration that is different in single discipline groups? Equally importantly, what attracts members to an HEC? Answers to these questions may help to develop criteria for HEC membership and address issues of professional/occupational domination of an HEC.

5. HECs in Canada have to turn their attentions to legal liabilities, a reality facing their American counterparts.

A number of promising possible studies were suggested by the data from this study. The participating HECs were not nearly as involved in patient care consultation as had been anticipated from the literature review. The HEC literature emphasized how much this function defined the HEC role. This study indicated that while case consultation occurred, it was not a major feature of Toronto HECs at this time. The results of the present study indicate that a number of HECs representing major hospitals in Toronto had not embraced case consultation. The reasons for this apparent difference between the Toronto experience and the US experience need to be pursued. Studying the development of case consultation within HECs might show movement toward a more patient-centred HEC. Other studies might examine an expanded role for HECs in the midst of health care reform and the appropriateness of increasing the actual authority of the HEC. In other words, should HECs have an authority similar to Research Ethics Boards, and how might new hospital management methods (e.g., Program Management) impinge on the role of HECs?

An issue of importance to many focus groups in this study was the power and authority of the committee. Participating HECs reported to the same authorities as the HECs described in the Canadian HEC literature (Jean et al 1991, Storch and Griener, 1992). The HECs in the surveys were almost all advisory in nature, with only a limited number of
HECs possessing decision-making authority (Storch & Griener, 1992). What does not emerge from the previous HEC literature is how HEC members regard this advisory role. Focus groups indicated that although they held influence in ethical issues, they were not being exposed to all the issues they felt they could address. The satisfaction or dissatisfaction of the HEC with the limits of their present role suggests a number of avenues for further research. Specifically, in the area of moral persuasion, are HECs' impressions of their influence accurate? Another area for study is the extent to which HECs feel ignored by the administration. Is this feeling accurate — in other words, how much do hospital administrators value HECs?

V. Concluding Remarks

It was a privilege to be able to conduct this study and to immerse myself in the difficult and topical issues with which Hospital ethics Committees struggle. My personal conclusion is that these committees, despite their self-doubts, perform a valuable service to the hospitals and communities they serve.
APPENDICES
APPENDIX A

LETTER TO HOSPITAL

PAMELA ADAMS
927 Royal York Road
Etobicoke, Ontario
M8Y 2V8

[Date]

[Name and Address of Contact]

Dear ____________________________:

This letter requests permission to conduct an ethics-focused study in your institution. I am a graduate nurse currently registered in the Institute of Medical Science (IMS), University of Toronto. This study is a requirement for the degree of Doctor of Philosophy and is under the supervision of Dr. M. Seeman (Chairman), a member of Graduate Faculty, IMS, and the Clarke Institute of Psychiatry; Dr. F. Lowy, Director of the Centre for Bioethics, University of Toronto; and Dr. E. Meslin, Assistant Director, Centre for Bioethics, University of Toronto.

The purpose of this study will be to investigate whether a HEC, as a multidisciplinary committee, is more likely to generate diverse clinical-ethical decisions than are individual members within various HECs, who represent the same professional/occupational or lay disciplinary backgrounds (physicians, nurses, clergy, ethicists, health administrators, social workers, lawyers, business, industry, and lay persons from the community). Since HECs have different functions within each hospital, members will be directed to disregard their terms of reference, insofar as these may limit their ability to participate in patient care consultation. First, HEC members will review a scenario setting out a clinical problem involving agitation in an elderly patient. Second, this study will identify ethical issues arising from the scenarios and members' recommendations regarding their reasonable next step (i.e., assisting in determining prognosis, seeking legal guidance, educating hospital personnel, suggesting patient-focused solutions, recommending policies) in managing the behavioural disturbances of agitation in the elderly patient. Third, focus groups will be conducted with each HEC to discuss ethical issues and recommendations as a multidisciplinary group.
The long-term objective of this study will be to provide a rich source of hypotheses and suggest directions for further research concerning the clinical-ethical decision-making processes of HECs. It is also essential to develop a clearer understanding of the effectiveness of HECs in their consultative capacity.

Participation in the study would require your permission and the participation of the Chairman of the Hospital Ethics Committee or their delegate, as well as attending a regularly scheduled HEC meeting to speak to committee members, advising them about the study, and asking if they are willing to participate.

Members of the HEC will be asked to complete a brief questionnaire and attend a focus group meeting. A date will be arranged with the HEC in your hospital. The chairman and participating HECs members will be contacted to confirm their attendance. Involvement of each participant in the study should be approximately 1½ hours. The planned sample size is 3–4 HECs and permission is also being sought to collect data from several other institutions. The names of participants will be confidential and will not be identifiable in any discussion or written report. The estimated time for completion of data collection is 6 months, commencing in May, 1994.

A copy of the research protocol, including a consent form and discussion guide is enclosed. The protocol has been approved by my thesis committee and is being reviewed by University of Toronto Research Services (978-2163). I would be pleased to provide any additional information you may require about the study. As indicated, I would like to start data collection by December, 1993.

I look forward to hearing from you and would be glad to present a summary of the findings upon completion of the study.

Yours very truly,

Pamela Adams

PA:tl
Encl.
APPENDIX B

LETTER TO CHAIRMAN HEC

PAMELA ADAMS
927 Royal York Road
Etobicoke, Ontario
M8Y 2V8

[Date]

[Name and Address of Contact]

Dear ____________________:

This letter requests permission to conduct an ethics-focused study with your committee. I am a graduate nurse currently registered in the Institute of Medical Science (IMS), University of Toronto. This study is a requirement for the degree of Doctor of Philosophy and is under the supervision of Dr. M. Seeman (Chairman), a member of Graduate Faculty, IMS, and Clarke Institute of Psychiatry; Dr. F. Lowy, Director of the Centre for Bioethics, University of Toronto; and Dr. E. Meslin, Assistant Director, Centre for Bioethics, University of Toronto.

