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**A COMPARATIVE STUDY OF ELDERLY PERSONS AND HEALTH CARE
PROFESSIONALS IN REGARD TO MAKING LONG TERM CARE DECISIONS
FOR A marginally INCOMPETENT PERSON LIVING ALONE**

by

Penny Lois Jean MacCourt
B.S.W., University of Manitoba, 1977
M.S.W., University of Manitoba, 1993

A dissertation Submitted in Partial Fulfilment of the

Requirements for the Degree of

DOCTOR OF PHILOSOPHY
in the Departments of Sociology and Psychology (INTD)

We accept this dissertation as conforming to the required standard

Dr. N. Chappell, Co-Supervisor (Department of Sociology)

Dr. H. Tuokko, Co-Supervisor (Department of Psychology)

Dr. D. Rutman, Outside Member (Department of Social Work)

Dr. M. Penning, Departmental Member (Department of Sociology)

Dr. P. Clark, External Examiner (Program in Gerontology, University of Rhode Island)

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Date August 21, 2002

University of Victoria

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Co-Supervisors: Dr. N. Chappell and Dr. H. Tuokko

ABSTRACT

The focus of this research was a comparison of the values of elderly people and health care professionals (HCPs) that underlay the care decisions they made for a hypothetical marginally incompetent elderly person living alone.

Frequently individuals come to the attention of health care professionals when they appear to be living “at risk” but do not want care. In the absence of clear roles and responsibilities the decisions made on these persons’ behalf could reflect the professional’s values. In that health care professionals are younger, and their practice is driven by discipline specific values and the values of the agencies employing them, it seems unlikely they would make decisions congruent with those of elderly people. Instead it was hypothesised that the values of elderly people would be more likely to reflect the values and perspectives of other elderly people.

A between group design was used to compare a group of elderly people (N= 82) with a group of health care professionals (N= 87). The sample was one of convenience, and a questionnaire was used to gather the data. A scenario was provided to participants concerning an elderly woman living alone “at risk”. They were asked to assess her safety and to make health care decisions for her, under varied conditions. The responses were compared between the groups and examined to determine what values were reflected.

There were similarities and differences in the care decisions of elderly participants and

HCPs, and the values that underlay them. Elderly participants and HCPs appraised the hypothetical elderly person's safety similarly, but elderly participants were more likely to suggest facility care for her, demonstrating paternalism. None of the participants demonstrated autonomy, most acted beneficently. Elderly participants, as opposed to HCPs, felt more influenced by the hypothetical elderly person's burdened children but did not make care decisions based on this. Elderly participants were more likely than HCPs to demonstrate paternalism if the hypothetical elderly person refused the care they originally suggested. Together the findings indicate that HCPs do not make the same care decision for a marginally incompetent elder that elderly persons do, and their decisions are based on different values.

Examiners:

Dr. N. Chappell, Co-Supervisor (Department of Sociology)

Dr. H. Tuokko, Co-Supervisor (Department of Psychology)

Dr. D. Rutman, Outside Member (Department of Social Work)

Dr. M. Penning, Departmental Member (Department of Sociology)

Dr. P. Clark, External Examiner (Program in Gerontology, University of Rhode Island)

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ACKNOWLEDGEMENTS

I would like to acknowledge the support of my committee Drs. Chappell, Tuokko, Rutman and Penning, who provided guidance, inspiration and support. My co-supervisors Drs. Chappell and Tuokko were always there for me when spirits or energy flagged, and reminded me to keep focussed on my goals. Dr. Tuokko provided friendship as well as mentorship, and was unflagging in her encouragement, for which I shall always be grateful. I would also like to acknowledge the support I received from the MOST team (and later SORT). They generously picked up the slack when I needed time off to study, and were unfailingly supportive over the years. I wish to acknowledge the sacrifices of my family, each of whom who gave up something of me while I pursued my goal. Finally, I acknowledge the financial support I received from the Alzheimer's Society of Canada through a training award to complete my Doctoral research.

DEDICATION

This research is dedicated to my family who allowed me the freedom to pursue my goals. They suffered in good spirits through the agonies of statistics, the frustrations of writing and rewriting, and the constant never-ending deadlines that were always THE END. They were the wind under my wings, for which I thank them.

INTRODUCTION

I - FOCUS OF THE RESEARCH

The thesis research focussed on a comparison of the values of elderly people and health care professionals underlying health care decision-making for marginally incompetent elderly individuals living alone.

II - INTRODUCTION

"Client centred care" has emerged as a basic tenet of health care policy for the frail elderly in the 1990's. Elderly people are no longer expected to be the relatively passive recipients of services provided by expert professionals, but instead partners and primary decision-makers in their own care (Keating, Fast, Connidis, Penning, and Keefe 1997). There is some research which supports that client-centeredness in the delivery of health care to the elderly produces a better outcome for clients (Timko and Moos, 1989) and is a critical component of seniors' independence (Keating et al., 1997).

The concept of clients as primary decision-makers in their own care is congruent with the concepts of informed consent and autonomy which regulate the relationships between health care professionals and clients. Clients are assumed to be competent autonomous beings with values that provide standards against which they will weigh information and make decisions. Clients are in the best position to make healthcare decisions on their own behalf, because they are the experts on what is important to them. The role of the professional is to provide technical knowledge to clients, so that clients can make healthcare decisions on the basis of

accurate information. It is accepted that competent clients may make, in the eyes of others, bad or foolish choices, but that it is their right to do so without interference. If a client is incompetent then there are legal and clinical practices in place that allow others to make decisions on the incompetent individual's behalf, and that clearly delineate the role of the health care professional. Problems arise when the client is neither competent nor incompetent, but falls into a gray area of marginal incompetence. Marginal incompetence undermines the assumption inherent in the partnership between the professional and the client that the client is always in the best position to make decisions on her own behalf. When clients are marginally incompetent, health care professionals are without clear guidelines about how to collaborate in decision-making with them. This lack of clarity in the relationship between the health care professional and the marginally incompetent person, as regards decision-making, creates clinical and ethical dilemmas for the professional.

Marginally incompetent elderly people living alone in the community are a growing population. The Canadian Study of Health and Aging found that an estimated 37,800 elderly persons, (or 31.4% of seniors with dementia) live alone in the community, and are potentially at risk (Hill, 1994). Dementia is a progressive brain disease affecting cognition; a period of marginal competence will occur between competence and incompetence. Frequently marginally incompetent individuals come to the attention of health care professionals when it appears they are "at risk" or unsafe, but adamant about remaining at home. Risk is a subjective notion and may be assessed differently by each observer on the basis of personal

values and personal tolerance for ambiguity (Clemens, Welte, Feltes, Crabtree, and Dubitzky 1994).

If marginally incompetent clients cannot be assumed to be autonomous decision-makers whose decisions are based on information filtered through personal values, then whose values should underlie decisions made about them or their circumstances?

Health care professionals can lay no claim to special expertise in making appropriate decisions for marginally incompetent people on the basis of their subjective assessments. They are trained to base their decisions on knowledge, technical criteria and objective data, and to avoid personal biases and subjectivity. In the absence of clear roles and responsibilities in these situations, the decisions that are made are nevertheless likely to reflect both the clinician's personal and professional values (Kaufman, 1995; Clemens & Hayes, 1997).

The values of health care professionals may differ from those of elderly people and therefore the decisions they make may not be reflective of elderly clients' values. Health care professionals are younger, and their professional practice is driven by discipline specific values and the values of the organizations that employ them. Given that the values of health care professionals are different from those of the elderly (McCullough, L., Wilson, N., Teasdale, T., Kolpakchi, A. and Skelly, J., 1993 ;Kane, R., Rockwood, T., Finch, M., and Philp, I., 1997), how likely is it that the care provided to marginally incompetent elderly people will be what they want or need?

It seems probable that the values of elderly people are more likely to reflect the values, life experiences, goals and perspectives of other elderly people, than those of younger health care professionals. Although the elderly are by no means a homogenous group, they share cohort experiences different from those of younger persons, that will have given a unique “stamp” to their world view, development and values.

This research gathered and compared data about the values of health care professionals and elderly people that underlie health care decisions they made on behalf of hypothetical marginally incompetent elderly individuals. If differences exist, it seems plausible that the care of marginally incompetent elderly clients could be improved by incorporating knowledge of the values and perspective of their contemporaries into decisions and policies made on their behalf by health care professionals, and the agencies that employ them.

LITERATURE REVIEW

The review of the literature will focus on values that underlay decision-making by elderly people and by health care professionals within the context of the health care system. In the first section values will be defined. Personal, collective, professional and organizational values that underlay health care decision-making will be explored. In the second section studies related to these areas will be examined.

I - VALUES

Values form the bedrock of health care decision-making and contribute to its complexity (McCullough, et. al., 1993). It is now accepted that clinical judgements - by professionals, family members and patients alike - are not purely technical judgements but value-laden (McCullough et al., 1993). Values are indicators of what is held in esteem; they act as standards or beliefs that guide actions and judgements across situations and time (Curtis, 1998). Values and resulting value systems (e.g.: the prioritizing of values), operate at the personal, professional, organizational and collective levels (Curtis, 1998). Personal and collective values will be discussed in the section below. Professional and organizational values will be discussed further on.

1- Personal Values

Everyone, including elderly people and health care professionals, possess personal values. Personal values are values that do not necessarily involve interactions with others, and are expressed by an individual's behaviour is generally aimed at bringing about value satisfaction (Curtis, 1998). Personal values are shaped at a young age within the crucible of structures and institutions that make up a society (e.g.: family, schools, culture, religion, the media, etc). Thus Italian-Canadian Catholics may be expected to share more personal values with each other than with Arabic-Canadian Muslims.

The values developed in childhood may be modified as the individual progresses through the life course, encountering new experiences, ideas and knowledge. New meanings for old

concepts (e.g.: "life", "family", "aging") are always being constructed, and we are constantly re-evaluating our values against the new paradigms that emerge. How our values change (or don't) with the influence of social trends will depend on our individual "value lense" through which we view the world. Everyone, to a greater or lesser degree, is affected by changes in collective values that evolve throughout our lives, and in this sense value systems are dynamic.

2- Collective Values

There are a number of competing social discourses that represent different "sets" of collective values that form the parameters of health care of the elderly. These discourses create a cultural and social backdrop against which health care decisions are made by both elderly clients and health care professionals. In this section some of the current social discourses pertinent to the care of the elderly will be discussed.

Bioethical values (particularly autonomy) frame debates about ethical dilemmas and value conflicts that occur in the context of health care decision making (Kaufman & Becker, 1996). These values, and issues related to them, through well publicized cases such as those of Karen Quinlan and Sue Rodrigiez, are in the public sphere.

Autonomy, paternalism, non-maleficence and beneficence have become the cornerstones around which ethical decision-making in health care takes place. With trends, however, like deinstitutionalisation, "client-centeredness" and a transformation of "patients" to "consumers",

autonomy has become the "correct" value (Collopy, Dubler, and Zuckerman 1990). Autonomy is the notion of self-determination, of freedom and liberty of choice concerning the various aspects of one's life (Clark, 1997).

Ethical conflicts in health care are often framed as dilemmas between the principle of autonomy vs the traditional paternalistic model of health care. Paternalism is the view that we can sometimes override a person's wishes wants or actions in order to benefit, or prevent harm, to that person (Beauchamp & Childress, 1979). Paternalism has a long history in the care of the elderly, with physical restraints, forced feeding, and "tricking" people into long term care facilities, not being uncommon. Although paternalism is largely considered the antithesis of autonomy and therefore "bad", Pullman (1999) contends that long-term care necessarily entails ever increasing degrees of paternalistic interventions as physical and mental functions deteriorate. He believes that paternalism can be justified and may even be required when individuals lack the capacity to make autonomous choices.

The tension between beneficence and autonomy guides much of the thinking about the care of vulnerable people (Madigan, Checkland, and Silberfeld 1994). The principle of beneficence maintains that we ought to prevent harm, remove harm and promote good or well being; the principle of autonomy directs us to honour the preferences of the client (Browne and Sweeny 1995.) Conflict can arise between these two principles when what the client wants appears to be harmful to her, (e.g. a frail elderly person in a hospital, admitted for the third time following serious falls, insists on returning home where she lives alone). The principle of

autonomy would say we ought not to interfere with her choice, while the principle of beneficence says we should.

The principle of non-maleficence is defined as the obligation to do no harm, and its thrust is expressed in two statements "Do not intentionally or knowingly injure the patient" and " Do not intentionally or knowingly expose the patient to unjustified risk" (Kluge, 1992). This would imply that when we allow persons with known cognitive impairment in reasoning to make decisions on their own behalf, and we then regard their decisions as autonomous, we are bordering on, if not guilty of, maleficence.

There is some question about the utility of a bioethical framework in resolving ethical dilemmas encountered in long term care practice. Certainly, bioethical values, because they dominate the health care system and the media, are germane to any discussion of values that underlay health care decision making. However a number of gerontologists (Clark, 1991, 1997; Collopy, 1988; Kaufman, 1994; Kaufman & Becker, 1996; Pullman, 1999), have suggested that bioethical decision-making frameworks developed in the crisis oriented high-tech life-and-death environments of acute care may have limited relevance to the world of long-term and/or chronic care in which many elderly people dwell. In the context of long term care for the elderly ethical dilemmas are less likely to be about life and death crises, but rather about day to day life and decisions about the use of community services or where to live. Clark (1991) observes that overemphasis on autonomy for the frail elderly may neglect the values of community, collectivism and interdependence, also important to people.

Kaufman & Becker (1996) note that in clinical decision-making in health care, the bioethical principle applied is usually the "autonomy paradigm" which places supreme value on the client's autonomy, generally understood as "unequivocal self-reliance" . They observe that this autonomy framework is often in conflict with another framework commonly applied to health care delivery to older persons: the biomedicalization of aging.

The biomedicalization of aging has been identified by Estes & Binney (1989) as a dynamic, complex and multidimensional process that socially constructs aging as a decremental physical decline, and equates it with illness. When aging becomes medicalized, personal and social problems and behaviours come to be viewed as diseases or medical problems, that health care professionals are mandated to treat (Kaufman & Becker, 1996). The elderly are especially susceptible to medical management of their lives once old age is equated with illness and dependency (Estes, 1979). Chappell (1988), states that a medical focus assumes a biomedical model of health and illness, and that this perspective further assumes that disease is accounted for by deviations from the norms of measurable biological variables. Medical care and treatment are defined primarily as technical problems; the goals of medicine are viewed in terms of technical criteria. According to Chappell (1988) the Canadian health care system is really a medical (or illness) system, organized around the services of physicians, and around institutional care (both acute and long-term). Within the medical paradigm, physicians remain the dominant definers of illness and health, controlling or influencing hospital admissions, prescribing of drugs, ordering of tests and recommending return visits.

The cultural ideals of personal autonomy and freedom from institutional constraint and domination compete for expression in health care decision making, with a contrary demand for biomedical science to thwart or manage aging. Kaufman and Becker (1996) state that an almost permanent tension exists between safety and supervision on the one hand, and risk and independence on the other, as a result of the competing medicalization and autonomy paradigms.

The notion of "at risk" is another concept that has entered the field of health care discourse about the care of the elderly. "At risk" is often invoked to resolve the tension between the medicalization/safety and autonomy/independence paradigms when the decisions of marginally incompetent elderly persons are suspect. Kaufman (1994) points out that this discourse of risk permeates our culture and influences the care of the elderly. She describes a language of risk, need, safety, and surveillance that have arisen as a response to the frailties and chronic conditions of the very old, leading to a focus on the "need" to minimize risks that others perceive as threats to the safety of older adults. Silberfeld (1992) states that there is no formula for drawing a line between acceptable and unacceptable levels of risk, and that risk assessments are largely value laden. He also notes that the notion of risk can become part of an unconscious rhetoric for controlling elderly people and is often at odds with the autonomy paradigm.

A relatively recent paradigm that is being applied to the health care of the elderly is that of "technical rationality", which denotes a "bottom line" and technocratic focus. This perspective

derives its authority and credibility from association with the traditional medical model and its relationship with "science" and "empirical fact", and places the highest value on "objectivity". Schon (1987) describes technical rationality as an important paradigm of professional rationality in health care and health care policy as:

"technical rationality is an epistemology of practice derived from positivist philosophy..... it holds that practitioners are instrumental problem-solvers who select technical means best suited to particular purposes. Rigorous professional practitioners solve well-formed instrumental problems by applying theory and technique derived from systematic, preferably scientific knowledge (p4).

Although technical rationality is purported to be value-neutral and objective, this is arguable.

Moody (1987) rejects the very idea of value-free pragmatism which he describes as,

"An attitude that often amounts to concealing or submerging value-laden decisions behind a facade of technical criteria (e.g. scales to determine entry to facility) - or equally that allows our own values to be buried beneath professional jargon that hides the reality of human choice and responsibility for that choice."(p.8)

Technical rationality deliberately sets about to reduce health care costs; the decisions made to implement this goal are based on values that are foreign to the concept of care, but nevertheless shape what care will be given, and how caring work is done.

To conclude this section, it has been stated that personal and collective values are in a constant state of dynamic interaction. Both elderly people and health care professionals possess personal values and these values are influenced or modified by collective values. A number of competing discourses, each representing a different configuration of collective values that frame the health care system in which elderly people and health care professionals must make decisions, have been discussed. Different values lead to different health care decision-making, and the choices made will influence individuals, policy, professional practice, and ultimately client care.

II-FACTORS THAT MAY DIFFERENTIATE THE VALUES OF HEALTH CARE PROFESSIONALS FROM THOSE OF THE ELDERLY

There are at least three reasons why we might expect the values of elderly people and health care professionals, to differ. These are (1) age cohort differences (2) discipline specific professional values, and (3) organizational values. While elderly persons and health care professionals may share some similar personal values, they come from different age cohorts and their values are quite likely to differ on this basis alone. By definition, health care professionals' practices are guided by values inculcated through their professional socialization. However the decisions made by health care professionals in their practice are also influenced by the values and goals of the health care system for which they work. These factors distinguish them from most of their elderly clients.

1-Age Cohort Differences

The decades in which we spend our formative years might be likened to different cultures, which is recognized in idioms like "generation gap". Even when people come from the same religious or ethnic backgrounds that create commonalities, there can be large cohort differences related to their ages at the time when significant historical events or social change occurred. A cohort is defined as a group of individuals who share societal experiences as they age, experiencing historical events and their consequences together (Chappell, Strain, and Blandford, 1986).

Hofland & David (1990) note that the perceptions of younger caregivers about the values elderly clients hold, often differ markedly from the reality, reflecting different value orientations. They cited findings by Kane and her colleagues (1990) that nursing assistants and elderly residents differed in ranking which aspects of daily life were most important for residents to control.

Most elderly people are part of a cohort where members typically were immigrants from Europe or children of immigrants, raised in rural oriented Canadian society, and seldom attended school beyond junior high. Traditional conservative patriarchal values dominated social and family life, and social norms/standards about the role of women, divorce and reproduction, for example, were very different from today. Many members of this cohort lived through the Great Depression and World War II as adolescents or adults. In contrast, most health care professionals today were born after WW II; most were not immigrants, were

raised in cities, and have at least a Grade XII education. Social norms about marriage, pre-marital sexual relations, gender roles and the role of women have changed dramatically since the advent of TV, the pill, legalized abortion, and feminism, to name a few marker events.

As an example of the impact of how a cohort's societal experience influences the values of the cohort members, consider cohort effects in relation to education. Individuals born at different points in time - such as 1920, 1940, and 1960 - have had varying opportunities for education, while individuals born in earlier years have had less access to education (Santrock, 1995).

There is, according to Oppenheimer (1991), a tendency on the part of health care professionals to view old age too much from the perspective of their relative youth. She observes that it is we "young ones" who assess, study and care for the elderly and write or teach about the problems the elderly experience. She suggests that this might not matter when the material is strictly factual; but where feelings, beliefs or rights are at issue, there is a great deal of room for subjectivity and unexamined assumptions. The likely sources of assumption, she says, are our own second-hand experiences of old age, derived from our observation of our clients - a select group - and maybe friends and relatives. In addition, our opinions of old age are often coloured by our beliefs and wishes about our own old age. They often come down to, "when I'm like that when I'm old, then I hope...." We should question how accurately one can look into one's own future in this way.

