

1999

# An analysis of physicians' reluctance to follow terminally ill patients' advance directives

Norma Poirier

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**An Analysis of Physicians' Reluctance to Follow Terminally Ill  
Patients' Advance Directives**

by

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**Dissertation Submitted in Partial Fulfillment  
of the Requirement for the Degree of  
Doctor of Philosophy  
Health Services**

**Walden University  
November 1999**

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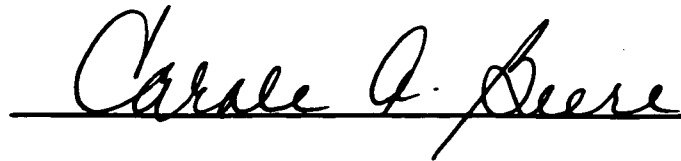
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**DOCTOR OF PHILOSOPHY DISSERTATION**  
**OF**  
**NORMA POIRIER**

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**Abstract**

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November 1999**

## **ABSTRACT**

**This study examined the reasons why physicians have difficulty respecting the wishes of terminally ill patients who refuse treatment. Consistent with the relevant literature, three alternative explanations were hypothesized in answering the question: fear of litigation, religious beliefs, and medical professional values.**

**Evidence was gathered from three different sources. Semistructured interviews were carried out with 24 emergency physicians from the Moncton Area in the Canadian province of New Brunswick and submitted to both quantitative and qualitative content analysis. Nineteen cases of terminally ill patients whose wishes not to be treated were not respected were collected and submitted to content analysis. Finally, administrative policies on resuscitative policies and on clinical ethics committees of all New Brunswick Hospital Corporations were collected and also submitted to content analysis.**

**The results of the study showed that fear of litigation may be a partial explanation in about one third of the cases, but contradictory evidence also pointed to diverging conclusions. Religious beliefs may also account for certain physicians' attitudes toward refusal of treatment by their terminally ill patients. Statistically significant differences were found between unilingual and bilingual physicians. However, medical professional values were demonstrated to be the single most important factor in explaining why physicians acted the way they did in the treatment of their terminally ill patients. Normative pluralism and especially Luhmann's self-reference concept may explain why physicians had so much difficulty adapting their behaviors to meet the courts' legal decisions and the legislative changes respecting the rights of terminally ill patients who refuse treatment.**

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# CHAPTER 1

## INTRODUCTION TO THE STUDY

### Introduction

Nurses caring for dying patients and their families experience a difficult clinical situation when they are confronted with physicians who do not respect their terminally ill patients' wishes not to be treated except to alleviate their pain. The following three cases in which the researcher was involved illustrate the issue.

The researcher was consulted in the case of an 87-year-old male who had written a living will to the effect that he was not to be resuscitated if he should have a cardiac arrest. He suffered a cardiac arrest and was transferred by ambulance to the emergency department of the hospital. He was resuscitated against the directives of his children, who had informed the physician of their father's wishes. The patient was put under a respirator and lived in a vegetative state. The family members had to hire a lawyer (who in this case was also a Catholic priest) who went to the medical director of the hospital. The doctor was still refusing to unplug the respirator. After 3 days and under the threat of a lawsuit, he finally did so.

A 67-year-old woman who had terminal cancer with bone metastases suffered adverse effects from chemotherapy and radiotherapy. She determined that she had a low quality of life with her treatments. She asked the oncologist to stop the treatments. Her husband agreed with her. The doctor responded by saying that if she died her husband would be personally responsible for her death. He also told her that if she insisted on refusing the treatments, she would no longer be given food or water, in order to accelerate the dying process. The nurses were very upset about the situation.

Finally, an 89-year-old man had cardiac surgery in June 1996. His wishes were not to be resuscitated if he should suffer a second cardiac arrest. He suffered another cardiac arrest and was nevertheless resuscitated. He was hospitalized having had bronchopneumonia, which led to adverse effects, tracheotomy, and blood transfusions on a daily basis followed by renal dialysis three times a week. A month later he had a bowel obstruction, and had bowel resection and removal of the anus because of intestinal bleeding and cancer of the rectum. He was under a respirator and in a coma for a few months, during which time he was unaware of what had happened. He never recovered. Some distant family members who never visited more than once a year had confronted the doctor stating that they would sue him if he did not do everything in his power to maintain the old man's life. This man died in April 1997 after being in a coma for more than 6 months.

Situations similar to the previous three cases happen daily in American and Canadian hospitals (Lewin, 1996; Teno, Licks, Lynn, Wenger, Phillips, Murphy, Connors, Desbiens, Fulkerson, Bellamy, & Knaus, 1997a; Wilson, 1997). Patients' advocates, families, ethicists, judges, and legislators have labored to understand the reasons why physicians do not respect their patients' wishes and to find adequate solutions to those situations. However, to this day, no adequate answers, and therefore no adequate solutions, have been found to that pressing question.

### **Research Problem**

The research poses one main question: Why do physicians have so much difficulty respecting their terminally ill patients' wishes to refuse treatment once there is no hope

for a cure? Taking into account the theoretical framework that will be described later and the available research data on the subject, several subquestions flow from that general question as to why physicians act the way they do: (a) physicians fear charges (for euthanasia or assisted suicide) and therefore are reluctant to follow their patients' wishes not to be treated from fear of contravening legal norms; (b) physicians think that accepting patients' wishes not to be treated is an abdication of their duties and thus in violation of generally accepted ethical norms; (c) physicians think that acknowledging their terminally ill patients' wishes is an abdication of their duties and thus contrary to their professional ideology, that is, medical professional norms; (d) hospital administrative norms with respect to terminally ill patients' wishes are generally preferable to physicians' because they take into account their professional ideological norms (medical professional norms), general ethical norms, and legal norms; and (e) physicians would accept respecting their patients' wishes not to be treated only when the hospitals' administrative norms or the legal and religious norms do not contradict their professional ideology, that is, their medical professional norms. Finally, the question of how to change physicians' attitudes and behaviors toward their terminally ill patients who refuse treatment once there is no cure left is a pressing one that has eluded the medical profession, patients advocates, social reformers, and even legislators.

### **Background**

The refusal of physicians to respect their terminally ill patients' wishes not to be treated is a pressing social concern in two aspects. First, in all societies, but especially in countries where resources are scarce and the health care system is publicly funded,

maintaining terminally ill patients artificially alive against their wishes poses the problem of fair allocation of resources among the generations. Second, it raises ethical and legal questions about physicians' and nurses' infringing upon the dignity of their patients.

### Demographic Changes and its Impact on Health Care Resources

The greying of populations in the Western countries has already begun, especially in Europe, and it will soon affect the United States and Canada. The percentages of people 65 years and older are around 12% in the United States (Jennet, 1995, p. 86) and in Canada (Foot & Stoffman, 1996, p. 285).

Policy analysts and researchers have shown that elders tend to use more health care resources than do younger populations. Thorslund and Parker (1995, Table 1) have shown that in 1992, Sweden has spent as much of its gross domestic product for medical care of persons 65 years and older as for those from 0 to 64 years (3.7% vs. 3.5%). These authors also showed that Sweden spend 150% more expenditure for inpatient and institutional care for its 65 years and older population than for its 0 to 64 year population (Thorslund & Parker, 1995, Table 2). For Canada, in 1981, the elderly comprised 9.7% of the total population but accounted for 40% of all Canadian health costs while taking up 48% of all general hospital beds (Roy, Williams, Dickens, & Baudouin, 1995, p. 321).

Although people of all ages are frequently overtreated, especially in the United States but also in other countries (Blendon et al., 1993), Jennett (1995) has shown that patients over 65 years of age were proportionally much more frequently on high-technology therapies than younger patients. He reported that 44% of United States patients and 31% of United Kingdom patients in intensive care units were 65 years and

older. What is maybe more surprising is that in the United States, 55% of the patients receiving resuscitation and 34% of those receiving ventilation were 65 years and older. Finally, 48% of the United States patients receiving artificial nutrition were 65 years and older. These high-technology therapies, especially resuscitation, ventilation, and tube feeding, are often seen as overtreatment. Jennett (1995, p. 92) cited research that showed that very few elderly patients survived cardio-pulmonary resuscitation (CPR) and that fewer than 2% went home. These figures are consistent with those found by Ghusn, Teasdale, and Boyer (1997).

Ter Meulen, Topinkowa, and Callahan (1995) came to the conclusion that modern medicine has separated aging from disease, and illness from death. Furthermore, they wrote that medicine “has created an enormous bias in most health care systems toward those forms of medicine -- especially hospital-based, acute-care medicine -- aimed at curing disease and forestalling death” (p. 155). This high-technology medicine has the adverse effect of creating more sickness because those who, in the past, would have died can now be saved, but not necessarily made well again. Therefore we have nowadays “a medicine that can save lives but leave more sick and damaged people in its wake ... and create even more problems than it solves, often sparing people a quick death but giving them, in its stead, a longer life marked by sickness and disability” (pp. 155-156).

Since the greying of the Western population is a phenomenon that is expected to grow well on into 2050 and since the elderly population is taking a greater proportion of health care services, greater pressure will confront governments and those others who are paying for medical services. Furthermore, researchers have shown that the dependency



ratio will increase dramatically in the next 50 years. The dependency ratio is an indicator relating the sector of the population that is not of working age to the one that is. Callahan (1990, Table 7) has shown that in 1990, people aged 65 years and older represented about 21% of the working-age population. This means that for every elder, five individuals are working to pay taxes. By the year 2035, intermediate estimates predict that the elderly will represent 40.6% of the working-age population, and pessimistic assumptions put those figures at 50%. This means that for every elder, 2 1/2 and even to 2 -- if the pessimistic assumption is true -- will be working to pay taxes. Similar predictions have been made for Canada (Denton, Heaver, & Spencer, 1998, pp. 33-35; Foot & Stoffman, 1996).

A high dependency ratio means that fewer people will be working in order to pay taxes for health and welfare services needed by the elderly and the youth who are not yet working. Callahan (1987, 1990) and Ter Meulen (1995) have argued that the increasing demand for care by the elderly is putting solidarity between the young and the old under strain. The strain comes from the over-medicalization of old age and the cost associated with it. It is also aggravated by the dependency of the elderly and the youth on the welfare state, the elderly insisting that they have a right to health services, and the youth insisting on the fact that it is not they who should pay for the elderly.

#### Physicians' Attitudes toward the Treatment of Terminally Ill Patients

Solomon et al. (1993) undertook a survey of 687 physicians and 759 nurses in five New England hospitals. The Institutional Profile was used; it contained 123 items in a self-completed questionnaire covering a range of issues such as knowledge and attitudes

regarding law, medical ethics and institutional guidelines, and perceived impediments to good decision making and quality care. The authors' objective was to investigate how professionals assess the care of hospital patients near the end of life and whether physicians and nurses were aware of and in agreement with national recommendations regarding a patient's right to forgo life-sustaining medical treatments and to receive adequate pain control.

Most respondents reported that they were aware of guidelines at their institution about obtaining informed consent, issuing do-not-resuscitate orders, and others of the regulation of end-of-life treatments. Almost 90% were in agreement that all competent patients, even if they are not considered terminally ill, have the right to refuse life support, even if that refusal may lead to death. However, almost half were reluctant to withhold treatment since they thought it active euthanasia and contrary to ethics. They were also reluctant to forgo artificial nutrition and hydration. Even more striking is that almost half (47%) of all respondents and fully 70% of the house officers reported that they had acted against their conscience in providing care to the terminally ill, especially by overtreating them.

Christakis and Asch (1995) undertook research to identify the attributes of physicians associated in decisions to withdraw life support. They surveyed 862 Pennsylvania internists with an instrument that had been previously validated. They asked them to make decisions in response to hypothetical vignettes and to report their actual experience with the withdrawal of life support. The vignettes described patients who were comatose and terminally ill and who had previously expressed their wishes clearly

regarding refusal of life-supporting therapy. Fifty-six percent responded. With other factors controlled, physicians were more willing to withdraw life support if they were young, practiced in a tertiary care setting, or spent more time in clinical practice; they were less willing if they were Catholics or Jews. Physicians reported a higher frequency of actually withdrawing life support if they had more contact with ICU patients, spent more time in clinical practice, or were specialists. Physicians with a greater willingness to withdraw were more likely to report having done so. An unexpected finding of the study was the extent to which subjects tend not to withdraw life support: 47.8% of respondents were either neutral or unwilling to withdraw life support.

Finally, a recent court case signaled that physicians' refusal to follow a patient's directive may still be frequent. Lewin (1996) reported that a 28-year-old female who had a brain hemorrhage had severe seizures that would worsen at a critical point, according to her doctors. The doctor suggested that she should sign advance directive refusing extraordinary life support measures in a critical phase of her illness. She gave her mother power of attorney to stop treatment if she became incapacitated. She had a bad seizure and was put on a ventilator, tube-fed, and maintained through a 2-month coma despite her mother's insistence that she did not want life support. In a lawsuit against the hospital, her mother won a \$16.5 million verdict. At trial, the hospital argued that her doctors believed that they were doing what was best for her and that they could not predict how disabled she would be. Lewin (1996) also mentioned four other similar cases of elderly persons who had been treated against their or their spouses' consent. Citing a study financed by the Robert Wood Johnson Foundation and published in late 1995, Lewin (1996) wrote

that advance directives had done little to change end-of-life medical care. That study found that fewer than half the doctors even knew when patients wanted to avoid resuscitation, and that more than one third of the ones who died had spent at least 10 days in intensive care, comatose, or on a ventilator. Those results were published recently in professional journals (Teno, Licks, Lynn, Wenger, Phillips, Murphy, Connors, Desbiens, Fulkerson, Bellamy, & Knaus (1997a); Teno, Licks, Lynn, Wenger, Connors, Phillips, O'Connor, Murphy, Fulkerson, Desbiens, & Knaus (1997b); Teno, Licks, Lynn, Connors, Wenger, Phillips, Alzola, Murphy, Fulkerson, Desbiens, & Knaus (1997c); Teno, Branco, Mor, Phillips, Hawes, Moris, & Fries (1997d).

#### Nurses' Attitudes toward Treatment of Terminally Ill Patients

Nurses as well as physicians are important to terminal patient care. An international study (Leverly et al., 1992) carried out with 531 experienced nurses, 65% of whom were Canadian nurses, examined nursing decision-making in the simulated treatment of a demented elderly man who had a life-threatening gastrointestinal hemorrhage. The study reviewed the treatment choices of the nurses in a controlled-fact situation that included three scenarios: (a) a comprehensive directive completed by the patient, the family, and the family doctor before hospital admission; (b) no directive, and (c) a written DNR order. The researchers found that the treatment decisions of the nurses varied greatly despite the presence of a written DNR order or advance health care directive. The presence of such an order or written directive was not sufficient to ensure nursing compliance in every situation.

In another study, Solomon et al. (1993) investigated whether physicians and

nurses were aware of and in agreement with national recommendations regarding a patient's right to forgo life-sustaining medical treatment and to receive adequate pain control. They surveyed 687 physicians and 759 nurses in five New England hospitals with the institutional profile described earlier. Most respondents reported that they were aware of guidelines at their institution about obtaining informed consent, issuing do-not-resuscitate orders, and other end-of-life treatments. Physicians and nurses did not exhibit different attitudes in most responses. Almost half of both groups were more likely to believe that food and water should always be continued even if life supports such as mechanical ventilation and dialysis are stopped.

However, the results of the Solomon et al. (1993) research showed differences between physicians' and nurses' attitudes in some areas. Three out of four nurses as compared to half of the physicians were dissatisfied with patient participation in various aspects of decision making. Almost half of the nurses and fully 70% of the house officers reported that they had acted against their conscience in providing care to the terminally ill. With respect to pain control, about one third of medical and surgical attending physicians compared with 44% of nurses believed clinicians give inadequate pain medications most often out of fear of hastening a patient's death.

In a study conducted by Jansson and Norberg (1989), 15 staff nurses and 5 ward sisters working with cancer patients were presented with the hypothetical situation of a terminally ill, mentally alert, old female cancer patient who refused food. All 20 interviewees were classified as choosing not to feed the terminally ill, mentally alert, old cancer patient who refused food. They stressed that they would not use either force or

violence. All described how they would try to give the patient different encouraging reasons for eating, and would offer food at every meal.

Concerning nurses' resistance to stopping artificial nutrition and hydration, Day, Drought, and Davis (1995) undertook a study to discover under what circumstances nurses feel justified in withholding artificial nutrition and hydration. Eighty nurses considered experts by supervisors volunteered to be included in the study. Forty were cancer care nurses from two sites, and 40 were dementia care nurses from two sites. Structured interviews were conducted based on two vignettes, one involving an alert patient with terminal cancer for the cancer nurses, the other a patient suffering end-stage Alzheimer's dementia for the dementia nurses. Of the 40 cancer nurses interviewed, two (5%) would attempt to feed in the given situation while 37 (95%) would not. Of the two nurses who would feed, both invoked sanctity of life as the underlying principle, but both would discontinue attempts if they caused suffering in the patient. Of the 40 dementia nurses, 73% would attempt feeding while 27 % would not. Those who would not feed most often indicated breach of autonomy and quality of life as the principles underlying their decision.

Finally, an exploratory study aimed to investigate the attitudes of nurses towards withdrawal of treatment and care of the terminally ill patients (McInerney & Seibold, 1995). It used a network sample of 10 registered nurses from a variety of practice settings. Their ages ranged from 24 to 48 years. Eight were Catholics and two had no religious affiliation. Semistructured interviews with the nurses were transcribed verbatim and content analysis conducted. The major finding of the study was the commitment of all

participants to caring for and ensuring the comfort of the dying patient. The concept of ordinary and extraordinary forms of treatment and heroic measures were seen as worthy of debate in the context of dying and dignity rather than of euthanasia. There was an associated aversion to inappropriate heroic measures, which were perceived as postponing death and interfering with dying with dignity.

From these few available research studies, it seems that physicians and nurses have similar attitudes towards caring for their terminally ill patients. Nurses, however, seem to be closer to their patients and thus more aware of what is really going on with them.

#### Purpose

Based on the author's personal experience and on empirical data reported in the literature, one question is recurrent: Why do a substantial proportion of physicians not respect their terminally ill patients' wishes to refuse treatment once there is no hope for restoration to health? The research literature gives some answers to the question. In their research, Solomon et al. (1993) stressed the fact that the physicians' views differ from those put forward by authorities in ethics and law in four different situations, namely, (a) withdrawal of treatment, (b) the distinction between ordinary and extraordinary treatment, (c) the provision of nutrition and hydration needs, and (d) pain control. However, they did not adequately identify why physicians and nurses perceive that they are acting against their conscience in treating terminally ill patients.

Buchan and Tolle (1995), throughout their analysis, acknowledged the need for physicians to update their education with respect to relief of pain and especially to better

educate themselves on what is ethically acceptable, even if respiratory depression and death were to follow the prescription of analgesics, as long as the patient's death was not intended. The authors also acknowledged that physicians do not give enough pain killers to terminally ill patients out of concerns and fears of hastening a patient's death and fear of litigation. These results are consistent with those of Solomon et al. (1993), who found that the most common form of narcotic abuse in the care of the dying is undertreatment of pain. This is due partly to lack of knowledge of appropriate techniques for pain control and partly to misplaced fear of causing addiction, as well as also to the fear for litigation in providing a last, lethal dose.

Others have reported that physicians and nurses may also be influenced by relatives of patients who insist that life-support treatments must continue. Fisher (1992) reported the case of life prolongation of an 87-year-old cardiac arrest and severe anoxic encephalopathy woman to whose husband the court had given guardianship. He then refused to stop treatment at \$700,000 cost to the state. Fisher (1992) noted that the law has moved doctors from different attitudes toward terminally ill patients. He wrote that

Physicians were so reluctant to tell patients that they had cancer, that in the fifties and sixties, they frequently, if not usually, lied to them. By the late seventies, that attitude had reversed itself, and most physicians told patients the awful truth, either because they thought it was the ethical thing to do or to protect themselves from malpractice litigation for failure to inform. (p. 107)

If the main reason why physicians and nurses do not respect patients' wishes not to be submitted to heroic treatment measures is their fear of malpractice litigation,



amending legislation to protect those physicians should change their attitudes.

Legislation has been enacted to protect patient rights to self-determination such as the U.S. Patient Self-Determination Act of 1990, which requires hospitals and nursing homes to tell patients, on admission, of their right to file an advance directive, and to refuse treatment. However, extensive studies published by Teno et al. (1997a, 1997b, 1997c, 1997d) have shown that the legislative amendments have not changed physicians' attitudes and behaviors with respect to their terminally ill patients who refuse treatments. Canadian studies on similar situations have also showed that changes in the law or in administrative policies do not bring about significant changes in physicians' attitudes or behaviors toward their terminally ill patients who refuse treatments (Wilson, 1996, 1997).

The research literature on the subject can be summarized as follows. Most physicians acknowledge that competent patients have the right to refuse life support, even if that refusal may lead to death. However, almost half are reluctant to withhold treatment since they think that constitutes active euthanasia and is contrary to medical ethics. The reasons given are threefold. First, physicians fear lawsuits; second, they think that such behaviors go against their medical ethics; and third, they think that it goes against the professional ideology of their profession.

However, not enough research has explored the reasons why physicians refuse to respect their terminally ill patients' refusal to treatment. Except for the first reason mentioned (fear of lawsuits), the others can only be presumed from the data; they are not explicit. This study explored the more profound and complex reasons why physicians refuse to respect their terminally ill patients' wishes to refuse treatment. It systematically

analyzed the various norms (legal, professional, religious, and administrative) that affect the way physicians respond to their patients' wishes. In the process of analysis of those norms and how they interact to influence physicians' attitudes and behaviors, it attempted to discover the reasons why physicians behave the way they do with terminally ill patients.

### **Definition of Terms**

Throughout this study, these terms have the following meanings.

#### **Terminally Ill Patients**

Patients having a life ending illness, such as cancer, AIDS, et cetera, and are in the last phase of an irreversible degenerative disease.

#### **Wishes of Terminally Ill Patients**

Wishes of terminally ill are views expressed by the patient regarding his treatments (refusal of certain treatments, procedures, etc.). These views may be expressed verbally by the mentally capable patient, in writing in a living will or advance directive signed by the patient, or verbally by a parent of the terminally ill patient who has become mentally incapable to communicate his or her views.

#### **Administrative Norms**

Administrative norms are written documents or policies, adopted by the administrative bodies of the hospital or nursing homes, that describe the procedures to be followed by physicians and/or nurses in dealing with the treatment of terminally ill patients.

### Ethical Norms

Ethical or bioethical norms are directives that have received general consensus from ethicists and the community generally and deal more specifically with the principles applicable to the treatment of terminally ill patients.

### Legal Norms

Legal norms are written rules that can be found in three different sources: the laws of the land, the regulations adopted pursuant to laws, and the judicial decisions of the courts (judge-made laws).

### Medical Professional Norms

Medical professional norms are directives that have received general consensus among a specific profession, especially physicians and nurses, and part of which may be codified in a document called the professional code of ethics, the remainder being transmitted to the professionals through training and the process of professional socialization.

### **Significance of the Study**

The results of the research should be of interest to physicians, nurses, hospital administrators, researchers, and policy or lawmakers who are concerned about pain relief of terminally ill patients and respect for their wishes in refusing treatment.

First, the research has theoretical implications, in showing to what extent medical professional norms are important reasons why a large proportion of physicians are reluctant to respect their terminally ill patients' wishes not to be treated. It explores to what extent the medical professional norms prevail when they conflict with legal,

administrative, or other norms. Second, if the first assumption is correct, it could also mean that the adoption of legal norms as a means to force physicians to respect the wishes of their terminally ill patients may not be enough. Discussions between governments officials and medical associations may be necessary to motivate the associations to change their own medical professional norms in such a way as to incorporate into their norms the legal norms that have been either legislated or made by the courts. Third, the results of the research could lead to courses being offered to medical students and other health professionals in New Brunswick and elsewhere. Finally, the results of the research may lead to additional discussion about end-of-life policies. This is especially important in New Brunswick, since it is one of two provinces in Canada that has neither yet adopted advance-directives nor living will legislation.

#### **Perspective from Which the Research was Undertaken**

Papers published in professional journals usually utilize positivist, critical, or constructivist paradigms. Even a positivist perspective can use either qualitative or quantitative methods. The fact that qualitative methods are used does not necessarily entail that a specific model must automatically be used.

Consequently, the researcher has used theory in the next chapter as is generally done by researchers using the positivist paradigm. Specifically, emphasis has been put on a theory of normativity that takes into account the legal, religious, administrative, and medical professional norms that could explain why physicians do not respect their terminally ill patients' wishes not to be treated. This theory has influenced the choice of relevant methods to achieve the research objectives. These methods are generally

classified as qualitative, since they consist of in-depth interviews and case studies.

However the data collected with those methods were submitted to both quantitative and qualitative content analysis wherever possible. Furthermore, three separate sources of data (interviews, case studies, and policy analyses) were used as triangulation, that is, to try to compare and validate the results found with the first source. Whenever possible, quantitative data and methods were used.

Finally, the collected data were discussed taking into account the theory that is explored in the next chapter. In other words, the research used a positivist paradigm in which the methods used were mostly, but not exclusively, qualitative in nature.

#### Limitations

This research is limited in the following ways. First, the research was limited to New Brunswick, one of Canada's 10 provinces. Second, although some aspects of the study covered the whole province (analysis of hospital administrative policies and case studies), in-depth interviews with physicians, were limited to a group of 24 oncologists and emergency physicians who lived in the Greater Moncton area of the province of New Brunswick. Those physicians represent Canada's two official languages (French and English) and different religious affiliations.

Third, since the purpose of qualitative research such as this one was not to produce data that could be generalized, but rather to explore the reasons why certain phenomena occur, it was more important to insist on variation than on generalizability. The results are limited to the physicians from a small part of the province, and, therefore, generalization to the remaining physicians of Canada is not possible. The qualitative

nature of the research (using semistructured interviews) permitted a sample of 24 interviews, which alone have yielded 300 pages of transcript for content analysis.

Fourth, although the researcher used quantitative methods in the coding and processing of content analysis, the interpretation of content analysis is always dependent on one's own readings and on the theoretical framework employed. Others might have used other theoretical perspectives in interpreting the results and arrive at different concluding interpretations (Denzin & Lincoln, 1994, pp. 481-482; Manning & Cullum-Swan, 1994).

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## CHAPTER 2 LITERATURE REVIEW

Physicians' reluctance to respect their terminally ill patients' wishes not to be treated is a much more complex phenomenon than could be seen at a first glance. Many factors come into play when that situation occurs. The purpose of this chapter is to review those factors while at the same time placing them into a theoretical framework.

### Systems Theory and Normative Pluralism

Since this research dealt with the reasons why physicians refused to change their attitudes and behaviors in order to respect their terminally ill patients' wishes not to be treated, the relevant theory to explain such attitudes and behaviors had to address the problems of social change and resistance to change. Systems theories are seen by many as an adequate theory to that goal (Bailey, 1994; Lugan, 1993; Sztompka, 1993). In fact many contemporary social theorists have advanced different versions of systems theory applied to human societies. Parsons (1968) was probably the most influential of them. He had a tremendous influence on contemporary social theorists, among whom are Luhmann, the most prolific to date, he has written some 40 books and 300 articles. Burns and his colleagues have also been influenced by Parsons in developing their theory of normative rule systems. Finally, another of Parsons's students, Guy Rocher, has proposed a pluralistic normative subsystems approach to the study of the global social system.

### Parsons's Structural Functionalism

Parsons's (1968) structural functionalism postulated that the social system is not itself a reality; it is a social construction which attempts to describe the social reality. In accordance with general system theory principles, each subsystem of the social system

must keep its individual properties and its relative autonomy in relation to other subsystems. Since all natural systems maintain themselves in a changing environment, Parsons has introduced the concept of equilibrium and structural change. However, he did insist on the stability of the system more than on its changes (Lugan, 1993, pp. 41-43).

The concept of action is essential to any social analysis. Parsons (1968, p. 459) defined action as any behavior, be it human, collective, individual, conscious or unconscious. Subsystems are recognized whenever a set of elements or relations between these elements are interdependent and rather stable in time (Lugan, 1993, p. 45). According to Parsons (1968, pp. 470-471), the social system consisted of four types of subsets of elements: (a) values which are ideals guiding and orienting action, (b) norms that are models of behavior, (c) communities forming around certain values, and (d) roles that define modes of belonging to different communities in the social system. The institutionalization of culture is accomplished through concrete structural sets such as the judicial apparatus, the political apparatus, the economic institutions, and the institutions whose functions are to promote socialization.

Turning to the social subsystem in Parsons's theory, it must be noted that it is also subdivided into four subsystems corresponding to the functions of adaptation, definition and pursuit of objectives, integration, and socialization. Concepts of society being a whole and a social system an abstraction allows one to analyze the social system's parts. In cutting the social system into parts, one needs, however, to take care to preserve the system's autonomy also.



Parsons's work has been very influential especially in the United States. However in the 1970s his work was highly criticized for failing to take into account the fact that humans are purposeful beings who enjoy some degree of autonomy, as well as for its failure to adequately explain social change. Bailey (1994) has stressed that systems theory has progressed tremendously in the 1990s and that it has much to offer to the field of sociology.

### Burns's Theory of Normative Rule Systems

Some recent sociological theorists who have tried to take the fact into account that human beings are agents of change have come up with normative theories. One version of such a theory is offered by Burns and his colleagues (Burns, Baumgartner, & Deville, 1985; Burns & Flam, 1987; Woodward, Ellig, & Burns, 1994) and is called the theory of rule systems. Burns and Flam (1987) insisted that human activity is organized largely by socially determined rules and rule systems (p. viii). These rules and rule systems make up the deep structure of human history (p. ix). The authors' intention was to show how rules bridge the gap between actors and these structure levels. The concept follows. Rules systems consist of sets of context-dependent and time-specific rules organized for structuring and regulating social transactions, for carrying out related activities, for performing specific tasks, for interacting in socially defined forms with others (p. 13). Rule regimes are authoritative institutions, backed by social sanctions via networks of power and control that hence acquire an external objectivity for human perception. Individuals regard the rule systems as a generative grammar for social action, used by themselves and others to structure and regulate their transactions with one another in

defined situations or spheres of activity (p. 14).

### Normative Orders and Pluralism

More sophisticated analysis of the rule systems have been carried out by normative pluralists. Normative pluralism is a tradition that started with Weber (1954) in his book Economy and Society. Weber distinguished between legal order (legal system) in its strict legal sense, which refers to the coherent and logical set of rules and norms in effect in a specific society. He also distinguished that first meaning from its sociological meaning in which it does not refer to a set of rules but to the complex set of motives behind men's real activity. In Weber's second conception of legal order, the state positivist law is but one of the several systems of motives which is added to economic, political, moral, religious, and professional motives that guide the behavior of human beings (Rocher, 1996, pp. 127-128). Weber then redefined *legal* to incorporate both meanings. He thus defined as legal rules "those whose validity is guaranteed externally by physical or psychological constraint through the activity of some human organization specifically instituted to that effect and that forces respect of order and punishes its violation" (Weber, 1954, p. 33). According to Rocher (1996, p. 129), Weber did not see the necessity to go any further since he did not intend to put these distinctions into application.

According to Rocher (1996, pp. 129-132), a second influence comes from Santi Romano (as cited in Rocher, 1996, p.130), an Italian jurist who wrote a small book in 1918 that had been translated into French in 1975 but has yet to be translated into English. For Romano, norms are only one component of law, that is, law in its totality is

more than norms. What gives law its unity is the system of special agents who adopt, interpret, and administer the norms or rules.

Jacques Chevalier (as cited in Rocher, 1996, p. 133) is a contemporary French author who wrote that the state positivist legal order is structured and informed by the social order to which it belongs. It is thus a sub-system or a sub-set of the larger social system. He thus placed normative pluralism within a systems theory framework.

Weber, Romano, Chevalier, Burns, and Rocher all recognized that rules are important in the control of human behavior. They were, however, not satisfied with general rule systems as a controlling concept and wanted to explain how different rule systems, which they called *normative orders*, can sometimes contradict one another. These normative orders are found where there are rules that are created, interpreted, and applied by specialized agents. The ideal type for the analysis of those normative orders is found in the state positivist legal order, which has extended its hegemony in our modern societies. However, the hegemony of state positivist legal order has not invalidated the fact that individuals are influenced by normative orders besides that of the state.

Guy Rocher (1996) has applied the concept of normative pluralism to explain how various normative orders may be working simultaneously on an individual. Professionals who are subject to various sets of rules that may contradict one another are often placed in such situation that the theory of normative pluralism envisages. Physicians, nurses, and social workers all fall into that category.

According to normative pluralism perspectives, professionals generally and physicians specifically are first members of the society in the state where they live. They

are thus subject to the laws and rules adopted by the state legal order. However, they may also be members of religious organizations and therefore subject to the rules adopted by their religious order. They are certainly also members of their respective medical professional organization that allow them to practice medicine. The medical profession also has specific rules that apply to all its members. Furthermore, physicians usually enjoy hospital privileges that allows them to admit patients into specific hospitals. That hospital also has the authority to make rules regulating the hospital, its functioning, and its employees and those who hold hospital privileges, including physicians. These administrative rules constitute another rule system that affects the physicians.

#### Luhmann's Systems Theory and Self-Referential Concept

Normative pluralism has not, however, been able to adequately answer the question of how the different normative orders influence one another. In other words, though they have succeeded in describing what goes on, as Luhmann (1983) wrote:

The main problem is rather to understand how a system can manage its own reproduction within an environment which is not in itself attuned to the requirements of the system; or in other words, how a system can transform noise into information which keeps in motion the self-referential network of internal processes. (p. 994)

Niklas Luhmann has proposed the theory of *auto-poiesis* (self-reference) in answering that question.

Luhmann was strongly influenced by his teacher and mentor at Harvard University, Talcott Parsons. Yet, in order to construct a general theory of society, even

more so than Parsons, Luhmann borrowed many of his concepts from the systems theory, cybernetic models, biology, and communications theories (De Berg, 1995; Grawitz, 1996, p. 131; Luhmann, 1983; 1994; 1995, ch. 1).

The departures from Parsons are accomplished through the acceptance and inclusion of the concept of autopoietic processes (self-reference) into systems theory. Luhmann (1985) wrote that self-reference does not apply only to self-programming of computers. Rather he is speaking “of self-referential systems which *themselves produce every type of unity* that they require and employ: even the unity of the system itself as well as the unity of those elements (e.g. actions) of which the system consists” (p. 281). The characteristics of autopoietic systems are “that they themselves produce and delimit the operative unity of their elements ... through the operation of their elements and that it is precisely this autopoietic process that lends its own unity to the system” (pp. 281-282).

One of the consequences of autopoiesis is that society itself, and each system in society, including the legal system which is taken as an example of a self-reference system, is a normatively closed system that

produces its own elements as legally relevant units by the fact that it lends normative quality precisely with the aid of such elements (e.g. birth, death, accident, actions, decision). These are given a special status that is solely relevant for the legal system on the basis of the normative context in which they function as elements upon which others depend. (p. 283)

However, society and its legal system are, at the same time, “a *cognitively open system*. It remains oriented to its environment despite its closedness, indeed, because of its

closedness" (p. 283).

The introduction of self-reference into the social system theory has a series of consequences, the most important being that

there is no import of normative quality from the environment into the system, and that means (in the case of the legal system), neither from the environment in general (nature), nor from the internal societal environment (such as religion and morality). (p. 284)

In that sense, Luhmann has abandoned Parsons's insistence on norms and normativity. Luhmann rejected the idea that the problem of double contingency can be solved "with reference to a prior social consensus concerning cultural norms and rules of conduct" (Knodt, 1995, p. xxviii). Knodt (1995, p. xxix) wrote that the only norms that Luhmann considered to be such are those which are created by the self-reference processes within the relatively closed systems.

Instead of thinking that systems are living systems, Luhmann (1995) proposed to think of them as systems whose basic elements consist of communications. He defined communication as a synthesis of three selections: information (a selection from a repertoire of referential possibilities), utterance (a selection from a repertoire of intended acts), and understanding (the observation of the distinction between utterance and information (Gras, 1990, p. 393). However, systems operating on the basis of communication require meaning for their production. Meaning is defined by Luhmann "as the horizon of possibilities that is virtually present in every one of its actualization" (Knodt, 1995, p. xxiii). Furthermore, communication allowed the social system to

observe itself (Izuzquiza, 1990, pp. 284-285).