The purpose of this study will be to investigate whether a HEC, as a multidisciplinary committee, is more likely to generate diverse clinical-ethical decisions than are individual members within various HECs, who represent the same professional/occupational or lay disciplinary backgrounds (physicians, nurses, clergy, ethicists, health administrators, social workers, lawyers, business, industry, and lay persons from the community). Since HECs have different functions within each hospital, members will be directed to disregard their terms of reference, insofar as these may limit their ability to participate in patient care consultation. First, HEC members will review a scenario setting out a clinical problem involving agitation in an elderly patient. Second, this study will identify ethical issues arising from the scenarios and members' recommendations regarding their reasonable next step (i.e., assisting in determining prognosis, seeking legal guidance, educating hospital personnel, suggesting patient-focused solutions, recommending policies) in managing the behavioural disturbances of agitation in the elderly patient. Third, focus groups will be conducted with each HEC to discuss ethical issues and recommendations as a multidisciplinary group.
The long-term objective of this study will be to provide a rich source of hypotheses and suggest directions for further research concerning the clinical-ethical decision-making processes of HECs. It is also essential to develop a clearer understanding of the effectiveness of HECs in their consultative capacity.

Participation in the study would require your permission to attend a regularly scheduled HEC meeting to speak to committee members advising them about the study and asking if they are willing to participate.

In the study subject participation would consist of completing a brief questionnaire and attending a focus group meeting. HEC members will attend the focus group meeting in the same way that they would attend a usual HEC meeting. A date will be arranged with you for this meeting. You and the members of your committee agreeing to participate will be contacted to confirm their attendance. Involvement of each participant in the study should be approximately 1½ hours. Permission is also being sought to collect data from several other institutions. The names of participants will be confidential and will not be identifiable in any discussion or written report. The estimated time for completion of data collection is 6 months, commencing in May, 1994.

A copy of the research protocol, including a consent form and discussion guide is enclosed. The protocol has been approved by my thesis committee and is being reviewed by University of Toronto Research Services (978-2163). I would be pleased to provide any additional information you may require about the study. As indicated, I would like to start data collection by December, 1993.

I look forward to hearing from you and would be glad to present a summary of the findings upon completion of the study.

Yours very truly,

Pamela Adams

PA/tl
Encl.
APPENDIX C

CHAIRPERSON'S CONSENT FORM

I have agreed to release the terms of reference of _______________ (name of hospital) HEC as well as any historical or developmental information about its inception, composition, function and reporting relationship, for a study by Pamela Adams, a graduate nurse and doctoral student in the Institute of Medical Science (IMS) at the University of Toronto. The study is supervised by Dr. M. Seeman (Chairman), a member of Graduate Faculty, IMS, and the Clarke Institute of Psychiatry; Dr. F. Lowy, Director at the Centre for Bioethics, University of Toronto; and Dr. E. Meslin, Assistant Director, Centre for Bioethics, University of Toronto.

The purpose of this study will be to investigate whether a HEC, as a multidisciplinary committee, is more likely to generate diverse clinical-ethical decisions than are individual members within various HECs, who represent the same professional/occupational or lay disciplinary backgrounds (physicians, nurses, clergy, ethicists, health administrators, social workers, lawyers, business, industry and lay persons from the community). Since HECs have different functions within each hospital, members will be directed to disregard their terms of reference insofar as these may limit their ability to participate in patient care consultation. First, HEC members will review a scenario setting out a clinical problem involving agitation in an elderly patient. Second, this study will identify ethical issues arising from the scenarios and members' recommendations regarding their reasonable next step (i.e., assisting in determining prognosis, seeking legal guidance, educating hospital personnel, suggesting patient-focused solutions, recommending policies) in managing the behavioural disturbances of agitation in the elderly patient. Third, focus groups will be conducted with each HEC to discuss ethical issues and recommendations, as a multidisciplinary group.

The long term objective of this study will be to provide a rich source of hypotheses and suggest directions for further research concerning the clinical-ethical decision-making
processes of HECs. It is also essential to develop a clearer understanding of the effectiveness of HECs.

I understand that the hospital or its HEC will not be identified in any of the study results or publications.

I understand that the information will be used to compile a profile of selected HECs in Metropolitan Toronto, and may be useful in interpreting HEC members' responses.

Signed this __________ day of ____________________, 1994.

Chairperson's signature: ____________________________

Witness' signature: ____________________________

Pamela Adams
(Investigator)
(416) 233-4887

Dr. M. Seeman
(Supervisor)
(416)
APPENDIX D

INFORMATION PROVIDED FOR PARTICIPANT

I would like to ask you to participate in a study by Pamela Adams, a graduate nurse and a doctoral student in the Institute of Medical Science (IMS) at the University of Toronto. The study is supervised by Dr. M. Seeman (Chairman), a member of Graduate Faculty, IMS, and Clarke Institute of Psychiatry; Dr. F. Lowy, Director of the Centre for Bioethics, University of Toronto; and Dr. E. Meslin, Assistant Director, Centre for Bioethics, University of Toronto.

The purpose of this study will be to investigate whether a HEC, as a multidisciplinary committee, is more likely to generate diverse clinical-ethical decisions than are individual members within various HECs, who represent the same professional/occupational or lay disciplinary backgrounds (physicians, nurses, clergy, ethicists, health administrators, social workers, lawyers, business, industry, and lay persons from the community). Since HECs have different functions within each hospital, members will be directed to disregard their terms of reference, insofar as these may limit their ability to participate in patient care consultation. First, HEC members will review a scenario setting out a clinical problem involving agitation in an elderly patient. Second, this study will identify ethical issues arising from the scenarios and members' recommendations regarding their reasonable next step (i.e., assisting in determining prognosis, seeking legal guidance, educating hospital personnel, suggesting patient-focused solutions, recommending policies) in managing the behavioural disturbances of agitation in the
elderly patient. Third, focus groups will be conducted with each HEC to discuss ethical issues and recommendations as a multidisciplinary group.