On the basis of cohort membership alone we might expect that there will be significant differences in the values of elderly individuals and health care professionals. Individuals within both groups of course may have different values based on differences in for example gender, culture, health, religion and socioeconomic status. Additionally some elderly persons may have health care professional backgrounds and/or share other characteristics with younger health care professionals. Nevertheless the shared experiences of the elderly cohort can be anticipated to have a strong influence on the values underlying the health care decisions they make, and reflect differences in priority from the values of the younger cohort of health care professionals.

2- Discipline Specific Values

A second anticipated source of difference, in values underlying health care decision-making and older adults, is the socialization of health care professionals into their particular disciplines.

Professional socialization can be defined as the acquisition of the knowledge, skills, values, roles, and attitudes associated with the practice of a particular profession. Professional identity is built upon a pre-existing personal identity with unique values that give life meaning and direction (Clark, 1997). Although it is generally assumed that professional values, through the socialization process, are fully integrated with personal values, to what extent this is true for each individual is not known. The professional values of health care professionals, as distinct from personal values, are meant to direct their professional practice.

For example, although I may believe homosexuality is a sinful perversion, as a professional I would still provide my services to these individuals. Professional values are a constellation of values that serve to express and encourage identification with the group's values; in a sense professional values serve as a group's standards (Schwartz, 1990).

The education and training of health care professionals shape their identities, values and norms of practice (Clark, 1997). The process of acquiring a professional identity and norms of practice is an ongoing socialization process that involves interaction between the self and others in the environment. The development of personal and professional values as they relate to patient care is an essential element of this identity (Schon, 1987). As physicians, nurses and social workers are the predominant disciplines influencing care to elderly people within the long term care system, the professional values of these disciplines will be explored.

Traditionally, beneficence and non-maleficence have been the core values of medicine. Recently the patient's right to control the direction of the health care relationship (autonomy) has assumed equal importance, (Kluge, 1992).

Bloom (1989) describes medical education and the socialization of physicians as locked in a struggle between two value systems, the "scientific" and the "humanistic"; the former is described by Clark (1997) as follows:

The "scientific" model entails faith in the rational solution of medical problems, disinterested concern for patient and society, and dedication to competency in practice

and to the community of science. This orientation discounts the social, behavioural and personal dimensions of illness; relegates familial and social dimensions of practice to the periphery; and dismisses ethical issues as simply "matters of opinions" not subject to rational discourse" (p. 108).

Clark argues that the scientific model is the more dominant in medicine, and in fact overshadows the entire health care system. The effect of this model, he contends, is to widen the distance separating the physician and the older patient, making it unlikely that the physician can appreciate the multiple impacts of chronic illnesses on their elderly patients' lives.

Kaufman (1995) found evidence that some physicians do practice medicine from a humanistic perspective. All the physicians she interviewed saw their role to be more multifaceted than the scientific model suggests. These physicians were not however necessarily typical of all physicians. They were all "seasoned" and selected to participate in the study by virtue of their interest in the elderly and that they provided care to a large number of elderly people.

The traditional nurse's view of patients has been one of caring for and undertaking tasks for vulnerable, sick people, and therefore inherently removing or diminishing risk as much as possible (MacMillan, 1994). Fagermoen (1995, in Clark, 1997) identified the core value of nursing as "human dignity" with other values (e.g.: security, integrity, personhood, autonomy, hope etc.) arising from it or aimed at preserving it. The training of nurses leads them to

develop a more holistic view of the patient than that promoted in physician education (Wright & Smith, 1993). Dealing with value conflicts is seen as an integral part of the nursing socialization process. Saarmann, Freistas, Rapp, and Riegel (1992) stress the importance of student nurses' internalizing particular values as part of their identity development as professional nurses.

Traditionally social workers attempt to allow clients to retain as much decision making as possible, and as a group, they are relatively comfortable with the idea of risk, (MacMillen, 1994). Tower (1994) identifies the principle of client autonomy or self-determination and empowerment as dominant values in social work practice. Qualls & Czirr (1988) state that social workers are taught the importance of feelings and relationships; development of self-awareness and the conscious use of self in relationships with others is emphasized. They are trained to broaden the basis for clinical discussion to "rule in" dimensions of problems that might be initially overlooked, rather than the more traditional "ruling out" of information in medical diagnosing. Values, they note, are put at the centre of social work whether with regard to professional-professional or professional-client relationships.

Clark (1997) describes both nurses and social workers as trained to be more holistic and inclusive than physicians, and to participate in the patient's world as a way of understanding patients as individual persons. Client autonomy and beneficence are central values in both nursing and social work, and are reflected in the ethical codes of both professions and in the case management literature (Clemens et al., 1994). Kane (1997) formulated the ethical

conflicts of case-managed care as conflict between individual freedom (autonomy) and social consensus regarding what is "good"/non-harmful (beneficence) in a particular situation.

While health care professionals have discipline specific ethical codes to guide them, the values that make up the codes are not mutually exclusive, meaning that it is not a simple matter of choosing, for example, autonomy over beneficence. A professional may experience value dilemmas in practice as she faces situations where opposing values compete for priority (e.g.: autonomy/risk vs beneficence/safety). Clemens et al., (1994) report that professional ethical codes are inadequate to help social workers, nurses, case managers and physicians with contemporary practice dilemmas.

In summary, health care professionals, through professional socialization, are assumed to have acquired discipline specific values that direct their practice. While their professional values may not differ from their personal values (or from those of elderly persons), it is expected that they are prioritized and applied in prescribed ways in the course of their work, as directed through codes of ethics. In client-centred practice, widely accepted as a basic tenet of health care practice today, professionals' ethical codes direct them to honour the decisions of clients, whether or not they agree with them. In situations where the client is marginally incompetent however, professionals' ethical codes do not provide clear guidelines about how to collaborate in decision-making with the client. As discussed earlier, given the lack of objective standards for capability and risk, the professional's personal values may then come

into play. It is in these ambiguous situations where differences between the values of health care professionals and elderly persons become salient.

3- Organizational and System Values

Health care planning and policy making are normative actions. They define a body of norms that apply to the choices of priorities, organizational methods, settings of goals and the mobilization of resources in a given field of activity (Beland and Arweiler, 1996). The values expressed in organizations' mission or goal statements reflect the philosophy and purpose of the organizations and are meant to guide the work (Curtis, 1998). Curtis states that these values set the standards which form the framework for an organization's daily practices, procedures, codes of conduct and mind set. A consideration of three primary roles of health care professionals - needs assessment, discharge planning, and case management - illustrate this.

An understanding of how "need" is defined may shed some light on how professionals make decisions about what services to offer clients. Essentially, although the care receiver may express "want", it is the health care professionals in their organizational roles that determine whether or not there is "need", how much of it there is, and what can be provided to meet the need (Dill, 1993). Dill observes that the premise underlying needs assessment is that they provide an objective measure of the client's needs, abilities, and limitations, from which the care plan is developed. Belief in the neutrality of needs assessment provides justification for

their use in the "better targeting" of services, which can just as easily mean either restricting or facilitating the use of formal services depending on the political climate in health care.

Dill (1993), in a critical analysis of the model of need assessment currently used in social service programs for the elderly, points out that "organizational imperatives shape the definition of client need while simultaneously obscuring the very process of this social construction" (p. 459). Need is defined as a property of the individual (as opposed to a creation of the organization). It is defined in instrumental terms (i.e., implying that goals can be set that result in the meeting of the needs) and in reference to categories already professionally and bureaucratically defined (i.e., a "need" for home support services). This process does not take into account the client's values. For example, in British Columbia, the long-term care assessor may determine that the client has a need for assistance in bathing, which can be met with home support help. The client may not feel she needs a bath, but would instead like help with dusting; this need, as defined by the client, would not be met as it is not defined as a need by the long-term care program.

For professionals in discharge planning, Proctor, Morrow-Howell and Lott (1993) have reported that ethical dilemmas frequently arise with loyalties split between the hospital and the best interests of the patients. Chadwick and Russell (1989) found that when resources were scarce, the financial concerns of hospitals took priority over quality of care issues in discharge decision-making. An example of this would be when an elderly person is sent home

prematurely to an over-burdened caregiver, without adequate supports, in order to free the hospital bed.

Clemens et al., (1994) in a discussion of case management practices, observed that client self-determination, a value adhered to by the nursing and social work professions, must be balanced against many competing pressures, such as: pressure from families and other professionals, to ensure client safety through placement; pressure from the reimbursement system to contain costs; and pressure from professional and legal responsibility to promote client well-being and protection from harm.

It seems evident that the values that shape the organizations for which health care professionals work, have an impact on their roles. The scope of the professional's authority and decision-making about clients is regulated by the systemic power of the organization. Professionals are on the one hand bound to advocate for the needs of an individual client, and on the other hand accountable to the health care system/organization for resource rationing. Elderly consumers, however, might be expected to be only concerned about their personal needs being met and to value this over, for example, limiting the range of home support services received on the basis of cost containment. Unlike professionals, there is no expectation that they consider other clients' or the systems' needs in making personal health care decisions. It seems quite likely that these differences in the perspectives/values of elderly people and professionals, affect the health care decisions each group makes. There seems

little reason to expect that decisions made by professionals about marginally incompetent elderly persons would reflect the values of these individuals.

Thus far a review of the theoretical literature has revealed that values are an important component in determining the health care decisions made by all individuals, including elderly persons and health care professionals. Further, there appears to be ample reason to believe that the values of elderly people and health care professionals that underlay the decisions they make in regards to health care, are likely to differ, on the basis of personal, professional and systemic factors. This has particular relevance when health care professionals are in the position of making decisions on behalf of, or about the care of, marginally competent elderly persons whose capability to be self-determining is questioned. In the next section the research literature will be reviewed to see if there are studies that support these notions.

III- RESEARCH LITERATURE

In this section studies that relate to values that underlay health care decision making by the elderly and by health care professionals will be reviewed. Firstly, studies about the values of elderly persons will be reviewed, focussing on: values held in relation to aging and to control over decision-making; the influence of values on decision-making; personal values identified in regard to health care decisions; and values that influence service use. Secondly, studies about surrogate decision-making by health care professionals on behalf of elderly persons will be examined, in order to explore the level of agreement between the two groups, and the

values underlying decisions made. Thirdly, studies that directly compare the values of elderly persons with those of health care professionals in relation to health care decisions, will be reviewed. Fourthly, the research literature related to the relationship between the decisions made by health care professionals and the values and demands of the organizations for which they work, will be explored.

1- Values of Elderly Persons

a) Perceptions of Aging

It has been reported that young adults evaluate problematic aspects of aging as more serious than do elderly adults. In a survey (n= 3452), using face-to-face interviews, the researchers asked adult American respondents of all ages to indicate how serious problems such as the following were for elderly persons: not having enough money to live on, poor health, loneliness, inadequate housing, fear of crime, and not enough medical care (Seccombe & Ishii-Kuntz, 1991). Among the elderly, the majority did not perceive these problems to be serious, but among the young, the majority believed each of these problems was serious for the elderly. The data for this study was from a nationally representative sample, obtained by using multistage random-cluster sampling. The population was first stratified by geographic region and size of place in a region, to ensure the participants would reflect the actual proportions of U.S. residents living in different regions and community types. The elderly population was over sampled, and combined into a single group of "over age 65".

In order to identify how the perceptions of aging and concern over problems faced by the aged in the United States vary among age cohorts of elderly persons, Seccombe & Ishii-Kuntz (1991) re-analysed the data from adults aged 55 years and over. They divided this subsample (n=2,329) into four age groups; middle-aged (55-64), the young old (65-74) the old (75-84) and the oldest-old (85+). The oldest old were the most optimistic in their view of aging. The middle-aged adults thought that the issues of money, housing, loneliness, fear of crime and jobs, were serious problems for the aged; the oldest-old viewed these issues as least problematic for the elderly. No differences among age groups were found as to how problematic each group estimated poor health, lack of education, and insufficient medical care, to be for the elderly. The authors concluded that overall the middle-aged are most likely to assume aging is problematic, while the oldest cohort is least likely to think so.

Ryff (1989) in a study of how adults themselves define positive functioning, interviewed 171 middle-aged (M = 52.5 years) and older (M = 73.5 years) community dwelling adults, about their views of the aging process. She asked respondents if they would wish to change themselves or their present life in any way. The most frequent response of older people was that they would change nothing, while this was the least frequent response of the middle-aged. These results suggest that older persons have a more optimistic appraisal of aging than do younger middle-aged adults.

Despite one study (Seccombe & Ishii-Kuntz, 1991) that showed no differences between elderly persons and younger adults in regards to some factors, the same study as well as

another, (Ryff, 1989) found that older people have different attitudes about old age than do younger people. Is it not likely that these attitudes are derived from different values that would also lead to different health care decisions by each group? It might be expected that decisions made by professionals about elderly marginally incompetent individuals would be less likely to reflect the elders' values than would be decisions made by other elderly people. Younger adults appear to have more negative attitudes about being old than do the old themselves. These negative appraisals of being old could lead to paternalistic interventions, or conversely, to therapeutic nihilism, when they make decisions about marginally incompetent elderly persons.

b) Control over Decision Making

Keating et al. (1997) suggest that personal autonomy of elderly people is a contemporary value. The current elderly cohort come from an earlier time when the doctor was a god and benevolent paternalism was at the centre of physician-centred medical practice (Shidler, 1998). Horowitz, Silverstone and Reinhardt (1991) suggest that elderly people place less value on autonomy when it conflicts with safety than do younger people. In a qualitative study of 15 caregiver dyads (one elderly person, one younger family caregiver), the researchers explored personal autonomy issues within the relationships. Five vignettes were used to describe hypothetical family situations involving autonomy conflicts, which provided for direct comparison of caregiver and elder reactions to autonomy dilemmas. Family members were more sensitive to autonomy issues than were their elderly relatives. Older persons were primarily concerned with ensuring the health and welfare of the elders in the vignettes, even

forcibly, and saw these concerns as overriding questions of self-determination or personal choice.

Other studies suggest the amount of information and control elderly people want is different from that wanted by younger people, or than is assumed by health care professionals. Strull, Lo and Charles (1984) administered questionnaires about three aspects of decision-making to 210 hypertensive outpatients and to their 50 clinicians, who represented three types of medical practice. They found that physicians underestimated their elderly patients' desire for information and discussion, but overestimated their desire to make decisions. More recently Beisecker (1988), in a comparison of information and decisional control preferences of older and younger people, found that while elderly patients wanted as much information as younger patients, they felt the physician should make the decision; younger patients preferred joint decision-making. Older patients were less likely than younger patients to express attitudes that challenged physician authority. In a scenario-based study (n=71) evaluating patient involvement in medical decision making and factors that influence their choices, Bradley, Zia and Hamilton (1996) found that age was a significant predictor of preference for control. Increased age was related to increased emphasis on the physicians as primary decision maker, and decreased age related to increased patient control.

Wetle, Levkoff, Cwikel and Roen (1988) found, in relation to decision-making about resuscitation (i.e., DNR), that about two-thirds of 198 nursing home residents interviewed believed the medical information they received was adequate. Seventy-one percent of the

residents, who were NOT involved in decision-making by their own account, thought that this was the right level of involvement. Nurses over-estimated the residents' actual involvement in decision-making. The same study found that only 61.4% of residents wished to be involved in the DNR decision for themselves.

Kelner (1995) interviewed 38 hospitalized elderly patients about their attitudes generally and personally, about exerting control over end-of-life decisions. When asked generally about how much control elderly people should have over end-of-life decisions, 19 individuals said that patients should have control, while 17 individuals thought that end-of-life decisions should be delegated to physicians, god or fate. In contrast to these findings, when participants were asked about how much control they personally would want over end-of-life decisions in relation to themselves, 27 individuals wanted control over at least some of the decision-making, while the remaining 11 still preferred to delegate control. This study highlights a discrepancy that may occur between what a person thinks is best for others compared to what she might choose for herself.

Together these studies suggest that elderly people, while wanting as much information as younger people, place less value on autonomous decision-making than do younger people, or than professionals think they do. When making value-laden decisions about marginally incompetent elderly persons, each decision-maker will likely be influenced by the value they place on autonomy for themselves. Professionals might be expected to support higher level

of autonomy/independence for a marginally incompetent individual living at risk, for example, than would be their elderly peers.

c) Influence of Elderly Persons' Values on Decision Making

That the values of elderly people underlay their health care decision making is demonstrated by a study by Schonwetter, Walker, Solomon, Indurkha and Robinson (1996). Their research found that certain life values play a greater role in elderly people's decision-making process about specific medical situations, than others. In order to study the relationship between life values and resuscitation preferences, 132 people over age 63, living independently, were asked to make decisions about accepting or rejecting resuscitation for themselves in five hypothetical situations. The percentage of respondents desiring cardiopulmonary resuscitation (CPR) in each scenario was as follows: current health condition of respondent (66%); acute illness (33%); terminal disease (8%); functional impairment (8%); and dementia (7%). As well, through structured interview questionnaires, participants were asked to assess and rate two general and 11 specific life value statements in terms of their importance for their medical decision-making (near the end of life). Five meaningful life value factors were identified; quality of life; capacity/autonomy; family relations; physical comfort; and treatment philosophy. Those who wanted good quality of life over increased length of life, regardless of quality, chose less CPR in the scenarios where they were not in their current state of health, but where there was acute illness and dementia. Those who valued capacity/autonomy and those who felt strongly about family relations wanted less CPR in scenarios of normal cognition and functional impairment. Those whose treatment philosophy

wanted a comfortable death chose less CPR in the scenarios of terminal disease and functional impairment with normal cognition. This study indicates that the values of elderly persons contribute to how they make specific health care decisions.

Lawton, Moss, Hoffman, Grant, Have, and Kleban (1999) studied how the value that elderly persons place on their life influences the health care decisions they make about treatment or end-of-life. The researchers developed an affective-cognitive schema (VOL, valuation of life), and investigated its' relations to elderly people's responses on a set of health utility (years of desired life) questions. VOL was defined as the extent to which the person is attached to her present life, for reasons related to a sense of enjoyment and the absence of distress, but also hope, futurity, purpose, meaningfulness, persistence and self-efficacy. Data were gathered from 600 people over age 70 representing the entire continuum from excellent to poor health. An interview schedule inquired about health, family, friends, activities, mental health and content relating to the prospect of the end of life. Ten vignettes were presented, using combinations of functional health, location, cognitive function and pain, and respondents were asked to state how long they would like to live (YDL) under each circumstance. Cognitive loss was the most eroding of the impairments on YDL- two thirds or more of the elderly participants would not wish to live any longer under all levels of cognitive impairment or in pain conditions that imply a loss of awareness.

d) Values Identified by Elderly Persons

Degenholz, Kane and Kivnick (1997) developed a brief protocol for exploration of client values, which was administered by 60 case managers in a Midwestern state and a Western state in the course of their usual client interviews. The researchers found that elderly consumers of community long term care, when asked to rate the importance of various choices related to the care they might need, attached the greatest importance to choices related to privacy and family involvement, and to freedom and safety. The question about the tradeoff between freedom and safety called for a discrete choice between "safety and protection" and "freedom to come and go" and for a qualitative elaboration. In the Midwestern state (n=421) 49% of clients preferred to have the freedom to come and go, while 41% preferred to accept some restrictions and be safe. In the Western state (n= 410) 62% of clients preferred to come and go while 26% preferred restrictions to be safe. By and large the researchers noted that the tradeoff between freedom and safety generated considerable ambivalence for clients who really want both. Clear differences were apparent across individuals. Privacy for example was highly rated as "very important" by 55% of respondents in the Midwestern state and 65.7% in the Western state. Privacy, however, had different meanings for different individuals: (e.g.: general privacy, personal/body privacy, financial and social privacy).

Raymond and Wentworth (1993) used a naturalistic multiple case study method to explore the views of four elderly home health clients regarding safety and autonomy. Participants viewed autonomy as the ability to make decisions, the right to in-home services, and the

importance of family and friends in promoting autonomy and safety. They did not view autonomy and safety as contradictory.