Among the most important subsystems of the social systems are the legal system, the economic system, the scientific system, and the religious system. As mentioned earlier, each subsystem is self-referent and closed on itself with the autopoiesis closure, which means that it is also impermeable to any of the others. Each subsystem is part of society and has the other subsystems as their own environment. They are able to observe themselves and observe the others at the same time. Each subsystem has its own media and codes of communications. For example, the legal subsystem has norms as its means of communications, its code is the duality of legal/illegal, and its program can be found in laws. The economic system has money as its means of communications; its code is the duality pay/do not pay, and its program may be represented by the costs. For science, the relevant means of communications, codes, and programs are respectively replicable truth, true-false duality, and theories. For religion, Luhmann does not provide a code; immanence and transcendence constitute both the means of communication and its programs (Gras, 1990, p. 395; Izuzquiza, 1990, p. 386-387).

The rest of this chapter will analyze the main characteristics of each of the normative orders with respect to the rules governing the attitudes of physicians and nurses against the refusal of treatment of terminally ill patients. It will start with the relevant rules of the state positivist legal normative order, then move to the religious normative order, the medical professional normative order, and the administrative order. Finally, those normative orders will be applied to the field of bioethics.

## **The Relevant Rules of State Legal Order**

According to theorists of normative pluralism (Côté & Rocher, 1994; Rocher 1996; Weber, 1954), the state legal normative order is the ideal type for the analysis of all normative orders. In the state legal order, the creation, the interpretation, and the application of the laws are done by agents authorized by the Constitution to do so. These are the agents that form the three branches of government: legislators, judges, and members of the executive branch. In the field concerning consent to or refusal of treatment, the relevant rules have generally been created by the judicial and legislative branches of government.

### **The Relevant Rules Created by the Judiciary**

Toffler (1990) insisted that the new technologies, and especially the availability of information to patients, are a powerful instrument of change. He stressed, maybe too optimistically, that "the knowledge monopoly of the medical profession has been thoroughly smashed. And the doctor is no longer a god" (p. 8). The availability of knowledge is but one factor that has driven patients to insist on their rights. As Konner (1994) has shown, the trust that once existed between physicians and patients has broken down. The large number of lawsuits is an indication of such a breakdown. Another author (Fisher, 1992) has claimed that the law has moved doctors to different attitudes toward terminally ill patients over the last 3 decades.

As it stands today, the rules regulating physicians' duty toward the treatment of their terminally ill patients are not uniform even in the common law countries. Until fairly recently, especially in Canada, the courts often incorporated the medical professional



rules of conduct into their decision-making process, thus insisting, just as physicians had, on the best interests of the patient more than on the patient's autonomy. There would have thus been no place for any theory of informed consent on which the system of medical and surgical treatment in the United States is based. That view was dominant in Canada until the 1980 landmark decision of Reibl v. Hughes (see Roy et al. 1995).

Now, however, judicial decisions have changed the position of physicians and nurses vis-à-vis their duty to the wishes of their terminally ill patients. Both in the United States (Bouvia, 1986 cited in Day et al. 1995, p. 296) and in Canada (Nancy B., 1992, cited in Rasooly et al., 1994), the law is clear that the competent patient may refuse treatment even if such refusal may lead to his or her death. These rulings clearly defined artificial nutrition, hydration, and respirator as life-sustaining medical interventions. They also made clear the competent patient's right to consent selectively to some medical interventions while refusing others. This legal approach is based on the principle that a human being is autonomous and free to make his or her own decisions.

The legal rights granted to terminally ill patients by the courts certainly go against the paternalistic attitudes advanced by physicians who once thought, and sometimes still think, that they are the ones who know better and so they should make the decisions whether to treat.

The legal theory about the autonomy and freedom of patients to refuse treatment has been pushed to its limits whenever the American courts have recognized the substituted judgment theory. This theory says that when an individual has previously expressed wishes concerning treatments, his or her next of kin may refuse treatment of

the patient when the individual is unable to make decisions because of altered consciousness or cognition. This theory was confirmed by United States Supreme Court in the 1990 Cruzan case (cited in Day et al., 1995, p. 296).

Canadian courts have not yet accepted the substituted judgment theory. In fact, the Supreme Court of Canada has explicitly rejected the theory especially in cases where the person never had the mental capacity to make informed decision. In the Eye case (1986), the mother of a mentally handicapped woman wanted her child to be sterilized in order to avoid an unhealthy pregnancy. The Supreme Court of Canada rejected the substituted judgment theory generally and more specifically in this case since Eve never had the capacity to express a voluntary judgement. The Court said that the only principle that must guide the treatment of an incompetent person is the best interests of that person, not the interests of others (Roy et al., 1995, pp. 234-238). Although most ethicists do not agree with the decision, it is still the law in Canada. This decision did have the effect of creating some roadblocks with respect to extending the autonomy and freedom of the person to her expression of substituted judgement (Rasooly et al., 1994).

The fear of lawsuits may have been an important factor in motivating physicians to better inform their patients; however, it has also had adverse effects as well. Buchan and Tolle (1995) acknowledged that physicians do not give enough pain control to terminally ill patients out of fear of hastening a patient's death and any resultant litigation or legal sanction. That fear has recently been reactivated in Canada when a Halifax respirologist was arrested and accused of first degree murder after one of her patients was found dead (R. v. Morrisson, 1998). That patient had cancer and had been operated on

some 16 times in the last years and six times in the last 2 months. He had been removed from a respirator and it had become impossible to alleviate his pain with morphine. Dr. Morrisson then gave him a dose of what the attending nurse described as K-C-L, a drug usually used to provoke cardiac arrest in cardiac surgery. The nurse revealed that to an older physician, who complained to the police. Dr. Morrisson was arrested 6 months later, in April 1997 (Queen Elizabeth II Health Sciences Centre, 1997). At her preliminary inquiry, the judge hearing the case dismissed the charges because he believed that no reasonable jury could find her guilty of any criminal charges due to lack of evidence. Although Dr. Morrisson was cleared of the criminal charges, this case has had a chilling effect on physicians who gave abundant analgesics to alleviate the pain of their patients (Dridger, 1998).

#### The Relevant Rules Adopted by the Legislative Bodies

Most social theorists recognize that changes in legislation may help change the behaviors of physicians. The social rule system theory advocated by Burns and Flam (1987) and Burns and Dietz (1992) insists very much on the importance of changes in legal rules as a change factor in society. If this is so, changes in legislation must work powerfully in changing the behavior of people, and especially of physicians, when the legislation concerns the physician-patient relationship. Different legislation has been adopted with this in mind.

Legislation has been enacted to protect patients' rights to self-determination, such as the U. S. Patient Self-Determination Act of 1990, which requires hospitals and nursing homes to tell patients, on admission, of their right to file advance-directives, and to refuse

treatment. Advance directives statutes have accordingly been adopted by the different states, the first one being Florida in 1983 (Kock, Rodeffer, & Wears, 1994). The goal of this legislation is to address the concerns of physicians and free them from having to worry about criminal charges whenever they provide appropriate terminal care, including pain relief for patients from whom life support has been withdrawn. Kock et al. (1994) have studied the changing patterns of terminal care management in an intensive care unit in Florida between 1984 and 1988. By 1988, DNR decisions occurred twice as often as in 1984, and 9.3% of the patients had a DNR order in their files.

Teno et al. (1997a) assessed whether advance directives were promoted by the Patient Self-determination Act of 1990. The medical files of a total of 9,105 patients with at least one of nine serious illnesses admitted in five United States teaching hospitals were analyzed. The patients were divided into two groups: one group of 4,301 patient in the 2 years (1989-91) before the enforcement of the Patient Self-Determination Act, and 4,804 in the 2 years (1992-94) after the Act. In the second cohort, a nurse tried to clarify the advance directives with about half of the patients while the other group served as a control. Interviews were conducted with patients, surrogates, and attending physicians about awareness of the completion and impact of advance directives. Medical records were also reviewed for discussion about preferences concerning resuscitation, living wills, and advance directives. Before the Act, 62% were familiar with a living will, and 21% had used advance directives. The percentages were similar for post Act and post Act plus intervention. However, just 6% of these directives were mentioned in the medical record before the Act in comparison with 35% after the Act and 78% after the Act plus

intervention.

Teno et al. (1997b) went farther in undertaking to assess what proportion of terminally ill patients had advance-directives in their medical files and what was the content of those advance directives. The medical files of a total of 4,804 patients with at least one of nine serious illnesses admitted in five United States teaching hospitals over a 2-year period were analyzed. A total of 688 directives were collected from 569 of the 4,804 patients (14%). The authors concluded that 2 years after implementation, the Patient Self-Determination Act had been relatively ineffective since only 14% of the patients had advance-directives in their files.

Finally, Teno et al. (1997d) assessed changes in advance care planning in nursing homes before and after the Patient Self-Determination Act in a 10-state survey. The research team communicated with a pool of 316 facilities in 10 states of which 270 facilities (85%) responded. Fifty-eight thousand patients lived in those facilities. In 1990, 2,175 residents were sampled, and in 1993, 2,088 residents were. The researchers were looking for advance directives documented in the medical records. They found that most patients still do not have living wills or proxies, that is, appointment of a substitute decision maker in case of mental incapacity. The rate of chart documentation of living wills increased from 4.2% in 1990 to 13.3% in 1993, and DNR orders increased from 31.1% to 51.5%. Orders to forgo artificial nutrition or hospitalization remained less than 8% in both years. The proportion of DNR varied greatly across the 10 states. The research team doubted that the Patient Self-Determination Act had an important effect on advance directives being written in nursing homes. The problem of futility of CPR is

especially severe in nursing homes where patients are very old.

Physicians attest that the law is the main instrument in changing physicians' attitudes toward terminally ill patients (Buchan & Tolle, 1995). However, Lewin (1996) noted that legislative changes may not be enough to make the desired policy changes operant. He wrote that advance directives have done little to better end-of-life medical care, according to a study financed by the Robert Wood Johnson Foundation and made public in late 1996. That study found that fewer than half the doctors knew when a patient wanted to avoid resuscitation, that half of the patients who died in the hospitals were in moderate to severe pain at least half the time, and that more than a third of those who died spent at least 10 days in intensive care, comatose, or under a respirator.

Research done by Teno et al. (1997a, 1997b) has shown that 2 years after implementation of the Patient Self-Determination Act, only 14% of the patients had advance-directives in their files which illustrated the relative ineffectiveness of that Act. Furthermore, the authors showed that most directives are not helpful in the care or treatment of terminally ill patients because such directives are too vague, and even when they are precise, the treatment course was consistent with the instruction in less than half of the cases. Furthermore, it has been shown that advance directives are usually suspended when a patient is sent to palliative surgery (Franklin & Rothenberg, 1992) or is transferred from ambulatory to acute care settings (Morrison, Olson, Mertz, & Meier, 1995).

This research shows that the law, even when it was unequivocal, did not always have its expected result because physicians did still refuse to respect their terminally ill

patients' wishes not to be treated. If as potent a tool as the law was not enough to budge physicians' attitudes toward their terminally ill patients who refuse treatment, one may well wonder, Why? A logical presumption could be that physicians responded to other normative orders that they feel were more relevant and more potent than the law. Religious beliefs have been known to exert stronger influence than the law on some people.

### **Relevant Rules of the Religious Normative Order**

Religions are normative orders distinct from the state positivist legal order: the agents for the creation, interpretation, and application of the religious rules are definitively different from the agents that create, interpret, and apply the state laws. It is also a fact that the rules in the legal and religious orders may contradict one another, especially in the area of life and death issues. This section will consider the empirical research relevant to the influence of religious beliefs on physicians' attitudes in respecting or not respecting the wishes of their terminally ill patients not to be treated.

A number of authors have shown that physicians and nurses are influenced by their religious values especially in making decisions about starting or withdrawing life-sustaining devices. Anderson and Caddell (1993) carried out a pilot project study on the attitudes of health care professionals toward euthanasia, and how those attitudes are affected by competing sources of normative control namely, professional norms, religious ethics, legal constraints, and public opinion, previous experience in withdrawing care, and years in the health care profession. Data from a sample of 63 health care professionals were collected in the context of a workshop for oncology professionals.

Forty (63.5%) were nurses, 13 (20%) pharmacists, 6 (9.%) were social workers and 4 (6.3%) were in related fields. Forty-one were Protestants, 14 Catholics, and 8 belonged to other denominations. Protestants (63%) tended to agree with the withholding/withdrawing treatment by the doctor in the vignette, while a majority of Catholics disagreed (57%).

In their research, the goal of which was to identify key factors that influence the attitudes and behavior of physicians and nurses concerning the control of patients over their own dying, Kelner and Bourgeault (1993) found that religion and religiosity were important factors and acknowledged physicians' moral scruples and uneasiness about cooperating with patients who want active treatment stopped. Physicians' unwillingness to accede to a patient's request if it violated their own personal moral or ethical code was an important factor in allowing patients the decision to treatment or not. Solomon et al. (1993) found similar results in a large survey of 687 physicians and 759 nurses in five New England hospitals. Similarly, Christakis and Asch (1995) surveyed 862 Pennsylvania internists with an instrument that had been previously validated. With other factors controlled, physicians were less willing to withdraw life support if they were Catholics or Jews. Finally, similar results were found by McInerney and Seibold (1995) with respect to registered nurses.

From this research, it can be seen that religious normative orders may influence the attitudes and behaviors of health professionals, including physicians, in their decision respecting the treatment of terminally ill patients, to the point where they may decide not to follow the law when it directly contradicts their religious beliefs.



These findings may well be explained by Luhmann's (1985) theory of self-reference. According to Luhmann (1985), the introduction of self-reference into the social system theory has a series of consequences, the most important being that "there is no import of normative quality from the environment into the system, and that means, neither from the environment in general (nature), nor from the internal societal environment" (p. 284). Knodt (1995, p. xxix) further noted that the only norms that Luhmann considered are those which are created by the self-reference processes within the relatively closed systems. Applying Luhmann's self-reference theory to the religious system, it means that some religions (especially Catholicism) may refuse to be influenced by the legal norms while other may accept such influence.

#### **Relevant Rules of the Medical**

#### **Professional Normative Order**

Professional organizations are also distinct normative orders, especially those like the nursing and medical professions, which are characterized by a professional culture, self-regulation, and a code of ethical conduct.

#### **The Professional Culture of Medical Professionals**

Du Toit (1995) has thoroughly explored the literature on the socialization of professionals and especially of nurses. She found three characteristics attributable to professional culture. First, professions apply certain procedures in order to merge novice practitioners into the profession so that they might become successful practicing professionals. The process is referred to as professional socialization and includes the recognition of an assumed identity by the outside world; it also involves the recognition

of that identity within the individuals themselves and the nondeliberate projection of themselves in its terms. Second, professions also develop their own unique subcultures, demanding specific normative standards from their members, that are further formalized by professional ethical codes. Third, the transformation process from a novice to a professional is essentially one of acculturation during which the values, norms, and symbols of the profession become internalized.

Scanlon and Glover (1995) and Frankel (1996) came to similar conclusions about the socialization of the medical professional, stating that cultural professional norms do exist long before a code of ethics is adopted. From his review of the literature, Frankel (1996) concluded that members of a discipline are bound together by common aspirations, values, and training. It is the discipline itself that transmits the values and the norms of the profession to the next generation. Hence, a discipline constitutes a major normative reference group that defines standards of conduct for its members. The professional society, as a stable and enduring entity that represents its members in their relationships with outsiders, is organized to discharge this normative function. It socializes new members of the discipline, transmitting the accumulated, collective wisdom of the group to individual practitioners. For members, the professional society is expected to be a strong voice in educating outsiders about the values and norms of the discipline and in securing public support for their work. Perhaps the most visible articulation of this normative role is a profession's ethical standards.

#### Paternalistic Perspective on Patients

A few researchers have explored the paternalistic characteristic of the medical

culture. Wulff's (1995) purpose was to discover to what extent it is possible for individual patients to influence and, possibly, to control the decision process when they seek the help of a physician. He first postulated that the advisor model is preferable in view of the autonomy principle. The advisor model is one of consultation where the physician gives all the facts and the patient decides. Wulff then applied this model to a clinical situation and analyzed it step by step before making his conclusion. His conclusion then was that the advisor model ought to be seen as the ideal from an ethical point of view. In accordance with the principle of autonomy, the patient ought to be the one to decide. However, Wulff concluded that in practice the advisor model is unrealistic. Patient information is important, but the complexity of clinical reasoning makes it impossible to separate facts from the physician's value judgments. The author claimed that there is an inherent element of paternalism in clinical decision-making and that clinical practice presupposes a mutual trust between physician and patient. That inherent element of paternalism stems from the clinical decision process having four components: (a) the biological component, wherein the physician possesses considerable biological knowledge; (b) the physician's empirical knowledge based on scientific controlled experiments done on other subjects on the effect of drugs and therapies; (c) an empathic hermeneutic component, which means that the physician is able to put himself or herself in the place of the patient and try to understand how that patient is influenced by his culture; (d) finally, the ethical component, by which the physician must ask what is best for the patient.

Emanuel (1995) came to a similar conclusion in describing the process of writing

advance directives. According to her, advance directives are a complex process with five phases: identifying the issue, structuring of information transmittal, identifying the content of the deliberation, reflecting on the process, and committing the decision to action. This process is long and physicians should be involved. However, in order to ensure this, the author proposed to pay them for the time they spent going through all five phases with the patient.

Kelner and Bourgeault (1993) and Kelner, Bourgeault, Hebert, and Dunn (1993) set out to verify the paternalism of the medical profession's culture. One of the objectives of the study was to identify who physicians and nurses believe should have the final authority for deciding whether to prolong the lives of terminally ill patients. They concluded that patient control represents a challenge to the clinical judgment of professionals who are reluctant to give up the right to use their clinical discretion in the face of a patient's wishes to make the final decision about his own fate. Their professional training had emphasized the obligation to use their skills in the best interests of the patient. Health care professionals perceived their role as that of healer-supporter, the whole thrust of their socialization as care-givers emphasizing the obligation to use whatever technology is available to try to cure the sick. When patients requested their lives not be unnecessarily prolonged, physicians often saw these requests as an insult to their core task of healing and thus promoting failure. The authors also concluded that physicians have enjoyed a position of respect and dominance in their relationships with patients in the past. Now, to share this power with patients requires a major shift in attitudes and behavior, one which physicians may have difficulty making. Finally, a

degree of tension between the interests of health care professionals who want to practice medicine as they think best, and the emergent consumer movement in health care, seems inevitable.

When confronted with the question of withholding or withdrawal of treatments to terminally ill patients, physicians have developed the concept of the futility of treatment. In order to compare the use of the medical futility rationale with other rationales (such as patient's wishes) in do-not-attempt-resuscitation (DNAR) orders, Curtis, Park, Krone, and Pearlman (1995) undertook a study with 44 second and third-year internal medicine residents. They were contacted weekly and were asked if a DNAR order had been written for any of their patients in the preceding week. In one third of the cases where qualitative futility applied, residents made the judgment of qualitative futility without discussing quality of life with communicative patients.

In other research, Miller, Gorbelen, Simbartl, and Jahnigen (1993) investigated what clinical variables and personal beliefs might influence physician's recommendations about cardio-pulmonary resuscitation (CPR). One thousand seventy-five physicians from the Cleveland Clinical Foundation were asked to answer a 21-item questionnaire. Four hundred eighty-two responded (44.8%), and responses from 451 physicians were processed for analysis. The physicians reported that the patient's self-reported wishes about resuscitation (98%) and physicians' judgment of medical utility (91%) were the most important influences on physician recommendations. However, with respect to medical utility (futility), physicians overestimated the likelihood of survival to hospital discharge after in-hospital CPR by as much as 300% for some clinical situations and

predicted an overall success rate of 30%. Even with patients 100 years old or more, 53% of the physicians said they would perform CPR. Finally, although they said that patient's wishes was the most important factor, only one third of the physicians reported initiating discussion with their patients about CPR and DNR orders.

As can be seen from the last three studies, physicians tend to insist on two aspects in deciding whether to prolong or forego treatment: patient's wishes and their own medical professional judgment. Even when advance directives are written in the file, physicians do not necessarily stop there. Their professional medical judgment is also an important, if not the most important, factor in the decision. However, they tend to grossly overevaluate the usefulness of CPR.

In earlier studies, Malasanos (1986) and Wear and Brahams (1991) also came to similar conclusions that physicians' clinical judgments are uncertain due to incomplete or imperfect mastery of available knowledge, the limitations of current knowledge, and an inability to distinguish between personal ignorance or ineptitude and actual limitations of present knowledge. Physicians' training and ideology causes them to think that patients do not have the capacity to understand complex matters and that discussing them would create anxiety and intolerable anguish for the patients. Furthermore, specialization tends to foster dogmatism and encourage beliefs in the superior effectiveness of treatments prescribed by that specialty.

### Self-Regulation and Professional Codes of Ethics

Self-regulation implies that the professional organizations that possess it have the power to make rules to govern themselves. Thus professional rules are created,

interpreted, and applied by agents that are different and distinct from the religious order and different from the state legal order.

Côté and Rocher (1994, pp. 25-27) have shown that self-regulation is an important aspect of the normative phenomena observed in the rise of new technologies. Self-regulation can develop either more or less spontaneously or else as a response to threats that government will regulate the relevant activities. It is voluntary by nature, and it happens under the form of normalization, a process of establishing rules in the interest of concerned parties and with their collaboration. When they must rule on cases dealing with life, health, and information technologies, even judges take into consideration the self-regulation norms of the relevant profession. Furthermore, these authors have shown that the ethical codes of conduct developed by professionals are self-regulatory in practice.

Most authors (Du Toit, 1995; Esterhuizen, 1996; Frankel, 1996; Hill 1994; Scanlon, 1996; Scanlon & Glover, 1995; Wulff 1995) agree that professional self-regulation very often takes the form of ethical codes of conduct. A code of ethics represents a mixture of creeds and commandments that delineates the highly regarded standards and ideals of the profession and the prescriptions one uses to guide professional responsibilities. These authors have pointed out the importance of codes of conduct in the respective medical professions. Scanlon and Glover (1995) and Scanlon (1996) both note that the formulation of a code of ethics is a defining feature of a profession and a means of articulating shared values and goals.

Anderson and Caddell (1993) concluded their research on a group of 63 health care professionals by saying that besides religious disagreement, a second area of

disagreement was based on professional norms concerning the role of the physician in a terminal case. These items discussed the assertion that the physician should not violate the convictions of his colleagues and that the patient should have complete faith in the physician's devotion to preserving life. Furthermore, professional norms against euthanasia and avoiding fear of legal reprisals emerged as strong bases for disagreement.

The aforementioned research tends to suggest that the single most important consideration of physicians when treating terminally ill patients is medical professional norms. These norms insist on three things. First, physicians are scientists and therefore have special knowledge that allows them to know what is in the best interest of the patients. Although patients' wishes should always be taken into consideration, many factors, such as illness, depression, and confusion, may affect their appreciation of their situation. Physicians are not so affected and have a more enlightened and objective perspective of the patient's real situation; therefore, physicians know better what is best for the patient. Secondly, it is very difficult to change physicians' attitudes and behaviors by changing the law. Thirdly, Luhmann's (1985, p. 284) self-reference theory could explain why it is so difficult for physicians to change their attitudes. In Luhmann's perspective, the medical professional subsystem is one in which there is no import of normative quality from the environment into the system. That means, in the case of the medical professional subsystem, there is no import neither from the environment in general (nature), nor from the internal societal environment (such as religion, morality, and the law).

The conflicts between medical and legal normative orders tend to have a



somewhat demoralizing effect on professionals working in the field. To avoid conflicts and give directives, hospitals have adopted administrative norms in the form of administrative policies concerning the proper conduct in difficult cases, especially cases involving the treatment of terminally ill patients.

### **The Relevant Rules of the Hospital**

#### **Administrative Normative Order**

The right of terminally ill patients to participate in decisions concerning their refusal of treatment and the discontinuation of their life sustaining devices have been generally accepted in the United States for at least a decade. However, in Canada, that right was not ascertained until 1992, when the Quebec Superior Court decided that a competent patient has the legal right to refuse treatment and to have the device sustaining her life disconnected, even if that decision means that she would die shortly thereafter (Nancy B., 1992).

Similarly, since the Cruzan (1990) case, decided by the United States' Supreme Court, terminally ill patients who are unconscious have the right to have life-sustaining devices withdrawn if it can be shown that they have given written or oral directives in that respect. That attitude was approved by the United States Congress when it passed the Patient Self-Determination Act in 1990. This act encouraged hospitals to instill regulations regarding do-not-resuscitate (DNR) orders and encouraged hospitals and physicians to discuss end of life treatments with their patients, especially with those who are terminally ill. In Canada, however, although similar legislation was initiated in Nova Scotia in 1988 and in Quebec and Ontario in 1992, and other provinces adopted advance

directive legislation in the mid 1990s, New Brunswick and Prince Edward Island have not yet changed the common law relevant to such thorny issues (Poirier, 1997).

Common law, which has not yet been altered in New Brunswick, considers that the power of attorney becomes invalid once the person becomes mentally incompetent (Poirier, 1997, pp. 197-199). The law, however may have been modified by Malette v. Shulman (1990). In that case a Jehovah's Witness had written a note refusing all blood transfusions. She arrived at the hospital unconscious as a result of a car accident. The nurses found the note and notified the surgeons, who nevertheless gave the patient blood transfusions. The Ontario Court of Appeal acknowledged the validity of the note written by Ms. Malette and awarded damages in the amount of \$20,000. It could be inferred from the Malette case that living wills duly signed by the patient while he or she was still competent could be legally binding on the medical personnel (Hébert, 1996, pp. 28-30; Poirier, 1997, p. 190).

#### Hospital Norms and Policies Respecting Advance Directives

The uncertainty regarding the state of the law in those provinces that have not yet adopted "Advance directive legislation" has left physicians to wrestle with their own professional medical judgment. To help physicians with their decisions, the Canadian Medical Association (1982, 1994) together with Canadian Hospital Association, the Catholic Health Association of Canada, and the Canadian Nurses Association have adopted a joint statement on resuscitative interventions. This joint statement encouraged hospitals to adopt administrative policies to fill the void and direct the physicians in how they should behave with respect to the treatment of terminally ill patients.

Before most provinces (except New Brunswick and Prince Edward Island) amended their legislation to allow for advance directives, Rasooly et al. (1994) conducted a survey of hospital policies on life-sustaining treatments and advance directives in all Canadian hospitals. This study is the only one in Canada that has systematically explored the DNR policies in all provinces. The number of respondents was high, a rate of almost 80%. The results were not as might be expected because the policies dealt mostly with incompetent patients and not with capable patients who normally would have the right to refuse treatment, especially since the Nancy B. case in 1992. Most Canadian provinces at the time of the survey did not provide for proxy or enduring advance directives in providing for cases of incompetence. However, in almost two thirds of the hospital policies, physicians, and nurses were authorized not only to by-pass the DNR order, but also to rescind it.

Wilson (1996, 1997) collected DNR policies in all Alberta hospitals and accredited acute care and long-term care facilities (N=175) and obtained 135 usable questionnaires (77.1% return). She found that most large health care facilities had a DNR policy (92.0%) in comparison to small (68.6%) or medium-sized (68 %) facilities. The most frequent influence for policy development reported by respondents was to improve the decision making process in regards to such cases.

However, the chart audits done by Wilson (1996, 1997) revealed that almost all patients (92 %) died with no CPR order in their chart and 94.2 % of patients still had at least one potentially life-sustaining technology in continuous operation. These results are consistent with research done by Teno et al. (1997a, 1997b, 1997c) indicating that DNR

policies are not accomplishing their intended purposes. Furthermore, Wilson (1996, 1997) showed that contrary to the intention of the policies, in the majority of reviewed cases, patients were not actually involved in the decision-making process for end-of-life treatments. This finding is consistent with other research showing that physicians tended to insist on two aspects in deciding whether to prolong or forego treatment: the patient's wishes and their medical professional judgment (Curtis et al., 1995; Miller et al., 1993). Even when advance directives were written in the file, physicians did not necessarily adhere to such policies. Their professional medical judgment is also very important if not the primary factor that affects the decision. However, they grossly overevaluated the usefulness of CPR (Ghusn, Teasdale, & Boyer, 1997).

#### Hospital Norms and Policies Respecting Ethics Committees

In its broadest sense, the words ethics committees applies to any group of persons whose primary task is to pass ethical judgement on, or undertake collective ethical consideration of, biomedical problems. The first clinical ethics committees emerged in the late 1960s and early 1970s. In 1970, the Catholic Health Association of Canada recommended the formation of medical morals committees in Catholic hospitals. However, the establishment of clinical ethics committees was boosted by In Re Quinlan (1976) in which the Supreme Court of New Jersey was of the opinion that a hospital ethics committee should assist in deciding whether to disconnect life-sustaining devices. This decision was interpreted as an admission by judicial authorities that the kind of decision that had to be made in such a case was not a legal one. Instead, it is a decision in which all interested parties had to be involved (Ambroselli, 1990, pp. 100-104; Law

Reform Commission of Canada, 1990, p. 7; NHLA, 1996, par. 8.30).

Three Canadian surveys have reported on the prevalence of clinical ethics committees. A survey published in 1985 suggested that only 18% of Canadian hospitals with 300 or more beds had set up such committees, compared with 47.6% of hospitals with more than 700 beds or a recognized religious affiliation (Avard, Griener, & Langstaff, 1985). In 1989, the prevalence of ethics committees was 58.3% in Canadian hospitals with 300 beds (Storch, Griener, Marshall, & Olineck, 1990). A survey conducted in the hospitals of the province of Quebec in 1989 showed that in 220 hospitals (small and big indiscriminately), only 53 (24.1%) had a clinical ethics committee (Parizeau, 1995, pp. 58-88).

Three main functions are generally attributed to clinical ethics committees. Their first function is to inform physicians and hospital staff and help them understand the issues, think them through, compare the views of others with their own, and make decisions. Their second function is to adopt general policies with respect to recurring issues, such as policies respecting do-not-resuscitate (DNR) orders. Their third function is to play a broad educational role in the hospital community. The most common issues addressed by these clinical ethics committees concern end of life issues such as requests by patients to withhold or withdraw treatments, refusal of and consent to treatments, cardio-pulmonary resuscitation, patients in coma, and patients with diminished mental capacities (Parizeau, 1995, pp. 58-88).

Why were clinical ethics committees developed? The Law Reform Commission of Canada (1990, p. 11) wrote that “ethics committees developed out of an authentic and

acute demand within the hospital community [and they] grew spontaneously out of the medical community itself.” After studying the conditions under which these committees were created, Parizeau (1995) contested the aforementioned statement and found that clinical ethics committees were not promoted by physicians who, in fact, did not agree with them in the first place. Such committees were pushed by groups outside the hospital, namely defenders of patients’ rights and professionals who wanted to profit from the legitimacy crisis affecting physicians. Storch and Griener (1992, p. 22) reported that physicians expressed the view that ethics committees had little relevance to their practice. However, they generally supported the idea of the ethics consultation committees even though some doubted that most physicians would ever consult such a committee. Storch and Griener (1992, p. 25) concluded their study of clinical ethics committees by saying that they are merely support for the existing power structures, and the trend toward small consulting teams, composed mainly of physicians, support this view further.

These concluding remarks by Storch and Griener (1992) are consistent with the trend of the 1990s in which physicians, reacting against the law empowering patients to make their own decisions, tried to regain control over the decision-making process especially in difficult end-of-life issues (King, 1996, pp. 227-229). The futility concept is the means by which physicians counterattacked. This concept is based on the medical evaluation that shows that the patient’s life is profoundly diminished; that prolongation of treatment may be cruel and even harmful; and finally, that prolongation of treatment is a waste of scarce resources.

Kuczewski (1996) has suggested that since families have been forgotten by the

focus on the legal aspects of informed consent and physicians and nurses have conflicting interests when advocating for the patient, a third party (an ethics committee or an ethicist) must help them clarify their values.

### Extension of Hospital Administrative Norms

Rocher (1996, pp. 261-285) has studied the relationship between the medical professional normative order, the bioethical normative order, and the administrative normative order. Besides showing the difficulties of bioethics in establishing itself as a new profession, he has examined the various competitors of bioethics. Economic rationality (i.e., the administrative normative order) has shown itself to be efficient in two aspects: planning and administration. In the planning stage, economic rationality becomes an important factor in the acquisition of new technologies. New norms have been developed with respect to that. In the second meaning under the heading of economic rationality, administrative norms have also been taking more and more space. Medical administrators are not doctors anymore. They are professionals who, having been shaped by the universities, are now in the process of forming a new profession.

In the groups formed by people working in hospital settings, as in all groups, there are those who make the rules, interpret, and apply them. Physicians are seen as just one group among others: other medical and social professionals, priest and ministers, patients, lawyers, and so forth. Those who administer must take into account all those interests. This new form of consensus building is being done without necessarily resorting to bioethics. As advocated by Grant (1993) who has analyzed situations where law and ethics differ, the solutions in those conflicting areas could take the form of administrative

directives proposed to the hospital administrations by ethics committees.

Rocher (1996, pp. 295-303) has studied the creation of norms (rules) for allowing the purchase of costly equipments in hospitals. He has shown that rules and norms are created in order to make decisions about the purchase of costly equipment. These rules are not state legal rules, but are normative rules within the hospital administrative normative order. The main function of that administrative normative order is to insist on economy and to administer the scarcity of resources and money. This is done by administrators who use economic language and rationality. Trustee boards also have an acculturation function. Most physicians are somewhat expelled from the decision process; they feel they are being colonized by the administrators and the experts. With respect to group processes of decision-making for hospital-based technology assessment committees, Goodman (1995) reached results similar to Rocher's research.

The fact that physicians felt more and more expropriated from their own practice of medicine, mentioned by Rocher (1996, pp. 299-302), is even more dramatically demonstrated by Mechanic and Schlesinger (1996). These authors examined the impact of managed care (HMOs) on patients' trust in medical care and in their physicians. They concluded that utilization review and structural arrangements in managed care potentially challenge trust in physicians as they restrict choice, contradict medical decisions and control, and restrict open communication with patients. Gatekeeping and incentives to limit care also raise serious trust issues. Put in the wording of normative pluralism, Mechanic and Schlesinger's research means that the administrative normative order (made by hospitals or insurance administrators) makes rules that may conflict with the



medical professional normative order.

Another example of the importance gained by the administrative normative order is taken from Clements's (1995) paper on multiple perceptions of discharge planning in one urban hospital. In his paper, the author examined the validity of advocacy groups who stated that although hospital discharge planners perceived the discharge planning schedule as helpful, elderly patients and their families did not. Data were collected from 40 hospital discharge planners and 40 family care-givers. The planners and care-givers were interviewed and asked open-ended and closed-ended questions about the choices given to the patient. There was a great discrepancy between what the social workers and planners thought they had given as adequate information and choices, and the fact that care-givers and patients thought they had little or no choice. Most comments about coercion came from family care-givers who felt that nursing home placement was forced on patients and that inadequate information about alternatives was given to them, even though, from a legal and ethical standpoint, competent patients may not be forced into nursing homes once the risk and benefits of refusing placement are understood by them. The National Association of Social Workers' Code of Ethics does not allow such behavior either. Furthermore, incentives in Medicare, Medicaid, and private insurance have favored care offered in institutions over care offered in the community. Here again, as in Mechanic and Schlinger's (1996) research, it seemed clear that the administrative normative order was taking over the professional normative order in the decision-making process. It is but a matter of time before conflicts become evident in that area.

Teno's et al. (1997a) study has cast doubts that merely increasing the rate of

advance directives or their documentation leads to better physician-patient communication or decision-making about resuscitation. It can be inferred from their study that laws, regulations, and directives do not automatically have the desired effects on physicians. Furthermore, Miller et al. (1993) investigated which clinical variables and personal beliefs may influence physician recommendations about CPR. This study showed that guidance from hospital policies and ethics committees had the least influence on physicians who are relying mostly on their professional judgment and on patient's wishes.

Most of the studies alluded to in this review of the literature lead to the conclusion that Luhmann's (1985) self-reference theory may explain why physicians are so little affected by laws and hospital policies, while responding mainly to their own professional norms. Each of those three orders of norms represent in fact a self-reference subsystem of norms. These three subsystems are somewhat independent although they constitute each other's outside environment. The norms of a system can only be affected by those of other systems if they are appropriated by the receiving system that incorporates them into its own system.

