

A SURVEY OF SENIORS' PERCEPTIONS OF SURROGATE DECISION MAKING,  
MEDICAL TREATMENT PREFERENCES AND ADVANCE HEALTH CARE DIRECTIVES.

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SURROGATE DECISION MAKING, MEDICAL TREATMENT PREFERENCES, AND  
ADVANCE HEALTH CARE DIRECTIVES

BY

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## ABSTRACT

This study examines community-living, independent seniors' perceptions and views of preferences for surrogate decision makers, life-sustaining medical treatment, and advance health care directives. Data were collected through in-depth personal interviews with 26 seniors living in the Hamilton-Wentworth area of Ontario. This study looked for differences in these perceptions by socio-demographic background characteristics. Using case vignettes involving elderly patients who are either decisionally or communicatively incapacitated, participants were asked who should make a decision regarding end-of-life medical care decisions for patients, and for their preferences regarding the life-sustaining medical treatments involving respirators, antibiotic intravenous, forced feeding and amputation. Participants were asked for their familiarity with and opinion of advance health care directives. Results suggest that most often seniors prefer to rely upon family members as surrogate decision makers and that most seniors are opposed to aggressive medical treatment. Most seniors were familiar with and have positive attitudes about advance directives, however very few have completed a directive. A discussion and concluding comments suggest themes, concepts and viewpoints that emerge from this study and suggest avenues for further research.

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"At its very simplest, the quality of dying is a reflection of the quality of living: a measure of the condition of human life.

On a personal level, dying and death are penultimate issues of existential significance. The fact of mortality is one of the most awesome and challenging dimensions of human life. The process of making reasonable and workable adjustments to the human fact of finitude is enhanced by coming to grips with patterns and issues that define the contemporary dying process. Coming to terms with dying and death intellectually facilitates a seedbed of knowledge that enables individuals to make an investment in greater autonomy and self determination."

David Moller, On Death Without Dignity  
the Human Impact of Technological Dying  
Preface, ix - x

"The final medical solution to humans problems: remove everything from the body that is diseased or protesting, leaving only enough organs which by themselves, or hooked up to appropriate machines -- still justify calling what is left of the person a "case"; and call the procedure "humanectomy".

Thomas Szasz, The Second Sin, p.70.

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## Chapter One

### Introduction

Our society is confronting a vast set of moral issues and decisions concerning the role, status and welfare of our elderly population. Major changes such as increased longevity, compression of morbidity, and chronicity of illnesses in our aged population dictate that health care for the elderly is a central issue for social scientists, economists, health care providers, and social policymakers. The aging of the Canadian population and its impact on the health care system at the administrative, financial, and ethical levels cause concerns regarding the "fit" between health care allocations, increasingly scarce and limited financial health care resources, and the challenge to meet the health care needs of the elderly (Chappell, 1992; Petruccelli & Henry, 1991; Estes & Binney, 1991; Lebel, 1991; Courchene, 1990; Rachlis & Kushner, 1989; Estes et al., 1989; Denton et al., 1988; Callahan, 1987; Evans, 1987). Media headlines such as "When it's time to leave: can society set an age limit for health care? and "Sick to death" reflect the demographic and financial pressures surrounding health care resources for seniors. Miller, (1991) reports that Gordon Cunningham, president of the Ontario Hospital Association, was quoted as saying:



"We can't deliver unlimited care for limited dollars and that's where it becomes a societal problem.---There are some people in hospital taking up acute care beds who shouldn't be there. But what are we supposed to do with old people and the chronically ill?" (p.41)

As a group, seniors consume about one-third of Canada's annual health care budget, the largest amount for any segment of the population (Miller,1991).

The advances and growth of medical knowledge in highly technical, life saving and sustaining techniques allow the extension of life. Never before in human history, have so many elders lived so long. Advances in biomedical technology in this century have increasingly made life-sustaining techniques and the process of dying events that require deliberate decision making. For almost any life-threatening illness/disease, some medical intervention can now delay dying. Dilemmas face modern medicine as life can be prolonged in ways never before possible. However, medicine cannot always provide life of acceptable quality.

The emphasis of ethical decision making in health care has been attributed, in part, to the extensive use of technology today. Health care professionals have been trained in a "technical imperative" which is the utilization of medical life-sustaining technology, that disregards patients' opinions regarding technology (Slomka, 1992). Ethical issues emerge over the quantity versus quality of life (Callahan,1990, 1987; Daniels,1988; Caplan, 1982). Moreover, the need to reduce expenditures on health care has

initiated the ethical discussion regarding the wisdom of keeping patients alive when they no longer wish to have their lives prolonged (Sprung, 1990).

Concomitant with the advances of medical technology is the continuing growth of individual autonomy and the consumerism movement in health care, which Haug & Sussman (1969) term the "revolt of the client". Today, as consumers of health care, seniors are generally better educated, more knowledgeable, demanding, and willing to question who should control decisions about their health care and their dying process. Such movements have combined to support the growing sphere of individual autonomy in health care decision making. Empowerment of the elderly within the health care system is a concept increasingly discussed in clinical and policy making contexts. Consumerist movements are increasingly calling for empowering the elderly and emphasizing the rights of elderly patients to make autonomous health care decisions (Clark, 1989). These movements challenge the authority of health care providers to make decisions for others based on specialized medical knowledge (NACA, 1993 a; Coburn, 1993; Kelner et al., 1993 a). Thus, public pressure for greater involvement in making decisions regarding health care and the process of dying has impacted on medical dominance in health care. Medical science and technology is experiencing its limits and facing choices that are frequently more ethical than medical. To the extent that medical technology or

palliative care do not deliver the anticipated benefits in terms of quality of life, nonetheless, the values of everyone involved the health care team, families and patients are now foremost (Saint-Arnaud, 1993).

One of many responses to consumerism in health care, has been the development of an individual's "right" to refuse/withdraw/forgo medical treatment /intervention or the "right to die with dignity". This has led to the development of an advance health care directive (Sachs et al, 1992; Doukas & McCullough, 1991; Molloy, 1991 a; Singer, 1991). An advance health care directive allows an individual, when competent, to make health care decisions in writing, which will become effective if the individual loses either decisional or communicative capacity. Health directives are premised on the philosophy and principle of autonomy or the right to self-determination of competent individuals. Autonomy dictates that individuals have the authority to make their own health care decisions after being informed of potential consequences of those choices. Advance directives such as living wills are attractive in theory, to the extent that they give individuals a sense of control over future health care decisions if incapacitated. Directives empower people by extending the scope of personal autonomy to situations in which autonomy cannot be directly exercised, thus gaining the assurance that he/she will later be viewed in light of previously expressed preferences. Further, directives allow

individuals the choice of medical treatment regardless of whether that choice is to preserve life with every medical technique available, or to forgo any medical treatment available which may result in death. Inherent in the autonomy of directives is the individual's decision to forgo medical treatment that prolongs the quantity of life and to choose a course that will enhance the quality of the remainder of life.

Recently, the National Advisory Council on Aging (NACA, 1993 a) has stated its position regarding seniors and advance health care directives by recommending that:

"Public debate be encouraged and include the views of seniors themselves, to clarify individual, community and societal standards concerning ethical issues such as living wills, advance directives, rationing of health and social service resources and euthanasia; and that necessary mechanisms be put in place to implement the resulting decisions." (p.35)

Further, NACA suggests that it must be determined what constitutes an acceptable quality of life. There is very little Canadian research regarding seniors' perceptions of advance health care directives (NACA, 1993 a). The objective of this thesis is to provide information regarding seniors perceptions regarding health care medical decision making, medical treatment preferences, and advance health care directives.

Based on interviews of twenty-six seniors, I will first examine senior's preferences regarding surrogate decision makers. Who should make life extending medical treatment decisions if a

patient becomes either decisionally or communicatively incapacitated. Do seniors see themselves, their immediate families, relatives, friends, physicians or significant others as preferential surrogate decision makers? If senior's preferences vary, do they appear to vary by socio-demographics or health characteristics? Second, I will examine seniors' preferences regarding life threatening/extending medical treatment. Do medical treatment preferences differ and if so, do these differences vary by socio-demographic and health characteristics? Third, I will examine seniors' perceptions of advance health care directives. In particular, do seniors perceive such directives as a viable and useful document to express and communicate their preferences regarding future medical decisions if they become decisionally or communicatively incapacitated?

The thesis begins with a discussion in Chapter Two of the demographic, social, economic, and political changes which occurred both within the structures of society and individuals and led to the emergence of advance health care directives will be examined. Chapter Three is an in depth review of the existing literature regarding seniors' perceptions of surrogate decision makers, medical treatment preferences, and advance health care directives. This literature review is largely based on American research, due to the lack of Canadian research on this topic. Chapter Four consists of a description of the methodology employed for the

interviews, the sample, and an explanation of the instruments used for the interviews. In Chapter Five, an analysis of qualitative and quantitative data from the interviews are presented. Chapter Six is a general discussion of the findings and results of the interviews and emerging themes regarding the seniors' perceptions of surrogate decision makers, medical treatment preferences, and advance health care directives. Chapter Seven presents some conclusions and suggests further research and directions.

## Chapter Two

### Social Change and Advance Health Care Directives

The objective of this chapter is to examine the demographic, social, economic, and political changes that occurred both within the structures of society and individuals and led to the emergence of advance health care directives. The sociological concept of social change will be the framework used for the discussion and analysis of the development of advance health directives.

Social change is central to much sociological study and research, since neither societies nor their constituent parts are ever static. Sociological giants such as Comte, Pareto, Marx, Durkheim, Weber and C.Wright Mills were all interested in social change. Sociologists are interested in the factor(s) that produced or caused the identified change(s) in the phenomenon studied (Allahar,1991).

Change may occur at individual levels and/or at the social structural level. Vago, (1980) explains:

"The assumption is that since groups and organizations are made up of individuals, therefore, individuals can bring about change in the systems in which they are members. Thus, a change on an individual level can be evaluated in terms of its possible benefits and usefulness to the system of which they are members." (p. 293)

Social change occurs when there has been an identified

change over time in the structure and functioning of the social relationships and/or the institutions of a society (Landis, 1974; Gerth & Mills, 1953). There are a number of factors which have been shown to be causal factors for social change. They are technological development, specialization and differentiation of society, and ideology.

Social change has been connected to technological development. The capacity for technology to change the circumstances of human life and the character of social institutions is quite recent (Vago, 1980). According to Vago:

"technology is a prime mover of society and it makes social change inevitable.---We must also point to the role of knowledge, beliefs, and values in society in bringing about change." (p. 13)

Technologies establish new alternatives and opportunities for humans and societies, however, Mesthene, (1977) suggests:

"it also generates new problems for them. It has both positive and negative effects, and usually has the two at the same time and in virtue to each other" (p.159).

The more complex, specialized and differentiated a society, the more likely it is to change and to change rapidly (Vago, 1980). The twentieth century has witnessed how our society is extremely complex, differentiated and specialized. There is diverse specialization in occupations. For example, today within the medical profession there is increasing specialization which requires specialized knowledge and expertise. Thirty years ago, a



geriatrician, a doctor who specializes in the health care of seniors, was novel. Today there are geriatric specialists in psychiatry and neurology to name but a few.

Another mechanism for social change is ideology. Ideology can be seen in this context as: "applied to those informal and diffuse collections of political views and values that many people share" (Vago, 1980, p. 98). Social movements can be broadly defined as organized collective activities aimed at correcting some perceived inadequacy in existing social arrangements. A social movement can be perceived as having a collection of views and values that people share and thus representative of a shared ideology on a specific social issue. Vago, (1980) contends that "Social movements are caused by social change and in turn bring about changes of their own" (p.277).

The next section of this chapter will apply the theory of social change to the emergence of advance health care directives. It will be argued that advances in medical technology, the specialization of the medical profession, the changing ideology of health care involving individualism, the consumer movement and perceptions of death and dying have all contributed to the emergence of advance health care directives.

### Medical Technology

In our Western industrialized civilization the dominance of scientifically based technology as seen in our values, beliefs, and

institutions, is a major social force. As a society, we have fallen in love with technology (Moller, 1990). Shils, (1974) observes that we have fully committed ourselves to a scientific way of life and death and as such, our faith in scientifically based technology is boundless. Moller, (1990) points out that:

"Dying points out the weaknesses of the technological and scientific lifestyle. The major societal response to the intolerable social evil of dying is technological intervention.---it is the technological orientation of society in general and of the profession of medicine in particular which is unable to provide for legitimation, purpose, and meaning to the dying experience. Consequently, an antagonistic relationship between technocratic consciousness and dying is spawned and the ultimate goal of the technological management becomes the defeat of death." (p. 9)

Technological medical advances have helped to increase life expectancy to the point where an unprecedented proportion of the population lives into old age, and new medical technology offers prolongation of life for elderly patients. Lefrak, (1985) points out that life support techniques are available today that will:

"breathe for the patient, oxygenate blood, circulate blood throughout the body, remove metabolic wastes from the blood system, drain urine from the bladder, supply water and all nutrients intravenously ---in general, much of physiological life can be sustained for the patient." (p. 145)

However, no amount of medical technology can sustain the social, emotional, psychological, and mental life that makes a patient a person, nor does it define or enhance a person's quality of life.

In the twentieth century race to "technologize medicine", physicians caught up with "halfway technologies", are more

reluctant than ever to "give up" an individual's life as defined in the physical/biological sense (Moller, 1990; Slomka, 1992).

"Halfway technologies" is a term coined by Thomas (1971) to describe attempts by medical technology to:

"compensate for the incapacitating effects of certain diseases whose course one is unable to do much about. It is a technology designed to make up for disease, or to postpone death."(p. 429)

Moller, (1990) suggests that in medicine these technologies are:

"applied beyond reasonable expectations that patients can be restored to functioning human beings. So long as the heart muscle can be kept beating, there is a wish, almost unconscious, that the body ensemble will achieve a recognizable living condition. Who knows? Tomorrow a new biomedical discovery may bring the patient around."(p.X111)

The rapid development of medical technology has intimidated people's sense of control and social critics refer to this as the inability of the average person to influence technology and a resulting experience of powerlessness (Kelner et al., 1993 b; Florman, 1981). Sampaio, (1992) expresses a deep concern with what seems to be the diametrically opposed paradigms of medical technology and individuals freedoms and rights, in stating:

"It has often been stated that scientific and technological developments provide increasing opportunities for better conditions of life. However, the same developments have provided the environment in which new social problems have developed, which challenge fundamental freedoms and human rights.---There have been disturbing reports of scientific and technological products and methods being utilized to keep individuals alive against their will or, more ominously, when their conditions of life can hardly be described as having anything to do with human life." (p. 433)

Health care professionals have been trained to use technologies that are available to them, even if the consequences of using this technology may be painful, undignified, dehumanizing and debilitating for patients. Life support systems, highly specialized intensive care units, and highly technical, mechanical and intrusive life sustaining interventions are now the norms facing most terminally ill patients today (Cochrane, Levy, Fryer & Oglesby, 1990-91; Callahan, 1987; Russell, 1977). These medical technological advances have produced situations in which many elders experience a diminishing of control over their lives, which in turn, manifests in feelings of helplessness and a loss of dignity. Daniel Callahan, (1987) philosopher and founder of bioethics in the United States, Director of the bioethic's institute, the Hastings Centre, in reference to medical technology comments:

"Technology has sometimes been likened to an addiction, or a force, that takes on a life of its own quite apart from human desires of intentions." (p. 162)

Finlay, (1985) echoes this sentiment in stating:

"Progressive technological advancements in medicine have led to situations in which ethical questions concerning the physician's commitment to the preservation of life at all costs are raised." (p. 548)

Hawkins (1990-91) in referring to advanced medical technology used in our culture to prolong life suggests:

"what many now fear is a "medical death" - the technological prolongation of life at the expense of any real sense of quality of life." (p. 302)

Moller, (1992) states that:

"Technological concerns displace or, at least, dampen social and emotional involvement. Dying is a reflection of the failure of technology: and modern medicine is nothing if not technology." (p. X1V)

Accordingly, the advances of medical technology, the "technological imperative" within the health care system, and the overuse of this technology to prolong life have combined and contributed to bring about a monumental change in how medicine is practised today.

### Specialization of the Medical Profession

Few family doctors today resemble family doctors of thirty or forty years ago. Rarely are family doctors/general practitioners totally responsible or in charge of an individual's health care. Rather, family doctors tend to refer their patients to specialists. Pregnancies and child birth are under the expertise of obstetricians, children are referred to pediatricians, and seniors referred to geriatricians. These specialities require special knowledge and expertise. Freidson, (1988) explains:

"Decisions requiring expertise are insulated from public debate, negotiation, and compromise---Layman are excluded from participating in decisions thought to require special expertise, even when those decisions are intended to improve their own well being.--we are on the brink of changes in the structure of our society which will have a massive effect on the quality of the lives of the individuals who compose it. The relation of the expert to modern society seems in fact to be one of the central problems of our time, for at its heart lie the issues of democracy and freedom and of the degree to which ordinary men can shape the character of their own lives. The more decisions are made by experts, the less they can be made by layman".(p. 335-336)

This increased specialized knowledge and expertise, has meant a greater division between an individual and the physician about decisions regarding their own bodies and ultimately their destinies. It is through this specialization and differentiation between physicians and individuals that the medical profession claims special status in order to have the sanctioned authority, control and power to define health, illness and death. In response to this, health care directives have been developed to countervail this power differentiation.

#### Individualism, Autonomy, and Consumerism in Health Care

In a contemporary, complex and interdependent society, such as Canada, individual autonomy, independence and/or self-determination of competent adults are cherished personal and societal values. The last decades of the twentieth century have spawned the age of individualism and a consumerist movement which recently has been incorporated into health care in Western Society (Saint-Arnaud, 1993; Kelner et al., 1993 b; Moller, 1990). Patients and their families are now demanding increasing control over their health care and ultimately their own destinies.

Health care is no longer totally controlled by nor is it the exclusive jurisdiction of the medical profession in Canada. Beginning in the early 1960's, the provincial and federal governments' involvement in health insurance coverage resulted in a restructured universal health care system and signalled a period

of decline in dominant medical control over health and health care (Coburn, 1993; Coburn, Torrance, & Kaufert, 1983). At the same time, health ministries had to respond to social movements that demanded different forms of health care (Coburn, 1993). The rigid medical model of health care once controlled by a scientific and technological based medical model of health and monopolized by the medical profession is now being replaced by a more holistic based model of health and health care which incorporates the social, cultural, ethnic, and psychological aspects of a patient. Thus, the acknowledged "true determinants of health today are the social, physical, economic and workplace environments we inhabit and the behaviours we develop that such environments support" (Premier's Council on Health, 1993). Informed consumer based and oriented health care and shared decision making between consumers of health care and the medical profession is now the goal of these relationships.

Based on our society's value of individualism, autonomy, and self determination, we strongly believe that no other person has the right to overrule an individual's decision regarding health care decisions if that person is competent to make it. The last few decades have witnessed a dramatic change in the physician-patient relationship as patients as consumers and clients of health care have become more active advocates for their own interests. The antiquated control, power and paternalism on the part of the

medical profession is beginning to be replaced by recognition of patients' autonomy. Thus the power relationship between health care professionals and patients is moving towards one that is based on an equal and shared relationship (Kelner et al. 1993 b).

Further, people are becoming more vocal in questioning the medical and technological control of the dying process evidenced by the growth of social movements and organizations such as the "Right to Die Society of Canada" and "Dying with Dignity" (Slomka, 1992; Moller, 1990). These two groups have a combined Canadian membership of approximately 8,400 persons (Dying with Dignity Newsletter, 1992; Humphry, et al., 1990).

Hawkins (1990-91) in reference to our culture and the individualistic movement regarding death suggests:

"In the past two decades there have been an efflorescence of books about death and dying. Today's popular narratives about illness and dying propose a variety of models for the "good death"." (p. 301)

Kubler-Ross's (1969) "On Death and Dying", Lofland's (1978) "The Craft of Dying", Glasser's & Strauss's (1968) "Time for Dying", and Humphry's (1991) "Final Exit", (1986) "The Right to Die", (1984) "Let Me Die Before I Wake", and (1978) "Jean's Way" are examples of the books available that prescribe and instruct readers in pursuing the "good death". Other responses to increasing consumerist knowledge regarding "graceful death", "happy death movement" and "dignified death" are the plethora of journals and



university courses available on the subject of death and dying. Journals such as Omega and Essence, the hospice movement, workshops and conferences on death and dying, all espouse how people should die, expose the barriers to the "good death", and promote individual autonomy in controlling the time and the circumstances of one's death.