Many seniors describe the most important component of their quality of life as their independence (National Advisory Council on Aging, 1992). Mack, Salmoni, Viverais-Dressler, Porter, and Garg (1997) asked older adults (n=103) to explain why it was important to remain living in their homes. Respondents identified the following reasons:

- 1) desire to maintain current levels of independence which meant freedom to come and go, control over daily activities, not wanting to burden others (83%)**
- 2) maintenance of a sense of identity (feeling comfortable/safe; familiar setting; own things; history) (53%)**
- 3) able to continue hobbies/activities (20%)**
- 4) space for belongings (8%)**

In a phenomenological study of elderly widows' lived experiences, Porter (1995) found that the women spoke of independence in terms of (1) creating their own schedules, (2) deciding how tasks would be done, (3) getting out into the community. Independence in terms of Activities of Daily Living (ADLs) was not their goal (or definition of independence). Instead their goal was to continue living alone at home.

In a study, (published after the data were collected for this study), the decision-making capacity of 51 persons aged 39- 89 years with mild to moderate cognitive impairments, was

examined (Feinberg and Whitlatch, 2001). The researchers found that participants could respond consistently to questions about preferences, choices, and their own involvement in decisions about daily living. Their results suggest that in spite of cognitive impairment, the perspectives of cognitively impaired persons should be given serious consideration in making decisions that concern them. (Had these results been available prior to the present study, mild to moderately cognitively impaired elderly persons would have been sought as participants in the research.)

Together, these studies demonstrated that if asked, elderly people are willing and able to articulate and prioritize the values they consider important in making health care decisions. The values that elderly people hold may influence decisions they make about using health services, as discussed below.

e) Values That Influence Service Use by Elderly Persons

Scott and Roberts (1985) note that elderly caregivers may decide not to use health services due to negative values they hold about receiving help or due to fears of loss of independence. Research by Kaufman (1994) found that some elderly people who used formal services felt that service providers were invasive and interfered with personal routines. For couples, preserving marital privacy may be a more important value than obtaining assistance. There is also reason to believe that elderly people may be reluctant to use formal services due to cultural values related to dependence, conceptualized in negative terms in western society, and equated with the use of formal services (Arber and Evandrou, 1993; Johnson, 1990). The

results of a study by Aronson (1993) suggest that some elderly persons may suppress or hide their needs to avoid being a burden on family or stigmatization as dependent. If, then, program design and delivery are not congruent with the values of elderly persons, it appears they will be reluctant to seek or accept services.

There is evidence that elderly persons' values do have impact on their decisions about using health services. King, Collin and Liken (1995) interviewed 34 elderly caregivers of people with dementia in an effort to understand how their values were linked to their decisions of whether or not to use informal or formal services to assist them. Four themes in the values expressed by caregivers were identified : (1) family boundaries govern help seeking - i.e. family looks to family to care for family; (2) families are owners of difficulties - problems within the family should be dealt with by the family and not become a problem for others; (3) families are protectors of vulnerable members - those outside the family cannot be trusted to provide the same kind and quality of care as family; (4) families are self-reliant units - caregivers don't want to accept assistance from other people when they don't feel able to reciprocate.

Taken together the foregoing studies demonstrate that the elderly can describe and order their values, and they use these values in making health care decisions.

To conclude this section, the research literature demonstrates that elderly people have a heterogenous array of beliefs, preferences and values about a number of issues, such as their

own aging, decisional control, surrogate decision-making, the care that they receive, and the components of good quality of life. Elderly individuals are able to identify and prioritize their values, and they use their values to make healthcare decisions. Prior to the evidence of the recent study by Feinberg and Whitlatch (2001), it was assumed that marginally incompetent elderly persons were not be able to articulate their values and/or defend them. This belief has left the door open for others to impose their values and decisions upon marginally incompetent individuals. In these instances other elderly people would be likely to make different decisions for them than would younger health care professionals. Although there are differences within the elderly age cohort, these differences are likely to be less than those between elderly persons and younger health care professionals. It seems plausible that the decisions of other elderly people, as opposed to professionals, would be more congruent with the decision these individuals would once have made themselves.

2- Values of Health Care Professionals

The hypothesis that health care professionals and elderly people may have different values from each other, in part on the basis of cohort differences, gains some support from studies of family members as surrogate decision makers on behalf of their elderly relatives. If cohort differences do not exist between younger and older groups, we might expect family members to make accurate surrogate decisions on behalf of elderly relatives, because family members generally share values derived from their common ethnic, religious and socio-economic backgrounds. Such is not the case. Zweibel and Cassel (1989), Seckler, Meier, Mulvihill, and Cammer (1991), Hare, Pratt, and Nelson (1992), Gerety, Chiodo, Kantan, Tuley, and Cornell

(1993), Tsevat, Dawson, Wu, Lynn, Soukup, Cook, Vidaillet, and Phillips (1998) all conducted studies about surrogate decision making by family members for their elderly relatives, using hypothetical health care situations. Overall, the results demonstrated that younger family members do not make the decisions the elderly person would make for herself. The most obvious difference between the elderly and the family members is membership in different age cohorts. It is reasonable to assume that health care professionals, generally part of the same age cohort as the younger family members, will share similar cohort related personal values. Thus, it is plausible that cohort differences could contribute to health care professionals making inaccurate surrogate decisions for elderly people that do not reflect their values.

Health care professionals are further distanced from the elderly by virtue of their professional values and roles. There is little reason to expect that the values of professionals that underlay the health care decisions they make, would be the same as those of older people. The following studies about surrogate decision making bear this hypothesis out: health care professionals do not tend to make the same decisions that elderly persons would make for themselves.

Research into quality of life by Pearlman & Uhlmann (1988) found differences in how chronically ill elderly people and physicians defined quality of life. Elderly people thought quality of life "good enough" if they had no major complaints, regardless of the objective severity of illness. Physicians rated the patient's quality of life worse than did the patient. Otto,

Dobie, Lawrence, and Sakai (1997) undertook a retrospective assessment of the self-reported impact of laryngectomy on the quality of life of 46 patients, as compared to the perceptions 13 health care professionals held about the impact the laryngectomy had on their patients' quality of life. Using the "time trade off" method it was found that 46% of health care professionals perceived that their patients would be willing to exchange a reduced life-span in order to preserve their voice, compared to only 20% of patients who would be willing to do so. These results suggest that the quality of life for most laryngectomy patients, as they appraise it, is substantially higher than their health care providers believe. The findings from these two studies suggest that elderly people and physicians hold different values from each other about what makes for quality of life.

Miller and Bolla (1998) found that physicians and other health care professionals may underestimate the perceived quality and enjoyment of life of the elderly, especially under adverse clinical conditions. This is borne out by a study by Seckler et al. (1991) where the surrogate decisions of physicians were compared to the decisions of their currently competent chronically ill elderly outpatients, (n=70), using two hypothetical CPR scenarios where the patient was in two different health states - current health or a state of diminished capacity. Most patients preferred resuscitation. These individuals' physicians were no more likely than chance to make the same decision as the patient did. In both scenarios, the physicians would have withheld care that their patients wanted, significantly more often than providing care that patients didn't want. In this study it appears that physicians underestimated the quality of life of their elderly patients (thus withholding treatment), compared to the elderly person's

own appraisal of her quality of life (thus choosing treatment). When the quality of life of elderly persons is underestimated, under treating or "letting them go" may result. Marginally incompetent elderly persons are particularly vulnerable to such attitudes as they are relatively voiceless and powerless.

In a retrospective study of former intensive care patients age 55 and older, and their physicians, (n=76 pairs), were asked through structured interviews, to determine how valuable they believed intensive care would be to the patient under actual and ideal circumstances (Danis, Gerrity, Southerland, and Patrick 1988). Patients and family members were extremely willing to have the patient receive intensive care under actual and ideal circumstances, even for one month of prolonged life, with no significant difference in willingness between the two groups. Physicians considered intensive care more useful under ideal rather than actual circumstances. In order to examine the possibility that physicians' personal preferences might influence the assessments they make for their patients, they were asked about their own willingness to undergo intensive care. Their responses indicated that the physicians appeared to use their own life circumstance, in part, as an ideal standard for their patients. Physicians' perspectives on the value of intensive care for their elderly patients may differ because they are younger and healthier than patients, and have a different view of the disease process (Starr, Pearlman & Uhlmann, 1986). Such differences could influence the decisions they would make for marginally incompetent elderly individuals who would fall well below the ideal standards of the physicians in this study.

Ouslander, Tymchuk and Rahba (1989) compared the treatment preferences of 70 elderly nursing home residents with the predictions of 11 nursing home professionals providing care to them (i.e., four nurses, two social worker and five physicians). Residents were asked to make healthcare decisions after being presented with four clinical vignettes. Two vignettes involved high risk procedures (aortic valve replacement and carotid endarterectomy) and two were low risk (flu vaccination and psychotropic medication). The health care professionals were asked to predict the choices that each resident would make. Overall the professionals were shown to have low levels of accuracy in predicting their elderly patient's wishes. The lowest agreement found was between what the physician thought the resident would choose for the two high-risk vignettes, and what the elder actually chose. Elderly residents choose the high risk procedures more than the physicians thought they would.

To summarize, there is considerable evidence that health care professionals make different decisions than the elderly would for themselves, perhaps accounted for by differences in each groups' beliefs about what makes a life worth living. It seems reasonable to assume that the health care professionals in these studies are likely to be in better health, generally, than the elderly, about whom they are making decisions. The same could also be assumed about the younger family members and independently living elderly persons who made surrogate decisions about less healthy elderly individuals, in other studies cited earlier. This raises the notion that the value of being healthy could negatively colour the evaluation made by healthy decision-makers, about the quality of life of persons who are less healthy than themselves. Decision-makers in all these studies were, it appears, making surrogate decisions on the basis

of their own values and using themselves (and their own health) as a reference point. The discrepancy between their own health and that of the surrogate may have made it difficult for them to imagine that they (or the person for whom they were deciding) could have a satisfactory quality of life, when less healthy or able. As a result healthy decision-makers who participated in the studies reported here, recommended less care for the surrogate than the surrogate would want for themselves. Some support for this hypothesis is found in other studies cited earlier, where chronically ill elderly (Pearlman & Uhlmann, 1988) and laryngectomy patients (Otto et. al., 1997) rated their quality of life as better than did their health care providers, and where nursing home residents chose higher levels of intervention than physicians thought they would want (Ouslander et. al., 1989). In essence, it appears that the greater the discrepancy between the health of the decision-maker and the health of the surrogate, the less likely the decision-maker is to recommend as much care as the surrogate would choose for herself.

The pertinent common thread in these studies is that professionals consistently underestimate the quality of life experienced, and the level of treatment desired, by their elderly patients. This has particular implications for marginally incompetent elderly persons who are doubly stigmatised and devalued in society. They are highly vulnerable to having their quality of life underestimated by professionals who may use what is important to themselves, to judge the quality of these individuals' lives. Such under-valuation will shape the decisions made about, and the care provided to, marginally incompetent elderly people. Is it possible that, based on their misperceptions, professionals may provide less care to marginally incompetent elderly

persons than these individuals would want, on the premise perhaps of not prolonging their suffering?

In the next section, these ideas are amplified by the results of two studies that directly compare what the elderly value with what health care professionals value.

3- Comparison of Values of Elderly Persons and Professionals

McCullough and colleagues (1993) used a mapping methodology to identify values that respondents retrospectively found to be relevant to the long term care alternatives they considered at a time when they had changed their living situation and/or had started receiving help with personal care due to functional changes. In this study the researchers "mapped" the self-reported values of the three most common participants in the long term care decision-making process: elders, involved family members and health care professionals. Respondents, (24 elderly people, and 23 family members and 13 professionals identified by the elders as involved in the decision), were interviewed using semi-structured questions to elicit a description of the decision-making process, and the self-reported values that respondents found relevant to the long-term care alternatives they had considered. Interviews were audio taped and transcribed, and then analysed to discover themes and patterns.

Thirty-six generic values were identified relating to such areas as environment (e.g., to be in a familiar setting), and care (e.g., to have reliable care). Both generic values and subcategories of values identified by each of the three groups showed similarities and differences of values.

(Values identified were overlapping between and among groups, as are the numbers following). For the whole sample 86% of the elder's generic values were also identified by family; 82% of family members' generic values were also identified by elders; 66% of the professionals' generic values were also identified by both elders and family, and 19% were identified by elders or family. In comparing the top three categories of generic values for each group, differences are noteworthy. The elderly persons top-listed values concerned environment (privacy and mobility), self-identity and relationship. Family members chose care (i.e.: supervision), security and psychological well-being as their top categories. Care, physical health and psychological well-being were the top categories identified by the professionals. Elders seemed primarily focussed on maintaining continuity of self amidst change, while family and professionals seemed focussed on caring for the elder's safety.

Overall value-mapping indicated that elderly persons have values and priorities of values other than health-related values. The number of values generated by each group suggests that the decision making process about long-term care options has complex value-related dimensions.

Research by Kane et al. (1997) discovered that health care professionals and elderly clients have different ideas about what needs the elderly have, and the relative importance of different functional impairment to elderly clients. In a survey of 27 professionals, representing the variety of health care disciplines involved in long term care, the professionals were asked to rate the relative importance of both activities of daily living (ADL) and instrumental activities of daily living (IADL) domains, and the levels of function within each domain, in terms of

their contribution to the overall disability of clients. A convenience sample of 51 older clients (unknown to the professionals), living in sheltered housing attached to nursing homes, were asked the same questions. In general the clients rated impairment in IADL functions (eg: abilities to make phone calls, manage finances), as most detrimental to their independence, while the professionals thought that impairment in ADLs (eg: transferring, bathing), was more detrimental to clients' independence. The professionals underestimated the importance of dependency in IADLs, and overestimated the importance of the inability to perform basic ADLs, to the clients. These findings bring into question the ability of (these) health care professionals to assume that clients share their values about what impairments are most important to clients, and therefore what care they want. The results also suggest that professionals cannot reliably represent the values of clients.

4- Organizational and System Values

Health care professionals work within a value-laden context wherein goals and objectives are established which impact the provision of ensuing services (Curtis, 1998). Studies around common roles and functions of health care professionals are illustrative of this.

Kaufman (1995) undertook a descriptive anthropological study exploring the nature of decision making of 40 physicians whose practices involved the care of old people who reside in the community. She found that their clinical decisions were influenced by professional values and institutional constraints. Physicians identified the value-laden nature of risk assessments and experienced tension in trying to balance risk reduction with the patient's right

to make independent choices, including being left alone. Some physicians faced pressure and criticism from other health care professionals when they attempted to support patient choice at the expense of safety. Other physicians experienced ethical dilemmas in supporting patients' choices when it meant not treating treatable conditions.

In a review of discharge planning by Pottoff, Kane and Franco (1997), constraints imposed by time pressures, stress and insufficient information were noted. It was also observed that conflicts that arose between patients, their families and discharge planners, while framed as decisions about facility vs home care, are really issues of values that underlie these service preferences. For example, an elderly woman hospitalized after a fall, may place a higher value on maintaining her independence by returning home, than on being safe in a facility. Family may value her safety highest and want facility placement for her. The professional may feel that the length of stay in hospital to rehabilitate her for independent living is too costly, and should outweigh her preference. Malony, Finn, Bloom, and Andersen (1996) in a study of decision-making for hospitalized elderly people in need of long term care, found that crisis-oriented decision-making tended to occur and frequently led to facility placement. Wells (1997) conducted a critical ethnography of the process of discharge decision-making for elderly patients to examine the process over the total course of the patient's stay in hospital. The focus was describing the timing and conditions of decision-making, the related activities of professionals, professionals' perception of the process, and the effects of the process on those involved and on the hospital organization. She found that,

"the process is not intricately linked with patients' clinical progress, that often inaccurate assumptions about the importance of patient-related clinical and social factors and organizational parameters underlie decisions, and that the professionals' perceptions of the process are shaped by organizational imperatives. In the current process, resources are used inefficiently and humanitarian and ethical consequences arise for all participants," (p 683).

Further support for the idea that the decisions and actions of professionals are affected by the values and demands of the organizations they work for, is found in another study of the discharge planning decision-making process in an urban hospital, conducted by Clemens (1995). Forty discharge planners and 40 family caregivers of high-risk elderly patients were surveyed for their perceptions of their influence on the process, and about the amount and adequacy of information, choice, and time in the discharge planning decision. The study examined how these perceptions differed among the three groups. It was found that the professionals greatly overrated caregiver influence, the amount and adequacy of shared information about post-hospital care (i.e.: choice of discharge to home or nursing home), and the time given patients to decide. Family members reported that the discharge planning process was coercive. A caregiver\care receiver who feels coerced may accept services against her will (i.e., placement), or may reject services all together.

Another study, conducted by Clemens et al. (1994) also supports the importance of including an understanding of professional and organizational needs in trying to explain health care

decision-making by health care professionals. They conducted qualitative interviews with case managers to determine the extent to which client centred theory (which values ethical principles of autonomy and self-determination) is incorporated into case management practice. They found a number of differences between reported client-centred theory and directive practice, which they organized into themes; (1) client wishes vs system constraints; (2) the paradox of working to keep people at home vs the perceived inevitability of nursing home placement; (3) client centeredness vs the case manager's care plan; and, (4) client self-determination vs strategies of persuasion. These researchers found that case managers expressed commitment to the principle of client self determination and freedom but frequently acted against autonomy (e.g., persuaded, coerced, manipulated) to maximize safety. The results of this study provide empirical evidence that organizational constraints and professional roles influence the decisions that are made about the elderly in opposition to the individual professional's commitment to the autonomy of the elderly.

A major influence on health care professionals' decision making is the concern about the cost of services to the elderly, especially in the community. Case-managers are expected to keep individual costs down as much as possible in order to protect the budget for all users and taxpayers. Although in the USA the profit motive in health care increases the financial accountability of case-managers and agencies compared to Canada, the conflict that case-managers experience in their dual roles as patient advocate and gatekeeper are instructive.

Hennessy (1989), using qualitative methods, studied the extent to which a client's choices are incorporated in care decisions within On Lok, a prepaid community-based long-term care program. Decision criteria used by the program's multi disciplinary team regarding client autonomy included indicators of risk to client stability and limits on organizational resource capacity. Generally the case management strategy for managing risks to the individual's ability to remain in the community, was to maximize risk reduction by using the least restrictive and intensive care plan options. Client choice was found to be primarily constrained by internal program limits in managing the care of the whole On Lok population. Under conditions they assessed as low-risk the team could honour the client's wish and meet the agency's need for a reasonable cost. As client risk rose, self-determination could decrease in importance in light of the care needs (i.e., cost) of the program's total population. This study showed that the agency's need for cost-containment underlay the healthcare decisions made by health care professionals about the long-term care needs of individual clients.

To summarize this section, research evidence exists to show that the values that underlay health care decision making by health care professionals are influenced by the values and goals of the health care system/organization for which they work.

In conclusion, personal, professional and systemic values were explored, and found to influence health care decision making. Elderly people were found to make health care decisions based, at least in part, on their values. Health care professionals were found to make decisions based on a mixture of personal and professional values, and their decision making

was also influenced by values and pressures inherent in the systems for which they work. It was found that health care professionals, within their professional roles, do not attribute the same importance to particular values as do elderly people, and thus make different surrogate decisions. This is problematic given that they are often in positions of making judgements and decisions when competence is questioned. Decisions about when and how to intervene in the lives of these individuals are value-laden. The literature reviewed suggests that professionals and elderly people may have different perceptions about the circumstances under which intervention in the lives of marginally incompetent people is warranted.

IV - STATEMENT OF HYPOTHESES

Differences in values between elderly persons and health care professionals (HCPs) underlie the long term care decisions made for a hypothetical marginally incompetent elderly person .Specifically:

- 1- When faced with a marginally incompetent elderly person, other elderly persons will rate her as less safe than will HCPs.
- 2- Overall, elderly people will rate the risks of harm to a marginally incompetent elderly individual as higher than will HCPs.
- 3- Elderly people will choose institutional care for a marginally incompetent elderly individual more frequently than will HCPs.