#### **An Example of Conflicting Values between Different Normative Orders:**

##### **The Bioethical Normative Order**

Rocher (1996, pp. 261-285) stated that bioethics is part of the larger general body of sociological norms, rules, values, and ideals which people obey or disobey and to which they refer, since bioethics does not yet have its own place in the social normative system. According to Rocher, the promoters of bioethics are looking to build a

normativity based on values, ideals, and a conception of virtue as a form of conduct everyone would adopt if they were informed. Bioethics is the product of techno-science whose innovations have brought the moral conscience to ask fundamental questions about the meaning of life, the right to life, freedom to accept or refuse treatment, and the future of human life generally.

The three main sources of inspiration for bioethics are professional medical ethics, religious normativity, and state legal normativity. Most, if not all, bioethical committees are composed of physicians, priests or ministers, and lawyers.

#### Principles of Bioethics Derived from Medical Ethics

According to Roy et al. (1995, p. 4) the word bioethics was first coined by Potter in 1971 in a book entitled Bioethics: Bridges to the Future. However, the principles that are found in bioethics come mostly from the medical ethics as developed first by Hippocrates, whose oath is generally considered as the basis of western medical ethics (Roy et al., 1995, p. 5). According to Roy et al. (1995, p. 6), the Hippocratic oath was not very much affected by Christian values.

However, it was John Gregory (1724-1773) and especially Thomas Percival, who published Medical Ethics in 1803 who systematically exposed the ethical views of physicians on the morality of the medical practice. From that seminal book, medical codes of ethics were adopted by the American Medical Association in 1847 and in 1868 by the Canadian Medical Association. For more than one century, professional medical ethics enjoyed an almost complete monopoly in the field of the morality of medicine. Although the autonomy of medical ethics has been severely challenged by the law in the

last 30 years, most basic contemporary bioethical principles are directly attributable to medical ethics. It is especially so with the principles of nonmaleficence, beneficence, and the double-bind situations.

**Nonmaleficence.** Beauchamp and Childress (1994) wrote that “the principle of nonmaleficence asserts an obligation not to inflict harm intentionally. It has been closely associated in medical ethics with the maxim, above all do no harm” (p. 189). These authors also stated that the nonmaleficence principle is especially used with the terminally ill patients in deciding to withhold or withdraw life-sustaining treatments and in making decisions about assisted suicide or letting a patient die. Beauchamp and Veatch (1996) wrote that “codes of health care ethics from the time of the Hippocratic oath to the present strictly prohibit direct assistance in causing death, even if a patient has good reasons for wanting to die” (p. 151). Both the Supreme Court of Canada (Rodriguez v. B.C., 1993) and the Supreme Court of the United States (Washington et al. v. Glucksbert et al. 1997; Vacco et al. v. Quill et al., 1997; Price & Mauro, 1997) have recognized the importance of the nonmaleficence principle in refusing to declare unconstitutional the provisions of the criminal codes prohibiting assisted suicide.

The Catholic teachings on the subject have been and are still very influential. According to O’Rourke (1992), the President’s Commission on Ethics in Medicine and Human Research has utilized many of the principles developed by Catholic theologians when considering the matter of pain relief for dying persons. The Catholic tradition with respect to hastening death is as follows: (a) No one shall intend to cause death either through active or passive euthanasia (when the cause of death is present but is not resisted

when there is a moral obligation to do so); (b) when there is a possibility of cure (with simple surgery, for example), there is a moral obligation to treat and not doing so is passive euthanasia and therefore morally wrong, and (c) pain medication cannot be used to put a person to sleep so he or she cannot feel death approaching, thus preventing the patient from carrying out of religious and moral duties.

Physicians, ethicists, and the courts have confronted those different types of euthanasia. Latimer (1991) analyzed three different cases involving cessation of treatment, use of morphine to alleviate pain that shortens life, and patients asking the physician to shorten life. These three cases are analyzed from five ethical principles: autonomy, nonmaleficence, beneficence, justice and the principle of double effect. Applying those principles to end-of-life issues, the author stated that (a) certain treatments or therapies should not be undertaken if they are unwanted or unwarranted. Furthermore, cessation of treatment is no different, ethically, than never having started it in the first place; (b) decisions about continued treatment cannot be made categorically, on the basis of policies, protocols, or impersonal generalization about age or diagnosis. Rather, they must be based on thoughtful analysis of the issues in a particular patient's situation and a clear exchange of information among patient, family, and health professional team; and (c) the physicians acts with the knowledge of the potential risk for shortening life, but does not primarily act to bring about death. However, the physician does not fail to act when the need exists, because the moral need to relieve suffering is recognized as being paramount.

**Beneficence.** The medical profession is deeply rooted into the principle of

beneficence. As mentioned earlier, Hippocrates's oath provides that "as to disease, make a habit of two things: to help, or at least to do no harm" (Beauchamp & Childress, 1994, p. 272). Most authors agree that the physician's primary obligation is to act for the patient's medical benefit. This means that physicians must act in the best interest of their patients, taking into consideration all relevant factors, including the patient's physical and mental pain and suffering, his or her mental capacity, the possibility of death, the usefulness of the proposed treatment, the patient's wishes and beliefs, and his or her quality of life (Beauchamp & Childress, 1994, p. 272; Beauchamp & Veatch, 1996, pp. 64-68; Hébert, 1996, p.109; Wicclair, 1993, p. 121).

The beneficence principle as applied by medical professionals as well as by other professionals who purport to act for the benefits of others (social workers, psychologists, etc.) is generally known as *paternalism*. Beauchamp and Childress (1994) defined paternalism as "the intentional overriding of one person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden" (p. 274).

Daly et al. (1993) did an analysis of ethical principles for and against withdrawal of mechanical ventilation in non-terminally ill cases. They came to the conclusion that physicians are concerned by the beneficence principle, that is, to work for the good of the patient and the public good. In that respect, physicians may not have to follow patients' wishes in cases where death may occur based on two potential prohibitions: the principle that killing is always wrong, and concerns about opening the door to helping patients end their lives. Even to this day, most physicians still consider the use of life support

measures as important. They tend to overevaluate the efficacy of CPR by as much as 300% (Miller et al., 1993).

Gert et al. (1994) took the view that patients can only make choices about different options given to them by physicians. According to the authors, it is the physician who makes the decisions about treatments. Consequently, with respect to refusal to treatment, the authors agreed that patients have a right to refuse treatments, but they do not have the right to request treatments that could end their lives. The authors' analysis was patently paternalistic in the sense that patients are deemed not able to make decisions about treatments because they are deemed not to have the necessary scientific knowledge to do so.

Researchers who have studied ethical reasoning in nurses and physicians come to the conclusion that while nurses insisted on patient autonomy, quality of life, and death with dignity, physicians insisted on patients' survival and preserving life, thus demonstrating a more paternalistic pattern based on the beneficence ethical principle (Davidson et al., 1990; Uden, Norberg, Lindseth, & Marhaug, 1992). Most authors acknowledged that beneficence and medical paternalism that stemmed from it are still alive and well in the medical profession. It has, however, taken new forms, the most recent one being the futility debate, which will be analyzed further in another sub-section.

**Rule of Double Effect.** Medical procedures are not always easy to fit within either the principles of beneficence or non-maleficence. Each medical procedure, as well as many human activities, may be intended as beneficent but may have secondary effects. It is often the case with medications and with surgical procedures. To take into account the

adverse effects of medical procedures, the ethical rule of double effects has been formulated. It states that “a single act having two foreseen effects, one good and one harmful (such as death), is not always morally prohibited if the harmful effect is not intended” (Beauchamp & Childress, 1994, p. 206). The classical formulations of the rule of double effect state that four conditions must be satisfied for an act with a double effect to be justified: (a) the nature of the act must be good or morally neutral, (b) the agent’s intention must be good, (c) the bad effect must not be a means to the good effect, and (d) the good effect must outweigh the bad effect (Beauchamp & Childress, 1994, p. 207). The rule of double effects was however criticized for its difficulty to distinguish intention to kill from causing unintended death.

One ethical problem physicians are confronted with is managing terminal dyspnea when caring for the patient who refuses intubation or ventilation or who asks that intubation or ventilation be withdrawn. Campbell (1996) acknowledged that reducing the patient’s terminal dyspnea can be done through non pharmacologic strategies: optimal positioning, oxygen, and balancing rest with activity, but that more effective are pharmacologic strategies such as opiates, bronchodilators, diuretics, and anxiolytics. Campbell stated that some professionals fear that morphine will cause a patient’s death. This can be ethically resolved by the rule of double effect: administration of morphine to a dying patient with dyspnea achieves the good effect of reducing the patient’s distress; the foreseen, but unintended effect of respiratory depression is overridden by the good effect. Therefore, administering the morphine is a morally sound action. Furthermore, as Latimer (1991) wrote with respect to the use of morphine to alleviate pain that shortens



life, the physician acts with the knowledge of the potential risk for shortening life, but does not primarily act to bring about death. The author further stated that the physicians cannot fail to act when the need exists, because the moral need to relieve suffering is recognized as being paramount and because it is ethically incorrect not to adequately relieve pain.

Wilson, Smedira, Fink, McDowell, and Luce (1992) did a retrospective case study in which the research team collected information about all critically ill patients who died during the withholding and withdrawal of life support in the intensive medical-surgical intensive care unit of a county hospital for one full year ( $n = 22$ ) and compared those patients with a random sample of 22 similar patients in the intensive care unit in the university hospital over the same period. Physicians and nurses were interviewed to determine their reasons for ordering and administering drugs, and medical records were reviewed to document amounts of drugs ordered and administered. Drugs were administered to 75% of patients during withholding and withdrawal of life support. The others were comatose and considered incapable of benefiting from sedation and analgesia. The median time of death was 3.5 hours in the patients who received drugs and 1.3 hours in those patients who did not. Physicians ordered drugs to decrease pain in 88% of patients, to decrease anxiety in 85%, to decrease air hunger in 76%, to comfort families in 82%, and to hasten death in 39%. In no instance was hastening death the only reason cited. Large doses of sedatives and analgesics were ordered primarily to relieve pain and suffering during the withholding and withdrawal of life support, and death was not hastened by drug administration.

The difficulties of interpreting correctly the rule of double effects brought Gert et al. (1994) to reflect on the need to address the confusion created in a 1992 report by the American Medical Association Council on Ethical and Judicial Affairs about the words choices, decisions, requests and refusal of treatment. The authors suggested that states should consider passing legislation that would say that 1. all physicians shall be informed that they are legally prohibited from overruling any rational refusal of a competent patient, including refusal of food and fluids, even though it is known that death will result; 2. there shall be no prohibition whatsoever placed upon any physician who provides pain relief in any form, in order to relieve the pain and suffering of the patient who has refused treatment, including food and fluids. In particular, providing pain medication shall not be considered as assisting suicide, and there shall be no liability for the physician who provides such pain medication for the purpose of relieving pain and suffering; and 3. finally, the physician shall not provide such medication for the purpose of hastening the time of death, but is not prohibited from providing medication which is consistent with adequate pain relief even if he knows that such medication will hasten the time of death.

#### **Principle of Bioethics Derived from the Law: The Autonomy Principle**

Authors of medical ethics acknowledge that the autonomy principle is now the most important principle applicable to physician-patient relationships (Beauchamp & Childress, 1994, p. 120; Hébert, 1996, p. 25; Wicclair, 1993, p. 4).

**Autonomy of mentally competent adults.** The concept of the autonomy of capable persons has always been considered important in law. In fact, the law considers that every

person is competent and autonomous unless proven otherwise. This concept according to Kant and Mill flows from the recognition that every person has unconditional worth, each having the capacity to determine his or her own destiny. "To violate a person's autonomy is to treat that person merely as a means, that is, in accordance with others' goals without regard to that person's own goals" (Beauchamp & Childress, 1994, p. 125).

The emphasis of medical professionals that they are entitled to act in the best interest of their patients is based on the concept that physicians know better because of their special training. Such a concept was brought to its limits by Skinner (1971) in his book entitled Beyond Freedom and Dignity. Skinner argued vehemently against such concepts as autonomy, freedom, and dignity. In Skinner's conception, autonomy is a concept that is part of a prescientific view; a person's behavior is to some extent his own achievement since he is free to deliberate, decide, and act in original ways (p. 96). The scientific view of the same phenomenon is that "a person's behavior is determined by a genetic endowment traceable to the evolutionary history of the species and by the environmental circumstances to which as an individual he has been exposed". (p. 96). Skinner's perspectives on autonomy and freedom have not been accepted by the courts nor by the legislators. Courts have always recognized a person's right to make the choice to accept or reject medical treatment. That right of self-determination included the right to refuse even life-saving surgery (NHLA, 1996, par. 8.6). Both in the United States (In re Farrell; 1987, cited in NHLA, 1996, par.8.9) and in Canada (Nancy B., 1992, cited in Rasooly et al., 1994), the law is now clear that the competent patient may refuse treatment even if such refusal may lead to his or her death. Latimer (1991) stated that

cessation of treatment at the request of the patient is no different, ethically, than never having started it in the first place.

Although the law is clear that patients have a right to refuse treatments, Gert et al. (1994) nonetheless suggested that states should consider passing legislation that would say that all physicians shall be informed that they are legally prohibited from overruling any rational refusal of a competent patient, including refusal of food and fluids, even though it is known that death will result.

Continuing effect of prior competent decision. The legal theory about the autonomy and freedom of patients to refuse treatment has been pushed to its limits whenever the American courts have recognized the substituted judgment theory. This theory says that when an individual has previously expressed wishes concerning treatments, his next of kin may refuse treatment when the individual is unable to make decisions because of altered consciousness or cognition. This theory was confirmed by United States Supreme Court in the Cruzan case (cited in Day et al., 1995, p. 296; NHLA, 1996, par. 811-812).

Canadian courts have not yet accepted the substituted judgment theory. However, in 1990 the Ontario Court of Appeal upheld the earlier decision in Malette v. Shulman (1990). In that case, Malette, a Jehovah's Witness was brought, comatose, to the emergency room from the scene of a car accident. Blood transfusions were necessary to save her life, but Malette had a signed card in her wallet, albeit neither dated nor witnessed, stating she never wanted to receive blood products. Despite knowing about this card, Dr Shulman gave her blood transfusion. The Ontario Court of Appeal said that

**“a doctor is not free to disregard a patient’s advance instructions any more than he would be free to disregard instructions given at the time of the emergency” (cited by Hébert, 1996, p. 29). Although this decision does not go as far as the American cases in that the ruling applies only to persons who have given advance instructions, it may be inferred that one need not put their instructions in writing in order for them to be valid.**

**Since written advance instructions by patients (and in the U.S., even oral indications of the patient’s intentions) are considered binding on the physicians, it can logically be concluded that living wills (also called written advance directives) and durable powers of attorney (appointing another to decide for the patient) are also valid and binding (Beauchamp & Veatch, 1996, pp. 253-56; Hébert, 1996, pp. 30-35). Although some courts have recognized that physicians must follow the patient’s previously expressed wishes regarding therapy, not all jurisdictions have handed down such decisions.**

**In order to lift any uncertainty in that respect, legislation has been enacted to protect patients' rights to self-determination such as the U. S. Patient Self-Determination Act of 1990, which requires hospitals and nursing homes to tell patients, on admission, of their right to file an advance directive and to refuse treatment. In Canada, most provinces except New Brunswick and Prince Edward Island, have legislated to recognize the legal validity of advance or proxy directives (Poirier, 1997, pp. 199-204).**

**Autonomy, substituted judgment and the never-competent adult. Decision-making for patients who lack mental capacity can be difficult, and it has been remarked that few areas in medicine are more complex (Wicclair, 1993, p. 40). Beauchamp and**

Veatch (1996, p. 307) wrote that approximately 80% of those who die each year in the United States die in nursing homes or hospitals under the care of strangers. Although this area covers children and mentally incapable adults, the discussion will be restricted to adults.

With respect to never-competent adults, the legal problem that went to court dealt mainly with court-approved sterilization or forcible administration of psychotropic drugs. Very few cases dealt with termination of life-sustaining care. The problem with cases of never-competent adults is what principle should be applied: autonomy (the substituted decision) or beneficence (the best interest) (NHLA, 1996, par. 8.13).

As with the autonomy principle, it is difficult to justify its application to never-competent adults, since for an action to be autonomous a substantial degree of understanding and freedom from constraint are required. If a person has the capacity to understand and is free from constraint, he or she is considered as mentally capable and therefore autonomous and capable to make decisions (Beauchamp & Childress, 1994, p. 123). Although there is uncertainty about the appropriateness of applying the substituted decision test in cases of never-competent adults, legal commentators and ethicists generally considered that the substituted judgment approach is unworkable since there is no evidence of a patient's preferences (Beauchamp & Veatch, 1996, p. 308; NHLA, 1996, par. 8.13).

When a patient never had the mental capacity, lost his/her capacity to express his or her wishes, or if there is insufficient information about a patient's goals and values, the patient's best interest approach should be taken (Wicclair, 1993, pp. 58-63). In Canada,

the Supreme Court has explicitly rejected the substituted judgment approach in the Eye case (1986). In that case, the mother of a mentally handicapped woman wanted her child to be sterilized in order to avoid an unhealthy pregnancy. The Court said that the only principle which must guide the treatment of an incompetent person is the best interests of that person, not the interests of others (Roy et al., 1995, pp. 234-238).

The best interest of never-competent adult. What is in the best interest of persons who cannot or have not expressed their wishes with respect to refusal or withdrawal of treatments such as ventilation, hydration, and nutrition? Canadian rulings in the Eye and the Rodriguez cases stressed that life is the most important interest a person has. It is difficult to see how it could be in the person's best interest to refuse or withdraw life-sustaining measures unless these are considered futile and medically unnecessary. In the United States, however, courts have dealt with such situations.

The first reported case was Superintendent of Belchertown State School v. Saikewicz (1977). In that case, 67-year-old Saikewicz had an IQ of 10 and a mental age of approximately 2 years and 8 months. He suffered from acute myeloblastic monocytic leukemia. Chemotherapy would have produced extensive suffering and possibly serious side effects. Without chemotherapy, Saikewicz could be expected to live for several weeks or perhaps several months, during which he would not experience severe pain or suffering. The Supreme Judicial Court of Massachusetts held that the best interests' of an incompetent person are not necessarily served by imposing on such persons results not mandated as to competent persons similarly situated. The court balanced prospective benefit against pain and suffering, finally determining that the patient's interests

supported a decision not to provide chemotherapy. However, the court unfortunately used the standard of substituted judgment, which nowadays is considered wrong in such cases since, the patient never had the mental capacity to give instructions or express his wishes with respect to different treatments (Beauchamp & Childress, 1996, pp. 307-308; 331-337).

In 1991, the Supreme Court of Indiana decided the In re Lawrance case involving a 40-year-old patient who had been brain damaged since the age of 9. The patient's parents were permitted by the court to order withdrawal of artificial nutrition and hydration because it was in the patient's best interest to do so (NHLA, 1996, par. 8.13).

Physicians have not yet reached consensus on what is in the best interests of incapable patient who would be in danger of dying if life-sustaining devices were either withheld or withdrawn. It seems accepted that there should be no ethical nor legal distinctions between withholding and withdrawing life-sustaining treatments (Beauchamp & Veatch, 1996, pp. 213-214; Latimer, 1991).

Daly et al. (1993) also support the view that it may be morally permissible to withdraw mechanical ventilation from patients who are neither terminally ill nor imminently dying based on the beneficence principle. The authors also suggested the following procedures for treatment withdrawal: (a) prior consultation with other professionals and health care team and reaching an agreement, (b) the decision must be explained and patient and family reassured, (c) at least one day delay should be observed, (d) timing is important, and finally (e) support should be given to parents and health professional staff.



### The Futility Concept: Return of Physicians' Authority and Paternalism

Advance directives written in a patient's file could be a good indication of how attending physicians should act if the only authority on the treatments were patients. In fact, physicians can and often do administer life-prolonging treatments to patients who did not wish those treatments. Those situations pose the problem of determining who has the final authority with respect to treatment: the patient or the physician. Very often, it is the physician who prevails. Furthermore, physicians can (although they seldom do) refuse treatment in cases where the patient or his surrogate insists that life prolonging measures be taken. In order to by-pass patients' specific requests, ethicists and physicians have developed the concept of the futility of treatment.

The medical futility concept. Morreim (1994) explored the different considerations involved in the futility debate. He acknowledged that at first physicians had all the rights regarding treatments. After court intervention, patients and their surrogate may now refuse treatments. More recently, physicians have taken upon themselves to refuse treatment based on the futility argument. The futility argument is based on the fact that the patient's life is profoundly diminished, on prolongation of treatment as cruel and even harmful, and finally on the wastefulness of prolonging treatments.

Tomlinson and Czlonka (1995) further acknowledged that the futility debate is governed by two fundamental considerations: the moral integrity of the health professionals and their obligation to enable autonomous choices by patients. The problem with futility is that it may be seen to depend only on the health professionals' opinions or,

on the other hand, the patient in exercising his autonomy may insist on treatments even if they are totally futile, taking away physicians' integrity.

Futility has been classified into two categories: (a) quantitative futility, where a procedure (like CPR) is futile if it has less than a 1% probability of succeeding, and (b) qualitative futility, where a procedure is considered futile if it merely preserves permanent unconsciousness or fails to end total dependence on intensive medical care.

Curtis et al. (1995) carried out a study about DNR orders and found that futility is becoming an important factor in giving physicians the power to make decisions regarding the withholding or the withdrawing of certain treatments. Kock et al. (1994) also found that medical futility was the main reason for implementing DNR. Finally, Pijnenborg et al. (1995) carried out national research to provide empiric information on the occurrence and background of nontreatment decisions in the Netherlands from 1991-1992 involving 2,257 deaths and the decisions physicians had or had not made in each case. Of all deaths, 70% appeared to be nonsudden and expected. In 39% of nonsudden deaths, a non-treatment decision was made. About half of all nontreatment decisions consisted of simply not starting a possibly life-prolonging treatment; in the remaining half, physicians had withdrawn treatment. Some reasons that were given by physicians for nontreatment decisions were explicit patient's request or wishes (74%) and futility of further treatment (72%). In their research, Miller et al. (1993) found that physicians reported that the most important influences on their recommendations about the withholding or the withdrawal of treatments were patients' self-reported wishes about resuscitation (98%) and their own judgment of medical utility (91%).

**Medical futility and value judgment.** It is generally acknowledged that medical judgments are the subject of concern in the futility debate. However, medical opinions are not only strictly scientific opinions, but also judgments relying on values (Beauchamp & Veatch, 1996, pp. 350-351).

In their research, Ghusn et al. (1997) compared clinical, functional, and social characteristics of DNR patients at the time of their cardio-pulmonary arrest with characteristics of patients who received cardiopulmonary resuscitation (CPR). A retrospective chart review was done of all 261 patients who had a cardiopulmonary arrest during a 6-month period in a teaching Veterans Affairs Medical Center. One hundred eighty patients (69%) had a DNR order and 81 patients received CPR. Demographic characteristics, medical diagnoses, and measures of functional status were collected when DNR orders were initiated and at the time of cardio-pulmonary arrest. The mean age of both groups was 61.7 years, but the proportion of patients who were age 75 years and older in the DNR group (16.7%) was significantly higher than in the CPR group (4.9%). Discussions to limit treatment were documented in 89% of the patients in the DNR group. At the time of cardiopulmonary arrest, a higher proportion of the CPR group had coronary artery disease or chronic renal failure, and a higher proportion of the DNR group had cancer or AIDS. Also at the time of cardiopulmonary arrest were the majority of both groups dependent in all functional domains, and 7% of the DNR group were stuporous or comatose compared with 47% of the CPR group. Six of the 81 patients who received CPR (7.4%) were alive at discharge. This research dealt in part with the problem of futility and the authors concluded that a significant proportion of patients with clinical

characteristics associated with poor CPR outcome are electing CPR and the health care professionals agree with the decision.

Morreim (1994) had previously explored the problem arising when parents or surrogate want the physician to do everything to maintain life while the physician would use the futility argument to stop the treatments. He stated that contrary to the right to refuse treatment, courts have not set guidelines here while physicians themselves do not agree on the precise point when treatments have become futile. This may lead to threats of lawsuits which physicians fear very much. Such threats constitute coercion as does the imposition by physicians of their position on patients.

In at least two American cases (In re: the Conservatorship of H.M. Wanglie, 1991; In the matter of Baby K, 1993), the courts have ordered physicians to treat even if they think it is medically futile. However, in Canada, the law is still unclear. The Manitoba Court of Appeal did not follow the American decision in Baby K and ruled that in the case of a vegetative child, it is in no one's interest to maintain the life of a terminally ill patient who is in an irreversible vegetative state (Child and Family Services of Central Manitoba v. R.L. and S.L.H., 1997). However, in November 1998, the wife of a hospitalized Parkinson patient who had suffered several strokes asked a Manitoba Court for an injunction to force physicians to remove a DNR order from the patient's medical chart (Roberts, 1998, Nov 7). The Court granted an interim ordering that the DNR order be lifted from the patient's chart (Fine & Roberts, 1998).

Morreim (1994) considered that physicians can protect themselves against coercion to continue futile treatments in two ways. One way is for them to work on

establishing consensus concerning demands for unlimited support of patients with profoundly diminished quality of life. Physicians should also be able to opt out of treatments which they believe are counter-indicated and go against their conscience. In doing so they should discuss their values with the patient and family at the beginning of treatments. Secondly, light must be shed on the problem of wastefulness. Distinctions must be made about commodity scarcity and fiscal scarcity. Physicians can and ought to be intimately involved in commodity allocation even if it sometimes denies hopelessly ill patients lifesaving but scarce commodities, but they should never be involved in fiscal scarcity, according to Morreim (1994). The latter should be left to social and political decision makers. Finally, the line between personal and common resources needs to be clarified: A person should be allowed to spend his or her own money as they see fit; however, it is not the case with moneys coming from taxes as they do in Canada, where Medicare is paid through general tax revenues.

#### Is There a Place for a Bioethics Normative Order?

Some authors (Roy et al., 1995, p. 77) have pointed out that in the United States, the legal aspect has all but absorbed the ethical considerations. In the different articles reviewed here, few distinctions were drawn between ethical and legal standards. On the other hand, in Canada, since so few cases have gone to court, the distinction may be more important because in the absence of definite legal direction, medical staff must rely on ethical considerations to guide their decisions.

While not attacking the universality of the notion of the absolute autonomy of the patient to accept or refuse treatment, Kuczewski (1996), as a bioethicist, insisted that

families have been forgotten by the focus on the legal aspects of informed consent in which the autonomy of the individual and his or her desires and wishes alone are taken into account. According to Kuczewski (1996), medical ethics is but a footnote to informed consent. From the legal perspective, families are often seen as competing interests. As an ethicist, he tried displacing the legal model, which has phagocyted the ethical aspects. As ethicist, he assumed that patients do not know what they want and so need someone (e.g., the ethicist) to help them to greater awareness of their own values. He also assumed that physicians and nurses have conflicting interests when advocating for the patient, and therefore came to the conclusion that a third party must help them clarify their values, which is the proper role of the ethicist.

Kuczewski's (1996) article reinforced Côté and Rocher's (1994, pp. 4-30) views that bioethics is trying to develop into a new profession. However, it has not yet had much success and is still trying to find its place among the state positivist legal order, religious legal orders, and hospital administrative orders. Another competitor for bioethics is the traditional medical ethics. The medical profession has a long tradition of ethics as part of its autonomy and the relationship between doctor and patient. Doctors have their image of their profession and also their image of hospitals and patients. From that perspective, the ethics committee is not necessarily seen in a positive way by physicians. The ethics committee further runs the risk of invading the private relationship between patient and physician. Physicians see ethics committees as another layer of bureaucracy that interferes with them. Another thing that intimidates physicians is that the idea of moral pluralism, which is specific only to bioethics, might act as a new moral

authority (Rocher, 1996, pp. 281-284). Finally, as it has been mentioned by other researchers (Bissonette et al., 1995; Fisher, 1992), physicians are not as well prepared as other hospital professionals to deal with ethical questions.

Confronted with the competitions, physicians are trying to reclaim some dominance. Hill (1994) advocated that medicine, like science, calls for an ethic derived directly from its own activity. Hill assumed scientific medicine to be morally neutral and having no ethical resources of its own. Society then proceeded to force medicine into a pre-existing framework of ethical analysis, culturally, and philosophically derived, in the expectation that this would help to distinguish between right and wrong medicine and guide its practice accordingly. But despite all the efforts, it is hard not to agree that it has amounted to nothing more than a superficial ethical exercise in bioethics. It has been an uncomfortable fit and has simply not resulted in a clarity of ethical judgement critical to an endeavor with such far-reaching ethical implications as scientifically structured and technologically delivered medicine. The only alternative in the face of this failure is, Hill believed, an ethic for medicine derived from the action of medicine itself, which would be understood as something medicine, by virtue of its activity, gives shape to, but meanwhile is indispensable to it if it is to be practiced ethically. The concept of medical futility may be the evolved form that could satisfy physicians' aspirations to develop an ethical criteria based on their professional and scientific values.

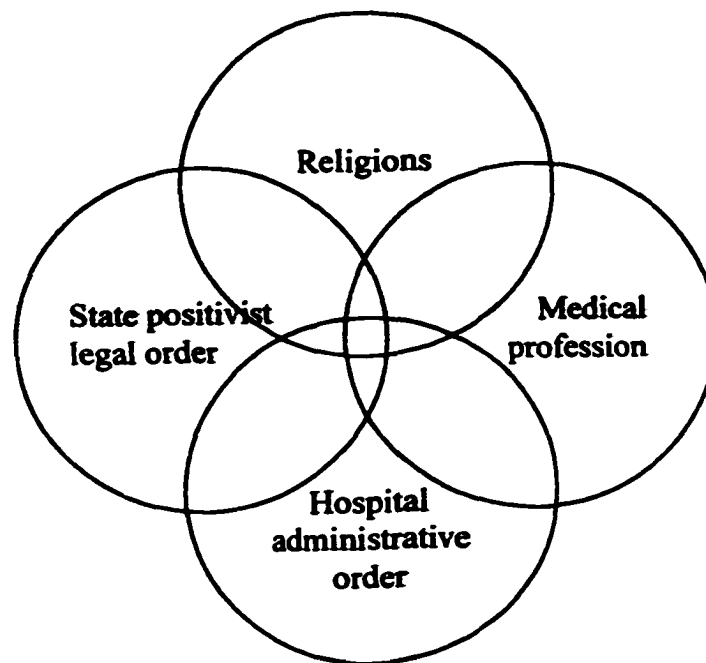
### Summary

The plurality of normative orders that have been described so far may be understood as subsystems of the larger social system. These systems and subsystems could be graphically described as in Figure 1.

So long as physicians were in control of their own work environment, which they were until the end of the 1960s, they seldom experienced any conflicts arising between the norms of normative orders different from their professional norms. Côté and Rocher (1994, pp. 25-27) have shown that until the last 2 or 3 decades, the courts usually incorporated the medical norms as part of the state legal rules, thus avoiding any conflict between the norms of the state legal order and those of the medical normative order. The same was true of hospital administrative normative order when the hospital administration was controlled by physicians as was the rule in the 20th century until the end of the 1960s (Starr, 1982, pp. 379-419). This also held true for ethics at a time when physicians were able to impose their conception of ethics on their patients, on courts, and on the hospital administrations.

The problem when those plural orders occur together is that the rules from the different normative orders contradict one another. Yet, those normative conflicts provide with an opportunity to consider which normative order is most influential in different given situations.





**Figure 1.** Presentation of the main normative orders that affect physicians living in a specific society at a specific time.

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Since the recent adoption of laws by the state legal order that respond to the principle of autonomy and freedom of a patient to consent to or to refuse treatment, and since the medical professional culture's insistence on the belief that physicians know what is in the best interests of their patients, it can already be seen that some potential conflicts may arise between those two normative orders to which individual physicians must respond. On the other hand, since the personal and religious values of physicians has been shown to be an important factor in directing their attitudes and behaviors, the

religious normative order may at times conflict with the legal norms and even with their professional norms. Consequently, these different values or norms may be able to explain why physicians have difficulty respecting their terminally ill patients' wishes not to be treated.

Although most current research has been conducted on American health institutions, it is nevertheless relevant to Canadians, since both practices are quite similar except for the health services delivery systems. Yet that research has not adequately addressed the question this research posed. On the other hand, the theoretical model described in this chapter may provide some elements needed to answer the question better. It is therefore logical and challenging to venture into an exploratory research project whose goal would be to study whether the theoretical model proposed here rings true or not, and if it is worth exploring any further.

## **CHAPTER 3 RESEARCH METHOD**

### **Research Questions**

**This study poses one main question: Why do physicians not respect their terminally-ill patients' wishes to refuse treatment once there is no hope for a cure?**

**Taking into account the theoretical framework and the available research data on the subject presented in the previous chapter, the following subquestions are justified:**

**(a) Are physicians influenced in their treatment of terminally ill patients by their religious affiliation? (b) Are physicians reluctant to follow their patients' wishes not to be treated from fear of contravening the state legal norms and thus be subjected to lawsuits? (c) Do physicians think that acknowledging their terminally ill patients' wishes is an abdication of their duties and thus contrary to their professional ideology ( i.e., medical professional norms)? (d) Would physicians accept to respect their patients' wishes not to be treated only when the hospitals' administrative norms or the state legal norms do not contradict their professional ideology (i.e., their medical professional norms)?**

### **Qualitative versus Quantitative Research**

**In order to investigate why physicians are reluctant to follow their patients' wishes respecting their refusal of treatment, a number of researchers surveyed samples of physicians and nurses (Buchan & Tolle, 1995; Christakis & Asch, 1995; Levery et al., 1992; Rasooly et al., 1994; Solomon et al., 1993; Teno et al., 1997a, 1997b, 1997c, 1997d; Wilson, 1996, 1997). These quantitative studies, however, did not adequately answer why physicians refuse to respect their patients' wishes. They give some direction,**

but do not provide adequate answers.

### Qualitative Research Applied to the Present Study

Babbie (1995) acknowledged that survey research can seldom cope with the context of social life. He wrote that "although questionnaires can provide information in this area, the survey research can seldom develop the feel for the total life situation in which respondents are thinking and acting" (p. 274). In the last few years, researchers have turned to content analysis of semistructured interviews with physicians and nurses in order to gain more insight into the reasons why they hesitate to respect their terminally ill patients' wishes not to be treated (Bailey, King, & Newton, 1994; Holm et al., 1996; Kelner & Bourgeault, 1993; Kelner et al., 1993; McInerney & Seibold, 1995; Tilden et al., 1995). The literature on methods in social research brings one to the conclusion that questions such as the one being asked in this research can best be addressed through the qualitative approach.

As will be discussed, the qualitative approach has its problems, too. It seldom yields precise description about large populations and therefore it has reliability and generalizability problems. For that reason, qualitative methodologists suggest the use of triangulation as a means to correct both reliability and generalizability problems.

### Enhancing Validity Through Triangulation

Bickman and Rog (1998) acknowledged that "one method of enhancing validity is to develop converging lines of evidence" (p. xvii). Tellis (1997) wrote that the need for triangulation arises from the ethical need to confirm the validity of the processes. Stake (1995) stated that the protocols that one uses to ensure accuracy and alternative

explanations are called triangulation.

**Multiple sources of data for enhancing construct validity.** Bickman and Rog (1998) insisted that a clarifying characteristic of applied research is the triangulation of methods and measures to compensate for the fallibility of any single method or measure. Yin (1994) wrote that “a major strength of case study data collection is the opportunity to use many different sources of evidence” (p. 91). Maxwell (1998) also acknowledged that triangulation “reduces the risk of systematic distortions inherent in the use of only one method, because no single method is completely free from all possible validity threats” (p. 93).

Maxwell (1998) wrote that effective triangulation requires the use of additional method that is not subject to the same particular threats of self-report bias or ideological distortion that may affect interviews, questionnaires, and documents. Yin (1998) considered that in using the triangulation concept for the case study method, “a robust fact may be considered to have been established if evidence from three (or more) different sources all coincide. To get such convergence, you must ask the same questions of the different sources of evidence” (p. 233). Triangulation, in other words correlating coincidences through the means of different data, enhances construct validity.

**Methodological triangulation in enhancing construct validity.** Patton (1990, pp. 187-198; 464-467) considered that one way to strengthen a study design is through a combination of methodologies in the study of the same phenomena. This can mean using both quantitative and qualitative approaches. Both Stake (1994) and Yin (1994) acknowledged that a case study may use quantitative or qualitative data or both.