Fox (1989) points out that sociologists Glaser's & Strauss's (1968) seminal research into death and dying "Time for Dying", predicted that advancing medical technology would become a public debate surrounding the issue of prolonging life. They suggested:

"The question of the circumstances under which procedures for prolonging life should be initiated, maintained, or discontinued must be debated by the more general public. With some certainty, one can predict that this issue will increasingly be discussed openly as medical technology becomes increasingly efficient." (p. 253)

Further, Fox (1989) suggests that amongst other indices and changes germane to the public's awareness of death and dying issues, is the:

"continuing, very public wrestling with the issues concerning the definition of death, quality of life, terminally ill patients' "right to know" and "right to die" and the forgoing of life-saving treatment" (p. 41)

In Canada, the "very public wrestling with the issues of the quality of life" and "the right to die" are evidenced by the recent appeal to the Supreme Court of Canada by Sue Rodriguez. Sue Rodriguez, a 42 year old woman, has Lou Gehrig's disease. Because

of the "ravages" of this progressive deteriorating disease, she "lacks the skills to terminate her own life" and "wishes to have dignity with death, and "to be able to choose her time" and has asked for an assistance in her suicide (1992, p. A-17). Her appeal was narrowly defeated. In December 1991, Nancy "B" a 24 year old, suffering from Guillain-Barre syndrome, petitioned the Quebec Supreme Court to grant her the right to refuse medical treatment and to terminate her life support system. The Supreme Court granted her this, and a month later with assistance, Nancy B. chose the time, the circumstances and controlled her "refusal of life-saving treatment" and her "right to die" (Deacon et al., 1991, p. 49). Dr. Kevorkian, alias "Dr.Death", an American retired pathologist, has assisted 20 people in controlling the time and circumstances of their "right to die". The plethora of media attention and coverage given to these issues symbolizes the "good death" ideology in our society.

This "good death" ideology has been adopted by a growing consumer population which when faced with a terminal illness, and/or a shortened life span filled with suffering devoid of human dignity and quality, are demanding autonomy and the right to choose the time and the place of their deaths. For many, this would mean the foregoing of life-saving /sustaining medical treatment that would interfere or diminish the definition of their quality of life. Perhaps, Robert Wenman, a MP from British Columbia

captures the essence of autonomy and decision making when faced with a terminal illness by stating:

"I am a responsible adult and I was taught that I had a broad range of choices. Why do I cease to have control over myself when I become terminally ill?" (Godley, 1992, p.609)

Dickens, (1993) comments:

"Courts have observed that a patient's decision on the rejection or use of medical procedures is not a medical but a personal decision. Patients are equipped to make decisions, not because of any detailed knowledge of medicine, but because of awareness of their own preferences, dislikes, discomforts ambitions and history." (p.79)

Slomka, (1992) refers to the consumerist movement regarding death and the dying process as the "negotiation of death" which involves deliberations amongst the physician, the family, and the patient. The negotiation of death also reflects the growing dissatisfaction with the medical control of death. She states:

"(consumers) are becoming more vocal in questioning the medical and technological control of the dying process. --- The social process of negotiating death is beginning to act as a check on the medical and technological control of the dying process." (p. 258)

Noyes et al. (1977) in discussing dying patients' attitudes comments:

"As patients become more aware of their rights and imbued with the consumerist point of view, requests of this kind (no life-prolonging measures) are likely to become more frequent. Thus, the support of an increasing practice may come from patients as they become more active participants in their terminal illness." (p. 473)

One recent reaction and change to the individualism, autonomy, and consumerism in health care is evidenced by a response

by the medical profession. Health care professionals are now obligated to promote the autonomy of patients (Stolman et al. 1990; Dossetor, 1991). The medical profession has recently recognized and accepted the right for a competent individual to make free, uncoerced, and authentic choices regarding health care decisions about their own bodies and ultimately their deaths. The Ontario Medical Association (1990) issued guidelines on caring for terminally ill patients in which it recommends that physician's: "incorporate systematically the patient's/family's ideas, feelings, and expectations into long-term clinical decision making" (p.764). Further, the Canadian Medical Association issued its policy statement and guidelines regarding advance directives in March 1992, directing physicians to "Honour a patient's advance directive" (Appendix-I). Saint-Arnaud, (1993) captures the essence of patient autonomy in decision making in the following statement:

"It is the patients themselves who know if a treatment is too difficult for them, whether they are prepared to accept resuscitation or chemotherapy that might lead to a longer, but qualitatively diminished life, whether they could accept a life in a coma, on intravenous feeding or on a respirator for the rest of life as a quadriplegic."(p.37)

Thus, the relatively contemporary development of individualism and the consumerist movement have brought social change in patient/physician relationships, health care and health care decision making, and the dying process and led to advance health care directives.

### Shifts in the Dominance of the Medical Model of Care

One result of the growth of the consumerism movement in health care is the scepticism and questioning of the medical profession's dominance, authority, power, and control over their health, health care and illness throughout a person's life. Consumers are no longer willing to unquestionably accept the "medicalization" of their life span. Medicalization refers to the medical and technological intervention by medical specialists in dealing with the various normal stages of the human life span. As Illich (1976) comments:

"life is turned into a pilgrimage through check-ups and clinics back to the ward where it started---life is reduced to a span--this life span is brought into existence with the pre-natal check-up, when the doctor decides if and how the foetus shall be born and it will end with a mark on a chart ordering resuscitation suspended." (p. 87)

Illich (1976) alludes to the fact that in our culture, life and death are defined, controlled and decided by the medical profession. Illich (1976) suggests that medicalization leads to "structural iatrogenesis" which is the loss of individual autonomy and the creation of dependency on the medical profession. Through the dominance and prevalence of the medical model of health/illness/death, and the medical institutions and practices, important human experiences such as pain, suffering, illness and death which can encourage the development of service to others, compassion and connectedness with others, have been medicalized and

bureaucratized to the extent that individual initiative and autonomy have been usurped by the medical profession (Clarke, 1990). Moller, (1990) suggests:

"As images of dying and death arise in a specific and historical context, the medicalization of death has emerged as a structural reflection of the specific cultural images and circumstances of contemporary (North) American society.---When one thinks of a person dying in modern civilization, hospitals, machinery, drugs, professional staff, alienation and a sterile environment typically and rapidly come to mind." (p. 98)

Further, Moller, (1990) alludes to the lack of control, choice and autonomy that patients have in making decisions about their own bodies. He states:

"It is interesting to observe how many decisions about the life of a patient are made without seriously consulting the patient. Patients often are informed of the treatment they will be receiving in a manner that is more of an after thought than anything else."(p. 57)

Beginning in the 1960's, the consumerist movement challenged and initiated a "de-medicalization" process. Apprehension surrounded not only the power and control exercised by the medical profession, but also as Fox (1989) points out: "criticism of the powerlessness, ostracism, dehumanization, and even "mortification of self" (p.29). One element of the demedicalization process transformed the asymmetrical hierarchy in the patient/doctor relationship into one that promoted a "greater degree of patient autonomy in the medical decision making process in which doctor and patient are mutually involved" (Fox,1989, p.31). Haug, (1988) commenting on this consumerist initiative

states:

"What we do have is information on the unwillingness of many patients in the Western industrialized world---to give unquestioning obedience to the doctor's authority. Whereas previously such disobedience was covert, in the form of noncompliance, it is now overt, in public demands for participation in decision making. The evidence is everywhere ---in scientific journals, the media, and popular books aimed at the general public. Patients are exhorted to demand and get their rights."(p.51)

Coburn (1993) comments that:

"even patients are infringing on medical privilege. Medicine, it is said, is declining in power. (p. 129)

Health care professionals are now confronted with new dilemmas in attempting to accommodate clients' preferences for self-determination during the dying process (Uhlman et al., 1989).

Doctors are educated in a "death as the enemy" imperative that conditions and commits them to a pursuing the biological life of patients at all costs regardless of the quality of that life (Larue,1992). Thus, the desire for many clients to forego life-sustaining treatments when facing death, is perceived as problematic by many health professionals (Quill, 1991; Kass, 1989; Anonymous, 1988; Gaylin et al., 1988; Vaux, 1988). Crane (1975) suggests that medical practitioners struggle with the complicated and many faceted medical, legal, and ethical issues involved in utilizing the new technologies that enhance the capacity to sustain life. Dossetor, (1991) suggests:

"We should be aware that physicians find it difficult to discuss the process of dying with their patients despite

a growing body of evidence that such patients overwhelmingly want such discussions."(p. 217)

The physicians' expectations of their patients' beliefs and values about the dying process are likely to be at variance with their patients' perceptions (Higgins, 1993). Justin (1987) states:

"Even dedicated family physicians know less than they realize about their patients' beliefs and values; hence, they may make unwarranted assumptions."(p.277)

For instance, Justin, (1987) a family physician distributed a questionnaire called a "value history" which included some questions related to values, beliefs, decision making and living wills to two hundred of her patients. She discovered that not only did she know less than she realized about her patients, but also, that some of her assumptions about her patients' beliefs and values were wrong.

Thus, the medical professions' relationship with its patients through the ideologies of individualism and consumerism have changed drastically over the last few decades.

### Changing Context and Ideology of Death and Dying

In our society and culture, death and dying are associated primarily with old age. Massive social movements and expenditures on sanitation, personal hygiene, immunization, preventive health measures, and medical care combine to increase life expectancy today. Thus, it is increasingly the old who die, making death predictable as a function of age. Death has come to be a timely



event, the completion of the life cycle in old age (Hooyman & Kiyak, 1993; Marshall, 1980, 1986).

The medical profession has control over the definition of death, to the extent that both the process of dying and death have become institutionalized, medicalized and bureaucratized (Marshall, 1986; Nash, 1977; Illich, 1976). Before the late twentieth century and advanced medical technology, death from pneumonia was referred to as "the old's mans friend", denoting a rather quick and relatively painless death. Today, with the advent of antibiotics and technically based medicine, most aged persons with terminal illness who acquire pneumonia, are faced with invasions that unnecessarily prolong and delay death. Today, a prolonged period of dying in an institution is part of the dying process which has changed from the private sphere of the family to the bureaucratic institutionalized public sphere. Regardless of the inroads made by the hospice movement and palliative team approaches to the dying process, most dying individuals are still incarcerated in institutions. Rarely does death occur in the serenity, comfort and familiarity of one's own home and surrounded by family as it did in the past. Rather, individuals are surrounded by insidious tubes, noisy machines, and constant medical and technical professional interruptions which are couched in the sterile, impersonal environment of an institutional setting. Blauner, (1966) states:

"When the dying are segregated among specialists for whom contact with death has become routine and even somewhat impersonal, neither their presence while alive nor as corpses interferes greatly with the mainstream of life." (p.384)

Even though most people express a preference to die at home surrounded by friends and family, in Canada almost 70% of all deaths occur in institutions (Amenta, 1985; Statistics Canada, 1978).

Accordingly, the aforementioned discussion has illustrated that changes in medical technology, specialization within the medical profession, the growth of individualism and consumerism, and the changing ideology of death and dying have led to the emergence of advance health care directives.

#### Emergence of Health Care Directives

More attention on death and dying issues and the subsequent emergence of advance directives are a direct result of the developments such as growing scepticism and fear of the excesses of medical technology, greater willingness of consumers to question medical treatment that unnecessarily prolongs life, consumerist demands for medical treatment that emphasizes quality of life criteria rather than quantity of life, and new demographic realities.

Popular interest in death and dying has grown immensely in recent years. The increasing aging population has resulted in the emergence of chronic diseases as the major cause of death for

seniors, and is partly responsible for the new emphasis on the quality of life and patients' rights, especially the right to choose death over medical technological intervention (Logue, 1993). The public's faith in medicine and medical technology diminished in the 1970's as evidence mounted that the medical industry often "caused harm and unnecessary suffering in the course of trying to cure, delaying death unduly with its heroic, yet futile, interventions" (Logue, 1993, p. 78). Consumers began to see a need for patient empowerment within medicine in order to prevent medical technological over-treatment by the medical profession. The advances in medical technology represented what Illich, (1976) refers to as a "modern form of torture, engendering fear, and anxiety rather than faith and trust" (p.26). Many became aware of instances of excessive and unwanted treatment through experiences with relatives and friends and through the horror stories in the mass media (Logue, 1993).

The historical origins of living wills, the precursor to advance health care directives, emerged from a deep concern that people might have their lives needlessly prolonged by medical interventions (Emanuel & Emanuel, 1989). Living wills were concerned with the explicit refusal in advance of artificial or mechanical means to sustain the lives of terminally ill patients. Living wills developed into more specific advance directives dictating in anticipation of personal incapacity how patients

wished to be treated in various circumstances that included both acceptance and/or refusal of medical treatment interventions (Dickens, 1993).

In particular, two highly publicized cases in the United States were highly influential in forcing Americans to confront the hard realities of modern medicine and the central issues of patient autonomy and death control debates. The Quinlan case (1975) and the Cruzan case (1983) made legal and medical history. Both young women suffered irreversible brain damage and were in permanent comas. Despite the pleas of their parents to disconnect life support, a respirator in Quinlan's case and a feeding tube in Cruzan's case, doctors refused to disconnect either. Their parents endured long court battles in petitioning Supreme Courts to disconnect life support, and the courts decided in their favour. (Singer, 1991 A) In Canada, the Nancy B. case (1991) and Sue Rodriguez's (1993) appeal to the Supreme Court to control her own death process, have had the same effect on the public's awareness of patient autonomy and a person's right to control their own dying process. In 1983, the British Columbia Court of Appeal held that forced feeding of a patient was not mandatory. In 1990, the Ontario Court of Appeal found a physician liable for battery for administering blood transfusions to an unconscious patient who carried a card stating the rejection of blood transfusions under any circumstances. This was the first case in Canada to support the

use of any form of advance directives. (Singer, 1991 a) These cases were instrumental in the public's awareness and subsequent demand to protect patients' autonomy and patients' rights such as the right to refuse treatment, the right to informed consent, and the emergence of living wills/advance directives as a document to protect their autonomy, beliefs and treatment preferences. Throughout North America consumerist movements such as the Hemlock Society, The Right to Die Society, and Dying with Dignity were gaining popularity and membership in an effort to promote an individual's right to control their own death when faced with terminal illness. As mentioned, a plethora of books, journals, and media attention heightened the public's awareness of death control issues and patient autonomy. These cases also represent the entry of patients' rights movement into the political arena. Singer et al., (1992) states:

"As medicine has moved from a paternalistic to a participatory model of practice, courts and state legislatures have granted increasing recognition to the right of patients to determine their own health care decisions."(p. 1165)

Political and government responses to these social changes encourage patients to give instructions regarding decisions about life-sustaining treatment in advance of critical illness and the loss of decision making capacity. For instance, in the United States, recently enacted are the Patient Self-Determination Act of 1990, living will statutes and recognition of a durable power of

attorney for health care have legal status (Sachs et al., 1992). Presently in Canada, there is no federal legislation that supports the use of advance directives, rather it is a provincial responsibility. Nova Scotia and Quebec have enacted legislation providing for the use of advance health care directives (Nova Scotia, Medical Consent Act, RSNS, 1989, c 279; Quebec, Public Curator Act, SQ 1989, c 54;). Ontario introduced two bills with provisions for advance directives (Bill 108, Substitute Decisions Act, 1st Sess, 35th Leg. Ont, 1991; Bill 109, Consent to Treatment Act, 1st Sess, 35th Leg. Ont. 1991). Manitoba, Alberta and British Columbia are currently in the process of seeking legislature to legalize advance health care directives.

The demographic realities of an aging Canada combined with the economic implications regarding health care are also responsible for the public's awareness of autonomy, patient's rights, and death/dying issues. Bugeja, (1991) reports that Dr. John Scott, in his opening remarks at the annual meeting of the OMA council stated:

"health care for those in the very last year of life will become a very rapidly growing problem for Ontario before the end of the century. In 1990, there were almost 18,000 deaths in the province. The care delivered to those patients during their last year represented a huge proportion of their total life-time health care costs.---we can expect a 50% increase just in cancer incidents between 1990 and the year 2000 mainly due to the rapid aging of our population.---Physicians should be seen as advocates for those in the last year of life by ensuring that suffering is relieved and life enhanced until the moment of death." (p. 17)

Further, The National Advisory Council on Aging (NACA,1990) states:

"Seniors have told NACA that the most important component of their quality of life is their independence. This ideally means being able to carry out our life's activities within normal community setting and being able to make choices about these activities and have control over one's life course."  
(p.6)

In its first report, "The Health Care System and Its Funding: No Easy Solutions" the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women (1993)

recommended that :

"resources be directed toward informing and empowering seniors as consumers of health care services in order that they can share, with their families, health care professionals and informal caregivers, the responsibility to make healthy choices about their own health."(1993,p.70)

The medical profession is not immune from public scrutiny nor from a desire to avoid negative public opinion. With mounting pressures from the public, the mass media, the patients' rights and consumerist movements, the backing of political and judicial systems regarding patient's rights, and the real threat of litigation, the medical profession responded to these issues. Until recently, the majority of doctors were opposed to telling a patient that an illness was terminal nor did physicians allow a patient any choices regarding medical treatment. Levine, (1989) a medical sociologist comments on the recent redefinition and shift in the patient/physician relationship from one in which:

"the doctor as scientific expert transmitted that knowledge to an ignorant but receptive patient who avidly and

unquestioningly followed instructions---to a more realistic, dynamic view of active engagement by both parties."  
(p.3-4)

He suggests that the new consumerist patients' demand for medical treatment based on quality of life criteria that encompass the individual's social, mental, emotional and psychological being is fastly becoming the paradigm of physicians' practices and has been incorporated into teaching medical students. Accordingly, the medical profession through public pressure and social movements has been compelled to respond and acknowledge these social dimensions and changes (Levine, 1989).

The recent modern hospice care and the discipline of palliative care are further evidence and responses from the medical fraternity to the public issues of controlling the death processes. The modern hospice care with the backing of the consumerist movement, has received wide popular support since the 1960's. Dame Cicely Saunders, an English doctor and founder of modern hospice care describes the hospice approach to the dying:

"Let us be with those who are dying, so we can learn what their needs are. We can't run from them, for the more you run, the worse their death appears---Although we do not hope to cure, we look at our patients as vital persons in distress and therefore concentrate on giving them relief that leads to an ability to enjoy family, friends and food and drink and all the activity they can."(p.185)

Accordingly, the very essence of hospice care is based upon a return to the "old ways" of the dying process, surrounded by family and without the advances and invasive procedures of medical



technology. Hospice care involves the medical technique of pain control through the administration of a wide variety of available drugs and removes the pain and loneliness of dying. It is ironic that society has come full circle. In the pre World War II era, it was common to see people dying at home and now we are seeing a resurgence of this phenomena fifty years later, to a great extent due to the consumerist movement.

Palliative care is a relatively new medical discipline based on the same approach to dying as hospice care. Hospitals now have palliative care sections in order to accommodate dying patients. As well, there are palliative care teams that respond to those dying patients who wish to remain in their homes and with their families and thus give treatment in the patients' homes. Palliative care teams consist of members representing the medical profession, social workers, members of the clergy and many volunteers especially trained in palliative care, which represent a more holistic approach to dying. Dr. Latimer, (1991) a palliative care doctor in Hamilton states the paradigm for palliative care in the following:

"We must first remember that each dying patient is unique and his/her uniqueness and individuality must be valued. Second, dying people are indeed living until they die and need to be treated that way with dignity and respect.--- Respect for autonomy recognizes that people no matter how frail and ill, have a right to information about what is happening to them, what the potential options for their care are, and what their choices might be. " (p. 19)

Thus, palliative care responds to individualism and autonomy of patients, and promotes dying with dignity and respect for patients.

Perhaps the most influential issue for the emergence of advance health care directives is the growth of the consumerist movement, individualism and the ethical principle of autonomy for competent adults. The very essence of advance directives is based of this principle. The enhancement of autonomy is more than mere decision making ability and authority. It is the exercise of such authority in the particular, concrete context of an individual's values and beliefs (Doukas & McCullough, 1991).

Accordingly, the combination of developments such as growing scepticism and fear of the excesses of medical technology, greater willingness of consumers to question medical treatment that unnecessarily prolongs life, the growing consumerist demands for medical treatment that emphasizes quality of life criteria rather than quantity of life, and new demographic realities combine to focus more attention on death and dying issues and the subsequent emergence of advance directives as a document to express individuals' autonomy and medical treatment preferences.

### Chapter Three

#### Seniors' Perceptions and Preferences of Surrogate Decision Makers, Medical Treatment and Advance Directives

In order to document and explore seniors' perceptions on these issues, this chapter will review the current research into seniors' perceptions and preferences in life threatening surrogate decision making, medical treatment, and health care directives. This will be done in order to give background information in relation to this thesis and to discover what, if any, void there is in research into seniors' perceptions and preferences of these issues. There is very limited research, especially in Canada, regarding seniors opinions of these issues.