The long-term objective of this study will be to provide a rich source of hypotheses and suggest directions for further research concerning the clinical-ethical decision-making processes of HECs. It is also essential to develop a clearer understanding of the effectiveness of HECs in their consultative capacity.

In the study, participation would consist of completing a brief questionnaire and attending a focus group meeting. Participants will attend the focus group as members of their HEC group. Taking part in this study involves a discussion lead by Pamela Adams. Each group session will take place in the usual HEC meeting room at the hospital and would take about 1½ hours of your time.

The questionnaire and the focus group meeting would involve identifying ethical issues in the care, treatment, and management of the agitated elderly, what recommendations you (or the committee) would make, and how your disciplinary background influences your recommendations. In the focus group meetings, responses will be tape-recorded.

The decision to take part in this study is entirely your own. Your decision will in no way effect your membership on the HEC. If you decide to participate, you are free not to discuss any specific topics, to leave the group at any time, and to withdraw from the study. If you
do not wish to discuss any issues, leave the group or the study, you will be asked your reason for doing so. If you do not wish to provide a reason, you do not have to do so.

Your name or number will not appear on any papers used to record your answers, which will remain confidential. As well, you will not be identified in any of the study results that might be published.

While you may not directly benefit from taking part in this study, the information you provide may assist others who work with agitated elders in the future. Your responses could suggest directions for further research concerning the clinical-ethical decision-making processes of health care providers, and improve the health care of the agitated elderly. If you would like, the general results of the study will be made available to you upon completion.

Interviewer's signature: ___________________________

Pamela Adams, R.N.
(416) 233-4887
APPENDIX E

CONFIRMATION LETTER

[Date]

[Name and Address of Participant]

Thank you for agreeing to participate in this study. Please find enclosed the HEC members' profile form. Please take a few minutes to complete the form prior to attending the focus group meeting. The focus group meeting is scheduled for _____________ at your usual meeting location.

Since only a limited member of people have been asked to participate in this discussion; the success and quality of the discussion is based on the co-operation of the people who attend. Because you have accepted my invitation, your attendance at the session is anticipated and will aid in making the research project a success.

The HEC members' profile form and the discussion you will be attending will be about identifying issues of care and concern in the treatment of agitated elderly. You will be asked to consider a scenario describing incidents of agitation in the elderly.

If for some reason you find you are not able to attend or you have any questions arising out of the HEC members' profile form, please call to let me know as soon as possible. My phone number is (416) 233-4887. I look forward to seeing you at the focus group meeting.

Yours very truly,

Pamela Adams, R.N.

PDA/tl
APPENDIX F

CONFIRMATION BY TELEPHONE

Hello

I am calling to confirm your attendance at the focus group meeting next ____. Do you intend to attend?

[If Yes] Thank you for your help. We look forward to seeing you.

[If No] I am sorry to hear that. Can you tell me why? Is there another date when you can.
APPENDIX G

PARTICIPANT'S CONSENT FORM

I have agreed to participate in a study by Pamela Adams, a graduate nurse and doctoral student in the Institute of Medical Science (IMS) at the University of Toronto. The study is supervised by Dr. M. Seeman (Chairman), a member of Graduate Faculty, IMS, and the Clarke Institute of Psychiatry; Dr. F. Lowy, Director, at the Centre for Bioethics, University of Toronto; and Dr. E. Meslin, Assistant Director, Centre for Bioethics, University of Toronto.

The purpose of this study will be to investigate whether a HEC, as a multidisciplinary committee, is more likely to generate diverse clinical-ethical decisions than are individual members within various HECs, who represent the same professional/occupational or lay disciplinary backgrounds (physicians, nurses, clergy, ethicists, health administrators, social workers, lawyers, business, industry, and lay persons from the community). Since HECs have different functions within each hospital, members will be directed to disregard their terms of reference, insofar as these may limit their ability to participate in patient care consultation. First, HEC members will review a scenario setting out a clinical problem involving agitation in an elderly patient. Second, this study will identify ethical issues arising from the scenarios and members' recommendations regarding their reasonable next step (i.e., assisting in determining prognosis, seeking legal guidance, educating hospital personnel, suggesting patient-focused solutions, recommending policies) in managing the behavioural disturbances of agitation in the elderly patient. Third, focus groups will be conducted with each HEC to discuss ethical issues and recommendations as a multidisciplinary group.

I understand that taking part in that study involves completing an HEC members profile form and attending a focus group discussion lead by Pamela Adams. Each group session will take place in the usual HEC meeting room, and would take about 1 1/2 hours of my time.

I understand that the HEC members profile form and the focus group discussion would involve identifying ethical issues in the care, treatment and management of the agitated elderly, what recommendations I would make (or the committee), and how my disciplinary background influences my recommendations.

Responses during the focus group discussion will be tape-recorded. I will also be asked to complete a HEC members profile sheet which asks demographic information about myself.

The decision to take part in this study is entirely my own. My decision will in no way effect my membership on the HEC. If I decide to participate, I am free not to discuss any specific topics, to leave the group at any time, and to withdraw from the study at any time. If
asked the reason for my decision to not discuss any topic or withdraw from the group, I am free not to answer such a question.

I understand that my name or phone number will not appear on any of the papers used to record my answers, which will remain confidential. As well, I will not be identified in any of the study results that might be published.

I understand that, while I may not directly benefit from taking part in this study, the information I provide may assist others who work with the agitated elderly in the future. I understand that my responses could suggest directions for further research concerning HECs' decision-making, and improve the health care of the agitated elderly. If I would like, the general results of the study will be available to me upon completion.

Participant's signature: _____________________________________________

Witness' signature: ________________________________________________

Pamela Adams
(Investigator)
(416) 233-4887

Dr. M. Seeman
(Supervisor)
(416)
APPENDIX H
THE CLINICAL-ETHICAL DECISION-MAKING
DISCUSSION GUIDE

Discussion Guide

At the beginning of the session, group participants will be asked to introduce themselves and describe their professional/occupational or lay disciplinary backgrounds.