Triangulation of qualitative and quantitative data is a form of comparative analysis. Methodological triangulation is not restricted to the use of quantitative and qualitative methods. It also applies to mixed methodological strategies. Patton (1990, pp. 190-198) gave the following as examples of mixed methodological research strategies: use of experimental design using qualitative data and content analysis; use of experimental design with qualitative data and statistical analysis; and use of naturalistic inquiry with qualitative data and statistical analysis; use of naturalistic inquiry with quantitative data and statistical analysis.

Theory triangulation for enhancing internal and external validity. Theory triangulation involves using different theoretical perspectives to look at the same data. Patton (1990) wrote that “more concretely, there are always multiple theoretical perspectives that can be brought to bear on substantive issues” (p. 470). Another version of theory triangulation is to examine the data from the perspective of various stakeholder positions with different theories of action about a program. These different stakeholder positions represent different theories of action that cast findings in a different light.

Stake (1995) insisted that the protocols that are used to ensure alternative explanations are called triangulation. Internal validity is the extent to which a causal relationship can be soundly established between two phenomena. Yin (1994) wrote that “internal validity is a concern only for causal (or exploratory case studies), in which an investigator is trying to determine whether event  $x$  led to event  $y$ ” (p. 35).

It is through theory triangulation that Yin (1998) wrote about rival theories. He considered that the “use of rivals not only strengthens the research design but also

sharpens theoretical thinking” (p. 234). In that respect, “the best rival would be a rival theory, an attempt to explain the same outcome with a different substantive theory than that of the target theory” (p. 235). Campbell (1994) considered that the use of rival theories in case study and quasi-experimentation in general “are more similar to the experimental isolation paradigm than to the randomized assignment to treatments model in that each rival hypothesis must be specified and specifically controlled for” (p. x). In that respect, the use of theory triangulation through rival theories allows one to make inferences whose explanation can be checked by the use of rival theories.

On the other hand, theory triangulation also enhances external validity (the extent to which the study results are generalizable). In order to be generalizable, a theory has to be tested through replications of the findings in subsequent studies. This replication logic can be achieved through multiple-case studies because “each case study relies on analytical generalization. In analytical generalization, the investigator is trying to generalize a particular set of results to some broader theory” (Yin, 1994, p. 36). Yin (1994) insisted that sample size is not a consideration for case studies because it does not follow the same logic as experimental studies. He wrote that the “*analogy to sample and universes is incorrect when dealing with case studies*. This is because survey research relies on *statistical* generalization, whereas case studies (as with experiments) relies on *analytical* generalization” (p. 36).

### Triangulation Applied to the Present Research

The problems of validity and reliability inherent to qualitative research can be alleviated. With respect to validity and reliability, it is possible to carry on research from

different angles in order to develop converging lines of evidence. In this doctoral research, the researcher used three converging lines of evidence, that is three different sources of evidence. The first source of evidence was gathered through research consisting of conducting semistructured interviews with 24 physicians from the Greater Moncton area in the Canadian province of New Brunswick. A second source of evidence was collected through 19 case studies from families of terminally ill patients from the province of New Brunswick. A third converging line of evidence consisted of the administrative policies respecting clinical ethics committees and do not resuscitate orders collected from all New Brunswick hospital corporations.

Methodological triangulation was also used in order to enhance the validity of the present research. The researcher used a combination of methodologies in the study of the same phenomena: whenever possible both quantitative and qualitative approaches were used, especially in analyzing the interviews. Furthermore, the researcher has also used the analysis of available survey data on the subject in order to prevent making unwarranted generalizations.

Finally, the researcher used theory triangulation for enhancing both internal and external validity. This means that the researcher used different theoretical perspectives in analyzing the same data. More specifically, this means that the same data were analyzed from each of the three alternative theoretical explanations that are present in the literature: these are: (a) physicians do not respect their terminally ill patients' wishes not to be treated out of fear of civil and criminal litigation (legal norms), (b) physicians do not respect their terminally ill patients' wishes not to be treated because their religious beliefs



(religious norms), and (c) physicians do not respect their terminally ill patients' wishes not to be treated because physicians follow their professional medical norms (professional norms) over any other norms.

### **Organization of Health Services in New Brunswick**

The province of New Brunswick is one of the 10 Canadian provinces. Situated along the Atlantic Ocean, it is neighbored in the north by the province of Quebec and in the west by the state of Maine. Its total population was 760,728 in 1997. New Brunswick is officially bilingual province, where about two thirds of the inhabitants speak English while a little more than one third speak French. About 40% of the population, mostly its French speaking citizens, speak both languages. All public services, including education and health services, at least in theory, are provided in the language of the service seeker. However, in practice, since most French speaking people live in the northern and eastern regions of the province, services there are provided mostly in French with a very good capacity to provide services in English. The English speaking population lives mostly in the western and southern parts of the province, where services are provided mostly in English with some French capacity.

Since October 1992, New Brunswick has been divided into seven health districts, each of which was regrouped under a Hospital Corporation. Hospital Corporations #4, #5 and #6 are situated in mostly French areas, while Hospital Corporations #2, #3, and #7 cover mostly English areas. The Moncton health district however has two Hospital Corporations, one for the English speaking population (#1A) and one for the French speaking population (#1B). Each Hospital Corporation has a general hospital and may

also include one or more smaller hospitals or health centers. Figure 2 gives a picture of the seven health districts for the province.

Table 1 gives the details for each of the eight Hospital Corporations in the province. It must be noted that the total population served by the New Brunswick Hospital Corporations is 773,885. Because both of two Hospital Corporations serve the French and English speaking people of the immediate Moncton area, and it is difficult to establish precisely who is being served by each Hospital Corporation. This explains the discrepancy of about 13,000 people.

In reading Table 1, it must be noted that the two psychiatric facilities for the province, Centracare (145 beds) in St John (mainly for English patients) and Restigouche (195 beds) in the northern part of the province (mostly for French patients) are not counted in the hospital beds available. Finally, attention must be called to the number of beds having been greatly reduced from 4,098 in 1991 to 3,810 in 1997. This represents a 7.3% reduction that was arrived at by cutting beds especially in the smaller hospitals since they now fall under the umbrella of Hospital Corporations.



- |   |  |
|---|--|
| <p>Region 1 (i) Kent County;<br/>(ii) Albert County;<br/>(iii) Westmorland County.</p> <p>Region 2 (i) Charlotte County;<br/>(ii) Saint John County;<br/>(iii) Kings County;<br/>(iv) Queens County, the parishes of Peterville, Hampstead, Wickham, Johnston and Brunswick.</p> <p>Region 3 (i) Queens County, less the parishes of Peterville, Hampstead, Wickham, Johnston and Brunswick;<br/>(ii) Victoria County, less the parishes of Drummond and Grand Falls;<br/>(iii) Carleton County;<br/>(iv) York County;<br/>(v) Sunbury County;<br/>(vi) Northumberland County, the parishes of Ludlow and Blissfield.</p> | <p>Region 4 (i) Victoria County, the parishes of Grand Falls and Drummond;<br/>(ii) Madawaska County;<br/>(iii) Restigouche County, the parishes of Grimmer and St-Quentin.</p> <p>Region 5 (i) Restigouche County, less the parishes of Grimmer and St-Quentin.</p> <p>Region 6 (i) Gloucester County.</p> <p>Region 7 (i) Northumberland County, less the parishes of Ludlow and Blissfield.</p> |
|---|--|

Health and Community Services

October 1982

**Figure 2. New Brunswick seven Health Districts with its by eight Hospital Corporations. From New Brunswick Department of Health and Community Services, 1997, Queen's Printer, Fredericton, NB.**

**Table 1**  
**Hospital Corporations with Number of Beds for Their Respective Population**

Hospital Corporation	Population Covered	Number of beds	Maximum allowed acute beds
1(A) Moncton (English)	122,357	592	435
Moncton (Civic)	106,232	547	
Sackville	13,727	45	
1 (B) Moncton (French)	85,782	403	320
Moncton (Dumont)	84,357	383	
Ste. Anne	1,200	20	
2 St John	194,392	964	725
St John(SJRH)	136,052	705	
St John (St Jos)	32,388	120	
St Stephen	12,903	80	
Sussex	11,308	45	
Grand Manan	1,536	14	
<i>Centracare(psychiatric)</i>		145	
3 Fredericton	164,415	709	620
Fredericton	114,296	430	
Woodstock	16,465	80	
Oromocto	14,775	65	
Perth	9,318	55	
Bath	3,678	23	
Minto	1,119	21	
Plaster Rock	2,108	15	
4 Edmundston	50,782	292	190
Edmundston	34,510	222	
Grand Falls	12,526	50	
St. Quentin	3,746	20	
5 Campbellton	37,770	235	145
Campbellton	23,339	175	
Dalhousie	12,718	60	
<i>Restigouche(psychiatric)</i>		195	
6 Bathurst	79,169	405	300
Bathurst	53,719	270	
Tracadie	11,518	70	
Caraquet	11,184	50	
Lamèque	2,748	15	
7 Miramichi	39,208	210	140
<b>Total</b>	<b>773,885</b>	<b>3,810</b>	<b>2,875</b>

**Note.** From "Hospital Financial and Utilization Management System Database", New Brunswick Department of Health and Community Services, Fredericton, NB, January 1997.

### **Multiple Sources of Data**

As mentioned earlier, in order to enhance the validity of this research, data were collected from three sources. First were in-depth semistructured interviews with 24 physicians practicing in the Greater Moncton Area in the province of New Brunswick, Canada. Data were also collected from a second source: written policies and relevant documents on clinical ethics committees and do-not-resuscitate order in all New Brunswick Hospital Corporations. The third source of evidence took the form of multiple-case studies gathered through written documents by nurses who were involved with 19 New Brunswick families who had a member whose wishes not to be treated were not respected by physicians.

#### **Semistructured Interviews with Physicians**

Interviews are one of the most common yet most powerful instruments used to try to understand human beings (Babbie, 1995, p. 289; Fontana & Frey, 1994, p. 361; Seidman, 1991). However, only a few studies could be located that used semistructured interviews in order to investigate the reasons why many physicians are reluctant to respect the wishes of their patients not to be treated once they are terminally ill.

McInerney and Seibold (1995) conducted field research to investigate the attitudes of nurses toward withdrawal of treatment, and care of then terminally ill patients using a network sample of 10 registered nurses from a variety of practice settings. A semistructured interview with the nurses was transcribed verbatim and a content analysis conducted.

More research relevant for this study was conducted by Kelner and Bourgeault

(1993) and Kelner et al. (1993), whose goal was to identify key factors that influence the knowledge, attitudes, and behavior of health care professionals concerning the control of patients over their own dying. In-depth semistructured interviews were carried out with 20 nurses and 20 physicians from four distinct clinical specialties (medicine, oncology, intensive care, and geriatric care). The interviews were tape-recorded, and summary notes of the health care professionals' responses were also taken. The taped interviews were transcribed and entered verbatim into a computer for coding. Various qualitative data analysis procedures, such as content analysis and concept saturation, were used to code and group the health care professionals' responses into key concepts. Finally, Tilden et al. (1995) used structured interviews with 32 family members of 12 patients who had died after withdrawal of life support to investigate which physicians and nurse behaviors families found supportive and which behaviors increased the family's burden.

**Respondents.** Similarly to the Kelner et al. (1993) research, the researcher interviewed a group of physicians. These physicians were affiliated to either Hospital Corporations 1A and 1B. About 200 physicians are affiliated with these two Hospital Corporations, some 50 being specialists in oncology and emergency medicine.

Kelner et al. (1993) found no differences between physicians and nurses, nor any differences by sex, years of practice, or other personal characteristics. Difference found was between religious beliefs. Another difference was between oncology and intensive care physicians compared to family physicians. "All of the oncologists and most of the intensive care physicians expressed reservations about the implementation of advance directives, whereas the physicians in family practice and geriatrics were more favorably

inclined" (p. 1334). Similar results were also found by Wear and Brahams (1991). Both groups of researchers carried out semistructured interviews for their research.

Following the results of Kelner et al. (1993), since it appeared that specialists were more hesitant to respect their terminally ill patients' refusal to treatment, this study focused on oncologists and intensive care physicians to investigate why that group has more difficulty respecting their terminally ill patients' wishes. Semistructured interviews were carried out with 24 oncologists and intensive care physicians. However, since some researchers have found differences between Protestants and Catholics (Anderson & Caldwell, 1993; Christakis & Asch, 1995; Kelner & Bourgeault, 1993; McInerney & Seibold, 1995; Solomon et al., 1993) and since the theoretical model used in this research postulates that the religious normative order may at times contradict the other normative orders, each physician interviewed was asked his religious affiliation.

Personal characteristics of physicians. The semistructured interviews were carried out with 24 physicians, specialists in oncology or emergency medicine. Table 2 shows the personal characteristics of those physicians. Of the 24 physicians, 75% were male. This percentage is about equal to the ratio of male/female physicians working in emergency medicine in the greater Moncton area.

Table 2

**Personal Characteristics of the 24 Physicians Who Were Interviewed**

Personal characteristics	N	%
<b>Sex</b>		
Male	18	75
Female	6	25
<b>Religion</b>		
Catholics	18	75
Jews	1	4.2
Others	5	20.8
<b>Language</b>		
English	8	33.3
French	3	12.5
Both	13	54.2
<b>Years of experience</b>		
Less than 5 years	5	20.8
Less than 10 years	4	16.7
10 years and more	15	62.5
<b>Hospital affiliation</b>		
French hospital	13	54.2
English hospital	8	33.3
Both hospitals	3	12.5



The age of the interviewed physicians varied from a minimum of 27 years to a maximum of 58, the average age being 42.2 years. The years of practice varied from one to 30 years, the average having been in practice for 13.6 years.

More than half of the physicians were bilingual, one third were unilingual English, and only three (12%) were unilingual French. Most bilingual physicians had French as their mother tongue. More than half of the interviewed physicians were solely affiliated with the French Hospital Corporation, one third were solely affiliated with the English Hospital Corporation, and three (12.5%) were affiliated to both hospitals. The higher number of French speaking physicians can be explained by the fact that the French Hospital Corporation in greater Moncton offers the most tertiary health services for the whole New Brunswick French speaking population. These services include, oncology, renal, radiotherapy, and so forth.

By contrast, although the English Hospital Corporation has more physicians affiliated with it, it does not offer as many tertiary health services: the Center for tertiary health services for the English speaking population are at Saint-John situated in Hospital Corporation # 2. Since the research was geared to physicians specializing in terminal illness and emergency medicine, it should not come as a surprise that more French speaking physicians were approached for interviews.

Most physicians interviewed were Catholics (75%), and one was Jewish. The others belonged to other Christian denominations. Considering that most French speaking New Brunswick citizens were traditionally brought up as Catholics, it is not surprising that more Catholics were interviewed, given that more than half of the

interviewed physicians were French speaking. Furthermore, in New Brunswick, about 54% of the total population is Catholic, and 40 % adhere to other Christian denominations ("Canada's Families-They Count", 1997), so that their religion roughly represents the population of the province as a whole.

**Semistructured interviews.** The interviews were carried out between June and September 1998. Each interview lasted from half an hour to about one hour, most interviews being completed in 45 minutes. The personal characteristics of each interviewee (age, sex, speciality, years of practice, religion, religiosity) was taken on a paper prototype form presented in Appendix A. This questionnaire guide was adapted from the one used by Kelner et al. (1993, p. 1338). A consent form for interviews (Appendix B) was also read and explained to each physician before he or she signed it. A copy was left with the physician and one copy was kept for the researcher's files.

Although the interviews were semistructured, they were guided by open questions aimed at soliciting responses relevant to the research questions. These questions, therefore, insisted on the different norms that physicians are aware of, and the absence or presence of conflicts between those norms each interviewee may have encountered in his treatment of terminally ill patients, especially those who refused treatment. The questions asked are presented in Appendix A. This guide was translated into French for use with the French speaking physicians.

Furthermore, before using the guide with physicians, a pilot study on several physicians was carried out. After each of the pilot interviews, the researcher asked the interviewee for his or her suggestions to improve the instrument. Their comments were

incorporated into the final version of the guide that was used for the research interviews.

Each interview was tape-recorded, and summary notes were taken by the researcher. The taped interviews were then transcribed verbatim by a professional secretary. The researcher then listened to each interview while reading the transcription to make sure that no errors had slipped in during the transcription phase. Errors and omissions were given to the secretary, who corrected them.

### Collection of Administrative Policies

Each of the eight New Brunswick Regional Hospital Corporations is responsible for the administrative policies of the hospitals or health centers under it. In order to collect the data for this research, the medical directors of each Hospital Corporation were contacted in January 1998 and asked to send the researcher a copy of their most recent administrative policies regarding clinical ethics committees and Do-not-resuscitate orders. By the end of February 1998, administrative policies were received from each of the eight Hospital Corporations.

### Multiple-Case Studies by Nurses

In order to triangulate the validity of the results obtained from interviews with physicians, some case studies with family members who had experienced problems in having physicians respect the wishes of their terminally ill parents were conducted. In these case studies, families members were asked to describe the factual situations leading to the rejection by the physician of the terminally ill patient's wishes not to be treated. Furthermore, they were asked to assess the reasons why physicians behaved as they did.

In the study, case studies were gathered by experienced nurses (from 10 to 20

years in practice) who were taking a televised course on death and dying that the researcher had given as a compulsory course for registered nurses (RNs) who were working toward their Bachelor's degree in Nursing (Poirier, 1998). The cases were collected in 1994 and 1995. The researcher asked that nurses should only do the case study if they had personally experienced a recent (within the last year) situation in which a physician had given a patient life-sustaining treatments despite their refusal of treatment. The other students were asked to write a paper from a subject chosen from a list. Of some 88 students, 31 did a case study. Only 19 of those case studies dealt with terminally ill adult patients, and, therefore, only those 19 case studies were retained for this study.

Those nurses were given specific instructions. They were asked to meet with a significant family member of the patient and to do an interview by following a form handed to them (see Appendix C). A consent form was completed by both the families and the nurses (Appendix D). The nurses were asked to write a case study of about 10 pages covering the following features: the facts of the situation, expression of the patient's wishes, process used by the physician to bypass patient wishes, family involvement, and how the patient's rights were violated.

#### **Methods for Analysis**

Different methods were used in analyzing the collected data from the three different sources. The general technical method used was content analysis. Content analysis, however, is not enough. Other methods recommended in qualitative research were also used, among them pattern-matching, explanation-building, and method logics.

### Quantitative Content Analysis

The three different sources used to collect data ended up as written documentation. The semistructured interviews with physicians, once typed verbatim, transformed into about 300 pages of written document. The hospital administrative policies respecting clinical ethics committees and resuscitative intervention policies were received in written form. Finally the multiple-case studies gathered by nurses were also available in the form of written reports. Researchers agree that the best method of analyzing written documents is through content analysis (Babbie, 1995, pp. 307-321; Grawitz, 1996, pp. 550-574).

There are three essential steps to content analysis. The first step consists of choosing the material to which the content analysis will apply. In research like the one that was conducted for this study, content analysis was applied to interview transcripts, written hospital administrative policies, and case studies. Content analysis was used in studies similar to this one in analyzing the responses of health care professionals to patients' control over dying (Kelner & Bourgeault, 1993; Kelner et al., 1993); nurses' attitudes towards euthanasia (McInerney & Seibold, 1995); physicians' referral decisions (Bailey et al., 1994); ethical reasoning in mixed nurse-physician groups (Holm et al., 1996); and the impact of physicians' behaviors on the family's decisions on life-sustaining treatment of a parent (Tilden et al., 1995).

The second step in content analysis is counting and recording. The main problem encountered at this step was that of defining the unit of recording, that is, deciding whether the unit would be words, ideas, or themes. Most of the research that dealt with

physicians' attitudes opted in favor of the idea or theme as the unit of measurement. For example, Holm et al. (1996) used the method of semantical content analysis, where the unit of measurement was the meaningful statement, which is similar to using ideas or themes as the unit of analysis. Consequently, ideas or themes were chosen as the unit of recording in the present study. The third step consisted in putting the themes into perspective and will be described latter.

Validity. The validity of content analysis posed the problem of deciding whether the instrument (content analysis) measured what it purported to measure. The last step of content analysis was to interpret the quantified findings resulting from the quantitative process of counting and recording the number of times specific themes or ideas appeared in the different written materials. In recent research on physicians' attitudes and behaviors, statistical comparisons were effective using different tests. The most often used is the Mann-Whitney U test for data on ordinal/interval scales (Bailey et al., 1994; Holm et al., 1996). However, other statistical tests have been also used. Smith, Sells, and Clevenger (1994) used a chi-square to compare therapist and couple perceptions across seven categories arising from their content analysis. Finally, Holm et al. (1996) used the Sign test for ratios, Fisher's exact test for discrete data, together with the Mann-Whitney U test for data on ordinal/interval scales, as statistical tests to validate their research.

In this study, chi-square and Fisher's exact test were used for statistical analysis, the results of which are presented in Appendix F. Chi-square is a frequently used test of significance in social science. It is generally used "to determine how close the expected values are to the actual values ... . Small values of chi square support the claim of

independence between the two variables” (Simon & Francis, 1998, p. 132). It is based on the assumption that there is no relationship between the two relevant variables in the total population. Therefore, in applying Chi square to the data of the present study, what was computed was the conjoint distribution that would be expected if there were no relationship between the two variables (Babbie, 1995, p. 437). The result of the process gave a set of expected frequencies for all the elements in the contingency Table. The expected distribution was then compared with the distribution of cases actually found in the sample data and the probability was determined concerning the fact that the discovered discrepancy could have resulted from sampling error alone (Babbie, 1995, p. 437).

**Reliability.** In content analysis, a major preoccupation is with the reliability of the coding. In other words, it is important to know whether the results obtained by the coders can be repeated by other coders using the same material. Reliability is, therefore, a very important consideration.

Kang, Kara, Laskey, and Seaton (1993) found intercoder reliability wanting in all but 13% of the 86 articles they reviewed by them. Unfortunately, most of the studies involving physicians did not use adequately tested intercoder reliability (Bailey et al., 1994; Holm et al. 1996; Kelner & Bourgeault, 1993, Kelner et al., 1993; McInerney & Seibold, 1995). Whenever intercoder reliability was used, only percentages were given and chance agreement was not taken into account (Schneider & Beaubien, 1996; Smith et al., 1994; Tilden et al., 1995).

**Procedure used in the study.** In this dissertation, the researcher followed closely the method used by Tilden et al. (1995) for intercoder reliability. First, the transcripts were read by the researcher while listening to the taped interviews. All discrepancies were corrected and retyped by the secretary. The transcripts were then handed over to a professional translator with a diploma in statistical mathematics who was hired by the researcher after consultation with a statistician. The translator then took all the statements made by the different physicians in answering each of the 14 open questions asked by the researcher and wrote them verbatim under each question. When that portion of the work was done, the researcher was left with some 524 statements. Table 3 shows the number and respective proportions of statements given by the physicians for each question. The more general questions yielded the most statements since the physicians were more free to expand on the questions.

The 524 statements were read by the researcher and another professor familiar with the issues and were broken down to eight main categories. The statements were read again independently by the researcher and the professor and were further assigned to 33 themes, as shown in Table 4.



Table 3

**Number of Statements for Each of the 14 Semistructured Questions Asked to Interviewed Physicians**

<b>Question number as in the interview guide ( )</b>	<b>Questions</b>	<b>N</b>	<b>%</b>
1. (1)	What has been your most difficult case in deciding what treatment to prescribe to a terminally-ill patient?	57	10.88
2. (2)	What problems, if any, do physicians encounter when they decide to withhold or withdraw treatments?	42	8.02
3. (3)	What are your views about the desire of patients to control the timing and circumstances of their own death?	47	9.00
4. (4)	What is your opinion about who has the final authority to make decisions regarding prolongation of terminally-ill patients' lives?	25	4.08
5. (5)	What are your views about patients who have previously arranged for advance directives respecting their refusal of treatment or their refusal to be resuscitated?	28	5.34
6. (6)	What problems do physicians encounter when a patient's desires to end life-sustaining efforts are resisted by family members?	28	5.34
7.(7&12)	How do you feel about the fact that laws and the courts are more and more involved in the decision-making process about the treatment of terminally-ill patients?	39	7.44
8. (8)	Under what circumstances do you feel that the law may conflict with your medical professional judgment in deciding the treatment of a terminally-ill patient?	32	6.11
9. (9)	What do you think about your hospital's policy on withholding or withdrawing medical therapy to terminally-ill patients?	27	5.15
10.(10)	How has the hospital's policy on DNR orders affected your practice in prescribing treatments to patients?	15	2.86
11. (11)	Under what circumstances do you feel the hospital's policies regarding DNR orders may conflict with your medical professional judgment in your decisions concerning the use of life-sustaining technology?	24	4.58
12. (13&14)	Under what circumstances do you feel your religious beliefs may affect your treatment of terminally-ill patients?	41	7.82
13. (15)	What kinds of strategies should be developed to make it easier for physicians to accommodate patients' wishes to influence the circumstances of their dying?	58	11.07
14. (16)	Do you have any opinions respecting the fact that Dr. Morrison was prosecuted for mercy killing a terminally ill patient? Do you think that physicians will be affected by that prosecution	61	11.64
Total		524	100 %

Table 4

**Distribution of Physicians' Ttatements Into Eight Main Categories and 33 themes**

Statements by physicians distributed into 8 categories and 33 themes	N	%
<b>TF1. Statements in relation to death</b>	<b>98</b>	<b>17.85</b>
TF1.1 Difficulty for physicians	16	2.91
TF1.2 Patients' decision about time of one's death	11	2.00
TF1.3 Patients' decision where to die	5	0.91
TF1.4 Physicians' diagnosis of terminal illness	20	3.64
TF1.5 Active euthanasia	46	8.38
<b>TF2. Statements in relation to withholding and/or withdrawing treatments</b>	<b>154</b>	<b>25.05</b>
TF2.1 Who should decide for the competent patient?	46	8.38
TF2.2 Who should decide for the incompetent patient?	52	9.47
TF2.3 People who should be involved in the decision process	18	3.28
TF2.4 Problems relating to refusal or withdrawal of treatments	38	6.92
<b>TF3. Statements of physicians about overtreatment of terminally ill patients</b>	<b>41</b>	<b>7.47</b>
TF3.1 Physicians' difficulties respecting overtreatment	15	2.73
TF3.2 Physicians' external motives to overtreat	7	1.28
TF3.3 Physicians' internal motives to overtreat	19	3.46
<b>TF4. Statements related to conflicts between law and medical profession</b>	<b>85</b>	<b>15.48</b>
TF4.1 Distinction between law and medicine	4	0.73
TF4.2 Situations where law creates problems for physicians	49	8.93
TF4.3 No conflict between law and medicine	3	0.55
TF4.4 Law's functions	29	5.28
<b>TF5. Statements concerning hospital administrative policies</b>	<b>61</b>	<b>11.11</b>
TF5.1 General comments	2	0.36
TF5.2 Procedures	11	2.00
TF5.3 Physicians' knowledge of hospital administrative policies	12	2.19
TF5.4 Influence of hospital administrative policies	17	3.10
TF5.5 Physicians' opinions with respect to Hospital administrative policies	14	2.55
TF5.6 Roles given to families by administrative policies	5	0.91
<b>TF6. Statements concerning pain control</b>	<b>57</b>	<b>10.38</b>
TF6.1 Physicians' difficulties respecting pain control	2	0.36
TF6.2 Physicians' perceptions respecting palliative care	11	2.00
TF6.3 Physicians' perceptions of patients' and families' needs	10	1.82
TF6.4 Strategies to help physicians accommodate patients' wishes	34	6.19
<b>TF7. Statements concerning the effect of physicians's religious beliefs on treatment of terminally ill patients</b>	<b>34</b>	<b>6.19</b>
TF7.1 Influence of religious beliefs on medical practice	22	4.01
TF7.2 Physician conformity to patients' beliefs	5	0.91
TF7.3 Conflicts between physicians' and patients' beliefs	7	1.28
<b>TF8. Statements in relation to patients' quality of life</b>	<b>7</b>	<b>1.28</b>
TF8.1 Who decides on patients' quality of life	1	0.18
TF8.2 Problems for physicians to decide on quality of life issue	2	0.36
TF8.3 Preferable attitudes from physicians	2	0.36
TF8.4 Administration of high doses of pain killers	2	0.36
<b>Others unable to classify</b>	<b>12</b>	<b>2.19</b>
<b>Total</b>	<b>549</b>	<b>100</b>

Each of the 33 themes were further refined into a total of 77 subthemes as shown in the Table contained in appendix E. Comparison of the two sets of sub-themes indicated 93% interrater reliability on assigning physicians' statements into of the different sub-themes. The two rater then jointly reviewed and discussed each statement until full agreement was achieved on the selection of sub-themes for the statements. At the end of this process, the total number of statements falling into the different themes amounted to 549 statements. The discrepancy between the 524 statements reported in Table 3 is due to the fact that a number of statements (25) were complex sentences that could be classified under more than one theme or sub-themes.

It should be noted that in Table 4 and appendixes E and F, each theme or sub-theme is preceded by TF. These were used by the statistician for identification purposes. These identifying letters were kept in order to facilitate the reading of the statistical analysis contained in the appendixes E and F.

For statistical analysis purposes, however, all the categories, themes, and sub-themes were submitted to statistical analysis as shown in appendix F. The independent variables were the following: sex, religion, language, years of practice, and hospital corporations with which affiliated.

### Qualitative Analysis

Quantitative content analysis as a technique has been criticized by Manning and Cullum-Swan (1994) for its incapacity "to capture the context within which a written text has meaning" (p. 464). Even though interpretation of interviews may be guided by the statistical tests that are carried out on the coded data, it is always over and above a

qualitative process (Grawitz, 1996, pp. 553-554).

During the interpretation phase the researcher tried to find the meaning of the data collected from the different sources: interviews, administrative policies, and case studies. This meaning was derived from reinserting the interviews within their context and interpreted in relation to the theoretical modal described earlier as recommended by methodology theorists (Creswell, 1994, pp. 156-157; Grawitz, 1996, pp. 575-578; Manning & Cullum-Swan, 1994, pp. 464-469).

Smith et al. (1994) have specifically compared the qualitative and quantitative content analysis methods in studying couple and therapist perceptions in a reflecting team setting. The purpose of the study was two-fold: (a) to refine and increase our understanding of theoretical relationships and categories developed in the ethnographic domain analyses, and to refine the description of emergent patterns, emphases, and themes; and (b) combine both ethnographic content analysis and quantitative content analysis in order to investigate the frequency of themes where they occur in the underlying meanings within the various transcribed interviews. The study demonstrated that quantitative numerical data and qualitative narrative data can examine the same phenomenon from multiple perspectives, allowing greater accuracy and stability in study findings. Ethnographic content analysis illustrated both its usefulness and rationale for discovering emergent patterns, themes, emphasis, and process. The strength of this research was that it showed how both qualitative and quantitative methods of content analysis might be useful and beneficial to conducting better and more complete research.

Other researchers have also carried out both methods of content analysis. Bailey et

al. (1994) started with quantitative content analysis in their analysis of general practitioners' referral decisions. However, since the interpretation of the data obtained from the quantitative content analysis was difficult to interpret, qualitative content analysis was also used. The authors concluded that the use of both quantitative and qualitative content analysis methods may act to triangulate or check the preliminary results obtained by using only one method.

Holm et al. (1996) also used quantitative content analysis, which he applied to another study using qualitative content analysis (including statistical tests) to study ethical reasoning of physicians. Schneider and Beaubien (1996) carried out a naturalistic investigation of compliance-gaining strategies employed by doctors in medical interviews. The authors said that their research was a qualitative one in the sense that the number of physician was small and the physicians had not been randomly chosen. However, the authors did use various techniques of quantitative content analysis. For example, they used intercoder reliability and made use of statistics in reporting their results. Finally, in interpreting their results they made use of existing quantitative survey research in the field. In that sense, they achieved their goal, having showed corroborating evidence of prior research on the subject.

Finally, Kelner and Bourgeault (1993), Kelner et al. (1993), and Tilden et al. (1995) studied the impact of physician behavior on making decisions about life-sustaining treatment of patients. These authors all acknowledged using qualitative content analysis methods. However, Tilden et al. (1995) also used intercoder reliability and related their findings to results of survey researches as a means of triangulation. All of these authors

used the computerized software “Ethnograph” in order to make their qualitative data analysis. These tools are based on counting the processes of coding and thus approximate, very closely, quantitative methods of content analysis.

In qualitative content analysis, methodological theorists do emphasize validity and reliability as they do in quantitative content analysis. However, Miles and Huberman (1994) and Creswell (1994, pp. 158-159) insisted on plans to triangulate or find overlapping among sources of information, different investigators, or different methods of data collection.

As researchers on physicians’ attitudes and behaviors using content analysis have done, this study, too, used both quantitative and qualitative methods of content analysis. Furthermore, the data from case studies will be used to further triangulate or check the data obtained from the interviews. Finally, comparison was made of the results obtained in this study with those obtained from other sources of information.

#### Analysis of Evidence Collected for the Case Study

Analysis in case studies means to link the data collected to the questions (why, how, what) that were asked at the beginning of the study. Yin (1994, pp. 102-106) wrote that the best preparation for conducting case study analysis is to have a general analytical strategy. One such strategy relies on theoretical propositions. Theoretical propositions will have shaped the data collection plan, thereby helping to focus attention on certain data while ignoring other data. “The proposition [will] also help to organize the entire case study and to define alternative explanations to be examined” (p. 104).

The purpose of the present case study was to explain why many physicians are

reluctant to respect the wishes of their terminally ill patients who refuse treatment once there is no hope for a cure. Explanation-building as a form of analysis was therefore commendable. Explanation-building is a special procedure whose “goal is to analyze the case study data by building an explanation about the case” (Yin, 1994, p. 110). This process is similar to the grounded theory proposed by Strauss and Corbin (1994). Yin (1998) wrote that “to explain a phenomenon is to stipulate a set of causal links about it” (p. 252). Yin also added that causal links are similar to the independent variables in other fields of science. He stated that “the gradual building of an explanation is similar to the process of refining a set of ideas, in which an important aspect is again to entertain other plausible or rival explanations” (Yin, 1994, p. 111).

#### **Ethics and Confidentiality**

In doing this research, problems of ethics and confidentiality must be confronted. The researcher explained both to the physicians interviewed and to the patients exactly what her purpose was. She also had them sign a consent form (Appendixes A and C) approved by both Walden University and the university where she presently works. Furthermore, the researcher told the physicians she interviewed that she would send them the transcript of their interview once it had been typed to make sure they still consented to her using the interviews. However, although some physicians listened to the tape of the interview, all clearly indicated that they did not wish to see the transcript of the interview.

As far as confidentiality is concerned, the researcher made it impossible to identify either the physicians in the interviews or the patients or their families mentioned in the case studies. No names and no identifying characteristics appeared on the questionnaires.

**Each of the questionnaires, the interviews, and the case studies were coded, and the codes were kept separate from the collected data.**



## **CHAPTER 4 RESULTS AND ANALYSIS**

### **Hospital Corporations Policies Concerning Ethics Committees and Do-Not-Resuscitate Orders**

The first finding of the survey of New Brunswick Hospital Corporations' policies was that all Hospital Corporations except Hospital Corporation #2 have an ethics committee, and all hospital corporations have adopted a policy pertaining to do-not-resuscitate orders, as can be seen in Table 5. The second finding was that while all ethics committees were adopted or revised after the constitution of Hospital Corporations in October 1992, only one half (#1B, #2, #5, #7) of the DNR policies were adopted after October 1992.

The purposes of the ethics committees appear in Table 5. It should be noted that only two hospital corporations (#1A & #7) have given the authority to their ethics committees to make administrative policies and monitor their application. Not surprisingly, administrators and board appointees are members of the ethics committees of these two hospital corporations, as shown in Table 6. The other corporations (#1B, #3, #4, #5) can only act in an advisory capacity with respect to administrative policies. Hospital Corporation #6 has inadvertently failed to mention any advisory capacity with respect to administrative policies. On the other hand, all ethics committees insist on their educational role to the hospital staff and patients (see Table 5).