4- For both the elderly respondent and HCP groups, the less safe a marginally incompetent individual is rated, and the higher the risks to the individual are rated, the more likely that institutional care will be selected as the appropriate long-term care choice.

5- Elderly people will be more likely to choose institutional care for a marginally incompetent individual on the basis of burden to others, than will HCPs.

6- Elderly people are more likely to over-ride a marginally incompetent individual's refusal of recommended services than are HCPs.

7- When a marginally incompetent individual refuses the care choice recommended for her, elderly people will choose a higher level of intervention than will HCPs.

8- For both elderly respondents and HCPs, the higher the risks to a marginally incompetent individual are rated, the higher the level of intervention that will be chosen if the individual refuses what is recommended.

9- Elderly people are more likely than HCPs to change their recommendation of community care for a marginally incompetent individual to institutional care, if her worried children want her placed in a facility.

V - FOCUS OF THE RESEARCH

The focus of the research presented here was to compare the values of health care professionals and elderly persons that underlay the health care decisions that they made on behalf of a hypothetical marginally incompetent elderly individual, under varied conditions.

VI - PROPOSED MEASURES OF VALUES AND RELATED HYPOTHESES

A marginally incompetent elderly woman living "at risk" was chosen as the focus of a scenario about which the research participants would make decisions. As discussed earlier, when clients are marginally incompetent, health care professionals are without clear guidelines about how to collaborate in decision-making with them. In the absence of clear roles and responsibilities in these situations, the ordering of values inherent in codes of ethics may not provide direction for professional behaviour, such that the decisions made are likely to reflect some blurring of the clinician's personal and professional values, (Kaufman, 1995; Clemens & Hayes, 1997). The presence of "risk" in the scenario, a subjective notion, assessed differently by each observer on the basis of values and personal tolerance for ambiguity (Clemens et al., 1994) increased the likelihood of value-laden decision making.

The scenario duplicated as much as possible, the circumstance under which health care professionals must make decisions on behalf of marginally incompetent individuals. Firstly, the scenario depicted a marginally incompetent elderly woman, who could not provide clear competent directions to guide the research participant's decision-making, but preferred to remain as she was. Secondly, a number of potential harms (risks) to this individual were built into the scenario, which participants were asked to assess. Thirdly, the individual was depicted as refusing the services participants recommended for her. Fourthly, the individual's burdened children were introduced and depicted as wanting their mother placed in a long term care facility for her safety, despite her objections.

Clark (1991) points out that many people do not consciously make health care decisions on the basis of their values. He suggests that while people can provide reasons for why they make particular decisions, even if asked, many people cannot articulate the values that underlie their decisions. Horowitz et al. (1991), in a scenario-based study of autonomy, noted that people did not explain their choices in terms of concepts like autonomy, beneficence or paternalism, but rather in terms of safety, rights and obligations. Therefore, for the purpose of data collection in this study, rather than directly asking respondents which values led to a particular decision, questions that reflect values, (e.g: autonomy, beneficence, non-maleficence, paternalism, and interdependence), were asked about the health care decisions that they made about a hypothetical marginally incompetent individual.

A series of questions to elicit the values underlying the decisions respondents made about the marginally incompetent individual, were developed. The questions were based on information derived from the literature review describing: values held by elderly persons, their families and health care professionals in regards to long-term care decisions (McCullough et al., 1993; King, Collin, and Liken 1995); values held by elderly persons and their families in regard to conflicts between the autonomy of elderly people vs. their health and safety needs, (Horowitz et al., 1991); the value that elderly community dwelling persons place on the tradeoff between freedom and safety, (Degenholtz, Kane, and Kivnick 1997; Raymond & Wentworth, 1993); the experience of risk to independent living as perceived by community-dwelling elderly persons, (Mack et al., 1997; Porter, 1994); how health care professionals balance safety and autonomy for elderly clients at risk (Clemens & Hayes, 1997; Kaufman, 1995); expectations

by policy makers that family members provide care (Keating et al., 1997); elderly persons' concerns about burdening family (Porter 1994; Horowitz et al., 1991; Aronson, 1990).

Frequently elderly individuals with a dementia living alone come to the attention of health care professionals when it appears they are "at risk" or unsafe, but adamant about remaining at home (Tuokko, MacCourt, and Heath 1999). Both the ratings of risk and safety, and what action is believed required on the basis of the judgement of risk and safety, are value-laden (Silberfeld & Fish, 1994). In this study respondents were asked to rate a marginally incompetent woman's safety and the risks to her, to determine whether or not there are differences between health care professionals and elderly people as to how they appraised/judged the individual's safety and the risks to her.

Perceptions of risk and safety as they affected the decisions made were also explored. After respondents rated the risks facing the marginally incompetent woman, they were then asked to decide what kind of care was best suited to her needs. For the purposes of this research, a choice of facility implied paternalism, a choice of community implied beneficence, and a choice of no care implied autonomy. Paternalism is defined as the view that we can sometimes override a person's wishes, wants or actions in order to benefit or prevent harm to that person (Beauchamp & Childress, 1979). In the paternalistic model, the professional ought to decide what counts as "best interest", and ought to make whatever decisions have to be made (Kluge, 1992). A choice of facility care in this study is the most intrusive and invasive care choice that participants can make, and therefore best represents paternalism. The choice of

community care best represents beneficence on the part of respondents. The principle of beneficence is to prevent harm, remove harm and promote good or well-being (Browne & Sweeny, 1995). Beneficence stops short of overriding a person's wishes, (in the study scenario the individual's desire to remain at home), and is thus differentiated from paternalism. Autonomy is equivalent to self-determination (Kluge, 1992). For the purpose of this study the value of autonomy is manifested when respondents do not interfere with the preference of the individual depicted in the scenario, either forcibly or by manipulation or persuasion, and recommend no care. The interpretation of these concepts are not inconsistent with those made by Collopy, 1998, Horowitz et. al, 1991. In summary, with these definitions in mind, the higher that the risks were rated and/or the lower her safety was rated, the more likely it would seem that respondents would act paternalistically and choose safety/facility care for the individual. If instead the respondents chose community care or no care for the individual this would imply that the highest value was placed on beneficence or "right to live at risk"/autonomy, respectively.

Horowitz et. al (1991) found that elderly people were more likely than younger adults to over-ride an elderly person's decision when they felt the person's health or safety was in jeopardy. To explore this, the scenario was presented to the respondents a second time but they were asked to imagine that the marginally incompetent individual has refused the care they recommended for her. Respondents were asked to re-evaluate their original recommendation for the individual's care in light of her refusal. Respondents then chose between respecting her wishes (demonstrating autonomy), forcibly placing her in a facility to

ensure her safety (demonstrating paternalism), or trying to persuade or coerce her into accepting care for her own good (demonstrating beneficence).

The value of interdependence was also explored in this study. Respondents were asked to rate how much the original care decision they made was influenced by the burden that they perceived the marginally incompetent individual placed on her family and friends. Those respondents who rated the influence of burden highly would appear to place a high value on interdependence, in that they looked beyond the individual's rights and preference alone, to consider the impact of her choice on the rights of others involved in her care. They recognized that the individual had obligations as well as rights and these could be in competition with those of her significant others.

Horowitz et al. (1991) found that some elders were willing to curtail the autonomy of a hypothetical elderly person on the basis of the burden she placed on her children. To explore this, a second question was designed to find out whether respondents would consider altering their original care choice for the marginally incompetent individual on the basis of her concerned/burdened children's wishes. If respondents did change their care choice this implied that they place a higher value on interdependence than on individual autonomy. That is, in this study, these respondents appeared to favour the rights of the children for peace of mind against their mother's right to self-determination. The type of intervention then chosen by these respondents (i.e., those who were willing to change their decision) revealed either beneficence or paternalism. Their decisions was interpreted as beneficent if they persuaded

the individual to accept either community or facility placement, and paternalistic if they forced her to enter a facility.

METHODS

The method chosen to conduct this study was a survey, utilizing a questionnaire designed for the purpose. There are both advantages and disadvantages to this methodology, which will be discussed below.

A survey method had the advantage of being convenient and time efficient, for both the participants and the researcher. Questionnaires were sent to senior's centres and organizations where health care professionals were providing care to older adults. Individuals who chose to participate were able to make the decision to do so without out any form of pressure. They were able to fill out the questionnaire where and when they wished, and could be certain of anonymity. The questionnaire was made up primarily of closed-ended and forced-choice responses, with only a few spaces left for open-ended responses. By structuring the questionnaire in this manner, participants might have felt the time commitment involved in answering the questions would be very short, and as a result be willing to participate in the study. In that there was no direct contact between participants and the researcher, the researcher could not unintentionally influence participants either to participate or in how to answer the questions. From the point of view of the researcher, a survey method by mail-out and drop-off allowed for many questionnaires to be distributed broadly in a very short time period. There was no

time invested in meetings, explaining the study, or in meeting the participants. Questionnaires were returned by mail and the data were available immediately as each questionnaire arrived. The fact that the questions were almost all closed-ended and forced-choice response meant that the data could be readily entered into the SPSS data file.

There are several disadvantages of a survey method. From the researcher's point of view a mail-out survey is costly. The response rate may be low and sample representativeness limited. This method does not allow for personal contact, which reduces the likelihood that potential respondents will participate. In that there is no opportunity for participants to clarify questions about the study, they may choose not to participate if they have unanswered questions. Without opportunity to question the researcher it is possible that some participants may misinterpret the questions, providing invalid and unreliable responses. A questionnaire presupposes a certain level of literacy in English that can not be determined for individual participants, again possibly leading to invalid responses. When there are missing responses the researcher is not able to go back to the participant. Without contact between the researcher and participants, there is no guarantee that the questionnaires arrive where they are intended to go, with perhaps ineligible people filling them out. An additional disadvantage is that those who choose to actually respond (or not) to the survey may make their choice on the basis of particular characteristics unknown to the researcher. Those who do participate then, may not be representative of the population, and could bias the results. For example, perhaps senior's who have low levels of education may choose not to do a pen and paper questionnaire.

I - PARTICIPANTS

Two groups of adults took part in this study; HCPs (N=87) and elderly people (N=82). The HCPs were recruited by distributing an information letter about the research with the questionnaires to professional associations, medical clinics, health units and hospitals. Approximately 200 packages were distributed, of which 88 were returned completed. Similarly, about 200 packages were distributed to seniors' associations and recreational centres, of which 86 were returned completed. Four of the elderly person and one of the HCP questionnaires were discarded as they were incomplete. The sole criteria for participating in the study for HCP was that they were employed in health care and aged 65 years or less. The only criteria for elderly participants was that they were over the age of 65 and lived in the community. No efforts were made to ensure that either group was representative of either a select group or all HCPs, or a select group or all elderly persons. All participants were self-selected and participated freely and anonymously in the study.

II - SAMPLE CHARACTERISTICS

1- Elderly Participants

The characteristics of the elderly sample, in regard to age, sex, marital status, living situation, health, education, past employment and income are presented in Table 1 to 3.

Table 1**Age, Sex, Marital Status of Elderly Persons**

Age		Sex			Marital Status		
Range	66 - 92	Female	73.2%	60	Married	54.9%	45
Mean	72.89	Male	26.8%	22	Widowed	25.0%	21
Median	71				Sep/divorced	14.8%	12
					Never married	3.7%	3

As can be seen 73.2% of respondents were female. Although the predominance of women is not surprising, given that women live longer than men (Martel and Belanger, 2000), and there are more community-dwelling older women than men (Lindsay, 1999), the proportion is. A large proportion of the participants in this study (35%), as will be presented below, had worked in health care, which is dominated by women.

Most of the participants were married (54.9%), and the majority lived with a spouse (54.3%), or other family member (1.4%). This is congruent with Lindsay's findings that most Canadian aged 65 and over are married and the majority of seniors live with immediate or extended family. The proportion of widows who participated in this study (25%), compared to other studies, seems low. Possibly this could be accounted for by the fairly young age of the seniors who participated in this study, and the fact that they were community dwelling.

Table 2
Living Situation and Health of Elderly Persons

Living Situation			Health		
With Spouse	54.3%	44	Excellent	23.2%	19
Alone with helpful family	29.6%	24	Good	55.7%	44
Alone without helpful family	13.6%	11	Average	12.75%	10
With other family	1.4%	1	Poor	6.3%	5
In facility	1.4%	1	Very Poor	1.3%	1

Almost all of the respondents reported good health. The majority rated their health as good or better (78.9%), while very few claimed poor health (7.6%). In a report on senior women in Canada, Lindsay (2000) stated that only 5% of senior women living in the community described their health as less than fair.

Table 3
Education and Work History for Elderly Persons

Education			Work History			Work History In Health Care		
College/Univer	48.8%	44	Professional	55%	40	Total	35%	28
High School	36.3%	29	Office Worker	25%	20	Nurse	16%	13
< High School	15.6%	12	Homemaker	12.5%	10	Other*	13%	10
			Service Industry	7.5%	6	Nurse Aid	6.2%	5
			Labourers	5%	5			

**"Other" is comprised of 5 office workers, 2 housekeepers, 2 social workers, 1 occupational therapist.*

Very few of the participants had not completed at least Grade 12 (15.6%), with the majority (48.8%) having gone on to college or university. The reported educational attainment of the sample is considerably higher than that of the general senior population, and could reflect where study participants were recruited from. Lindsay (2000) reported that in Canada in 1996, only 6% of women and 11% of men over age 65 had completed a university program. Sixteen percent of senior women had completed some other form of post secondary training, while six in 10 had never completed high school. Most of the participants (80%) had been white-collar workers which would be expected given the over-all high levels of education achieved by the group. Over half of all participants (55%) identified themselves as professionals. A very small number (12.5%) had never worked outside of the home. This is in contrast to Lindsay's finding that in 1999, 22% of all senior women and 3% of senior men had never worked outside of the home.

Over one third of participants had at one time been employed in in the health care sector, primarily as professionals. Almost one quarter of all participants had worked with older people prior to their retirement. The proportion of elderly respondents who have been employed in health care seems high; participation in a study related to their past employment may have attracted them. The participants who were employed as health care professionals in the past could have tended to draw on their past experience to respond to the study questionnaire, had not the information sheets about current services been provided. The high proportion of elderly participants with past training and experience as health care providers may have an influence on this study. For this group of elderly participants, whether the

decisions they make in this study reflect their prior professional values or their age. will have to be explored, post hoc.

Respondents were asked whether or not they received the British Columbia guaranteed annual income supplement (GAIN), as a measure of low income. Lindsay (2000) reported that in Canada in 1997, 24% of senior women and 12% of senior men lived in a low-income situation. The income of most (55%) participants was not supplemented by the receipt of GAIN, which would be expected given their educational and occupational backgrounds. This said though, it was surprising that close to half (45%) of the participants did receive GAIN.

Respondents were asked about their experience as caregivers to a family member, and whether or not they had received community or facility services for themselves. Table 4 displays the information gathered.

Table 4

Care Giving Experience: Elderly Persons

Care Giving Provided			Relationship of Care Receiver			Years Care Provided	
Never	73%	54	Parent	42.1%	8	N Respondents	10
In past	20.3%	15	Spouse	31.6%	6	Range	2-58
Currently	6.8%	5	Other	26.3	5	Mean	31.7
						Median	49

The majority of respondents (73%) had never been a caregiver to a family member with a dementia. Of those who had provided this care (27%), it had most often been to a parent. Caregiver respondents provided care to a family member for an average of three years. Most frequently (58.8%) the care receiver had lived with them.

Just under half of the family members respondents cared for had received community care (40%) or facility care (45%). Almost all of these respondents (92% in each case) felt the care had been appropriate.

Respondents were asked if they, personally, had ever received community or facility services, and if so how satisfactory they were. Only 13 participants had ever received community services themselves, and of those who did almost half had been dissatisfied with the services. Only four participants had ever received care in a facility and most (75%) were very dissatisfied with the service.

Although the sub-sample of respondents who ever received community or facility care themselves is small (n=13), a striking trend is apparent. These respondents reported much higher levels of dissatisfaction with the care they received, than those expressed by participants about the appropriateness of services received by their family members. This trend is supported by the results of a study by Miller and Bolla (1998), reported earlier, where physicians chose a higher level of health care intervention for themselves than they did for their elderly patients, in the same hypothetical circumstances. It appears that more is expected for oneself than for an other.

2-Health Care Professionals

The characteristics of the HCP sample in regards to age, sex, and marital status is displayed in Table 5.

Table 5

Age, Sex, and Marital Status for HCPs

Age		Sex			Marital Status		
Range	26-65	Female	85.1%	74	Married	84.9%	73
Mean	46.8	Male	14.9%	13	Separated/div	7.3%	6
Median	47				Never married	4.7%	4
					Widowed	3.5%	4

Health care professionals (HCP) ranged in age from 26 to 64 years old, but their mean and median age was 47 years. Only one quarter of the HCPs were age 40 or under. The sample seems consistent with concerns about the aging baby boom work force in health care. Almost all of the respondents were female (85.1%) which is not surprising, as women make up the bulk of the most common health care professions. The vast majority of respondents (84.9%) were married.

Respondents' professional discipline and information about their work in health care was gathered, and is displayed in Tables 6 and 7.

Table 6
Discipline and Practice Areas of HCPs

Professional Discipline			Currently Practising		
Nurse	58.8%	50	Community	39%	32
Physician	18.9%	11	Facility	25.6%	21
Social Worker	9.4%	8	Acute Care	28%	23
Other*	18.8%	16	Other	6.1%	5

The respondents were primarily nurses (58.8%), followed by physicians (18.9%) and social workers (9.4%). There were 4 occupational therapists, 3 psychologists, 2 physiotherapists, 2 recreational therapists, 2 psychologists, and 3 unspecified professionals. The majority of the health care professionals (39%) described their current practice as situated in the community.

Table 7
Years in Areas of Practice for HCPs

	Professional		Total		
	Practice	With Elderly	Community	Facility	Acute Care
Years	1.5 TO 43	1 TO 35	0.4 TO 29	1 TO 21	0.5 TO 35
Mean	19.15	13.18	9.74	8.43	12.5
Median	20	12	8	7	11

Respondents had, on average, practised their professions for 20 years, twelve with elderly persons. On average, throughout their careers, health care professionals in the sample had worked between eight and 12 years in each of facility, community and acute care settings. (These numbers are not necessarily mutually exclusive).

Respondents were asked whether or not they had provide care to a family member with a dementia, and about their experience with community and facility services. Their responses are displayed in Table 8.

Table 8
Care Giving Experience of HCPs

Care Giving Experience						Years Care Provided	
Care Provided			Relationship			N Respondents	7
Never	80.7%	67	Parent	81.3%	13	Range	0.04-21
In past	12%	10	Sibling	18.8%	3	Mean	82.4
Currently	7.2%	6				Median	24

Most HCPs (80.7%) had never been an informal caregiver for an elderly relative with dementia, but of those who had (19.2%), the care receiver was most frequently a parent (81.3%). The majority of care giving respondents cared for their family member for about three years, (as did elderly caregivers). Just over half (56%) had provided the care in their own home.

The majority (75%) of family members cared for by HCPs had received community services, and 77% of the them reported that the care was appropriate to their relative's needs. The majority (63%) of family members had also received facility care, which most (83%) of care giving HCPs found appropriate to their family member's needs.

III- RESEARCH DESIGN

The study was designed to allow for the comparison of the care choices that a group of elderly respondents and a group of health care professionals made for a marginally competent elderly woman living alone "at risk". The design afforded the opportunity to evaluate the influence of particular factors (e.g., risk and safety ratings; influence of burden on others and wishes of children; refusal of service) on the care decisions made by each group.

Methods developed by Kelly, Knox, and Gekoski (1998) were modified for use in this study. Kelly and her colleagues surveyed 434 women between the ages of 18 and 92 years of age about the long term care choice (community or facility care) they felt appropriate for a hypothetical elderly woman. Scenarios were varied by the functional and cognitive status of the hypothetical person, and by their informal social support, to yield six versions which were randomly distributed to respondents. The researchers did not ask the respondents on what basis they made their particular choice for the hypothetical person.