#### Advance Directives

Several studies in the United States have found that patients usually express a positive attitude towards discussing life-sustaining treatment and advance directives (Steinbrook et al., 1984; Lo et al., 1986; Rye et al., 1985; Wagner et al., 1984). Stelter et al., (1992) in their research on advance directive completion amongst the elderly report that seniors have strong feelings about their end of life health care. Nearly 95% indicated that they wanted to participate in their health care decisions including the end of their life. This research also reported that 71% of the seniors in the study thought that physicians keep

patients alive too long (Stelter et al., 1992). Studies indicate that most patients want to have an influence on decisions concerning the circumstances of their dying (Emanuel et al., 1991; Zweibel et al., 1989). Molloy's, (1991 b) and Cranston's et al., (1992) studies with institutionalized seniors in Ontario, support the assertion that seniors wish to participate in their own health care decisions including their death processes, and given the opportunity, will complete directives.

Nonetheless, actual completion and usage rates of advance directives are exceedingly low. Studies report the rates of advance directive completion and use among elderly persons to be between 0% to 18% (Sachs et al., 1992; Gamble et al., 1991; Zweibel & Cassel, 1989; High, 1988).

### Surrogate Decision Makers

Studies show that seniors tend to rely upon family members for shared decision making about life sustaining treatment and that medical treatment to prolong life, if cognitive dysfunction is implicated, is not favoured (Cohen-Mansfield et al., 1992, 1991; High, 1990 a & b, 1988; Shmerling 1988; Finucane, 1988; Uhlmann et al., 1988).

Kapp, (1991) suggests that shared decision making with family members can be empowering to the older person involved, relieve burdens on the older person and family members, and facilitate better surrogate decision making.

Many American studies suggest that competent elderly patients rely heavily on family members or their family physician for assistance in medical decision making (Gamble, 1991; Stolman et al., 1990; Henderson , 1990; Prat et al., 1989; Collopy, 1988). Smith et al., (1988) and Prat et al., (1989) submit that many older persons do not want exclusive autonomy, but rather find that their autonomy is enhanced by sharing with family members, medical decisions and treatment preferences.

Informal social supports, relationships and networks established with families, relatives, and friends are extremely important to seniors (Chappell, 1992). The informal network is considered to be the support group that seniors discuss with and rely upon to help them make important and critical decisions when considering their health care. Research suggests that it is this informal network that the medical profession rely upon to serve as surrogate decision makers for decisionally incapacitated patients (High, 1990 a).

#### **Medical Treatment Preferences**

Cohen-Mansfield et al., (1992) studied non-acutely ill, elderly hospitalized patients, their life sustaining-treatment preferences, and factors affecting these preferences. The study suggested that patients' specific life sustaining treatment preferences were dependent on a number of factors. The authors reported that:

"All situational factors examined---future cognitive functioning, permanency of treatment procedures, and the nature of the treatment---were found to play significant roles in patient's treatment preferences. A majority of patients had a cognitive-dependent treatment pattern indicating that as they thought about future cognitive functioning decline, the patients were less likely to want treatments. Patients were less likely to opt for a treatment when they perceived it to be permanent." (p. 93)

The authors found that the least preferred treatments in order were: permanent tube feeding, permanent respirator, resuscitation, chemotherapy, dialysis, amputation, radiation, temporary respirator, temporary tube feeding, blood transfusion, and antibiotics. Henderson's (1990) research of residents in a retirement community, suggests that most seniors did not want treatments to prolong their lives if they were terminally ill and found that the least preferred treatments in order were: respirator, tube feeding, CPR, IV fluids, antibiotic therapy and oxygen for comfort. Michelson et al. (1991) report that most residents of a nursing home were opposed to aggressive care unless the purpose was to enhance comfort or safety. Nonetheless, the authors suggest there was sufficient diversity of opinions. This points to the need for the promotion of advance directives based on individual values and beliefs. Shadlen et al., (1990) report the results of their study of nursing home residents. They suggest that patients' preferences should be determined independently for various life support measures, but that when such information is unavailable substituted judgement based on stated preferences to

forego one intervention may be inferred with some reliability. The study by Cohen-Mansfield et al., (1992) also suggests that some demographic characteristics were correlated with treatment preferences. Patients with no treatment preferences were more than likely to have lower levels of education, higher levels of depression and less likely to have discussed their health care decisions with someone. Other demographic characteristics such as age, gender, marital status, religiosity and cognitive functioning were not statistically significant in determining treatment preferences. Patients reported being influenced most by their personal values such as importance of life, quality of life and limiting burden on others. This study supports similar findings with nursing home populations (Cohen-Mansfield et al., 1991; Everhart's & Pearlman's, 1990). However, these studies involved institutionalized elderly patients who one might expect to be traumatized by being institutionalized and more anxious regarding health care decisions.

#### Canadian Research

Mehran et al., (1993) point out that American studies and data may not be generalizable to the situation in Canada. They suggest that this is due to the highly public debates surrounding living wills/directives and the subsequent emergence of these documents which occurred at a much earlier time in the United States than in Canada. Thus, the American public has had more time

to become familiar with directives. They suggest also that the United States is much more legalistic and litigious than Canada, which may account for the highly publicized legal battles concerning directives.

Differences in health care systems between the countries may also be a contributing factor in not generalizing American data to the situation in Canada. Canada's universal health care system may affect the usage and completion of directives. Canadian consumers, at the present time, do not have to be concerned with personal financial responsibility for health care costs. Therefore, consumers who wish every medical treatment used in efforts to prolong their life do not have to be concerned with the financial costs of that medical treatment. Financial responsibility for medical treatment, through private insurance companies or subsidized Medicare/Medicaid may not cover medical treatment that prolongs life regardless of the costs in the United States. It may be of great concern and a contributing factor in the way Americans choose their death processes and complete directives.

Four studies have examined public opinion in Canada regarding advance directives, (Singer, 1993 a; Mehran et al., 1993; Molloy et al., 1991 a; Singer et al., 1991 b) and two studies have examined the use of an advance directive in a home for the aged (Molloy et al., 1991 b; Cranston, 1992).

Singer et al., (1993) did a random digit-dialing telephone



survey of one thousand randomly selected adults living in Ontario regarding advance directives, substitute decision, emergency treatment, and advocacy. With regard to advance directives, 36% of respondents had had advance discussions with their families, and 12% had completed a living will. However, in this survey only 8% of respondents were seniors.

Mehran et al. (1993) recently did a study regarding outpatients knowledge and experience of advance directives at a internal medicine out-patient clinic at a teaching hospital. The report suggests that 16% knew about living wills, 4% knew about directives, 22% had thought about preferences for life-sustaining treatment, 19% had discussed them and 0% had written them down. The sample population, however, was not exclusively seniors and they were all outpatients with either previous or present illnesses.

Molloy et al., (1991 a) report: that most participants (93.6%) in their study wanted to control or to participate in their own health care; that 70.8% reported that they were extremely concerned that they would receive tests or procedures without their knowledge or consent; and that 65.6% were extremely concerned that they would be treated too aggressively. Further, over 90% thought that it was important to have a directive and more than 88% reported a preference to document their desired level of care. This research included individuals whose mean age was 56.8 years and

individuals who were interested in "the mechanics of using advance directives". Thus, this study is not representative of seniors' perception, although they were seniors in the study and there is a bias towards people who were, at the very least, familiar with the purpose of directives.

In a statement to the Legislative Committee of the House of Commons, Singer (1991 b) reported that 56% of internal medicine out-patients said they wished to discuss their treatment preferences although only 25% has done this. Also reported in this study were the results of a random telephone survey, in which 85% of an Ontarian sample agreed that "people have the right to request the withholding or withdrawal of medical treatment". However, this study did not exclusively ask seniors.

Molloy et al., (1991 b) report in a study that 76% of the residents of a home for the aged completed a directive, after voluntarily attending an informational advance directive presentation and a subsequent follow up visit by personnel familiar with advance directives. The study also reported that in the year following the introduction of the directive, the number of deaths almost doubled (9:17), and the proportion of deaths of residents dying in the home for the aged increased significantly (from 1 at the home to 8 in hospitals, to 11 and 6, respectively) To the authors this study shows that: "elderly people wish to participate in their own health care decision and, given the opportunity will

complete directives."

Cranston et al., (1992) in a letter to the Canadian Medical Association Journal reports the use of a health care directive at Providence Centre, a long-term care facility in Scarborough, Ontario. They state that initial feedback regarding the directive is positive and that patients want to be active participants in their own health care decisions.

Many Canadian surveys regarding the medical profession's attitude and acceptance of advance directives have been conducted (Kelner et al., 1993 a; Hughes & Singer, 1992; Lever et al., 1992; Alemayehu et al., 1991). Generally, these surveys suggest that physicians and nurses support directives use, nonetheless, when confronted with them a significant proportion of these professionals ignore these written directives and provide care that is incompatible with patients' preferences. Kelner et al. (1993a) suggest four themes emerging from health care professionals regarding patient control over dying: first, patient control represents a challenge to their clinical judgement; second, at issue is health care professionals' perception of their role as healer/supporter; third, physicians indicated that they felt a challenge to their professional autonomy and power; fourth, was concerns regarding their personal ethics and the potential for legal liability.

Further, Molloy (1993) and Singer (1993b) report that

little research has been carried out regarding the implementation or use of directives in the Canadian health care system. However, Johnston (1992) reports that Dr. W. Sibbald, co-ordinator of the critical care unit at Victoria Hospital in London, Ontario stated that he saw fewer than ten advance directives in the past year (1991) even though 1500 patients were admitted to the hospital's intensive care unit. He argues that a written statement (directive) is not necessarily the best route for a patient to follow:

"I am seeing more patients and their families who are at least talking about his issue. They haven't gotten to the point of putting their wishes on paper yet, but as long as they are talking about it that's all you need. If you put your wishes on paper, it creates a boundary that is very narrow --- but if we can at least get a sense of what an ICU patient might have wanted, if he has at least talked about quality of life or the results of a terminal condition with his family, then we are getting somewhere." (p.1370-71)

These results are rather discouraging to the extent that they indicate that the medical profession continues to want to have control and power over medical treatment preferences in spite of the growing consumerist's acceptance of advance directives.

### Control, Health, and Seniors

The notion and significance of locus of control has been frequently applied to the area of health and health care outcomes (England & Evans, 1992; Coulton, 1989; Wallston et al. 1983, 1976; Lau, 1982). Internal locus of control has been linked to knowledge about health and health care and positive outcomes (England & Evans, 1992; Lau, 1982).

Rotter (1954) conceptualized locus of control orientation within a social learning theory and defined it as a generalized expectancy regarding the degree to which an individual's own behaviour is seen to be the controlling factor in assuring reinforcements (Pines, 1973). Locus of control is a measure of one's perception of the extent to which an individual is an agent in determining her/his life events. Individuals with a highly developed internal sense of control perceive themselves as having control over environmental forces, in other words, they generally expect that what happens to them will be contingent on their own behaviour. Conversely, a high level of external locus of control characterizes individuals who perceive that outcomes of life events are primarily the results of forces external to themselves such as fate, luck, chance, or powerful others. Locus of control seems to be a relatively stable character trait for individuals throughout their life course (Lau, 1982; Wallston & Wallston, 1978).

Rotter (1975) suggests that health locus of control and beliefs develop from specific experiences and past reinforcement history. Lau, (1982) states that:

"individuals who have experienced or been reinforced for successful control attempts in the past will be more internal than those who have experienced unsuccessful attempts at control." (p. 322)

Accordingly, prior experiences with illness, disease and health care can then be expected to contribute to either internal or

external health locus of control (Lau, 1982).

Research has linked positive health outcomes and a sense of personal control over one's life for seniors (Kane & Kane, 1986; Moody, 1985; DeFries & Woomart, 1983). As well, the relationship between a sense of control or autonomy and successful outcomes in aging has been reported (Clark 1988; Rodin, 1986). Lack of control over decisions has been linked to negative consequences in some situations, and the positive effects of decision control among the elderly have also been demonstrated (Mercer & Kane, 1979; Mills & Krantz, 1979; Beaver, 1979; Langer & Rodin, 1976; Kempf, 1969).

Research supports that death anxiety amongst seniors is commonly expressed as "I don't fear death; I fear the process of dying." denoting the loss of control over the dying process (Henderson, 1990, p. 480). Molloy (1993) a Hamilton geriatrician comments that:

"What many fear most from illness is the loss of control that it brings. Illness can wrench away from us our dignity and privacy, and we can be left incapacitated, dependent and in pain. Faced with this prospect, many people would choose to control not only the manner of their living, but also the circumstances of their dying. " (p.171-172)

Kelner, (1993b) points out that:

"Many patients are worried about loss of control regarding their dying, and their fears can cause conflicts between health care professionals and patients or their families." (p. 758)

Stelter's et al. (1992) study found:

"that older adults have strong feelings about their end-of-life health care. Nearly all the respondents (95%) indicated that they wanted to participate in their health care decision up to the end of their life." (p.958)

Accordingly, it can be postulated that seniors with internal locus of control will choose to participate in health care decisions and control their own death process and conversely, that seniors with an external locus of control will not necessarily want to participate in and have some control over their death processes.

Rodin (1986) suggests that the relationship between health and a sense of control may grow stronger in old age and submits that there is considerable evidence that the effects of restrictions in control are detrimental to the health of older people. Medical care may restrict opportunities for control at any age, but with the more frequent contact with the health care system by seniors, it may heighten the effects of this restriction in control for seniors. Evidence suggests that medical professionals prefer the most compliant, obedient patients which may also erode control (Freidson, 1988; Illich, 1976).

Studies examining the desire and expectancy of control in health care situations by the elderly, suggest that older adults are more likely to accept physicians' decisions and less likely to challenge their authority (Cassileth et al., 1980; Haug, 1979). Wallston et al. (1988) and Lachman & Smith (1986) found that generally, older adults hold greater belief in the ability of

powerful others to control their health than did younger adults.

Diane Goldstein, (1993) a gerontology professor at Ryerson Polytechnical University in Toronto and board member of Concerned Friends of Ontario Citizens In Care Facilities, suggests that seniors have a "white coat syndrome" which refers to "the feeling that those in authority (medical profession) are always right and they (clients) are always wrong".(p. L-22) She comments that there is an imbalance of power relationship between seniors and their doctors. Some physicians send a message to seniors that explicitly comes across that his/her (physician) time is more important than yours: "You're old, you're retired, what do you have to do?" (p. L-22).

The objective of this thesis is to provide information regarding seniors' perceptions regarding health care medical decision making, medical treatment preferences, and advance health care directives. This review has identified many generalizable seniors' opinions and perceptions regarding surrogate decision making, medical treatment preferences, advance health care directives, locus of control issues and the dying process. However, most of the review has focused on American seniors' perceptions. This review demonstrates that there is little if any research on Canadian seniors. Moreover, any research with seniors as the focus, has been done with institutionalized seniors whose perceptions may already be compromised and who represent only 6.4% of Canada's



senior population (NACA, 1993b). Presently, there does not seem to be any studies or research on seniors' perceptions of these issues for community dwelling seniors which represent approximately 94% of Canadian seniors. Therefore, in keeping with the objective of this research, an attempt will be made to fill that void by interviewing non-institutionalized seniors in order to provide information regarding their perceptions of surrogate decision makers, medical treatment preferences and advance health care directives.

The following chapter introduces the methodology used for this research. Subsequent chapters focus on the results and analysis of the interviews with twenty-six non-institutionalized seniors. I will first examine senior's preferences regarding surrogate decision makers. Questions addressed are: Who do they think should make life extending medical treatment decisions if a patient becomes either decisionally or communicatively incapacitated? Do seniors see themselves, their immediate families, relatives, friends, physicians or significant others as preferential surrogate decision makers? If senior's preferences vary, do they appear to vary by socio-demographics or health characteristics? Second, I will examine seniors' preferences regarding life threatening/extending medical treatment. Do their medical treatment preferences differ and if so, do these differences vary by socio-demographic and health characteristics? Third, I will examine seniors' perceptions of advance health care

directives. In particular, do seniors perceive such directives as a viable and useful document to express and communicate their preferences regarding future medical decisions if they become decisionally or communicatively incapacitated?

## Chapter Four

### Methodology

#### Sample

This study is based on interviews with twenty-six non-institutionalized seniors. The seniors interviewed for this research were a convenience sample taken from three different groups of seniors residing independently in the Hamilton-Wentworth area of Ontario. In order to examine gender and age effects the sample was stratified. Five age categories were established and in first three age categories three or four women and three men were interviewed. In the fourth age category of 80-84 years there were three females and two males interviewed, and in the fifth age category, 85 to 93 years of age, one female and one male were interviewed. All participants were over the age of 65, retired, self-sufficient, and socially functioning seniors. The interviews began with senior participants (N=13) who are active members supporting a senior, volunteer, research pool at McMaster University (SHARE: Seniors Helping Advance Research Excellence). Other senior participants (N=4) were active members of the Main-Hess Street Seniors Centre. Participating seniors were asked to suggest other seniors who might be willing to participate in this research and consequently nine (9) seniors became participants through this snowball technique. Therefore, the convenience sample

consists of twenty-six participants. (N=26)

### Design and Procedure

Participants were initially contacted by telephone, given an explanation and the agenda of the research project and asked if they would like to participate. A convenient interview time was set up and interviews were conducted either in the participants' residences, McMaster University, or the Main-Hess Seniors' Centre.

The interviews ranged in length from 1 to 1 1/2 hours. Interviews were conducted using a semi-structured pre-tested instrument which allowed for open ended questions in which the respondents were asked for explanations of their responses (Appendix-II). Written informed consent and permission to tape the interviews was obtained from all participants.

There were four parts to the interview schedule. The first part consisted of a structured demographic questionnaire. The second part of the schedule consisted of four brief hypothetical vignettes. The third part of the schedule consists of asking respondents about their knowledge and opinion of advance health care directives. The fourth part of the interview schedule is a multidimensional health locus of control scale that the respondents filled out.

The use of vignettes in sociological research is a relatively new technique. Vignettes are short stories about hypothetical individuals in specified circumstances to which the participant is

asked to respond. Finch (1987) explains that one of the advantages of the technique of vignettes is:

"that the respondent is being invited to make normative statements about a set of social circumstances, rather than to express his or her "beliefs" or "values" in a vacuum. It is a method which, in other words, acknowledges that meanings are social and that morality may well be situationally specific." (105-106)

Thus, one advantage in using vignettes is allowing a respondent to define the meaning of the situation for her/him self.

Vignettes also have the potential to gain access to very sensitive and personal issues, such as in this research, life-threatening illnesses, death, and dying. By using the hypothetical third person characterization in each vignette, (Mrs. K., Mr. S.) vignettes not only distance the issue for the respondent and make questions less personally threatening in sensitive situations, but also, reduces the initial sense of personal identification and thus, stress, that respondents might feel when confronted with the word "you". The vignette technique offers a way both of asking questions concretely and of distancing them from personal experiences (Michelson et al., 1991; Finch, 1987).

Nonetheless, vignettes have some associated problems. First, vignettes must be constructed in such a way that both the characters and the story are credible. The vignettes used in this research were created, developed and used by a group of researchers guided by experts in biomedical ethics, geriatrics and gerontology

(Tomlinson et al., 1990; Zweibel & Cassel, 1989). They have been used in research by Michelson et al., (1991), Tomlinson et al., (1990), and Zweibel et al., (1989). These vignettes present scenarios which are typical of elderly people in life-threatening illnesses.

A second problem arises with the interpretation of the responses, and knowing what element in a vignette triggered a particular response. However, as Finch (1987) suggests, it is possible to control for each element by constructing a series of vignettes which systematically vary the variables such as gender and age. This has been done for these research vignettes resulting in half the hypothetical patients being women the other half men, and a different senior age cohort is presented in each vignette.

A second interpretation problem arises due to the differences between hypothetical and reality situations. There may be large differences between individual beliefs and actions. Therefore, interpretations must not be used in a predictive capacity for respondents nor generalizations, but rather as an attempt to gather exploratory information, patterns, trends or concepts about a specific social phenomenon.

The vignettes used in this research describe scenarios in which decisions about the use of life-extending care are required for an older patient unable to decide or speak for him/herself. These vignettes deal with: (1) mechanical ventilation for a woman

in a coma, (2) a man in end stage Alzheimer's disease with reoccurring bouts of pneumonia, (3) tube feeding for a woman refusing to communicate with her doctors, and (4) an amputation in a demented elderly man.

Vignettes were specifically chosen and presented for the content and scenario that is depicted. As discussed in the literature review, seniors tend to choose family members as surrogate decision makers, and thus, in three of the four vignettes family members are a choice that is available to be designated as surrogates by the respondents. In vignette three, family and/or relatives are absent as a choice of surrogate decision makers. The choice in this vignette is limited to friends and a physician. This vignette was presented in order to explore whether or not friends would be designated as surrogates by the respondents.