Table 5

**Comparison of Purposes Present in the different Committees on Ethical Policies of New Brunswick Hospital Corporations**

Purposes	1(A)	1 (B)	2	3	4	5	6	7
1. Develop and recommend policies on Ethical issues related to patient care	X							X
2. Advice on ethical policies that concern patient care	X	X		X	X	X		X
3. Monitor compliance with ethical policies	X							X
4. Make recommendations when appropriate	X	X		X	X	X		X
5. Do not arbitrate matters relating to individual patients	X						X	
6. Answer to ethical questions raised by professionals, patients or their families		X		X	X	X	X	X
7. Offer a forum for reflection and discussion to professionals about ethical problems		X		X	X	X	X	
8. Educate the staff, patients, and their parents on ethical issues		X		X	X	X	X	X
9. Educates itself in the principles of biomedical ethics				X				X
10. Policies approval date	95/11	93/11		95/11	98/1	97/1	97/11	97/2

**Note.** 1A = Moncton (English); 1B = Moncton (French); 2 = St John; 3 = Fredericton; 4 = Edmundston; 5 = Campbellton; 6 = Bathurst; 7 = Miramichi.

Finally, it seems that most ethics committees, except for the ethics committee of Hospital Corporation #1A, can answer requests by professionals, administrators, patients, or their families about ethical questions. Only two corporations (#1A & #6) make it clear that the ethics committees are not involved in individual cases in a decision-making capacity but only in an advisory capacity.

Table 6 shows the composition of the different ethics committees. The total number of members varies from six to 17 members. Some ethics committees (#1A, #1B, #5) are composed in such a way that health professionals constitute the majority.

On those committees, physicians and nurses are generally well represented. Representatives from pastoral care and biomedical ethicists are also present on most ethics committees, except for the ethics committee of Hospital Corporation #1A. Lawyers and social workers are also present on four of the seven hospital corporations who have ethics committees. Five ethics committees have a representative from the community over and above representatives of the boards of trustees who are taken from the community.

Table 6

**Comparison of Membership Present in the Different Committees on Ethical Policies of New Brunswick Hospital Corporations**

Membership	1(A)	1 (B)	2	3	4	5	6	7
1. Chairman of the Board (ex-officio)	1							
2. Representative of the Board of trustees	1			1	1	1	1	1
3. General director (or representative of administration)		1		1				1
4. Vice president of medical services (ex-officio)		1				1		1
5. Representative of the Medical staff	3	4		1	2	4	1	2
6. Vice president of Nursing								1
7. Representative of Nursing	1	4		1	1	1	1	2
8. Representatives of the hospital staff	2				1			
9. Representative from quality assurance				1				
10. Lawyer		1		1	1			2
11. Psychologist (mental health)		1		1				
12. Social worker		1		1	1	1		
13. Pastor		1		1	1	1	1	1
14. Bioethicist (or representative from bioethics services)		1		2	1			
15. Representative from the community		1		2	1		1	2
16. Consumers of health care				2				
17. Representative from faith communities				2				1
18. Others					2		1	
19. Total	8	16		17	12	9	6	14
20. Policies approval date	92/3	93/11		95/11	98/1	97/1	97/11	97/2

**Note.** 1A = Moncton (English); 1B = Moncton (French); 2 = St John; 3 = Fredericton; 4 = Edmundston; 5 = Campbellton; 6 = Bathurst; 7 = Miramichi.

**The guiding principles governing the Canadian Medical Association (1994) policy statement on resuscitative interventions and the administrative policies adopted by different New Brunswick Hospital Corporations are presented in Table 7.**

**Two things should be noted about that Table. First, only three Hospital Corporations (#2, #5, #7) have updated their administrative policies to take into account the CMA (1994) statement. Second, the principles that appear in the guiding principles sections of each Hospital Corporation policy may be contradicted by more specific policies expanding on the guiding principles as shown in Table 8, exposing the criteria for the implementation of DNR policies. For example, the guiding principles in Table 6 show that the general policies of Hospital Corporations #1A, #2, #5, #6 and #7 adhere to the principle that a competent person has the right to refuse or withdraw consent to any clinically indicated treatment, including life-sustaining treatments. However, in Table 8, the criteria for the implementation of the DNR policies state that the policy applies only in cases of irreversible condition or damage, thus contradicting the general principle found in four (#1A, #2, #5, #6) out of five Hospital Corporations.**

Table 7

**Comparison of Guiding Principles Present in the Different Policies of New Brunswick Hospital Corporations and in those of the Canadian Medical Association Policy Statement (1994)**

Principles	CMA	1(A)	1(B)	2	3	4	5	6	7
1. General policy of hospital is to preserve life					X		X	X	
2. The decision to provide or refuse available life-sustaining treatment is made within the context of civil law and policy of hospital.									X
3. Open communication, discussion and sensitivity to cultural and religious differences	X								
a) Decisions about life-sustaining measures to be discussed before crisis occurs									X
b) Try to reach a consensus about DNR				X					
c) Interdisciplinary team approach									X
d) Explain the decision of discontinuance of life-support to family				X					
4. Sufficient information about the benefits, risks & likely outcomes of all treatment options to enable patient to make informed decisions	X	X	X						X
5. A competent person has the right to refuse consent to any clinically prescribes treatments including life-sustaining treatments	X	X		X			X	X	X
a) No moral difference between withholding/withdrawal of treatment									X
b) Capable patients have right to decide, but only when irreversible condition			X						
6. When a person is incompetent, treatment must be based on her wishes, if these are known	X								
7. When incompetent person's wishes are unknown, treatment decisions must take into account:	X								
a) the person's known preferences,	X				X				
b) information received or surrogate,	X		X	X	X	X	X	X	X
c) the person's culture and religion,	X								
d) diagnosis and prognosis	X	X	X	X	X	X	X	X	X
8. No obligation to offer futile or non beneficial treatment	X	X	X				X		X
a) No obligation for life-sustaining measures if futile even if requested by the patient or substitute decision-maker								X	
b) DNR initiatives on physicians and/or at request of patient							X		
9. Policies approval date	94/10	92/3	93/11	95/6	92/3	87/11	97/1	90/9	97/2

**Note.** 1A = Moncton (English); 1B = Moncton (French); 2 = St John; 3 = Fredericton; 4 = Edmundston; 5 = Campbellton; 6 = Bathurst; 7 = Miramichi.

**The conditions of implementation of Hospital Corporations policies in Table 8 deal most extensively with the written DNR order, its charting, and the reasons for the order.**

**The guidelines in each Hospital Corporation's policies clearly identify the criteria justifying changes of DNR orders. However, the conditions of implementation for capable patients are somewhat lacking in force since only two Hospital Corporations (#6 and #7) acknowledge that the competent patient must give his or her consent. In half of the Hospital Corporations (#1A, #1B, #2, #4), the capable patient does not need to give his or her consent, and in two more Hospital Corporations (#3, #5) the family's consent is required together with the patient's consent.**

Table 8

Comparison of different criteria and conditions of implementation justifying DNR's present in the different policies of New Brunswick Hospital Corporations and in those of the Canadian Medical Association Policy statement (1994)

Criteria and Conditions of implementation	CMA	I(A)	I(B)	2	3	4	5	6	7
<b>1. Type of orders</b>									
a) Withholding/withdrawing life-sustaining treatments	X			X					X
b) Do-Not-Resuscitate (DNR) orders	X	X		X	X	X	X	X	
c) Palliative care only			X						
<b>2. Criteria</b>									
a) Patient's request in all cases of medical treatment, including life saving or life-sustaining treatment		X	X						X
b) Only in cases of irreversible condition or damage such as irreversible coma or brain death		X	X	X	X	X	X	X	
c) Treatment judged medically futile	X	X	X						X
d) Patient has a terminal illness		X	X		X	X	X	X	
e) Burdens or consequences of life-sustaining treatment	X	X	X		X		X	X	X
<b>3. Criteria justifying changes of DNR orders</b>									
a) Patient's request to change DNR order	X	X	X	X	X	X	X	X	X
b) Any changes in the patient's health status		X	X	X	X		X	X	X
c) Regular review of the DNR order		X	X	X	X	X	X	X	X
d) Physician may alter the DNR order		X	X	X	X	X	X	X	X
e) Nurses may alter the DNR order			X		X		X	X	
<b>4. Conditions of implementation for capable patients</b>									
a) Obtain consent of the patient	X				X		X	X	X
b) Obtain consent of patient and family		X	X		X	X	X		
c) Order may be initiated by medical professional	X			X		X	X		X
d) Physician discussed DNR with nursing staff		X		X		X	X	X	X
e) Physician writes the DNR order in the patient's chart		X	X	X	X	X	X	X	X
f) Physician also writes the reasons for the DNR				X	X	X		X	X
<b>5. Implementation conditions for incapable patients</b>									
a) Treatment decisions to be based on patient's wishes, if these are known	X								
b) When an incompetent person's wishes not known, treatment decisions must take into account:									
i) the person's known preferences,	X				X				
ii) information received surrogate,	X		X	X	X	X	X	X	X
iii) the person's culture and religion,	X								
iv) diagnosis and prognosis	X	X	X	X	X	X	X	X	X
c) Order may be initiated by medical professional	X			X		X	X		X
d) Physician discuss DNR with nursing staff		X		X		X	X	X	X
e) Physician writes DNR order in patient's chart		X	X	X	X	X	X	X	X
f) Physician also writes the reasons for the DNR				X	X	X		X	X
<b>6. Policies approval date</b>									
	94/10	92/3	93/11	95/6	92/3	87/11	97/1	90/9	97/2

**Note.** IA = Moncton (English); IB = Moncton (French); 2 = St John; 3 = Fredericton; 4 = Edmundston; 5 = Campbellton; 6 = Bathurst; 7 = Miramichi.



### **Multiple-Case Studies Collected by Nurses**

**Under the direction and supervision of the researcher, the experienced nurses registered in her course on death and dying collected 19 cases that dealt with elders who were terminally ill. Among those 19 case reports, 11 concerned male patients, and eight female. The average age of the patient was 79.84, ranging from 63 to 96 years of age. The characteristics and a summary description of each case of the 19 patients involved in the case studies are reported in Table 9.**

**Most patients in the reported cases had terminal diseases. Almost half (nine ) suffered from respiratory failure or problems; eight suffered from different cancers; while four had cardiac diseases. There was also one case of severe depression and one case of prolonged fainting. Some patients exhibited more symptoms than one such as cancer and cardiac and/or pulmonary problems.**

Table 9

Characteristics of Case Studies Collected by Experienced Nurses Under the researcher's Supervision

	SEX	AGE	REASONS FOR HOSPITALIZATION	PATIENT'S WISHES	PROCESS USED BY PHYSICIAN	FAMILY'S INVOLVEMENT	PROBLEMS WITH CONSENT
1	Female	76	Breast cancer. Metastases	Necessary to have radio-therapy and chemotherapy. Medical staff insisted very much against patient's wishes.	Asking another medical opinion even if patient refused to have treatments	Husband intervened asking that the treatments be stopped	Pressure exerted by physician until the patient consented to undergo the treatments against her will
2	Female	86	Pneumonia. Cancer of the pancreas	Consents to all treatments but refuses any extraordinary measures	Treatment is essential according to the doctor. Gavage and intubation had to be done. Treatments were imposed on the patient even if she had specifically refused.	Attending physician discussed only with family members but did not discuss directly with the patient	Attending physician did not respect the will of his patient and imposed treatments against her will
3	Male	65	Diarrhea and dehydration during hospitalization after a cardiac arrest	While still conscious, patient had clearly indicated his refusal to be operated on	Surgeon wanted to do surgery on the unconscious patient. He therefore asked permission to operate from the patient's wife, who gave her consent	Wife gave authorization although her husband had clearly refused the surgery.	Non respect of the will of the patient. The criteria for mental incapacity was dealt with very poorly
4	Male	75	Pulmonary emphysema and auricular fibrillation. Cancer of the lung and also had cardiac arrest during hospitalization	Patient had clearly indicated not be resuscitated should he suffer a cardiac or respiratory arrest. This information was written very clearly on his chart.	Upon the demands insisted on by the patient's wife, the doctor agreed to do CPR. The patient remained unconscious for more than 6 weeks. When patient awakens, he insisted that the tubes be removed.	The wife was not respectful in regards to her husband being resuscitated and she also insisted that the tubes be left in place	Non respect of the will of the patient. Constant insistence and pressure against it exerted by some family members.

(Table continues)

	SEX	AGE	REASONS FOR HOSPITALIZATION	PATIENT'S WISHES	PROCESS USED BY PHYSICIAN	FAMILY'S INVOLVEMENT	PROBLEMS WITH CONSENT
5	Male	96	Arthritis, Parkinsons, chronic hypertension and dysphagea	Patient had clearly indicated to the director of nursing of the nursing home his refusal of extraordinary measures. This was clearly written on his chart.	Admitted to the hospital after resuscitation. Died at the hospital shortly after his admission		Non respect of the patient's wishes although clearly written on his chart
6	Female	76	Cancer of the spinal cord.	Patient told the specialist many times that she did not want chemotherapy.	A second opinion is sought and the second doctor does not accept her refusal. On a daily basis, that physician exerted pressure on her to consent to chemotherapy.		Non respect of the will of the patient. However, the physician tried to coerce her by telling her that if she refused chemotherapy, she would be left alone to die.
7	Male	96	Prostate cancer.	While still conscious, the patient had clearly indicated to both physician and his family that he did not want another surgery.	Surgeon wanted to do the surgery, with the help of the family, finally convinced the patient to accept the surgical procedures.	The patient's family got involved to pressure him into accepting the surgery.	Non respect of the will of the patient
8	Male	89	Pulmonary oedema.	While conscious, patient had clearly indicated his refusal to be resuscitated if he had a cardiac arrest.	The patient is resuscitated twice by health professionals after two cardiac arrests although the patient had insisted on no CPR.	Family members insisted on the patient's wishes, but the health professionals did not listen to them	Non respect of the patient's wishes. The criteria for mental incapacity was dealt with very poorly
9	Male	72	Prostate cancer.	Wanted to die at home and not go to the hospital.		The family did not respect his wishes	His family brought to the hospital where he died.

	SEX	AGE	REASONS FOR HOSPITALIZATION	PATIENT'S WISHES	PROCESS USED BY PHYSICIAN	FAMILY'S INVOLVEMENT	PROBLEMS WITH CONSENT
10	Male	84	Fracture of the right femur. Cancer of the colon is later diagnosed.	Patient gave consent to the first surgery on the femur. He was not informed that he had cancer before he underwent a second surgery for a realignment of the hip. Had he known, the patient would have refused the second operation since he had to be transferred to another hospital.	Physician refused to inform the patient that he had cancer of the colon.	The patient's family agreed to the patient's transfer only because they did not know he had cancer.	The patient was never informed that he had cancer of the colon.
11	Male	76	Pulmonary distress and unconscious	While still conscious, patient had clearly indicated his refusal of extraordinary measures.	The patient is placed on a respirator and intravenous therapy is started.	Family members insisted on the patient's wishes. At first they agreed with the physician but they finally insisted on the patient's wishes but the physician did not listen to them.	Non respect of the patient's wishes as expressed to his family members.
12	Male	72	Patient suffering from depression. Patient put on Prozac by the physician. Secondary effects from the medication.	Patient had clearly indicated to the physicians that he did not want to take Prozac anymore because of very serious and numerous secondary effects.	Physician refused to listen to the patient. Finally, upon acknowledging the serious secondary consequences of the medication, the physician changes the prescription.	The patient's daughter went twice to the doctor to tell him about the side effects of the medication. The physician refused to listen to her or her father.	The patient was never informed of the adverse consequences of Prozac. Although he did not want to take it, but he was forced to because he was told that if he refused he would be admitted involuntary to a mental institution.
13	Male	82	Thoracic pain and respiratory tract infection.	Patient verbally expressed to his family and medical staff that he did not want extraordinary measures.	Patient was intubated and placed on a respirator despite his explicit wishes to the contrary		Treatment was started against the patient's wishes

(Table continues)

	SEX	AGE	REASONS FOR HOSPITALIZATION	PATIENT'S WISHES	PROCESS USED BY PHYSICIAN	FAMILY'S INVOLVEMENT	PROBLEMS WITH CONSENT
14	Female	76	Lymphoma	Patient first gave consent to chemotherapy, but after complications, she refused any further treatments.	The physician reinforced the family's insistence on chemotherapy treatments.	The family did not agree with the patient. They insisted and the patient felt guilty and did continue the chemotherapy treatments.	The patient finally voluntarily gave her consent to treatments because she was tired and because she was told that if she did not accept, she would be left to die alone.
15	Female	83	Cardiac arrest and pneumonia	Patient had written a living will indicating she did not want any extraordinary measures. She also verbalized her wishes in the last 2 years before being hospitalized.	She was placed on a respirator.	The family first tried to dissuade her. They finally agreed to respect her wishes when she wrote a living-will.	The patient had clearly indicated in writing that she did not want any life sustaining treatments, including respirators.
16	Female	85	Respiratory distress	Patient has previously told her children that she did not want to be maintained alive through artificial measures.	Patient was not consulted. The physician decides to intubate her without even consulting her.	One of her sons gave the consent to the physician to intubate her.	Family members did not respect their mother's wishes and exerted pressure on the physician to intubate her.
17	Male	74	Respiratory failure and loss of consciousness.	No one was asked to give consent.	The patient is resuscitated twice. On his way to a second hospital, he died.	No consent asked from the family members	No consent. Emergency.
18	Female	92	Prolonged fainting.	Patient has verbally indicated that she did not want extraordinary measures to niece and to physician	Against the patient's consent, physician ordered various tests.	Patient's niece told the physician that her aunt did not want any extraordinary measures.	Tests were done against the patient's consent.
19	Female	63	Respiratory failure	The patient signed her refusal of treatment at the hospital	Without her consent treatments are given to the patient.		Although the patient did not consent, the treatments were beneficial and the patient was satisfied.

Nonrespect of patients' wishes occurred mostly with physicians, but in about one third of the cases (six out of 19), family members also participated in the non respect of their parent's wishes. Nonrespect by physicians became apparent as treatments were undertaken against the patients' expressed wishes, as shown in Table 10.

Table 10

**Type of Procedures Undertaken Upon Insistence by Physicians and Family Members Against Patients' Wishes**

Procedures	Physicians %	Family members %	N/A	%	Total	%
Resuscitation	3 15.75	0 0			3	15.75
Intubation	1 5.25	2 10.50			3	15.75
Ventilator:	3 15.75	0 0			3	15.75
Chemotherapy	2 10.50	1 5.25			3	15.75
Surgery	1 5.25	1 5.25			2	10.50
Medications	1 5.25	0 0			1	5.25
Did not inform patient of cancer	1 5.25	0 0			1	5.25
Tests	1 5.25	0 0			1	5.25
Hospitalization	0 0	1 5.25			1	5.25
Emergency: no wishes expressed			1	5.25	1	5.25
<b>Total</b>	<b>13 67.75</b>	<b>5 26.25</b>	<b>1</b>	<b>5.25</b>	<b>19</b>	<b>100.00</b>

The most frequent procedures used by physicians were life-sustaining treatments (47.1%), such as resuscitation, intubation, and ventilator. Chemotherapy and surgery made up another 26.2% of the cases. Only four (15.9%) of the cases dealt with less

serious interventions such as giving medications, performing tests, or hospitalizing against the patient's consent. In another case, the physician did not inform the patient nor his family that he had cancer.

Table 11 shows that all patients except one (an emergency situation) had clearly expressed the wish not to be aggressively treated through heroic or extraordinary measures.

Table 11

**Patients' Expression of Their Wishes to Medical Personnel and/or Family Members**

Expression of patients' wishes	Numbers	%	Total	%
1. Expressed wishes to medical personnel			12	63.1
living will	1	5.3		
written on patient's chart	4	21.1		
not written	7	36.7		
2. Expressed wishes to family members only	6	31.6	6	31.6
3. Emergency: no expression of wishes to medical personnel	1	5.3	1	5.3
4. Total	19	100 %	19	100 %

In most cases, the patients had told physicians or nurses that they did not want any extraordinary treatments (63.1%). In the other cases (31.6%), the patients had clearly made their views known to significant others. Furthermore, in five of the 12 cases where the patients had explicitly told the medical personnel of their desire not to be aggressively

treated, the expressed wishes of the patients were written on the chart or were recorded in a living will. In the remaining cases, even though the patients had explicitly expressed their wishes respecting treatments to the medical personnel, no indications were written on the patient's chart.

### **Interviews with Physicians**

#### **Themes and Patterns Found in the Interviews**

As shown in Table 3, the 14 open questions put to the physicians by the researcher yielded some 524 statements. The most general questions, like the opening question and the two closing questions, altogether yielded about one third of all statements made by physicians. The questions that produced fewer statements were those concerning hospital's administrative policies.

Physicians' statements were distributed into eight categories as shown in Table 4. About one quarter of all statements fell into the category concerning withholding and/or withdrawing treatments. This category included four themes: (a) Who should decide for the competent and (b) incompetent patients, (c) Persons who should be involved in the decision process, and (d) problems relating to refusal or withdrawal of treatments. From the high proportion of statements made by physicians concerning these four themes, it is clear that physicians are highly preoccupied by who has the deciding power when it comes to withholding and withdrawing treatments.

Furthermore, a proportion of almost 18% of statements made by physicians were in relation to death. Almost half of those statements were about active euthanasia. This shows that euthanasia is not only a question discussed by intellectuals, but that it is a



concern to physicians who are in daily contact with dying patients. The fact that the interviews were carried out in the midst of the prosecution of Dr. Morrisson, a Maritime respirologist who was accused of mercy killing one of her patient with a lethal injection, may have caused the physicians of being more wary of the subject.

Finally, a further 7.47% of physician statements dealt with the problem of overtreatment of terminally ill patients. This category explored physicians' difficulties and motives in overtreating their terminally ill patients. As can be seen from Appendix E, which provides additional details about the sub-themes for each theme of the category containing physicians' statements about overtreatment, most statements (16/19) tended to indicate that their internal motives to overtreat were to follow the medical ideology (12/19) and because physicians know best (4/19). In fact, when taking into consideration all statements concerning physicians' motives for overtreatment (26 statements), motives relating to the medical ideology and paternalism (16) comprised almost two thirds of all statements related to motives to overtreat.

Altogether, physicians' statements concerning death, withdrawing, or withholding treatments and overtreatment of terminally ill patients make up 50% of all statements. The three categories can, therefore, be considered as important for physicians who, like those interviewed, face their patients' death day in and day out.

It was somewhat surprising that only about 1% of all physicians' statements dealt with the quality of life of their patients, especially since about 10% of statements concerned pain control. Physicians' statements concerning pain control fell into four themes: (a) their difficulties about pain control, (b) their perception concerning palliative

care and (c) the needs of patients and families, and (d) strategies to help physicians accommodate patients' wishes. Sixty percent of all relevant statements (34/57) were about strategies to help physicians accommodate patients' wishes. These statements insisted mainly on three strategies: continuing education of physicians, enhancing physicians' capacity to be more open and listen more to their patients, and learning more about ethics. These data tended to show that physicians are somewhat divided between the appropriate behaviors as members of the medical profession and the demands that are being put on them by patients and their families.

About one third of all statements by physicians were about the four main normative orders postulated by the theoretical model described in chapter 2. In fact, physicians made the most statements about the conflicts between the legal norms and the norms of the medical profession (15.48%). About 11% of their total number of statements were made concerning hospital administrative policies, that is, hospital administrative norms. Finally, a little more than 6% of all physicians' statements concerned the effect of physicians' religious beliefs on the treatment of their terminally ill patients. This last category of statements dealt with religious norms.

Concerning the statements made by physicians about the conflicts between law and medicine, two themes were most frequently mentioned: situations where law creates problems for physicians (49/85 = 58%) and law's functions (29/85 = 34%). As can be seen by looking at Appendix E, which describes the statements falling into subthemes, situations where law creates problems for physicians most often identified were pain control (21/49), fear of litigation (11/49), and euthanasia (8/49). The high proportion of

statements concerning the law may be an indication that physicians perceive that the legal norms may contradict their medical professional norms and that this situation is an important concern for physicians.

Statements made by physicians concerning hospital administrative policies are distributed about equally into four themes: (a) physicians knowledge of hospital administrative policies, (b) procedures relating to those policies, (c) influence of hospital administrative policies on physicians, and (d) physicians' opinion concerning hospital administrative policies. More statements were made by physicians stating that they were not aware of hospital administrative policies (7/12) than statements to the effect that they were aware of such policies (5/12). On the other hand, only 18% of relevant statements acknowledged that administrative policies may be useful. Another 18% of relevant statements even said that they could be harmful, while two thirds of the relevant statements were to the effect that administrative policies had no influence on physicians because it was they who decided anyway.

In relation to statements falling into the religious norms category, two thirds of relevant statements ( $22/34 = 65\%$ ) were made concerning the effect of religious beliefs of physicians on the treatment of terminally ill patients. Of those statements, about one third stated that religious beliefs had no influence on the treatment of terminally ill patients, while almost two thirds were to the effect that religious beliefs were either very influential or helpful in treating terminally ill patients.

#### **Statistical Analysis of Physicians' Statements**

**In order to analyze the statements made by physicians in the semistructured**

interviews, the 118 categories, themes, and subthemes were submitted to statistical analysis, as shown in Appendix F. The following independent variables were considered: sex, religion, language, years of practice, and Hospital Corporations affiliation. Both chi-square and Fisher's exact test were used. The results of all statistical analyses are presented in Appendix F. However, in the following paragraphs only results that were statistically significant at 5% are presented.

**Sex.** Very few differences were found in the proportion of statements made on the 118 categories, themes, and sub-themes when the sex of the respondent physicians was taken into account. However as shown in Table 12, some statistically significant differences were found ( $p < .04$ ) on the proportion of male and female physicians who made statements about telling the patient about his terminal illness, the ethical perspective, and on the role of the family with respect to administrative policies relating to advance directives.

Table 12 shows that no women physicians made any statements relating to a physician breaking the news of diagnosis of terminal illness to the patient, while 56% of male physicians made statements in that regard ( $p < .046$ ). This may be consistent with the fact that women are more at ease with emotions while men tend to suppress them (Gilligan, 1982, pp. 164-168; Janson & Norberg, 1989).

Table 12

**Differences in the Proportion Between Female and Male Physicians Who Made Statements About the Enumerated Themes**

Themes	Proportion of physicians who made statements (%)		p-value of Fisher exact test
	Female (n=6)	Male(n=18)	
1. Physician breaking the news of terminal illness diagnosis to the patient	0	56	0.046
2. Ethical perspective on active euthanasia	60	11	0.046
3. Family's roles in advance directives mentioned in hospital administrative policies	40	0	0.040

On the other hand, a statistically significant, greater proportion of female physicians than male physicians made statements with respect to ethical perspective concerning active euthanasia (60% vs 11%,  $p < .046$ ) and family's role in advance directives (40% vs 0%,  $p < .040$ ). Although no differences attributed to the sex of the respondent were reported in other studies involving physicians, Bissonette et al. (1995) and Fisher (1992) found that nurses were more prepared to deal with ethical issues than physicians. Some authors (Jansson & Norberg, 1989; McInerney & Seibold, 1995) have imputed such differences to gender.

**Religion.** Since only one physician had declared being Jewish, he was counted with the Catholics. Christakis and Asch (1995) have shown that Jewish and Catholic physicians had similar attitudes with respect to the problem under study. Here again, not many differences were found between the Catholics/Jews and others, except on the categories shown in Table 13.

Table 13

**Differences in the Proportion of Catholic and Jewish Physicians and Physicians from Other Christian Denominations Who Made Statements**

Themes	Proportion of physicians who made statements (%)		p-value of Fisher exact test
	Cath & Jews(N=19)	Others(N=5)	
1. Sub-theme concerning patient's choice of time of death	79	20	0.028
2. Patients should be able to choose time of their death	79	20	0.028
3. Consequences of advance directives on the family	21	80	0.028
4. Physicians' difficulty in withholding or withdrawing treatments	42	100	0.041
5. Physicians' motivation to overtreat their patients	90	40	0.042
6. Do not know the hospital administrative policies	74	20	0.047
7. Religious beliefs are helpful	58	0	0.041

**A significantly larger proportion of Catholic/Jewish physicians than those belonging to other denominations made statements with respect to the following themes: whether patients should be able to choose the time of their death (79% vs 20%;  $p < .028$ ); physicians' motivation to overtreat their patients (90% vs 40%;  $p < .042$ ); lack of knowledge about hospital administrative policies (74% vs 20%;  $p < .47$ ); and the fact that religious beliefs are helpful in the practice of medicine with terminally ill patients (58% vs. 0%;  $p < .041$ ). On the other hand, a significantly larger proportion of physicians other than Catholics/Jewish made statements about the consequences of advance directives on the family (80% vs 21%;  $p < .028$ ) and about physicians' difficulty in withholding or withdrawing treatments (100% vs 42%;  $p < .041$ ).**

**As could be expected from research done by others (Anderson & Caddell, 1993; Christakis & Asch, 1995; Kelner & Bourgeault, 1993; McInerney & Seibold, 1995; Solomon et al., 1993), the interviews with physicians showed that a significantly larger proportion of Catholic and Jewish physicians than physicians belonging to other denominations made statements with respect to whether patients should be able to choose the time of their death; physicians' motivation to overtreat their patients; and the fact that religious beliefs are helpful in the practice of medicine with terminally ill patients (see Table 13). These areas are in fact at the center of Catholic beliefs (Catholic Health Association of Canada, 1991; Jean-Paul II, 1995; O'Rooke, 1992).**

**However, other differences between Catholic/Jewish physicians and others were more difficult to explain. The interviews with physicians showed that Catholic physicians lacked knowledge about hospital administrative policies when compared to other**

physicians (see Table 13, no. 6). On the other hand, a significantly larger proportion of physicians other than Catholics and Jews made statements about the consequences of advance directives on the family and about physicians' difficulty in withholding or withdrawing treatments (see Table 13). These data could be interpreted as meaning that Catholics and Jews are less interested in hospital administrative policies about advance directives because their religious convictions already guide them to specific answers. The same is true with the problem of withholding/withdrawal of treatment. Physicians from several other Christian denominations do not have as much guidance from their religious beliefs to those questions. Protestant philosophy leaves people to their conscience, therefore explaining why Protestant physicians may have to do more soul searching and resort to more reasoning in order to answer those difficult questions.

**Language.** Statistically significant differences at a degree of probability of 5% suggested the influence of maternal language on the proportion of physicians who made statements about the 14 issues that were presented to them during the interview. A significantly larger proportion of bilingual physicians -- those who spoke both French and English -- made statements than those who were unilingual. This was observed with respect to diagnosis respecting terminal illness (77% vs 25% & 33%;  $p < .05$ ); problems caused to physicians by withholding/withdrawing of treatments (46% vs 0% & 0%;  $p < .034$ ); and situations where the law creates problem for physicians with respect to overtreatment (100% vs 0% & 67%;  $p < .026$ ).



**Table 14**  
**Differences in the Proportions of English, French, and Bilingual Physicians Who Made Statements Concerning the Enumerated Themes**

Themes	Proportion of physicians who made statements (%)			p-value Chi-square
	English N=8	French N=3	Both N=13	
1. Patient's decision about the time of his death	25	100	69	0.040
2. Diagnosis in respect to terminal illness	25	33	77	0.050
3. Physicians' are of opinion that family should decide to withdraw/withhold treatments for incompetent patients	0	67	46	0.040
4. Courts should decide to withhold or withdraw treatments for incompetent patients	0	33	0	0.026
5. Withholding/withdrawal of treatments causing problems to physicians	0	0	46	0.034
6. Situations where the law creates problems for the physicians with respect to overtreatment	0	67	100	0.026
7. Assisted suicide creating problems for physicians	0	33	0	0.026
8. Decisions concerning the time of one's death	38	100	77	0.075
9. Patient should be able to choose time of his death	38	100	77	0.075
10. Tell patient about diagnosis of terminal illness	25	0	62	0.075
11. Legal aspect of euthanasia	25	100	38	0.075
12. Ethical aspect of euthanasia	0	0	38	0.069
13. Consequences of advance directives on family	63	33	15	0.084
14. Families involved in advance directives	50	0	69	0.091
15. Conflicts between Law and Medicine: fear of litigation	75	0	62	0.075

**A statistically higher proportion of unilingual French physicians than the unilingual English physicians made statements on the subthemes shown in Table 14. This was observed with respect to the following sub-themes: patient's decision about the time of his or her death (100% vs 25%;  $p < .040$ ); physicians' opinions that families should decide to withdraw/withhold treatments for incompetent patients (67% vs 0%;  $p < .040$ ); physicians' opinions that courts should decide to withhold or withdraw treatments for incompetent patients (33% vs 0%;  $p < .026$ ); situations where the law creates problem for the physicians with respect to overtreatment (67% vs 0%;  $p < 0.026$ ); and statements that assisted suicide creates problems for physicians (33% vs 0%;  $p < .026$ ).**

**Furthermore, when a degree of probability of 10% is chosen, eight more sub-themes would also be added to those mentioned, as shown in Table 14. A significantly greater proportion of bilingual and French speaking physicians than unilingual English physicians made statements with respect to the following themes: decisions concerning the time of one's death and the facts that the patient should be able to choose the time of his death (76% & 100% vs. 38%;  $p < .075$ ). Similarly, a larger proportion of unilingual English speaking physicians than bilingual and unilingual French speaking physicians made statements with respect to the consequences of advance directives for the patient's family (63% vs. 15% & 33%;  $p < .084$ ) and fear of litigation as creating problems to physicians (75% vs. 62% & 0%;  $p < .075$ ).**

**The fact that proportionally more unilingual French speaking physicians made statements than their unilingual English counterparts does not come as a surprise for**

anyone who is familiar with both French and English cultures. No research had compared the attitudes of physicians across cultures with respect to the treatment of terminal illness. However, research on nurses' attitudes on the subject have shown differences across cultures (Davidson et al., 1990; Levery et al., 1992; Wilkies, White, & Tolley, 1993).

The fact that statistically significant differences occur in the proportion of unilingual French physicians compared to bilingual physicians who made statements on themes shown in Table 14 is somewhat surprising since most bilingual physicians in the study were French speaking (10/13). It is therefore difficult to explain why significantly more bilingual physicians than unilingual French physicians made statements about the fact that withholding or withdrawal of treatments causes problems to physicians (46% vs 0%;  $p < .034$ ). On the other hand, a significantly greater proportion of unilingual French physicians when compared to bilingual physicians (33% vs 0%;  $p < .026$ ) made statements to the fact that courts should decide to withhold or withdraw treatments for incompetent patients and that assisted suicide created problems for physicians. Furthermore, when a degree of probability of 10% is chosen, a higher proportion of bilingual physicians than unilingual French speaking physicians made statements on the following sub-themes: telling a patient that he is terminally ill (65% vs. 0%;  $p < .075$ ); involving the family in the decision process respecting advance directives by a patient (69% vs. 0%;  $p < .091$ ); fear of litigation as one aspect where the law created problems for physicians (62% vs. 0%;  $p < .075$ ).

The linguistic milieu where physicians work. Language is an inextricable component of the culture. It is one very important vehicle through which culture is

expressed. The cultural milieu in which physician work may shed some more light on the problem raised in the preceding sub-section. More than half of the physicians interviewed were affiliated with the French Hospital Corporation. Most unilingual English physicians would normally be affiliated with the English Hospital Corporation. Unilingual French speaking physicians could not be affiliated with the English Hospital Corporation where the language of work is English. Normally, if language also defines culture, there should not be much differences between unilingual French speaking and bilingual physicians; one would rather expect differences between English speaking physicians and the others.

In fact, some statistically significant differences were found between the proportion of physicians who made statements on themes shown in Table 15 and were affiliated with the English Hospital Corporation and those affiliated with the French Hospital Corporation and those who were affiliated to both. However, since the general chi-square test could not discriminate where the differences were between the three groups, further tests were carried out on various combinations of groups. The Pearson chi-square showed differences in the proportion of statements made between physicians affiliated with the English Hospital and the two other groups of physicians on only one theme: the fact that physicians experience problems with the Law concerning withholding/withdrawal of treatments (value = 6.1895,  $df = 1$ ,  $p < .013$ ). Another difference was found between physicians working in the French Hospital and the others in that the former made proportionally less statements about physician deciding for competent patient to withhold or withdraw treatments (value = 6.2544,  $df = 1$ ,  $p < .012$ ).