Before we begin, I want to emphasize that: (a) it is necessary to stay on topic; (b) what I am interested in is your point of view/opinions, and I want to hear as many different points of view about the topic as possible; (c) if your experience on a topic is a little different, then that is exactly what I want to hear; (d) even if you think your experience is just like everyone else's, don't just say, "I agree". I want you to tell us your story, because there is always a unique dimension to each person's experience. I am here to learn from you. Please note: As I am sure you are aware, you should avoid references to the names or identifying characteristics of actual patients.

The purpose of this discussion is not to evaluate your performance as a HEC member. There are no right or wrong answers, so please relax and take your time in discussing the topics. Throughout this session, I will be asking you to comment on and discuss specific topics. I have obtained your permission to tape-record the sessions, and at the same time will be taking notes.

Assume that you are not limited by the Terms of Reference for your HEC. In other words, you are free to participate in discussing the clinical-ethical scenario involving an agitated patient and to identify ethical issues and make recommendations.
The discussion will be conducted by the chairperson and we will try to keep to the procedural structure with which you are familiar.

You may also find it helpful to refer to the definitions.

Scenario:

Let me review the scenario with you [moderator will review the events in the scenario for group participants]. Consider that someone from the health care team has asked you to help him/her clarify the ethical issues and to make recommendations about the appropriate ethical options involving this patient.

I. Issue Identification:

Let's talk about the ethical issues in this scenario. Have any of you encountered this type of patient situation? When you hear the words agitated elderly, what comes to mind?

Some of you may have had previous experience with this kind of patient/family member or friend. What is important to you when you address the issue of agitation in the elderly? [Probe: your personal beliefs/values, your general clinical experience, observing the actions of someone whom you respect and admire, your family background, influence of your colleagues, your supervisor's beliefs/attitudes, your religious beliefs, your philosophical background, views expressed through professional literature, hospital rounds, discussion at interdisciplinary team meeting, workshops/seminars, references, hospital policies, law/legal standards, possibility of professional discipline and other].

In summary, what ethical issues are involved? [Probe: restate the ethical issues identified] Does any member agree/disagree with any of the ethical issues as identified? Why is the group satisfied with this?

[Prompt] Why?
[Prompt] Is the group satisfied with this list?
[Prompt] Can you be more specific?
[Prompt] Can any of these issues be grouped together?
[Prompt] Are any issues more important than other issues?

II. Recommendations:

In this scenario, what recommendations would you suggest?
[Prompt] Restate the recommendations made.

Does any member agree/disagree with any of the recommendations as proposed?

[Prompt] Why?
[Prompt] Is the group satisfied with this list?
[Prompt] Can you be more specific?
[Prompt] Can any of these recommendations be grouped together?
[Prompt] Are any more important than other recommendations?

Within the hospital, there are various disciplinary groups involved in health care. For example physicians, nurses, clergy, ethicists, health administrators, social workers, lawyers, and people from the community are just a few of the many resources. What does this HEC offer to the overall health care team effort?

[Prompt] Can you be more specific?
[Prompt] Do you see yourselves as the ethical conscience of the hospital?
[Prompt] Would you make any changes to your role?
[Prompt] What might prevent you from serving as a resource to other members of the hospital?

Do you consider any particular group within the hospital more effective in caring for, and/or managing the behaviour of, the agitated elderly.

Please now turn to Part III of your HEC member's profile and complete the last few questions.

Thank you for your participation.
APPENDIX I

HEC MEMBERS' PROFILE

The following information would help in interpreting the results obtained during the course of the group discussion. Your answers to these questions will be held in confidence. If you choose not to answer a question, leave it blank, but please indicate why you have left it blank.

PART I

Background Information

1. Do you hold any special position on the HEC (such as chairman or secretary)?
   □ (a) yes;
   □ (b) no.
   If YES, please specify:

QUESTIONS 2 – 11: TO BE ANSWERED BY HEC CHAIRPERSON

2. How many members (including yourself) does your Hospital Ethics Committee have? members.

3. Write in the number of members of the HEC who fall into the following categories:
   (a) physicians
   (b) nurses
   (c) clergy
   (d) ethicists
   (e) health administrators
   (f) social workers
   (g) lawyers
   (h) business
   (i) industry
   (j) community members
   (k) other (specify)

4. Are there any members of your institution who are involved on a full-time basis with HEC activities?
   □ (a) yes
If YES, check all that apply:

(a) full-time chairman;
(b) full-time clerical secretary;
(c) other (please specify) ____________________________

If you are a full-time chairman, what is your professional/occupational training and experience? [For example, you might say: pediatric surgeon with research background; or clinical nurse specialist in gerontology with experience in practice and administration.]

Which of the following procedures apply to your HEC? [Check all that apply]

(a) entire committee meets as a body regularly;
(b) entire committee meets as a body whenever an issue arises requesting their attention;
(c) committee divides into sub-groups to consider specific issues;
(d) committee responds to issues in writing ____________;
(e) other (please specify)

If the HEC meets as a body:

(a) How often does it generally meet? ______ time(s) per year
(b) Roughly how many issues are considered at a committee meeting?

When did the latest modification in your HEC's terms of reference take place?
______________________ (month/year)

Has your HEC ever consulted with the same committee in another hospital for any purpose (eg., concerning policy matters, concerning procedural matters when the committee was first being set up).

(a) yes;
(b) no.

If YES, briefly describe the purposes of one such consultation.
12. How long have you been a member of the HEC? *Please write in number of years*
   _____ years

13. Do you have any other formal affiliation with other hospital committees (ie., research ethics boards, nursing education, etc.)
   □ (a) yes;
   □ (b) no.
   If YES, please specify.