The literature review suggests that certain illnesses and conditions were significant factors that seniors considered in choosing medical treatment preferences. For instance, cognitive dysfunction, permanency of treatment, and prolongation of life without concern for the quality of that life, were some of the factors that seniors considered before choosing whether or not medical treatment should be initiated. Three vignettes present patients whose cognitive and mental functioning are described as either non existent or very compromised, and one vignette presents a forced feeding treatment to a withdrawn and depressed patient.

The reason for the presentations of these vignettes is twofold. First, is to understand who seniors prefer as surrogate decision makers, that is to say, who do seniors perceive as the surrogate decision maker for elderly patients who have become either decisionally or communicatively incompetent. The sample participants were asked the following open ended question after each vignette presentation: "Who should make a decision for the patient"; "How did you arrive at this decision"; and "What factors did you consider in choosing this surrogate decision maker?" Through analyzing the responses to these questions, it may be possible to establish concepts, trends and/or patterns of seniors' preferences for surrogate decision makers.

The second reason for the presentation of these vignettes is to explore, what, if any, medical treatment seniors prefer if faced with life-threatening illnesses. Respondents were asked to imagine themselves in the same position as the vignette patient and what, if any, medical treatment they would want for themselves. The intention of presenting these illnesses was an attempt to discover if seniors' have a criteria for acceptable medical treatment intervention and what, if any, criteria seniors consider as an acceptable quality of living. Through analyzing the responses to this question, it may be possible to establish concepts, patterns and/or trends to seniors' preferences for medical treatment when faced with a life-threatening illness.



Thus, each vignette scenario depicts either a decisionally or communicatively incapacitated elderly person whose caregivers face a stark medical situation. Treatment choices were narrow, as options for medical treatment were limited to life and death. With treatment the vignette patients would more than likely live for a short period of time, and without treatment vignette patients would more than likely die.

It must be pointed out that the presentation order of vignettes was not controlled or pre-arranged.

Vignettes were read aloud to the participants and the following questions were asked after each vignette: Who should make the decision regarding the medical treatment for the patients? How did you arrive at this decision and what factors did you consider? How would you feel if the doctor made a decision without regard to or consulting with the informal caregivers? The participants were then asked what treatment choice they would make for themselves if they were faced with that situation, followed by these questions: How did you arrive at this decision and what factors did you consider? How would you feel if the doctor made a decision without regard to or consulting your family? The preceding question was asked of participants in order to explore seniors' perceptions regarding the relationship between doctors and families. Specifically do seniors perceive this relationship based on a power authoritarian relationship on the part of the physician

or do seniors perceive this relationship as a shared client based relationship? Participants were also asked how they could make their treatment preferences and personal values known.

The third part of the interview inquired about the participants knowledge, awareness and opinion of advance health care directives. Participants were asked whether or not they were familiar with the existence of an advance health care directive and if so, had they written or considered writing and completing one? Those participants who were not aware of a directive were informed of its existence and its purpose. Participants were then asked for their opinion regarding advance health directives, whether or not if given the opportunity they would complete one, and if the vignette patients had completed such a directive when competent, should their directives be honoured regardless of their family's or physician's opinion of their preferences?

The fourth part of the interview consisted of participants filling out a multidimensional health locus of control questionnaire designed by Wallston & Wallston (1978). This was used in order to evaluate, analyze and correlate the participants' locus of control with their responses to the vignettes and their medical treatment preferences, and their usage of an advance health care directive. (Appendix-III)

Tape recorded responses were transcribed, SPSS-PC was employed for quantitative statistical data analysis, and Denton's

et al., (1989) analysis technique allowing the incorporation of qualitative data into quantitative analysis was also utilized.

### Limitations of the Study

This study has three general limitations. First, caution must be used in generalizing this study's findings to the population at large, due to its small size and its socio-demographic characteristics. Participants on the whole are better educated, wealthier, healthier and more satisfied with their lives than the seniors' population at large. This limitation must be kept in mind when interpreting any findings.

A second limitation is that questions regarding the participants own medical treatment preferences required subjects to enter into an imaginary situation that may be very dissimilar from any perceived or real situation they might experience. Then, they were asked to judge what they would decide in those hypothetical circumstances. There may be genuine differences between real and imagined preferences.

A third limitation emerges with the content of the vignettes. Although used in other research, the author found that attempts to control for age, condition, and medical intervention were very complex. Specifically, in vignette four, respondents generally suggested that age (92), condition (gangrene), pain, and suffering were important variables, however, this vignette also presented the only surgical intervention (amputation). Thus, it

became very difficult to discern which variable was the most important in determining medical treatment preferences in vignette four.

## Chapter Five

### Results

This chapter presents the demographic characteristics of the sample and qualitative and quantitative results of the interviews with seniors.

#### Demographic Characteristics of the Sample

An attempt was made to form a stratified sample with equal representation of females and males in five age categories; 65-69, 70-74, 75-79, 80-84, and 65 and over. The sample was formed this way to allow assessment of possible age or gender differences in the respondent's opinions on surrogate decision makers, medical treatment preferences and advance health care directives. This sample will be compared to the findings reported by NACA (1993b) in "Aging Vignettes" a statistical portrait of seniors in Canada. The NACA sample were collected in 1992 to provide background demographic material for discussions of the future of aging in Canada.

Table One illustrates the frequencies of the demographic characteristics of this sample.

**Table One****Demographic Characteristics of the Sample**

<b>Demographic</b>	<b>Frequency</b>	<b>Percentage</b>
<b>Gender</b>		
Female	14	53.8%
Male	12	46.2%
Total	26	100.0%
<b>Age</b>		
65-69	6	23.1%
70-74	6	23.1%
75-79	7	26.9%
80-84	5	19.2%
85-93	2	7.7%
Total	26	100.0%
<b>Marital Status</b>		
Married	13	50.0%
Widowed	11	42.3%
Divorced/Single	2	7.7%
Total	26	100.0%
<b>Education</b>		
Elementary	3	11.5%
Some Secondary	8	30.8%
Completed Secondary	5	19.2%
Some Post Secondary	6	23.1%
University	4	15.4%
Total	26	100.0%

Table One (Continued)Demographic Characteristics of Sample

Income	Frequency (n=23)	Percentage
under \$10,000	1	4.3%
\$10,000 - \$20,000	7	30.4%
\$20,000 - \$30,000	9	39.2%
\$30,000 - \$40,000	2	8.7%
\$40,000 - \$50,000	2	8.7%
\$50,000 +	2	8.7%
Total	23	100.0%
<b>Health Status</b>		
Excellent	1	3.8%
Very Good	14	53.8%
Good	6	23.1%
Fair	4	15.4%
Poor	1	3.8%
Total	26	100.0%
<b>Life Satisfaction</b>		
Excellent	3	11.5%
Very Good	13	50.0%
Good	7	26.9%
Fair	3	11.5%
Total	26	100.0%
<b>Life Threatening Decision</b>		
Yes	8	30.8%
No	18	69.2%
Total	26	100.0%

The sample consisted of 26 respondents, 14 women (53.8%) and 12 men (46.2%) ranging in age from 65 to 93 with a mean age of 75 years. The attempt to equally represent both genders was not accomplished with women being slightly over represented in the sample. Locating males willing to be interviewed in two of the age categories was not possible within the time constraints of this thesis. Due to the aforementioned gender disparity, there is one more woman than man in both 70-74 and 80-84 age categories.

Overall, 50.0% of the respondents were married, 42.3% were widowed, and 7.7% were either divorced or single. There is a gender difference in marital status generally reflecting the gender differences in overall seniors' marital status (NACA, Aging Vignettes, 1993). Ten of the fourteen women respondents (71.4%) are widowed, three are married (21.3%) and one (7.1%) is divorced. Ten of the twelve men respondents are married (83.3%), one is single (8.3%) and one is a widower (8.3%).

This sample of seniors had on average more education than seniors in the Canadian population. Fifteen respondents (57.7%) graduated from secondary or a post-secondary educational institution, compared to 27% of Canadian seniors (NACA, 1993). Overall, men were more likely (41.5%) than women (35.7%) to have attained higher level education. As well, no women in the sample have a university degree compared to 25.2% of men who have a university degree or higher, which may reflect past trends of gender inequality in education. This over representation reflected



the fact that many of the respondents come from **SHARE** which had a membership with a disproportionate number of members with post secondary education.

Nine respondents (39.2%) reported their annual household as between \$20,000 and \$30,000, and seven respondents (30.4%) reported their annual income to be in the \$10,000-\$20,000 category. Six respondents (26.1%) indicated their annual income to be in the \$30,000-\$50,000 or over category and one respondent's (4.3%) annual income was designated as under \$10,000. Three respondents declined to indicate their annual income. There is great income disparity between the genders in household incomes. For instance, the average household income for women is between \$10,000 and \$20,000 whereas the average for men is between \$20,000 and \$30,000. However, 54.6% of men earned over \$30,000 per year, whereas no women respondent reported receiving over \$30,000 and the lowest income category, under \$10,000, was reported by one woman. Nonetheless, this sample of respondents was above Canadian seniors' median annual total income (NACA in 1991).

The most common occupation before retirement for the respondents was in the professional category (26.9%), followed by white collar (23.1%) and blue collar (15.4%), and further followed by all other categories (34.6%) such as housewives, owning their own business and professionals who owned their own business.

Religious affiliation was reported by 69.2% of the

respondents, with the vast majority being protestant. Women (71.4%) were slightly more likely than men (66.7%) to report religious affiliation.

Over 80% of the respondents reported that their subjective health was either excellent, very good, or good, (84.6%) whereas 15.4% reported their (subjective) health as fair or poor. The proportion of the sample respondents reporting excellent, very good or good health is considerably higher than the national seniors' population reporting in the same categories 64.0% (NACA,1993). Women were more likely to report their health as excellent, very good, or good, (92.8%) than men (75.0%), and conversely, more men were likely to report their health as fair or poor (25%), than women (7.1%). Over 90.0% of respondents had visited their physician in the past year (92.3%). Just under three quarters (73.1%) of the respondents reported visiting their family physician over the past year between 1 and 5 times. There were no gender differences in the number of visits to a physician. Noteworthy, regarding subjective health and physician visits, is that the sample respondents reported better subjective health and slightly less visits to their physician in the past year compared to the national senior's population survey (NACA,1993). This finding may reflect this sample's bias in terms of higher education and income than the national average, as it has been demonstrated that there is a correlation between higher income, higher education

and the reporting of better (subjective) health (Clarke, 1990; Dutton, 1986).

More than 85.0% of the respondents reported that their life satisfaction was excellent, very good or good (88.5%) which was slightly lower than that reported by NACA for seniors (92%) (NACA,1993). Men were more likely than women to report higher levels of life satisfaction. The gender disparity may be attributable to the gender differences in marital status and income.

Respondents were asked about the presence of immediate family members, such as, siblings, spouse, parents and/or other relatives. Four (15.4%) respondents reported having no children, and all respondents reported having other relatives particularly siblings.

Respondents were asked whom they would want to speak on their behalf in a medical emergency, if for any reason they became decisionally and/or communicatively incapacitated. More than 75% reported that they would choose either their spouse, child or sibling (76.9%), whereas 7.7% would choose some other person at the time of the question, and 15.4% of the respondents did not know.

Respondents were asked if they had any experience dealing with life threatening decision making situations. Overall, 61.5% of the respondents had no experience and 38.5% had such experience. However, there is a gender difference as 50% of women respondents

compared to 25% of men respondents had experience with life threatening decision making situations. This difference may be due to the fact that more women were widowed than men, which accounts for the fact that more women experience life-threatening decision making for their spouses and other family members.

For each vignette, differences in preferences for surrogate decision makers and medical treatment preferences were examined by: age, gender, health, life satisfaction, marital status, income, and education. The demographics of age, income, education and marital status categories were collapsed because the sample size did not permit an examination of differences for each category of the variable. Thus, for the purpose of this analysis the demographic characteristics were collapsed as follows: age (under 75 = young seniors; over 75 = older seniors); marital status (married and single); income (low = under \$10,000 to \$20,000, middle = \$20,000 to \$30,000, high = \$30,000 to over \$50,000); education (secondary, post-secondary). The measures of subjective health and life satisfaction did not provide enough variation in the independent variable to look for differences in the dependent variable. For example, over three quarters (76.9 %) of the respondents in this sample stated that their subjective health status was either very good or good, and 88.6% of the respondents reported their life satisfaction as either excellent, very good or good. (1)

(1) The sample is not large enough to allow a test for significant differences. Percentage differences of over 10% will be presented as showing a substantive finding and/or possible trend/pattern.

### Vignette One

"Mrs. K. is an elderly widow of 86 years and has recently suffered a major stroke, leaving her in a coma and unable to breathe without a machine. After a few months, the doctors suggest to her family, that it is unlikely that Mrs. K. will come out of the coma and that no can be certain what her level of functioning would be if she ever did come out of the coma. The doctors and her family are discussing whether or not the breathing machine should be removed."

This vignette presents an elderly widow of 86 years who is in a coma as a result of a stroke and for some months has required a respirator to breathe for her. It is unlikely that this woman will recover from the coma and further, it is uncertain at what level of functioning she would have if she did recover from the coma. The doctors and her family are discussing her case in regards to what course the medical treatment should take, in effect, if the respirator should continue or should it be removed.

When responding to the question of who should make the decision for the widow, 61.5% (16) of the respondents stated that it should be decided by the family alone, while 19.2 % (5) of the respondents stated that the doctor alone should and 19.2% (5) stated that it should be a joint decision, between the doctor and the family. The following table shows the frequencies for surrogate preferred decision makers for vignette one.

### Preferred Surrogate Decision Makers

Surrogate	Frequency	Percentage
Family	16	61.5%
Doctor	5	19.2%
Joint	5	19.2%
Total	26	100.0%

Young seniors (69.2%) were more likely than older seniors (53.8%) to choose family as surrogate decision makers. Married respondents (76.9%) were more likely than single respondents (46.2%) to prefer family surrogate decision makers, whereas more single respondents (30.8%) than married respondents (7.1%) prefer the doctor as surrogate decision makers.

With regards to income levels, all three levels equally preferred family surrogate decision makers. Middle income respondents (33.3%) were more likely than low income respondents (12.5%) and high income respondents (16.7%) to choose doctors as surrogate decision makers. Also middle income respondents did not prefer joint decision makers (0.0%), whereas both low income (25.0%) and high income (16.7%) respondents choose joint decision makers.

There were substantive differences in the relationship between preferences for surrogate decision makers and educational levels. Both educational levels prefer family surrogate decision makers, however, respondents with secondary education (68.8%)

compared to respondents with post-secondary education (50.0%) were more likely to choose family surrogate decision makers. Post-secondary educated respondents (30.0%) were more likely to choose the doctor as surrogate decision makers compared to secondary educated respondents. Substantive differences were not found for preferences in surrogate decision makers for other sample demographic characteristics. The following tables demonstrate these differences in preferences for surrogate decision makers.

#### Age

Preferred Surrogate Decision Makers	65-74 (13)	75-93 (13)
Family	69.2%	53.8%
Doctor	15.4%	23.1%
Joint	15.4%	23.1%
Total	100.0%	100.0%

#### Marital Status

Preferred Surrogate Decision Makers	Married (13)	Single (13)
Family	76.9%	46.2%
Doctor	7.7%	30.8%
Joint	15.4%	23.0%
Total	100.0%	100.0%

### Education

Preferred Surrogate Decision Makers	Secondary (16)	Post-Secondary (10)
Family	68.8%	50.0%
Doctor	12.5%	30.0%
Joint	18.8%	20.0%
Total	100.0%	100.0%

### Income

Preferred Surrogate Decision Makers	Low (8)	Middle (9)	High (6)
Family	62.5%	66.7%	66.7%
Doctor	12.5%	33.3%	16.7%
Joint	25.0%	0.0%	16.7%
Total	100.0%	100.0%	100.0%

When asked how they arrived at the decision and what factors they considered in deciding whom should make the decision, those who responded that the family should make the decision, overwhelmingly stated that it was the family's decision because the family was "closest", "knows the patient better", "knows what is best for the patient", and "it is the family's right to make the decision". Typical of such a response is the following:

"The family. They are the closest to her and part of her. It's up to them to make the decision, not the doctor. They know her history and her feelings and know best what she would want. The MD is a professional and doesn't know the patient or her feelings."

As well, some respondents considered and mentioned that the patient



might have discussed what treatment she preferred with her family as evidenced by the following response:

"The family---because the family knows and cares for her. Maybe she has mentioned to her family what she would want to happen if she were in a coma. The doctor can suggest a treatment but he has no decision making authority. The decision must be made by the family as they have the most input".

One respondent who indicated a family decision suggested that:

"I don't think that it should be a medical decision, it's a family's decision."

Two respondents who indicated the family should make the decision recall current issues in the news:

"The family decides. What if you had a Dr. Kevorkian? The family should work with the doctor, but the family has the final say and decision. They know best."

"The family decides. Some doctors believe in prolonging life for the sake of prolonging. Look at Sue Rodriguez. they're just prolonging her life. She wants to die."

Those who responded that a joint decision should be made, stated that a joint decision between the doctor and the family was "the best of both worlds". Typical of the joint decision response was:

"Absolutely a joint decision. They both have input--the doctor has the professional medical knowledge, and the family knows her best and may know what she wants in this scenario."

One respondent changed preferences twice and in weighing the issues indicated that cost was important:

"The family definitely--maybe the doctor --no I've changed my mind it should be a joint decision. The physician should tell the family the whole scenario and then the family would

make the decision. Physicians know how much it costs. --it's expensive and she's taking up a bed that someone else could use. She's in a coma and doesn't know what's going on. The family knows her best and must speak up for her. I imagine most people would want her to go and not linger or suffer."

Those who stated that the doctor should make the decision suggested that the doctor has the expertise and experience and that the doctor should understand the situation better than the family.

"Well, you trust your doctor. The doctor should make the final decision. He should understand the situation better than the family. He has the experience and knowledge and expertise."

When asked how they would feel if the doctor made the decision on his/her own without consulting or discussing with the family, or if they were in this situation, overwhelmingly, respondents stated that they would be "very angry", "upset", "mad", "annoyed", "indignant", and /or "outraged". One respondent stated that the doctor would be sued and forced to lose his/her license. Three respondents stated that they trusted their doctor to make the right decision for them and thus it would not bother them. Two respondents could not accept that today a doctor would make a decision without discussing and consulting with family. One respondent stated:

"I would not feel good about it. I would like to think that a physician, because of ethics, would always talk with the family regarding decisions. It shouldn't happen. I would be disturbed and concerned if a physician made a decision on his/her own. It's difficult for me to comprehend this."

When asked the question of what medical treatment preference the participants would choose for themselves if they

were in the identical scenario, all respondents (100.0%) replied that they would want the ventilator removed.

#### Medical Treatment Preference

Treatment	Frequency	Percentage
No Treatment	26	100.0%

There was little, if any, hesitation for the participants in arriving at this decision. When asked the reasons for their treatment choice, respondents suggested the quality of life in this state (coma and/or ventilator, not wanting to continue in a vegetative state, not wanting to be a burden, or a worry to their family, not wanting to be kept alive by machines and not being useful to themselves or others.

"Discontinue. Stop the machine, most definitely. Because the quality of life is not such that it should be continued. Being on a ventilator and in a coma is not living."

"I would want it stopped. I'm taking up space being a vegetable and life is not worth living like this. The mental state is the most important quality to life."

Many participants expressed more than one reason, for example:

"I would not want the machine to keep me alive. Turn it off. I would not want to be just a vegetable and a big worry to my family. I would want to relieve my family from further distress. You're a vegetable living on a machine."

When asked further if the coma or the ventilator or the combination of both was the determining factor in their decision, most answered that it was a combination of both, and suggested that one's mental functioning and capability was more important than any

limiting physical impairment:

"I would want the machine withdrawn. I'm in a coma and unable to communicate. Why should I continue to be a burden on my family and society. The quality of life and mental state are the most important in this case. Because of the mental state the quality of life can not be enjoyed --the quality of life especially in a coma is virtually nil."

"I would want it stopped. There's no hope -you are a burden to others. That's not a meaningful life --in a coma and on a machine. You're not functioning. I don't want that."

Being independent was important to some participants, evidenced by the following statement:

"I'm nothing but a vegetable and I would need constant care and someone always around me. I wouldn't want that. I wouldn't want my daughters to have the burden and responsibility of looking after me. What good is it to live in a state like this, Why ? "

In summation, most seniors regarded the family as the "rightful" decision makers, most would be angry if a physician were to decide independent of the family, none of the respondents wanted to be kept alive in a coma with a ventilator. The most common reason for their decision of non treatment was a combination of not wanting to be in a vegetative state, mental incapability denoting a poor quality of life, and/or being a burden and responsibility to their families. No participant mentioned wanting to be in control of their own destiny as a reason for not wanting the treatment.