Table 15

**Differences in the Proportion of Statements Made by the Interviewed Physicians According to Which Hospital Corporation They Were Affiliated With**

Themes	Proportion of physicians who made statements (%)			p-value Chi-square
	B (1B) N=13	Both N=3	M (1A) N=8	
1. Physician decide for competent patient to withhold or withdraw treatments	31	100	75	0.033
2. Patient must make an informed decision about withholding or withdrawal of treatments	38	67	0	0.053
3. Physicians experience problems with the Law's position with respect to withholding/ withdrawal of treatments	8	0	50	0.043
4. Physicians experience problems with the nursing staff with respect to withholding/ withdrawal of treatments	0	33	0	0.026
5. Motives for physician to stop treatment: request by the patient	8	67	13	0.044
6. Conflicts between religious beliefs of patient and beliefs of physicians	38	67	0	0.053
7. When there are conflicts between beliefs of patients and beliefs of physicians	23	63	0	0.051
8. Themes related to quality of life	15	67	75	0.017

**Note.** B(1B) = Beauséjour Hospital Corporation (Moncton French) # 1B; M (1A) = South East Hospital Corporation (English) # 1A; Both = Beauséjour and South East Hospital Corporations.

**Number of years in practice.** Generally, as in any profession, it could be expected that differences may appear between physicians who have more experience and those who have less experience. However, as shown in Appendix F (pp. 209-212) and contrary to expectations, few statistically differences (only on five of the 118 themes) were found between the proportions of physicians who had less than 5 and 10 years experience and those who had more than 10 years of practice. Furthermore, the difference are clustered around statements falling into the themes concerning the legal and ethical aspects of death and dying and opinions relating to administrative policies respecting the withholding/ withdrawal of treatments to terminally ill patients.

Although significant differences were found between the proportions of physicians with less than 5 and 10 years of practice and those with more than 10 years of practice who made statements on five of the 118 themes, it was not possible to discriminate what it was that accounted for the differences. However, when the physicians were regrouped between those having less than 5 years of practice and those having more than 5 years of practice and Pearson chi-square was applied, differences appeared on the three themes reported in Table 16.

Table 16

**Differences in the Proportions of Physicians Who Made Statements According to Their Number of Years in Practice (More or Less Than 5 Years)**

Themes	Proportion of physicians who made statements (%)		p-value of X <sup>2</sup>
	< 5 years (n=5)	> 5 years (n=19)	
1. Physicians' perspective on the legal aspects of death and dying	79	21	0.0154
2. Opinions respecting administrative policies	25	75	0.0014
3. Physicians see no problems with administrative policies respecting withholding or withdrawal of treatments	25	75	0.0012

A greater proportion of physicians with less than 5 years of practice made statements concerning physicians' perspective on the ethical aspects of death and dying (79% vs 21%,  $p < .0154$ ). This may show that the physicians coming out of medical schools are now better prepared than their predecessors to recognize and deal with ethical issues.

A greater proportion of physicians with more than 5 years of practice made statements concerning administrative policies generally (75% vs. 25%,  $p < .0014$ ) and concerning the fact that physicians see no problems with administrative policies in

relation to withholding/withdrawal of treatments (75% vs. 25%,  $p < .0012$ ).

Furthermore, when physicians were regrouped in two groups with 10 years of practice as the discriminating factor, significant differences in the proportion of physicians of less or more than 10 years of practice have been found in three more themes, as shown in Table 17.

Table 17

**Differences in the Proportions of Physicians Who Made Statements According to Their Number of Years in Practice (More or Less Than 10 Years)**

Themes	Proportion of physicians who made statements (%)		p-value of $X^2$
	< 10 years (n=9)	> 10 years (n=15)	
1. Physicians' perspective on the legal aspects of death and dying	58	42	0.0054
2. Administrative policies respecting withholding/ withdrawal of treatments may be harmful	87	13	.017
3. Physicians see no problems with administrative policies respecting withholding or withdrawal of treatments	37	63	0.022

A greater proportion of physicians with less than 10 years of practice made statements concerning physicians' perspective on the legal aspects of death and dying (58% vs. 42%,  $p < .0054$ ) and concerning the fact that administrative policies respecting



**withholding/ withdrawal of treatments may be harmful (87% vs. 13%,  $p < .017$ ). A greater proportion of physicians with more than 10 years of practice made statements concerning the fact that physicians see no problems with administrative policies in relation to withholding/withdrawal of treatments (63% vs. 37%,  $p < .022$ ).**

**The minute differences found between less and more experienced physicians tend to support the view advanced by authors (Du Toit, 1995; Frankel, 1996; Scanlon & Glover, 1995) that professional socialization is successfully accomplished during the training years through medical school and internship. The lack of difference found between less experienced physicians may be due to the fact that in the last 5 to 10 years, high profile cases concerning euthanasia have been the subject of court decisions that have been hotly debated in the news media, which includes medical journals.**

## CHAPTER 5

### SUMMARY, CONCLUSION, AND RECOMMENDATIONS

#### **Main Explanation in Answer to the Research Question**

As will be discussed in this chapter, the literature suggests three reasons why many physicians have difficulty respecting their terminally ill patients' wishes not to be treated once there is no hope for a cure. These explanations are the physicians' fear of legal procedures, their religious beliefs, and their medical professional values. Put into the context of the theoretical model of normative pluralism, these explanations could be re-labelled as legal norms, religious norms, and medical professional norms. In other words, three main normative orders have been offered as explanations for the difficulty physicians have in respecting their terminally ill patients' wishes not to be treated. The results of this study will be discussed in the light of those three explanations.

#### **Fear of Litigation: The Legal Normative Order**

Fear of litigation has been given as one of the main reasons why physicians are reluctant to respect their patients' wishes not to be treated (Buchan & Tolle, 1995; Solomon et al., 1993). Three aspects will be explored in this subsection: fear of criminal and civil litigation, research evidence contradicting the fear of litigation theory, and their theoretical implications considering normative pluralism.

**Fear of criminal prosecution and civil litigation.** Since the arrest and accusation of Dr. Morrisson of willfully and intentionally causing the death of one of her terminally ill patients, Canadian physicians are even more fearful of criminal litigation if they give high

doses of analgesics (Dridger, 1998). In the current study, physicians' statements related to that case constituted 11.6% of all their statements (see Table 2, no. 14). Respondent physicians were also very much preoccupied with euthanasia, since 8.38% of all statements made by physicians were about medical, legal, ethical, religious, and societal considerations about active euthanasia. Another 8.93% of all statements concerned euthanasia and assisted suicide as situations creating problems and conflicts between law and the medical profession. Taken together, these two aspects represent 17.31% of all statements made by physicians (see Appendix E). It therefore seems clear that physicians are preoccupied with the fear of possible criminal prosecution.

Although physicians may be leery of criminal prosecution, some research suggests that it is mainly fear of civil litigation that physicians are worried about. The case studies collected for this study showed that in almost one third of the cases (6/19, see Table 11), family members participated with the physician in the refusal of the patients' wishes and therefore in overtreatment of the patients. When confronted by a fairly large proportion of parents who insist that the patient's wishes not be respected, physicians may fear civil or criminal litigation, and/or complaints to the discipline committees of their profession if they do not use all means in their power to keep their patients alive.

The fear of litigation is therefore present, especially in New Brunswick, where the law is not clear on incompetent patients' rights. All policies of New Brunswick Hospital Corporations provide for the physicians to take into consideration information received from surrogates, usually next of kin, before deciding on the treatments for incompetent patients. This is understandable since New Brunswick's law provides that a person who is

next-of-kin may give consent to treatment for an incompetent patient (Poirier, 1997, p. 190).

Research evidence contradicting fear of litigation theory. Fear of litigation cannot be completely discarded as a real motive why physicians overtreat patients. However, contradictory evidence also exists to show that physicians are not necessarily guided mainly by such fear.

In the interviews for this study, respondent physicians gave 23 statements regarding their motivation for overtreatment of terminally ill patients. Only a quarter of those statements referred to pressures from families and society and fear of litigation as motives for overtreatment. Almost 75% of relevant statements gave medical and professional reasons for physicians' overtreatment. In fact, fear of litigation itself was only mentioned twice by respondent physicians as a motive for overtreatment.

If fear of litigation could be legitimated in the case of incompetent patients, Canadian law is very clear that a competent patient should not be treated against his or her will (Reibl v. Hughes, 1980). Although there was some hesitation with respect to the right of a patient to insist on the withdrawal of treatments, it became clear in the Nancy B. (1992) case that there were no legal distinctions between the withholding and the withdrawal of treatment and that a competent patient has the right to ask that treatment be withdrawn, even if such withdrawal would surely cause death. According to the law of the province, physicians who do not respect the wishes of their terminally ill patients should fear litigation and should therefore be presumed to respect their patients wishes if fear of litigation is the main reason for their intervention.

Respondent physicians in the interviews for this study produced 46 statements respecting the right of competent terminally ill patients to withdraw treatments. In more than half of the statements (25/46), the respondent physicians expressed the opinion that it was the physician's decision to withdraw treatments. In 37% of those statements (17/46), respondent physicians identified the patient as having the right to decide. In four of these statements, they mentioned that the family had the right to decide to withdraw treatment. An analysis of these figures suggests that either those physicians did not know the applicable New Brunswick law or, if they knew the law, they thought they did not need to follow it. They certainly did not mention the fact that they could be sued for ignoring the patient's right.

In New Brunswick, however, the law concerning the wishes of terminally ill patients has been muddled. Half of New Brunswick Hospital Corporations' DNR policies (#1A, #1B, #2, #4) do not provide for competent patients to insist that a DNR order be placed on their chart. Furthermore, even when the policies recognize this right (Hospital Corporations #3, #5, #6, #7), in two of those Hospital Corporations (#3 and #5) the consent of the family members is also required and can therefore bypass the competent patient's wishes and consent (see Table 8, no 4 a-b).

Furthermore, whereas the Canadian Medical Association (1994) joint statement on resuscitative interventions is intended to apply to the refusal of treatment by all patients, only Hospital Corporation #7 out of the eight New Brunswick Hospital Corporations followed these guidelines. In all the other cases, the policies apply only when terminally ill patients suffer from an irreversible condition or when treatments are

judged medically futile, thus giving physicians the right to withdraw or withhold treatments. Rasooly et al. (1994) expressed concern that 88.7% of the Canadian DNR policies they evaluated were restricted to terminally ill or hopelessly ill patients even if all patients have the legal right to forgo life-sustaining treatment, and that hospital policies should be revised to reflect this. The CMA's (1994) statement on resuscitative interventions was revised to take into account the Rasooly et al. comment, but most New Brunswick Hospital Corporations have not followed suit.

Explanation for physicians' refusal to follow the law. The fact that physicians bypass the competent patient's wishes is blatantly contrary to the laws of the province and the common law, which insist that a competent patient must give his or her consent to treatment and has the right to refuse any treatment even if it leads to his or her death. However, in all fairness to the respondent physicians, when most New Brunswick Hospital Corporations do not follow the law, bypass it, or contradict it, it should not come as a surprise that some respondent physicians think that they, and not the patients, have the right to withdraw treatments. However, fear of litigation does not seem a reasonable explanation. Physicians do not express any fear of litigation when acting against the expressed wishes of their competent patients, the situation where most litigation against physicians is instituted.

In terms of normative pluralism, it could be argued that physicians are aware that the legal normative order is powerful and can cause them problems if they do not adhere to the legal norms. However, it is clear that physicians choose to adhere to certain legal norms but not to others. Why it is so? This research suggests that legal norms are adhered

to by physicians when they do not contradict their religious or medical norms or values. When legal norms do contradict their religious or medical norms or values physicians have difficulty adhering to the legal norms.

Most of the studies alluded to in the literature review lead to the conclusion that Luhmann's (1985) self-reference theory may represent a strong explanation why physicians are so little affected by laws or hospital policies and respond mainly to their own professional norms. According to Luhmann (1985), two consequences of autopoiesis (self-reference) are, first, that society itself and each system in society is a normatively closed system. Second, "there is no import of normative quality from the environment into the system, and that means neither from the environment in general (nature), nor from the internal societal environment (such as religion and morality)" (p. 284).

According to Luhmann's (1985) self-reference theory, the only norms that medical professionals are willing to consider are those which are created by the self-reference processes within the relatively closed systems. Each of the orders of norms studied (medical order, religious order, legal order, administrative order) represent in fact a self-reference subsystem of norms. These subsystems are somewhat independent although they do constitute each other's outside environment. The norms of a subsystem -- say the medical professional normative order -- can only be affected by those of other systems if they are appropriated by the receiving system (medical professional normative order) and incorporated into its own system.

#### **Religious Beliefs: Religious Normative Order**

**Physicians' religious beliefs have been given as another reason why physicians**

have so much difficulty respecting their terminally ill patients' wishes not to be treated aggressively once there is no hope for a cure. Some studies (Anderson & Caddell, 1993; Christakis & Asch, 1995; Kelner & Bourgeault, 1993; McInerney & Seibold, 1995; Solomon et al., 1993) showed that Protestants tended to agree with the withholding/withdrawing treatment by the doctor, while a majority of Catholics disagreed.

Research evidence about religious beliefs. The interviews with physicians for this study did not yield a large number of statements concerning physicians with religious beliefs on treatment of terminally ill patients. The interviewed physicians only made 34 (6.19% of all statements) statements in relation to the impact of religious beliefs (see Appendix E, TF7). However, when religious affiliation was taken as an independent variable, some significant differences (see Table 13), were found between Catholic and Jewish physicians and the others on seven of the 118 themes and subthemes.

As could be expected from research done by others (Anderson & Caddell, 1993; Christakis & Asch, 1995; Kelner & Bourgeault, 1993; McInerney & Seibold, 1995; Solomon et al., 1993), the interviews with physicians showed that a significantly larger proportion of Catholic/Jewish physicians than physicians belonging to other denominations made statements with respect to whether patients should be able to choose the time of their death; physicians' motivation to overtreat their patients; and the fact that religious beliefs are helpful in the practice of medicine with terminally ill patients (see Table 13). These areas are in fact at the center of Catholic beliefs (Catholic Health Association of Canada, 1991; John Paul II, 1995; O'Rourke, 1992).

According to O'Rourke (1992), the Catholic tradition with respect to hastening



death is as follows: (a) No one shall intend to cause death either through active or passive euthanasia (when the cause of death is present but is not resisted when there is a moral obligation to do so). (b) When there is a possibility of cure (with simple surgery for example), there is a moral obligation to treat and not doing so is passive euthanasia and therefore morally wrong. (c) Pain medication cannot be used to put a person to sleep so he or she cannot feel death approaching, thus preventing the patient's carrying out of religious and moral duties. (4) However, Pope John-Paul II (1995, no. 65) acknowledged that Pius XII had already stated that it is permissible to alleviate pain by using opiates even if an unintended effect is to shorten life or reduce consciousness.

The Catholic Health Association of Canada (1991, par. 73-84) has specifically applied Catholic teachings in a guide for Catholic health workers. This guide outlined the behavior that Catholic health professionals should have with respect to end-of-life treatment. The guide provided that the most important person in deciding whether to withhold or withdraw treatments is the patient. Furthermore, the guide provided that medical professionals have no moral obligation to treat if the treatments have no positive effects or if their results are outweighed by their adverse consequences.

The Catholic Health Association of Canada (1991) guidelines concerning competent patients' right to refuse treatment has been accepted and incorporated into the Canadian Medical Association (1994) joint statement of resuscitative interventions, which insisted that a competent person has the right to refuse or withdraw consent to any clinically indicated treatment, including life-sustaining treatments. However, it seems as if most of New Brunswick Hospital Corporations and their physicians are still following

the 1982 joint statement and have not yet decided to follow the new directives.

**Religious beliefs and religious normative order reconsidered.** Taking into considerations the above-mentioned guidelines from the authorities of the Catholic Church, the religious beliefs of Catholic physicians did not seem a plausible explanation for not respecting the wishes of competent terminally ill patients who refused extraordinary measures.

However, there are ambiguities within the Catholic teachings about end of life treatments. Although the Catholic Health Association of Canada (1991) guidelines directed medical personal to acknowledge a competent patient's right to refuse treatment, the authors nevertheless stated that it is morally wrong for a patient to commit suicide, directly or indirectly (no. 87). Furthermore the guidelines stated that medical decisions concerning treatments for patients should never involve interventions capable of intentionally causing death (no. 85). Furthermore, Pope John-Paul II (1995) devoted the whole Encyclical letter titled Evangelium Vitae to the meaning of human life. It is there that the Pope vehemently condemned abortion as a crime against life (no. 44-45; 58-63). He also reasserted the sacred character of human life (no. 53-57) and condemned euthanasia and assisted suicide (no. 64-67).

Considering the ambiguities of the Catholic teachings and discrepancies between Catholic dogmatic and applied teachings, it should not come as a surprise that Catholic physicians made more statements than physicians from other Christian denominations with respect to whether patients should be able to choose the time of their death; physicians' motivation to overtreat their patients; and the fact that religious beliefs are helpful in the

practice of medicine with terminally ill patients (see Table 13). These are areas where authors have difficulty reconciling Catholic dogma and humanistic applications to medical realities (Catholic Health Association of Canada, 1991; Jean-Paul II, 1995; O'Rooke, 1992).

From this and other research it can be seen that although some differences can be identified between Catholic and other physicians from other Christian denominations, these differences are limited to subjects such as the right of patient to choose the time of their death, physicians' motivation to overtreat their patients, and the usefulness of religious beliefs in the practice of medicine with terminally ill patients. This is not surprising since, according to Luhmann's self-reference theory, the medical professional normative order is not directly affected by religion or morality. The medical profession has developed its own morality based primarily on the sanctity of life. In that sense, medical and Catholic moralities converge and do not contradict one another.

However, in certain conflicting areas, such as withholding and withdrawal of treatments; allowing the patient to choose the time of his death (euthanasia and assisted suicide); and the fact that religious beliefs are helpful in treating terminally ill patients, it could be argued that physicians can adopt responses that are either coherent with a Catholic one or with each physician's individual conscience. This is especially true in areas where medical values have not yet been adhered to by the medical professional normative order. In areas where physicians are asked to act against the obligation not to inflict harm intentionally (for example, in practicing abortions), physicians have not yet reached a consensus. Beauchamp and Veatch (1996) wrote that "codes of health care

ethics from the time of the Hippocratic oath to the present strictly prohibit direct assistance in causing death, even if a patient has good reasons for wanting to die” (p. 151) be it through abortion or assisted suicide. However, the medical code of ethics was changed by the medical profession to allow physicians to perform abortions, thus incorporating into the medical professional norms values that were not recognized before.

#### Medical Professional Values: Medical Normative Order

The insistence of families under threat of lawsuits that everything be done to keep their sick parents alive may explain why physicians act against their patients’ wishes. Physicians’ religious beliefs may also explain the physicians’ reluctance to follow their terminally ill patients’ wishes and try to change their minds. However, these explanations do not stand when both patients and families clearly oppose treatments, as was found in about two thirds of the cases collected for this study (see Table 11). The physicians’ refusal to follow their patients’ wishes is even more difficult to explain since both the law and the Catholic guide for health professionals are clear that no treatment can be commenced nor continued against the patient’s wishes. A more plausible explanation may be found in the values of the medical profession. These values are centered on paternalism and on professional knowledge of when treatments are medically futile.

Paternalism as a medical value. Since Hippocrates, physicians have always insisted that their main goal is to maintain life. According to Roy et al. (1995, p. 6), Hippocrates’ oath was not very much modified by Christian values. For about one century (1870-1970), the medical ethics enjoyed almost complete autonomy in the field of the morality of medical practice (Armstrong, 1997; Foucault, 1963; Starr, 1982). The

ethics of the medical profession is deeply rooted in the principle of beneficence.

Hippocrates's oath provides that "as to disease, make a habit of two things -- to help, or at least to do no harm" (Beauchamp & Childress, 1994, p. 272). Most authors (Beauchamp & Childress, 1994; Hébert, 1996; Wicclair, 1993) agree that the physician's primary obligation is to act for the patient's medical benefit. This entails that physicians must act in the best interest of their patients, taking into consideration all relevant factors.

The beneficence principle as applied by medical professionals is generally known as paternalism. Beauchamp and Childress (1994) define paternalism as "the intentional overriding of one person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden" (p. 274). Medical professionals have based their paternalism on the fact that as professionals they have superior training, knowledge, and insight and are placed in an authoritative position to determine the patient's best interests (Beauchamp & Childress, 1994, p. 274; Beauchamp & Veatch, 1996, pp. 64-68; Hébert, 1996, p.109; Wicclair, 1993, p. 121).

Until the courts handed down judgments affirming the autonomy of patients in decision-making about medical treatments, physicians acted in a paternalistic way, deciding what treatment was best for the patient regardless of his or her opinion. In many cases, they still consider that they are in the best position to make such decisions. From the cases collected for this study, in at least two (Table 9, cases #18, #19), the physician may have been well advised to go ahead with his own judgment. In case #18, a 92-year-old woman complained of prolonged fainting. Although the patient and her niece insisted

that they did not wish any extraordinary measures, the physicians ordered a series of tests that proved ineffective. However, no extraordinary measures were undertaken in this case. In case #19, treatments were given without her consent to a 63-year-old patient with respiratory failure. The treatments were eventually beneficial and the patient was ultimately satisfied. The results in these two cases are reinforced by a study done by Taube, Jenkins, and Bruera (1997), who found that elderly patients are sometimes misdiagnosed as terminal patients. Furthermore, Daly et al. (1993) did an analysis of ethical principles for and against withdrawal of mechanical ventilation in non-terminally ill cases. They came to the conclusion that physicians are concerned by the beneficence principle (to work for the good of the patient and the public good). In that respect, physicians considered that they did not have to follow their patients' wishes in cases where their interventions might lead to the impression that they were opening the door to killing patients.

Gert et al. (1994) further demonstrated physicians' paternalism in stating that patients can only make choices about different options given to them by physicians. According to the authors, it is the physician who makes the decisions about treatments. Consequently, with respect to refusal to treatment, the authors agreed that patients have a right to refuse treatments but that they do not have the right to request treatments that could end their lives. The authors' analysis is patently paternalistic in the sense that patients are deemed not able to make decisions about treatments because they are deemed not to have the necessary scientific knowledge to do so.

Researchers who have studied ethical reasoning in nurses and physicians came to

the conclusion that physicians still stand by the beneficence principle while nurses tended toward patient's autonomy. Uden et al. (1992) carried out a study consisting in comparing ethical reasoning in nurses' and physicians' stories about care episodes with a convenience sample of 23 registered nurses and 9 physicians in the departments of Internal Medicine and Oncology at the University Hospital of Tromsø, Norway. While nurses insisted on patient autonomy and quality of life and death with dignity, physicians insisted on patients' survival and preserving life, thus demonstrating a more paternalistic pattern based on the beneficence ethical principle. In other studies on the differences in the ethical reasoning of nurses and physicians, Janson and Norberg (1989) interpret the nurses' attitudes as being in agreement with Gilligan's (1982) position concerning the ethics of care, which depends on situations. The authors conclude that the nurses reasoned more in accordance with ethics based on empathy and caring, which are seen as preconditions for being moral.

Medical futility as paternalistic value judgment. Since the 1990s, a new trend appeared in which physicians, reacting against the patients' empowerment by the law to make their own decisions, have regained control over the decision-making process by applying the futility concept (King, 1996, pp. 227-229). It is generally acknowledged that the futility debate is a matter of medical judgments. However, medical opinions are not only strictly scientific opinions, but also judgments relying on values (Beauchamp & Veatch, 1996, pp. 350-351).

The Canadian Medical Association's (1994) statement on resuscitative interventions is consistent with the findings of empirical research that the two most

important factors affecting physicians' decisions to withhold or to withdraw treatment are the patients' wishes and the physicians's judgment of medical futility (Curtis et al., 1995; Kock et al., 1994; Miller et al., 1993; Pijnenborg et al., 1995). It is therefore not surprising that the main criteria for DNR orders recommended in the CMA's (1994) statement are the patient's request and the physicians' judgment that the treatment is medically futile (see Table 7, no 8). Although only half of the hospital corporations (#1A, #1B, #5, #7) have adopted the wording of the CMA (1994) statement concerning the absence of obligation to offer futile or nonbeneficial treatment, all hospital corporations have recognized that the diagnosis, prognosis, burdens, and consequences of life-sustaining treatment can be considered by physicians. These physicians, consequently, have the authority to alter DNR orders. Hospital Corporation # 7 goes even further than the CMA (1994) statement in providing that there is no obligation to provide life-sustaining intervention if such treatment is futile, even in the event that further treatments are requested by the patient or his parents or children.

A plausible explanation of the powers granted to physicians may be found in the unwillingness of physicians to allow the patient to decide for him or herself as shown by Kelner and Bourgeault (1993) and Kelner et al. (1993). This unwillingness is further illustrated by the fact that both the CMA (1994) statement and all New Brunswick Hospital Corporations' policies provide that physicians have the authority to bypass the competent patient's refusal of CPR. They can also base the DNR order on their own evaluation of the patient's irreversible condition or damage, the medical futility, and the burdens or consequences of life-sustaining treatment. This is the acknowledgment that



physicians have the last word and that their professional medical opinion is the governing factor.

Rasooly et al. (1994) found that only 52.7% of the Canadian hospital policies made reference to futility. They nevertheless wrote that “since use of the futility standard in health care decision-making remains highly controversial, frequent reliance on futility in Canadian policies is disturbing and deserves further attention” (p. 1269). It should be even more disturbing in New Brunswick, where the policies of 100% of Hospital Corporations insisted on the use of the futility standard. Wilson (1996) commented that “DNR policies may be immaterial to clinical decision-making, with autonomous health professionals functioning in ways not entirely dissimilar to, but separate from, policy” (p. 277).

The attempt by physicians to regain the decision-making control in terminal care treatments has moved them to do things that were unthinkable a few years ago. More and more physicians now use medical futility to decide not to treat patients even when the patient and his family are asking them to do all in their power to maintain the patient’s life. The law, however, is not clear on the matter. In at least two American cases (In re: the Conservatorship of H.M. Wanglie, 1991; In the matter of Baby K, (1993), the courts have ordered physicians to treat even if they think it is medically futile. In Canada, the Manitoba Court of Appeal did not follow the American decision in Baby K, and ruled that in the case of a vegetative child, it is in no one’s interest to maintain the life of a terminally ill patient who is in an irreversible vegetative state (Child and Family Services of Central Manitoba v. R.L. and S.L.H., 1997). However, in 1998, two cases have made

the headlines. In July 1998, Montreal physicians ignored the family's opposition to the hospital decision to turn off the system that had helped the patient breathe for the past 4 weeks because they were unable to reverse the unrelenting course of his disease (Ha, 1998). In November 1998, the wife of a hospitalized Parkinson's patient who had suffered several strokes asked a Manitoba Court for an injunction to force physicians to remove a DNR order from the patient's medical chart (Roberts, 1998). The Court granted an interim injunction ordering that the DNR order be lifted from the patient's chart (Fine & Roberts, 1998).

Medical normative order restated. Keeping in mind the similarities between Catholic religious and the medical normative orders, on the one hand, and the discrepancies between the legal and medical normative orders, on the other, one may wonder how physicians can live in any North American society without being affected by the law. It is generally accepted that the law has invaded most areas of our lives, so much so that Roy et al. (1995, p. 77) have stated that it has "phagocyted" bioethics. Furthermore Fisher (1992) acknowledged that the law is one of the most powerful instruments in changing physicians' attitudes and behaviors. Finally, many researchers have asked legislators to clarify the law in order to facilitate changes in the medical profession concerning the treatment of terminally ill patients (Gert et al., 1994; Tomlinson & Czlonka, 1995). However, Teno et al. (1997a, 1997b, 1997c, 1997d), Wilson (1996, 1997), and the results of the present study show that physicians do not necessarily follow the law. In fact, many times, they patently go against the law when it contradicts their medical professional values.

Tomlinson and Czlonka (1995) proposed a model policy that tries to conciliate patients' rights and physicians' integrity. That policy provided that resuscitation be attempted for all patients in cardiopulmonary arrest unless the patient is brain-dead and declared legally dead, or the patient or his surrogate has requested a DNR order, or there has been a determination that attempted resuscitation would be futile or harmful. That policy is quite similar to the one approved by the CMA (1994) on resuscitative interventions. However, as was seen, it was not followed everywhere by New Brunswick physicians.

Confronted with the competitors of medical ethics, physicians are trying to reclaim some dominance. Hill (1994) advocated that medicine, like science, calls for an ethic derived directly from its own activity. The only alternative, he believed, is an ethic for medicine derived from the action of medicine itself, which would be understood as something medicine, by virtue of its activity, gives shape to, but meanwhile is indispensable to it if it is to be practiced ethically. The concept of medical futility may be the form that could satisfy the aspirations physicians have to develop an ethical criteria based on their professional and scientific values.

Hill's preoccupations may not be farfetched in the light of Luhmann's (1985) self-reference theory. Luhmann's (1983) preoccupations was to know "how a system can transform noise [information coming from other subsystems] into information which keeps in motion the self-referential network of internal processes" (p. 994). The characteristics of autopoietic (self-reference) systems are, according to Luhmann: "that they themselves produce and delimit the operative unity of their elements ... through the

operation of their elements and that it is precisely this autopoietic process that lends its own unity to the system” (pp. 281-282).

In order to derive an ethics from the medical professional values that would include the legal norms adopted by courts or by legislators, one would have to know how Luhmann’s self-reference theory explains how social systems (such as the medical professional normative order) produce and delimit their own elements as medically relevant units. Luhmann (1985) wrote that a social system

produces its own elements as legally relevant units by the fact that it lends normative quality precisely with the aid of such elements (e.g. birth, death, accident, actions, decision). These are given a special status that is solely relevant for the [medical] system on the basis of the normative context in which they function as elements upon which others depend. (p. 283)

In other words, it seems clear that changes to physicians’ attitudes and behaviors in respecting their terminally ill patients’ wishes not to be treated can only occur from within the medical profession. These changes cannot be extracted by force from the law, which is a normative order seen by physicians as totally different from the medical normative order. In their statements, physicians in this study described their perceived differences between law and medicine: Law is general while medicine deals with particular cases; law is based on precedents while medicine deals with facts. On the other hand, some statements by physicians say that lawyers deal with facts while physicians deal with disease, emotions, and ethical problems. Strangely, some physicians’ statements say that lawyers are not preoccupied by patients wishes but that physicians do try to

respect a patient's wishes. Finally, statements were made by physicians to the effect that law courts are not competent to deal with moral and ethical problems; that should be left to competent bodies, that is, the medical profession.

If Luhmann's self-reference theory is true, forcing physicians to respect their terminally ill patients' wishes by using the law might not be very useful. Effective change could be achieved only through an educational process that has to be carried out by physicians themselves in concurrence with their medical activity.

### Cultural Values

The most significant differences among the physicians in this study, in addition to their religious beliefs and affiliations, were their cultural differences. There is considerable research dealing with the influence of cultural values on terminally ill patients (Anderson, Blue & Lau, 1991; Beechmen, 1995; Blackhall, Murphy, Frank, Michel, & Azen, 1995; Schwartz, 1994). Several studies have explored the influence of ethnicity or culture in the attitudes of nurses toward terminally ill patients (Davidson et al., 1990; Levery et al., 1992; Wilkies, White, & Tolley, 1993). However, no such studies could be found regarding the attitudes of physicians in treating terminally ill patients.

Furthermore, cultural values are not directly taken into account by the systemic normative pluralism model that was described. According to Luhmann, six main subsystems are at work within society: the economic system, the legal system, the political system, the scientific system, the religious system, and the educational system (Gras, 1990, p. 395). Although cultural values are not specifically recognized by Luhmann, one could argue that they fall in with the educational system. The educational

system is generally seen as including not only the school system but also the whole educational system, including education received from the family.

Furthermore, some authors who have examined normative pluralism have recently integrated cultural values into a systems analysis. De Sousa Santos (1985, 1988) has proposed a map of normative orders that allows one to take into consideration power relations within society. According to De Sousa Santos, four structural areas exist within society, each of which corresponds a form of power: systemic normative order concerns the state and international relations; territorial normative order deals with regulation of the country; productive normative order is concerned with labor market and production; finally, domestic normative order regulates the private area of the family. In the domestic normative order, one would also put cultural, religious, and ethnic values. The rules of the domestic normative order are not produced by each individual family but by the social structure as a whole. These rules are transmitted through what is generally called culture.

The results of interviews with physicians lead to the conclusion that cultural values should be taken into consideration in explaining physicians' attitudes toward treatment of terminally ill patients who refuse treatment.

### Conclusion

The present study was carried out with the purpose of answering the following question: "Why is it many physicians do not follow terminally ill patients' directives for nontreatment once there is no reasonable hope for a cure?" Six findings or conclusions can be derived from the study. Before outlining the conclusions, one important insight

must be mentioned. Using different sources was very helpful in the study of why physicians tend not to respect their terminally ill patients' wishes not to be treated. In this study, evidence was collected from three different sources: case studies respecting treatments of New Brunswick terminally ill patients against their consent; analysis of New Brunswick Hospital Corporations' policies on end-of-life treatments; and semistructured interviews with physicians. Using different sources was instrumental in achieving three things. First, it provided a more complete picture of the different reasons why physicians act as they do. Second, it allowed to supplement missing information from a specific single source. Third, it helped to avoid certain assumptions that would have been accepted without question if only one source of evidence had been available. Finally, the use of both qualitative and quantitative analysis was important. Without a statistical test applied to the analysis of physicians' interviews, it would not have been possible to discover the effect of culture on the attitudes of physicians, since neither available research nor the theoretical model pointed in that direction.

The first finding is that in cases where parents of terminally ill patients insisted that every available measure be taken by physicians to keep their parent alive, physicians were placed in difficult situations. No research could be found to corroborate the figures from this study that this situation occurred in about one third of the cases. Fear of litigation may then be a powerful reason for physicians to bypass their terminally ill patients' wishes not to be treated. Fear of litigation may be an even stronger argument in New Brunswick, since this province has not yet changed the common law, especially with respect to power of attorney and proxy designation in provision of incapacity. The

blurring of the law was further aggravated by New Brunswick Hospital Corporation's policies on "Do-not-resuscitate" orders that gave physicians the power to bypass their patients' wishes, especially when parents do not agree with those wishes.

The second finding from this study is that physicians' fear of litigation, however, was not the sole reason why physicians did not respect their terminally ill patients' wishes not to be treated. Fear of litigation, on the contrary, should prod physicians not to treat their terminally ill patients against their wishes since the law is clear that competent patients cannot be treated against their will. Fear of litigation was, therefore, advocated as a reason by physicians not to respect their patients' wishes in cases where families did not agree with the patients' refusal of treatment, but was rejected by physicians when both patients and their families insisted that physicians respect the patient's wishes.

The third finding of this study is that religious beliefs may be important in explaining why physicians refused to respect their terminally ill patients' wishes not to be treated. Still, more research should be conducted with physicians in order to pursue the effects of their religious beliefs.

The fourth and most striking finding of this research, however, may be that medical professional values were demonstrated to be the single most important reason why physicians acted the way they did in the treatment of their terminally ill patients. Even when the law was clear about the obligation to follow the wishes of capable terminally ill patients, most New Brunswick Hospital Corporations' policies provided that physicians did not have to take into account these wishes except when the patient was in an irreversible condition. Although blatantly against the law of Canada and against the



CMA's (1994) statements, this policy was promoted by most New Brunswick Hospital Corporations. Thus professional medical values are much more important than the established law in New Brunswick. Furthermore, when there were conflicts between professional medical values and the law, the New Brunswick administrative policies sided with the medical profession and turned their backs on the law of the land.

The fifth finding was unexpected. Neither the relevant literature nor the theoretical model could lead one to foresee that cultural values could play such an important role in defining the attitudes of physicians concerning treatment of terminally ill patients. However, the use of a statistical test in analyzing the interviews done with physicians showed that the most discrepancies were found with respect to cultural differences. A suggestion was made to merge into the systemic normative pluralism model, the concept of the domestic or cultural normative order described by De Sousa Santos (1985, 1988).

Sixth, this research showed that the normative pluralism model used in this study is far from irrelevant. Different normative orders, especially the legal, religious, administrative, professional, and cultural orders, did interact to regulate physicians' interventions in difficult situations. For example, administrative policies were being used to supplement the void in the legal norms applicable to terminally ill patients in New Brunswick. This was especially true for incapable patients. On the other hand, the different normative orders may be more self-regulating and less permeable to one another than it was first thought. Luhmann's (1985, 1994) concept of self-reference, that is, the internal processes of the system which lead to self-reproduction, may explain why physicians have so much difficulty adapting their behaviors to meet the courts' legal

decisions and the legislative changes respecting the rights of terminally ill patients who refuse treatments.