The task of the respondents for this study, as in the Kelly et al. (1998) study, was to choose community support services, institutional services or no services for a hypothetical elderly marginally incompetent woman, (to be referred to as Mrs. Smith), based on what they thought was most appropriate for her given the description of her situation and the information provided about both forms of service in their region. The information component will be discussed below.

The scenario was varied and re-presented three times. The first time the scenario was presented respondents were asked to rate the safety of an elderly marginally incompetent woman, (Mrs. Smith), and the specific risk factors that could threaten her ability to live alone. Respondents were then asked to make a recommendation for community, facility or no care for her. The second time the scenario was presented, respondents were asked to imagine that Mrs. Smith has refused the care they recommended for her. They were then asked to re-evaluate Mrs. Smith's situation in light of her refusal, and to choose between forcing or persuading her into a facility or respecting her wishes. For the third presentation respondents were asked to imagine that Mrs. Smith's worried children requested that she be placed in a facility to protect her. They were then asked to reconsider their original care choice for Mrs. Smith and to choose between forcing or persuading her to accept facility or respecting her wishes.

IV - MATERIALS AND PROCEDURES

1- Ethical Approval

Ethical approval was obtained from the University of Victoria prior to beginning the research. Consent to participate in this study was implied by virtue of respondents returning their questionnaire to the researcher. No identifying information was requested and questionnaires were mailed to the researcher.

2- Data Collection

Data were collected between September and December 2000. Packages were distributed to potential respondents that included information about the research (Appendix B); an information sheet about community and facility care (Appendix C); and a questionnaire (Appendices D, E and F) and a stamped addressed envelope. There were no face to face interviews undertaken.

Data were entered into the SPSS statistical program, which was employed for data analysis.

V- INSTRUMENTS

Each participant was given an information sheet about community and facility care, and data were gathered via a questionnaire. What follows is a description of these instruments.

1-Information Sheets

In order to ensure that respondents based their decisions on current and accurate information about community support services and institutional care, they were asked to read two information sheets prior to filling out the questionnaire. Based on information sheets designed by Kelly et al. (1998) for use in Ontario, an information sheet about cost, eligibility, living accommodations and services available in British Columbia, was developed. The information was corroborated by an administrator of a long term care facility and by two long term care case managers. The information sheets were then reviewed by four health care professionals working with elderly people, in respect to objectivity of information and presentation. Finally, after making some minor revisions, the information was given to a

convenience sample of four elderly individuals, to ensure that the information was understandable to elderly people.

In order to ensure content validity one administrator and two long term care case managers were asked to rate the information sheets, using a five point scale (1=poor, 5=very good), on each of the following dimensions: accuracy of information; clarity of presentation; and, objectivity of presentation. The other health care professionals and the elderly persons were asked to rate the information sheets only on the basis of clarity and objectivity of presentation. When ratings of 100 (i.e., 5 on the scale) on each dimension were achieved, the information sheets were distributed.

2-Scenario

One of Kelly and her colleagues' scenarios was used as the basis for developing a scenario for this study, (Appendix A) As the focus of this study was a marginally incompetent person, the chosen scenario was based on moderate cognitive impairment. The level of cognitive impairment was based on descriptions from Zuckerman (1991, in Kelly et al., 1998) and items taken from the Memory and Behaviour Problem Checklist (Zarit & Zarit, 1982, in Kelly et al, 1998). A modification was made to the scenario for the present study, based on the Global Deterioration Scale developed by Reisberg, Ferris, de Leon, and Crook (1982). In order to maximize value-laden decision making, the scenario was further modified to depict a hypothetical elderly woman as living alone, without nearby helpful family.

3-Questionnaire

The questionnaire, a self report, consisted of three sections (Appendices D, E and F). In the first section demographic information was gathered (e.g., age, sex, marital status, and education), for both groups. Discipline, years of experience with elderly persons and primary place of employment, (e.g., community, institution), was gathered only for the HCPs. Living situation, health status, income and past employment, was gathered only for the elderly participants. The second section, for both groups, assessed respondents' personal experience caring for elderly family members with a dementia and their experience with community and facility care. The third section, presented the scenario of Mrs. Smith, (discussed above), about which respondents were asked assess her situation, and to make decisions about her care based on variations to the scenario.

VI - INSTRUMENT VALIDATION

To ensure that the scenario was realistic and reasonably representative of a typical elderly person with a cognitive impairment living alone, the scenario and questionnaire were presented to a multidisciplinary group of four psychogeriatric clinicians (two nurses, a physician and a social worker). They were asked to rate the scenario on a five point scale (1=poor, 5=very good) in terms of it's: representativeness of their clients; and clarity of presentation. The scenario was distributed when a rating of 100 was achieved (ie: 5 on both dimensions).

The questionnaire (along with the validated information sheets and scenario) was then administered to a convenience sample of four elderly persons. They were asked to rate each question on a five point scale (1=poor, 5=very good) on the basis of clarity. A discussion with the writer followed about any areas of ambiguity that arose, and this discussion was used to refine the questions as needed. Once a rating of 100 (5 on the scale) was reached the questionnaire was administered to three Home Support Supervisors and to four (different) psychogeriatric clinicians (but still two nurses, a physician and a social worker), following the same process used with the elderly participants. When a rating of 100 (5 on each scale) was reached by this group, all the materials were distributed to the study sample. None of the participants involved in validating the instruments participated further in the research.

VII - STATISTICAL ANALYSIS

The literature review suggested that differences in values between elderly persons and health care professionals would underlie the long term care decisions each group makes for a hypothetical marginally incompetent elderly person. A between-groups design to examine this general hypothesis was used in this research. The *Statistical Program for the Social Sciences* (SPSS) was employed for the data analysis.

The level of measurement for some of the data is nominal and ordinal, for which non-parametric statistics were used. In order to determine relationships between categorical variables, chi square tests were used.

Ordinal variables (e.g: level of risk, safety) that were measured using Likhert scales of 1-5., were treated as though the level of measurement was interval. These variables were treated as though the "distance" between each of the points on the scale were exactly the same, (which in reality can not be determined). These variables were treated as though the level of measurement was interval, to enable parametric statistics to be used to test the relations between these variables and others. An underlying assumption of parametric tests is that variables are normally distributed. In order to ensure that this assumption would not be violated, frequencies of the relevant variables were conducted. The variables were found to be normally distributed.

Frequency tables, means, medians, range, modes, and standard deviations were calculated on the variables identified. Correlations were used to measure the direction and strength of the associations of interval variables. The two groups were compared using t-tests. The use of a t-test requires that the sample be drawn from a normally distributed population, which was the case in this study. However, even if the population is not normal, violating this assumption would have had only a minor effect on the t score computation (Bohnstedt and Knoke, 1994). T-tests are used for measured variables in comparing the means of two independent samples. In this study one tailed t-tests were used because the direction of differences between groups was hypothesized.

Analysis of variance (ANOVA) allows comparison of the means for more than two groups.

In the calculations of F-tests, means, the sum of squares, degrees of freedom, mean squares and F tests were generated, for between groups and within groups.

Multivariate analysis of variance (MANOVA), was used to compare the means for a series of continuous variables between the two groups. MANOVA allows for the inclusion of any number of dependent variables and two or more groups in the analysis. MANOVA was chosen instead of multiple regression since the study hypotheses were framed as between groups comparisons. Frequencies, means, and the sums of squares, degrees of freedom, mean squares, and F- tests, between and within groups, were calculated. Omnibus tests were inspected to determine whether, over-all, the groups differed on all of the independent variables. Where the omnibus test was significant, the contribution of independent effects were examined.

An alpha (probability) level for rejection of the null hypotheses was set at .05 (that is, one chance in 20). Setting alpha level at .05 means that the chance of making a Type 1 (or false rejection) error is also .05. Reducing the chance of making a false rejection error could be accomplished by setting alpha at a lower level, but this would tend to increase the likelihood of making a Type 2 (or false acceptance) error. Bohrnstedt and Knoke (1994) state that false acceptance errors can be offset by increasing the sample size or by replicating the study using another independently drawn sample. As neither of these strategies were practical, the risk of Type 1 errors was accepted.

The sample size of 169 is sufficient for this study, as the power calculation conducted for Hypothesis 1 (Elderly persons will rate the safety of a marginally incompetent person lower than will HCPs), illustrates. A two group t-test with a 0.050 one-sided significance level will have 95% power to detect the difference between a Group 1 mean, \bar{D}_1 , of 2.253 and a Group 2 mean, \bar{D}_2 , of 2.256, (a difference in means of -0.003), assuming that the common standard deviation is 0.006, when the sample sizes in the two groups are 87 and 82, respectively (a total sample size of 169).

VIII - SUMMARY

In this chapter the methodology selected to investigate the hypotheses derived from a selective review of relevant theoretical and research literature, was discussed. The participants, design, procedures, instruments, and statistics employed in the study were described. The methods employed were chosen to test hypotheses related to care choices and the impact of specific factors, as well of underlying values, on the decisions made by each group. In the next chapter the results are reported.

RESULTS

The analysis of the data collected for this study consists of a statistical comparison of a group of elderly persons with a group of health care professionals in terms of the care decisions they

make on behalf of a marginally incompetent individual (Mrs. Smith), under varied conditions. Results were considered significant if an alpha of .05 was reached.

I - RESULTS FOR THE RESEARCH HYPOTHESES

Hypothesis 1: Elderly people will rate a marginally incompetent individual as less safe than will HCPs.

This hypothesis was not supported. No significant relationship was found between group membership and the ranking of a marginally incompetent individual's safety.

A one-tail t-test was used to test the relationship between group membership and the appraisal of how safe Mrs. Smith was perceived to be. Elderly persons appraised her safety between "somewhat unsafe" and "very unsafe" (M 2.256, SD .766). HCPs also appraised her safety between "somewhat unsafe" and "very unsafe" (M 2.252, SD .702). The difference between groups was not significant, ($t(df\ 163) = -.028, p\ .488$)

Hypothesis 2: Overall elderly people will rate the risks higher than HCPs.

There is little support for this hypothesis. Elderly people rate only the risk of poor hygiene higher than do HCPs.

First, a one-tail t-test was used to test the relations between group membership and the overall risk rating (RISK 1), created by adding the six individual risk factors into one variable.

Elderly persons rated the over-all risk between "medium risk" and "substantial risk" (M 22.911, SD 4.267), while HCPs rated them slightly lower (M 22.290, SD 4.141). The differences between groups was not significant, ($t(df\ 161) = -.947, p .172$)

All risk factors were ranked between medium risk (3) and substantial risk (4) by both groups. The order in which risk factors were ranked by elderly respondents and HCPs differed, as displayed in Table 9.

Table 9

Mean Ratings of Risk Factor by Group (1=HCP; 2=ELDERLY)

Risk	Group *	Mean	Std. Dev.	N
Not receiving help quickly enough if falls or sick	1.00	4.2907	0.9925	86
	2.00	4.4937	0.7489	79
	Total	4.3879	0.8875	165
At risk for victimization (crime)	1.00	3.2442	1.4628	86
	2.00	3.6709	1.4476	79
	Total	3.4485	1.4667	165
Risk from isolation/loneliness	1.00	3.7791	1.0221	86
	2.00	3.5823	1.0204	79
	Total	3.8648	1.0229	165
Risk of not eating properly	1.00	4.4070	0.7727	86
	2.00	4.0253	0.8161	79
	Total	4.2242	0.8141	165
Risk of/from poor hygiene	1.00	3.1860	1.2972	86
	2.00	3.5823	1.0932	79
	Total	3.3758	1.2165	165
Risk of self injury	1.00	3.3837	1.2095	86
	2.00	3.5570	1.2377	79
	Total	3.4667	1.2224	165

Second, a multiple analysis of variance (MANOVA) was computed that compared membership in two different groups, (i.e: elderly participants and HCPs) on each of six

dependant variables (not receiving help quickly; crime; isolation; not eating properly; poor hygiene, and self injury) simultaneously. There were no co-variates. A main effect of group membership ($F(6, 165) = 5.624, p .000$) on the rating of risk factors was observed.

There were significant relationships found between group membership and 2 of the risk factors. HCPs (N 86) rated the risk of not eating properly as a significantly higher risk (M 4.407, SD .772) to Mrs. Smith than did elderly persons (N 79), (M 4.025, SD .8 (16). The difference between groups was statistically significant ($F(1, 165) = 9.519, p .002$). Elderly participants rated poor hygiene as a significantly higher risk (M 3.5823, SD 1.093) to Mrs. Smith than did health care professionals, (M 3.1860, SD 1.297). The differences between groups was statistically significant ($F(1, 165) = 4.460, p = .036$).

Hypothesis 3: Elderly people will choose institutional care more frequently than HCPs.

This hypothesis was supported.

A chi-square was used to test for significant differences between groups in making a long-term care choice. There was a significant relationship ($\chi^2(1, 167) = 16.973, p < .001$) found between group membership and the long-term care choice made, with 37.8% of elderly respondents selecting institutional care compared to 10.6% of HCPs. The majority (76%) of all respondents chose community care for the individual. No participants selected "no care" for her.

Hypothesis 4: For both groups, (1)the lower safety is rated and the higher risk is rated, (2) the more likely that institutional care will be selected as the appropriate long-term care choice.

Some support was found for this hypothesis. It was found that the lower safety was rated (i.e. the less safe the individual was perceived to be), the higher the risk to her was rated. There were significant relationships between specific risks and care choice for each group and for groups combined. There was a significant relationship between safety and care choice for the combined groups.

The analysis to test this hypothesis was conducted in two parts. First, the relations between risks and safety ratings (by all respondents) was explored by examining correlations between each of the risk factors, over-all risk (ie: Risk 1, the sum of the individual risk factors); and safety (i.e. how safe the individual was perceived to be).

With the exception of crime, significant negative correlations were found between safety and all individual risk factors. All correlations were significant at the 0.01 level, except for poor hygiene at 0.05. The less safe respondents rated the individual, the higher they rated the risks to her.

Table 10

Intercorrelation Between Risks and Safety for Combined Groups

	Risk 1	safety	self-injury	poor hygiene	not eat properly	isolation	crime	help not quick
Risk 1								
safety	-0.462**							
self-injury	0.596**	-0.535**						
poor hygiene	0.657**	-0.178*	0.232**					
not eat properly	0.662**	-0.324**	0.324**	0.365**				
isolation	0.673**	-0.348**	0.307**	0.361**	0.543**			
crime	0.543**	-0.099	0.087	0.155*	0.144*	0.117		
help not quick	0.732**	-0.350**	0.349**	0.435**	0.421**	0.457**	0.295**	

** Correlation is significant at the 0.01 level (1-tailed).

* Correlation is significant at the 0.05 level (1-tailed).

Second, MANOVA were used to examine relations between care choice and risk/safety within each group, and between groups. Findings for each group will first be reported separately and then the differences between groups will be reported.

(i) The HCP group was first examined. To explore whether or not the care choice made by HCPs was associated with how they rated risk and safety, a MANOVA was computed that compared two groups (i.e: HCPs who chose community care and HCPs who chose facility care) on each of seven different variables (i.e: safety; self injury; poor hygiene; not eating

properly; isolation; crime; not getting help) simultaneously. There were no co-variates. Results of the omnibus test did not show a main effect of care choice on the risk and safety ratings ($F(7, 84) = 1.478, p .188$), suggesting that over-all there is not a significant relation between the care choice made by HCPS and how they rated safety and risk measures. There were however significant relations found between the care choice and not receiving help quickly ($F(1, 84) = 5.324, p .024$); and, risk from poor hygiene ($F(1, 84) = 7.387, p .008$). The higher these risks were rated, the more likely facility care was recommended.

(ii) The elderly group was next examined to see whether the care chosen for the individual was associated with how they rated safety and risks. A MANOVA was computed that compared two groups (i.e: elderly participants who chose community care and elderly respondents who chose facility care) on each of seven different dependant variables (i.e: safety; self injury; poor hygiene; not eating properly; isolation; crime; not getting help quickly) simultaneously. There were no co-variates. The omnibus test results ($F(7, 79) = 1.476, p .190$) did not show an over-all main effect of care choice on the risk and safety measures. There were, however, significant relations found between the care chosen by elderly respondents and the risk of not eating properly ($F(1, 79) = 6.082, p .016$); and the risk of poor hygiene, $F(1, 79) = 6.804, p .011$). The higher these risks were rated, the more likely that facility care was chosen.

(iii) Both groups were examined together to see if the care chosen by respondents was associated with the risk or safety measures. A MANOVA was computed that compared two

groups (i.e: all respondents who chose community care and all respondents who chose facility care) on each of seven dependent variables (i.e: safety, self injury; poor hygiene; not eating properly; isolation; crime; not getting help quickly) simultaneously. There were no covariates. The omnibus test showed an over-all main effect of risk and safety measures on care choice ($F(7, 163) = 3.011, p = .005$). Significant relations were found for the combined groups (i.e., elderly and HCPs) between choosing facility care and several risks: risk from not receiving help quickly, ($F(1, 163) = 4.082, p = .045$); poor hygiene ($F(1, 163) = 17.032, p = .000$); and risk of self injury, ($F(1, 163) = 5.741, p = .018$). There was also a significant relation found between the choice of facility care made by respondents and the safety measure ($F(1, 163) = 4.732, p = .031$).

Hypothesis 5: Elderly people will be more likely to choose institutional care on the basis of burden to others than will HCPs.

Some support was found for the hypothesis. Elderly people reported feeling more influenced by the burden Mrs. Smith placed on others, than did HCPs, but they did not make a long-term care choice on this basis.

A 2x2 analysis of variance (ANOVA) was used to explore the relations between care choice and the influence of burden rating, with group (elderly persons and HCPs) and care choice as between subject factors.

The main effect of group (i.e., being elderly vs a HCP) was significant ($F(1, 161) = 29.81, p .000$). HCPs who selected community care for Mrs. Smith appraised the influence of "burden on others" on their decision as between "insignificant" and "mild" (M 1.534). In comparison, elderly respondents who chose community care appraised this influence as between "mild" and "quite a bit" (M 2.562). Of those choosing institutional care, HCPs appraised the influence of burden on others as "insignificant" to their decision (M 1.00), and elderly appraised this influence as "quite a bit" (M 2.967). The contribution of the influence of burden on the care choice is however quite small ($F(1, 161) = .200, p .656$). This was to be expected in that a significant relations between group membership and care choice was demonstrated in Hypothesis 3.

Overall HCPs believed that their long-term care decision for Mrs. Smith was less influenced by the burden she placed on family and friends, than did the elderly. In neither case was there a significant relation found between the influence of burden and the care choice they made for her.

Hypothesis 6: Elderly people are more likely to over-ride a marginally incompetent individual's refusal of recommended services than are HCPs.

There was some support for this hypothesis. It was found that elderly respondents were more likely to over-ride the Mrs. Smith's refusal of care, but only if their original care choice for her had been facility care.

Chi-square tests were used to determine whether or not there was a relation between group membership and willingness to over-ride Mrs. Smith individual's refusal to accept either of the original care choices recommended (ie: community or facility care).

First, only respondents (N 127; 68 HCPs, 47 elderly, 12 missing) who originally recommended community care for Mrs. Smith, were included in this analysis. A chi-square test was conducted to examine the relations between group membership and over-riding Mrs. Smith's refusal of community care by force, persuasion or coercion. Fifty-eight (85.3%) HCPs were willing to over-ride Mrs. Smith's refusal, while only 10 (14.7%) chose to respect her wishes. Thirty-seven (78.7%) of elderly respondents over-rode Mrs. Smith's refusal, and 10 (21.3%) did not. No significant relations were found between group membership and willingness to over-ride Mrs. Smith's refusal of recommended community care, $\chi^2(1, 115) = .835, p = .361$, with both groups being willing to over-ride her refusal.

Second, only those respondents (N 40, 24 elderly, 7 HCP, 9 missing) who originally chose facility care for Mrs. Smith were included in this analysis. A significant relation, $\chi^2(1, 31) = 6.348, p = .012$, between group membership and willingness to over-ride Mrs. Smith's refusal of recommended facility care was seen. A greater percentage of HCPs (71.4%), compared to elderly persons (20.8%), would respect Mrs. Smith's refusal of recommended service. Twenty-eight percent of HCPs and 79.2% of elderly would now force, persuade or coerce Mrs. Smith individual into a facility.