14. In what professional/occupational field or specialty are you engaged in (either in this hospital or elsewhere)? *Check all that apply*
   □ (a) physician;
   □ (b) nurse
   □ (c) clergy
   □ (d) ethicist
   □ (e) health administrator
   □ (f) social worker
   □ (g) lawyer
   □ (h) business
   □ (i) industry
   □ (j) other (specify) __________________________

15. Please indicate below your official title(s) in this hospital or elsewhere and the number of years you have held the title(s).
   (a) __________________________  _____ years
   (b) __________________________  _____ years
   (c) __________________________  _____ years

16. What is the role of the HEC in your hospital? *Check all that apply*
   □ (a) education;
   □ (b) policy-making;
   □ (c) patient-care consultation;
   □ (d) staff consultation;
   □ (e) other (*please specify*)
17. How effective, would you say, is the operation of your HEC in helping to protect the rights and welfare of patients or providing a mechanism for ethical deliberation? [Check one only]

☐ (a) very effective;
☐ (b) effective to a degree;
☐ (c) ineffective because it has little power;
☐ (d) other (please specify)

18. What proportion of the membership of the HEC is required for agreement in ethical deliberations:

☐ (a) unanimity among committee members voting;
☐ (b) two-thirds majority of the voting;
☐ (c) simple majority of the voting;
☐ (d) some other proportion (please specify)

☐ (e) no specific proportion stipulated by our procedure.

19. Do you agree or disagree with the following:
"In practice, when our HEC makes a recommendation, it is almost always by a unanimous decision. If even one member has serious question about the ethical aspects of an issue, we would probably either table the discussion, require revisions to our recommendations to satisfy the dissenting member, or even reject the concern."

☐ (a) agree;
☐ (b) disagree;
☐ (c) can't say.

20. How long have you been a member of this hospital? [please write in the number of years]

_____ years

21. What is your highest academic degree?
22. What was your age at your last birthday? _____ years old

23. Did you have any experiences before becoming a member of a HEC which made you aware of ethical issues?
   □ (a) yes;
   □ (b) no.

24. If YES, can you describe these experiences?

   _______________________________________________________________________
   _______________________________________________________________________
   _______________________________________________________________________

25. Please indicate below any previous or current training (or courses) in ethics.

   _______________________________________________________________________
   _______________________________________________________________________
   _______________________________________________________________________

26. Gender
   □ Female
   □ Male

27. Country of birth? ________________________________

28. What ethical issues do you identify in this clinical scenario? Please specify and give your reasons.

   _______________________________________________________________________
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29. What recommendations would you suggest? Please specify and give your reasons.
30. Within the hospital, various disciplinary groups may act as a resource in resolving patient care issues. For example, physicians, nurses, clergy, ethicists, social workers, psychologists, and HECs are just a few of many resources. Do you think health care providers could benefit from using a HEC as a way to resolve patient issues similar to those previously discussed?

31. What do you believe your professional/occupational or lay disciplinary background contributes to the deliberations of your HEC? Please specify and give reasons.
32. Does your HEC provide patient care consultations?

33. If YES, do you think the clinical description was typical of patients referred to your committee?

☐ (a) yes;  
☐ (b) no;  
☐ (c) other comments

PART II

Please read the attached clinical scenario.

Agitation in the elderly, primarily those who develop a dementing illness, is one of the challenges currently facing health care providers. These patients have significant behavioural problems. This may include noise-making, wandering, demanding — disruptive, restless, aggressive and socially objectionable conduct — and even hurting each other and staff.

The agitated elderly are a vulnerable population. Sometimes they pose less an ethical dilemma than a practical management problem. However, when these patients are not comprehending or capable of appropriate behaviour, someone else will have to intervene on their behalf. Many health care providers now find themselves struggling with the ethical dilemma of the right course of action. The possibly unsolvable nature of agitation, the relentlessness of the behaviours, and the patient’s cognitive unpredictability make these decisions complex for whoever is involved.

As you try to identify ethical issues and recommendations (assisting in determining prognosis, seeking legal guidance, educating hospital personnel, suggesting patient-focused solutions and recommending policies), the fundamental question is: What are the ethical issues and recommendations of HECs to the behavioural disturbances of agitation in the elderly and how are these issues and recommendations related to the professional/occupational or lay disciplinary backgrounds of individual members?

Although there is no established definition of agitation, the term itself refers to an array of patient responses, ranging from severe to mild disturbances. Agitation may mean any of the following: intermittent yelling, pacing, fretting, fidgeting, rocking, crying, as well as physical aggression. The care, management and treatment of the agitated elderly require the involvement
of health care providers from many disciplines. Inter-professional collaboration about issues arising from the care of these patients could then lead to reshaping the way we handle the agitated elderly.

The following definitions may be of assistance to you:

**Agitated Elderly** refers to patients with a dementing illness suffering from some degree of global cognitive impairment which has progressed to a point where they exhibit socially inappropriate, uncontrollable, restless and disruptive behaviour (Baumgarten, et al., 1990; Cohen-Mansfield & Marx, 1990; Hallburg, et al., 1990; Salzman, 1987). As seen in hospital settings, some elderly are in a constant state of agitation. Often the elderly patient with cognitive impairment overreacts to seemingly minor problems: feelings of being overwhelmed by environment or experience, of being lost or abandoned, or of being frightened by strange people (Aronson, 1988). The agitated elderly manifest such behavioural signs as excessive verbal, vocal and motor restlessness (Ancill & Holliday, 1988; Cohen-Mansfield, 1986; Cohen-Mansfield & Billig, 1986; Cohen-Mansfield, et al., 1987; Struble & Sivertsen, 1987; Taft, 1989; Curl, 1989). Examples of such behaviour include: hitting, kicking, cursing, pacing, inappropriate robing/disrobing, complaining, negativising, and shouting repetitious phrases (Cohen-Mansfield, Marx & Rosenthal, 1990). Other behaviours might also include sexual disinhibition, sleep disturbances, wandering, incontinence, paranoid symptoms, hostility and aggression, impaired communication, and deterioration of previously well-learned abilities (Wasylkni, Martin, Clark, Lennox, Perry & Harrison, 1987).