## Vignette Two

"Mr. D., a 66 year old senior had Alzheimer's disease and has been living in an institution for the past three years. Although alert, he cannot walk, has lost basic toileting skills, can no longer communicate with others and does not recognize his family and friends. Sometimes he is frightened by ordinary objects (the shower, for example). At other times, Mr. D. takes delight in events around him such as watching T.V. and sing songs. Mr. D., has had repeated bouts of pneumonia, unrelated to Alzheimer's disease, however each bout of pneumonia leaves him a bit weaker than before. The pneumonia responds to antibiotic intravenous treatment. These treatments are becoming more frequent, as each subsequent bout of pneumonia becomes harder to treat. Mr. D. becomes very agitated and frightened by the treatment and lately, the nurses have had to restrain Mr. D. with cuffs around his wrists in order to give him the intravenous antibiotic treatment. Over the duration of the treatment, Mr. D. screams unintelligible words and cries. The doctors have suggested to Mr. D's family that more than likely within a year, Mr. D. will die from Alzheimer's. The doctors are discussing Mr. D's case with his family and whether or not to medically treat the next bout of pneumonia."

This vignette presented a 66 year old man, who was in end stage Alzheimer's disease, suffering repeated bouts of pneumonia which were becoming progressively harder to treat. He has moments of pleasure, has lost basic toileting skills, can no longer recognize his family, and friends. However, the intravenous antibiotic treatments for pneumonia are a source of extreme agitation to him and he had to be physically restrained with cuffs in order to facilitate the treatments. The doctors suggest that it is likely that he will die within a year from Alzheimer's disease. The doctor and the patient's family are discussing what treatment course should be taken.

When responding to the question of who should make the decision for the patient, 50% (13) of the respondents stated that it should be decided by the family alone, while 11.5% (3) of the respondents stated that the doctor alone should and 30.8% (8) stated that it should be a joint decision, between the doctor and the family. One participant (3.8%) stated that the patient in his pleasant moments should make the decision while another participant (3.8%) suggested that there was no decision to be made by anyone, because the pneumonia must be treated.

#### Preferred Surrogate Decision Makers

Surrogate Decision Maker	Frequency (n=26)	Percentage
Family	13	50.0%
Doctor	3	11.5%
Joint	8	30.8%
No Surrogate	1	3.8%
Patient	1	3.8%
Total	26	100.0%

This vignette tended to elicit more joint decision makers (11.6%), less family decision makers (11.5%) and slightly less doctor decision makers (7.7%) than the first vignette.

Young seniors (61.5%) were more likely than older seniors (38.5%) to prefer family surrogate decision makers, whereas older seniors (38.5%) choose joint decision makers more often than younger seniors (23.1%). Women (57.6%) were more likely to select

the family as decision makers than men (41.7%). Men respondents (41.7%) were more likely to select joint decision makers than women (21.4%). Single respondents (23.1%) choose the doctor as surrogate decision maker compared to 0.0% of married respondents.

Substantive differences were found for preferences in surrogate decision makers for income and educational characteristics. Respondents in the low income category (62.5%) were more likely than middle income respondents (44.4%) and high income respondents (50.0%) to prefer family surrogate decision makers. Middle income respondents (22.2%) were more likely than low income respondents (12.5%) and high income respondents (0.0%) to prefer the doctor as surrogate decision maker, whereas both middle and high income respondents (both 33.3%) were more likely than low income respondents (12.5%) to prefer joint surrogate decision makers. High income respondents were the only respondents who choose the patient himself as the decision maker. Respondents with post secondary education (60.0%) were more likely than secondary educated respondents (43.8%) to prefer family surrogate decision makers. Secondary educated respondents (37.5%) compared to post secondary respondent (20.0%) to prefer joint surrogate decision makers. The following charts illustrate the differences in preferred surrogate decision makers.

## Age

Preferred Surrogate Decision Makers	65-74 (13)	75-93 (13)
Family	61.5%	38.5%
Doctor	7.7%	15.4%
Joint	23.1%	38.5%
No Surrogate	7.7%	0.0%
Patient	0.0%	7.7%
Total	100.0%	100.0%

## Gender

Preferred Surrogate Decision Makers	Women (14)	Male (12)
Family	57.6%	41.7%
Doctor	14.3%	8.3%
Joint	21.4	41.7%
No Surrogate	7.7%	0.0%
Patient	0.0%	8.3%
Total	100.0%	100.0%

## Marital Status

Preferred Surrogate Decision Makers	Married (13)	Single (13)
Family	53.8%	46.2%
Doctor	0.0%	23.1%
Joint	30.8%	30.8%
No Surrogate	7.7%	0.0%
Patient	7.7%	0.0%
Total	100.0%	100.0%



## Income

Preferred Surrogate Decision Makers	Low (8)	Middle (9)	High (6)
Family	62.5%	44.4%	50.0%
Doctor	12.5%	22.2%	0.0%
Joint	12.5%	33.3%	33.3%
No Surrogate	12.5%	0.0%	0.0%
Patient	0.0%	0.0%	16.7%
Total	100.0%	100.0%	100.0%

## Education

Preferred Surrogate Decision Makers	Secondary (16)	Post-Secondary (10)
Family	43.8%	60.0%
Doctor	12.5%	10.0%
Joint	37.5%	20.0%
No Substitute	8.3%	0.0%
Patient	0.0%	10.0%
Total	100.0%	100.0%

When asked how they arrived at the decision and what factors they considered in deciding whom should make the decision, those who responded that the family should make the decision, again as in the first vignette, overwhelmingly stated that it was the family's decision because the family "knows the patient better", "knows what is best for the patient", and "it was the family's right to make the decision". The following are some typical

statements:

"The family. They know what's best for the person."

"The family has the last word and final decision."

"The family. I went through this with my husband. The family knows best and knows him better than the doctor."

Of those who responded that it should be a joint decision most suggested that both the family and the doctor have input into this case. One respondent indicated that costs were important and as well experiences with Alzheimer's patients.

"It should be a joint decision. Maybe OHIP should have a say about continuing treatment. It's so expensive and it's a terrible thing to waste money. The family wants to have a say but so few families are reasonable. It's too hard to part with a loved one. One of the worst parts is making the decision. I don't want people to suffer. Alzheimer's gets to be abusive. They're not living --just breathing--not thinking--in two minutes they forget. I've looked after five women who had Alzheimer's."

Another respondent whose spouse has Alzheimer's disease and is institutionalized, indicated that it should be a joint decision and further shared a very personal and painful thought:

"It should be a joint decision with the family after much discussion with the doctor. We've talked (respondent and doctor) to my boys about this. I'm not a terribly religious person, but for the last two years, I've gone into the chapel and said a little prayer that my spouse would just pass away while sleeping. The first time pneumonia is evident, I'll never do anything about it. Our family is close and we've all discussed what we would want, even the boys. We all agree that when someone is of no use to anyone and that all you are doing is prolonging a useless life, you shouldn't prolong life."

Three respondents designated the doctor as surrogate decision

maker and state:

"The doctor. It puts a lot of responsibility on the doctor, but I've known too many families who don't make good decisions. Most family groups are afraid of making decisions. Families get churned up about having to make decisions they don't want to make. At least a doctor has a profession where he's been making these decisions for years."

"The doctor should decide, because the doctor knows the patient's health isn't ever going to improve. The doctor should relieve the family of the responsibility of making a decision."

"The doctor should in this case. It's hard for the family."

The respondent who stated that there was no decision to be made suggested:

"There's no decision to be made in this one. The doctor must treat the pneumonia. There must be a way to sedate him and get on with the treatment. He has life and some enjoyment, thus there is no decision to be made. It might not seem much of a life, but it's all he has."

The respondent who stated the patient should make the decision explains:

"This (scenario) is a weird one. The patient should. (make the decision) We have a computer (brain) here that's clicking in and out of service. When it's working the patient should be asked. He enjoys T.V., therefore he's thinking. Because of his repeated bouts of pneumonia, he should get another doctor. Nor is his family taking good care of him, thus it's not their decision either. There must be another way to treat him."

Regarding the treating preference of the pneumonia, twenty one respondents (80.8%) stated that they would not want the treatment and five respondents (19.2%) stated that they would want treatment. In statistical comparison to vignette one, in which no respondent preferred treatment, practically a fifth of the

participants preferred treatment.

Medical Treatment Preference

Treatment	Frequency	Percentage
Treatment	5	19.2%
No Treatment	21	80.8%
Total	26	100.0%

Regarding treatment preferences in this vignette, there are no substantive findings for demographic characteristics. However, although not substantive, the life satisfaction demographic had an interesting finding. There is a negative relationship between life satisfaction and preference for treatment. Preference for treatment was 0.0% for those with excellent life satisfaction, 16.7% for those with very good, (25.0%) for those with good, and (33.3%) for those with fair life satisfaction. The percentage for non treatment followed the same path but in reverse order: fair life satisfaction (66.6%) to good (75.0%) to very good (83.3%) to excellent life satisfaction (100.0%). Thus for this sample and vignette, a pattern could be established suggesting that the higher life satisfaction is, the less treatment is preferred.

Those who did not want the pneumonia treated gave various reasons. Some felt that the pneumonia was "an easy way out" or the "short way out", while others thought that the I.V. treatment for pneumonia was so traumatic, disturbing and stressful that it was "inhumane and "we treat animals better". Many respondents were

concerned about "not putting their families through anymore stressful experiences." Nonetheless, the majority of those who choose not to treat the pneumonia echoed the following responses.

"I would not want the IV treatment. With Alzheimer's, life is useless. There's nothing in life to enjoy. There's no usefulness left in life. There's no quality of life---nil."

"There's no hope for Alzheimer's. There's nothing left to look forward to. I would want to end my life ASAP."

One respondent was upset with the IV treatment.

"I would not want to be treated, No IV, it's artificial. Let me go gradually."

Past life experiences were recalled for one respondent in making a treatment choice.

"I would not want the treatment, because I'm suffering from the treatment and my family doesn't want to see me suffer. Once I was restrained in the hospital and I did not like it and I was fighting everyone because of it. To be restrained with Alzheimer's must be pretty terrible."

Interestingly this respondent was the only one who exhibited concern regarding the restraints.

Those respondents (4) who had life experiences with Alzheimer's disease all choose to forego treatment, on the premise that death from pneumonia is nearer, kinder and less traumatic than to continue living with Alzheimer's for less than a year.

Those respondents whose preference choice was to be treated for the pneumonia suggested that where there's life, there's hope and a chance that within the year a cure may be found. Another stated that:

"Even with Alzheimer's, I still have enjoyment sometimes."

One respondent said:

"I'd want the pneumonia treated. I would hang onto the very end. Where there's life, there's hope. You must get yourself ready for death. It's hard to do though."

Another respondent was very philosophical about treatment choice as evidenced by the following:

"No heroics, no treatment, let me go. I'm philosophical about this. Sometimes God puts us in these situations in order to benefit the family and bring out some learned qualities that you are forced to face in these situations like caring, sacrifice, generosity and devotion. These qualities are learned and sometimes have to be brought out. Anyways, most of the time these people (Alzheimer patients) are living in limbo. I've had a good life and I've been healthy. If I'm not contributing to others, it's not good. Alzheimer's is the determining factor--you're not "there" anymore --age is not a factor here."

It was apparent through analyzing the treatment choices that for most respondents Alzheimer's disease was a predicated factor in terms of not wanting treatment. It is important to realize that although the patient's age of 66 years in this vignette was the youngest aged vignette patient overall, this younger age did not appear to be a predictor of treatment preference as it was not mentioned as a reason or factor.

Although most of the respondents would be angry and upset if a doctor made a decision without discussing/consulting with the family, three respondents changed their opinion for this vignette. Two respondents who in vignette one had replied that they would be angry, in this vignette said:

"In this scenario it would be OK either way, it takes the onus of the family to make a decision."

"In this case, I think the doctor knows best, so it doesn't matter in this case whether he spoke to the family."

This vignette has elicited slightly different responses from those in the first vignette, notably, more joint and less family and physician decision makers, more respondents who would prefer to be treated and slightly more respondents less likely to be angry if a physician made a decision regarding treatment without consulting or discussing with the family.

### Vignette Three

"Miss M. is a 79 year old single woman with no family or relatives. She has broken a hip and is recuperating from an operation to repair it. Miss M. has had arthritis for over thirty years. Since the operation, Miss M. has become very withdrawn and will not speak to any of her nurses or doctors. Friends who visit with her, also find that Miss M. is uncommunicative and withdrawn. Miss M. refuses to eat, and after several days, the doctor wants to feed Miss M. using a feeding tube inserted through her nose into her stomach."

This vignette presents a 76 year old single woman with no family or relatives who has broken her hip and is recuperating from surgery. She has had arthritis for over 30 years and, since the operation has become very withdrawn and refuses to speak to her nurses and doctors. Friends visit and also find that she is uncommunicative and withdrawn. She refuses to eat and after several days the doctor wants to feed her using a feeding tube inserted through her stomach.

The researcher observed that many respondents seemed

appalled at this vignette and as well, took the longest deliberations in answering all of the questions with the exception of one asking how they would feel if the doctor made a decision without consulting/discussing with the family. Again, one can only speculate or hypothesize to the reason. It may be that the forced tube feeding was considered an intolerable treatment considering that the patient was not mentally incompetent nor suffering from a disease as in the previous vignettes.

When responding to the question regarding who should make the decision for the patient, 68.4% (18) participants responded that the doctor should make the decision, 15.2% (4) thought that it should be a joint decision between the doctor and her friends, or a joint decision amongst a panel of doctors, 11.4% (3) thought it should be the patient herself, and one respondent (3.8%) was undecided.

#### Preferred Surrogate Decision Makers

Surrogate	Frequency	Percentage
Doctor	18	68.4%
Joint	4	15.2%
Patient	3	11.4%
Undecided	1	3.8%
Total	26	100.0%

There are substantive findings for most demographic characteristics regarding surrogate decision makers for this



vignette. Younger seniors (76.9%) were more likely than older seniors (61.5%) to designate the doctor as surrogate decision maker. All respondents in the low income category designated the doctor as surrogate decision maker, compared to middle (55.6%) and high (50.0%) income category respondents. Women respondents (85.7%) were more likely to select the doctor as surrogate decision maker compared to 50% of men. Men (25.0%) were more likely than women (7.1%) to designate joint surrogate decision makers and patient surrogate decision makers (16.6% compared to 7.1%). Single respondents (84.6%) were much more likely than married respondents (53.8)% to prefer the doctor as surrogate decision maker. Married respondents (23.8%) were more likely than single respondents (7.1%) to designate joint surrogate decision makers. The following charts illustrate these differences.

#### Age

Preferred Surrogate Decision Makers	65-74 (13)	75-93 (13)
Doctor	76.9%	61.5%
Joint	15.4%	15.4%
Patient	7.7%	15.4%
Undecided	0.0%	7.7%
Total	100.0%	100.0%

## Income

Preferred Surrogate Decision Makers	Low (8)	Middle (9)	High (6)
Doctor	100.0%	55.6%	50.0%
Joint	0.0%	22.2%	16.7%
Patient	0.0%	11.1%	33.3%
Undecided	0.0%	11.1%	0.0%
Total	100.0%	100.0%	100.0%

## Gender

Preferred Surrogate Decision Makers	Women (14)	Male (12)
Doctor	85.7%	50.0%
Joint	7.1%	25.0%
Patient	7.1%	16.6%
Undecided	0.0%	8.3%
Total	100.0%	100.0%

## Marital Status

Preferred Surrogate Decision Makers	Married (13)	Single (13)
Doctor	53.8%	84.6%
Joint	23.1%	7.7%
Patient	15.4%	7.7%
Undecided	7.7%	0.0%
Total	100.0%	100.0%

Of those who preferred the doctor to make the treatment decision, most respondents indicated that there simply was no one

else to make the decision and that "friends don't count, "friends are not family" and "friends do not have the right to make a decision". For example:

"The doctor--friends don't count. I wouldn't want to burden my friends with the responsibility."

"The doctor is the only one qualified to make the decision. The nurse and staff are not qualified. If her friends are long standing--10-15 years, the situation should be discussed with them, but not to make a decision, but to make the doctor feel better and to back him up. Friends do not have the right to make the decision."

Those who preferred joint decision makers expressed various reasons. One respondent suggested a joint decision amongst doctors:

"A group of doctors should decide. Something else is bothering her--she's withdrawn---a sympathetic panel of doctors--- not too young though."

Others who favoured a joint decision considered the patient's friends as important and a source of information to the doctor as the following indicate:

"Sometimes a relationship between friends can be as close as in a family."

"In the absence of blood relatives, her friends might know what she would want in this situation."

"She should have had a living will to state her preferences. I suppose her minister or friends, whom ever is closest to her. I think whom ever has her best interests at heart---her friends."

This is the first time that a living will/advance directive has been mentioned by any of the respondents. This respondent has a living will/advance directive, although this is the first vignette

in which it was mentioned.

Those respondents who designated the patient as the decision maker were in agreement and rather adamant as to the reason. They considered that she's mentally capable of making the decision and by refusing to eat she has, in fact, made a decision for no treatment, as evidenced in the following response:

"She gets to decide on the premise that she wants to starve. She doesn't want to live. It's her decision, no one else's."

In responding to how they would feel if a doctor decided on his/her own without consulting/discussing with anyone else, this vignette, because of the absence of family and relatives elicited somewhat different answers than the previous vignettes. Some indicated anger at the lack of control over the treatment. Some respondents stated:

"I'd be angry, if he tried this on me. I want no part of it. I would fight him off."

"I would fight him and pull the tube out. This would be a form of torture to me. I would really fight the doctor."

"I'd spit at him. I'd be very angry--don't force me to do anything I don't want to do."

Although stating that they would be upset, another group indicated that just the threat of tube feeding would be enough to force them to talk with the doctor.

"I'd be very upset, but what can I do? I think that if he started to force tube feed me, he would also force me to talk. I would then tell him to let me go (die)."

Others accepted the doctor's decision to tube feed on the premise that the doctor had no choice but to force feed and that by not communicating, it was their own "fault".

"It's my own fault if the doctor has to force tube feed me, because I'm not talking to him. I would not like it though."

"It's O.K. If I'm not communicating with the doctor, then he can go ahead and tube feed."

One respondent indicated that:

"I'd be upset, but it's O.K. It might be the one hope of getting going again and getting out of that depression and mental block."

One respondent after considerable thought, combined legal concern for the doctor, control of the situation, personal autonomy and surprisingly, ageism in the following answer:

"I would not be happy, but the doctor doesn't have a choice in this situation. I'd argue with him if necessary and give him written permission to make it an ethical decision not to feed me. I'd let him off the hook, so it's legal. Surely a person should have the right over their own life at that age, if the facts are put before them. At a younger age, that's different ---people don't always know, then, what's best."

Another respondent, although upset, used the hippocratic oath to "justify" the doctor's "right" to make a decision:

"The doctor has to do this because of the hippocratic oath. They have to keep people going. She's just existing, not living. I've come to the conclusion that doctors don't care, they don't give a damn about the quality of life."

One respondent philosophized about the decision, but in the end indicated that it was OK for the doctor to make the decision.

"It's hard to know if the patient realizes the consequences. Like Sue Rodriguez and patients of Dr. Kevorkian--they know what they want, they do not have the quality of life that they want. Is this not the patient's way of expressing that she does not want to live, does not want to be a burden to her friends and society in general?---why not let her go. She absolutely just wants to go---die. It's OK for the doctor to decide on his own."

When indicating their preference for treatment, 61.5% (16) respondents did not want tube feeding and 38.5% (10) would want treatment.

**Medical Treatment Preference**

Treatment	Frequency	Percentage
Treatment	10	38.5%
No Treatment	16	61.5%
Total	26	100.0%

More younger seniors (46.2%) wanted treatment compared to older seniors (30.8%). Respondents in the low income category (37.5%) were more likely than middle (11.1%) and high (16.7%) income categories to want treatment. Respondents with a post-secondary education (60.0%), were more likely than secondary educated respondents (25.0%) to prefer treatment. Single respondents (46.2%) were more likely to want treatment compared to married respondents (30.8%). No substantive differences were found in other demographic characteristics. The following tables illustrate the differences in treatment preferences for these demographic characteristics.

**Age**

Treatment Preference	65-74 (13)	75-93 (13)
Treatment	46.2%	30.8%
No Treatment	53.8%	69.2%
Total	100.0%	100.0%

**Income**

Treatment Preference	Low (8)	Middle (9)	High (6)
Treatment	37.5%	11.1%	16.7%
No Treatment	62.5%	88.9%	83.3%
Total	100.0%	100.0%	100.0%

**Education**

Treatment Preference	Secondary (16)	Post Secondary (10)
Treatment	25.0%	60.0%
No Treatment	75.0%	40.0%
Total	100.0%	100.0%

**Marital Status**

Treatment Preference	Married (13)	Single (13)
Treatment	30.8%	46.2%
No Treatment	69.2%	53.8%
Total	100.0%	100.0%

The factors and reasons that were given by those respondents who indicated that they would not want to be tube fed are quite varied. Some indicated:

"It's God's message to let nature take its course."