### **Recommendations**

The results of this study lead to the following recommendations. A first set of recommendations will be directed at future researchers. The statistical analysis of the interviews with physicians showed that cultural values (French, English, and bilingual) were the single most important variable influencing which issues physicians will talk about concerning treatment of terminally ill patients. Since no other study could be found that considered the effect their ethnic and cultural values had on physicians' attitudes regarding treatment of their terminally ill patients, more research is needed that would include cultural values.

Since little research has explored why and in what ways physicians act against their patients' wishes when refusing them life-prolonging treatments, more research is needed in that area. The study gives some indications explaining why physicians acted the way they did, but this research was limited to one Canadian province and may not be valid for other Canadian provinces, let alone the American context.

Researchers should take into account the relative strengths of using different sources to collect evidence for their research. Using more than one source of evidence facilitated the building of a more complete picture of the situation under study. It also provided evidence that can question the evidence gathered from other sources. Finally, the use of both quantitative and qualitative data may also be very valuable in discriminating

between different factors or variables, especially when statistical tests can be used together with qualitative analysis.

The second set of recommendations could be aimed at social theorists. As was explained and demonstrated throughout this research, systems theory combined with normative pluralism does represent an interesting way of looking at the problem of how different social organizations function, influence each other, and change their own norms and values. Luhmann's theory of self-reference provides an interesting explanation to those questions.

The third set of recommendations could be addressed to social policy makers. If Luhmann's self-reference theory correctly describes how each social organization functions and changes, adopting laws does not necessarily determine that they will be followed by the professions aimed at which they are aimed, most specifically the medical profession. Since according to Luhmann's self-reference theory the norms of a specific organization such as the medical society can only be transformed by self-reference, that is, by assimilation of external norms by transforming them into the norms of that specific organization, legislators should embark on a process of discussion with the medical profession before imposing upon them particular rules and regulations. Of course, the same is also true for laws affecting other organizations.

Finally, it should be mentioned that medical professional values and ethical norms would not necessarily be destroyed if physicians were to respect their patients' wishes not to be treated once there is no hope for a cure. The medical profession already has among its numerous principles the obligation of physicians to respect the autonomy of their

patients. As one physician stated in his interview: “the law may go against a patient’s wishes but physicians want to respect their patient’s wishes.” Let us hope that the majority of physicians will adhere to such statements in the near future.

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## Appendix A

### Guide for the Interview of Physicians

#### Introduction

I am Norma Poirier, a Registered Nurse, teaching at the Université de Moncton School of Nursing, and a Ph.D. (Health Services) candidate at Walden University. My doctoral dissertation research deals with the perceptions of physicians regarding terminally-ill patients who refuse treatment.

As I told you when you agreed to participate in this research, strict confidentiality will be observed: the records of this study will be kept private and it will not be possible to identify any physician or patient.

I will send you the transcript of the interview once it has been typed to make sure you still agree with what you have said and still allow me to use the interview.

#### Opening questions

1. What has been your most difficult case in deciding what treatment to prescribe to a terminally-ill patient?
2. What problems, if any, do physicians encounter when they decide to withhold or withdraw treatments?

**[Questions regarding the possible conflicts between different normative orders]**  
**[Questions respecting the possible conflicts between medical ideology and the law]**

3. What are your views about the desire of patients to control the timing and circumstances of their own death?
4. What is your opinion about who has the final authority to make decisions regarding prolongation of terminally-ill patients' lives?  
*[Do not ask the following questions but explore further if the physician does not cover the following: (1) the role of the patient when he is competent and he is incompetent; (2) the role of the family in both cases (competent and incompetent patient) (4) the role of the physician; (5) the role of the health professional team].*
5. What are your views about patients who have previously arranged for advance directives respecting their refusal of treatment or their refusal to be resuscitated?
6. What problems do physicians encounter when a patient's desires to end life-sustaining efforts are resisted by family members?
7. How do you feel about the fact that laws and the courts are more and more involved in the decision-making process about the treatment of terminally-ill patients?
8. Under what circumstances do you feel that the law may conflict with your medical professional judgment in deciding the treatment of terminally-ill patient?

*[Do not ask the following questions but explore further if the physician does not cover the following: (1) What should a physician do when he encounters conflicts between the law and his medical professional judgment in the treatment of terminally-ill patients? (2) How can conflicts between the law and physician's medical professional judgment affect his treatment of terminally-ill patients?]*

*[Questions respecting the possible conflicts between medical ideology and the hospital administrative policies]*

9. What do you think about your hospital's policy on withholding or withdrawing medical therapy to terminally-ill patients? *[if asks for precision, rephrase using Do-not-resuscitate orders]*
10. How has the hospital's policy on DNR orders affected your practice in prescribing treatments to patients?
11. Under what circumstances do you feel the hospital's policies regarding DNR orders may conflict with your medical professional judgment in your decisions concerning the use of life-sustaining technology?  
*[Do not ask the following questions but explore further if the physician does not cover the following: (1) What should a physician do when he encounters conflicts between the hospital's policy and his medical professional judgment in the treatment of terminally-ill patients? (2) How can conflicts between the hospital's policy and physician's medical professional judgment affect his treatment of terminally-ill patients?]*
12. *[To be asked only if question 7 was not answered adequately]*. What are your concerns about that increased regulation of the dying process (by law or by hospital's administrative policies)?

*[Questions respecting the possible conflicts between medical ideology and the physician's religious beliefs]*

13. Under what circumstances do you feel your religious beliefs may affect your treatment of terminally-ill patients?
14. What do you do in those circumstances?  
*[Do not ask the following questions but explore further if the physician does not cover the following: (1) What should a physician do when he encounters conflicts between his religious beliefs and his medical professional judgment in the treatment of terminally-ill patients? (2) How can conflicts between religious beliefs and physician's medical professional judgment affect his treatment of terminally-ill patients?]*
15. What kinds of strategies should be developed to make it easier for physicians to accommodate patients' wishes to influence the circumstances of their dying?

#### **Closing questions**

- 16 Do you have any opinions respecting the fact that Dr. Morrisson was prosecuted for mercy killing a terminally ill patient? Do you think that physicians will be affected by that prosecution?

#### **Demographic profile**

Age \_\_\_\_\_ Sex \_\_\_\_\_  
 Language \_\_\_\_\_ Where studied medicine? \_\_\_\_\_  
 Specialty: \_\_\_\_\_ Number of years in practice \_\_\_\_\_  
 Hospital Corporation: Moncton City \_\_\_\_\_ George L. Dumont \_\_\_\_\_ Both \_\_\_\_\_  
 Religion \_\_\_\_\_  
 Religiosity (Do you consider yourself a religious person?) \_\_\_\_\_

## **Appendix B**

### **Interview Consent Forms**

You are invited to participate in a research study on the perceptions of physicians regarding terminally-ill patients who refuse treatment. You were selected as a possible participant because you are one of some 20 selected physicians from the Greater Moncton Area where the research is conducted.

The research is being conducted by Norma Poirier, a Registered Nurse, teaching at the School of Nursing, Université de Moncton, and a Ph.D. (Health Services) candidate at Walden University.

#### **Background information:**

My research deals with the perceptions of physicians regarding terminally-ill patients who refuse treatment.

If you agree to be in this study, we would ask you to submit to a semi-structured interview on your perceptions regarding the treatment of terminally-ill patients. The interview will be taped, then transcribed verbatim before being submitted to content analysis, together with the interviews of other physicians.

#### **Confidentiality:**

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be kept in a locked file; only the researcher will have access to the records. After being transcribed, the tapes will be erased.

#### **Voluntary Nature of the Study:**

Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

#### **Contacts and Questions:**

The researcher conducting this study is a student at Walden University. You may ask any questions you have now. If you have questions later, you may contact her at the School of Nursing, Université de Moncton, Moncton (NB) E1A 3E9; 506-858-4263. You will be given a copy of this form to keep for your records.

**Statement of consent:**

**I have read the above information. I have asked questions and received answers. I consent to participate in the study.**

**Signature: \_\_\_\_\_ Date: \_\_\_\_\_**

**Signature of  
Investigator: \_\_\_\_\_ Date: \_\_\_\_\_**

**I will send you the transcript of the interview once it has been typed to make sure you still agree with what you have said and still allow me to use the interview.**

## **Appendix C**

### **Case Studies Interview Guide**

#### **FACTS**

- 1) describe the events which brought the hospitalization of the patient.

#### **EXPRESSION OF PATIENT'S WILL**

- 2) did the patient express his intent before his hospitalization? If so, in what form? verbally, by writing, through a living will, through a personal or legal representative, etc.
- 3) upon being hospitalized, what problems, if any, did he or she encounter with respect to consent or refusal to consent to treatment?

#### **REASONS GIVEN BY THE PHYSICIANS FOR REFUSING TO FOLLOW PATIENT'S WISHES NOT TO BE TREATED**

- 4) what reasons (ethical, moral, legal, social, cultural, economic or other) were given by the medical persons in refusing to respect the patient's wishes concerning the treatments?

#### **CONSEQUENCES**

- 5) What were the consequences of the refusal to respect the patient's wishes?
  - a) economic consequences of the patient's hospitalization for himself and/or for his family?
  - b) social consequences for the patient and/or his family?
  - c) health consequences for the patient and/or his family?
  - d) consequences on the family life of the patient and/or members of his family?

## Appendix D

### Case Studies Consent Form

#### PRESENTATION

I am \_\_\_\_\_ and I am doing a university course under the supervision of Norma Poirier, a professor of nursing at Université de Moncton.

#### OBJECT OF THE INTERVIEW

Our research deals with one of the problems that elders encounter when they insist that their views and wishes be respected concerning their right to accept or refuse treatment and their right not to be resuscitated nor maintained alive artificially.

#### CONFIDENTIALITY

I, (name of student \_\_\_\_\_) and my professor Norma Poirier, hereby undertake not to make public any information which could lead to the identification of persons who will be mentioned in your interview.

#### CONSENT

I, (name of patient or next-of-kin \_\_\_\_\_), hereby, freely give the information with respect to the case history and consent to Norma Poirier and (name of student: \_\_\_\_\_) using the relevant information in as much as no one will be able to identify anyone mentioned in my interview. However, I reserve the right to revoke consent and my participation at any time of the project.

\_\_\_\_\_  
Name of informer

\_\_\_\_\_  
witness (student)

\_\_\_\_\_  
Day Month Year

Approved by the Université de Moncton ethics committee, February 1994.



## Appendix E

Distribution of physicians' statements into 8 main categories, 33 themes and 77 sub-themes

Categories, themes and sub-themes of statements by physicians	N	%
<b>TF1. Statements in relation to death</b>	<b>98</b>	<b>17.85</b>
<i>TF1.1 Difficulty for physicians</i>	16	2.91
<i>TF1.2 Patients' decision about time of one's death</i>	11	2.00
TF1.2.1 Patient should be able to decide	9	1.64
TF1.2.2 Patient should not be able to decide	2	0.36
<i>TF1.3 Patients' decision where to die</i>	5	0.91
TF1.3.1 Patient decides	4	0.73
TF1.3.2 Family decides	1	0.18
<i>TF1.4 Physicians' diagnosis of terminal illness</i>	20	3.64
TF1.4.1 Mental problems affecting patient's competency	10	1.82
TF1.4.2 Make the proper diagnosis	2	0.36
TF1.4.3 Tell the patient about his terminal illness	8	1.46
<i>TF1.5 Active euthanasia</i>	46	8.38
TF1.5.1 Physician's perspective	20	3.64
TF1.5.2 Legal perspective	12	2.19
TF1.5.3 Religious perspective	1	0.18
TF1.5.4 Ethical perspective	5	0.91
TF1.5.5 Society's perspective	8	1.46
<b>TF2. Statements in relation to withholding and/or withdrawing treatments</b>	<b>154</b>	<b>25.05</b>
<i>TF2.1 Who should decide for the competent patient?</i>	46	8.38
TF2.1.1 Patient should decide	17	3.10
TF2.1.2 Family should decide	4	0.73
TF2.1.3 Physician should decide	25	4.55
<i>TF2.2 Who should decide for the incompetent patient?</i>	52	9.47
TF2.2.1 Problem of defining competency and incompetency	1	0.18
TF2.2.2 Patient should decide	43	7.83
TF2.2.2.0 problem of informed consent	3	0.55
TF2.2.2.1 patient decides through verbal expression when competent	3	0.55
TF2.2.2.2 patient decides through living will or advance directives	11	2.00
TF2.2.2.3 consequences of advance directives on families	16	2.91
TF2.2.2.4 perception of advance directives by physicians	10	1.82
TF2.2.3 Family should decide	5	0.91
TF2.2.4 Physician should decide	3	0.55
<i>TF2.3 People who should be involved in the decision process</i>	18	3.28
TF2.3.1 Should involve the family	8	1.46
TF2.3.2 Should involve the whole medical team	5	0.91
TF2.3.3 Courts should decide	1	0.18
TF2.3.4 Should consult the clinical ethics committee	4	0.73
<i>TF2.4 Problems relating to refusal or withdrawal of treatments</i>	38	6.92
TF2.4.0 Physicians' problems relating to refusal or withdrawal of treatments	7	1.28
TF2.4.1 Conflicts created by family members opposing patient's wishes	22	4.01

TF2.4.2	Problems created by the law	5	0.91
TF2.4.3	Conflicts created by the medical personnel	4	0.73
<b>TF3. Statements of physicians about overtreatment of terminally ill patients</b>		<b>41</b>	<b>7.47</b>
<i>TF3.1 Physicians' difficulties concerning overtreatment</i>		15	2.73
<i>TF3.2 Physicians' external motives to overtreat</i>		7	1.28
TF3.2.1	Patient's request	3	0.55
TF3.2.2	Family's request	2	0.36
TF3.2.3	Society's request	2	0.36
<i>TF3.3 Physicians' internal motives to overtreat</i>		19	3.46
TF3.3.1	To avoid criminal and civil litigation	2	0.36
TF3.3.2	To follow medical ideology	12	2.19
TF3.3.3	Physician knows best	4	0.73
TF3.3.4	Fear patient may be abandoned by the nursing staff	1	0.18
<b>TF4. Statements related to conflicts between law and medical profession</b>		<b>85</b>	<b>15.48</b>
<i>TF4.1 Distinction between law and medicine</i>		4	0.73
<i>TF4.2 Situations where law creates problems for physicians</i>		49	8.93
TF4.2.1	Euthanasia	8	1.46
TF4.2.2	Assisted suicide	2	0.36
TF4.2.3	Fear of litigation	11	2.00
TF4.2.4	Pain control	21	3.83
TF4.2.5	Failure of communication	7	1.28
<i>TF4.3 No conflict between law and medicine</i>		3	0.55
<i>TF4.4 Law's functions</i>		29	5.28
TF4.4.1	Determines how to behave	6	1.09
TF4.4.2	Establishes controls	2	0.36
TF4.4.3	States patients' rights	8	1.46
TF4.4.4	Courts lack of knowledge about medicine to make decisions	4	0.73
TF4.4.5	Laws are general	1	0.18
TF4.4.6	Lawyers	6	1.09
TF4.4.7	Physicians lack of knowledge about the law	2	0.36
<b>TF5. Statements concerning hospital administrative policies</b>		<b>61</b>	<b>11.11</b>
<i>TF5.1 General comments</i>		2	0.36
<i>TF5.2 Procedures</i>		11	2.00
TF5.2.1	Write the order and circumstances in patient's file	7	1.28
TF5.2.2	If unsure, consult	4	0.73
<i>TF5.3 Physicians' knowledge of hospital administrative policies</i>		12	2.19
TF5.3.1	Administrative policies do exist	5	0.91
TF5.3.1	Not aware of any administrative policies	7	1.28
<i>TF5.4 Influence of hospital administrative policies</i>		17	3.10
TF5.4.1	No influence - physician decides	11	2.00
TF5.4.2	May be useful	3	0.55
TF5.4.3	May be harmful	3	0.55
<i>TF5.5 Physicians' opinions with respect to Hospital administrative policies</i>		14	2.55
TF5.5.1	No problem with administrative policies	7	1.28
TF5.5.2	Unsatisfied with administrative policies	6	1.09
TF5.5.3	The problem is more complex than appears	1	0.18

<i>TF5.6 Roles given to families by administrative policies</i>	5	0.91
<b>TF6. Statements concerning pain control</b>	<b>57</b>	<b>10.38</b>
<i>TF6.1 Physicians' difficulties as regards pain control</i>	2	0.36
<i>TF6.2 Physicians perceptions concerning palliative care</i>	11	2.00
TF6.2.1 Palliative care by physicians	10	1.82
TF6.2.2 Palliative care by nursing staff	1	0.18
<i>TF6.3 Physicians' perceptions of patients' and families' needs</i>	10	1.82
TF6.3.1 Physicians' opinions respecting palliative care	4	0.73
TF6.3.2 Physicians' perception of patients' and families's needs	6	1.09
<i>TF6.4 Strategies to help physicians accomodate patients' wishes</i>	34	6.19
TF6.4.1 Continuing education of physicians	11	2.00
TF6.4.2 Physicians must be more open and listen more	10	1.82
TF6.4.3 Laws and policies	3	0.55
TF6.4.4 Work more closely with lawyers	1	0.18
TF6.4.5 Be more informed about ethics	9	1.64
<b>TF7. Statements concerning the effect of physicians' religious beliefs on treatment of terminally ill patients</b>	<b>34</b>	<b>6.19</b>
<i>TF7.1 Influence of religious beliefs on medical practice</i>	22	4.01
TF7.1.1 Religious beliefs are helpful	12	2.19
TF7.1.2 Religious beliefs have no influence	8	1.46
TF7.1.3 Religious beliefs have a big influence	2	0.36
<i>TF7.2 Physician conformity to patient beliefs</i>	5	0.91
<i>TF7.3 Conflicts between physicians' and patients' beliefs</i>	7	1.28
TF7.3.1 When there are conflicts	5	0.91
TF7.3.2 There are no conflicts	2	0.36
<b>TF8. Statements respecting patients' quality of life</b>	<b>7</b>	<b>1.28</b>
<i>TF8.1 Who decides on patient's quality of life</i>	1	0.18
TF8.1.2 Patient decides	1	0.18
<i>TF8.2 Problems for physicians when deciding on quality of life issue</i>	2	0.36
<i>TF8.3 Desirable attitudes from physicians</i>	2	0.36
<i>TF8.4 Administration of pain killers in high dosages</i>	2	0.36
<b>Others unable to classify</b>	<b>12</b>	<b>2.19</b>
<b>Total</b>	<b>549</b>	<b>100</b>

## **Appendix F**

**Results of statistical analysis of themes taking into consideration  
sex, religion, language, hospital corporation affiliation,  
and years of practice**

Theme		Proportion mentioning the theme (%)		p- value for the Fisher exact test on equality of proportions
		Sex		
Code	Description	F	M	
	<b>Number of subjects</b>	<b>6</b>	<b>18</b>	
TF1	Statements in relation to death	100.0	94.4	1.000
TF1_1	Difficulty for physicians	100.0	50.0	0.116
TF1_2	Patients' decision about time of one's death	100.0	55.6	0.122
TF1_2_1	Patient should be able to decide	100.0	55.6	0.122
TF1_2_2	Patient should not be able to decide	0.0	11.1	1.000
TF1_3	Patients' decision where to die	0.0	11.1	1.000
TF1_3_1	Patient decides	0.0	11.1	1.000
TF1_3_2	Family decides	0.0	5.6	1.000
TF1_4	Physicians' diagnosis of terminal illness	40.0	61.1	0.618
TF1_4_1	Mental problems affecting patient's competency	20.0	22.2	1.000
TF1_4_2	Make the proper diagnosis	20.0	5.6	0.395
TF1_4_3	Tell the patient about his terminal illness	0.0	55.6	0.046**
TF1_5	Active euthanasia	100.0	72.2	0.545
TF1_5_1	Physician's perspective	40.0	55.6	0.640
TF1_5_2	Legal perspective	60.0	33.3	0.127
TF1_5_3	Religious perspective	0.0	5.6	1.000
TF1_5_4	Ethical perspective	60.0	11.1	0.048**
TF1_5_5	Society's perspective	20.0	27.8	1.000
TF2	Statements in relation to withholding and/or withdrawing treatments	100.0	100.0	n.a.
TF2_1	Who should decide for the competent patient?	100.0	100.0	n.a.
TF2_1_0	n.a.	0.0	22.2	0.539
TF2_1_1	Patient should decide	100.0	100.0	n.a.
TF2_1_2	Family should decide	0.0	16.7	1.000
TF2_1_3	Physician should decide	40.0	55.6	0.640
TF2_2	Who should decide for the incompetent patient?	100.0	100.0	n.a.
TF2_2_1	Problem of defining competency and incompetency	20.0	0.0	0.217
TF2_2_2	Patient should decide	100.0	100.0	n.a.
TF2_2_2_0	problem of informed consent	40.0	27.8	0.621
TF2_2_2_1	patient decides through verbal expression when competent	40.0	11.1	0.184
TF2_2_2_2	patient decides through living will or advance directives	60.0	94.4	0.395
TF2_2_2_3	consequences of advance directives on families	20.0	33.3	1.000
TF2_2_2_4	perception of advance directives by physicians	20.0	66.7	0.127
TF2_2_3	Family should decide	60.0	27.8	0.297
TF2_2_4	Physician should decide	40.0	11.1	0.184

Theme		Proportion mentioning the theme (%)		p- value for the Fisher exact test on equality of proportions
Code	Description	Sex		
		F	M	
	Number of subjects	6	18	
TF2_3	People who should be involved in the decision process	80.0	66.7	1.000
TF2_3_1	Should involve the family	40.0	55.6	0.640
TF2_3_2	Should involve the whole medical team	20.0	16.7	1.000
TF2_3_3	Courts should decide	20.0	0.0	0.217
TF2_3_4	Should consult the clinical ethics committee	0.0	16.7	1.000
TF2_4	Problems relating to refusal or withdrawal of treatments	100.0	94.4	1.000
TF2_4_0	Physicians' problems relating to refusal or withdrawal of treatments	20.0	27.8	1.000
TF2_4_1	Conflicts created by family members opposing patient's wishes	100.0	94.4	1.000
TF2_4_2	Problems created by the law	0.0	22.2	0.539
TF2_4_3	Conflicts created by the medical personnel	0.0	5.6	1.000
TF3	Statements of physicians about overtreatment of terminally ill patients	100.0	100.0	n.s.
TF3_1	Physicians' difficulties respecting overtreatment	40.0	61.1	0.618
TF3_2	Physicians' external motives to overtreat	40.0	27.8	0.621
TF3_2_1	Patient's request	20.0	16.7	1.000
TF3_2_2	Family's request	0.0	16.7	1.000
TF3_2_3	Society's request	20.0	5.6	0.395
TF3_3	Physicians' internal motives to overtreat	60.0	63.3	0.291
TF3_3_1	To avoid criminal and civil litigation	0.0	16.7	1.000
TF3_3_2	To follow medical ideology	60.0	72.2	0.621
TF3_3_3	Physician knows best	0.0	27.8	0.545
TF3_3_4	Fear patient may be abandoned by the nursing staff	0.0	5.6	1.000
TF4	Statements related to conflicts between law and medical profession	100.0	100.0	n.s.
TF4_1	Distinction between law and medicine	20.0	11.1	0.539
TF4_2	Situations where law creates problems for physicians	100.0	94.4	1.000
TF4_2_1	Euthanasia	20.0	33.3	1.000
TF4_2_2	Assisted suicide	20.0	0.0	0.217
TF4_2_3	Fear of litigation	60.0	55.6	1.000
TF4_2_4	Pain control	80.0	72.2	1.000
TF4_2_5	Failure of communication	40.0	38.9	1.000
TF4_3	No conflict between law and medicine	0.0	22.2	0.539
TF4_4	Law's functions	60.0	66.9	0.539
TF4_4_1	Determines how to behave	40.0	22.2	0.576
TF4_4_2	Establishes controls	20.0	5.6	0.395
TF4_4_3	States patients' rights	20.0	27.8	1.000
TF4_4_4	Courts lack of knowledge about medicine to make decisions	20.0	22.2	1.000
TF4_4_5	Laws are general	0.0	5.6	1.000

Theme		Proportion mentioning the theme (%)		p- value for the Fisher exact test on equality of proportions
		Sex		
Code	Description	F	M	
	<b>Number of subjects</b>	<b>6</b>	<b>18</b>	
TF4_4_6	Lawyers	20.0	38.9	0.621
TF4_4_7	Physicians lack of knowledge about the law	20.0	5.6	0.395
TF5	Statements respecting hospital administrative policies	100.0	100.0	n.a.
TF5_1	General comments	0.0	11.1	1.000
TF5_2	Procedures	60.0	33.3	0.343
TF5_2_1	Write the order and circumstances in patient's file	60.0	27.8	0.297
TF5_2_2	If unsure, consult	0.0	22.2	0.539
TF5_3	Physicians' knowledge of hospital administrative policies	100.0	72.2	0.545
TF5_3_1	Administrative policies do exist	20.0	44.4	0.611
TF5_3_2	No aware of any administrative policies	100.0	50.0	0.116
TF5_4	Influence of hospital administrative policies	60.0	66.7	1.000
TF5_4_1	No influence - physician decides	60.0	61.1	1.000
TF5_4_2	May be useful	20.0	11.1	0.539
TF5_4_3	May be harmful	20.0	11.1	0.539
TF5_5	Physicians' opinions with respect to Hospital administrative policies	40.0	83.3	0.069*
TF5_5_1	No problem with administrative policies	20.0	72.2	0.056*
TF5_5_2	Unsatisfied with administrative policies	20.0	22.2	1.000
TF5_5_3	The problem is more complex than appears	0.0	5.6	1.000
TF5_6	Roles given to families by administrative policies	40.0	0.0	0.040**
TF6	Statements respecting pain control	100.0	94.4	1.000
TF6_1	Physicians' difficulties as regards pain control	20.0	11.1	0.539
TF6_2	Physicians perceptions concerning palliative care	20.0	38.9	0.621
TF6_2_1	Palliative care by physicians	20.0	38.9	0.621
TF6_2_2	Palliative care by nursing staff	0.0	5.6	1.000
TF6_3	Physicians' perceptions of patients' and families' needs	0.0	27.8	0.545
TF6_3_1	Physicians' opinions respecting palliative care	0.0	11.1	1.000
TF6_3_2	Physicians' perception of patients' and families' needs	0.0	16.7	1.000
TF6_4	Strategies to help physicians accommodate patients' wishes	100.0	77.8	0.539
TF6_4_1	Continuing education of physicians	80.0	33.3	0.127
TF6_4_2	Physicians must be more open and listen more	40.0	38.9	1.000
TF6_4_3	Laws and policies	0.0	22.2	0.539
TF6_4_4	Work more closely with lawyers	0.0	5.6	1.000
TF6_4_5	Be more informed about ethics	40.0	27.8	0.621

Theme		Proportion mentioning the theme (%)		p- value for the Fisher exact test on equality of proportions
		Sex		
Code	Description	F	M	
	<b>Number of subjects</b>	<b>6</b>	<b>18</b>	
TF7	<b>Statements concerning physicians' religious beliefs on treatment of terminally ill patients</b>	100.0	100.0	n.a.
TF7_1	<b>Influence of religious beliefs on medical practice</b>	100.0	88.9	1.000
TF7_1_1	<b>Religious beliefs are helpful</b>	40.0	44.4	1.000
TF7_1_2	<b>Religious beliefs have no influence</b>	100.0	55.6	0.122
TF7_1_3	<b>Religious beliefs have a big influence</b>	0.0	5.6	1.000
TF7_2	<b>Physician conformity to patient beliefs</b>	40.0	38.9	1.000
TF7_3	<b>Conflicts between physicians' and patients' beliefs</b>	40.0	27.8	0.621
TF7_3_1	<b>When there are conflicts</b>	20.0	22.2	1.000
TF7_3_2	<b>There are no conflicts</b>	20.0	5.6	0.395
TF8	<b>Statements respecting patients' quality of life</b>	20.0	44.4	0.611
TF8_1	<b>Who decides on patient's quality of life</b>	0.0	5.6	1.000
TF8_1_2	<b>Patient decides</b>	0.0	5.6	1.000
TF8_2	<b>Problems for physicians when deciding on quality of life issue</b>	20.0	5.6	0.395
TF8_3	<b>Desirable attitudes from physicians</b>	0.0	16.7	1.000
TF8_4	<b>Administration of pain killers in high dosages</b>	0.0	16.7	1.000



Theme		Proportion mentioning the theme (%)		p- value for the Fisher exact test on equality of proportions
		Religion		
Code	Description	Catholic and Jew	Other	
	Number of subjects	19	5	
TF1	Statements in relation to death	100.0	80.0	0.208
TF1_1	Difficulty for physicians	68.4	20.0	0.122
TF1_2	Patients' decision about time of one's death	78.9	20.0	0.028**
TF1_2_1	Patient should be able to decide	78.9	20.0	0.028**
TF1_2_2	Patient should not be able to decide	10.5	0.0	1.000
TF1_3	Patients' decision where to die	10.5	0.0	1.000
TF1_3_1	Patient decides	10.5	0.0	1.000
TF1_3_2	Family decides	5.3	0.0	1.000
TF1_4	Physicians' diagnosis of terminal illness	63.2	20.0	0.142
TF1_4_1	Mental problems affecting patient's competency	26.3	0.0	0.544
TF1_4_2	Make the proper diagnosis	10.5	0.0	1.000
TF1_4_3	Tell the patient about his terminal illness	47.4	20.0	0.358
TF1_5	Active euthanasia	78.9	60.0	0.568
TF1_5_1	Physician's perspective	47.4	60.0	1.000
TF1_5_2	Legal perspective	47.4	20.0	0.358
TF1_5_3	Religious perspective	5.3	0.0	1.000
TF1_5_4	Ethical perspective	26.3	0.0	0.544
TF1_5_5	Society's perspective	31.6	0.0	0.280
TF2	Statements in relation to withholding and/or withdrawing treatments	0.0	0.0	n.a.
TF2_1	Who should decide for the competent patient?	0.0	0.0	n.a.
TF2_1_0	n.a.	21.1	0.0	0.544
TF2_1_1	Patient should decide	0.0	0.0	n.a.
TF2_1_2	Family should decide	21.1	0.0	0.544
TF2_1_3	Physician should decide	52.6	60.0	1.000
TF2_2	Who should decide for the incompetent patient?	0.0	0.0	n.a.
TF2_2_1	Problem of defining competency and incompetency	5.3	0.0	1.000
TF2_2_2	Patient should decide	0.0	0.0	n.a.
TF2_2_2_0	problem of informed consent	31.6	20.0	1.000
TF2_2_2_1	patient decides through verbal expression when competent	21.1	20.0	1.000
TF2_2_2_2	patient decides through living will or advance directives	89.5	100.0	1.000
TF2_2_2_3	consequences of advance directives on families	21.1	80.0	0.028**
TF2_2_2_4	perception of advance directives by physicians	52.6	80.0	0.358
TF2_2_3	Family should decide	42.1	0.0	0.130
TF2_2_4	Physician should decide	10.5	40.0	0.179

Theme		Proportion mentioning the theme (%)		p-value for the Fisher exact test on equality of proportions
		Religion		
Code	Description	Catholic and Jew	Other	
	Number of subjects	19	6	
TF2_3	People who should be involved in the decision process	73.7	60.0	0.608
TF2_3_1	Should involve the family	57.9	40.0	0.630
TF2_3_2	Should involve the whole medical team	15.8	20.0	1.000
TF2_3_3	Courts should decide	5.3	0.0	1.000
TF2_3_4	Should consult the clinical ethics committee	15.8	0.0	1.000
TF2_4	Problems relating to refusal or withdrawal of treatments	94.7	100.0	1.000
TF2_4_0	Physicians' problems relating to refusal or withdrawal of treatments	31.6	0.0	0.280
TF2_4_1	Conflicts created by family members opposing patient's wishes	89.5	100.0	1.000
TF2_4_2	Problems created by the law	21.1	20.0	1.000
TF2_4_3	Conflicts created by the medical personnel	5.3	0.0	1.000
TF3	Statements of physicians about overtreatment of terminally ill patients	0.0	0.0	n.a.
TF3_1	Physicians' difficulties respecting overtreatment	42.1	100.0	0.041**
TF3_2	Physicians' external motives to overtreat	31.6	20.0	1.000
TF3_2_1	Patient's request	21.1	0.0	0.544
TF3_2_2	Family's request	10.5	20.0	0.521
TF3_2_3	Society's request	10.5	0.0	1.000
TF3_3	Physicians' internal motives to overtreat	89.5	40.0	0.042**
TF3_3_1	To avoid criminal and civil litigation	15.8	0.0	1.000
TF3_3_2	To follow medical ideology	73.7	40.0	0.289
TF3_3_3	Physician knows best	28.3	20.0	1.000
TF3_3_4	Fear patient may be abandoned by the nursing staff	5.3	0.0	1.000
TF4	Statements related to conflicts between law and medical profession	0.0	0.0	n.a.
TF4_1	Distinction between law and medicine	15.8	0.0	1.000
TF4_2	Situations where law creates problems for physicians	94.7	100.0	1.000
TF4_2_1	Euthanasia	31.6	40.0	1.000
TF4_2_2	Assisted suicide	5.3	0.0	1.000
TF4_2_3	Fear of litigation	57.9	60.0	1.000
TF4_2_4	Pain control	73.7	80.0	1.000
TF4_2_5	Failure of communication	36.8	40.0	1.000
TF4_3	No conflict between law and medicine	15.8	20.0	1.000
TF4_4	Law's functions	84.2	100.0	1.000
TF4_4_1	Determines how to behave	31.6	20.0	1.000
TF4_4_2	Establishes controls	10.5	0.0	1.000
TF4_4_3	States patients' rights	21.1	60.0	0.128
TF4_4_4	Courts lack of knowledge about medicine to make decisions	21.1	20.0	1.000

Theme		Proportion mentioning the theme (%)		p- value for the Fisher exact test on equality of proportions
		Religion		
Code	Description	Catholic and Jew	Other	
	Number of subjects	19	8	
TF4_4_5	Laws are general	5.3	0.0	1.000
TF4_4_6	Lawyers	31.6	40.0	1.000
TF4_4_7	Physicians lack of knowledge about the law	5.3	20.0	0.380
TF5	Statements respecting hospital administrative policies	0.0	0.0	n.a.
TF5_1	General comments	5.3	20.0	0.380
TF5_2	Procedures	31.6	60.0	0.326
TF5_2_1	Write the order and circumstances in patient's file	26.3	60.0	0.289
TF5_2_2	If unsure, consult	15.8	20.0	1.000
TF5_3	Physicians' knowledge of hospital administrative policies	84.2	60.0	0.270
TF5_3_1	Administrative policies do exist	31.6	60.0	0.326
TF5_3_2	No aware of any administrative policies	73.7	20.0	0.047**
TF5_4	Influence of hospital administrative policies	57.9	60.0	0.615
TF5_4_1	No influence - physician decides	52.6	80.0	0.358
TF5_4_2	May be useful	10.5	20.0	0.521
TF5_4_3	May be harmful	15.8	0.0	1.000
TF5_5	Physicians' opinions with respect to Hospital administrative policies	73.7	60.0	1.000
TF5_5_1	No problem with administrative policies	63.2	60.0	1.000
TF5_5_2	Unsatisfied with administrative policies	21.1	20.0	1.000
TF5_5_3	The problem is more complex than appears	5.3	0.0	1.000
TF5_6	Roles given to families by administrative policies	10.5	0.0	1.000
TF6	Statements respecting pain control	94.7	100.0	1.000
TF6_1	Physicians' difficulties as regards pain control	21.1	0.0	0.544
TF6_2	Physicians perceptions concerning palliative care	31.6	40.0	1.000
TF6_2_1	Palliative care by physicians	31.6	40.0	1.000
TF6_2_2	Palliative care by nursing staff	5.3	0.0	1.000
TF6_3	Physicians' perceptions of patients' and families' needs	15.8	40.0	0.270
TF6_3_1	Physicians' opinions respecting palliative care	5.3	20.0	0.380
TF6_3_2	Physicians' perception of patients' and families' needs	10.5	20.0	0.521
TF6_4	Strategies to help physicians accommodate patients' wishes	84.2	80.0	1.000
TF6_4_1	Continuing education of physicians	47.4	40.0	1.000
TF6_4_2	Physicians must be more open and listen more	42.1	40.0	1.000
TF6_4_3	Laws and policies	21.1	20.0	1.000
TF6_4_4	Work more closely with lawyers	5.3	0.0	1.000