**Ethical Issue** refers to the consideration of human values or beliefs about right or wrong conduct or behaviour (Lemieux-Charles & Meslin, 1992). Identifying ethical issues is a preliminary step to ethical decision-making and does not necessarily entail making ethically defensible clinical judgments, resolving moral dilemmas, analyzing concepts, acknowledging closure, or justifying actions (Hébert, Meslin & Dunn, 1992). Ethical issues unique to the care and treatment of the agitated elderly may be described by health care providers, other professionals and lay persons in different ways and involve extensive overlapping. It is likely that health care providers, other professionals, and lay persons have different understandings of what constitutes an ethical issue. For the purpose of this study, an issue identified as an ethical issue by a HEC member will be termed an ethical issue (Gramespacher, Howell, Young, 1986; Lemieux-Charles & Meslin, 1992).

**Recommendation** refers to HEC members' choice regarding their reasonable next step related to the care, treatment and management of the agitated elderly, which may involve making recommendations, assisting in determining prognosis, seeking legal guidance, educating hospital personnel, suggesting patient-focused solutions, and recommending policies.

**PART III**
Complete following the focus group discussion.

What did you think about this discussion? *(Check as many adjectives as appropriate)*

☐ interesting
☐ boring
☐ clear
☐ intrusive
☐ confusing
☐ fun
☐ difficult
☐ other comments?

________________________________________

________________________________________
APPENDIX J

CLINICAL SCENARIO

** This scenario was developed through interviewing staff nurses and personal clinical experience.

Mr. O., 78 years old of age, has been assessed as suffering from moderate agitation. Tonight, he is resistant and restless. He paces anxiously. He pulls at the door handles making a rattling noise. When he is approached quietly by a nurse, he tries to push her away. He shouts over and over again: "I have no money", while at the same time fidgeting with the buttons on his shirt. Mr. O. gets angry when he is reminded by you that other patients are trying to sleep. He begins to curse loudly moving his arms uncontrollably. It is eleven o'clock, and the nursing shift is about to change. On this unit, the staff try to have the patients settled before the night staff come on.
APPENDIX K Frequency List of Code Words

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APPENDIX L
Sample of Data Analysis using the Ethnograph

to very adversely affect the peace and well being of many other patients.

Whether it is ethical to apply physical restraints to a human being in a demented state, who may be terribly frightened by his surroundings, even without the restraints.

Whether it is ethical to administer medication to the patient to control his behaviour.

Whether medication is being administered for the convenience of the staff rather than the benefit of the patient.

I think the reasons are implicit in the issues mentioned.

Respondent No. 6

Assuming all clinical reasons are ruled out:

1) Competency ie. a) participate in health care decisions, specifically remaining in the institution and b) accepting care/treatment modalities.

2) Autonomy v. justice - allowing patient to be "himself" vs. sleep of other patients.

3) Non-maleficence - use of restraints if necessary.

4) Surrogacy - who speaks for him if he cannot.

Respondent No. 7

Autonomy of patient, ability to express self in non-self/others injuring way.

Safety of others especially patients, health care providers.

Peace of the community, important in therapeutic goals of elder care.

Power and control, agitation controls rather than person.
APPENDIX M

HEC PROFILE DATA

General Information:

i. Total Number of Respondents: 67
   Number of Respondents in
   Group A: 5 (7.5 %)
   Group B: 14 (20.9 %)
   Group C: 11 (16.4 %)
   Group D: 10 (14.9 %)
   Group E: 8 (11.9 %)
   Group F: 5 (7.5 %)
   Group G: 1 (1.5 %)
   Group H: 7 (10.4 %)

ii. Total Number of Physicians: 15
[A - 1; B - 5; C - 1; D - 2; E - 3; F - 1; G - 0; H - 2]

iii. Total Number of Nurses: 21
(incl. health adm./nurses etc.)
[A - 2; B - 1; C - 4; D - 1; E - 2; F - 2; G - 4; H - 2]

iv. Total Number of Chairs, Co- and Vice-Chairs: 10

PART I
Background Information

1. Do you hold any special position on the HEC?

   i. All Respondents:
      Yes 18 (26.9 %)
      No 47 (70.1 %)
      No response 2 (3.0 %)
      Specify:
      Chair 7
      Co-Chair/Vice Chair 3
      Secretary/Assistant 4
      Nursing Rep. of NEG 1
      Cross-appointed from
      MAC research committee 1
      Community Rep. 1
      Liaison to Mgt. Committee 1
ii. Physicians Only
   Yes 5 (33.3 %)
   No 9 (60.0 %)
   No response 1 (6.7 %)

Specify:
   Chair 3
   Co-Chair/Vice-Chair 2

iii. Nurses Only:
    Yes 8 (38.1 %)
    No 13 (61.9 %)

Specify:
   Chair 4
   Co-Chair/Vice-Chair 2
   Secretary/Assistant 2
   Nursing Rep. of NEG 1

Questions 2 - 11: Please refer to previous Document

12. How long have you been a member of the HEC?

i. All Respondents:
   Range <1 - 13 years
   Mean length 3.06 years
   S. D. 2.22
   Sum 196 years

ii. Physicians Only:
    Range <1 - 7 years
    Mean length 3.5 years
    S. D. 2.35
    Sum 49 years

iii. Nurses Only:
     Range 1 - 7 years
     Mean length 3.45 years
     S. D. 1.69
     Sum 69 years

iv. Chairs, Co- and Vice-Chairs Only:
    Range 1 - 7 years
    Mean length 4.33 years
    S. D. 2
    Sum 39 years
13. Do you have any other formal affiliation with other hospital committees?

i. All Respondents:

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ii. Physicians Only:

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<tr>
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iii. Nurses Only:

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iv. Chairs, Co- and Vice-Chairs Only:

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14. In what professional occupational field or specialty are you engaged in? [Check all that apply]

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<td>Clergy</td>
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<tr>
<td>Health Administrator</td>
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<td>[5 out of those 9 were also nurses]</td>
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<td>1.5%</td>
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<td>Other Mentions</td>
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<td>10.4%</td>
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iv. Chairs, Co- and Vice-Chair Only:
   Physician 5 (50.0 %)
   Nurse Only 2 (20.0 %)
   Nurse + Health Adm. 1 (10.0 %)
   Nurse + Other 1 (10.0 %)
   Clergy 1 (10.0 %)

15. Please indicate below your official title(s) in this hospital or elsewhere and the number of years you have held the title(s).