"Tube feeding isn't natural."

"It's beneath my dignity to be forced to be tube fed."

One respondent indicated that it was a "quality of life" that was important.

"I don't want to be kept alive under those circumstances."

For one respondent a combination of present age and life experiences with tube feeding left enough of an impact that he would rather forego the treatment:

"I would not want to be tube fed. I've lived long enough.(85) I've seen friends go through this and breathing tubes. It's trouble and terrible. I don't want to go through that."

One respondent talked about personal autonomy in decision making and the medical profession in suggesting:

"I would not want to be fed. It's my life and my decision. Why should you have to suffer before death. The medical profession doesn't want to let people die. It's like Sue Rodriguez. I support her and Dr. Kevorkian. These people have made their own decisions."

Generally speaking, those who wanted the treatment indicated that it was not a life threatening condition and although unpleasant, the tube feeding might bring them out of their depression and that there was a good chance of recovery.

"It sounds like you might recover to some degree of satisfactory quality of life. Maybe tube feeding isn't that bad. I'd want the tube feeding There's a good chance of recovery and it's not a fatal condition."

"I would want the tube feeding. It might help mentally, down the road. I would take a chance that something might develop This treatment might help in the mental block I'm in. Some specialist might be able to help me. Maybe this specialist might just click with me personally and get to me mentally."



Two respondents had experienced tube feeding either personally or through family and friends experiencing tube feeding, and did not think that it was that bad.

"I would want the tube feeding. It's not frightening to me, because I've had it done."

"I would try the tube feeding at that age because of my sister's-in-law experience."

One respondent suggested:

"I would want the tube feeding for a month with input from a palliative care team that would involve my family. This team is very qualified and take a holistic approach and covers the social aspects. I would wonder why I am so anti-social and withdrawn. There maybe a deep hidden reason---maybe I feel that no one cares. If my nutrition improved, I might feel differently. I would only want the tube for a limited time, not for a year--only one month, then reassess."

In summation, this vignette seemed to be the most difficult for the respondents. It may be that lack of family and relatives combined with a non life threatening disease and a mentally competent patient were significant enough to produce a predicament for the respondents. As well, after analyzing the three vignettes, differences are emerging. Each succeeding vignette elicits less family decision makers, more active/pro treatment preferences and somewhat less anger towards doctors making decisions.

### Vignette Four

"Mr. S. is a 92 year old widower who is unable to make medical decisions for himself, because he has become mentally confused and incompetent. Mr. S. has diabetes. Because of diabetes, he has developed gangrene in one of his legs, which has not responded to conventional treatment. The doctors suggest to Mr. S's family that unless Mr. S's leg is amputated, he will almost surely die in a very short time. The doctors and Mr. S's children are discussing whether or not to amputate his leg."

This vignette presents a 92 year old widowed gentleman who is unable to make medical decisions for himself because he has become confused and is mentally incompetent. Because of diabetes, he has developed gangrene in one of his legs. The doctor suggests to his family that unless his leg is amputated, the patient will almost certainly die in a very short time.

When responding to the question regarding who should make the decision for this patient, 50% (13) of the respondents indicated the family, 26.9% (7) the doctor, and 23.1% (6) designated that it should be a joint decision between the doctor and the family.

#### Preferred Surrogate Decision Makers

Surrogate	Frequency	Percentage
Family	13	50.0%
Doctor	7	26.9%
Joint	6	23.1%
Total	26	100.0%

Both genders prefer family surrogate decision makers, however, women (57.1%) were more likely than men (41.7%) to choose the family, whereas men (33.3%) were more likely than women (14.3%) to choose joint decision makers. Married respondents (61.5%) were more likely than single respondents (38.5%) to choose family as surrogate decision makers, whereas single respondents were (46.1%) were more likely than married respondents (7.7%) to choose the doctor as surrogate decision maker. As well, married respondents (30.8%) were more likely to choose joint decision makers compared to single respondents (15.4%). Respondents with secondary education (56.2%) were more likely than post-secondary (40.0%) educated respondents to choose family as surrogate decision makers. Respondents with post-secondary education (40.0%) were more likely to choose the doctor as the surrogate decision maker, compared to secondary (18.8%) educated respondents. Substantive differences were not found in other demographic characteristics. The following charts illustrate the differences in preferred surrogate decision makers for these demographic characteristics.

#### Gender

Preferred Surrogate Decision Makers	Women (14)	Male (12)
Family	57.1%	41.7%
Doctor	28.6%	25.0%
Joint	14.3%	33.3%
Total	100.0%	100.0%

### Marital Status

Preferred Surrogate Decision Makers	Married (13)	Single (13)
Family	61.5%	38.5%
Doctor	7.7%	46.1%
Joint	30.8%	15.4%
Total	100.0%	100.0%

### Education

Preferred Surrogate Decision Makers	Secondary (16)	Post-Secondary (10)
Family	56.2%	40.0%
Doctor	18.8%	40.0%
Joint	25.0%	20.0%
Total	100.0%	100.0%

As in the previous vignettes, those respondents who indicated that the family should make the decision, the overall reason pertained to the family being the closest, knowing the patient better and knowing what's best for the patient, and having insight into the patient's preference of treatment.

"The family has the final say and decision. They know what's best for him. It's not up to the doctor, it's up to the family to decide."

"His family--his kids, the dearest and nearest and most trustworthy. If his children said to amputate, it's O.K. It's his family's prerogative to decide."

Again, as in the previous vignettes, those who designated a joint decision suggested that both the doctor and family had input

as they represented professional medical knowledge and personal patient knowledge.

"It should be a joint decision, because they both have input, and the doctor and the children should talk it over."

Those who indicated that the doctor should make a decision gave various reasons for their answers. Reasons varied from anger at the family, to euthanasia, to compassion to medical expertise. The following answers illustrate these reasons.

"The doctor. The kids are not paying enough attention to him. They should've done something already before it got to this bad stage. The physician should notify the family, not consult with them. They have let it go too long. The doctor doesn't need their permission. He should just amputate."

"Well, the doctor should, but the children have some say. If the children thought that by amputating, it would make the rest of his life more comfortable and reasonable and that he wouldn't be suffering with gangrene-he might live longer and not suffer. The doctor should discuss the treatment with the children. Why do we keep elderly people going and going for so long? Sometimes I believe in euthanasia. We put animals out of their misery but we do not have the same considerations for humans. We are more humane to animals than to humans."

"The doctor should let him go--don't amputate, it's too late in life. He should tell the children why he's not going to amputate. Just tell them and explain to them that at 92, he shouldn't be put through this, this late in life. Too much suffering and agony. Why put him through it this late in life? The doctor has to tell his children that it's too much."

"The doctor. This is a different case. It's surgical and it has to be amputated. It can't be let go, he'll get sepsis. The children don't know enough about their father's condition."

"Oh, dear. Sooner or later he's going to lose his leg or his life. This is difficult, but sometimes the doctor knows more than the family."

When indicating how they would feel if a doctor decided without consulting/discussing the patient's case with the family, seven respondents indicated that it would be OK and wouldn't bother them.

"It's O.K., especially to amputate."

"It's O.K. , I think he (the doctor) has the right to amputate."

"It wouldn't bother me. I would go along with the doctor's decision."

Most (14) would feel angry, annoyed and upset.

"I would not like this. He must talk with the family".

"I would be angry. It's inconceivable to me that a doctor today wouldn't discuss this with the family. He should never decide on his own."

One respondent stated despairingly:

"You don't have much choice. You have to go along with the doctor. Doctor's don't respect patient's opinions."

However, four conditional responses were given which was not evidenced in the other vignettes.

"If he decided to amputate, I would be upset. It would be OK if he did not amputate."

"At 92, I can't see a doctor doing this. I'd be angry if he did, not angry if he did not."

"I'd be angry if the doctor amputated, that's terrible. I wouldn't be angry if he didn't operate."

"I would fight him if he decided to amputate. I would tell him not to amputate and to leave things the way they are."

Interestingly, these conditional responses were elicited only if

the doctor decided to amputate, not if he/she decided not to amputate.

More respondents (57.7%) indicated that they would not want treatment, then those (42.3%) who wanted treatment.

#### Medical Treatment Preference

Treatment	Frequency	Percentage
Treatment	11	42.3%
No Treatment	15	57.7%
Total	26	100.0%

Women were evenly divided as to treatment preference, whereas men were more likely (66.7%) to not want treatment. Middle income respondents (77.8%) were more likely to choose non treatment then low income (50.0%) and high income (50.0%) respondents. Substantive findings were not found for other demographic characteristics. The following charts illustrate these findings in demographic characteristics.

#### Gender

Treatment	Female (14)	Male (12)
Treatment	50.0%	33.3%
No Treatment	50.0%	66.7%
Total	100.0%	100.0%

## Income

Treatment	Low (8)	Middle (9)	High (6)
Treatment	50.0%	22.2%	50.0%
No Treatment	50.0%	77.8%	50.0%
Total	100.0%	100.0%	100.0%

Those respondents who indicated that they would want treatment, overwhelmingly stated that the pain, agony and suffering associated with gangrene was the determining factor. Some intimated that it would be life saving and better than dying and one respondent implied:

"I would want the amputation--it has to be done. It would be awful not to treat gangrene. What a horrible experience."

However, two respondents agreed on amputation in order to alleviate the pain.

"I would want the amputation to avoid the pain. I would hope that at that advanced age that I would not survive the operation. If I died during the operation or shortly after, it's OK. It would be less painful than gangrene, which is terribly painful. I think lots of MDs would not want to operate, knowing this condition."

Another respondent indicated in the beginning that an amputation was preferred but changed to no amputation because of the mental state:

"Amputate to relieve the suffering. Once the suffering is relieved, I could still enjoy life.---No wait--I'm mentally incompetent in this one, right?----Let me go because of the mental state of incompetence."

This was one of three respondents who indicated that mental



incompetency was an issue. It is interesting to note, that apparently, this is not as an important issue in this vignette, as it was in the other vignettes.

For those who indicated that they would not want the amputation, there were many issues. For some, age was the important variable to be considered.

"Do not amputate! Why would you put the poor thing through such an operation at the age of 92!"

"Don't amputate, let me go. At 92, what reason is there to go on. Why? I've lived my life. To me if amputation took place at age 92---that's experimenting! Life isn't worth living."

"I wouldn't want the amputation. Once you get to that age, 92, they should let you go. Age is the important factor here."

"Don't amputate, because at 92 that's pretty old for surgery. I'm not sure I could live with an amputation. At that age, I'm not useful to myself or anyone else."

"I would not want the amputation. I would be too old at 92 to go through this traumatic experience of losing a leg. Age is the most important factor here."

Life experience with diabetes or gangrene was important to others.

"Dear Lord, let me go. Don't amputate. I wouldn't want to go through that operation at 92. It's hopeless if you have diabetes, anyways. My friend died of diabetes."

For one respondent, gangrene brought back an unpleasant association with gas gangrene from war injuries, that obviously dictated his non treatment preference.

"I don't like gangrene, During the war, they just kept chopping at it and there was no guarantee that they would get it all. Guys would die after having surgery. I saw it happen during WW1. Let me go. There's no guarantee that they would get all of the gangrene."

Some did not want amputation because it was the quicker way to die.

"Let me go. Its a means to an end of life."

"I would not want my leg amputated. It would be such a short time before the gangrene would cause death. The quality of life is important here."

One respondent was concerned about being a burden to their family, not being able to contribute to his own care.

"Don't amputate, let me die. There's no quality of life left. I'm not contributing to myself or to anyone and I'm a burden on my family."

A health care directive was mentioned by one respondent who declared:

"I would never get into this scenario. I've already filled out a directive with my family with instructions not to amputate. I'm not mentally competent, I'm not useful and I'm not going to get better at age 92. It's too old. It's time to go."

Another respondent was concerned about the expense to the state.

"If my think tank (brain) was lucid for one moment, I wouldn't want the amputation. To hell with it. I'm not one to use up state dollars for unnecessary things. If I can't contribute to myself, family or society---you're just meat on the hook without that computer.(brain)"

In summation, this vignette elicited more decisions decided by a doctor than others, with the exception of vignette three in which there were no family members. Also, it may be that this vignette was the only one that involved major surgery, which perhaps predicated a medical decision rather than a familial or joint decision.

The researcher observed two phenomena that occurred during the

interviews. Every respondent indicated what treatment preference they would choose for the vignette patient, although this was not a question asked of them at any time during the interview. This information was recorded, and the treatment preferences respondents choose for the vignette patients were identical to those chosen for themselves which can be thought of as reflecting their personal choices. Also observed was the absolute certainty of the respondents regarding treatment preference. Generally speaking, there was no hesitancy observed when asking respondents treatment preference.

#### Advance Health Care Directives

In the third stage of the interview, respondents were asked for their opinions and thoughts regarding advance health care directives. These questions were open ended in order to record the various opinions of the respondents. This stage was divided into two parts. In the first part, respondents were asked: if they had heard of or were familiar with directives, had they ever written or considered writing a directive; their opinion of a directive; if they thought a directive was an important document; and if they would complete a directive if given the opportunity. The second part asked respondents if directives should be honoured.

Just over three quarters of the respondents (76.9%) have heard of advance directives and understood the intention of such a document. An informative paragraph regarding the intent of

directives was read to those respondents (23.1%) who were not familiar with a directive and any ensuing questions answered.

Heard of Directive	Frequency	Percentage
Yes	20	76.9%
No	6	23.1%
Total	26	100.0%

Some interesting statistics emerge regarding knowledge of a directive. Older seniors (92.3%) were more likely than younger seniors (61.5%) to have heard of directives. Men (83.3%) were more likely than women (71.4%) to have heard of directives. High income respondents (100.0%) were more likely to have heard of directives than middle income (66.7%) and low income (75.0%) respondents. Single respondents (84.6%) were more likely than married respondents (69.2%) to have heard of directives. There is no qualitative data to be analyzed for this question as it was simply a yes or no answer. The following illustrates the differences in knowledge of a directive for demographic characteristics.

#### Age

Heard of Directive	65-74	75-93
Yes	61.5%	92.3%
No	38.5%	7.7%
Total	100.0%	100.0%

## Gender

Heard of Directive	Women	Male
Yes	71.4%	83.3%
No	28.6%	16.7%
Total	100.0%	100.0%

## Income

Heard of Directive	Low (8)	Middle (9)	High (6)
Yes	75.0%	66.7%	100.0%
No	25.0%	33.3%	0.0%
Total	100.0%	100.0%	100.0%

## Marital Status

Heard of Directive	Married (13)	Single (13)
Yes	69.2%	84.6%
No	30.8%	15.4%
Total	100.0%	100.0%

When asked their opinion of a directive, respondents answers may be classed into three categories: good idea, not a good idea, and no opinion. Most respondents, 88.5% (23) declared that they thought it is a good idea, 7.7% (2) replied that it was not a good idea, and one respondent (3.8%) did not know what his opinion was of directives.

Opinion of Directive	Frequency	Percentage
Good Idea	23	88.5%
Not A Good Idea	2	7.7%
Do Not Know	1	3.8%
Total	26	100.0%

All (100.0%) post-secondary educated respondents thought that directives were a good idea compared to secondary educated respondents (81.3%). Substantive findings were not found for other demographic characteristics.

When asked if they had ever thought about or considered completing a directive, ten respondents (38.5%) indicated that they had, of which three respondents had actually completed a directive, and sixteen respondents (61.5%) stated that they had not.

Considered A Directive	Frequency	Percentage
Yes	10	38.5%
No	16	61.5%
Total	26	100.0%

Single seniors (46.2%) compared to married seniors (30.8%) were more likely to indicate that they have considered or were in the process of completing a directive. Women (50.0%) were twice as likely as men (25.0%) to indicate that they have considered or were in the process of completing a directive. Substantive findings were not found for other demographic characteristics. The following charts illustrate these findings.

### Marital Status

Considered A Directive	Married (13)	Single (13)
Yes	30.8%	46.2%
No	69.2%	53.8%
Total	100.0%	100.0%

### Gender

Considered A Directive	Women (14)	Men (12)
Yes	50.0%	25.0%
No	50.0%	75.0%
Total	100.0%	100.0%

When asked if they would complete a directive if the opportunity presented itself, five responses emerged: yes, no, unsure, probably, and already completed. Three respondents (11.5%) had completed a directive, two respondents (7.7%) indicated that they probably would, three respondents (11.5%) were unsure, four respondents declared that they would not, (15.8%) and 14 respondents (53.8%) indicated that they would complete a directive.

Complete Directive If Opportunity	Frequency	Percentage
Yes	14	53.8%
No	4	15.8%
Unsure	3	11.7%
Probably	2	7.7%
Have Completed	3	11.7%
Total	26	100.0%

When combining the responses of yes, probably and have completed a directive to indicate yes to completing a directive if the opportunity presented itself, and combining the categories of no and unsure to indicate a negative response to completing a directive if the opportunity presented itself, some interesting findings emerge.

Women (85.6%) were more likely than men (58.3%) to complete a directive if given the opportunity. Noteworthy, is the finding that two men and one women have completed a directive. Low income respondents (87.5%) compared to middle income (77.8%) and high income (50.0%) respondents were more likely to complete a directive. Although not substantive, the income demographic had an interesting finding. There is a negative relationship between completing a directive if given the opportunity and income. Completing a directive was 87.5% for low income respondents, 77.8% for middle income respondents, and 50.0% for high income respondents. The percentage for not completing a directive followed the same path but in reverse order: high income (50.0%) to middle income (22.2%) to low income (12.5%) respondents. Thus for this sample, a pattern could be established suggesting that the lower the income the more likely an individual would complete a directive if given the opportunity. Noteworthy, is the finding that all respondents who have completed a directive have secondary education. Single respondents (84.62%) were more likely to complete



a directive compared to married respondents (61.6%). Substantive findings were not found for other demographic characteristics.

#### Gender

Complete Directive If Opportunity	Women (14)	Male (12)
Yes	85.6%	58.3%
No	14.4%	41.7%
Total	100.0%	100.0%

#### Income

Complete Directive If Opportunity	Low (8)	Middle (9)	High (6)
Yes	87.5%	77.8%	50.0%
No	12.5%	22.2%	50.0%
Total	100.0%	100.0%	100.0%

#### Marital Status

Complete Directive If Opportunity	Married (13)	Single (13)
Yes	61.6%	84.6%
No	38.4%	15.4%
Total	100.0%	100.0%

Family related reasons were the most important determinant indicated for not completing a directive. The reasons given by some respondents for not completing a directive included unfamiliarity with a directive and the presence of family.

"I've never heard of it. My family knows what I would want done. I don't see that I need one. I guess it's OK for some people. I don't think it's an important document. I would not fill one out."

"I've never heard of this before. It's OK for some people especially those without family. it's not for me though. I would not fill one out. I have family, however, I have not discussed these things with my family."

"Yes, I've heard of it, but I haven't written one. I trust my wife. She'll live longer than I will. She'll make the right decision. We've talked it over. I wouldn't write one because of the difference in health between my wife and myself."

Accordingly, reliance on family to speak in one's best interest is important and supports other research that suggests that seniors rely on family members to make decisions for them (Gamble, 1991; Stolman et al., 1990; Henderson, 1990; Prat et al., 1989; Collopy, 1988; Smith et al., 1988).

Some respondents without family mention that the lack of family is a determining factor for completing a directive.

"It's a great idea. I have told my friends because I have no family. I have not written it down legally though. I should---to make it legal. It would take the onus off my friends to make these decisions."

Another participant without children stated:

"It's OK. especially if you have no children like me. It would relieve the pressure for my niece if I had one. She won't have to make the decision. I haven't talked to my niece about my medical preferences---not yet. it would help her though. I'd probably complete one, if the opportunity arose."

One respondent who personally doesn't believe in directives, indicated that "for my family's sake" a directive might be filled out:

"I've never heard of it. Never considered it. My family knows what I want. I don't think you need a living will. Everyone should be treated. Treatment should never be withdrawn. For my family's sake, I would probably fill one out."

Another important theme that emerged is that of relieving the onus/pressure from others:

"This is a good idea and I would complete one. It relieves the family of the responsibility of making decisions."

"It's a good idea and a way to reduce the guilt and responsibility for your family."

"It's a good thing, this directive, because it takes pressure off your family to make decisions."