Hypothesis 7: When a marginally incompetent individual refuses the care choice recommended for her, elderly people will choose a higher level of intervention than will HCPs.

This hypothesis was not supported. Whether the original care choice was community or facility, there was no significant difference found between group membership and the level of intervention chosen for Mrs. Smith when she rejected the original care choice made for her.

To test for differences between the HCP and elderly groups, chi-square tests were used. Only those who originally chose community care for Mrs. Smith were included in the first analysis. The choices made by these respondents for Mrs. Smith if she refused the recommended care (i.e., place in facility; persuade her to accept services; respect her wishes; other), were examined by group membership. There was no significant relations found between being either elderly or an HCP and the level of intervention chosen when Mrs. Smith refused recommended community care ($\chi^2(3, 125) = 3.931, p .269$)

Next those respondents who originally chose facility care for Mrs. Smith were examined. Respondents (N=42), told that the individual had rejected facility care, now chose between four alternatives: forcing (8; 19%) or persuading (15, 35.7%) Mrs. Smith to accept facility, respecting her decision (14, 33.3%), or "other" (5, 11.9%). A chi square test was conducted to see whether being elderly or a HCP was associated with the level of intervention

respondents chose after Mrs. Smith refused their original suggestion of facility care. No significant relations were found ($\chi^2(3, 36) = 7.241, p .064$).

Table 11

Groups by Care Choice When Community Care Refused-Cross Tabulation

		Most appropriate step if community supports refused				Total	
		In facility for safety	Persuade to accept	Respect wishes	Other		
GROUP	H.C.P.	Count	6	52	10	8	76
		% within GROUP	7.9	68.4	13.2	10.5	100
		% within most appropriate step if community supports refused	46.2	63.4	50	80	60.8
		% of total	4.8	41.6	8	6.4	60.8
	Elderly	Count	7	30	10	2	49
		% within GROUP	14.3	61.2	20.4	4.1	100
		% within most appropriate step if community supports refused	53.8	36.6	50	20	39.2
		% of total	5.6	24	8	1.6	39.2
TOTAL	Count	13	82	20	10	125	
	% within GROUP	10.4	65.6	16	8	100	
	% within most appropriate step if community supports refused	100	100	100	100	100	
	% of total	10.4	65.6	16	8	100	

Hypothesis 8: For both groups the higher the risks are rated, the higher the level of intervention that will be chosen if a marginally incompetent individual refuses the original care recommended.

There is some support for the hypothesis. If Mrs. Smith rejected the community care originally chosen for her, respondents would then recommend a higher level of care if they had also originally appraised certain/specific risk factors high.

Correlations between individual risk ratings, over-all risk, safety ratings and the level of intervention respondents chose for Mrs. Smith following her refusal of the care originally recommended, were examined.

In the first analysis, all respondents who originally chose community care ($n=127$) for Mrs. Smith were included. Significant negative correlations were found between the new care choice made by the combined groups and over-all risk rating ($t=-.163$, $p .035$), and for the specific risks of not receiving help quickly enough ($t=-.170$, $p .029$). The higher these risks were rated, the more likely respondents were to choose a higher level of care for Mrs. Smith than they had originally chosen. A significant positive relation was found between safety rating ($t=.240$, $p .004$) and level of intervention. The higher safety is rated the less likely respondents are to choose a higher level of intervention for Mrs. Smith than their original choice.

In the second analysis, only HCPs who originally chose community care (N=76) were included. There is a positive correlation ($r = .272, p .009$) between safety rating and level of care chosen for the individual after she refuses the original care choice. The more safe Mrs. Smith was seen to be, the less likely a higher level of intervention was chosen by HCPs if Mrs. Smith refused their original recommendation of community care.

In the third analysis, only elderly respondents (n=51) who originally chose community care for Mrs. Smith were included. There was a negative correlation ($r = -.252, p .041$) between risk of poor hygiene and level of intervention chosen after Mrs. Smith refuses the original care choice. The higher the risk of poor hygiene was rated the more likely elderly respondents were to choose a higher level of care than their original choice, refused by Mrs. Smith.

In the next analyses, only respondents who originally chose facility care for Mrs. Smith were included (N=40). This group was examined in three different ways: both groups combined; HCPs only; and elderly only. Correlations were examined between each of the elderly, HCPs and combined groups, and the individual risk ratings, over-all risk rating, safety rating, and the level of intervention of care chosen for Mrs. Smith when she refused their original recommendations.

No significant correlations were found between group membership, risk or safety ratings or level of care recommended by respondents when Mrs. Smith refused the facility care they had chosen.

Hypothesis 9: Elderly people are more likely than HCPs to change their recommendation of community care for a marginally incompetent individual to institutional care, if her worried children want her placed in a facility.

There was no support for this hypothesis. No significant relations were found between being elderly and either reporting (1) feeling influenced by the wishes of children, or (2) actually changing the original care decision on the basis of the wishes of children.

The analysis was conducted in two parts. In the first analysis, only those respondents who originally chose community care for Mrs. Smith were included (N 126). Only 11 (14.7%) of the HCPS and 12 (23.5%) of the elderly respondents stated that the wishes of Mrs. Smith's children would cause them to alter their original choice of community care for her. A chi-square test was computed to examine the relations between group membership and whether or not respondents said that the wishes of children would alter their original care decision. There was no significant relations found, ($\chi^2 (1, 126) = 1.598, p .206$).

In the second analysis, a chi-square test was conducted to explore the relations between group membership and whether or not respondents actually changed their original care choice to facility care on the basis of children's wishes. Only respondents who originally chose community care and thought that they would alter their decision on the basis of Mrs. Smith's children's wishes, were included in this analysis. Four (44.4%) of the HCPs, compared to 7 (58.3%) of the elderly, changed their original recommendation of community care to

institutional care. No significant differences between the groups were found ($\chi^2(1, 21) = .398$, $p = .528$), however in both groups about half of each group changed their decision.

Summary of Results

Reviewing the results of this study, of the nine hypotheses tested, one was unequivocally supported (Hypothesis 3), five received partial support (Hypotheses 2, 4, 5, 6, 8) and three remained entirely unsupported (Hypotheses 1, 7, 9). As anticipated, elderly persons chose institutional care for Mrs. Smith more frequently than did HCPs, even though there were no significant differences between the groups in how they rated either the overall risk to Mrs. Smith or her safety. Together, elderly persons and HCPs who chose facility care (as opposed to community care) for Mrs. Smith, did so when they had rated particular risks high, and safety low. Each group however differed in which risk factors, rated high, were associated with facility care being recommended.

It had been expected that if Mrs. Smith refused recommended care, that elderly persons would be more likely than HCPs to override Mrs. Smith's refusal. This was only true if the original choice made by elderly participants had been facility care. If the original care choice had been community, HCPs and elderly participants were equally willing to over-ride Mrs. Smith's refusal of care by persuasion, but not force. It had also been hypothesized that elderly persons, compared to HCPs, would choose a higher level of intervention upon Mrs. Smith's refusal of their recommended care, but such was not the case. No differences were found

between groups, for the level of intervention chosen, regardless of whether community or facility care had originally been chosen. However, of those who originally recommended community care, associations were found between particular risk factors and the levels of intervention chosen by each group, in the face of Mrs. Smith's refusal. There were no differences between groups for those who originally chose facility care, in regards to the level of intervention chosen following Mrs. Smith's refusal.

As anticipated, elderly persons felt more influenced than HCPs by the burden Mrs. Smith placed on others. Contrary to the expected results however, elderly persons did not recommend institutional care on this basis; nor did they change a care decision already made, on the basis of children's worries/wishes.

To summarize, overall there were statistically significant differences found between HCP and elderly groups in: how each group rated particular risk factors; the original care choice made for a marginally incompetent individual; the risks that predicted each group's choice of facility care; how influenced each group felt by burden on family and friends; who over-rode Mrs. Smith's refusal of facility care; and, the factors that led each group to select a higher level of intervention for Mrs. Smith after she had refused the original recommendation for her care. There were no statistically significant differences found between the HCP and elderly groups in regards to: safety rating; over-all risk rating; relationship between care choice and safety and over-all risk ratings; willingness to change care choice on basis of burden to children;

over-riding refusal of community services; level of intervention recommended when care refused; or, over-all risk and level of intervention chosen when community care refused.

DISCUSSION

The focus of the research was to compare a group of elderly people with a group of HCPs in regard to the values that underlie the care decisions they made for an elderly woman with mild cognitive impairment, living alone.

Respondents were not asked directly about their values, for as pointed out by Clark (1997) many people cannot articulate the values that shape their decisions. This was borne out by a study of autonomy and decision-making, conducted by Horowitz et al. (1991), where elderly persons and their children made decisions about a variety of vignettes illustrating autonomy conflicts. In discussing their reasoning, neither elderly persons nor their children spoke of abstract values such as autonomy, beneficence, maleficence, paternalism or interdependence. Instead they spoke in terms of safety and risk, rights, loyalties and obligations.

In this study the participants were presented with a scenario about an elderly woman, and asked to imagine what she is like, taking into account the information described. On the negative side the woman was portrayed as: living alone; having no children nearby; being frail; needing reminders about bathing and changing clothes; sometimes mentally confused; forgetful; losing or misplacing things; sometimes having difficulty remembering recent events;

unable to manage banking or finances; not able to make adequate meals; and known to burn pots.

A series of questions followed that was designed to reveal the values that underlay the care decisions participants then made for Mrs. Smith, based on her needs and limitations. As pointed out by Kapp (1988), judgements about what course of action will serve a client's best interests necessarily are determined by the subjective values, goals and preferences of the proxy decision maker.

Initially respondents were told that Mrs. Smith had no community support services, and asked to rate her safety. There was no difference in how HCPs and elderly persons rated Mrs. Smith's safety; both groups said she was between "somewhat unsafe" and "very unsafe".

Given the limited information provided about Mrs. Smith, on what basis did respondent decide how safe she was? Little is actually known about the prevalence, incidence or home management of safety problems or accidents in dementias, (Lach, Reed, Smith, and Carr 1995). It seems entirely plausible that the judgement of Mrs. Smith's safety was subjective, derived from the values of Mrs. Smith respondents.

Silberfeld (1992) notes that assessing risk involves gauging both the probability and undesirable consequences of something occurring, and that different people often have

different perceptions of each. He suggests that the perception of what is undesirable is a value judgement and depends on vantage point, and varies according to responsibility.

When respondents were asked to rate the risk to Mrs. Smith's independence from six specific factors (self-injury, crime, isolation, not eating properly, poor hygiene, not getting help quickly), both groups rated all of the risks as between "medium" and "substantial", but HCPs and elderly respondents ranked the risk factors differently. HCPs ranked the risks as follows, beginning with the highest rated: not eating properly; not getting help quickly enough; isolation/loneliness; self-injury; crime; poor hygiene. Elderly persons, on the other hand, ranked the risks as follows, beginning with the highest rated: not getting help quickly enough; not eating properly; crime; poor hygiene; isolation/loneliness; self-injury. The differences in how the risks were ranked reveal differences in how important HCPs and elderly respondents believe each of the risk factors are as threats to Mrs. Smith's ability to live independently.

The different ranking of risks between HCPs and elderly respondents, suggesting that they hold different values about what constitutes risk to independence, is consistent with research by McCullough et al. (1993). In a study of long-term care decisions it was found that in dyads of elderly people and HCPs, each party identified different values that they had found most relevant to making a long term care decision for the elder. HCPs identified care, physical health and psychological well-being as the values most relevant to their decisions, while elderly persons chose environment (mobility and privacy), self-identity and relationship. Additionally, when Kane & Finch (1997) asked HCPs and elderly people (unknown to each

other), to rate 12 items of activity of daily living or ADLs (eg: bathing, toileting, transferring) and instrumental activities of daily living or IADLs (eg: using telephone, meal preparation) in terms of the debility that could result to an elder from deficits in the domains, the two groups rated the items differently. In general elderly persons rated impairment in IADL functions as most detrimental to their functioning, while HCPs rated impairment in ADL as most important. HCPs over-estimated the importance dependency in ADLs to the elderly, while underestimating the importance of dependency in IADLs to them.

In this study a significant difference was found between the elderly and HCPs groups, in regard to the risks that poor hygiene and not eating properly were believed to pose to Mrs. Smith's ability to live independently. Elderly persons rated poor hygiene as a higher risk to Mrs. Smith than did HCPs, while HCPs rated not eating properly as a higher risk to her than did the elderly respondents. In the study conducted by McCullough and his colleagues, health care professionals identified care/supervision and health as the most important values in making a long-term care decision, while elderly people identified values concerning environment (privacy) and self-identity as most important. In this study it is possible that poor hygiene was construed by elderly respondents as evidence of failure by Mrs. Smith to maintain continuity of her self/persona/image as an adult with dignity. HCPs may have perceived not eating properly as a significant health risk for Mrs. Smith.

It was hypothesized that safety and risk ratings would predict the choice of community care, facility care or no care that HCPs and elderly persons would make for Mrs. Smith. In fact,

only the safety rating and specific risk factors (ie: risk of not getting help quickly enough, poor hygiene and self-injury) predicted the care choice made by respondents, regardless of whether they were HCPs or elderly.

There exists a seemingly permanent tension between safety and supervision on the one hand, and risk and independence on the other. These values compete in the delivery of health care and in our conceptions of whom the elderly are and how they should be treated (Kaufman & Becker, 1996). Healy (1999) described the core of the concern for safety in the community as derived from the concept of beneficence, defined as the duty to care, to do good, or to actively benefit others. She contends that the tension between respecting autonomy and beneficence is reflected in the concern for safety in home care situations.

Only forty respondents, largely elderly, of the total sample of 167, chose facility care for Mrs. Smith, in spite of rating risk high and safety low. This suggests that the majority of participants in this study placed a higher value on risk and independence than on supervision and safety. The community care choice represented beneficence in this study. While Mrs. Smith's preference for remaining at home was respected, services to benefit her and ameliorate some of the safety/risk concerns, were recommended. None of the respondents, however, chose neither community nor facility care for Mrs. Smith, which would have represented the highest regard for her autonomy, given that she is not depicted as wishing services. When other's protective conduct is not desired by an individual, it conflicts directly with the person's autonomy (Kapp, 1997).

Another factor that was thought to influence the care choice of elderly persons to a greater extent than HCPs, was the influence of children who wanted their mother in a facility to alleviate their caregiving burden. As Raymond and Wentworth (1993) have reported, the impact of the family and social cultural structures on the autonomy vs. independence debate about elderly people, is large. Many families express concerns about their relative's safety and about the stress they experience as caregivers, to health care providers. Hardwig (1990) asks if health care providers do not have a duty/right to involve family when the outcome of a decision for the elder may affect other family members. Healy (1999) found that in response to vignettes depicting situations with various levels of caregiver burden, the greater the caregiver's burden, the less the elderly client's autonomy would be supported by care providers. In contrast, in the present study health care professionals felt that the burden Mrs. Smith placed on others was an insignificant influence on the care decision they made.

Elderly people on the other hand experienced burden placed on others by Mrs. Smith as significantly more influential than did HCPs. This finding is corroborated by Horowitz et al. (1991), where dyads of elderly persons and their children, were asked to make decisions about vignettes representing inter-generational autonomy conflicts. The reasoning of the elderly people, in comparison to their children, was saturated with concerns about the burden the parent was placing on the children, and rights vs. obligation. Horowitz and her colleagues also found that the elderly people in their study made decisions on this basis, unlike the elderly in the present study. Although the respondents in this study reported feeling influenced by the burden Mrs. Smith placed on others, they did not make their care choice for her on this

basis. These findings suggest that elderly people place a higher value on interdependence than do HCPs, but that they hold autonomy higher than interdependence. When asked to make a new decision for Mrs. Smith's care on the basis of her children's worry and burden, neither elderly persons nor HCPs (as groups) changed their original care decision.

In the present study it had been anticipated that elderly people would be more likely than HCPs to choose facility care for Mrs. Smith. There was in fact a significant difference between groups in terms of the care choice made for Mrs. Smith. This finding corroborates Horowitz's study where elderly persons were quite prepared to make decisions that overrode the autonomous preferences of hypothetical older individuals in vignettes. In the present study, elderly persons were more likely than HCPs to choose facility care for Mrs. Smith, thus contradicting her preference to live in her own home. These respondents may have judged that Mrs. Smith had made the wrong decision for herself; they therefore made what in their opinion was a better decision for her. By recommending facility care they behaved in a paternalistic manner. Paternalism is the view that we can sometimes override a person's wishes or actions in order to benefit or prevent harm to the person (Beauchamp and Childress, 1979).

Kaufman (1995) has noted that risk assessments and the perception of need for placement differ among health care providers, patients and family members, and that each perspective is shaped by values. In a study by Krothe (1997) poor mobility, the absence of family resources, and declining mental functioning - (the latter two characteristics shared by Mrs.

Smith in this study) - were identified by community dwelling elderly as primary reasons warranting facility care.

It was not surprising that few HCPs chose to contradict Mrs. Smith's preference to remain at home, in spite of concerns about her safety. Kapp (1997) observed that the imperative to save elderly persons from themselves is increasingly outweighed by a growing philosophical commitment among health care professionals to protect and promote the autonomy of the clients including the right to live at risk. In a vignette - based study of case managers' support for the autonomy of frail elderly people, Healy (1999) found high levels of support for the autonomy of cognitively impaired elderly persons even when safety risks were quite highly rated.

Regarding the HCPs who behaved paternalistically, they may be subject to what Moody (1987) describes as the "logic of incarceration":

"For the elderly 'at risk' for nursing home placement, an ideology of professional control and interpretation of behaviour produces a logic of incarceration. The professional ideology amounts to a claim for superior knowledge in predicting the future course of chronic disease, especially the trajectory of decline in the patient's capacity to cope with activities of daily living. This appeal to superior professional knowledge is combined with an appeal to the principle of paternalistic beneficence toward the patient "(p 17).

The relatively few respondents overall who chose facility care for Mrs. Smith in this study do however stand in contrast to findings by Kelly et al. (1998). In their vignette-based study, women from age 18-92 were asked to make a long term care choice for hypothetical elderly women in a variety of living situations, and with varying degrees of cognitive and functional impairment. It was found that the overwhelming majority of respondents chose facility care as the most appropriate choice for targets living alone, regardless of their own age or the target's level of functional and cognitive impairment (i.e. even when impairments were minimal). The fact that lay women under 65 years of age in Kelly et al.'s study chose facility care while health care professionals of a similar age in the present study did not, suggests that health care professionals in this study may have considered Mrs. Smith's situation from the perspective of their professional experience (which Kelly's respondents did not share) of who actually qualifies for facility placement.

When respondents were asked how safe they thought the hypothetical individual would be with community services in place, most thought that she would be "safe enough". Respondents likely made this rating on the assumption that Mrs. Smith would accept the services offered. Indeed, the original care choice made for her likely followed from this assumptions as well. If this is true, when the services were rejected, the threat from the risks may have seemed magnified. As well, we might speculate that respondents questioned whether or not the occasional mental confusion ascribed to the hypothetical individual was the cause of her refusal, and in itself, suggestive of need for protection. Kapp (1988) points

out that an individual's competency is often questioned for the first time when that person refuses a helping professional's recommendations.

The scenario was re-presented to respondents and they were told that the hypothetical individual had refused the care that they had recommended. The respondents who had recommended community care were asked to decide what the next step should be. Only a small percentage (16%) divided equally between the HCPs and elderly persons who had first chosen community care, again did so. Their choice demonstrated a belief in autonomy, which directs us to honour a person's preferences (Browne and Sweeny, 1995). Their choice to respect Mrs. Smith's refusal and her right to live at risk, illustrates the cultural ideals of personal autonomy and freedom from institutional constraint and domination that have become reified in contemporary society (Kaufman and Becker, 1996). The fact that so few respondents respected Mrs. Smith's refusal may relate to the derogatory social image of old age, described by Norman (1988), the consequence of which is that elderly people are seen as having a reduced right to liberty, choice and self-determination. The majority of respondents (65%) continued to demonstrate beneficent behaviour by choosing to persuade/coerce Mrs. Smith to accept services. Silberfeld (1992) suggests that as soon as risk to another person is invoked, thoughts turn to protection and that it may seem natural if not obligatory to interfere in the person's life for her own good. Kapp (1988) observes that persuasion by helping professionals and informal supports can become a form of "ganging up" on or manipulation of the older person. Clemens et al. (1994), in a study of case management, found many instances of directive practice, including persuasion and coercion, used for

achieving acceptance of care by frail elders, in spite of professional and agency values of client empowerment. Of those who first chose community, the smallest percentage (10%) almost evenly split between elderly and HCPs, behaved in a paternalistic fashion and recommended that the hypothetical individual be placed in a facility against her will.