   - please analyze as qualitative question

16. What is the role of the HEC in your hospital? [Check all that apply]

i. All Respondents:
   Education 56 (83.6 %)
   Policy-making 53 (79.1 %)
   Patient-care Consultation 32 (47.8 %)
   Staff Consultation 46 (68.7 %)
   Other 15 (22.4 %)

   (for specifics, please refer to questionnaires)

ii. Physicians Only:
   Education 12 (80 %)
   Policy-making 10 (66.7 %)
   Patient-care Consultation 8 (53.3 %)
   Staff Consultation 11 (73.3 %)
   Other 2 (13.3 %)

iii. Nurses Only:
   Education 19 (90.5 %)
   Policy-making 16 (76.7 %)
   Patient-care Consultation 8 (38.1 %)
   Staff Consultation 10 (47.6 %)
   Other 4 (19.0 %)

iv. Chairs, Co- and Vice-Chairs Only:
   Education 10 (100 %)
   Policy-making 9 (90.0 %)
   Patient-care Consultation 3 (0.0 %)
   Staff Consultation 8 (0.0 %)
   Other 2 (0.0 %)
17. Does the committee examine issues?

i. All Respondents:
   - Retrospectively Only: 4 (6.0 %)
   - Prospectively Only: 8 (11.9 %)
   - Both R. and P.: 50 (74.6 %)
   - Comments: 4 (6.0 %)
   - No response: 5 (7.5 %)

ii. Physicians Only:
   - Retrospectively Only: 1 (6.7 %)
   - Prospectively Only: 1 (6.7 %)
   - Both: 12 (80.0 %)
   - Comments: 0 (0.0 %)
   - No response: 1 (6.7 %)

iii. Nurses Only:
   - Retrospectively Only: 2 (9.5 %)
   - Prospectively Only: 2 (9.5 %)
   - Both: 16 (76.7 %)
   - Comments: 3 (14.3 %)
   - No response: 1 (4.8 %)

iv. Chairs, Co- and Vice-Chairs Only:
   - Retrospectively Only: 2 (20.0 %)
   - Prospectively Only: 0 (0.0 %)
   - Both: 8 (80.0 %)
   - Comments: 1 (10.0 %)

18. How effective, would you say, is the operation of your HEC in helping to protect
   the rights and welfare of patients or providing a mechanism for ethical deliberation?

i. All Respondents:
   - Very effective: 4 (6.0 %)
   - Effective to a degree: 46 (68.7 %)
   - Ineffective because it has little power: 3 (4.5 %)
   - Other Comments: 13 (19.4 %)
   - No response: 3 (4.5 %)

ii. Physicians Only:
   - Very effective: 1 (6.0 %)
   - Effective to a degree: 10 (66.7 %)
### iii. Nurses Only:

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<td>15 (71.4%)</td>
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### iv. Chairs, Co- and Vice-Chairs Only:

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19. What proportion of the membership of the HEC is required for agreement in ethical deliberations:

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<td>Some other proportion</td>
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<td>Unsure</td>
<td>8 (11.9%)</td>
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<tr>
<td>No response</td>
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### ii. Physicians Only:

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<td>0 (0.0%)</td>
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<tr>
<td>Simple majority...</td>
<td>3 (20.0%)</td>
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<tr>
<td>Consensus</td>
<td>2 (13.3%)</td>
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### iii. Nurses Only:

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<tr>
<td>Two-thirds majority...</td>
<td>0 (0.0%)</td>
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</table>
Simple majority... 1 (4.8 %)
Consensus 1 (4.8 %)
No specific proportion 14 (66.7 %)
Some other proportion 0 (0.0 %)
Unsure 2 (9.5 %)

iv. Chairs, Co- and Vice-Chairs Only:
Unanimity... 0 (0.0 %)
Two-thirds majority... 0 (0.0 %)
Simple majority... 2 (20.0 %)
Consensus 2 (20.0 %)
No specific proportion 6 (60.0 %)
Some other proportion 0 (0.0 %)
Unsure 0 (0.0 %)

20. Do you agree or disagree with the following:
"In practice, when our HEC makes a recommendation..."

i. All Respondents:
Agree 29 (43.3 %)
Disagree 8 (11.9 %)
Can't say 25 (37.3 %)
N/A 1 (1.5 %)
No response 4 (6.0 %)

ii. Physicians Only:
Agree 7 (46.7 %)
Disagree 2 (13.3 %)
Can't say 5 (33.3 %)
No response 1 (6.7 %)

iii. Nurses Only:
Agree 13 (61.9 %)
Disagree 4 (19.0 %)
Can't say 3 (14.3 %)
N/A 1 (4.8 %)

iv. Chairs, Co- and Vice-Chairs Only:
Agree 7 (70.0 %)
Disagree 1 (10.0 %)
Can't say 1 (10.0 %)
N/A 1 (10.0 %)
21. How long have you been a member of this hospital?