Few respondents who have talked with their families regarding their medical treatment preferences have discussed this with their physicians. When asked why not, most replied that they just had not got around to it. However, one respondent who had discussed preferences with the family physician gave some insight into how she felt about the conversation:

"I've told my doctor, but he won't remember. I bet it's never registered with him. He's Catholic, you know, and they have slightly different ideas than I do."

Obviously, the respondent did not feel that the doctor seemed particularly interested or comfortable with the conversation, which supports research that suggests that doctors generally struggle with such conversations (Dosseter, 1991).

Two respondents were sceptical of completing a directive too soon and were concerned about what the future will be in terms of illness and medical preferences, as evidenced in the following

responses:

"I've heard of it, but I haven't written one. It's better to wait and you don't know what it will be like. It's a better and more valuable a time to wait until the situation arises and then do it. I really don't know how or what I would want."

"It is completely different what you might think now and in the future. It's very difficult to project what you would want between now and then."

Life experience was stated by one respondent as the impetus for writing a directive, and as well, offers some insight as to why a completed directive is not particularly important to her:

"Yes, I've written one but I haven't finished completing it. The experience with my husband taught me. A will makes you think about what your future medical preferences will be. I don't think a completed will is important, because the kids might disagree with what you want and they will make their own decisions."

For some respondents, their present age, health status or family heritage of a long life were determining factors in not writing a directive and/or for not discussing their preferences with their family, as the following illustrate:

"I haven't written or discussed my preferences with anyone. No one knows what I want. I'm only 65 and I intend to be around for another 25 years. I feel great most days. I guess this is when you should do it though, when you're healthy."

"Yes, I've heard of it, but haven't written or considered writing one. I'm too healthy, I'm not sick. When you're healthy, you don't think about it. I've not had any conversation with either my wife or kids. We've talked about Sue Rodriguez and how we feel about the outcome."

"Yes, I've heard of this, but I haven't written one yet. I've not had any serious illness."

"I'll fill one out ten years from now. I come from a line of long lifers."

Respondents who were unsure of completing a directive gave various reasons. One respondent was concerned about filling one out wrongly and stated:

"Yes, I've heard of it. I think it's a good idea as you can express what you want. I'm not sure if I would fill one out. I get depressed sometimes, and I might fill it our wrong if I was depressed."

Another respondent who had not heard of a directive was quite methodical in stating:

"I've not heard of this and never thought or considered it. I think it's a good idea and an important document. I would have to think about completing one---I wouldn't necessarily complete one though."

A few respondents who indicated that they would complete a directive but had not, declared that they were procrastinating, or too "lazy" as evidenced in the following typical response:

"Yes, I've heard of it and we have discussed and considered it, but have not written one. We both know what each other wants, I guess I'm just lazy--procrastinating and putting it off."

One respondent shared a very personal reason for not filling out a directive:

"Yes, I've heard of it. I've had the papers for five years, but I've never had the courage to fill them out. I don't think I would fill one out, because I've had this for five years, so the opportunity has been there and I haven't done it yet."

Various reasons were given for those respondents who have completed directive. One respondent combines important factors in declaring:

"I've written a living will and left an instructional letter for my daughter. The biggest part is I don't want to worry my daughter. Another part is the expense of the treatment and dying, and the other part is I want to have control of my own dying process."

Another respondent suggests that:

"I've filled one out. We've discussed this many times. Nothing would change my mind about my decisions. I've heard of too many family disagreements. These are my decisions, therefore there is no disagreement. I'm in control. My sons know what I want. A directive helps my sons --there are no tough decisions to be made, I've already made them. It's the way to go if you're competent. I'm in control of my own destiny. It should be this way."

One respondent who is in the process of completing a directive offers:

"I'm in the process of completing a living will. It let's me express what I want done and tells my family my wishes."

Thus, it appears that controlling one's own destiny for these respondents is an important issue. However, only three respondents (11.4%) have completed a directive. This supports other research that suggests that amongst seniors, the completion of a directive is very low, between 0% and 18% (Sachs et al., 1993; Emanuel et al., 1991; Zweibel et al., 1989).

### Should Directives Be Honoured?

Respondents were asked the following question:

"In the vignettes you have just heard, if all the hypothetical patients previously had completed a health care directive, when competent, documenting their treatment preferences that explicitly covered the exact situations they were in, do you think that their preferences should be honoured regardless of whether or not their physicians and families agree with those preferences?"

Twenty one respondents (80.8%) indicated that a directive should be honoured, three respondents (11.5%) replied yes with reservations/conditions, one respondent (3.8%) replied no, and one respondent (3.8%) did not know if a directive should be honoured.

The following chart illustrates these frequencies.

#### Advance Health Care Directives

Honour A Directive	Frequency	Percentage
Yes	21	80.8%
No	1	3.8%
Yes With Reservations	3	11.5%
Do Not Know	1	3.8%
Total	26	100.0%

Substantive differences were found for the variable of income. All middle income respondents (100.0%) compared to low income (87.5%) and high income (50.0%) respondents indicated that directives should be honoured.

#### Income

Honour A Directive	Low (8)	Middle (9)	High (6)
Yes	87.5%	100.0%	50.0%
No	12.5%	0.0%	0.0%
Yes with Reservations	0.0%	0.0%	33.3%
Do Not Know	0.0%	0.0%	16.7%
Total	100.0%	100.0%	100.0%

The respondent who indicated that a directive should not be honoured, believes that medical expertise will continue to provide life sustaining technology as she stated:

"No, I don't think they should be honoured. Medicine might have a new idea or cure in five years."

The participant who did not know about honouring a directive gave an insightful explanation:

"I don't know. I can't answer this. It's the ideal situation if you are single and have no relatives. If my siblings predecease me, I'd certainly make one out. It's not easy facing up to death. I haven't talked it over with my brothers, nor them with me. It's not a pleasant subject."

Those respondents who answered yes with reservations offered various insights into their reservations. One respondent reiterated concern that the person must be competent when the directive was completed. Another respondent voiced reservations regarding advances in medical technology and cures in stating:

"if there was no improvement in medicine since a directive was filled out".

One participant who is in the process of completing a directive, added an important dimension to directives by suggesting:

"The broad answer is yes, however a living will can not possibly anticipate every situation, in which case the MD has no directions from his patient. But by filling out a living will, it points an apparent direction regarding death, dying, and your own life's values."

One respondent gave a combination of reservations in regards to honouring directives:



"This is the toughest question of all. I assume that everyone would say no to heroics. Directives should be honoured but only to a point. It must be re-assessed every 6 months by the competent person, their family and physician. The situation dictates whether it should be honoured or considered. I believe the increase in the aging population and the concomitant economic costs and health care dollars and resources are going to have to be considered. I don't see how we cannot consider this."

Thus, those participants who have reservations about honouring directives, brought out some potential important limits and problems with honouring directives.

One respondent who supports honouring a directive shared some life experience he had witnessed regarding honouring directives.

"Yes, their wishes should be honoured. But I've experienced differently when the person's wishes were not honoured by her own spouse."

In summary, 21 (80.8%) of the respondents indicated that directives should be honoured if completed by a competent person. Most used one word responses such as "absolutely", "definitely", and "certainly" to answer the question. Others declared that the wishes should be honoured because its the person's preferences. For example, One respondent replied:

"Most definitely, it should be honoured. Their preferences for treatment are the only ones that count."

In summation, most respondents are familiar with directives, believe that directives are a good idea, would complete one if given the opportunity and believe that directives if completed by a competent person should be honoured. Despite these

testimonies and beliefs few seniors have completed a directive.

### Locus of Control

The fourth part of the interview consisted of participants filling out a multidimensional health locus of control questionnaire designed by Wallston & Wallston (1978). This was used in an attempt to evaluate, analyze and correlate the participants' locus of control with their responses to the vignettes, their medical treatment preferences, and their usage of advance health care directives. Research suggest that some sociodemographic characteristics tend to be related, but not exclusively, to internal locus of control (Lefcourt, 1982; Kuypers, 1972).

The hypothesis generated by research with the health locus of control suggests that seniors with an internal health locus of control would choose to participate in health care directives and control their own death processes and conversely seniors with an external health locus of control would not necessarily want to participate in and have control over their own death processes.

A health locus of control scale was completed by the respondents at the end of the interview. Seventeen respondents (65.4%) were designated as having an internal health locus of control. Six respondents (23.1%) were designated as being influenced by either powerful others or chance in health control denoting an external health locus of control. Three respondents (11.5%) were designated as having various combinations of the three

measured categories: internal, powerful others, and chance. Thus no health locus of control could be determined. These findings do not support other findings regarding seniors and control which suggest that generally, older adults hold greater belief in the ability of powerful others to control their health than did younger adults (Wallston et al., 1988; Lachman & Smith, 1986). The following chart illustrates the frequencies for the categories of health locus of control.

**Health Locus of Control**

Locus of Control	Frequency	Percentage
Internal	17	65.4%
Powerful Others	3	11.5%
Chance	3	11.5%
Internal & Chance	1	3.8%
Powerful Others & Chance	2	7.7%
Total	26	100.0%

Older seniors (76.9%) compared to younger seniors (53.8%) were more likely to have an internal locus of control. Women (71.4%) were more likely than men (58.3%) to have an internal locus of control as were low income respondents (87.5%) compared to middle (55.6%) and high income (50.0%) respondents. Substantive findings were not found for other demographic characteristics.

The analysis did not find that locus of control was relevant to any particular choice of decision makers, medical

treatment preferences, opinions, completion and/or honouring directives. Thus, in this research, health locus of control was not a predictive instrument in correlating these outcomes. These results may be due to two factors. The sample was small and internal locus of control appeared to be over represented in the sample. Internal locus of control may be over represented because this sample of seniors were generally better educated, healthier, have more income and were more satisfied with life than the senior population at large. The second reason may be that all the respondents are living independently in the community. Thus, one could perceive this sample group as generally being in control of most facets of their lives, which may indicate internal control over their health and health care.

## Chapter Six

### Discussion

This chapter will discuss the overall results of the respondents' perceptions of surrogate decision makers, medical treatment preferences, and seniors' attitudes towards physicians not consulting with families regarding medical treatment.

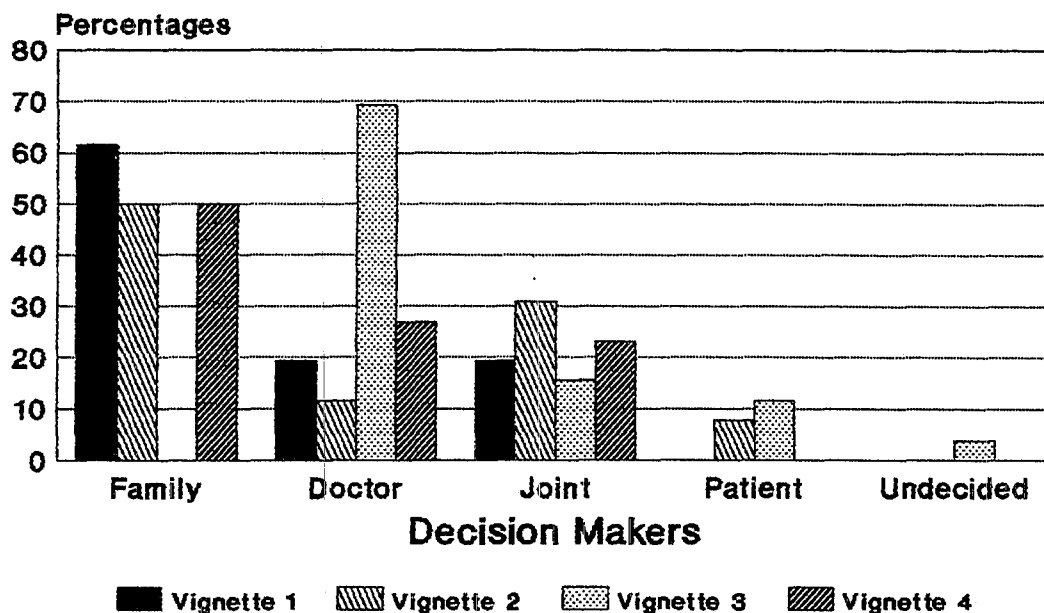
#### Vignettes and Results

Through the analysis of responses to the vignettes, ideas and concepts can be established concerning seniors' perceptions of surrogate decision makers, medical treatment preferences and seniors' attitudes towards physicians not consulting family members regarding medical treatment.

For the purpose of a general discussion of the results, responses have been grouped together for all four vignettes regarding surrogate decision makers and treatment preferences. The chart on the following page illustrates the four grouped vignette responses for surrogate decision makers and medical treatment preferences.

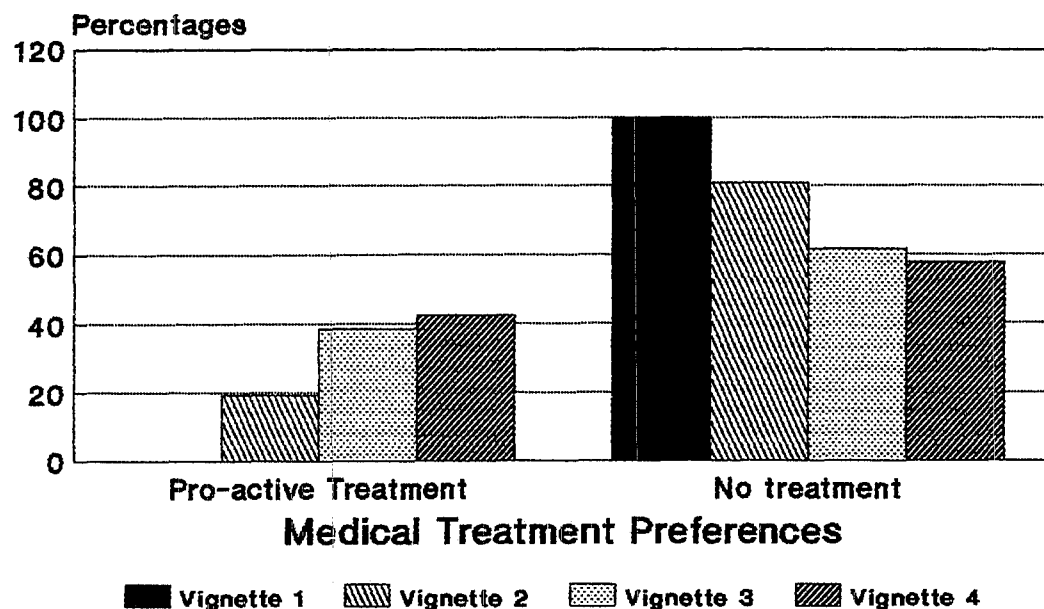
## Vignettes

### Preferred Surrogate Decision Makers



## Vignettes

### Medical Treatment Preferences



### Preferred Decision Makers

Noteworthy regarding the respondents' choice of decision makers is the fact that few respondents choose the same decision maker for each vignette. Only two respondents, both men, answered each vignette with the same choice of decision maker. Perhaps, this could be perceived as the respondents' open mindedness to novel situations and willingness to consider each vignette on its own merit.

Across all four vignettes, family decision makers (40.3%) were more likely to be designated than doctors (31.7%), joint decision makers (22.1%), patients (3.8%), or others (undecided/no decision) (1.9%). In the vignettes in which family decision makers were available (vignettes one, two, and four), at least 50% of the respondents indicated the family in each vignette. This finding supports other studies that suggest seniors frequently rely on family members as surrogate decision makers (Cohen-Mansfield et al., 1992, 1991; High, 1990 a & b, 1988; Shmerling 1988; Finucane, 1988; Uhlmann et al., 1988).

In vignette three where there was an absence of family and/or relatives, physicians were most likely to be chosen as decision makers, (69.2%) followed by joint (15.4%) and patient (11.5%) decision makers. As aforementioned, the vast majority of this sample generally did not think that friends had the "right" to make decisions. However, some respondents (3) felt that in the

absence of relatives, friends should have some input into this decision. One respondent indicated that they would not want to put that decisional responsibility on their friends. These findings support other research that suggests family members and family physicians are relied upon heavily as decision makers (Gamble, 1991; Stolman et al., 1990; Henderson, 1990; Prat et al., 1989; Collopy, 1988).

Surrogate joint decision making (22%) was not a particular favoured choice by respondents as most choose either family or physicians as decision makers. Friends are not regarded by the vast majority of respondents as "appropriate" decision makers. This study indicates that this segment of the informal network is not as important as decision makers with seniors as some studies suggest. When friends were available as part of a joint decision maker with a physician, only three respondents (11.4%) indicated preference for a joint decision, the lowest percentage of all the vignettes.

Overall, respondents definitely did not think that patients with cognitive dysfunction should be the decision makers. It seems that patients as characterized in these vignettes were not considered as capable of making decision for themselves as overall, only 3.8% of the respondents choose patients as decision makers. However, the patient in vignette three, although she was not communicating with the medical staff and appeared withdrawn, there was no indication given of cognitive dysfunction. Only three



respondents (11.4%) designated this patient as capable of making a decision. This finding may indicate that being characterized in the role of a hospitalized patient might be an important factor on its own that respondents considered in not choosing a patient as a decision maker.

Analyzing the demographic characteristics for preferred decision makers, four characteristics emerge as substantive: age, gender, marital status, and income. The demographic characteristics of education, health, life satisfaction, religion, visits to physicians and presence of family were not found to be substantive in determining preferred surrogate decision makers.

Younger seniors (46.3%) were more likely than older seniors (33.75%) to prefer family surrogate decision making. Gender seemed to be an important variable for choice of decision makers. Overall, women (45.8%) were slightly more likely than men (35.4%) to indicate family decision makers. Women (35.7%) were also more likely than men (27.1%) to designate a doctor as the decision maker. Conversely, men (29.2%) were more likely than women (16.0%) to indicate joint decision makers and men (8.3%) were more likely than women (3.5%) to designate patient decision makers.

Overall, married respondents (48.0%) compared to single respondents (32.5%) prefer family decision makers, and single respondents (46.1%) compared to married respondents (17.3%) prefer doctors as surrogate decision makers. One could suggest that this

is a normal finding in that married people would choose their spouse as surrogate decision maker rather than their doctor and that single people would choose their doctor because of the absence of a spouse. However, all respondents in this sample had family or relatives, thus, one can exclude the presence of family as a determining factor in choosing doctors as a surrogate decision makers by single seniors.

Respondents in all income categories prefer family as surrogate decision makers. However, high income respondents (25.0%) were more likely to prefer joint decision making, compared to middle income (16.6%) and low income (12.5%) respondents. Low income respondents (40.6%) compared to middle income (33.3%) and high income (20.6%) choose doctors as surrogate decision makers. Due to the small size of this sample, these findings are not generalizable to the population.

In summation, this sample supports other research that suggests that seniors rely heavily on family members and physicians as surrogate decision makers (Gamble, 1991; Stolman et al., 1990; Henderson, 1990; Prat et al., 1989; Collopy, 1988). This sample indicated that family members not only had the "right" to make decisions, that family had the patients' "best" interest at heart, knew the patient better, and was closer to the patient. Some respondents implied that patients might have discussed what decision they themselves would make if in this condition. This

study also supports Pratt's (1989) and Smith's (1988) research suggesting that some seniors do not want exclusive autonomy, but rather autonomy is enhanced by sharing with family members, medical decisions and treatment preferences.

### Treatment Preferences

Overall, three quarters (75.0%) of all respondents preferred non treatment to treatment. None of the vignettes elicited more active/pro treatment preference than non treatment preference. Further, starting with vignette one, each succeeding vignette elicited more active/pro treatment preferences than non treatment preferences. Accordingly, the least preferred treatment in order are artificial ventilation, treatment for pneumonia, forced tube feeding, and amputation. These findings are slightly different than other studies regarding seniors' treatment preferences (Cohen-Mansfield et al., 1992: Henderson, 1990). Cohen-Mansfield et al., (1992) found that the least preferred treatments in order were: permanent tube feeding, permanent respirator, resuscitation, chemotherapy, dialysis, amputation, radiation, temporary respirator, temporary tube feeding, blood transfusion, and antibiotics. Henderson's (1990) research of residents in a retirement community, suggests that most seniors did not want treatments to prolong their lives if they were terminally ill and found that the least preferred treatments in order were: respirator, tube feeding, CPR, IV fluids, antibiotic therapy and

oxygen for comfort. Both these studies are American and it may be that economic cost considerations account for the differences.

An overall pattern emerges for seniors' medical treatment preferences. It shows that generally, respondents were opposed to aggressive medical treatment, except where intervention alleviated pain and/or result in greater patient comfort as evidenced in the amputation vignette. This pattern was particularly evident when respondents were confronted with dementia patients, as in the coma vignette in which no respondent preferred treatment and in the Alzheimer's vignette in which only five (19.2%) indicated that they would want treatment. In vignette four, even though the patient was mentally incompetent, alleviation of pain was the most frequent mentioned criteria for medical treatment preference. This finding supports similar results in other studies that found permanent cognitive dysfunction as a important variable for non medical treatment (Cohen-Mansfield et al., 1992, 1991; Michelson et al., 1991; High, 1990 a & b, 1988; Shmerling, 1988; Finucane, 1988; Uhlmann et al., 1988).

Overall, participants' responses suggest that there are some important criteria that were considered in making medical treatment preferences. The most frequent criteria mentioned were: cognitive dysfunction, quality of life, pain, prolongation of life, and limiting burden and stress on others. This finding supports other studies in which these criteria were found to be the most

frequently mentioned (Michelson et al., 1991; Tomlinson et al., 1990; Zweibel et al., 1989).

Overall, substantive findings were not found for demographic characteristics in deciding treatment preferences.

#### Seniors' Attitudes Towards Physicians Not Consulting With Family

As evidenced by the responses to the question regarding physicians making treatment decisions without consulting/discussing with family members, the majority of respondents were angry, annoyed and/or upset. Few respondents perceived this to be proper procedure. Three seniors could not believe that this actually could take place today.

This finding lends support to the rising consumerist and individualist movements in health care today where consumers demand to be at the very least, equal partners in decisions regarding their own health, health care, and ultimately their own destinies and dying processes.

However, there were a few seniors who perceived doctors as an authoritarian figure who possessed the specialized knowledge and expertise and should make medical treatment decisions without consulting family members which supports the power imbalance in patient/physician relationships. This emerges in responses such as:

"It would be OK whatever way the doctor decided. The doctor knows best and has the expertise."

"I trust the doctor."

Accordingly, this study has shown that the majority of seniors feel that doctors do not have the right to make medical decisions on their own and that family members, at the very least, should be consulted by doctors when discussing medical treatments.

## Chapter Seven

### Conclusions

#### Themes and Patterns

As exploratory and qualitative, this study attempted to discover themes and patterns of seniors' preferences for surrogate decision makers, medical treatments and opinions of advance health care directives. It was anticipated that in-depth interviews of non-institutionalized healthy seniors, in advance of any severe disability, chronic illness or decisional/communicative incapacity would function as an information base to explore their perceptions and to generate themes. This would be of interest to legislative bodies, the medical profession, those who envision advance health care directives as being an adopted, ethical and autonomous evoking practice in the physician/patient relationship, and those who urge its acceptance and use. To the extent that the interviews did supply senior's perceptions and opinions and that some themes emerged, this study successfully fulfilled this purpose.

Although this study is exploratory in nature, several important findings emerged and it is possible to discern some themes in the responses.

The first theme to emerge is that family members are the preferred surrogate decision makers when a patient is decisionally or communicatively incompetent. Respondents indicated that family

had the "right" to make decisions. These decisions would be based on closeness and knowledge of the patient and the patient's preferences. These decisions would be directed by the "best" interest of the patients. This study suggests that seniors have a strong expectation for familial surrogate decision making in the event that an elderly individual is no longer personally capable of making health care decisions. Responses also suggest that familial surrogate decision making is an extension of a patient's autonomy and can effectively function to promote patient autonomy as evidenced by the repeated response of "best interest". Accordingly, this study supports other research that suggests that family is the most relied upon surrogate decision makers and that family members most likely act as extenders of personal autonomy for seniors. (High, 1993, 1990 a,b, 1988; Gamble et al. 1991)

Further, this study suggests that there is a hierarchical order that seniors rely upon as preferred surrogate decision makers: (1) family, (2) doctors, (3) joint, (4) patients themselves and (5) others. This order is somewhat different than other studies. Some studies found doctors were the least preferred surrogates (Shanas, 1979; Scott, 1983) whereas, this study and other studies suggest that doctors are the second most preferred surrogates (Gamble, 1991; Stolman et al., 1990; Henderson, 1990; Prat et al., 1989; Collopy, 1988).

A second theme stems from respondents' views of treatment



preferences and medical interventions. Responses generally show that participants are opposed to aggressive medical intervention and treatment and prefer limited medical intervention in the event of cognitive dysfunction and terminal illnesses, with the exception of alleviating pain and suffering. Non treatment emerged as the choice for three-quarters of the respondents. Several factors contributed to this preference criteria such as cognitive dysfunction, prolongation of life, quality of life, pain and suffering, and limiting burden and stress on others. This reaction was particularly prominent when participants were confronted with patients with cognitive dysfunction as in the coma and Alzheimer's vignettes, in which no participant wanted treatment and in the Alzheimer's vignette in which only 19.2% of participants favoured treatment.

Another sub theme also emerges in terms of a hierarchy of acceptable treatment. The least preferred treatments for respondents, with percentage frequencies in parenthesis, in order are: mechanical ventilation (100%) treatment for pneumonia (80.8%), forced tube feeding (61.5%), and amputation (57.7%). As illustrated before, this finding is different from American research findings (Cohen-Mansfield et al., 1992; Henderson, 1990).

A third theme emerges that suggests that seniors' perceptions are positive regarding advance health care directives which supports other research (Stolman, 1990; Steinbrook et al.,

1986; Lo et al., 1986; Rye et al., 1985; Wagner et al., 1984). Opinions of advance health care directives were generally positive. Seniors perceived directives to be a positive and important document that most had some familiarity with prior to the interview. Most participants said that they would complete a directive if given the opportunity.

Accordingly, the fourth theme stems from the non use and non completion of directives by seniors. Despite these positive perceptions, only 38% of the respondents have ever considered writing or completing a directive and only three respondents have completed a directive. This is certainly an enigmatic finding but supports other research suggesting that seniors overall have exceedingly low completion rates for advance health care directives (Sachs et al., 1992; Gamble et al., 1991; Zweibel & Cassel, 1989; High, 1988).

A fifth theme emerges from this study which indicated that women are more likely than men to complete a directive if given the opportunity. Twelve women (85.6%) indicated that they would complete a directive if given the opportunity. This may reflect that in this sample, most senior women (83.3%) are single, and women (71.4%) are more likely to have an internal health locus of control. This finding suggests that research must be done in terms of discovering what this "opportunity" is, and how to deliver this opportunity to senior women who choose to complete health care

directives and empower their autonomy in health care decisions.

### Concluding Comments

The exploratory study discussed here suggests several emerging themes that are important to seniors regarding surrogate decision makers, treatment preferences and advance health care directives. If our society is going to give credibility to enhancing the health care decision-making autonomy of seniors, then we are obligated to take seriously their preferences and opinions in initiating, incorporating and carrying out medical, governmental and public practices and policies. The thematic implications of this study suggest further research and exploratory studies with seniors into surrogate decision makers, medical treatment preferences, and advance health care directives. For instance, do non-institutionalized seniors differ from institutionalized seniors in surrogate decision makers, medical treatment preferences and the completion and/or use of advance directives? Do these issues change over time as seniors become older? What are the existing barriers for community seniors in completing and using directives? How reliable and valid are directives and what, if any, impact do directives have on treatment utilization rates and health care costs? How are directives to be promoted for greater knowledge and completion rates for community seniors? How is the "complete directive if given the opportunity" operationalized for seniors? If directives are to become a policy statement in medical and seniors'

institutions, what changes must be made to existing directives in order to promote seniors' autonomy and choices regarding their death processes? Will the medical profession honour directives regardless of their own professional treatment preferences? With escalating health care costs and the increasing senior population, will directives become a mandatory completed document for seniors, thus defeating the purpose of autonomy in directives? If directives become a mandatory completed document for institutionalized seniors, will the next step allow seniors' any choice in medical treatment? Will health care directives approach this "slippery slope" of death control for seniors in terms of saving health care costs?

Clearly demonstrated by this study is that seniors are not reluctant to discuss their personal feelings, opinions and preferences regarding life threatening illness, death, dying processes, and treatment preferences. The participants were aware of the content of the interview and no respondent refused to be interviewed for this reason. At the end of the interview, respondents were asked whether they thought the content of the interview was too intense or emotional. Participants unanimously indicated that it was neither. Rather than remain a taboo subject for seniors, this research suggests that seniors seem willing to discuss death and dying issues and treatment preferences. They want to have some control over these processes. Indeed quite a few

participants indicated that they have informally discussed these issues with their families and friends, however, few have formally discussed these issues with their physicians. The lack of discussion between physicians and their clients regarding these issues may reflect the general reluctance on the part of the medical profession to discuss death or it may be that clients prefer not to formally discuss these issues with their physicians. Regardless as to the reasons why, research is indicated in order to understand this barrier.

Also demonstrated is the reliance upon family as the primary surrogate decision maker for incapacitated patients. This preference should be noted by the medical profession and medical institutions who should initiate and encourage conversations with their senior clients and families as to their choice of surrogate decision makers if clients have not made their preferences known.

Seniors in this study have indicated that not only do they have strong feelings towards end of life care but also, they have definite medical treatment preference patterns. Both demonstrate that prolongation of life for the sake of prolonging life without any quality to that life is considered futile. The medical profession should be aware of these preferences and instead of prolonging biological life, concentrate on enhancing the quality of end of life in terms of the reduction of pain, suffering, and intensive, intrusive, medical intervention according to their

clients' preferences.

Seniors have made a strong statement about the use of advance health care directives. Regardless of their positive endorsement of directives, and their apparent strong preferences to control their own destinies, few have completed a directive. This is a contradictory result. Much more research is required to investigate what barriers exist to seemingly prohibit most seniors from using advance health care directives. It may be that directives are not perceived to be "user friendly" to seniors, or it may be that seniors do not trust directives to be honoured or it just may be that present directives are not particularly suitable for seniors. If advance health care directives are to become a useful and suited document for seniors, future research that calls upon seniors' preferences and opinions must be initiated in order to create and promote a directive that allows seniors to become effective users of advance health care directives.



# CMA POLICY SUMMARY



## ADVANCE DIRECTIVES FOR RESUSCITATION AND OTHER LIFE-SAVING OR SUSTAINING MEASURES

Some people want to specify in advance the types of medical procedures they would or would not want to undergo in the event that they become incompetent. They can fulfil this desire through a written advance directive, or by appointing a proxy decision-maker, or both. Physicians should assist their patients in these endeavours. They should honour a patient's advance directive unless there are reasonable grounds for not doing so.

In recent years patients' concerns over decision making in the medical setting have increasingly focused on advance directives for cardiopulmonary resuscitation, resuscitation in general and other life-saving or sustaining measures. The CMA holds that the right to accept or reject any treatment or procedure ultimately resides with the patient or appropriate proxy. This includes the right to accept or refuse resuscitative as well as other life-saving or sustaining measures should they become medically indicated. Furthermore, under certain circumstances it may be appropriate for a patient to indicate to the physician and other relevant people, by means of an advance directive, whether he or she wants such resuscitative measures taken should the need arise.

Patients frequently believe that an advance directive to refuse life-saving or sustaining measures will be honoured under all circumstances. The reality of medical practice makes this impossible. If an advance directive is specific to a particular set of circumstances the directive will have no force when these circumstances or ones essentially similar to them do not exist. On the other hand, if an advance directive is so general that it applies to all possible events that could arise it is usually too vague to give any usable direction to the physician. In either case physicians will have to rely on their professional judgement to reach a decision.

### Implementation

1. A physician should assist a patient in a

consultative capacity in the preparation of an advance directive concerning life-saving or sustaining measures if the patient requests such assistance. In the course of this consultative process, the physician should try to ensure that the patient understands the limits of such documents. Also, the physician should impress upon the patient the need to make advance directives reasonable and accessible. Any such directive should be in writing.

2. A patient's duly executed advance directive shall be honoured by the attending physician unless there are reasonable grounds to suppose that it no longer represents the wishes of the patient or that the patient's understanding was incomplete at the time the directive was prepared.

3. Some patients may not wish to execute an advance directive but are concerned about who will make health care decisions for them when they are no longer able to do so. Physicians should explore with these patients the possibility of identifying a specific person who will have the legal power to make health care decisions on their behalf in such an eventuality.

4. Physicians whose patients do wish to draw up advance directives should explore with them the possibility of identifying a specific person who will have the legal power to act as their proxy decision-maker should the need arise for clarification of the directive. ■

## Appendix Two

### INTRODUCTION

Before we begin this interview, I would like to inform you that there are no right or wrong answers to these questions. I am interested in your opinion. Some of the questions require only a short answer while others will ask you to tell about things in your own words. I would like to use a tape recorder to help me remember the things that you tell me, would that be alright with you?

As you may recall, all information is confidential and anonymous. Your participation is voluntary, and if we should come to a question you would rather not answer, just let me know and we will skip it.

### DEMOGRAPHIC CHARACTERISTICS

I.D.#: \_\_\_\_\_ TAPE# : \_\_\_\_\_

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

TELEPHONE NUMBER: \_\_\_\_\_

1. BIRTHDATE: \_\_\_\_\_

1a. GENDER : FEMALE 1 MALE 2

2. MARITAL STATUS: MARRIED 1 SEPARATED 2

DIVORCED 3 SINGLE 4 WIDOW 5

WIDOWER 6



## 3. WHAT LEVEL OF EDUCATION HAVE YOU COMPLETED ?

NO FORMAL SCHOOLING 1 SOME ELEMENTARY 2  
 COMPLETED ELEMENTARY 3 SOME SECONDARY 4  
 COMPLETED SECONDARY 5  
 SOME POST SECONDARY, COMMUNITY COLLEGE OR SOME UNIVERSITY 6  
 B.A. OR HIGHER 7 OTHER (SPECIFY) 8 DON'T KNOW 9

## 4. HOW WOULD YOU RATE YOUR OVERALL HEALTH AT THE PRESENT TIME ?

EXCELLENT 1 VERY GOOD 2 GOOD 3 FAIR 4 POOR 5  
 VERY POOR 6 DON'T KNOW 9

## 5. HOW OFTEN HAVE YOU SEEN A FAMILY PHYSICIAN IN THE PAST 12 MONTHS ?

0 = 0 1-5 = 1 6-10 = 2 10-15 = 3 MORE THAN 16 = 4

## 6. HOW WOULD YOU RATE YOUR OVERALL WELL BEING /LIFE SATISFACTION AT THE PRESENT TIME ?

EXCELLENT 1 VERY GOOD 2 GOOD 3 FAIR 4 POOR 5  
 VERY POOR 6 DON'T KNOW 9

## 7. WHAT WAS YOUR OCCUPATION/JOB BEFORE RETIREMENT ?

UNSKILLED 1 BLUE COLLAR 2 WHITE COLLAR 3  
 PROFESSIONAL 4 OWN BUSINESS 5 HOUSEWIFE/HUSBAND 6  
 UNEMPLOYED 7 OTHER 8 DON'T KNOW 9

8. COULD YOU TELL ME YOUR APPROXIMATE HOUSEHOLD ANNUAL INCOME ?

UNDER \$10,000 1                      BETWEEN \$10,000 - \$20,000 2

BETWEEN \$20,000 - \$30,000 3      BETWEEN \$30,000 - \$40,000 4

BETWEEN \$40,000 - \$50,000 5    OVER \$50,000 6

DON'T KNOW 9                      NO ANSWER 99

9. HAVE YOU EVER HAD ANY EXPERIENCE DEALING WITH LIFE THREATENING  
DECISION MAKING SITUATIONS?

YES 1      NO 2      DON'T KNOW 9      NO ANSWER 99

10. DO YOU HAVE ANY RELIGIOUS AFFILIATION ?

YES 1      NO 2

10a. IF YES, WOULD YOU TELL ME WHICH RELIGIOUS AFFILIATION ?

PROTESTANT 1      CATHOLIC 2      JEWISH 3      MOSLEM 4

HINDU 5              OTHER 8

11. DO YOU HAVE ANY CHILDREN, SIBLINGS, OTHER RELATIVES ?

YES 1              NO 2

11a. IF YES, COULD YOU TELL ME HOW MANY ?

1. CHILDREN :      SONS \_\_\_\_\_      DAUGHTERS \_\_\_\_\_

2. SIBLINGS :      BROTHERS \_\_\_\_\_      SISTERS \_\_\_\_\_

3. COUSINS              4. OTHERS

11b. GEOGRAPHICALLY SPEAKING, WHO LIVES THE CLOSEST TO YOU ?

1. CHILDREN :      SONS \_\_\_\_\_      DAUGHTERS \_\_\_\_\_

2. SIBLINGS :      BROTHERS \_\_\_\_\_      SISTERS \_\_\_\_\_

3. COUSINS

4. AUNTS              UNCLES      5. OTHERS

11c. WHO WOULD YOU WANT TO SPEAK ON YOUR BEHALF IN AN MEDICAL EMERGENCY, IF FOR ANY REASON YOU COULD NOT COMMUNICATE FOR YOURSELF ?

1. CHILDREN :        SONS \_\_\_\_\_        DAUGHTERS \_\_\_\_\_
2. SIBLINGS :        BROTHERS \_\_\_\_\_        SISTERS \_\_\_\_\_
3. COUSINS
4. AUNTS                UNCLES
5. OTHERS

QUESTIONS TO BE ASKED FOLLOWING EACH VIGNETTE

1. Who should make the decision regarding the medical treatment?

Followed by probing questions such as:

2. How did you arrive at this answer ?
3. What factors did you consider regarding who should make this decision ?
4. If the doctor made the decision on his/her own, how would you feel about this ?
5. Imagine you were the patient in the situation like the one just described. What would be your decision regarding the medical treatment ?

Followed by probing questions such as :

6. How did you arrive at this decision ?
7. What factors did you consider regarding this decision ?
8. If the doctor made this decision on his/her own, how would you feel about this ?

## ADVANCED HEALTH CARE DIRECTIVES

9. ARE YOU AWARE OF THE EXISTENCE OF A DOCUMENT CALLED AN ADVANCE HEALTH CARE DIRECTIVE OR A LIVING WILL ?

YES 1 NO 2

An advance health care directive is a document containing specific written instructions about one's preferences and/or wishes for one's own health care treatment. If you should become incapacitated by disease, illness, or injury and cannot communicate for yourself at some time in the future, a health directive will speak for you. Most directives use some medical terms so that doctors can interpret them effectively. Directives deal with a variety of treatment options such as whether or not a person would choose to have CPR, artificial ventilation/respiration, tube feeding and/or antibiotic treatment. The purpose of such a directive is to allow a person to choose the level of care he/she would prefer if or when that person should become incapacitated.

10. HAVE YOU WRITTEN OR CONSIDERED WRITING INSTRUCTIONS INVOLVING YOUR OWN DECISIONS REGARDING FUTURE MEDICAL TREATMENT IF YOU BECOME INCAPABLE OF MAKING SUCH A DECISION ?

YES 1 NO 2

11. CAN YOU TELL ME WHY YOU HAVE/HAVE NOT WRITTEN OR CONSIDERED SUCH A DIRECTIVE ?

12. CAN YOU TELL ME WHAT YOUR OPINION IS OF SUCH A DIRECTIVE ?

13. DO YOU THINK THAT A COMPLETED DIRECTIVE IS IMPORTANT ?

14. WOULD YOU COMPLETE A HEALTH CARE DIRECTIVE IF GIVEN THE OPPORTUNITY ?

15. IN THE VIGNETTES THAT YOU HAVE HEARD, IF ALL THE HYPOTHETICAL PATIENTS PREVIOUSLY HAD COMPLETED A HEALTH CARE DIRECTIVE, DOCUMENTING THEIR MEDICAL TREATMENT PREFERENCES WHEN COMPETENT, DO YOU THINK THAT THEIR DIRECTIVES SHOULD BE HONOURED REGARDLESS OF WHAT THE PHYSICIANS AND/OR FAMILIES MIGHT WANT?

### Appendix Three

#### MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL

This is a questionnaire regarding a measurement of personal health beliefs. There are no right or wrong answers. I am interested in your beliefs and opinions regarding health. For each statement, please indicate with an X whether you strongly agree, agree, disagree or strongly disagree.

1. If I get sick, it is my own behaviour which determines how soon I get well.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

2. No matter what I do, if I am going to get sick, I will get sick.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

3. Having regular contact with my physician is the best way for me to avoid illness.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

4. Most things that affect my health happen to me by accident.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

5. Whenever I don't feel well, I should consult a medically trained professional.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

6. I am in control of my health.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

7. Other people play a big part in whether I stay healthy or become sick.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

8. When I get sick I am to blame.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

9. Luck plays a big part in deciding how soon I will recover from an illness.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

10. Health professionals control my health.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

11. My good health is largely a matter of good fortune.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

12. The main thing which affects my health is what I myself do.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

13. If I take care of myself, I can avoid illness.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

15. No matter what I do, I'm likely to get sick.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

16. If it's meant to be, I will stay healthy.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

17. If I take the right actions, I can stay healthy.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

18. Regarding my health, I can only do what my doctor tells me to do.

Strongly Agree\_\_\_\_ Agree\_\_\_\_ Disagree\_\_\_\_ Strongly Disagree\_\_\_\_

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