There was no relation between being either elderly or a HCP, and the level of care that was recommended when Mrs. Smith refused the care (either community or facility) initially chosen for her. When Mrs Smith refused community care, the level of intervention recommended was chosen, not on the basis of being a HCP or elderly, but on the basis of respondents' original appraisal of risks and safety. The higher specific risks had originally been rated, (e.g., over-all risk and accident for all respondents; poor hygiene for the elderly group), the higher the level of intervention that was chosen following Mrs Smith's refusal of community care. Higher levels of intervention chosen by health care professionals and the combined groups could also be predicted by low safety ratings. Respondents who rated risks highest/safety lowest chose institutionalization by force, demonstrating paternalism. Beneficence was demonstrated when risks were rated somewhat lower and/or safety higher and respondents choose a lower level of intervention (eg: persuading or coercing into facility, rather than forcing). The lowest level of intervention, associated with high safety and low risk ratings, was "respect her wishes-she has a right to her choice", demonstrated the value of autonomy.

This finding supports a study by Degenholtz et al. (1997) where it was found that elderly people living in the community, were prepared to give up some of their freedom to come and

go in favour of being safe. In another study, elderly community dwelling persons identified accidents as a potential risk that would jeopardize their living at home (Mack et al. 1997).

The finding here, related to health care professionals, is also somewhat consistent with the results of other studies. Case managers, in a study conducted by Healy (1998), were found to rank safety as the second factor, (following evaluation of cognitive status), in decisions concerning support for autonomy of elderly people. In a second study, a vignette based analysis of case manager's decisions concerning support for the autonomy of cognitively impaired community-dwelling frail elderly, Healy (1999) found that case managers supported less autonomy for cognitively impaired elders, in the presence of high safety risk. Clemens and her colleagues (1994) found that the attention of case managers was deflected from support for autonomy by their concerns about safety, in spite of strongly stated support for self-determination.

When the Mrs. Smith refused the facility care recommended for her, elderly persons were more likely than HCPs to override her refusal and to recommend that she be forced to go into a facility. The majority of HCPs who had originally chosen facility care for Mrs. Smith stopped short if it came to forcing her.

Given that only nine or 10.6% of HCPs as opposed to 31 (37.8%) of elderly persons originally chose facility care, it was not surprising that the elderly respondents were most likely to choose the higher levels of care now. Those respondents who had originally chosen

facility care for Mrs. Smith, had already demonstrated paternalistic behaviour, prior to Mrs. Smith's refusal. This suggests that these individuals already had a strong belief in the necessity of providing safety and supervision to Mrs. Smith. When Mrs Smith refused facility care respondents who chose to force her may have done so on the basis of the value of non-maleficence. The principle of non-maleficence is to do no harm, which includes not knowingly exposing the patient to unjustified risk (Kluge, 1992). Kapp (1997) suggests that the most significant impediment to the uncontested implementation of older person's choices is a fear of the potential consequences of an individual's poor decision, and then being held accountable for it. HCPs in particular might have made their decision with thoughts to professional liability.

In conclusion, this study has demonstrated that there are differences in the values of elderly persons and HCPs that underlie health care decisions they made for a marginally incompetent elderly woman living alone. There were both similarities and differences found between elderly persons and HCPs in terms of the decisions they made about Mrs Smith's care, and of the factors that influenced these decisions. The appraisal of risk and safety were similar between groups; the appraisal made by each group could be explained in terms of each group's values. Decisions made by respondents could be accounted for by the underlying values of autonomy, beneficence, paternalism, non-maleficence, and interdependence. Overall the participants in this study did not place a high value on autonomy, when they had appraised the risk to Mrs. Smith high, and her safety low. In these circumstances, a significant number of elderly respondents made paternalistic decisions while HCPs made beneficent ones. Most

elderly respondents and HCPs however, acted beneficently if Mrs. Smith refused the care they recommended, providing they had originally chosen community care. However, of these participants, HCPs who originally rated safety low, and overall risk and “not getting help quickly enough” as high, became paternalistic, by choosing a higher level of intervention for Mrs. Smith. The elderly respondents who were most likely to become paternalistic upon Mrs. Smith’s refusal, were those who had rated the risk from “poor personal hygiene” as high. Both elderly respondents and HCPs who had originally demonstrated paternalism by choosing facility care for Mrs. Smith, increased their paternalistic behaviour by choosing to force her into facility against her wishes. HCPs may have been, in this instance, acting on the basis of the value of non-maleficence. It was found that elderly respondents value interdependence more highly than did HCPs. However, valuing interdependence did not lead to over-riding a beneficent decision they had already made on Mrs. Smith’s behalf with a paternalistic one.

I - ALTERNATIVE HYPOTHESIS

There is an alternative hypothesis, not investigated in this study, that might explain similarities in how HCPs and elderly respondents appraised risks and safety, and the care decisions they made for Mrs. Smith. Ageism and associated labelling that exists in our society could be powerful influences on the values of all respondents.

Many of the negative characteristics attributed to Mrs Smith might equally be attributed to a lovesick teenager, (eg: forgetful, losing things, can't manage finances, difficulty

remembering, burnt pots, etc.), but would others rate her safety as low, or the risk to her as high, as Mrs. Smith's were rated by respondents in this study? Collopy, Dubler, and Zuckerman (1990) suggests that we look at the dangers and problems confronting elderly people through ageist glasses. Is it possible that health care professionals and elderly persons in this study evaluated Mrs Smith from an ageist perspective, which could account for the low rating her safety was given? Norman (1988) states that one very powerful image of aging in our society is that of pathetic, powerless, mentally incompetent old persons who are objects of charity. She suggests that this image is a social construct that has more to do with the comparative longevity of women, lifelong occupational status, poverty and the inadequacy of appropriate social/community services, than with aging per se. As members of our society, both health care professionals and elderly respondents could well be influenced by ageism.

It had been hypothesized that elderly persons would rate Mrs Smith's as less safe and at more risk than would HCPs. It was reasoned that health care professionals, who embrace client-centred values of self-determination and autonomy (Clemens et al., 1994), and who could be expected to have a wider experience than would elderly respondents of situations like Mrs Smith's, would be less alarmed by the description of her situation. Perhaps HCPs' roles and experience added to the ageist perspective already suggested, rather than modifying it. Raymond and Wentworth (1993) observed that health care professionals, often with the consent or insistence of the family, tend to focus adamantly on the physical safety needs of the elderly client over other needs such as privacy and autonomy.

Given that the concepts of safety and risk are intertwined, with the evaluation of one dependant on the other, (as was demonstrated in this study), it had been hypothesized that elderly people would rate the risk to Mrs Smith higher than would HCPs. This was not the case, possibly for the same reasons that it was suggested elderly people did not rate Mrs Smith's safety lower than the HCPs. Although the results of this study indicated that the lower that Mrs. Smith's safety was rated, the higher the over-all risk to her was seen, there were no significant differences in ratings between the HCP and elderly groups.

Oppenheimer (1991) speaks of the halo of disability conferred on the elderly in our society. It is conceivable that respondents reacted to the labels given to Mrs. Smith, particularly those of "mentally confused" and "frail". Kaufman & Becker (1996) describe the concept of frailty as a cultural construct informed by biomedical views of risk, that "comes into focus at the moment when any combination of an old person's symptoms and behaviours is construed to tip the balance towards more dependence than independence with regard to functional ability and social role performance" (1996, p. 54). The label of "mental confusion", often used interchangeably with dementia, Alzheimer Disease and/or senility, may carry with it images of incompetence and vulnerability. Labelling theory posits that negative societal conceptions of mental illness exist independent of a labelled person's actual behaviour. Labels have been found to activate pre-existing stereotypes about a labelled individual; these ideas then influence how a labelled person's behaviour is interpreted and how they will be treated. Saleeby (1996) observes that diagnostic labels influence health care professionals by leading them to emphasize pathology and focus on deficits rather than on strengths. Some support

for these notions comes from a study by Healy (1999) that found that social workers supported less autonomy for frail elders depicted as having a dementia than for those with stroke. Additionally, McRae, Stangor & Milne (1994) reported that some professionals tend to seek out information that confirms stereotypes in the presence of ambiguity. In summary, ageism and labelling theory could provide a basis for the shared subjective perception of respondents in both groups, that Mrs. Smith is unsafe and at risk of losing her independence.

II- LIMITATIONS OF THE STUDY

I-Limitations of the Data Analyses

The results of this study should be viewed with some caution. An alpha level of $p .05$ was chosen as the level at which results were considered significant. Had we corrected for Type I errors using the Bonferroni correction method, only results of at an alpha of $.005$ would be considered significant. On this basis very few of the results reported in the data analysis would be considered significant here, instead being considered spurious (Myers, J., 1979).

For some hypotheses (i.e: Hypothesis 6, part 2 and Hypothesis 9, part 1), the sample sizes were very small, resulting in 20% or more of the cells having expected frequencies of 5 or less. This violated the chi square assumption that the sampling distribution of all possible sample test statistics is accurately described by the chi square distribution. In these instances the value of chi square (obtained) was adjusted by applying Yate's correction for continuity. (There was no change to results).

For the purposes of this study, the care decisions that respondents made for Mrs. Smith under varying conditions were interpreted as manifestations of the values of autonomy, beneficence, paternalism, non-maleficence and interdependence. The relationships between each care decision with each specific value may not be as clear cut as this procedure implied. Additionally, it is possible that if respondents had been directly asked about why they made the decisions they did, they might have had alternative explanations that did not reflect the values ascribed to them by the researcher.

2 - Limitations of the Sample

All of the respondents were self-selected, which could have some effect on the results. In particular, volunteerism is often associated with higher levels of education, better health and higher socio-economic status. The elderly persons in this study are more highly educated (Lindsay, 2000) and have higher incomes than the elderly population generally. The effect of these factors on the decisions the respondents made about Mrs. Smith, and on their values, is unknown.

In this study 29 of the 83 elderly participants had a health care background, possibly confounding the results attributed to being elderly. An argument was put forth earlier that the values of HCPs (and therefore the health care decisions they make) are likely to differ from the values (and decisions) of elderly participants, in part because of the influence of professional socialization on HCPs. In order to explore the extent to which the health care background of elderly participants might have affected the results, the tests that included the

all of the elderly participants (i.e.: Hypotheses 1, 2 and 3) were re-run, controlling for health care background. There was no impact on the results, suggesting that the main effect on the results for this study is age, as opposed to health care background. This suggests that being elderly over-rides earlier professional socialization. Perhaps once outside of settings that support/reinforce professional values, and that "direct": professional work/decisions, professional values are shed, and individual make decisions based on personal values.

It is also possible that some of the differences found between health care professionals and elderly persons in this study could be age effects, but these were not tested for. The background literature reviewed for the research, indicated that elderly persons and adults under age 65 in general, each have different perceptions of aging (Seccombe & Ishii-Kuntz, 1991); and, different values about control over decision making (Bradley et al., 1996). Studies examining surrogate decisions made by family members about their older relative, overall demonstrated a lack of congruency between the decisions of younger family members and the decisions their relatives would have made for themselves, further suggesting possible age effects, (Seckler et. al., 1991; Gerety et. al., 1993; Tsevat et. al., 1998).

It is also plausible that some of the similarities found between health care professionals and elderly persons in this study could be health effects, but these were neither planned for nor tested for. Health care professionals were not asked about their health, although given their relative youth (mean age 47 years), and that they are all employed, it seems reasonable to assume that they are generally in good, or at least not poor, health. Starr et. al. (1986), as

discussed in the background literature review for this study, found that physicians used their own health, in part, as a yardstick to measure the quality of life they perceived their elderly patients to have. Elderly respondents were asked to rate their health on a scale of 1-5 with 1 being poor health and 5 being excellent. Only six of the 79 elderly persons who responded to this question, reported their health as less than good. This is surprising given that it is reported that elderly Canadians suffer from more chronic diseases and have more episodes of acute illness than do younger adults (National Advisory Council on Aging, 1993). Perhaps the elderly respondents in this study described better health than might be expected because they are more healthy than non-community dwelling seniors who were not included in the sample. In any event, as indicated in the background literature reviewed, elderly people generally perceive their health as better than do those who are objectively assessing it, and make decisions on the basis of their perceived health (Otto et. al., 1997; Miller & Bolla, 1998). Of importance here is, if respondents in both groups are generally healthy, both groups may have made decisions about Mrs. Smith from this perspective, which might have over-ridden differences between being elderly or an HCP. Unfortunately, the effect of health could not be examined, given the distribution of degrees of health within the variable for the elderly respondents.

There were very few men in either the health care professional or elderly sample. It is possible that many of the findings are an effect of being female. There may be important differences in the life experiences of men that would lead them to, for example, hold different values

about risk or control over decision making, than women. This may be especially true when the person about whom men are making decisions about, are women.

The representativeness of both the elderly and health care professional samples are not known. We do not know enough about either group to know how homogenous or heterogenous they are, individually or in comparison to the other. We know nothing about the ethnicity, culture or religion of either the elderly persons or health care professionals who participated in this study. Each of these factors could potentially account for value choices made by respondents, and could be more significant than being either elderly or a health care professional.

3 - Limitations of the Instruments

The use of an anonymous questionnaire that provides categories for respondents to choose from, is necessarily limited. We do not know if the categories provided fully captured the responses to the questions that participants might have made, had the questions been open ended. It should be noted however that hardly any of the participants provided open-ended personal responses when this option was offered.

The use of a scenario depicting a hypothetical person about whom respondents must make decisions, has some disadvantages. Although respondents are asked to imagine Mrs. Smith and her situation, we do not know how fully they were willing or able to do so. Additionally,

Kane (2000), states that there is no research that shows whether or not people would make the same decisions in real life that they make in scenario studies.

In the letter inviting potential participants to participate in the study, (Appendix B), the term “marginally incompetent” was used as a description of the older adults who were the focus of the research. The term “marginally incompetent” was deliberately used in order to make clear that the person in the scenario about whom participants were to make decisions, was neither “competent” nor “incompetent”. It was anticipated that making this distinction clear would provide HCPs with unambiguous direction about decision making and increase the likelihood that value laden decisions would be made. However, it is not known how elderly participants would understand the label “marginally Incompetent”. It seems quite possible that they may simply have interpreted the label literally, as meaning neither competent nor incompetent. For the approximately one-third of elderly participants with previous employment in health care, the label could be expected to trigger a similar response to that anticipated for current health care professionals. For the remaining elderly participants, the label would not indicate to them a particular path (i.e: they could not assume that the usual professional procedures for either a competent client nor an incompetent client could be put in place). In the end it is not known what effect the use of this term may have had on either health care professional’s or elderly person’s decision to participate in the research or their actual responses to the study questions. For future research this lack of certainty might be avoided by providing a definition of the term "marginally incompetent", along with

information about the rights of competent and incompetent adults to make health care decisions.

III - IMPLICATIONS OF THE RESEARCH

Overall, the findings from this study indicated that: (1) Elderly participants and HCPs each rated the safety low, and the risk of harm high, for a marginally incompetent woman living alone. (2) Each group appraised individual risk factors differently in terms of the risk they felt they presented to a marginally incompetent woman living alone. (3) Neither HCPs nor elderly persons valued autonomy more highly than safety, when making a care decision. (4) On the basis of their concerns about safety, elderly participants were more likely to act paternalistically than were HCPs, who acted beneficently. (5) Overall both groups stopped at force, choosing a beneficent response instead, when the care they recommended was refused. (6) While elderly persons value interdependence, they did not make care decisions on the basis of other's concerns or wishes.

1 - Policy Implications

Despite potential study limitations, several implications arise from this study. The differences in the care decisions made by elderly persons for Mrs Smith, compared to those made by health care professionals, suggests that both practice and policy could better reflect the concerns, priorities, goals and values of marginally incompetent elderly people, if other elderly persons were able to provide input into these areas. Although there is much rhetoric in the health care and human services area about client-centeredness, consumers and empowerment,

this may not be equivalent to wanting to be guided by the input of those who receive the care and services. These highly promoted trends have been viewed with suspicion by some, who believe the force behind them may be to transfer the responsibility and cost of care to consumers, families and volunteers (Walker, 1991).

Elderly persons (perhaps all persons) should be encouraged by all health care professionals to document or share their values and beliefs in regard to long term care planning in case of mental impairment. Representation agreements, currently being promoted in British Columbia, could be expanded to incorporate this type of information. Degenholtz et al. (1997), however, commented that some of the health care professionals involved in their study expressed concern about even asking elderly people about their preferences in case it led to raised expectations that it might not be possible to meet. Additionally, we do not know the extent to which individual's keep to their original decisions over time.

Social workers could be charged with collecting information from older adults and their families when they first enter the long term care system, in order to document the elderly person's social history, and advance directives (where possible). These social histories would focus on what the person believes, has valued, and ways they have coped throughout life. A social history might provide some insight for other health care professionals about what might have been important to Mrs. Smith, if they are later unable to make decisions on their own behalf.

2 - Practice Implications

The most important implication for practice is finding that the care decisions made by elderly respondents differed from those made by HCPs and this appeared to reflect an emphasis on different values. It is important for all health care professionals to be aware that their values, and therefore what they may think is important and/or best for elderly clients, are quite likely to be different than those of elderly person. This information and its' implications need to be made available to health care professionals from all disciplines through education. Through this education and the development of related practice standards, health care professionals could be expected to explicitly share with clients/patients their personal/professional biases in making particular recommendations (as opposed to providing clinical reasons only). They could also be expected to explore the decision making process undertaken by elderly persons regarding care and treatment, rather than asking only for their decisions per se. By exploring assumptions, beliefs and values behind choices about potential interventions with clients, health care professionals might develop a more accurate understanding as to what the clients view as important.

When elderly persons are unable to provide fully competent direction to health care professionals, consultation with their family members about the particular decision at hand, should be undertaken. Some studies have found that many older adults would choose family members to make proxy decisions for them if they become unable to make decisions on their own behalf (High, 1989). As the literature reviewed earlier indicates, however, family members do not generally make accurate surrogate decisions for older relatives, and their

interests may conflict with those of the elderly person. Family relations may have to be examined by health care professionals prior to acting on the information family members provide, to ensure decisions are being made in good faith and with the “best” intentions.

One way in which input from elderly persons could be utilized in decision making about marginally incompetent individuals, is by involving them as consultants. Formal decision makers could recruit elderly persons of varying gender and backgrounds (e.g., educational, socio-economic, ethnic, cultural and religious), to create a pool of consultants to match to the diversity of the heterogenous elderly population. When confronted with ethically challenging situations involving making care decisions on behalf of older adults, health care professionals could choose to explore relevant issues with a selected consultant, (of course protecting the confidentiality of the client). This might be considered a time consuming approach, but perhaps should be weighed against the increased likelihood of making decisions on behalf of marginally incompetent persons that are more in keeping with their beliefs and values. Additionally, efforts could be made by gerontologists to capture and make available to those caring for older adults, narratives that reflect the life course of elderly individuals within the context of their particular times, culture, gender, religious beliefs, etc. These narratives, or similar broader histories of specific groups, might help care providers to understand where their clients have come from, possibly providing insights into what might be important to individuals.