Theme		Proportion mentioning the theme (%)		p-value for the Fisher exact test on equality of proportions
		Religion		
Code	Description	Catholic and Jew	Other	
	Number of subjects	19	6	
TF6_4_5	Be more informed about ethics	31.6	20.0	1.000
TF7	Statements concerning physicians' religious beliefs on treatment of terminally ill patients	0.0	0.0	n.a.
TF7_1	Influence of religious beliefs on medical practice	94.7	80.0	0.380
TF7_1_1	Religious beliefs are helpful	57.9	0.0	0.041**
TF7_1_2	Religious beliefs have no influence	57.9	80.0	0.615
TF7_1_3	Religious beliefs have a big influence	5.3	0.0	1.000
TF7_2	Physician conformity to patient beliefs	36.8	60.0	0.615
TF7_3	Conflicts between physicians' and patients' beliefs	31.6	20.0	1.000
TF7_3_1	When there are conflicts	21.1	20.0	1.000
TF7_3_2	There are no conflicts	10.5	0.0	1.000
TF8	Statements respecting patients' quality of life	36.8	60.0	0.615
TF8_1	Who decides on patient's quality of life	5.3	0.0	1.000
TF8_1_2	Patient decides	5.3	0.0	1.000
TF8_2	Problems for physicians when deciding on quality of life issue	10.5	20.0	0.521
TF8_3	Desirable attitudes from physicians	10.5	20.0	0.521
TF8_4	Administration of pain killers in high dosages	10.5	20.0	0.521

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Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Language			
Code	Description	English	French	Both	
	Number of subjects	8	3	13	
TF1	Statements in relation to death	87.5	100.0	100.000	0.352
TF1_1	Difficulty for physicians	25.0	100.0	69.231	0.040**
TF1_2	Patients' decision about time of one's death	37.5	100.0	76.923	0.075*
TF1_2_1	Patient should be able to decide	37.5	100.0	76.923	0.075*
TF1_2_2	Patient should not be able to decide	0.0	33.3	7.692	0.203
TF1_3	Patients' decision where to die	0.0	0.0	15.385	0.397
TF1_3_1	Patient decides	0.0	0.0	15.385	0.397
TF1_3_2	Family decides	0.0	0.0	7.692	0.643
TF1_4	Physicians' diagnosis of terminal illness	25.0	33.3	76.923	0.050*
TF1_4_1	Mental problems affecting patient's competency	0.0	33.3	30.769	0.205
TF1_4_2	Make the proper diagnosis	0.0	0.0	15.385	0.397
TF1_4_3	Tell the patient about his terminal illness	25.0	0.0	61.539	0.075*
TF1_5	Active euthanasia	62.5	100.0	76.923	0.429
TF1_5_1	Physician's perspective	62.5	33.3	46.154	0.634
TF1_5_2	Legal perspective	25.0	100.0	38.462	0.075*
TF1_5_3	Religious perspective	0.0	0.0	7.692	0.643
TF1_5_4	Ethical perspective	0.0	0.0	38.462	0.069*
TF1_5_5	Society's perspective	25.0	0.0	30.769	0.540
TF2	Statements in relation to withholding and/or withdrawing treatments	100.0	100.0	100.000	n.a.
TF2_1	Who should decide for the competent patient?	100.0	100.0	100.000	n.a.
TF2_1_0	n.a.	12.5	33.3	15.385	0.699
TF2_1_1	Patient should decide	100.0	100.0	100.000	n.a.
TF2_1_2	Family should decide	25.0	0.0	15.385	0.602
TF2_1_3	Physician should decide	75.0	66.7	38.462	0.237
TF2_2	Who should decide for the incompetent patient?	100.0	100.0	100.000	n.a.
TF2_2_1	Problem of defining competency and incompetency	0.0	0.0	7.692	0.643
TF2_2_2	Patient should decide	100.0	100.0	100.000	n.a.
TF2_2_2_0	problem of informed consent	12.5	0.0	46.154	0.127
TF2_2_2_1	patient decides through verbal expression when competent	25.0	0.0	23.077	0.633
TF2_2_2_2	patient decides through living will or advance directives	100.0	66.7	92.308	0.203
TF2_2_2_3	consequences of advance directives on families	62.5	33.3	15.385	0.084*
TF2_2_2_4	perception of advance directives by physicians	75.0	33.3	53.846	0.408
TF2_2_3	Family should decide	0.0	66.7	46.154	0.040**
TF2_2_4	Physician should decide	25.0	33.3	7.692	0.416
TF2_3	People who should be involved in the decision process	62.5	66.7	76.923	0.768

Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Language			
Code	Description	English	French	Both	
	Number of subjects	8	3	13	
TF2_3_1	Should involve the family	50.0	0.0	69.231	0.091*
TF2_3_2	Should involve the whole medical team	12.5	33.3	15.385	0.699
TF2_3_3	Courts should decide	0.0	33.3	0.000	0.026**
TF2_3_4	Should consult the clinical ethics committee	0.0	0.0	23.077	0.234
TF2_4	Problems relating to refusal or withdrawal of treatments	100.0	100.0	92.308	0.643
TF2_4_0	Physicians' problems relating to refusal or withdrawal of treatments	0.0	0.0	46.154	0.034**
TF2_4_1	Conflicts created by family members opposing patient's wishes	87.5	100.0	92.308	0.794
TF2_4_2	Problems created by the law	37.5	0.0	15.385	0.308
TF2_4_3	Conflicts created by the medical personnel	0.0	0.0	7.692	0.643
TF3	Statements of physicians about overtreatment of terminally ill patients	100.0	100.0	100.000	n.a.
TF3_1	Physicians' difficulties respecting overtreatment	75.0	33.3	46.154	0.323
TF3_2	Physicians' external motives to overtreat	25.0	33.3	30.769	0.947
TF3_2_1	Patient's request	12.5	0.0	23.077	0.581
TF3_2_2	Family's request	25.0	0.0	7.692	0.397
TF3_2_3	Society's request	0.0	33.3	7.692	0.203
TF3_3	Physicians' internal motives to overtreat	62.5	100.0	84.615	0.306
TF3_3_1	To avoid criminal and civil litigation	0.0	0.0	23.077	0.234
TF3_3_2	To follow medical ideology	50.0	100.0	69.231	0.281
TF3_3_3	Physician knows best	37.5	0.0	23.077	0.429
TF3_3_4	Fear patient may be abandoned by the nursing staff	0.0	0.0	7.692	0.643
TF4	Statements related to conflicts between law and medical profession	100.0	100.0	100.000	n.a.
TF4_1	Distinction between law and medicine	12.5	0.0	15.385	0.768
TF4_2	Situations where law creates problems for physicians	100.0	66.7	100.000	0.026**
TF4_2_1	Euthanasia	50.0	0.0	30.769	0.281
TF4_2_2	Assisted suicide	0.0	33.3	0.000	0.026**
TF4_2_3	Fear of litigation	75.0	0.0	61.539	0.075*
TF4_2_4	Pain control	87.5	33.3	76.923	0.176
TF4_2_5	Failure of communication	25.0	33.3	46.154	0.615
TF4_3	No conflict between law and medicine	12.5	0.0	23.077	0.581
TF4_4	Law's functions	100.0	100.0	76.923	0.234
TF4_4_1	Determines how to behave	37.5	33.3	23.077	0.768
TF4_4_2	Establishes controls	0.0	0.0	15.385	0.397
TF4_4_3	States patients' rights	50.0	33.3	15.385	0.234
TF4_4_4	Courts lack of knowledge about medicine to make decisions	12.5	33.3	23.077	0.719
TF4_4_5	Laws are general	12.5	0.0	0.000	0.352
TF4_4_6	Lawyers	37.5	33.3	30.769	0.951
TF4_4_7	Physicians lack of knowledge about the law	12.5	0.0	7.692	0.794

Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Language			
Code	Description	English	French	Both	
	Number of subjects	8	3	13	
TF5	Statements respecting hospital administrative policies	100.0	100.0	100.000	n.a.
TF5_1	General comments	12.5	33.3	0.000	0.148
TF5_2	Procedures	37.5	0.0	46.154	0.330
TF5_2_1	Write the order and circumstances in patient's file	37.5	0.0	38.462	0.424
TF5_2_2	If unsure, consult	12.5	0.0	23.077	0.581
TF5_3	Physicians' knowledge of hospital administrative policies	62.5	100.0	84.615	0.306
TF5_3_1	Administrative policies do exist	50.0	33.3	30.769	0.668
TF5_3_2	No aware of any administrative policies	37.5	100.0	69.231	0.123
TF5_4	Influence of hospital administrative policies	50.0	66.7	69.231	0.668
TF5_4_1	No influence - physician decides	50.0	66.7	61.539	0.831
TF5_4_2	May be useful	12.5	33.3	7.692	0.481
TF5_4_3	May be harmful	0.0	33.3	15.385	0.296
TF5_5	Physicians' opinions with respect to Hospital administrative policies	87.5	66.7	69.231	0.604
TF5_5_1	No problem with administrative policies	75.0	33.3	61.539	0.443
TF5_5_2	Unsatisfied with administrative policies	25.0	33.3	15.385	0.740
TF5_5_3	The problem is more complex than appears	0.0	0.0	7.692	0.643
TF5_6	Roles given to families by administrative policies	0.0	33.3	7.692	0.203
TF6	Statements respecting pain control	100.0	100.0	92.308	0.643
TF6_1	Physicians' difficulties as regards pain control	25.0	33.3	7.692	0.416
TF6_2	Physicians perceptions concerning palliative care	37.5	33.3	30.769	0.951
TF6_2_1	Palliative care by physicians	37.5	33.3	30.769	0.951
TF6_2_2	Palliative care by nursing staff	0.0	0.0	7.692	0.643
TF6_3	Physicians' perceptions of patients' and families' needs	25.0	0.0	23.077	0.633
TF6_3_1	Physicians' opinions respecting palliative care	12.5	0.0	7.692	0.794
TF6_3_2	Physicians' perception of patients' and families' needs	12.5	0.0	15.385	0.768
TF6_4	Strategies to help physicians accommodate patients' wishes	75.0	100.0	84.615	0.602
TF6_4_1	Continuing education of physicians	37.5	66.7	46.154	0.688
TF6_4_2	Physicians must be more open and listen more	37.5	0.0	53.846	0.224
TF6_4_3	Laws and policies	25.0	33.3	15.385	0.740
TF6_4_4	Work more closely with lawyers	0.0	0.0	7.692	0.643
TF6_4_5	Be more informed about ethics	25.0	0.0	38.462	0.397
TF7	Statements concerning physicians' religious beliefs on treatment of terminally ill patients	100.0	100.0	100.000	n.a.
TF7_1	Influence of religious beliefs on medical practice	87.5	100.0	92.308	0.794

Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Language			
Code	Description	English	French	Both	
	<b>Number of subjects</b>	<b>8</b>	<b>3</b>	<b>13</b>	
TF7_1_1	Religious beliefs are helpful	25.0	66.7	53.846	0.323
TF7_1_2	Religious beliefs have no influence	75.0	66.7	53.846	0.615
TF7_1_3	Religious beliefs have a big influence	0.0	0.0	7.692	0.643
TF7_2	Physician conformity to patient beliefs	50.0	33.3	38.462	0.831
TF7_3	Conflicts between physicians' and patients' beliefs	12.5	0.0	46.154	0.127
TF7_3_1	When there are conflicts	12.5	0.0	30.769	0.386
TF7_3_2	There are no conflicts	0.0	0.0	15.385	0.397
TF8	Statements respecting patients' quality of life	62.5	0.0	38.462	0.163
TF8_1	Who decides on patient's quality of life	0.0	0.0	7.692	0.643
TF8_1_2	Patient decides	0.0	0.0	7.692	0.643
TF8_2	Problems for physicians when deciding on quality of life issue	25.0	0.0	7.692	0.397
TF8_3	Desirable attitudes from physicians	12.5	0.0	15.385	0.768
TF8_4	Administration of pain killers in high dosages	25.0	0.0	7.692	0.397



Theme		Proportion mentioning the theme (%)			p-value for the Chi-2 test on equality of proportions
		Hospital affiliation			
Code	Description	Beauséjour (francophone system)	Both	Moncton (anglophone system)	
	Number of subjects	13	3	8	
TF1	Statements in relation to death	100.0	100.0	87.500	0.352
TF1_1	Difficulty for physicians	78.9	33.3	37.500	0.132
TF1_2	Patients' decision about time of one's death	84.6	66.7	37.500	0.084*
TF1_2_1	Patient should be able to decide	84.6	66.7	37.500	0.084*
TF1_2_2	Patient should not be able to decide	7.7	33.3	0.000	0.203
TF1_3	Patients' decision where to die	0.0	33.3	12.500	0.148
TF1_3_1	Patient decides	0.0	33.3	12.500	0.148
TF1_3_2	Family decides	0.0	0.0	12.500	0.352
TF1_4	Physicians' diagnosis of terminal illness	61.5	66.7	37.500	0.505
TF1_4_1	Mental problems affecting patient's competency	23.1	33.3	12.500	0.719
TF1_4_2	Make the proper diagnosis	15.4	0.0	0.000	0.397
TF1_4_3	Tell the patient about his terminal illness	46.2	33.3	37.500	0.662
TF1_5	Active euthanasia	78.9	100.0	62.500	0.429
TF1_5_1	Physician's perspective	38.5	100.0	50.000	0.158
TF1_5_2	Legal perspective	53.8	66.7	12.500	0.113
TF1_5_3	Religious perspective	7.7	0.0	0.000	0.643
TF1_5_4	Ethical perspective	30.8	0.0	12.500	0.386
TF1_5_5	Society's perspective	23.1	33.3	25.000	0.934
TF2	Statements in relation to withholding and/or withdrawing treatments	100.0	100.0	100.000	n.s.
TF2_1	Who should decide for the competent patient?	100.0	100.0	100.000	n.s.
TF2_1_0	n.s.	23.1	0.0	12.500	0.581
TF2_1_1	Patient should decide	100.0	100.0	100.000	n.s.
TF2_1_2	Family should decide	15.4	0.0	25.000	0.602
TF2_1_3	Physician should decide	30.8	100.0	75.000	0.033**
TF2_2	Who should decide for the incompetent patient?	100.0	100.0	100.000	n.s.
TF2_2_1	Problem of defining competency and incompetency	7.7	0.0	0.000	0.643
TF2_2_2	Patient should decide	100.0	100.0	100.000	n.s.
TF2_2_2_0	problem of informed consent	38.5	66.7	0.000	0.063*
TF2_2_2_1	patient decides through verbal expression when competent	23.1	0.0	25.000	0.633
TF2_2_2_2	patient decides through living will or advance directives	84.6	100.0	100.000	0.397
TF2_2_2_3	consequences of advance directives on families	23.1	33.3	50.000	0.446
TF2_2_2_4	perception of advance directives by physicians	38.5	66.7	67.500	0.062*
TF2_2_3	Family should decide	46.2	33.3	12.500	0.283
TF2_2_4	Physician should decide	15.4	0.0	25.000	0.602
TF2_3	People who should be involved in the decision process	78.9	66.7	62.500	0.768
TF2_3_1	Should involve the family	53.8	66.7	50.000	0.885
TF2_3_2	Should involve the whole medical team	23.1	0.0	12.500	0.561
TF2_3_3	Courts should decide	7.7	0.0	0.000	0.643
TF2_3_4	Should consult the clinical ethics committee	23.1	0.0	0.000	0.234

Theme		Proportion mentioning the theme (%)			p-value for the Chi-2 test on equality of proportions
		Hospital affiliation			
Code	Description	Beauséjour (francophone system)	Both	Moncton (anglophone system)	
	Number of subjects	13	3	8	
TF2_4	Problems relating to refusal or withdrawal of treatments	92.3	100.0	100.000	0.643
TF2_4_0	Physicians' problems relating to refusal or withdrawal of treatments	23.1	66.7	12.500	0.176
TF2_4_1	Conflicts created by family members opposing patient's wishes	92.3	100.0	87.500	0.794
TF2_4_2	Problems created by the law	7.7	0.0	50.000	0.043**
TF2_4_3	Conflicts created by the medical personnel	0.0	33.3	0.000	0.026**
TF3	Statements of physicians about overtreatment of terminally ill patients	100.0	100.0	100.000	n.s.
TF3_1	Physicians' difficulties respecting overtreatment	38.5	66.7	75.000	0.237
TF3_2	Physicians' external motives to overtreat	23.1	66.7	25.000	0.310
TF3_2_1	Patient's request	7.7	66.7	12.500	0.044**
TF3_2_2	Family's request	0.0	33.3	25.000	0.123
TF3_2_3	Society's request	15.4	0.0	0.000	0.397
TF3_3	Physicians' internal motives to overtreat	84.6	100.0	62.500	0.308
TF3_3_1	To avoid criminal and civil litigation	7.7	33.3	12.500	0.481
TF3_3_2	To follow medical ideology	69.2	100.0	50.000	0.281
TF3_3_3	Physician knows best	7.7	33.3	50.000	0.068*
TF3_3_4	Fear patient may be abandoned by the nursing staff	7.7	0.0	0.000	0.643
TF4	Statements related to conflicts between law and medical profession	100.0	100.0	100.000	n.s.
TF4_1	Distinction between law and medicine	15.4	0.0	12.500	0.768
TF4_2	Situations where law creates problems for physicians	92.3	100.0	100.000	0.643
TF4_2_1	Euthanasia	23.1	66.7	37.500	0.337
TF4_2_2	Assisted suicide	7.7	0.0	0.000	0.643
TF4_2_3	Fear of litigation	61.5	0.0	75.000	0.076*
TF4_2_4	Pain control	61.5	100.0	87.500	0.232
TF4_2_5	Failure of communication	38.5	66.7	25.000	0.443
TF4_3	No conflict between law and medicine	7.7	33.3	25.000	0.416
TF4_4	Law's functions	76.9	100.0	100.000	0.234
TF4_4_1	Determines how to behave	23.1	33.3	37.500	0.768
TF4_4_2	Establishes controls	7.7	33.3	0.000	0.203
TF4_4_3	States patients' rights	23.1	0.0	50.000	0.207
TF4_4_4	Courts lack of knowledge about medicine to make decisions	15.4	66.7	12.500	0.111
TF4_4_5	Laws are general	0.0	0.0	12.500	0.362
TF4_4_6	Lawyers	30.8	33.3	37.500	0.961
TF4_4_7	Physicians lack of knowledge about the law	7.7	0.0	12.500	0.784
TF5	Statements respecting hospital administrative policies	100.0	100.0	100.000	n.s.
TF5_1	General comments	7.7	0.0	12.500	0.784
TF5_2	Procedures	38.5	33.3	37.500	0.966
TF5_2_1	Write the order and circumstances in patient's file	30.8	33.3	37.500	0.961
TF5_2_2	If unsure, consult	15.4	33.3	12.500	0.699
TF5_3	Physicians' knowledge of hospital administrative policies	84.6	66.7	75.000	0.740
TF5_3_1	Administrative policies do exist	30.8	0.0	62.500	0.123
TF5_3_2	No aware of any administrative policies	76.9	66.7	37.500	0.181

Theme		Proportion mentioning the theme (%)			p-value for the Chi-2 test on equality of proportions
		Hospital affiliation			
Code	Description	Beauséjour (francophone system)	Both	Moncton (anglophone system)	
	Number of subjects	13	3	8	
TF5_4	Influence of hospital administrative policies	66.2	66.7	50.000	0.688
TF5_4_1	No influence - physician decides	61.5	66.7	50.000	0.831
TF5_4_2	May be useful	15.4	0.0	12.500	0.788
TF5_4_3	May be harmful	23.1	0.0	0.000	0.234
TF5_5	Physicians' opinions with respect to Hospital administrative policies	61.5	66.7	100.000	0.133
TF5_5_1	No problem with administrative policies	46.2	66.7	87.500	0.162
TF5_5_2	Unsatisfied with administrative policies	15.4	0.0	37.500	0.306
TF5_5_3	The problem is more complex than appears	7.7	0.0	0.000	0.843
TF5_6	Roles given to families by administrative policies	15.4	0.0	0.000	0.397
TF6	Statements respecting pain control	92.3	100.0	100.000	0.843
TF6_1	Physicians' difficulties as regards pain control	15.4	0.0	25.000	0.802
TF6_2	Physicians' perceptions concerning palliative care	30.8	66.7	25.000	0.409
TF6_2_1	Palliative care by physicians	30.8	66.7	25.000	0.409
TF6_2_2	Palliative care by nursing staff	7.7	0.0	0.000	0.843
TF6_3	Physicians' perceptions of patients' and families' needs	15.4	0.0	37.500	0.306
TF6_3_1	Physicians' opinions respecting palliative care	7.7	0.0	12.500	0.794
TF6_3_2	Physicians' perception of patients' and families' needs	7.7	0.0	25.000	0.397
TF6_4	Strategies to help physicians accommodate patients' wishes	92.3	66.7	75.000	0.416
TF6_4_1	Continuing education of physicians	53.8	33.3	37.500	0.688
TF6_4_2	Physicians must be more open and listen more	38.5	66.7	37.500	0.843
TF6_4_3	Laws and policies	15.4	33.3	25.000	0.740
TF6_4_4	Work more closely with lawyers	7.7	0.0	0.000	0.843
TF6_4_5	Be more informed about ethics	38.5	0.0	25.000	0.397
TF7	Statements concerning physicians' religious beliefs on treatment of terminally ill patients	100.0	100.0	100.000	n.s.
TF7_1	Influence of religious beliefs on medical practice	92.3	100.0	87.500	0.794
TF7_1_1	Religious beliefs are helpful	46.2	66.7	37.500	0.688
TF7_1_2	Religious beliefs have no influence	53.8	66.7	75.000	0.616
TF7_1_3	Religious beliefs have a big influence	7.7	0.0	0.000	0.843
TF7_2	Physician conformity to patient beliefs	38.5	66.7	37.500	0.843
TF7_3	Conflicts between physicians' and patients' beliefs	38.5	66.7	0.000	0.053*
TF7_3_1	When there are conflicts	23.1	66.7	0.000	0.051*
TF7_3_2	There are no conflicts	15.4	0.0	0.000	0.397
TF8	Statements respecting patients' quality of life	15.4	66.7	75.000	0.017**
TF8_1	Who decides on patient's quality of life	7.7	0.0	0.000	0.843
TF8_1_2	Patient decides	7.7	0.0	0.000	0.843
TF8_2	Problems for physicians when deciding on quality of life issue	7.7	0.0	25.000	0.397
TF8_3	Desirable attitudes from physicians	0.0	33.3	25.000	0.123
TF8_4	Administration of pain killers in high doses	0.0	33.3	25.000	0.123

Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Years of practice			
Code	Description	Less than 5 years	5 to 9 years	More than 10 years	
	Number of subjects	6	4	16	
TF1	Statements in relation to death	100.0	100.0	93.333	0.731
TF1_1	Difficulty for physicians	60.0	75.0	53.333	0.735
TF1_2	Patients' decision about time of one's death	80.0	75.0	60.000	0.662
TF1_2_1	Patient should be able to decide	80.0	75.0	60.000	0.662
TF1_2_2	Patient should not be able to decide	0.0	25.0	6.667	0.375
TF1_3	Patients' decision where to die	0.0	0.0	13.333	0.520
TF1_3_1	Patient decides	0.0	0.0	13.333	0.520
TF1_3_2	Family decides	0.0	0.0	6.667	0.731
TF1_4	Physicians' diagnosis of terminal illness	60.0	0.0	66.667	0.057*
TF1_4_1	Mental problems affecting patient's competency	40.0	0.0	20.000	0.338
TF1_4_2	Make the proper diagnosis	0.0	0.0	13.333	0.520
TF1_4_3	Tell the patient about his terminal illness	40.0	0.0	53.333	0.157
TF1_5	Active euthanasia	100.0	75.0	66.667	0.329
TF1_5_1	Physician's perspective	60.0	50.0	46.667	0.875
TF1_5_2	Legal perspective	80.0	75.0	20.000	0.021**
TF1_5_3	Religious perspective	0.0	0.0	6.667	0.731
TF1_5_4	Ethical perspective	60.0	0.0	13.333	0.045**
TF1_5_5	Society's perspective	40.0	25.0	20.000	0.670
TF2	Statements in relation to withholding and/or withdrawing treatments	100.0	100.0	100.000	n.a.
TF2_1	Who should decide for the competent patient?	100.0	100.0	100.000	n.a.
TF2_1_0	n.a.	20.0	50.0	6.667	0.115
TF2_1_1	Patient should decide	100.0	100.0	100.000	n.a.
TF2_1_2	Family should decide	0.0	50.0	13.333	0.115
TF2_1_3	Physician should decide	40.0	75.0	53.333	0.575
TF2_2	Who should decide for the incompetent patient?	100.0	100.0	100.000	n.a.
TF2_2_1	Problem of defining competency and incompetency	0.0	0.0	6.667	0.731
TF2_2_2	Patient should decide	100.0	100.0	100.000	n.a.
TF2_2_2_0	problem of informed consent	20.0	0.0	40.000	0.259
TF2_2_2_1	patient decides through verbal expression when competent	40.0	25.0	13.333	0.434
TF2_2_2_2	patient decides through living will or advance directives	100.0	75.0	93.333	0.375
TF2_2_2_3	consequences of advance directives on families	20.0	50.0	33.333	0.638
TF2_2_2_4	perception of advance directives by physicians	40.0	75.0	60.000	0.558
TF2_2_3	Family should decide	60.0	25.0	26.667	0.363
TF2_2_4	Physician should decide	20.0	0.0	20.000	0.619

Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Years of practice			
Code	Description	Less than 5 years	5 to 9 years	More than 10 years	
	Number of subjects	5	4	15	
TF2_3	People who should be involved in the decision process	60.0	75.0	73.333	0.834
TF2_3_1	Should involve the family	40.0	50.0	60.000	0.727
TF2_3_2	Should involve the whole medical team	40.0	0.0	13.333	0.237
TF2_3_3	Courts should decide	0.0	25.0	0.000	0.074*
TF2_3_4	Should consult the clinical ethics committee	0.0	0.0	20.000	0.358
TF2_4	Problems relating to refusal or withdrawal of treatments	100.0	100.0	93.333	0.731
TF2_4_0	Physicians' problems relating to refusal or withdrawal of treatments	40.0	0.0	26.667	0.376
TF2_4_1	Conflicts created by family members opposing patient's wishes	100.0	75.0	93.333	0.375
TF2_4_2	Problems created by the law	20.0	50.0	13.333	0.276
TF2_4_3	Conflicts created by the medical personnel	0.0	0.0	6.667	0.731
TF3	Statements of physicians about overtreatment of terminally ill patients	100.0	100.0	100.000	n.a.
TF3_1	Physicians' difficulties respecting overtreatment	20.0	50.0	66.667	0.190
TF3_2	Physicians' external motives to overtreat	20.0	50.0	26.667	0.580
TF3_2_1	Patient's request	0.0	25.0	20.000	0.517
TF3_2_2	Family's request	0.0	25.0	13.333	0.523
TF3_2_3	Society's request	20.0	25.0	0.000	0.157
TF3_3	Physicians' internal motives to overtreat	80.0	100.0	73.333	0.508
TF3_3_1	To avoid criminal and civil litigation	20.0	0.0	13.333	0.658
TF3_3_2	To follow medical ideology	60.0	75.0	66.667	0.894
TF3_3_3	Physician knows best	0.0	50.0	26.667	0.221
TF3_3_4	Fear patient may be abandoned by the nursing staff	20.0	0.0	0.000	0.136
TF4	Statements related to conflicts between law and medical profession	100.0	100.0	100.000	n.a.
TF4_1	Distinction between law and medicine	40.0	0.0	6.667	0.106
TF4_2	Situations where law creates problems for physicians	100.0	75.0	100.000	0.074*
TF4_2_1	Euthanasia	20.0	25.0	40.000	0.662
TF4_2_2	Assisted suicide	20.0	0.0	0.000	0.138
TF4_2_3	Fear of litigation	80.0	50.0	53.333	0.540
TF4_2_4	Pain control	60.0	75.0	80.000	0.670
TF4_2_5	Failure of communication	20.0	25.0	46.667	0.462
TF4_3	No conflict between law and medicine	0.0	0.0	26.667	0.237
TF4_4	Law's functions	80.0	100.0	86.667	0.658
TF4_4_1	Determines how to behave	40.0	25.0	26.667	0.834
TF4_4_2	Establishes controls	20.0	0.0	6.667	0.520
TF4_4_3	States patients' rights	0.0	50.0	33.333	0.220
TF4_4_4	Courts lack of knowledge about medicine to make decisions	20.0	25.0	20.000	0.975

Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Years of practice			
Code	Description	Less than 5 years	5 to 9 years	More than 10 years	
	Number of subjects	5	4	15	
TF4_4_5	Laws are general	0.0	0.0	6.667	0.731
TF4_4_6	Lawyers	20.0	50.0	33.333	0.638
TF4_4_7	Physicians lack of knowledge about the law	20.0	0.0	6.667	0.520
TF5	Statements respecting hospital administrative policies	100.0	100.0	100.000	n.a.
TF5_1	General comments	0.0	25.0	6.667	0.375
TF5_2	Procedures	60.0	0.0	40.000	0.172
TF5_2_1	Write the order and circumstances in patient's file	60.0	0.0	33.333	0.165
TF5_2_2	If unsure, consult	20.0	0.0	20.000	0.619
TF5_3	Physicians' knowledge of hospital administrative policies	100.0	75.0	73.333	0.434
TF5_3_1	Administrative policies do exist	0.0	25.0	53.333	0.088*
TF5_3_2	No aware of any administrative policies	100.0	75.0	46.667	0.088*
TF5_4	Influence of hospital administrative policies	60.0	50.0	66.667	0.822
TF5_4_1	No influence - physician decides	40.0	50.0	66.667	0.540
TF5_4_2	May be useful	0.0	25.0	13.333	0.523
TF5_4_3	May be harmful	40.0	25.0	0.000	0.046**
TF5_5	Physicians' opinions with respect to Hospital administrative policies	20.0	100.0	66.667	0.005**
TF5_5_1	No problem with administrative policies	0.0	75.0	80.000	0.005**
TF5_5_2	Unsatisfied with administrative policies	20.0	25.0	20.000	0.975
TF5_5_3	The problem is more complex than appears	0.0	0.0	6.667	0.731
TF5_6	Roles given to families by administrative policies	20.0	25.0	0.000	0.157
TF6	Statements respecting pain control	100.0	100.0	93.333	0.731
TF6_1	Physicians' difficulties as regards pain control	20.0	25.0	13.333	0.835
TF6_2	Physicians perceptions concerning palliative care	60.0	0.0	33.333	0.165
TF6_2_1	Palliative care by physicians	60.0	0.0	33.333	0.165
TF6_2_2	Palliative care by nursing staff	20.0	0.0	0.000	0.138
TF6_3	Physicians' perceptions of patients' and families' needs	20.0	0.0	26.667	0.506
TF6_3_1	Physicians' opinions respecting palliative care	0.0	0.0	13.333	0.520
TF6_3_2	Physicians' perception of patients' and families' needs	20.0	0.0	13.333	0.658
TF6_4	Strategies to help physicians accommodate patients' wishes	100.0	100.0	73.333	0.237
TF6_4_1	Continuing education of physicians	40.0	50.0	46.667	0.951
TF6_4_2	Physicians must be more open and listen more	80.0	25.0	33.333	0.142
TF6_4_3	Laws and policies	20.0	50.0	13.333	0.278
TF6_4_4	Work more closely with lawyers	0.0	0.0	6.667	0.731

Theme		Proportion mentioning the theme (%)			p- value for the Chi-2 test on equality of proportions
		Years of practice			
Code	Description	Less than 5 years	5 to 9 years	More than 10 years	
	Number of subjects	6	4	16	
TF6_4_5	Be more informed about ethics	40.0	25.0	28.667	0.834
TF7	Statements concerning physicians' religious beliefs on treatment of terminally ill patients	100.0	100.0	100.000	n.a.
TF7_1	Influence of religious beliefs on medical practice	100.0	100.0	88.667	0.520
TF7_1_1	Religious beliefs are helpful	60.0	75.0	33.333	0.257
TF7_1_2	Religious beliefs have no influence	80.0	50.0	60.000	0.619
TF7_1_3	Religious beliefs have a big influence	0.0	0.0	6.667	0.731
TF7_2	Physician conformity to patient beliefs	0.0	50.0	53.333	0.104
TF7_3	Conflicts between physicians' and patients' beliefs	20.0	0.0	40.000	0.259
TF7_3_1	When there are conflicts	20.0	0.0	26.667	0.508
TF7_3_2	There are no conflicts	0.0	0.0	13.333	0.520
TF8	Statements respecting patients' quality of life	20.0	50.0	46.667	0.540
TF8_1	Who decides on patient's quality of life	0.0	0.0	6.667	0.731
TF8_1_2	Patient decides	0.0	0.0	6.667	0.731
TF8_2	Problems for physicians when deciding on quality of life issue	20.0	25.0	6.667	0.523
TF8_3	Desirable attitudes from physicians	0.0	0.0	20.000	0.358
TF8_4	Administration of pain killers in high dosages	0.0	25.0	13.333	0.523

## Appendix G

### Norma Poirier's Brief Curriculum Vitae

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#### **Education**

1. R.N. Hôtel-Dieu St-Joseph, Campbellton, NB, 1968
2. B.Sc.N. Université de Moncton, Moncton, NB, 1972
3. B.Ed Université de Moncton, Moncton, NB, 1980
4. Cert. in psychiatric nursing Université de Moncton, Moncton, NB, 1981
5. M.A.Ed. Université de Moncton, Moncton, NB, 1985
6. Cert. in gerontology Université de Moncton, Moncton, NB, 1985
7. M.N. Dalhousie University, Halifax, NS, 1992
8. Cert. in religious sciences Université de Moncton, NB, 1992.

#### **Professional experience**

July 1996 to November 1999 Associate professor, School of Nursing, Université de Moncton

June 1979 to June 1996 Instructor, École d'Enseignement Infirmier Providence, Moncton.

Sept. 1972 to August 1978 Instructor, Bathurst School of Nursing, Bathurst.

#### **Publications**

Poirier, N. (1999). Treatment of terminally ill older patients against their will: A form of elder abuse and abuse of power. In Proceedings of the Second National Conference on Elder Abuse. (Pp. 193-211). Institute for Human Development, Life Course and Aging, University of Toronto.

Poirier, N. (To be published). Comparison of the CMA (1994) statement on resuscitative interventions and New Brunswick hospital corporations' policies on end-of-life treatments. Journal of Palliative Care.



- Poirier, N. (To be published). Some factors discriminating between battered women admitted to a psychiatric unit and other women inpatients. Journal of the American Psychiatric Nurses Association.
- Poirier, N. (1998). A pedagogy for televised learning by care-givers of terminally ill patients. Communiqué 13(3&4), 9-11.
- Poirier, N. (1994). Manuel d'accompagnement "Le processus de la mort et du deuil" [Companion manual for the course on death and dying]. Moncton, NB, Continuing Education, Université de Moncton, 315 p.
- Poirier, N. & Poirier, D. (1987). Politique du vieillissement: comparaison entre la région de Grenoble en France et le Nouveau-Brunswick [Aging policy: a comparison between Genoble in France and New Brunswick]. Revue de l'Université de Moncton, 20(2); 55-79.
- Poirier, N., & Gregor, F. (1987). La formation des infirmières intervenant auprès des mourants [Educating nurses interveening with dying patients]. Nursing Québec, 7(2), 15-19.
- Poirier, N. (1985). L'impact du développement de la profession infirmière sur la formation [The impact of the progress of the nursing profession on nursing education]. Revue de l'Université de Moncton, 18 (2-3): 141-152.

#### **Previous master's dissertations**

- Poirier, N. (1985). Application de la théorie de Kübler-Ross à une population de malades en phase terminale [Application of Kubler-Ross's theory to a group of terminally ill patients]. Master's dissertation, Faculty of Education, Université de Moncton, 80 p.
- Poirier, N. (1992). Some Factors Discriminating Between Battered Women in a Psychiatric Unit and Other Women Inpatients. Masters' dissertation, Faculty of Nursing, Dalhousie University, 98p.

#### **Scientific conferences**

Since 1992, Norma Poirier has given 10 papers to scientific, peer reviewed conferences, mostly in Canada and one in London, UK.

#### **Community Services**

Norma Poirier has been actively involved since 1985 as a member of the Canadian Nurses Association's Committee on Testing and Registration Licensure Examination Committee and as President of the New Brunswick Nurses Asssocation's committee (1987-88) on the professional education of nursing instructors.