   i. All Respondents:
      N/A or No Response    7 (10.4 %)
      Range                1 - 35 years
      Mean length          11.54 years
      S. D.                8.29 years
      Sum                  692.5 years
   
   ii. Physicians Only:
      Range                1.5 - 28 years
      Mean length          12.36 years
      S. D.                8.54
      Sum                  173 years
   
   iii. Nurses Only:
      Range                2 - 29 years
      Mean length          10.38 years
      S. D.                7.07
      Sum                  218 years
   
   iv. Chairs, Co- and Vice-Chairs Only:
      Range                2 - 25 years
      Mean length          10.4 years
      S. D.                7.29
      Sum                  104 years

22. What is your highest academic degree?

   i. All Respondents:
      Diploma             4 (6.0 %)
      Bachelor            14 (20.9 %)
      Masters             19 (28.4 %)
      Ph D                9 (13.4 %)
      MD/FRCP             13 (19.4 %)
      RN                  4 (6.0 %)
      LLB                 1 (1.5 %)
      No response         3 (4.5 %)
   
   ii. Physicians Only:
      PhD                 1 (6.7 %)
      MD/FRCP             13 (86.7 %)
      No response         1 (6.7 %)
### iii. Nurses Only:
- Diploma: 2 (9.5%)
- Bachelor: 7 (33.3%)
- Masters: 8 (38.1%)
- RN: 4 (19.0%)

### iv. Chairs, Co- and Vice-Chairs Only:
- Diploma: 1 (10.0%)
- Masters: 3 (30.0%)
- MD/FRCP: 5 (50.0%)
- RN: 1 (10.0%)

---

23. **What was your age at your last birthday?**

i. **All Respondents:**
   - Range: 29 - 72 years
   - Mean age: 46.06
   - S. D.: 9.40

ii. **Physicians Only:**
   - Range: 37 - 64 years
   - Mean age: 49.93
   - S. D.: 9.56

iii. **Nurses Only:**
   - Range: 29 - 59 years
   - Mean age: 45.05
   - S. D.: 8.26

iv. **Chairs, Co- and Vice-Chairs Only:**
   - Range: 40 - 64 years
   - Mean age: 49.5
   - S. D.: 8.32

---

24. **Did you have any experiences before becoming a member of a HEC which made you aware of ethical issues?**

i. **All Respondents:**
   - Yes: 58 (86.6%)
   - No: 7 (10.4%)
   - No response: 2 (13.0%)
ii. Physicians Only:
   Yes: 12 (80.0 %)
   No: 2 (13.3 %)
   No response: 1 (6.7 %)

iii. Nurses Only:
   Yes: 20 (95.2 %)
   No: 1 (4.8 %)

iv. Chairs, Co- and Vice-Chairs Only:
   Yes: 10 (100 %)
   No: 0 (0.0 %)

25. If YES, can you describe these experiences?
   - please analyze qualitatively

26. Please indicate below any previous or current training (or courses) in ethics

   i. All Respondents:
      Yes (i.e., written something): 41 (61.2 %)
      No (i.e., nothing written): 26 (38.8 %)

   ii. Physicians Only:
      Yes: 7 (46.7 %)
      No: 7 (46.7 %)

   iii. Nurses Only:
      Yes: 17 (81.0 %)
      No: 4 (19.0 %)

   iv. Chairs, Co- and Vice-Chairs Only:
      Yes: 7 (70.0 %)
      No: 3 (30.0 %)

27. Gender

i. All Respondents:
   Female: 48 (71.6 %)
   Male: 19 (28.4 %)
### ii. Physicians Only:
- Female: 8 (53.3 %)
- Male: 7 (46.7 %)

### iii. Nurses Only:
- Female: 21 (100 %)
- Male: 0 (0.0 %)

### iv. Chairs, Co- and Vice-Chairs Only:
- Female: 6 (60.0 %)
- Male: 4 (40.0 %)

28. **Country of Birth?**

#### i. All Respondents:
- Canada: 52 (77.6 %)
- India: 1 (1.5 %)
- United Kingdom: 6 (9.0 %)
- Ireland: 1 (1.5 %)
- United States: 2 (3.0 %)
- Hungary: 1 (1.5 %)
- No response: 4 (6.0 %)

#### ii. Physicians Only:
- Canada: 9 (60.0 %)
- United Kingdom: 2 (13.3 %)
- United States: 1 (6.7 %)
- Hungary: 1 (6.7 %)
- No response: 2 (13.3 %)

#### iii. Nurses Only:
- Canada: 19 (90.5 %)
- United Kingdom: 2 (9.5 %)

#### iv. Chairs, Co- and Vice-Chairs Only:
- Canada: 8 (80.0 %)
- United Kingdom: 2 (20.0 %)
PART II
Clinical Scenario

Questions 29 - 32 require qualitative analysis

33  Do you think the clinical description was typical of patients referred to your committee?

i.  All Respondents:
    Yes                      5 (7.5 %)
    No                       39 (58.2 %)
    N/A                      2 (3.0 %)
    Comments                 26 (38.8 %)
    No response              8 (11.9 %)

ii. Physicians Only:
    Yes                      0 (0.0 %)
    No                       11 (73.3 %)
    Comments                 6 (26.7 %)

iii. Nurses Only:
    Yes                      4 (19.0 %)
    No                       11 (52.4 %)
    Comments                 5 (23.8 %)

iv. Chairs, Co- and Vice-Chairs Only:
    Yes                      0 (0.0 %)
    No                       8 (80.0 %)
    Comments                 1 (10.0 %)
    No response              2 (20.0 %)

PART III

Complete following the focus groups discussion.

What did you think about this discussion? (Check as many adjectives as appropriate)

i.  All Respondents:
    Interesting             58 (86.6 %)
    Boring                  1 (1.5 %)
    Clear                   22 (32.8 %)
    Intrusive               0 (0.0 %)
    Confusing               4 (6.0 %)
    Fun                     19 (28.4 %)
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REFERENCES


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Weber, L.J. (1994). Do Hecs have a responsibility to the non-medical community rather than only to the institution, physician and patient: Yes, HEC Forum 6(2) 117-118.