The present study demonstrated that most health care professionals, in spite of discipline specific values supporting autonomy and self-determination, primarily recommended some safety and supervision for Mrs. Smith. They took the middle ground between no services and institutionalization. If disparity between values ascribed to and practice behaviours occurs in the management of elderly persons, it is important to make this visible. Conflict between the ethical principles that one believes in and behaviour can lead to burn-out for professionals, with implication for both themselves and their clients. Opportunities for education about ethical decision-making when principles compete could be protective for health care professionals. Additionally, the opportunity in the field to process difficult cases in order to make subjectivity and biases explicit, and to share responsibility, could increase the accountability of health care professionals for their practice behaviours and decisions. While shared decision making could reduce the possibility of decisions being made on the basis of a single individual's biases, it would be important that it occur only in the context of power-sharing teams (as opposed to hierarchical ones), lest "ganging up" occur on dissenting professionals.

IV - SUGGESTIONS FOR FUTURE RESEARCH

An underlying assumption of this research was that elderly people share more values with other elderly people than with health care professionals. Following from this it was postulated that elderly people would make better decisions for other elderly people than would health care professionals and policy makers. The findings from this study indicated that HCPs and

elderly persons do indeed make different care decisions based on different values. The study could not of course reveal which group's decisions would have been more congruent with those Mrs. Smith would have made for herself when in her previously competent state. This study, then, has not proven, but merely suggests, that elderly individuals might make proxy decisions for other elderly people that are more congruent with their values than decisions made for them by health care professionals or younger adults generally. A study that compares proxy decisions made by elderly persons, for other competent elderly persons, with the decisions actually made by the "target", would make a valuable contribution to research.

Neither the group of elderly participants nor the group of HCPs who participated in this study can be considered heterogenous, and in particular, are composed of several different age cohorts, that could have affect the study results. A future replication of this study could break down both the group of elderly persons over age 65, and the group of HCPs under age 65, into several different age group segments, to more fully explore age cohort effects.

The effect of gender on the values underlying health care decision making for marginally incompetent individuals could be explored through future research. This study could be replicated by having the person about whom decisions are made be male, and by ensuring that a greater proportion of both HCP and elderly participants in the study are male. These procedures would make it possible to examine any effects that gender may have had (i.e., care recipient, respondents).

A comparison of health care professionals and non-health care professional adults under the age of 65, would be useful in exploring the effect of age alone on care decisions and values. In order to explore the effect of health on care decisions and values, a comparison of older adults who are in good health with those in poor health, would also be useful. Similarly, the study reported here could be replicated but with samples of elderly, health care professionals and non-health care professionals under age 65 that included more men, and people from a variety of ethnic, cultural and religious background, in order to explore the effects of these factors on decisions and values.

Naturalistic qualitative studies could be designed to explore through individual interviews undertaken with both elderly persons and HCPs, the reasoning and values behind the decisions they would make for a hypothetical marginally incompetent individual. This sort of enquiry would create a greater understanding of the complexities of the relationship between values and decision making in health care, from the perspectives of each group.

Given that safety and specific risk factors were significantly related to the care choice made by respondents in this study, more knowledge about how these areas are evaluated would be useful. Qualitative research could be undertaken with both elderly people and with health care professionals about how they assess these factors. In reality, little is known about the impact of risk factors on real life elderly marginally incompetent individuals living in the community. An examination of actual fire calls to persons identified as suffering from a dementia and living alone, could, for example, be undertaken. A study comparing the pre-placement

assessment of risk and safety of elderly persons by health care professionals to what actually occurs in the community, and how the community is exited, could be undertaken. Research in this area could provide knowledge about the probability of risks being potentiated, and about contributory and protective factors.

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APPENDICES

APPENDIX A

SCENARIO

Mrs. Smith is 84 years and lives alone. She has become increasingly frail. She is mobile and physically able to carry out ordinary activities of daily living such as getting dressed and bathing. She often needs reminders to bath or change her clothes. Mentally, Mrs Smith is sometimes confused. Although she can remember things such as her name and address, she is quite forgetful. She often loses or misplaces things, and sometimes she has difficulty remembering recent events. She is able to make some simple decisions for herself, like what clothes to wear, but she is unable to manage major things such as banking and finances. She can not make an adequate meal and has been known to burn pots. She does not feel she requires services.

APPENDIX B**INFORMATION ABOUT THE RESEARCH****Dear Potential Participant:**

There are a growing number of elderly persons with a dementia living in the community. Often these persons are only marginally competent and not able to manage well independently. These individuals often present dilemmas for the family, friends and health care professionals involved. It would be helpful to have a better understanding of the decisions that are made in these difficult circumstances. I am asking for your help in conducting research in this area for my Doctoral thesis in Interdisciplinary Studies which I am working on at the University of Victoria with Dr. Tuokko and Dr. Chappell. This study, "Health Care Decision-Making For Marginally Incompetent Persons Living Alone." will examine views about appropriate long term care choices for marginally incompetent frail elderly persons living alone.

Your participation would require: (1) reading an information sheet;(2) filling out a questionnaire about long term care choices for the elderly; and (3) providing a limited amount of demographic information about yourself. The questionnaire should take between 15 and 20 minutes to complete.

You are not asked for your name, address or any other identifying information- your answers to the questionnaire are given anonymously. Your participation in the study is finished once you have completed the questionnaire. Once your information is "put into" the

study it can no longer be identified as yours.

Any information you provide will not be used now or in the future in any way that would allow you to be identified or that would jeopardize your access to long term care services. The results of the research will be presented at my thesis meeting, at scholarly meetings and perhaps published.

If you have any questions or comments, or would like to know more about this project, please feel free to call me at (250) 756-2129. My supervisors Dr. Tuokko and Dr. Chappell can be contacted at the Centre on Aging, (250) 721-6576. The Vice President of research at the University of Victoria can also be contacted, at (250) 472-4362. I believe this is an important area of research and your participation in this study is greatly needed and would be very appreciated. Thank you for your time.

Yours sincerely

Penny MacCourt MSW

APPENDIX C

INFORMATION ABOUT COMMUNITY SUPPORT AND INSTITUTIONAL SERVICES

Community Support Services

There are a wide variety of community support services that are available to older people who live in their own home, and who can no longer fully care for themselves because they are physically or mentally frail. Many, but not all of these services are organized or provided through what is called the Continuing Care Services (CCS), funded by the British Columbia Ministry of Health. Long Term Care services, one component of CCS, provide services to older people living in the community, through Home Support services and Adult Day Care programs. Another component of CCS, Home Nursing Care, provides nursing and palliative care. Rehabilitation services are also provided through CCS. Older persons can refer themselves or be referred by others to CCS.

The kind of help that someone in the Long Term Care program receives is determined by a Long Term Care Case Manager and depends on the particular older person's needs. For people who require nursing care such as receiving medication, treatment of infections, or monitoring blood pressure, regular visits from a nurse can be arranged. There is no cost to the older person for these services.

If the person needs help around the home, a Homemaker can visit at prearranged times during the week. The British Columbia government subsidizes the cost of Homemaker services. The portion the older person pays is based on an income assessment, and can vary from \$0 to \$25.00 per visit. The amount of time a Homemaker can be provided is based on the actual care needs of the older person. The maximum number of hours that can be provided, barring extraordinary circumstances, is 120 hours per month (about 4 hours per day). Because help from a Homemaker is limited, the kind of help provided depends on the older person's most important needs, such as bathing or assisting with dressing. If the older person needs more help than CCS can provide than it is up to her (or family or friends) to arrange and pay privately for the additional help that is needed. The kind of assistance that a Homemaker gives also depends on whether or not there is someone else available to help the older person. For example, an older person might depend on family members or friends to help them with grocery shopping so that the Homemaker can spend time doing other things. If the older person needs help with meal preparation, and no other way can be found, a Homemaker may provide this service. For most older persons arrangements can be made so that a hot mid-day meal is delivered Monday to Friday from "Meals on Wheels". If needed, the Homemaker can prepare breakfast or an evening snack. Generally, the older person (or family member or friend) is responsible for preparing other meals through the week and on Saturday and Sunday.

In addition to the services provided through the Home Support program, CCS can offer Adult Day Care programs to eligible older persons at a minimal cost. The older person is driven to and from the program, which consists of social activities, bathing, and a hot meal.

There are many other non-governmental community services that are available to frail older people who need help in order to continue living in their own home at minimal risk. Some of these services are provided by volunteer organizations such as the Alzheimer Society Visiting program, while other services such as additional nursing or housekeeping assistance, can be paid for privately. A family member can also arrange for a volunteer to provide some companionship for the older person by visiting once or twice a week.

PLEASE TURN OVER AND READ ABOUT INSTITUTIONAL CARE

Institutional Care

There are many facilities that provide institutional care to older people who are physically or mentally ill. Some facilities are run by church groups, some are run by service groups, and others are run by private organizations. The most common type of institutional care is Nursing Homes or Long Term Care Facilities. The cost of these homes is subsidized with the government paying most of the cost. The older person generally pays part of the cost based on an income assessment. The older persons portion could be up to \$50.00 per day.

A person must apply to be put on a waiting list for admission to a Nursing Home or Long Term Care Facility. Eligibility is based on need and on community resources being exhausted.

The length of time on the wait list varies, but is generally at least a year. Individual exceptions can be made by Long Term Case Managers when the older person is living at high risk.

Although institutional care involves moving out of one's own home, the older person is encouraged to bring along important personal items to furnish his or her room. Generally, people living in these type of facilities have their own room and bathroom, although some may share with another person.

The older person who lives in an institution can get medical care whenever they need it. Nurses and long term care aides are present at all times to care for residents who are ill or confused. Doctors are also available if serious medical emergencies occur. Depending upon the seriousness of the situation, the doctor may come to see the older person, or may send the person to the emergency department of a nearby hospital.

Twenty-four hours assistance is also available for people who need help with walking, getting in and out of a bed or a chair, bathing, getting dressed, and using the toilet.

Older people who live in a Nursing Home or Long Term Care Facilities no longer have to be responsible for daily housekeeping activities. Cleaning staff look after their bedrooms and bathrooms, and do their laundry. Daily meals are prepared by kitchen staff and served in a nearby dining room. Usually, the resident can choose from at least two different types of meals. Separate meals are made for residents who are on special diets.

Residents can participate in a variety of recreational and social activities such as bus trips, arts and crafts, Bingo, clubs, and social get-togethers. There are large common rooms where residents can go to socialize. Visitors are welcome, and residents are encouraged to spend time away from the institution visiting with their family or friends.

*******NOW THAT YOU HAVE READ THE INFORMATION SHEETS, PLEASE COMPLETE PART TWO OF THE QUESTIONNAIRE*******

APPENDIX D

QUESTIONNAIRE - PART I FOR ELDERLY

1- Age _____

2- Sex _____

3- Marital Status _____ Single (never married) _____ Married/Common-law
_____ Separated/Divorced _____ Widowed

4 - Education _____ less than Grade 12 (specify) _____

_____ Grade 12

_____ College

_____ University

5- How would you rate your overall health?

1- very poor

2- poor

3- no more poor than good

4- good

5- excellent

6 - Do you receive the old age supplement or GAIN?

Yes _____ No _____

7 - What kind of work did you do, primarily, before retirement?

8 - In your working years have you ever worked in health care?

Yes _____ No _____

If YES, what did you do?

Did you work with old people?

No _____ Yes _____ years

9 - What is your living situation?

_____ alone with no family near by

_____ alone with helpful family close by

_____ with spouse

_____ other family

_____ with someone I provide care to

_____ in a facility

_____ other (specify) _____

10- How satisfied are you with your current living arrangements?

1- very unsatisfied

2- unsatisfied

3- no more unsatisfied than satisfied

4- satisfied

5- very unsatisfied

11- Do/have YOU receive(d) community support services?

Yes, now ____; Yes, before ____; Never ____

If YES how satisfied are/were you with the services?

1- very unsatisfied

2- unsatisfied

3- no more unsatisfied than satisfied

4- satisfied

5- very satisfied

12 - Do/have YOU receive(d) facility (nursing home) care?

Yes, now ____; Yes, before ____; Never ____

If YES how satisfied are/were you with the services?

1- very unsatisfied

2- unsatisfied

3- no more unsatisfied than satisfied

4- satisfied

5- very unsatisfied

13 - Are/have you been a family caregiver for an elderly person with dementia?

Yes currently _____; Yes, before _____; Never _____

If you answered NEVER do not answer the next questions – go onto
INFORMATION ABOUT COMMUNITY SUPPORT AND INSTITUTIONAL
SERVICES

If YES, what is their relationship to you?

Spouse _____

Parent/in-law _____

Sibling/in-law _____

Other (specify) _____

How long have you been a caregiver to this person? _____ years

Does this person live with you ?

Yes, currently _____; Yes, before _____; Never _____

If YES, for how long? _____years

Does/has this person receive(d) community support services?

Yes____; No____

Given the person's needs and limitations, how appropriate is (was) this kind of care?

1- very appropriate

2- inappropriate

3- no more appropriate than inappropriate

4- appropriate

5- very appropriate

Does/has this person receive(d) institutional care?

Yes____; No____

Given the person's needs and limitations, how appropriate is (was) this kind of care?

1- very appropriate

2- inappropriate

3- no more appropriate than inappropriate

4- appropriate

5- very appropriate

On the next page (INFORMATION ABOUT COMMUNITY SUPPORT AND INSTITUTIONAL SERVICES) you will find a description of community care available to elderly people who can no longer care for themselves. The description is based on British Columbia documents. The information was corroborated by two long term care case managers. The description is intended to describe Community Support Services available to frail older people in your community. Please read the description carefully and then turn to Part II of the questionnaire.

APPENDIX E

QUESTIONNAIRE - PART I FOR HCP

1 - Age _____

2 - Sex _____

3 - Marital Status _____ Single (never married) _____ Married/Common-law
_____ Separated/Divorced _____ Widowed

4 - Education _____ Physician _____ Social Worker
_____ Nurse _____ Other (specify: _____)

5 - How many years have you practised in your profession? _____ years

6 - In your professional career, how many years have you worked with elderly
people? _____ years

7 - What is your current role/position? _____

Is this in community?____; acute care?____; facility? ____other?
 (specify)_____

8 - How long, in your total career, have you worked in your profession?

in the community? _____years

in acute care ? _____years

in a long term care facility? _____years

9 - Are/have you been a family caregiver for an elderly person with dementia?

Yes currently____; Yes, past____; Never_____.

If you answered NEVER do not answer the next questions - go onto the information sheets.

If yes, what is their relationship to you?

Spouse _____

Parent/in-law _____

Sibling/in-law _____

How long have you been a caregiver to this person? _____years

Does this person live with you ? Yes, currently;

Yes____; past____; Never_____.

If yes, for how long? _____years

(PLEASE TURN OVER)

Does/has this person receive(d) community support services?

Yes____; No____

Given the person's needs and limitations, how appropriate is (was) this kind of care?

1- very appropriate

2- inappropriate

3- no more appropriate than inappropriate

4- appropriate

5- very appropriate

Does/has this person receive(d) institutional care?

Yes____; No____

Given the person's needs and limitations, how appropriate is (was) this kind of care?

1- very appropriate

2-inappropriate

3- no more appropriate than inappropriate

4- appropriate

5- very appropriate

On the next page (INFORMATION ABOUT COMMUNITY SUPPORT AND INSTITUTIONAL SERVICES) you will find a description of community care available to elderly people who can no longer care for themselves. The description is based on British Columbia documents. The information was corroborated by two long term care case managers. The description is intended to describe Community Support and Institutional services available to frail older people in your community. Please read the description carefully and then turn to Part II of the questionnaire.

APPENDIX F**QUESTIONNAIRE - PART 2 FOR ALL**

Keeping in mind the descriptions of and Community Support And Institutional Services that you have just read, please read the following vignette and answer the questions in PART 2 of the questionnaire.

VIGNETTE

Mrs. Smith is 84 years and lives alone, with no children living nearby. She has become increasingly frail. She is mobile and physically able to carry out ordinary activities of daily living such as getting dressed and bathing. She often needs reminders to bath or change her clothes. Mentally, Mrs Smith is sometimes confused. Although she can remember things such as her name and address, she is quite forgetful. She often loses or misplaces things, and sometimes she has difficulty remembering recent events. She is able to make some simple decisions for herself, like what clothes to wear, but she is unable to manage major things such as banking and finances. She can not make an adequate meal and has been known to burn pots. She does not feel she needs services.

Take a minute or two to try and imagine what this person is like, taking into account all of the characteristics described above. Then please answer the following questions.

QUESTIONNAIRE

1 - Overall, how safe do you feel Mrs. Smith is at this time? (She has no Community Support Services)

1- extremely unsafe

2- very unsafe

3- somewhat unsafe

4- safe enough

5- completely safe

2 - Please rate each of the following in terms of how much risk you think each factor poses to Mrs Smith ability to live independently at the current time: (Use "0" = no risk, 1 = insignificant risk; 2= mild risk; 3 = medium risk; 4 = substantial risk; 5= major risk).

___ self-injury

___ crime

___ isolation/loneliness

not eating properly

poor hygiene

not getting help quickly if sick or falls

3 - Given her needs and limitations, and the information provided about each type of care, which type of care do you feel is best suited for Mrs Smith? (Please check).

Institutional Care ; Community Support ; Neither .

4 - Please circle how much each of the following influenced your decision?

Safety Concerns

0 no influence - not an issue

1 insignificant

2 mildly

3 quite a bit

4 substantial influence

5 major influence

Health Needs

0 no influence - not an issue

1 insignificant

2 mildly

3 quite a bit

4 substantial influence

5 major influence

Social Needs

0 no influence - not an issue

1 insignificant

2 mildly

3 quite a bit

4 substantial influence

5 major influence

Personal Care Needs (bathing, toileting, meals)

0 no influence - not an issue

1 insignificant

2 mildly

3 quite a bit

4 substantial influence

5 major influence

Need for Supervision

0 no influence - not an issue

1 insignificant

2 mildly

- 3 quite a bit**
- 4 substantial influence**
- 5 major influence**

Burden on Family/Friends

- 0 no influence - not an issue**
- 1 insignificant**
- 2 mildly**
- 3 quite a bit**
- 4 substantial influence**
- 5 major influence**

Other _____

5 - If you chose Community Support Services, please answer the following questions, otherwise go to Question 6.

(a) How safe do you feel Mrs Smith is with Community Support Services in place?

1 extremely unsafe

2 very unsafe

3 somewhat unsafe

4 safe enough

5 completely safe

(b) Imagine that Mrs Smith refuses Community Support Services. What would be the most appropriate thing to do?

1 - Place her in a long-term care facility to ensure her safety

2 - Attempt to persuade/coerce her into accepting the services for her own good

3 - Respect her wishes - she has a right to her choice

4 - Other

6 - If your original choice for Mrs. Smith was Institutional Care imagine that she is adamant about remaining at home "no matter what", and refuses placement. Circle the most appropriate thing to do now.

1 - Place her in a long-term care facility to ensure her safety, in spite of her wishes

2 - Attempt to persuade/coerce her into accepting long-term care facility placement for her own good

3 - Respect her wishes - she has a right to her choice-provide Community Support Services and see how she manages

4 - Respect her wishes - she has a right to her choice - but do not provide Community Support Services

5 - Place her in a long-term care facility - someone could be sued if something happens to her.

6 - Other _____

7 - Recall Mrs Smiths circumstances. Now imagine that her adult children who try to provide help at a distance are increasingly worried about what may happen to their mother. They want her to be placed in a long term care facility to keep her safe, even though she objects.

(a) Do the wishes of the children alter your decision above?

Yes _____; No _____

(b) If yes, please explain why:

(c) If yes which choice would you make for Mrs. Smith now?

1 - Place her in a long-term care facility to ensure her safety, in spite of her wishes

2 - Attempt to persuade/coerce her into accepting long-term care facility placement for her own good

3 - Respect her wishes - she has a right to her choice-provide Community Support Services and see how she manages

4 - Respect her wishes - she has a right to her choice - but do not provide Community Support Services

5 - Respect her wishes - the children do not have the right to direct her care.

6 - Place her in a facility - she has no right to burden her children.

7 - Place her in long-term care facility- someone could be sued if something happens to her.

8 - Other _____

**PLEASE RETURN BOTH PART 1 AND PART 2 OF THE QUESTIONNAIRE IN THE
RETURN ENVELOPE PROVIDED TO :**

Penny MacCourt, 2940 Killarney Place, Nanaimo, BC, V9T 1A6.

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY.