

**DISCUSSION AND COMPLETION
OF ADVANCE DIRECTIVES
AMONG COMMUNITY DWELLING
OLDER ADULTS**

BY

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A Thesis

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In Partial Fulfilment of the Requirements
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Discussion and Completion of Advance Directives Among
Community Dwelling Older Adults

BY

Carole F. Hamel

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
of

Master of Nursing

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Abstract

Advance directives (ADs) in Manitoba are documents that allow competent individuals to set forth their medical treatment wishes and to name a health care proxy in the event that they lose the capacity to make or communicate these decisions at some time in the future. Despite the benefits of such documents and widespread support for advance planning, very few people have completed an advance directive. Using the Health Belief Model as a conceptual framework, this post-test only experimental study examined whether an individualized intervention (phone call reminder) given to half of the older adults who attended an AD educational session increased the discussion and/ or completion rate of ADs. Two questionnaires (self-administered and telephone) were administered to a convenience sample of 74 older adults living in a large midwestern Canadian city, who had been randomly assigned to control and intervention groups. Of the 74 participants, 25.7% ($n = 19$) completed an AD. There were no significant differences between control and intervention groups on the discussion and/ or completion of ADs. Both bivariate and multivariate analysis suggested a significant relationship between AD discussion and completion and perceived barriers associated with ADs. Overall, the study findings indicate a positive attitude toward advance directives and their completion, but significant barriers to discussion and completion included a present orientation, procrastination, busy lifestyles, and not thinking about one's own death. Future research is needed to explore factors influencing completion and non-completion of ADs.

TO MY LOVING HUSBAND, ANDRE
AND MY TWO WONDERFUL CHILDREN, AMANDA AND DALE

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Chapter One

Statement of the Problem

With the increasing capabilities of medical technology to extend life, the distinction between life and death has become blurred. At times of severe illness, some elderly patient's lives are extended through medical life support, including such measures as cardiopulmonary resuscitation (CPR), use of respirators, tube feedings, and intravenous fluids and medications. The conviction to preserve life and cure disease has inadvertently suspended some patients in a "living death". Conscious, competent adults have the right to refuse medical care, but this right is denied when an individual is unable to make informed decisions due to incapacity (Moore & Sherman, 1999).

Without clear directions as to a patient's preferences regarding life-sustaining treatment, emotional and monetary costs can run high for family members and health care providers when they experience someone being kept alive with medical support. Life support measures can cause prolonged suffering, pain, and degradation for the patient, thus reducing quality of life. Some people choose to be free from interventions that prolong the dying process. Nursing literature is rich with suggestions for preserving self-determination, or autonomy, at the end of life (Hackler, Moseley, & Vawter, 1989; King, 1991). In response to these issues of promoting autonomy and reducing ambiguity, conflict, and cost surrounding end of life decisions, advance directives have been developed (Moore & Sherman, 1999; Nazerali, Ska, & Lajeunesse, 1998; VandeCreek & Frankowski, 1996).

The province of Manitoba introduced legislation on advance directives (ADs) in 1992. An AD allows competent adults to retain control over their health care by documenting how medical decisions should be made if they should become mentally or physically unable to communicate their wishes (Luptak & Boulton, 1994). Completing ADs is critically important in today's society where advanced medical technology has led to increasing pressures to keep bodies alive longer than quality of life can be maintained (Parker & Nettles-Carlson, 1995).

Surveys and research studies involving both patients and physicians have found widespread support for ADs, and provide evidence that patients (Bedell & Delbanco, 1984; Cugliari, Miller, & Sobal, 1995; Davidson, Hackler, Caradine, & McCord, 1989; Emanuel, Barry, Stoekle, Ettelson, & Emanuel, 1991; Lo, McLeod, & Saika, 1986; Singer, Choudhry, & Armstrong, 1993), and especially those who are older (Kohn & Menon, 1988; Schmerling, Bedell, Lilienfeld, & Delbanco, 1988), want to be involved in planning for end of life care. Research findings suggest that many people choose a natural death when presented with accurate information about end of life treatments (Emanuel et al., 1991; Parker & Nettles-Carlson, 1995; Stolman, Gregory, Dunn, & Levine, 1990). Protecting clients' choices for end of life care is an ethical and professional duty of each nurse (Scanlon, 1993).

However, despite legislation and a positive attitude toward advance planning, a relatively small number of people have actually written an advance directive. Based on American studies, fifteen to 25% of the general population

(Cugliari et al., 1995; Emanuel et al, 1991; Gamble, McDonald, & Lichstein, 1991; Rodriguez, 1990; Palker & Nettles-Carlson, 1995; Stelter, Elliott, & Bruno, 1992; Stolman et al., 1990); and 1% to 40% of adult hospitalized patients and nursing home residents have an AD (Cohen-Mansfield, Droge, & Billig, 1991; Emanuel & Emanuel, 1989; Janovsky & Rovner, 1993; Stelter et al., 1992; Suri, Egleston, Brody, & Rudberg, 1999). Rates of AD completion among community dwelling elderly persons appear to be little or no higher than those for the overall population, ranging from 0 to 17.5% (Gamble et al., 1991; High, 1988; Zwiebel and Cassel, 1989).

Health care literature contains little explanation of why individuals fail to prepare advance directives (Lynn and Teno, 1993). In 1993, Lynn and Teno reviewed the literature on ADs and emphasized that empirical research was needed to identify the reasons why people do or do not write ADs, and to examine whether the rate of AD use can be improved. Since that time, investigators have begun to explore some of the reasons why ADs are underused and to identify factors associated with their completion, but little has been documented about the specific reasons that people give for why they have or have not completed an AD (Fairchild, 1998; Heffner, Brown, & Barbieri, 1997; Hofman et al., 1997; Stelter et al., 1992). The nursing literature is highly supportive of documenting patient choices. Scanlon (1993) insists that nurses must ensure that clients are aware of advance directives. Dimond (1992) also argues that nurses should actively engage their clients in discussions about end of life care as a general principle of health care.

Given the widespread support for the concept of ADs, juxtaposed against their infrequent completion, more research is needed to identify both enabling factors and barriers to their completion, including the use of various interventions to trigger completion. Generally, studies of interventions to increase use of ADs in both hospital and outpatient settings have increased completion rates from zero to 22% (Cugliari et al., 1995; Hare and Nelson, 1991; Rubin et al. 1994). Some studies have achieved higher rates of completion (44% to 71%), depending on the type of intervention involved (High, 1994; Luptak & Boulton, 1994; Meier et al., 1996; Reilly et al., 1994; Sachs, Stocking & Miles, 1992). Further research is warranted to identify specific interventions that increase AD completion in order to better promote ADs to the general public (Rosenstock, 1966; Stelter et al., 1992). Identifying and exploring barriers to communication may help health professionals promote more effective discussions by providing patients with more appropriate and useful information (Hofman et al., 1997). Increased satisfaction with ADs is expected to enhance public use of these documents (Fade, 1993).

The purpose of this study was to determine whether an individualized intervention (a phone call reminder and offer of more information) would lead to increased discussion and completion of ADs in a sample of older adult community dwellers. All participants attended an educational session on ADs, and then were randomly assigned into control and intervention groups. The control group received the education session only. The intervention group received a phone call from the researcher at one month after the education

session to ask if they had any questions about advance directives, and to offer more information if they expressed an interest in AD completion. At the end of the three month study period both groups received a phone call interview to see if they had completed an AD or had discussed ADs with someone. The initial self-administered questionnaire, as well as telephone interview by the researcher, determined the factors associated with discussing and completing ADs in both groups. Nurses and other health care providers can use findings from this study to determine effective and ineffective measures to increase the use of ADs, and thereby promote a more dignified death for older adults.

Chapter Two

Literature Review

In the following review of the literature on advance directives and advance care planning (ACP) definitions of advance directives (ADs), the history of ADs, the advantages and problems associated with ADs, the rate of completion of ADs, factors associated with completion or noncompletion, and interventions to increase the completion of ADs are discussed. Major areas of agreement between the various research studies are identified, as well as gaps in the research.

Definitions:

Broadly defined, an AD is “a written document in which a competent person sets out health care preferences before incapacity occurs” (Markson, Fanale, Steel, Kern, & Annas, 1994, p. 2321). In the United States and Australia, advance directives may include two documents: one in which individuals can specify their wishes for future medical treatment (instruction-type directive or living will), and another in which they can appoint an individual (or proxy) to make medical treatment decisions on their behalf when they become incompetent (durable power of attorney for health care) (Grossberg, 1998; Stelter et al., 1992). There is some disagreement as to which type of format is most useful. Instruction directives are extremely valuable when they contain instructions that apply to the patient’s actual circumstances. However, circumstances often arise that were not anticipated or addressed in the directive. Proxy directives are straightforward documents that identify a decision maker for all circumstances;

however, they may provide little in the way of substantive guidance for decision making (Markson et al., 1994). For many people, there is no person that they would be comfortable with as an agent to make all health care decisions (Orentlicher, 1990). Some hybrid directives, such as those in Manitoba, incorporate features of both types just described. ADs in Manitoba are documents which allow a competent individual to set out future medical treatment wishes and to name a health care proxy in the event that they lose the capacity to make and communicate health care decisions (Manitoba Law Reform Commission, 1991).

In an AD, individuals can express wishes ranging from having all possible accepted medical treatments carried out, to having all life-prolonging procedures withheld or withdrawn if they are persistently unconscious or if there is no reasonable expectation of recovery from a seriously incapacitating or terminal illness. Life-prolonging procedures include artificially supplied nutrition and hydration, such as tube feedings and intravenous (whether temporary or permanent), cardiopulmonary resuscitation (CPR), mechanical ventilator use, as well as other life-prolonging medical or surgical procedures that are intended to keep the person alive without reasonable expectation of improving their condition or curing their illness or injury (Grossberg, 1998).

The concept of advance care planning (ACP) is also pertinent to the discussion of ADs. ACP planning is the process of reflection, discussion, and communication of treatment preferences for end of life care that precedes and may lead to an AD. Several authors have proposed that ACP may be more

important to individuals than completion of a written document (Martin, Thiel, & Singer, 1999; Miles, Koepp, & Weber, 1996; Singer, Martin, Lavery, Thiel, Kelner, & Mendelssohn, 1998; Teno, Nelson, & Lynn, 1994). Discussion about end of life care with significant others fulfills important psychosocial goals such as preparing for death, achieving a sense of control, and strengthening relationships with loved ones. Often, once these goals have been met, patients no longer feel the need to complete a written AD (Martin, Thiel, & Singer, 1999).

History/ Legislation:

Advance directives and living wills are fairly new concepts in health care. In the United States, the term "living will" was first coined in 1969 (Annas, 1995; Callahan, 1995; Eisendrath & Jonsen, 1983; Stelter et al., 1992). California was the first state to recognize living wills in 1976 (Wold, 1992). Interest in living wills has continued to expand over the past 20 years, and now all the American states and the District of Columbia have statutes about living wills or powers of attorney (High, 1993a; Stelter et al., 1992).

Canada has recently adopted legislation on ADs. In Manitoba, a discussion paper on advance directives and durable powers of attorney for health care was published in July 1990, and a report called *Self-Determination in Health Care (Living Wills and Health Care Proxies)* was published in 1991 by the Manitoba Law Reform Commission. Bill 73, *The Health Care Directives and Consequential Amendments Act* was passed in the third session of the 35th legislature of Manitoba in 1992, and the *Manitoba Health Care Directives Act* was proclaimed in 1993 (Singer et al., 1993). Various forms of advance directive

legislation also exist in Nova Scotia, Quebec, Ontario, Alberta, Newfoundland, Prince Edward Island, and Saskatchewan (Singer et al., 1993; University of Toronto Joint Centre for Bioethics, 1999). See Appendix A for the name of legislation in each province.

In order to support and promote the completion of ADs in the United States, the American government passed the Patient Self-Determination Act (PSDA) in December 1991, following the U.S. Supreme Court decision on living wills in the Cruzan case. Nancy Cruzan was a 25-year old woman left in a persistent vegetative state after a car accident, who was denied removal of nutritional support as requested by her parents, because there was no "clear and convincing evidence" in a written statement that this would have been Nancy's wishes (Saultz, 1990). The PSDA requires all health care institutions (hospitals, nursing facilities, hospice programs, and health maintenance organizations) that receive federal reimbursement to inquire whether adult patients have advance directives, to educate patients about advance directives, and to document their wishes for life-sustaining treatment in certain situations (Bradley, Walker, Wette, & Horwitz, 1998; Emanuel, Emanuel, Stoeckle, Hummel & Barry, 1994; Grossberg, 1998; Stelter et al., 1992).

Although no similar federal legislation exists in Canada, ADs are endorsed by several national and provincial professional organizations such as the Canadian Nurses Association, the Catholic Health Association of Canada, the Canadian Medical Association, and the College of Physicians and Surgeons in Manitoba. Thus, in Canada there exists legislative and organizational support

provincially and organizational support nationally for ADs.

Why are advance directives important? What are their advantages and problem areas?

There are both advantages and problems associated with the use of ADs (Grossberg, 1998). The following sections deal with first, the advantages of ADs and why they are important, and secondly, the problems that ADs possess.

Advantages: The importance of ADs is underscored by recent issues and trends including: an increasing proportion of older adults needing to make end of life decisions, advances in medical technology, desire for patient autonomy, surrogate decision making not always indicative of individuals' wishes, and a desire to control health care costs (Layson et al., 1994). The advantages of ADs in light of each of these trends is discussed in more detail. The absence of an AD raises critical and difficult questions of what medical steps to take and who should make decisions about medical care (Grossberg, 1998).

Address the Wishes of an Increasing Proportion of Older Adults: Although illness and accident can occur at any age, facing one's mortality and determining ADs is a more immediate issue for older adults. Canadian seniors represent a growing population in Canada. Presently, Canadians 65 years and over constitute approximately 12% of the population, and by the year 2031 it is anticipated that they will represent 23% of Canadians (Statistics Canada, 1997; Task Force on Canada in 2030, 1996). As of June 1, 1995, approximately 13.6% of Manitoba's population was age 65 or over. Of these, it is estimated that approximately 24% were more than 80 years of age. By the year 2005, it is

expected that the senior population in Manitoba will not only increase, but it will age, with the numbers of individuals more than 80 years reaching 32% of an estimated 161,300 seniors (Statistics Canada, 1997). Given that the population is aging, that older people are extensive users of formal health services, and that decisions whether to use life-prolonging treatment will have to be made by about 70 percent of older adults (Christie, Skinner, & Weatherill, 1997), the use of advance directives is an important consideration (Bradley et al., 1998; Miles & Gomez, 1989).

Promote a good death in the face of medical technology: The aging of the population and the wide availability of advanced medical technology has led to increased pressures to keep bodies alive longer than quality of life can be maintained (Palker & Nettles-Carlson, 1995; Storch & Dossetor, 1994).

Physicians in hospitals have a great deal of control in medical decision making, and to date the socialization, education, and values of physicians and nurses has been directed toward the preservation of life. Thus, the decision to let a patient die is sometimes difficult, especially when technology exists to keep them alive (Wold, 1992). There is a reluctance to "lose" patients (Basile, 1998), and a peaceful death may be denied by an overwhelming desire to take action, to cure the problem, and to do something to overcome the debilitating force of disease and the sense of helplessness it might evoke (Kaufman, 2000; Marshall, 1995).

Callahan (1995) suggested that changes in technology and the role of medicine in alleviating pain and suffering have created "longer lives and worse health, longer illness and slower deaths, and longer aging and increased

dementia". The prospect of a painful, drawn-out and burdensome death spurred development of laws and forms to facilitate documentation and implementation of end of life treatment preferences. Widespread adoption of treatment directives may enable more people to attain a more peaceful death, different from the sudden and painful passing of their ancestors, and better than the drawn-out and often painful deaths of their peers (Richter et al, 1995).

A "good death" expresses a cultural ideal in which dying persons can freely reject use of medical technologies that prolong the dying process, are able to manage their own pain, and can control the environment of their deaths (Kaufman, 2000). A good death is achieved when end of life planning is combined with an ethic of care that ensures that the actual process of dying incorporates factors such as readiness to die, appropriate interpretation of advance directives, and proper timing of death (Basile, 1998; Lynn et al., 1997; Moskowitz and Nelson, 1995). A study of renal failure patients on chronic dialysis suggested that the outcome is more favorable when patients with ADs withdrew from treatment in a "reconciled fashion" (Swarz & Perry, 1993). They concluded that addressing ADs before a medical crisis ensues may increase the likelihood of a good death (one more in keeping with their wishes).

Enhance autonomy: Over the past several decades there has been rising support and increasing emphasis on individual autonomy, and expanded opportunities to express preferences and make choices about health care decisions. One aspect of autonomy is the right of the individual to control his or her own life (Wetle, 1995). No longer passive recipients of health care, people

expect to influence the decisions directly affecting them. This involvement has moved the ethical principles of autonomy, justice, and beneficence, self-determination, and choice to the forefront of clinical practice (Callahan, 1995; Kohn & Menon, 1988). The importance of empowering older adults to gain greater control over their health and personal care, strengthening their role in decision making, and allowing them to make informed choices is being increasingly recognized (Molloy, Russo, & Pedlar, 2000).

Discussing and completing ADs may enhance autonomy. Studies have shown that AD communication with a physician decreases a patient's depression, enhances a sense of being in control, and helps to stabilize treatment preferences (Miles et al., 1996). Advance directives enhance autonomy at the end of life by allowing individuals to choose the type of care that fits with their wishes and beliefs and by increasing the chance that they will receive the type of care they want (Gleeson & Wise, 1990; Murphy, 1990; O'Brien et al., 1995). Some people fear that they will languish for months or even years, perhaps in a vegetative state, unable to control their medical treatments. They fear that they will be subjected to procedures that may save their lives, but will reduce or destroy the quality of that life. Choices may be made on their behalf that they would not have approved. An AD is one way individuals can exert some control over end of life decision making (Emanuel et al., 1991; Wold, 1992).

Health care professionals suggest that ADs have the potential to be a very important component of medical decision making (Emanuel, 1995; Lynn & Teno,

1993). A fundamental claim of medical ethics today is that “the decisions made in the care of a patient should be those that are expected to deliver the best possible outcome for that patient, as judged by the patient” (Lynn & Teno, 1993, p. 20). However, when the patient cannot make his or her own assessment of alternative outcomes it is very difficult for others to make decisions that reflect patient preferences. ADs provide a way for the individual's authority to endure into a period of incompetence and thereby make the medical decision making more expeditious and congruent with the individual's own preferences. Having the individual make AD decisions in advance of incompetence allows others to avoid the often quite difficult and uncertain task of making choices for them, and provides a way for the individual to maintain responsibility for decisions (Lynn & Teno, 1993).

Avoids problems with surrogate decision making: Another benefit of completing an AD is that an individual's wishes are carried out without total reliance on surrogate decision makers (proxies). Some commentators have argued that proxy decisions are less representative of a individual's wishes than treatment preferences expressed in an AD (Emanuel & Emanuel, 1989; Orentlicher, 1990). Without advance planning, conflicts often exist among individual wishes, family choices, and physician recommendations on the procedures to be performed. These conflicts may prevent a good dying experience for individuals and their families (Basile, 1998).

Simply relying on family members or physicians to make accurate end of life decisions is not sufficient, as several studies have demonstrated that both

physicians and family members are not always able to accurately predict individual wishes (Bedell & Delbanco, 1984; Lynn & Teno, 1993; Uhlman, Pearlman, & Cain, 1988). For example, a study by Cohen-Mansfield, Droge and Billig (1991) showed that physicians often can either over or under estimate the degree of aggressiveness with which a patient would want to pursue end of life choices. A spouse, on the other hand, will tend to be more aggressive than the patient and will usually overestimate how much treatment the patient would want. Other studies have found discrepancies between what the surrogate chose and what the patient would have chosen in the same circumstances (Hare, Pratt, & Nelson, 1992; Zwiebel & Cassel, 1989). With advances in medical science, this responsibility becomes more onerous for family and significant others. Recent studies have concluded that families are poor substitute decision makers for elderly relatives as their estimates of preferences do not greatly differ from chance, suggesting that decisions made by family members should be supported by evidence of the patient's own wishes (Miles et al., 1996; Sonnenblick, Friedlander, & Steinberg, 1993; Uhlmann et al., 1988; Zweibel & Cassel, 1989).

The findings on surrogate decision making are often taken as a strong argument for encouraging advance directives, since relying on a family surrogate appears flawed. The results of these studies underscore the importance of effective patient-surrogate communication before patient decision making incompetence occurs and of completing ADs to ensure that the patient receives the care he or she desires (Grossberg, 1998; Hare, Pratt, & Nelson, 1992). However, two studies suggest that patients prefer to identify a surrogate decision

maker rather than focus on the details of the decisions made (High, 1993b; Kapp, 1991).

Potential cost control: In recent years, health professionals, legislators, and patients alike have expressed discontent with the high cost of end of life medical care (Marshall, 1995). Physicians have been accused of using complex technology to prolong the dying of the old, resulting in the disproportionate use of health care resources in the period immediately preceding a patient's death. There is hope that the widespread use of advance directives will give physicians permission to abandon aggressive treatments in the face of terminal illness and that this will result in cost savings (Hesse, 1995).

Given the findings that many older adults will choose less intensive therapy when they are offered alternative treatment strategies (Cohen-Mansfield et al., 1991b; Fried and Gillick, 1994; Reilly et al., 1994), and that many dying persons are receiving more resource-intensive medical care than they want (Rodriguez, 1990), use of advance directives could potentially save money. Following an individual's wishes to limit treatment could save costs both financially, and as measured in human suffering (Callahan, 1995).

There are conflicting opinions on how much money is spent on care at the end of life (Bayer et al., 1983; Emanuel & Emanuel, 1994), and indeed whether the presence of ADs leads to cost savings (Emanuel & Emanuel, 1994; Loewy & Carlson, 1994; Singer & Lowy, 1992). Some studies found no evidence of cost savings related to the use of ADs (Schneiderman, Kronick, Kaplan, Anderson, & Langer, 1992); while other studies have shown significant cost savings related to

physicians' awareness of treatment preferences regarding do not resuscitate orders (Teno et al., 1995); and cost savings in hospital charges during the last hospitalization of a patient's life associated with a discussion of advance directives (Chambers, Diamond, Perkel, & Lasch, 1994). Molloy et al. (2000) found that systematic implementation of an AD program in nursing homes resulted in fewer hospitalizations per resident and less resource use (average total cost per resident, \$3490 vs \$5239 Canadian dollars, $p < .01$) than control nursing homes with no AD program.

Despite a lack of clear evidence, it seems reasonable to assume that as new medical technologies lengthen the time span between onset of terminal illness and death, and as the number of persons over age 65 (the largest age group of terminally ill patients) increases, the cost of care for the terminally ill will surely rise above its present level (Bayer et al., 1983). If patients and their families had greater decision making powers to limit care, the cost of care at the end of life might be reduced. However, the cost-saving effects of ADs will vary according to the institution, population, and degree to which ADs change the course of medical care (Miles et al., 1996).

Whether money should be spent on care which patients do not want is a dilemma. Some find it hard to justify spending scarce resources on mechanical ventilation and CPR in patients with end stage diseases when many other services are cut. ADs provide the opportunity to prevent society from delivering invasive, painful, undignified, and wasteful high technology care to patients who neither want nor can benefit from that care (Berwick, 1995).

From the preceding discussion, it is suggested that ADs provide an opportunity to allow an increasing proportion of individuals who will be faced with end of life decisions to exert autonomy in end of life decision making. Such decision making promotes the likelihood of a better death, and one that incorporates individuals' wishes. By providing direction for care in an AD, it is also likely that costs, both in terms of human suffering and economics, will be reduced.

Problems: Although there are several advantages to completing an AD, there are also several problems associated with them as well. These problems include concerns with the vagueness of the document, decisions based on hypothetical situations, uncertainty regarding end of life care, instability of treatment choices, and noncompliant medical treatment or problems with communication of treatment decisions. The great difficulty of anticipating, articulating, and then communicating wishes for care in case of incompetence makes the likelihood that any person can accurately convey their wishes to another person uncertain (Emanuel, Danis, Pearlman, & Singer, 1995). Each of these potential problem areas with ADs will now be discussed in greater detail.

Vagueness of document: The language in an AD can be vague, ambiguous, and open to interpretation. For example "heroic measures", "extraordinary care", and "artificial nutrition" can mean very different things to different people (Dimond, 1992; Wetle, 1995). If the directions in an AD are not specific and clear, physicians or the courts may disregard them (Orentlicher, 1990).

Hypothetical situations: Opponents often denounce ADs for requiring

individuals to make decisions regarding life-sustaining treatments based on hypothetical situations. The assumption underlying ADs is that individuals are able to imagine situations in which they might subsequently find themselves, and to decide what approach to care they would want under such circumstances. Some documents demand that individuals specify in detail which of a variety of technological interventions they would want if they found themselves in one of a number of devastating clinical situations. However, most people have limited experience with such situations and would not be able to make appropriate decisions (Gillick, Hesse, & Mazzapica, 1993). Many people do not understand medical terms used by physicians, such as “being resuscitated” or “being on a ventilator” (Loewy & Carlson, 1994). When the actual clinical situation evolves, with all of its intricacies, the AD may not be applicable or may not address the realities of the current situation. An AD cannot substitute for a human being’s interpretative and assessment abilities, nor can it interact with the health care team (Dimond, 1992).

Uncertainty regarding end of life care: In a similar vein, it is often presumed that people will know what they really want in terms of care at the end of their life, that they can know in advance what they want, and that clear choices (yes/no, on/ off) will present themselves. This may be a wrong, excessively rationalistic presumption. Callahan (1995) says with introspection: “I wish I knew myself that well--and especially knew how I will react to the once-in-a-lifetime circumstance of my dying. Where am I supposed to get that kind of knowledge about myself, much less certainty about what I think I know? Where is anyone to

get it?" (p. S34). Individuals can change their mind, not really know their mind in the first place, or fail to understand the ambiguous circumstances that may arise regarding end of life situations (Callahan, 1995).

Instability of choices: The common assumption justifying the use of ADs is that an individual's prior expression of treatment choices accurately represents his or her future choices; that is, treatment decisions are stable over time. Various studies have produced mixed results, but generally show that AD preferences are stable for months to a couple of years (Miles et al., 1996). Emanuel et al. (1994) found that patients and members of the public can make advance choices that are reasonably stable, that their choices become more stable with repeat consideration, especially if they have discussions with their physicians, and that illness had little effect on the stability of choices. Their findings also suggested that stability may be improved by periodic review of decisions and discussion with physicians; and that ADs can be relied on 1 to 2 years after completion to reflect a person's choices.

Thus, the choices listed on an AD can only be assumed to be accurate within a fairly short time frame, unless ongoing discussions occur. Treatment preferences may not remain stable as health changes, particularly for those with lower functional status (Finucane, Shumway, Poweres, & Alessandri, 1988; Hesse, 1995). In addition, life events, such as experiencing the prolonged suffering of a loved one or limited access to necessary treatment, may influence preferences and whether they will apply for the long term (Wetle, 1995). Kohut et al., (1997) concluded that patients and doctors should consider the treatment

preferences that are recorded in ADs to be unstable, and encourage people to update their ADs at regular intervals. The opportunity to review one's previous preferences might have an anchoring effect and reduce the instability of treatment preferences.

Noncompliant medical treatment and problems with communication of treatment decisions: Two closely related problems with advance directives are that caregivers may choose not to comply with AD wishes for a variety of reasons, or may not clearly understand the wishes of patients due to problems with communication. Perhaps the gravest problem with ADs is that it is not always clear if they will be obeyed, particularly in a medical emergency. A patient who has a "do not resuscitate" order, for example, may receive CPR in the middle of an acute medical emergency (Grossberg, 1998). According to some authors, formal ADs appear to play only a small role in medical decision making (Greco, Schulman, Lavizzo-Mourey, & Hansen-Flaschen, 1991; Hesse, 1995). One study found "little evidence that [ADs] are associated with enhanced communication" (Virmani, Schneiderman, & Kaplan, 1994), while another found that such a legal document "had no significant positive or negative effect on a patient's well-being, health status, medical treatments, or medical treatment charges" (Schneiderman et al., 1992). This lack of effect of ADs could be related to significant others or physicians not being aware of the existence of an AD, or to a deliberate disregard of the wishes expressed in an AD. For example, physicians are often unaware that their patients have ADs, and very few have had any discussion of treatment decisions with their patients (Virmani et al., 1994). As well, family

members may not comply with ADs for a number of reasons. A study of 108 adult offspring of 48 terminally ill elderly showed that 50% did not comply with their parents' wishes, despite knowing what they wanted (Sonnenblick et al., 1993). Even in the presence of an AD, grieving significant others often struggle with problems of their own, find it hard to let go, and so often disregard loved ones' wishes to forego treatment.

However, other studies point in a different direction. Danis et al. (1991) studied 175 nursing home residents (126 outpatient and 49 inpatients) who had initiated ADs. The medical care they received was consistent with the directive in 75% of the cases. The reasons cited for not following the directive in the remaining 25% of cases included: initial preferences that were too restrictive to allow appropriate care, treatments outlined that would not benefit the patient, patients or family members changing their minds, or providers not being aware of the existence of an AD. Hammes & Rooney (1998) found that treatment preferences expressed in advance directives seemed to be consistently followed while making end of life decisions in their study of 540 decedents in La Crosse County in Wisconsin (of whom 85% had advance directives).

Problems with communication, especially between patients and their physicians, is a definite barrier to the successful implementation of ADs. The delivery and execution of ADs are fairly new to the medical profession, and some clinicians are reluctant to discuss them because of lack of time or knowledge, inaccurate beliefs, and discomfort with the subject (Morrison, Morrison, & Glickman, 1994). Promoting self determination is a complex and hard task

because it raises a number of problems: dealing with such deep issues as life, death, self-knowledge, the proper use of technology, and the patterns, practices, and institutions of medicine and health care (Callahan, 1995). The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) highlights such problems with communication.

One goal of the SUPPORT study was to increase communication with and understanding of a hospital's dying patients and to aid in benevolent care. Doctors received a prognosis of survival report for each patient experiencing a life-threatening condition, and reports on patients' specific wishes in terms of CPR and ADs. Nurses were responsible for communication among patients/proxies and the health care team. Doctors were responsible for writing the DNR orders. The outcomes of this massive four year study of 9,105 hospitalized patients were disturbing. There was no significant improvement in the timing of DNR orders, in physician-patient agreement on DNR orders, in the number of undesirable hospital days, in the prevalence of pain, or in resources consumed. The study found that "while 59% of physicians were aware of receiving the prognostic report and 34% reported receiving written information regarding patient preferences, only 15% actually discussed this information with the patient or proxy" (Moskowitz & Nelson, 1995). This physician-focussed study demonstrated that communication was not improved despite intense efforts (Basile, 1998).

However, a number of commentators on SUPPORT (writing in the 1995 Hastings Center report titled "Dying Well in the Hospital") found the study

methodology flawed, with too heavy a dependence on nurses, too little attention paid to the means of communication, and lack of flexibility and possibility of change as the study progressed (Berwick, 1995; Emanuel, 1995; Lo, 1995; Marshall, 1995).

In addition, some of the assumptions of the study may have been incorrect. For example, the subject of end of life care might have been broached too late in the illness continuum and in a time of stress. As well, the fundamental assumption that the course of care for the seriously ill hospitalized patient is the result of the decision making of the patient, and could therefore be improved with better counseling by health care providers, may be false. Instead, the course of care may well be shaped largely by how the care system is organized and by the interpersonal meanings ascribed to various cues and signals that shape the predictable patterns of care (Lynn et al., 2000).

All commentators on SUPPORT do not doubt the necessity of continuing the struggle to better manage patient care at the end of life, but the diversity of the responses suggests that much work still needs to be done. Improving communication between physicians and patients about end of life care appears to be a difficult challenge. No one fully understands what most patients really want, including the patients themselves, or what is involved in the promotion of good communication between doctor and patient. Research might be more fruitful if it shed light on the psychological, sociological, and anthropological factors that shape the course of care (Lynn et al., 2000). Work must continue to refine ADs and the communication between doctors and other health care

professionals and patients, and to stimulate in society more broadly an engaged dialogue about the meaning and place of death in human life (Callahan, 1995).

Despite the various problems associated with ADs, these documents can be an important method to foster autonomy. Many of the problems can be handled by ongoing discussions with physicians and family, and by naming a health care proxy. Family physicians or other health care providers, who remain in a relationship with patients and families over time, are in an excellent position to discuss values and preferences, share informational resources, and help articulate advance directives. As stated previously, an individual's wishes may change over time and so an ongoing relationship and knowledge gained over time is important (Palker & Nettles-Carlson, 1995).

Do patients and physicians support advance planning?:

Substantial evidence in the literature suggests that patients want to be involved in discussions about the use of life-sustaining treatment and about advance planning in general (Bedell & Delbanco, 1984; Elpern, Yellen, & Burton, 1993; Emanuel et al., 1991; Kohn & Menon, 1988; Lo et al., Schmerling et al., 1988). Surveys of both patients and physicians have found widespread support for advance directive documents (Cugliari et al., 1995; Davidson et al., 1989; Emanuel et al., 1991; Moore & Sherman, 1999; Orentlicher, 1990; Singer et al., 1993; Storch and Dossetor, 1994). Emanuel et al. (1991) found that of 405 outpatients and 102 healthy subjects, 93% of the outpatients and 89% of the healthy subjects wanted some form of AD. Doukas (1999) states that ADs offer a sense of control, liberty, and dignity. Patients have a right to information about

ADs. Patients need to be well informed if they are to be free to discuss their concerns and to be well grounded in their end of life decisions.

Rate of completion of ADs:

Despite public and private endorsement of ADs as well as educational efforts, few people have actually formalized their preferences for health care treatment with a written document (Hare et al., 1992). Based on primarily American research, fifteen to 25% of the general population (Cugliari et al., 1995; Emanuel et al., 1991; Gamble et al., 1991; Rodriguez, 1990; Palker & Nettles-Carlson, 1995; Singer et al., 1993; Stelter et al., 1992), and 1% to 40% of adult hospitalized patients and nursing home residents have an AD (Cohen-Mansfield et al., 1991; Emanuel & Emanuel, 1989; Janovsky & Rovner, 1993; Stelter et al., 1992; Suri et al., 1999). Rates of AD completion among community dwelling elderly persons appear to be little or no higher than those for the overall population, ranging from 0 to 17.5% (Gamble et al., 1991; High, 1988; Zwiebel and Cassel, 1989). People with acquired immunodeficiency syndrome (AIDS) or terminal cancer are much more likely to have begun advance planning or have ADs; often more than half have done so (Chambers et al., 1994; Virmani et al., 1994; Miles et al., 1996).

Why is there this paradox which characterizes advance planning: that is, continued modest use of ADs despite strongly voiced public support? What are the factors associated with both completing and not completing an AD? Empirical research is needed to identify the reasons why people do or do not write AD documents, and to examine whether the rate of AD use in practice can be

improved (Fairchild, 1998; Heffner et al., 1997; Hofman et al., 1997; Lynn & Teno, 1993; Moran, 1993). Investigators have begun to explore some of the reasons why ADs are underused and to identify factors associated with their completion, but little has been documented about the specific reasons people give for why they have or have not completed an AD (Fairchild, 1998; Stelter et al., 1992). Research that has explored factors associated with AD completion is reviewed next.

Factors Associated with Completion of Advance Directives

Demographics: Studies of AD use or completion in different settings have noted various demographic factors associated with completion or noncompletion of ADs. Based primarily on American research studies dealing with adult age groups in a variety of settings, factors associated with advance planning discussions and/ or completing an AD include being female, being White, and having 9 or more years of education (Ali, 1999; Bradley & Rizzo, 1999; Colenda et al., 1998; Luptak & Boulton, 1994; Lynn & Teno, 1993; Silverman, Tuma, Schaeffer, & Singh, 1995; Singer et al., 1993; Stetler et al., 1992; Stolman et al., 1990; Suri et al., 1999), being married (Singer et al., 1993); having a lower income (Suri et al., 1999), being in worse health (Elpern et al., 1993; Emanuel et al., 1991; Gordon & Shade, 1999; Suri et al., 1999), and older age (Ali, 1999; Bradley & Rizzo, 1999; Elpern et al., 1993; Emanuel et al., 1991; Gordon & Shade, 1999; Havens, 2000; Orlander, 1999; Singer et al., 1993; Suri et al., 1999).

VandeCreek, Frankowski, & Johnson (1995), in their study of 200 hospital

outpatients and factors associated with completion of a living will, found that only age demonstrated a significant ability to predict living will completion. The mean age of participants was 47.0 years, with a range of 14 to 85 years. The authors postulated that age is a proxy variable for changes in attitude, beliefs, and thoughts that occur as persons grow older. Certainly the simple passing of years does not by itself seem to produce an increased interest in completing a living will.

Religion: Another factor found to influence the decision to complete an AD is religious affiliation and/ or religiosity (that is, how important religion is to an individual). In Luptak and Boulton's (1994) intervention study, some of the individuals who chose not to complete an AD cited religious reasons. Sansone & Phillips (1995) found that the religious affiliation of the elder's residential facility (Catholic vs. Jewish) was significantly associated with the decision to complete an AD. Moore and Sherman (1999) found that religious affiliation and religiosity were related to completion of an AD. Those who completed an AD were more likely to be Catholic; and to have higher scores on the Intrinsic Religious Motivation Scale. VandeCreek, Frankowski, & Johnson (1995) also found that religious faith may be an important variable with regard to AD completion, although in an unpredictable manner. Some patients and their families cite their religious faith as the reason for completing a living will ("God does not intend for us to linger and suffer"), while others cite it as a reason for noncompletion ("when our time is up, God will take us; we have to stay out of the way") (p. 214).

Culture: Culture plays a prominent role in understanding AD choices and

other behaviors related to health care decision making. Based on American research to date, it has been found that frail older White, Black, Hispanic and Asian Americans differ significantly in their health care wishes and how they choose to express them (Caralis, Davis, Wright, & Marcial, 1993; Eleazer et al., 1996; Mebane, Oman, Kroonen, & Goldstein, 1999). The influence of culture on ADs has only recently received attention. For example, some cultures, such as Asian cultures, favour family decision making over the individualistic approach inherent in directives devised to date; and may regard the completion of such a document as inviting bad luck and challenging fate (Gordon & Singer, 1995). Because culture is, in part, defined by collective beliefs and values, behaviors determined by such beliefs and values vary along cultural lines (Bradley et al., 1998; Sonnenblick et al., 1994).

Self-perceived health: Perception of health was explored in at least three studies of advance directives. In earlier studies, High (1990) used participants drawn from hospitals and nursing homes, and because such subjects were often frail and perceived themselves to be close to the end of their lives they were more anxious to complete ADs. Suri et al. (1999), also studying nursing home residents, found that deteriorating physical function had a significant association with writing a subsequent AD. In addition, Moore and Sherman (1999) found poorer self-rated health status associated with seniors who were more likely to want to complete an AD.

Role of family/ significant others: The 'role of family and influence of significant others' is another variable that seems to figure prominently in the

decision to complete an AD. In Moore and Sherman's 1999 study, consideration of family leads to some seniors preferring either the living will or health care proxy. Those seniors who were not close to their families and who did not feel comfortable designating people who were not familiar with the details of their lives as their proxies, or who did not have a family, or who did not want to "saddle" their family with that type of decision, opted for an instruction versus a proxy directive. However, other seniors felt that having a proxy would be helpful to their children. Some said that adult children may object to their completing an AD, because it acknowledges the ultimate demise of their parent. Swarz and Perry (1993) found that dialysis patients making ADs were more likely to have a close relationship with a significant other. Both Moore and Sherman (1999) and VandeCreek, Frankowski, & Johnson (1995) found that being childless and having few living family members or friends prompted some individuals to complete an AD.

High (1993a) found that concern for family was the primary reason given by older adults for completing ADs. Most indicated that they wanted to prevent their family members from incurring the burden of proxy decision making should they become mentally incapacitated. On the other hand, older adults who do not make AD preparations believed that family members would successfully handle any health care decisions on their behalf. High (1994) argued that the elderly prefer to rely informally on the character and good faith of a family member to make medical decisions for them in the event of incapacity, and so often do not complete ADs. Frequently, it is the discussion of wishes with family or friends

(and not a physician) that is more important than the actual completion of an AD (Hines et al., 1999; Kapp, 1991).

Desire for control: Desire for control as a factor related to signing of living wills was examined by Rye, Wallston, Wallston, and Smith (1985). Using the 14 item situation-specific desire for control (DCON) scale, they found that although their sample (N=70) of middle-aged adults recruited from churches and primary care clinics rated highly in both their positive attitude toward living wills and their desire for control, these factors did not translate into completion of a living will. The authors concluded that the desire for control is a factor in the intention to sign a living will, but that information about the document itself and about the consequences of signing one may act as a mediator between the two variables. For example, some high control individuals may regard endorsement of a living will as abdication of control. Slavenas, Karuza, and Katz (1990) found that support of living wills was significantly correlated to a feeling of internal control in nursing home residents, while the endorsement of medical proxies was significantly related to the belief that powerful others controlled one's fate. Molloy, Guyatt, Alemayehu, & Mcilroy (1991) examined the attitudes of 909 members of the general public who attended public presentations about ADs about their desire for control of health care decisions, concerns about the care they might receive, treatment preferences, and the use of ADs. Desire for control was measured by the question "How important is it to have a say in deciding what type of health care you receive?" (answered on a five-point scale). More than 90% of the sample wanted some control over decisions regarding their own

health care and expressed a desire to put their preferences on record. Over 80% were concerned that they would receive treatment without being consulted.

Similarly, Ali (1999) found that an individual's desire to participate in his or her own end of life decisions was the most frequently cited reason for completing ADs.

Swarz and Perry (1993) found that dialysis patients who made ADs and withdrew from treatment were those with an "internal locus of decision making" who did not want to rely on others to make decisions for them. The determination of "locus of decision making" was determined by the consensus of the treatment team. Kelner (1995) asked 38 elderly hospitalized patients a series of five questions concerning control over the dying process (end of life decisions), and found that a majority ($n = 27$) could be categorized as "activists" in that they preferred to have a voice in decision-making at the end of life. Those who did not seek control preferred to delegate the decision-making to their physicians, to God, or to fate.

Other researchers have found that a desire to achieve a sense of control is one key goal of patients for advance care planning (Martin et al., 1999; Singer, Martin, & Kelner, 1999). Bradley et al. (1998) found that nursing home residents reporting a desire for more versus less control in medical decision making were approximately eight times more likely to complete ADs. VandeCreek, Frankowski, & Johnson (1995) postulated that intolerance of ambiguity concerning one's last days (a manifestation of a need for control) may influence whether a living will is completed. Chipperfield and Greenslade (1999) suggested

a positive relationship between perceived control and use of health services. A sense of control likely facilitates behavioral responses and actions aimed at improving situations. In fact, with regard to health care decisions, high-control individuals have been shown to be more likely than their low-control counterparts to seek and act upon health information (Quadrel & Lau, 1989; Wallston et al., 1976).

Beliefs, Values, and Attitudes: Other factors associated with completing an AD include a belief that planning for the future is important, a belief that an advance directive makes your wishes known, and hearing a presentation at a senior centre (Stelter et al., 1992). Bradley et al. (1998) also found that those residents reporting more versus less trust in the medical system were about five times more likely to complete ADs.

Reasons for not completing an AD include inconsistency with religious beliefs, procrastination (Elpern et al., 1993; Luptak & Boulton, 1994; Sachs, Stocking & Miles, 1992; Silverman et al., 1995), too distressing to think about (Luptak and Boulton, 1994), trust in family members to make appropriate decisions (High, 1990; High, 1993a; Gamble et al., 1991; Luptak & Boulton, 1994; Palker & Nettles-Carlson, 1995; Sachs et al., 1992; Silverman et al., 1995), little knowledge, opportunity or interest in preparing directives (Elpern et al., 1993; Gamble et al., 1991; Gordon & Singer, 1995; LaPuma, Orentlicher, and Moss, 1991; Moore & Sherman, 1999; Murphy, 1990; Palker & Nettles-Carlson, 1995; Silverman et al., 1995; Steinberg, Cartwright, McDonald, Najman, & Williams, 1997), needing assistance to complete the form (Stelter et al., 1992), non-

support of loved ones (Gordon & Singer, 1995), and the physician's failure to discuss the issue (Ali, 1999).

Sam and Singer (1993) found the perceived barriers to completing an AD were inability to write, the belief that an AD was unnecessary, a fatalistic attitude, previous discussion of preferences, a desire to leave the decision to doctors, uncertainty about preferences, a desire to discuss preferences rather than document them, a desire to wait until the situation arose, a desire to write down preferences in the future, and a desire to avoid thinking about preferences for ADs.

Diverse and complex values and a lifelong system of beliefs underlie preferences regarding end of life decisions and decisions to complete ADs (Clark, 1996; Doukas, 1999; Doukas & McCullough, 1991; Schonwetter, Walker, Solomon, Indurkha, & Robinson, 1996; Wetle, 1995). These include valuing life and quality of life (avoidance of a long, painful death process), wanting to spare family members these decisions (not being a burden), and wanting to preserve dignity, avoid degrading therapies, affirm religious beliefs, remain in control during disability, and remain communicative (High, 1993; Miles et al., 1996; Moore & Sherman, 1999; Zwiebel & Cassel, 1989). Several of these authors have emphasized the importance of eliciting and including life values when discussing ADs with patients.

The completion of ADs seems to be an outcome of a process in which an individual examines his/her attitudes surrounding death. Individuals must perceive the advantages to completing an AD as outweighing the disadvantages

associated with that action; hence, one's beliefs and attitudes toward the documents could heavily influence one's behavior in preparing an AD (Moore & Sherman, 1999; VandeCreek & Frankowski, 1996).

Summary: Factors influencing an individual's desire to formulate an AD are multifaceted and complex. They range from a macro policy level (e.g. how and when information on ADs is presented to patients) to a micro personal level (e.g., demographic characteristics, interpersonal interactions, beliefs, attitudes, and preferences, and the perceived advantages and disadvantages to formulating ADs) (Moore & Sherman, 1999; Sam & Singer, 1993).

The literature is based on studies with varying methodology, samples, and settings. Levels of data analysis also vary, with some studies employing bivariate analysis (Sam & Singer, 1993; Elpern et al., 1993), while others (especially the more recent studies) used multivariate analysis (Bradley et al., 1998; Bradley & Rizzo, 1999; Meier et al., 1996b; Stelter et al., 1992; Suri et al., 1999). As a result, characteristics associated with completing advance directives are known only for select populations with limited generalizability. According to Miles et al. (1996), who reviewed 120 empirical studies on the use of ADs and advance care planning published between 1985 and 1995, "many studies use small, uncontrolled, descriptive, single institution, or retrospective samples that can lead to misleading, unrepresentative, or nongeneralizable results" (p. 1062). Nevertheless, the literature provides some guidance regarding factors associated with completion or noncompletion of ADs.

Intervention strategies to promote the discussion and completion of ADs:

If researchers are able to determine both the enabling factors as well as the barriers to AD completion, then AD completion can be promoted. Several studies have sought to determine whether various interventions could increase the rate of AD completion. The success of programs to promote greater use of ADs depends on a clearer understanding of the factors that influence both the decision and action to execute an AD (Elpern et al., 1993). To date, researchers have speculated that the low national rate of AD use is due, at least in part, to a lack of information and a lack of encouragement from health care professionals and families (Elpern et al., 1993; Emanuel & Emanuel, 1989; LaPuma et al., 1991; Murphy, 1990; Zwiebel & Cassel, 1989). However, Gamble et al. (1991) found that persons over 60 years are not executing living wills in significant numbers despite high levels of familiarity and understanding.

Intervention studies assist in discovering whether education alone or in combination with some other type of intervention will increase the use of ADs (High, 1993). Several intervention studies, in both hospital and outpatient settings, have attempted to increase the discussion and/ or completion of ADs using various strategies. The findings of the studies are summarized according to those strategies that were minimally successful, those that were moderately successful, and those that proved most successful with regard to promoting AD completion.

Minimal success: Interventions which have focussed mainly on the provision of information only (both written and verbal) have met with very limited success. For example, Silverman et al. (1995) surveyed 219 patients from an

American university hospital that implemented a nurse-dependent AD program. The program consisted of asking patients on admission if they had an AD, documenting this in the chart, giving patients a brochure on ADs, and asking them if they wanted further discussions about ADs (Silverman et al., 1995). Results showed that only 2% of the patients requested additional information on ADs and no patients completed an AD during their hospital stay. The authors speculated that these findings are probably related to limited patient-nurse interaction caused by a nursing shortage and busy work schedules. Silverman et al. suggested that nurses need more education on ADs, as well as more time in their schedules to effectively discuss this matter with their patients.

Sachs, Stocking, and Miles (1992) conducted a randomized controlled trial of an educational intervention versus usual care in a sample of 131 patients over the age of 65, with 48 patients in the intervention group and 83 in the control group. The intervention consisted of three parts. First, there was a 20-30 minute interview in which data was collected on demographics, and information on the role of advance directives was given. Second, copies of forms for the Illinois living will and durable power of attorney for health care (DPAHC) were given to patients. Third, patients were given a reminder card that encouraged them to discuss these issues with their doctor at their next clinic visit, as well as with their families. Subjects were followed for six months from their date of enrollment. After six months, the researchers examined their charts for evidence of new copies of a living will or DPAHC, or doctor's notes describing a new discussion about ADs. At the end of the study, seven subjects in the intervention

group (15%) and eight subjects in the control group (10%) had new directives or discussions, a difference that was not statistically significant. Of the 15 subjects with documentation, only four were living wills or DPAHCs, and 11 were physicians' notes documenting discussions. Again, the simple provision of information produced only modest results with regard to AD completion.

Moderate success: Intervention studies combining educational materials with some form of follow-up or personal reminder have proved somewhat more successful in the completion of ADs. Reilly et al. (1995) attempted to promote inpatient directives about life-sustaining treatments in a community hospital, using a time-series intervention trial. The trial consisted of an education intervention (in which reminders, education and feedback to attending physicians was given), an intervention phase (in which a documentation form for listing the type of intervention desired to be completed by the attending physicians was promoted), and a control phase (in which no intervention occurred). While the proportion of inpatients with directives increased significantly during the intervention phase, this was a very physician-centred approach. As well, the documentation was not an advance directive, but a directive for life-sustaining intervention.

Other studies have focussed on education and reminders to medical outpatients. Hare and Nelson (1991) found that 15% of the patients who received a high-intensity intervention (written materials followed by physician-initiated discussion as well as telephone reminders), and none of those who received a low-intensity intervention (written materials only) subsequently

recorded a living will. The researchers explain this somewhat modest effect by stating that patients were offered only living wills and not proxy forms, and that a transient relationship existed between patients and physicians (which could have had an effect on intimate discussions about end of life issues).

In his study, High (1993a) found that the provision of moderate amounts of education materials plus an invitation to attend a meeting (at which older adults could receive counselling regarding ADs and free legal assistance to complete an AD), produced statistically significant increases in the use of ADs ($p < .05$) when compared to a control group. These findings by High suggest that interventions can increase the use of ADs among older adults, but not dramatically. The study suggests that the most effective intervention is one that provides older people with a moderate level of well-written, easily understood educational materials accompanied by easy access to assistance in completing the documents.

Richter et al. (1995) performed a randomized controlled trial to examine the effects of structured discussions, information, and mailed reminders on the completion of ADs by 176 internal medicine outpatients. Patients in the control group received a brochure on ADs only. Chart reviews found statistically significant differences between the number of ADs on file in the experimental and control groups at two follow-up periods. Six weeks following the intervention, 15 of 87 patients in the experimental group and two of 89 patients in the control group had ADs on file ($p = .0003$). Six months following the intervention, 20 ADs were on file in the experimental group, and three were on file in the control

group ($p = .001$).

Most success: Finally, interventions which have produced the most success in AD completion rates are those which employ education in conjunction with ongoing discussions with a trusted person, include some form of reminder or assistance to complete the form, and encourage an outcome of a proxy designation only.

Meier et al. (1996a) and Meier et al. (1996b) performed studies in both the hospital and outpatient setting to determine if individualized counseling by either a hospital representative or the patient's physician (compared with no counseling) improved the rate of proxy appointment. In the hospital study, a randomized controlled trial in which control subjects received no counseling, 48% of intervention patients completed a new proxy or had a previously completed proxy identified, compared with 6% of controls. Thirty-six percent of intervention patients appointed a proxy decision maker compared with 0% of controls. The authors concluded that counselling by hospital staff (physicians or hospital representatives) is an effective and generalizable means of improving recognition and execution of ADs in the acute care hospital.

In the outpatient study, of 466 patients who were deemed eligible by their physician for proxy counselling, 348 were approached and counselled by their physicians. One hundred forty-seven (31%) of the 466 eligible patients, and 44% of the intervention patients completed the proxy appointment. The higher post-intervention proxy completion rates in this study could be explained by such factors as: counselling done by a primary physician with whom the patient had a

relationship; proxy appointment may be an easier concept for both physicians to present and for patients to contemplate; the population was older than in other studies (mean of 78 years); and perhaps “sicker” populations (such as the old-old or HIV-infected groups) may both see themselves and be seen by their physicians to be in more imminent need of ADs.

A few studies highlight the importance of ongoing discussions and the development of a trusting relationship. Luptak and Boulton (1994) studied the effectiveness of an interdisciplinary intervention designed to help ambulatory frail elders who attended a geriatric evaluation and management (GEM) clinic to record an AD. In collaboration with physicians and a trained lay volunteer, a social worker provided information and counselling to the elderly subjects and their families in a series of visits to the GEM clinic. During the first clinic visit, the social worker provided verbal information about ADs, offered written information about and a copy of the Minnesota living will, and responded to patients' questions. Patients were encouraged to take the information home, to review it, discuss it with family and significant others, and to write down questions. At subsequent visits (an average of three or four over a two to four month period), all clinic staff were available and knowledgeable to discuss and assist patients if they decided to record an AD. In this study, 71% of the subjects recorded an AD. Possible reasons for this higher completion rate could be the intervention's intensity, its episodic nature, its flexibility, and its high priority within the GEM program. Subjects received easily understood education materials with offers of assistance. The incremental process permitted patients who had differing levels

of familiarity with ADs to integrate information and to articulate preferences at their own pace. Tailoring the intervention to meet the needs of individual patients helped to develop trusting relationships between patients and team members, which could be essential when addressing issues as sensitive as ADs.

In another study, Landry, Kroenke, Lucas, and Reeder (1997) showed significant differences in the rates of AD completion and discussions on advance planning when medical outpatients attended a one hour interactive seminar in addition to receiving informational pamphlets and AD forms. The researchers concluded that interactive group seminars for medical outpatients increased discussions and use of written ADs by allowing patients to ask more questions, receive more answers, and share experiences.

Finally, three studies indicate the importance of offering assistance to complete an AD on the rate of completion. Rubin, Strull, Fialkow, Weiss, and Lo (1994) studied 1101 elderly patients discharged from an acute care hospital. They were randomly assigned to control or intervention groups. The intervention group received an initial mailing of education materials and forms, a second mailing four weeks later, and offers of telephone assistance throughout the study. The control group received none of these measures. Results showed that 18.5% of the intervention group completed a DPAHC form. Such forms were completed by only 0.4% of the control group. The results suggest that education coupled with telephone assistance can increase the numbers of ADs completed. It is also possible that thinking about these issues at home with printed materials is more comfortable than face to face discussions with physicians.

In Markson et al.'s 1994 study, physicians were asked to discuss ADs with newly enrolled patients in either primary care home care services or primary care nursing home service and to assist interested patients to complete ADs. Physicians approached 74 of 356 competent home care patients, of whom 48 (65%) completed directives. Of the 42 competent nursing home patients approached, 38 (90%) completed directives. The high response rate suggests that patients will complete ADs if physicians initiate the discussion and help them navigate through the process of completing the form. However, this type of physician intervention is not likely to occur in very many situations. Limitations of the study include lack of generalizability to other populations, a possible lack of representativeness of home care clients, as only 21% of eligible clients were approached; and possible biases related to the directors of both services being co-investigators in the study.

Patterson et al. (1997) educated community nurses from the Victorian Order of Nurses (VON) in Ontario to implement ADs with their clients. The intervention group received education and assistance about ADs, while the control group did not. In the intervention group, the VON nurse scheduled an appointment to educate the client on the use and completion of the directive. In a subsequent visit, nurses reviewed the directive of clients wishing to complete it. Seventy percent of experimental subjects completed an AD while none of the control group did so. Younger patients were more likely to complete a directive than older patients ($p = 0.01$), and the individual nurse was a significant predictor of AD completion ($p = 0.04$).

Overall, the studies utilizing various educational and other interventions have proved mildly to moderately successful, depending on the intensity of the intervention, and the amount of assistance offered to complete an AD. Studies varied according to the setting, sample size, characteristics of the target population (age, health status), whether the intervention was aimed at physicians or at patients, length of intervention period, lack of comparison or control groups, different outcome variables (e.g. the signing of a proxy and/ or completing an instruction directive) and the involvement of the investigators in the care of the patients or in directly promoting ADs. Most studies were conducted by physicians, and the study subjects were usually attached to a medical facility, outpatient clinic, or general medical outpatient setting. None of the studies focussed on the well elderly living in the community, and only one utilized a nurse-based intervention.

What seems to be clear from the review of the studies is that more intensive or personalized interventions which offered ongoing follow-up, and offers of more information or assistance, proved most effective. As Haisfield et al. (1994) learned from focus groups consisting of cancer patients and health care providers, several proactive strategies that nurses can use to increase AD completions include: answering questions in easily understood terms, providing clear, concise information about ADs, directing patients to other resources about ADs, and advocating for patients who need assistance. While it cannot be concluded that the community interventions are more successful than hospital ones, given the few similarities between the hospital and community studies, it is

likely that a more relaxed atmosphere and seemingly better cognitive ability of community subjects might lead to higher AD completion rates. On the other hand, individuals in the community might be less likely to complete ADs because they are in a healthy state and don't see themselves as vulnerable to illness or death.

Possible reasons for the lack of success in the hospital setting include a minimalistic approach to education of health professionals and patients about ADs, the intimidation and stress of hospitalization, and the lack of time to consider the options and discuss them with loved ones (Cotton, 1993; Cugliari et al., 1995; Goold, Arnold, & Siminoff, 1993; Greco et al., 1991; LaPuma et al., 1991; Loewy & Carlson, 1994; Saultz & Rogriguez, 1990). As well, physical incapacity and mental incompetence are often likely to accompany admission to a hospital or nursing home (Cohen-Mansfield et al., 1991b; Janofsky & Rovner, 1993; Meier et al., 1996; White, 1997). Again, this underscores the importance of formulating advance directives prior to such occurrences, in the community setting (Dimond, 1992; Murphy, 1990).

Studies of patients and their preferences for advance discussions clearly suggest that patients want to discuss this topic with their physician, in an outpatient setting, and well before incapacity occurs (Cotton, 1993; Cugliari et al., 1995; Edinger & Smucker, 1992; Elpern et al., 1993; Emanuel et al., 1991; Finucane et al., 1988; Goold et al., 1993; Johnston, Pfeifer, & McNutt, 1995; LaPuma et al., 1991; Layson et al., 1994; Lo et al., 1986; Meier et al., 1996; Palker & Nettles-Carlson, 1995; Schmerling et al., 1988; Stolman et al., 1990).

Many patients feel that it is the physician's responsibility to initiate the discussion (Gamble et al., 1991; Kohn & Menon, 1988; Lo et al., 1986; Reilly et al., 1994; Schmerling et al., 1988; Stelter et al., 1992; Stolman et al., 1990), and a number of outpatient or community intervention studies aimed at increasing AD completion involve physicians. Encouraging the formation of written documents for medical outpatients during times of relative wellness seems logical. However, the optimal format for educating patients and encouraging completion of these documents has yet to be determined as even time-intensive, physician-directed interventions have had varied results (Landry, Kroenke, Lucas, & Reader, 1997).

The results of intervention studies suggest that much more needs to be learned about why adults, and especially older adults in the community, decide not to execute an AD, as lack of information is not the sole barrier. Further studies are needed on the possible psychological barriers to AD discussions and completion, and how these might be overcome with the use of various interventions.

The above studies suggest other research questions. These include: Is it possible that interventions that offer assistance to complete AD forms are the most effective? Is it possible that health care professionals other than physicians might better promote increased completion of ADs? Should the outcome of intervention studies be discussion of ADs and end of life treatment decisions and not just the completion of a written document?

Summary:

ADs have the potential to increase patient autonomy, improve end of life

care, and reduce health care costs. Both the public and health care providers need more education about ADs and end of life treatments. Many adult patients, especially older adults, want continuous and informed communication on death and dying issues, and are interested in advance planning. Health care professionals have an important role to play in this area.

However, although there is support for AD documents and a desire for education about them, there are definite barriers to their completion. More needs to be learned about the nature of these barriers and how they can be overcome. The research suggests that information alone does not change behavior. There seems to be a significant difference between people saying that they are interested in and support ADs, or even want an AD, and the actual completion of an AD (High, 1993b).

Chapter Three

Conceptual framework

Decision making occurs in all aspects of human life, and a broad area of decision making includes that related to health behavior. Like many of the decisions individuals make to protect their health, completion of advance directives (advance planning) may be thought of as a form of health behavior (Emanuel et al., 1995). With regard to health behavior, value expectancy theories are a family of cognitive theories which emphasize the role of subjective hypotheses or expectations held by the subject. Behavior is a function of the subjective value of an outcome, and of the subjective probability or expectation that a particular action will achieve that outcome (Rosenstock, 1990). Value expectancy theories, such as the Health Belief Model (HBM) provide a way to define and assess the elements of health decisions. For this study, the HBM is used to understand health behavior and to guide and test interventions.

Health Belief Model:

The HBM was developed by Rosenstock, Levanthal, and Hochbaum in the early 1950's to account for personal health decisions that are made in the absence of clear-cut symptoms. The model shows promise for explaining preventive health behavior (Maiman & Becker, 1974; Rosenstock, 1966; Rosenstock & Kirscht, 1979). Health behavior is defined as an activity undertaken by individuals in an asymptomatic state for the purpose of preventing disease. The HBM seeks to identify which factors will predict who will and who will not undertake regimens to prevent disease, and believes that behavior is

based on an individual's cognitive and affective orientation. If behavior can be understood and predicted, then an attempt can be made to persuade people to modify their health practices.

The model identifies both "health beliefs" and "cues to action" as predictors of health behavior (see Appendix B). It suggests that health beliefs create an intent to act, and cues to action convert that intent into action, ie. to undertake a certain health behavior. The model contains three broadly defined health beliefs which govern health behavior. These beliefs include: 1) the perceived susceptibility to the disease, 2) the perceived severity of the disease, and 3) the perceived benefits and costs (barriers) of the proposed preventive regimens (Janz & Becker, 1984; Rosenstock, 1966).

The acceptance of one's susceptibility to a disease, which is also believed to be serious, provides a force leading to action, but it does not define the particular course of action that is likely to be taken. The person's belief about the availability and effectiveness of various courses of action, and not the objective facts about the effectiveness of action, determines what course will be taken. In turn, beliefs are influenced by the norms and pressures of the individual's social groups (Rosenstock, 1966).

An individual may believe that a given action will be effective in reducing the threat of disease (benefit), but at the same time see that action as being inconvenient, expensive, unpleasant, painful, or upsetting (barriers). Perceived barriers might outweigh the perceived benefits of the proposed health action. The greater the perceived susceptibility to and severity of the disease (perceived

threat), and the greater the perceived net benefits of the preventive regimen as opposed to barriers, the more likely one is to undertake health behaviors (Rosenstock, 1974; Rosenstock & Kirscht, 1974).

In addition, some cue to action is believed necessary to trigger the desired health behavior. The level of readiness to take action may reach considerable levels of intensity without resulting in overt action unless some instigating event occurs to set the process in motion. The cue could be internal (eg. a physical symptom) or external (eg. interpersonal interactions, educational interventions, phone call reminders) (Rosenstock, 1966). Recent studies have shown positive relationships between the use of an intervention strategy (based on the HBM as the theoretical framework) and desired health behaviors (Baker, 1989; Carmel, Shani, & Rosenberg; 1996; and Hughes & Tartasky, 1996).

Much of the research that has been conducted on the relationship of the HBM variables to both preventive health behavior and illness behavior has demonstrated support for the model. High levels of perceived susceptibility, perceived severity, and perceived benefits are positively correlated with a variety of desirable health behaviors. (Hallal, 1982). Since the 1960's the HBM has been a widely accepted theoretical orientation used in the predictions of health-related behaviors.

Janz and Becker (1984) summarized results from 46 studies of the HBM, 29 (63%) of which were published between 1974 and 1984, and 18 (39%) which were prospective in design. Overall, these investigations provided substantial empirical evidence supporting HBM concepts as important contributors to the

explanation and prediction of individuals' health-related behaviors. While there are many other models of health-related behavior, Janz and Becker could think of none that approach the HBM in terms of research attention or research corroboration. This support is particularly remarkable given the wide diversity of populations and settings studied, health conditions and health-related actions examined, and the multiplicity of different approaches and tools used to assess health beliefs and behavioral outcomes.

The strengths of the HBM are that it has proved adequate to account for variations in behavior in groups of individuals in a variety of settings, is composed of a small number of elements, is capable of application to wide variety of health actions, and it suggests that beliefs are, at least in principle, capable of change through education (Rosenstock, 1966). The HBM is one of the few social-psychological models to be developed expressly to understand health behavior. One of the most appealing aspects of the HBM is its acceptance not only by health educators, but also by psychologists, physicians, dentists, nurses, and other professionals. It has intuitive logic, its central tenets are clearly stated, and it can be measured by means of a variety of techniques ranging from interviews to population-based surveys. It is an economical model in terms of the number of questions needed to assess the key variables (Rimer, 1990).

There are some limitations to the model, including that the model is predicated on the premise that health is a highly valued concern or goal for most individuals, and also that cues to action are widely prevalent. Where these conditions are not satisfied, the model is not likely to be useful in explaining

behavior (Rosenstock 1990). Another criticism of the HBM is that behavior cannot always be accounted for by reference to beliefs. However, Rosenstock (1990) states that it has not been suggested that beliefs in themselves are sufficient conditions for action. Researchers must seek out that constellation of conditions and factors, including beliefs, which accounts for major variations in behavior. A further criticism of the HBM is that by focusing on the individual determinants of health behaviors, there is a danger that victim-blaming will be encouraged when appropriate health action is not taken. However, in answer to this Rosenstock (1990) suggests that the client should not be blamed for having a problem but is the one expected to assume responsibility for solving the problem.

The HBM can be best improved through its continued use in the real world and its application to the development of interventions (Rimer, 1990). Attempts to refine the model and improve its predictive validity have led to the incorporation of such concepts as the individual's locus of control expectations, health motivation and the value of health, and a variety of other modifying and enabling factors into the model (Carmel et al., 1996; Thibodaux & Shewchuk, 1988).

Although the HBM has been typically applied to preventive health activities, it is relevant to the completion of ADs. Preventive health behavior includes advance planning (Emanuel et al., 1995), and the HBM has been used to describe the process associated with completing or not completing ADs in a few studies (Stelter et al., 1992; Bradley et al., 1998; VandeCreek & Frankowski,

1996). In the case of AD completion, the disease or condition to be prevented is a “bad death”, defined broadly as a death in which one’s medical treatment wishes are not honored. This might include death after prolonged, unwanted life support, or survival for an indefinite amount of time in a dependent or incapacitated state (Basile, 1998). If a bad death is a disease to be prevented, then one might think of the completion of an AD as a preventive regimen, or health behavior. This conceptualization suggests that health beliefs may be fundamental to AD completion (Bradley et al., 1998). Health beliefs in this context include one’s perceived severity (or consequences) of a bad death, and the perceived benefits and costs of completing an AD. With regard to ADs, several personal (demographic), psychological, and interpersonal factors, as well as beliefs about the benefits of planning for end of life care, could indicate a readiness to act. However, beliefs do not always lead to behavior and there may exist various barriers to completing an AD, including the action being inconvenient, time-consuming, unpleasant, or upsetting. At this point, a cue or trigger to trip off appropriate action may be necessary, such as providing information or assistance with completion, or a phone call reminder (Rosenstock, 1966). According to the HBM, completion of ADs occurs as an interaction of certain motivators (cues and beliefs) and barriers, and this behavior is reached only after the barriers are overcome (Appendix C represents the conceptual framework for this study).

A few studies have applied the HBM to AD completion. In 1992, Stelter, Elliott, and Bruno performed a cross-sectional study using a convenience sample

of 214 elderly individuals in the community. The study provided evidence supporting the role of health beliefs in individual's decisions to complete living wills, with perceived efficacy of living wills being a central predictor of living will completion, but found only limited evidence of the roles of other health beliefs. However, the study had a low response rate, and although beliefs about trust and personal control were identified in the conceptual model, the data supporting these important factors was not reported. VandeCreek and Frankowski (1996) sought to identify perceived barriers and benefits to completing living wills for 176 medical outpatients or their family members, using a questionnaire based on the HBM. For their sample, the researchers found that perceived barriers to living wills are greater than perceived benefits, and these beliefs contributed to a low completion rate. Some barriers, such as believing that "I will live a lot longer", and "I will likely change my mind about future treatment", were found to be the most significant.

A recent study by Bradley et al. (1998) utilized the HBM to examine the role of health beliefs in determining AD completion among a dependent, nursing home population. This study demonstrated that health beliefs are important factors in nursing home residents' completion of ADs, especially beliefs regarding trust in the medical system and desire for control in medical decision making. Qualitative analysis of interviews also revealed four different "voices" or approaches to individuals' decisions concerning advance directives. These included taking charge, delegating autonomy, denial, and wanting to die. These results suggest that better understanding of individual health beliefs related to

personal autonomy and underlying trust of the medical system is required not only for explaining but also supporting individuals' decisions regarding ADs. Thus, evidence exists to suggest that the HBM is an appropriate model to study completion of ADs.

In this study, a cue to action (phone call reminder to the intervention group) was used to promote discussion and completion of an AD in a sample of community dwelling older adults. In addition, demographic and sociopsychological variables related to AD discussion and completion, as well as individual beliefs about perceived benefits and barriers to completing an AD were examined.

Chapter Four

Research Methods

This chapter delineates the research methods used in this study. This includes the purpose and research questions, hypotheses, measurement methods, setting, sample, procedure, design, data analysis, and ethical considerations for the study.

Research Questions and Hypotheses

Purpose: The purpose of this study was to determine a) if an educational session coupled with an individualized intervention leads to increased completion and/ or discussion of ADs in a sample of older adult community dwellers, and b) the factors associated with completing or not completing ADs.

Independent variables: include demographic characteristics, perceived control, social support, self-rated health, and beliefs about perceived benefits and barriers to completing an AD. **Dependent variables** are 1) the completion of an AD, and 2) discussion of ADs with significant others.

Research questions:

Based on the knowledge and insights gained from reviewing the literature on ADs, and the Health Belief Model as a conceptual framework appropriate to study the completion of advance directives, the following research questions and research hypotheses were identified:

1. Will an educational intervention including one-on-one follow-up (cue to action) increase the completion rate of ADs in a sample of community dwelling older adults compared with an educational intervention with no follow-up?

2. Will an educational intervention including one-on-one follow-up (cue to action) increase the rate of discussion with significant others about ADs and end of life care in a sample of community dwelling older adults compared with an educational intervention with no follow-up?
3. What are the characteristics of older adults and enabling factors associated with completion of ADs? What are the barriers to completion of ADs in older adults?
4. What are the characteristics of older adults and enabling factors associated with discussion of ADs? What are the barriers to discussion of ADs with significant others?

Research Hypotheses:

1. a) The intervention group (those who attend the educational session and receive a follow-up phone call to offer information and answer questions regarding ADs) is more likely to complete ADs compared with the control group (those who attend the education session but receive no reminder phone call).
1. b) The intervention group is more likely to have discussions about ADs with significant others compared with the control group.
2. Completion of ADs is directly related to various demographic characteristics.
 - Completion of ADs is directly related to older age.
 - Completion of ADs is directly related to being female.
 - Completion of ADs is directly related to being married.
 - Completion of ADs is directly related to having higher levels of education
 - Completion of ADs is directly related to having adequate income.

3. Completion of ADs is inversely related to self-rated health status.
4. Completion of ADs is directly related to perceived control.
5. a) Completion of ADs is directly related to the presence of family and significant others (social support).
b) Completion of ADs is directly related to the presence of close confidante relationships with family or significant others.
6. a) Completion of ADs is directly related to perceived benefits of ADs.
b) Completion of ADs is inversely related to perceived barriers of ADs.

Measurement Methods:

Two questionnaires were administered to all participants in this study, one at the beginning of the study, and the second after the three month study period was concluded. The initial questionnaire (Questionnaire #1) was based on the Health Belief Model and previous literature on AD completion, and included questions related to demographic characteristics, self-rated health, perceived control, social support, and beliefs and attitudes regarding the perceived barriers and benefits of ADs. (See Appendix E). Additional open-ended questions in Questionnaire #2 helped to identify how enabling experiences and barriers influenced decisions to complete an AD, including discussions with friends or family members. (See Appendix F).

A pilot test of Questionnaire #1 was done on a small group of older adults attending a day program (the Rendezvous Club at Riverview Health Centre). The Rendezvous Club is a day program offered four days a week to community dwelling older adults which provides opportunities for socialization. The pilot test

included five women aged 73 to 86 years old (mean age of 81.2 years, $SD = 5.7$) from the Rendezvous Club. The pilot test participants had difficulty with the wording of some demographic questions, and most of the statements in VandeCreek and Frankowski's Living Will Barriers and Benefits Scale (1996). (The original statements developed by VandeCreek and Frankowski were used on a medical outpatient population with a mean age of 44 years). Minor modifications to some demographic questions and to the wording of the barrier and benefit statements were made to ensure that potential participants would find the questionnaire clear and easy to understand and complete. (See Appendix M for specific modifications to the Living Will Barriers and Benefits Scale). Subsequent testing with the same group of Rendezvous Club members revealed that the minor revisions accomplished these goals. The Rendezvous Club members took about 15 to 20 minutes to complete the questionnaire.

Questionnaire #2 was based on examples of open-ended interview guides provided by Douglas Martin and Peter Singer which they used in their advance directive studies with HIV and dialysis patients (Martin, Thiel, & Singer, 1999; Singer et al., 1995). Due to the qualitative nature of their studies, the interview guides used by Martin and Singer were fairly detailed in that they contained a number of probe questions to elicit more information from participants. In order to prevent the telephone interview from being too lengthy, only the questions used by Martin and Singer which pertained to the research questions in this study (factors related to AD discussion and completion) were used. For example, questions related to how the experience of completing an AD, or discussing the

AD with someone, made participants feel were omitted from this study, as these emotional responses to AD discussion and completion were not part of this research. More details on the components of Questionnaire #1 and Questionnaire #2 are provided below.

Questionnaire #1:

Several key variables, namely, demographic characteristics, self-rated health, perceived control, social support, and perceived benefits or barriers to completing an AD were examined with regard to their relationship to the completion and/ or discussion of ADs. In order to further clarify and define each of the research variables, operational definitions and specific instruments used to measure each variable are described here. See Appendix N for an operationalization of all variables examined in the study. Specific test scores and reliability coefficients found for each of these variables/ tools will be provided in Chapter 5.

Demographic questions include those related to age, gender, marital status, occupation, education level, satisfaction with income, ethnicity, and religion. Demographic questions used in this study (and their coded responses) were adapted from the Centre on Aging, University of Manitoba January 1996 study "Adult Day Care in Manitoba: A Survey of Clients".

Age was treated as both a continuous variable, and divided into the categories of less than 65 years, 65 to 74 years, 75 to 84 years, and 85 years and over. Gender was categorized as either male or female. The original marital status categories consisted of widowed, married, divorced or separated, and

single or never married. These categories were further collapsed to 'single, married, widowed', 'married and other', and 'single and other' due to small cell sizes. Number of children was measured as a continuous variable. Occupation was divided into categories based on the responses given, including homemaker, laborer, clerical, sales, service, professional, and management. These categories were further collapsed into homemaker, 'clerical, sales, and service', 'professional/ management', and laborer for analysis related to small cell sizes for some items. In the same way, the large number of educational level categories was divided into the categories of elementary/ some high school, completed high school, some post-secondary education, and Bachelor's degree due to small cell sizes.

Ability of income to satisfy needs was measured categorically on an ordinal scale of responses (not very well, with some difficulty, adequately, and very well). Ethnicity, religion, and place of birth, were divided into categories based on the responses given, and frequencies obtained for univariate analysis (description of the sample). Ethnicity and religion, as well as place of birth and number of children, were not tested in bivariate analysis as no hypotheses were generated regarding these variables. All other demographic variables were used in both univariate and bivariate analysis, and age (continuous) and gender were used in multivariate analysis.

Self-rated health (people's subjective ratings of their own global health status) was measured using a single item question in which subjects were asked to rate their overall health as excellent, very good, good, fair, or poor. Studies

examining the validity and reliability of self-rated health have demonstrated that this global rating of health status is stable over time, correlates with physician ratings of health and utilization of health care services, and is predictive of mortality (Hooker & Siegler, 1992; Idler & Kasl, 1991; Mossey & Shapiro, 1982; Strain, 1993). Furthermore, self-rated health has been used extensively as a measure of health status in older adult populations (Idler & Kasl, 1991; Leinonen, Heikkinen, & Jylha, 1999; Strain, 1993).

For bivariate and multivariate analysis, the question regarding self-rated health was reduced to a two-item categorical variable, due to the small number of cases in the poor and excellent categories. The resulting categories were poor, which included the poor and fair choices (coded as 0), and good, which included the good, very good, and excellent choices (coded as 1). Wolinsky & Arnold (1988) recommend that the measure of self-rated health status should be dichotomized as excellent or good versus fair or poor.

Subjects were also asked to identify their current health conditions from a chronic illness checklist. Each health condition was coded as either being present or not present. The mean number and frequency of the various health conditions were used for univariate (descriptive) purposes only. The large number of health conditions identified and the resulting small cell sizes for many of the conditions did not allow for further analysis.

Perceived control can be defined as one's perceived ability to influence outcomes/events in the environment (Chipperfield & Greenslade, 1999).

Perceived control was measured by a single item visual analog scale used by

Menec, Chipperfield, & Perry (1999) in their study to examine the association between health perceptions and outcomes such as mortality, control beliefs, and morbidity in older community-dwelling adults. Menec et al. measured perceived control with the following question: "thinking about life in general, some people generally feel out of control and helpless, while others feel in control and able to cope. How do you generally feel?" (1=out of control; 10=totally in control). Participants were asked to rate their perceived control by placing an "X" somewhere along a ten centimetre horizontal line labelled "out of control" at one end and "totally in control" at the other end. Similar questions have been used in previous research and have been found to predict adjustment to illness (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Helgeson, 1992) and mortality (Menec & Chipperfield, 1997b).

Although specific validity and reliability testing are not available for this tool, both Verena Menec (personal communication, June 14th, 1999) and Judy Chipperfield (personal communication, June 24th, 1999) stated that they preferred the use of the single item with older adults, and said they considered it to be valid. A single item scale was also chosen so as to keep the questionnaire from being too lengthy for the older participants. Perceived control was treated as a continuous variable in bivariate analysis.

Social Support: The term social network is often used interchangeably with social support. Social networks can be defined as including "all of an individual's social contacts.... [and include dimensions of] size, source of ties, member homogeneity, frequency of contacts, and opportunity for reciprocal

exchange of support" (Lubben, 1988, p. 45). A social support system is the subset of persons within an individual's social network on whom that individual can rely to provide emotional, physical, or material support, or information (Hibbard, 1996; Lubben, 1988).

In this study, social support was measured by the Lubben Social Network Scale (LSNS). This scale was developed specifically for use with older adults, is valid and reliable, and takes only 5 to 10 minutes to complete. The scale consists of 10 simple items that tap family networks, friends networks, confidante relations, helping others, and living arrangements. Scores range from 0 to 50, and scores below 20 qualify as a cutoff point for screening those older adults who are at greater risk of social isolation (Lubben, 1988). The LSNS was found to be significantly correlated with the Berkman-Syme Social Network Index (Mor-Barak and Miller, 1991). Lubben (1988) reported that all ten items of the scale are highly intercorrelated (Cronbach's $\alpha = 0.70$) (p. 46). As well, Rubenstein, Lubben and Mintzer (1994) demonstrated a high interrater reliability (.85) between judgements of social workers and the ability of the LSNS to screen for social isolation. For this study, the LSNS was treated as a continuous variable. The reliability of the scale in this study is discussed in Chapter 5. Missing cases were discretely coded and were not used in data analysis.

To measure close confidante relationships with significant others, a single item from the LSNS, "When you have an important decision to make, do you have someone you can talk to about it?", was used. The original responses were collapsed into two categories. Always, very often, and often were coded as a yes

response and sometimes, seldom, and never were coded as a no response for bivariate analysis. Further data about the role of family and/ or significant others in the decision to discuss and complete an AD was provided by answers to the open-ended questions in Questionnaire #2.

Perceived benefits and barriers to completing an AD: For this study, not all concepts of the HBM were examined regarding completion of ADs. It was assumed that most people would consider a death contrary to their wishes as a bad death, and something to be avoided. The concepts of barriers and benefits to action were the focus in this study.

Perceived benefits: As stated in the HBM, taking a particular course of action not only depends upon the perceived threat of not taking action, but upon beliefs regarding the effectiveness of the various available actions in reducing the threat (perceived benefits of taking action). Action will only be taken if it is perceived as feasible and efficacious. Beliefs in this area are undoubtedly influenced by life experiences and the norms and pressures of an individual's social groups (Rosenstock, 1966, 1974, 1990).

Perceived barriers: The potential negative aspects of a particular health action, or perceived barriers, may act as impediments to undertaking the recommended behavior (Rosenstock, 1966, 1974). With regard to barriers, a nonconscious, cost-benefit analysis is thought to occur as the individual weighs an action's effectiveness against perceptions that it may be expensive, dangerous, unpleasant (painful, difficult, upsetting), inconvenient, or time-consuming (Rosenstock, 1990). The greater the perceived threat and the greater the

perceived net benefits of the preventive regimen as opposed to barriers, the more likely one is to undertake health behaviors (Rosenstock, 1974; Rosenstock & Kirscht, 1974).

In order to measure **perceived barriers and benefits of completing an AD**, the Living Will Barriers and Benefits Scale developed by VandeCreek and Frankowski, based on the HBM, was used. Although a 23 item instrument was originally developed by the authors, principal components analysis with varimax rotation of the 23 items resulted in 12 items with adequate reliability (7 barrier items and 5 benefit items). These 12 items loaded at 0.50 or above (which is the standard cutoff point) in that analysis (VandeCreek and Frankowski, 1996). The Cronbach's alpha for barriers was 0.76, and for benefits was 0.75. It was suggested by L. VandeCreek (personal communication, Sept. 9th, 1999) that the 12 item version be used and items deleted as necessary.

The entire 12 item Living Will Barriers and Benefits Scale developed by VandeCreek and Frankowski (1996) was used in this study. Modification in the wording of the items was made (in relation to pilot test findings) to ensure ease of comprehension by older adults. No items were deleted due to the high reliability scores achieved for each of the subscales. The specific test scores and the reliability of the two subscales for this study are provided in Chapter 5.

The barrier subscale consists of seven items. Each of the items is scored along a four point Likert-type scale ranging from strongly disagree to strongly agree. Total scores in the barrier subscale can range from 7 to 28 and higher scores indicate higher levels of perceived barriers to the completion of an AD.

The benefit subscale consists of five items. Each of the items is scored along the same four-point scale as the barrier subscale. Total scores in the benefits subscale can range from 5 to 20 with higher scores indicating higher levels of perceived benefits to completing an AD. The variables of perceived barriers and perceived benefits were continuous for both bivariate and multivariate analysis. Missing cases for these two subscales were discretely coded and were not used in data analysis.

Questionnaire #2:

Open-ended qualitative questions, including: "What prompted you to complete an AD?" or "What prevented you from completing an AD?" were asked in Questionnaire #2. In addition, questions were asked about whether the subject discussed the AD with someone, whether someone else helped them complete an AD, and whether anything about their medical condition and family or cultural background influenced their decision to complete or not complete an AD (see Appendix F). These interview questions were adopted from the interview guide used by Douglas Martin and Peter Singer in their studies of AD completion in HIV and dialysis patients, in accordance with the theoretical model and literature review of this study.

Internal validity of the interview process was obtained by using a tested interview schedule used by researchers in the area of AD completion and discussion. External validity (the extent to which the method of data collection provides data compatible with other relevant evidence) was enhanced through the use of questions based on the Health Belief Model and the review of the

literature. Reliability in this study was enhanced in that only one person, the researcher, was involved in the data collection. Therefore, a relatively consistent approach was used in interviewing participants. However, as the interviews were not tape-recorded, but merely recorded manually as they occurred, some information may have been lost (Diers, 1979).

Dependent variables: The dependent variables, or outcomes, of the study measured during the final telephone interview were:

1. Whether the individual had completed a written AD.
2. Whether the individual had discussed ADs or plans for end of life care with anyone. For each of these categorical dependent variables, a no response was coded as zero (0) and a yes response was coded as one (1), and this coding was used in all forms of data analysis.

Sample and Setting: The target population for this study was community dwelling older adults. This population was chosen for study because of the benefits of discussing end of life issues in the community setting before a medical crisis occurs (Haynor, 1998; Molloy, Russo, & Pedlar, 2000). The convenience sample was obtained from seniors belonging to the St. James Assiniboia Senior Centre, Inc. Educational sessions on ADs were advertised in the St. James Assiniboia Senior Centre newsletter, bulletin boards at the Centre, community newspapers and via public service announcements. The sample consisted of older adults who attended an advertised educational session on ADs and who subsequently agreed to be part of the study. Inclusion criteria for the sample was an age of 50 or older, being able to read, write, and understand

English, and having no prior completed AD.

The St. James Assiniboia Senior Centre, Inc., whose mission it is to improve the quality of life of seniors by providing educational, recreational, health and social opportunities has a current membership of 620 members (Karen Pirnie, Executive Director, personal communication, September 16th, 1999). The projected sample size was 70, with 35 in the control group and 35 in the intervention group. Such a sample size would provide a power of 0.70, a medium effect size and a one-tailed level of significance of 0.05 for t-tests for independent means, and 0.10 for correlation coefficients (Cohen, 1988). To ensure a large enough sample size, several educational sessions, at different times of the day, and at different locations, i.e. various elderly persons housing units, were held. A fairly low attrition rate was expected.

Response rate: A total of 79 older adults (including five married couples) met the inclusion criteria and initially agreed to participate in the study. This number was reduced to 74 when one member of each of the five married couples was randomly excluded from the sample. This exclusion was performed to eliminate any possibility of bias during the intervention phase of the study, where only one spouse might be selected to be in the intervention group, but nevertheless might discuss the intervention with their partner. Of the 74 participants who completed the initial questionnaire, 37 participants were each randomly assigned to the control and intervention groups. All study participants (n=74) were reached by telephone and administered the follow-up questionnaire (Questionnaire #2) at the end of the study. All members of the intervention group (n=37) were reached

by telephone and administered the intervention protocol. In order to reach some participants, a number of phone calls were made (up to 3 or 4 for some participants) and messages were left for those participants with answering machines to call the researcher at their convenience. The high participation rate in this study can probably be attributed to the time of year the study was conducted (that is, this was not a travel or vacation period), the short time frame of the study, and the stable nature of the population (a group of seniors most of whom are retired and living in their home community).

Procedure: The researcher developed an educational session on ADs, which was presented to older adults who were members of the St. James Assiniboia Senior Centre, Inc. Educational sessions provided by the researcher were approximately 30 to 35 minutes in length. The material covered included: definitions of ADs, reasons why completing an AD is important, key things to remember when completing an AD, information on choosing a proxy, a list of commonly asked questions about ADs, a description of life-sustaining treatments, and three different examples of advance directive forms. Handouts were given to all attendees regarding the above information, including the Manitoba Health fact sheet on Health Care Directives in Manitoba.

In all, five different educational sessions on ADs were presented by the researcher between February 22nd and March 16th, 2000 (See Appendix J). A record of the total number of attendees was not kept, but sessions were well-attended (an average of 20 people per session). Overall, the audiences attending the educational sessions seemed receptive and interested in the topic.

All participants left the educational session with a handout. Many participants expressed concerns regarding the legalities of ADs, making it known that you have an AD, wondering if ambulance attendants will follow an AD, and reliability of proxies.

After the educational session, the researcher informed participants about the study, asked for volunteers, and distributed a copy of the disclaimer (Appendix D) and a copy of Questionnaire #1 to each of the study participants. The questionnaire was completed immediately following the education session during a "coffee and snack" break. On the disclaimer, the participants included their name and phone number so that they could be contacted later by telephone to a) receive the intervention and complete Questionnaire #2 (intervention group) or b) to complete Questionnaire #2 only (control group). The disclaimer informed participants that they would be contacted by the researcher by telephone one or two times within the next three months to ask them more questions and to provide additional information if requested. At the end of the educational session, the researcher suggested that upon returning home participants review the content of the educational session (handouts) and discuss the information with family members or significant others.

After each educational session, the participants were randomly assigned into two groups. Participants were blind to the randomization process. To randomly assign participants, coins were used. The researcher obtained a number of coins equal to the number of participants for each session, with half of these coins being odd numbered years and half being even numbered years. For

each case number, a coin was randomly chosen from the pile of coins. If it was an odd year coin, the participant was assigned to the control group. If it was an even year, the participant was assigned to the intervention group.

The control group received the education session only. The intervention group received a phone call from the researcher at one month after the education session to ask if they had any questions about advance directives, and to offer more information if they expressed an interest in AD completion. These questions were part of a set script. (See Appendix H for a copy of the Intervention protocol). The phone call lasted five minutes or less. If a request for assistance to complete the form was made, the participant was referred to his or her family doctor or a family member. At the end of the 3 month study period both groups received a phone call to see if they had completed an AD or had discussed ADs with someone else (Questionnaire #2). This telephone interview generally lasted five to 10 minutes, depending on how much detail the participant provided.

Research Design: The study used an experimental posttest-only control randomized group design. Such a design has strong internal validity, controlling for the effects of history, maturation, testing, instrumentation, regression, selection, and mortality. External validity is enhanced by the omission of a pretest, but generalizability is limited to a population similar to the one tested (Campbell and Stanley, 1963). Potential participants who presented for an educational session on advance directives, and who agreed to participate in the study, were randomly assigned to either a control or an intervention group.

Randomization minimizes the occurrence of bias and promotes the validity of the research. As far as randomization has succeeded in equalizing characteristics of control and intervention groups, a valid assessment of treatment effectiveness can be made (Rabeneck, Viscoli, & Horwitz, 1992). In addition, validity is enhanced when the implementation of the intervention protocol is the same for each subject. The intervention protocol (Appendix H) was exactly the same for each subject in this study. Also important in promoting validity of results is the environment in which the intervention is performed (Egan, Snyder, & Burns, 1992). As the intervention in this study occurred by telephone, and the subjects were in their own homes, it was hoped that they would be relaxed and there would be minimal distractions. The intervention was performed for each of the five groups approximately one month after the education session (See Appendix L). All 37 members of the intervention group were contacted. No one refused follow-up.

At three months, Questionnaire #2 was administered to determine whether an AD was completed and whether the participant had discussed the AD with anyone. Again, all 74 participants in the study were reached for follow-up. If discussion had occurred, then information was collected on with whom the discussion took place, the nature of the discussion, and factors associated with why or why not an AD was completed. The participants were asked to respond to open-ended questions asking why they chose to complete or not to complete an AD, and so data of a qualitative nature was obtained from these oral communications. However, the transcribed interview responses were analyzed

quantitatively using content analysis. It was anticipated that the responses to the open-ended questions would yield data that would further describe or explain variation among older adults on outcome variables, and verify outcomes obtained from standardized instruments (Sandelowski, 1996). For this study, it was seen as important to combine both qualitative and quantitative data sources to gain insight into the complex behavior of AD completion (Teno, Spertak, & Lynn, 1998).

Data Analysis

Both the quantitative data obtained from Questionnaire #1 and the qualitative oral communications from Questionnaire #2 were analyzed using quantitative methods. Data from Questionnaire #1 were numerically coded. Analysis of the data, including both descriptive and inferential statistics, was conducted using the Statistical Program for the Social Sciences (SPSS) Version 10.0. The level of significance for all statistical tests was set at 0.05, which is the standard for the alpha criterion (Polit & Hungler, 1995). Basic content analysis, specifically the quantification of narrative, qualitative material (Weber, 1990), was used to analyze the data from Questionnaire #2.

The variables used in the study were measured primarily on nominal, ordinal, and interval scales, and included both categorical and continuous types. See Appendix N for an operationalization of the study variables. The statistical analyses used depended on the type and distribution of the variables. To determine whether each variable was normally distributed, histograms and the Pearson's skewness coefficient were examined. Skewness coefficients above

0.2 or below -0.2 indicate severe skewness (Munro, 1997). Both visual inspection of the histograms and the skewness coefficients indicated that none of the variables, except possibly age, were normally distributed (see Appendix O). For some analyses, variables were collapsed to allow the researcher to analyze the data in different ways and to enhance the ability to detect differences between groups based on larger combined responses.

Frequency distributions and, when appropriate, descriptive statistics including measures of central tendency (mean, median, and mode) and measures of variability (range and standard deviation) were computed for all independent and dependent variables. Cronbach's coefficient alpha was calculated to determine the internal consistency reliability of the instruments used in the study. Results of these analyses will be presented in Chapter 5.

Bivariate analysis: Nonparametric statistical tests (Chi-square and Mann-Whitney U) were used to test differences between variables (two-group comparisons) due to small sample size, the level of the dependent variables being categorical, and non-normal distribution of the variables (Munro, 1997). The Chi-Square test was used to examine the differences in proportions of subjects between each outcome variable (did complete/ did not complete an AD; discussed/ did not discuss an AD) and the independent variables that were also categorical in nature (age, gender, marital status, occupation, satisfaction with income, educational level, and self-rated health). The Chi-square distribution is appropriate for both nominal level and ordinal level data that are grouped into categories (Mason, Lind, & Marchal, 1991; Munro, 1997).

To compare the means or ranks between the dependent variables which are categorical and those independent variables which are continuous, e.g., age, perceived control, level of social support, perceived barriers, and perceived benefits, the Mann-Whitney U test was used. The Mann-Whitney U test is a nonparametric alternative to the independent samples t-test when the variables have a non-normal distribution. Mean rank values are a nonparametric measure comparable to the mean where results are ranked from smallest to largest, summed, and divided by the number of cases (Munro, 1997; Norusis, 2000).

P-values (significance values) were calculated for each statistical procedure. As the SPSS program was able to calculate actual p-values, rather than simply relying on assessing significance by comparing the strength of evidence to a pre-determined alpha level (0.05), actual p-values are reported.

There were very few missing cases for this sample. Where appropriate, missing cases will be highlighted in Chapter 5. There were no missing cases for most variables, except one case for the LSNS, one case for the benefit subscale, and 5 cases for the barrier subscale. Missing cases were discretely coded and were not used in statistical analysis.

To describe the strength of association between all variables, correlation statistics were generated. The correlations provided information on the strength and direction of the relationships between variables. The most commonly used correlation coefficient is the Pearson's product moment correlation coefficient. However, appropriate use of this test assumes that the variables are normally distributed and at the interval or ratio level (Munro, 1997). Since none of the

variables in the data set (except age) met the criteria for the Pearson's correlation coefficient, nonparametric Spearman's rho correlations were calculated (Polit & Hungler, 1995; Munro, 1997). Correlations of less than 0.2 were considered weak, between 0.2 and 0.3 were considered moderate, and those greater than 0.3 were considered strong. These criteria are based on the assumption that correlations between variables of a psychosocial nature are typically in the 0.10 to 0.40 range (Polit & Hungler, 1995; Munro, 1997).

Testing for Multicollinearity: The variables in the study were also tested for multicollinearity. A problem for behavioral researchers is the interrelatedness of the independent variables (or multicollinearity). If variables are collinear, they provide similar information and evaluation of results is problematic (Munro, 1997). Therefore, assessment for multicollinearity between the independent variables in this study was conducted. Two methods of assessment for multicollinearity were used: the Spearman's rank correlation coefficient (bivariate) and the collinearity diagnostics procedure from the linear regression function in the SPSS program (multivariate).

Analyzing the Spearman's rank correlation coefficient allows the researcher to look directly at the intercorrelation of the independent variables. Correlations among the independent variables were conducted, using a coefficient of 0.80 or larger as the cutoff for high multicollinearity. None of the variables in the study were multicollinear (that is, had a coefficient value greater than 0.8). The Spearman rank correlation was selected as the most appropriate test (instead of the Pearson product-moment correlation) because it can assess

collinearity between variables that do not follow a normal distribution and are categorically or ordinally scaled (Menard, 1995).

The bivariate Spearman's rho correlation fails to take into account the relationship of an independent variable with all the other independent variables. The collinearity diagnostics procedure regresses each independent variable on all the other independent variables, and is found in the linear regression test in SPSS (Norusis, 2000). It is the only way to test for collinearity, even in a logistic regression model (Menard, 1995). The collinearity procedure provides the tolerance statistic of a variable, which is a measure of collinearity. It is the proportion of the variance in a variable that is not accounted for by the other independent variables (Munro, 1997). Tolerance values range from 0 to 1. A value close to 1 indicates that an independent variable has little of its variability explained by the other independent variables. A value close to 0 indicates that a variable is almost a linear combination of the other independent variables. Such data are called multicollinear (Norusis, 2000). A tolerance of less than 0.20 indicates that the possibility of collinearity exists (Munro, 1997). None of the variables used in logistic regression were multicollinear. The specific results of collinearity testing are presented in Chapter 5.

Multivariate analysis: Logistic regression modeling was chosen for the multivariate analysis. Logistic regression is used to describe the relationships between a set of independent variables and a dichotomous dependent variable (Menard, 1995; Munro, 1997). Logistic regression is used to determine which variables affect the probability of a particular outcome, in this case, completion or

discussion of ADs. Two models were analyzed in this study: Model A--Completion versus noncompletion of ADs, and Model B--Discussion versus no discussion of ADs. In logistic regression, the independent variables may be at any level of measurement, but nominal variables must be coded prior to entry. The dependent variable is categorical (dichotomous) (Munro, 1997).

Model-Building: In this study, two regression models were tested, one predicting AD completion (Model A) and one predicting AD discussion (Model B). Selection of variables for inclusion in the model should be based on clear scientific rationale (Munro, 1997). Two specific criteria for inclusion of independent variables in the models are statistical and theoretical significance. Although statistical significance was set at 0.05 for bivariate analysis, it is suggested that this criterion should be relaxed for logistic regression to prevent the failure to find a relationship when one exists. The recommended range is from 0.15 to 0.20 (Menard, 1995). The criterion chosen for this study was 0.15 in order to be more lenient and yet remain fairly cautious. In addition, variables with theoretical support in the literature, as suggested by the Health Belief Model and the findings of previous studies, were included in the regression. A detailed description of the independent variables included in both models in the regression analysis is provided in Chapter 5.

As stated previously, nominal level variables can be included in a regression analysis, but they must be coded to allow for proper interpretation. There are three coding techniques: dummy, effect, and orthogonal. In all the coding methods, variables are coded into vectors, and the rule is that $n - 1$

vectors are used to describe the categories. If the variable has two categories, such as gender, one vector is enough (Munro, 1997). The researcher used dummy coding for gender and self-rated health. All males were coded as 0 and all females as 1. Poor health was coded as 0 and good health was coded as 1. All other independent variables in the model were interval level. Dummy coding was also used for the two dependent variables: a) no completion (0) versus completion (1), and b) no discussion (0) versus discussion (1).

Entering variables into the regression equation: There are a number of ways in which to enter the independent variables into the regression equation (model). They may be entered all at once or may be entered in a stepwise fashion including various forward and backward solutions. In forward entry, independent variables are added one at a time, and the independent variable that has the highest correlation with the dependent variable is entered first. As each variable is added, the new model is compared to the old model through the log likelihood ratio test. In the backward method, all independent variables are entered into the equation. Variables are then deleted according to whether the variable is contributing significantly to the model. Only significant variables will remain in the final equation (Munro, 1997; Norusis, 2000).

In this study, both forward and backward stepwise approaches were used. Initially, the backward method was chosen due to the advantage of backward elimination having less risk of failing to find a relationship when one exists, related to the suppressor effect (Menard, 1995). According to Agresti & Finlay (1986), a variable may appear to have a statistically significant effect only when

another variable is controlled. This is called a suppressor effect. Forward selection may exclude variables involved in suppressor effects. The advantage of backward elimination is that both variables are already in the model resulting in less risk of failing to find a relationship when one exists. However, in this study, a forward method was also tested in order to compare the findings for both methods. The criterion for the entry and removal of variables from the models was set high (.75 and .95 respectively) so that all independent variables in the block would be entered into the equation (A. Blanchard, personal communication, September 14, 2000). Missing cases were not used in the analysis (resulting in an n of 68).

To describe the results of the logistic regression model overall, the -2 times the log of the likelihood (-2LL) and the improvement in the Chi-square were examined. The -2LL is a measure of how well the estimated model fits the data, and is a comparison of observed to predicted values. Smaller values of -2LL indicate a higher likelihood of the observed results, and larger values indicate a poorer fit between the model and the data (Munro, 1997; Norusis, 2000). The model Chi square is the difference between the -2LL for the model with only a constant and the -2LL for the complete model. The improvement in Chi square depicts the change in the -2LL between successive steps of the regression equation. It tests the null hypothesis that the coefficients for the variables added to the model are 0 (Munro, 1997).

To examine the influence of each of the independent variables on the dependent variable, the Beta (B), the significance, and the odds ratio Exp (B)

are reported. The B is the unstandardized regression coefficient that measures the relationship between each of the independent variables and the dependent variable, while the influence of the other independent variables is held constant. The B weights are used to determine the probability of a subject doing one thing or the other. The B tells us whether the independent variable associated with it is contributing significantly to the variance accounted for in the dependent variable. Positive values indicate an increase in the odds of an event occurring, and negative values a decrease in odds (Munro, 1997). The Wald statistic is not reported due to small sample size in this study. The odds ratio is defined as the probability of occurrence over the probability of nonoccurrence (Munro, 1997). The odds ratio is the number by which we would multiply the odds of completing an AD for each one unit increase in the independent variable. The clearest use of the odds ratio is when the independent variable is categorical, that is, a one point increase on a variable results in an increase in odds as listed in Exp (B) (Munro, 1997). For this study, an odds ratio greater than 1 indicates that the odds of completing an AD increase when the independent variable increases; and an odds ratio of less than 1 indicates that the odds of completing an AD decrease when the independent variable increases (Menard, 1995).

Content Analysis: Content analysis of the responses to the open-ended questions in Questionnaire #2 was performed. The quantitative method of basic content analysis was used, given the method of data collection and the type of interview data collected. Although qualitative researchers who do not quantify their data sometimes refer to their analytic work as content analysis, the term in

its classic sense refers to "a research technique for the objective, systematic, and quantitative description of the manifest content of communication"

(Berelson, 1971, p. 18). Basic content analysis is a quantitative classification of a given body of content in terms of a system of categories devised to yield data relevant to specific hypotheses concerning that content (Berelson, 1971; Weber, 1990). Content analysis in this sense involves the quantification of narrative, qualitative material and is applied to written and oral communications, which can include open-ended interviews. Analysis can range from a simple coding scheme to an elaborate computer-aided analysis of content (Weber, 1990). The inclusion of content analysis in a quantitative study is important because data obtained from content analysis can be related to the data obtained from statistical analysis to validate the findings or to provide missing information (Krippendorff, 1980).

Administration of Questionnaire #2 consisted of the researcher telephoning each participant and asking them a series of ten open-ended questions. As the participant provided responses, the responses were recorded on the questionnaire form by the researcher. Although the researcher attempted to record word for word the responses of the participants, some information (text) may have been lost. Once the interview was completed, the researcher transcribed the participant's responses to a master response sheet where all the participants' responses to each question were recorded. For this study, each question was analyzed independently. Thus, the initial sort of the interviews was by question number. From this initial sort, the responses provided by the participants to each question were first read in their entirety to allow the

researcher to develop an awareness of the underlying content. Notes were made regarding key words or ideas that arose from the message of the content.

A number of steps must be followed in content analysis. The first step is to define the unit of analysis, or the basic unit of text that will be used to categorize the content into meaningful groupings. Although individual words are often the unit, a theme is a larger and more inclusive unit of analysis. A theme may be a phrase, sentence, or paragraph embodying ideas or making an assertion about some topic (Krippendorff, 1980; Weber, 1990). For this study, the unit of analysis was defined as phrases, given the relatively brief responses given by participants.

Next the categories must be defined, often in a category dictionary. The categories of analysis should be defined so precisely that different analysts can apply them to the same body of content and secure the same results (Berelson, 1971). All relevant content is to be analyzed in terms of all the relevant categories so as to eliminate partial or biased analyses in which only those elements of content which fit the analyst's thesis are selected (Berelson, 1971). Category definitions were developed for each of the categories in this study and are described in more detail in Chapter 5. Wherever possible, the categories were named with the phrases used by the participants in the study. For example, words or phrases such as "procrastination" or "trust my family to decide for me" were taken simply from repeated use of these terms by participants. Some phrases may be classified into two categories, where one is a total category and one is a subcategory (Weber, 1990).

The third step in content analysis is test coding by at least two human coders on a sample of text to test the clarity of the category definitions and to ensure objectivity and reliability of the content analysis (Berelson, 1971; Weber, 1990). If reliability of the interrater coding is low, the coding rules must be revised (Weber, 1990). The responses to interview questions were coded first by the researcher and were independently reviewed by the thesis advisor. Any incidents that were not sufficiently clear examples of a particular category were reclassified after negotiation.

Once categories have been established, the number of times that they occur in the text is counted. Of primary importance in content analysis is the extent to which the analytic categories appear in the content (Berelson, 1971). Counting assumes that higher relative counts (proportions, percentages) reflect higher concern with the category (Weber, 1990). By far the most common form of representation of data is in terms of frequencies: absolute frequencies, such as the number of incidents found in the sample, or relative frequencies, such as the percentages of the sample size (Krippendorff, 1980). In quantitative content analysis, the selection of quotations from the content to enliven the report of the findings is not necessary, as it merely provides exemplifications of the categories used in the study (Berelson, 1971). In this study, both absolute and relative frequencies are provided for each category of responses.

Gaining Access to the Research Setting

Access to the research setting was obtained from the Board of Directors of the St. James Assiniboia Senior Centre, Inc. A presentation was made at a

board meeting of the Centre where the research study proposal and proof of ethical approval from the University of Manitoba Faculty of Nursing Ethical Review Committee were provided. Approval to conduct the study at the Centre was received at that time.

Ethical considerations

Ethical approval for this study was obtained from The University of Manitoba, Faculty of Nursing Ethics Committee. See Appendix I for a copy of the Ethical Approval letter. The ethical considerations of informed consent, confidentiality, and protection of research participants were addressed in this study. *In order to obtain informed consent, the researcher provided each participant with both a detailed verbal and written description of the research.* Each participant was asked to read and sign the disclaimer form. Potential participants understood that participation in the study was strictly voluntary. (See Appendix D).

The confidentiality of all the study participants was maintained throughout the entire course of this research study. Although the names and phone numbers of the respondents appeared on the disclaimer forms and were used to complete the intervention and posttesting, only the researcher had access to this information.

Finally, efforts were also made to protect participants from any mental, emotional, or physical harm associated with the research study. The length of questionnaires and interviews, as well as the intervention, were all kept short to minimize any inconvenience surrounding time commitments and to prevent

respondents from becoming fatigued, given their age. Potential benefits of the study to the older adult participants included increased level of knowledge and awareness of advance directives, and often some discussion within families about end of life issues. Several respondents commented on the positive nature of the educational session and handouts, and seemed pleased to receive the researcher's phone call(s). Potential risks could have included stress induced by talking about events related to mortality, or conflicts within families related to discussing such issues, but these seemed minimal. No one in the study declined to be interviewed, or expressed any emotional distress during the interviews.

Chapter 5

Research Findings

In this chapter, the findings of the study are reported. More specifically, univariate analysis including the demographic profile of the sample, the internal consistency (reliability) of the instruments, and the results of bivariate and multivariate data analysis are presented. In addition, frequencies of the categories stemming from the content analysis of the open ended questions on the second questionnaire are provided and discussed.

Univariate data analysis:

Description of the Sample: Of the 74 participants, there were 58 women (78.4 %) and 16 men (21.6 %). The high percentage of female participants reflects the higher proportion of women in older age groups. The mean age of the older adult participants was 72.6 years (SD= 7.6). Ages of the participants ranged from 54 to 93 years. The mean number of children was 3.2 (SD = 1.7). Sociodemographic characteristics for the entire sample, as well as for the control and intervention groups are depicted in Table 1. There were no significant differences in gender, age, marital status, occupational group, satisfaction with income, and educational level between the control and intervention groups, and therefore results reported here pertain to the entire sample.

The most frequently reported marital status was widowed (48.6%) followed by married (35.1%). The most common occupation group was homemaker (37.8 %) followed by clerical/sales/service (32.5%). The majority of participants indicated that their income adequately satisfied their needs (64.9%).

Approximately two thirds of participants reported having completed high school, some post-secondary education, or a Bachelor's degree.

Of the 74 participants, 53 (71.6%) considered themselves a member of a particular religious group. Of the 53, there were 21 (39.6%) United, 12 (22.6%) Anglican, 11 (20.8%) Roman Catholic, and 9 (16.9%) other denominations. Of the 74 participants, only 32 (43.2%) considered themselves to be a member of a particular ethnic group. Of these 32, there were 14 (43.8%) British/English/Anglo Saxon, 8 (25.0%) Canadian, and 10 (31.2%) other ethnic groups. Findings with regard to birthplace are as follows: 28 (37.8%) were born in Winnipeg, 26 (35.1%) were born outside Winnipeg but in Manitoba, 15 (20.3%) were born outside Manitoba and 5 (6.8%) were born outside Canada. Overall, sociodemographic findings indicate a relatively homogeneous sample.

Table 1

Sociodemographic Characteristics of the Sample

Characteristic	Entire sample n=74		Control n= 37		Intervention n=37		X ² / Significance
	N	%	N	%	N	%	
GENDER							
Female	58	78.4	28	75.7	30	81.1	.319 p = .572 NS
Male	16	21.6	9	24.3	7	18.9	
AGE							
Less than 65 years	14	18.9	7	18.9	7	18.9	.245 p = .970 NS
65 to 74 years	29	39.2	14	37.8	15	40.5	
75 to 84 years	29	39.2	15	40.5	14	37.8	
85 years and over	2	2.7	1	2.7	1	2.7	
MARITAL STATUS							
Widowed	36	48.6	17	45.9	19	51.4	5.226 p= .156 NS
Married	26	35.1	15	40.5	11	29.7	
Divorced/Separated	8	10.8	5	13.5	3	8.1	
Single/Never married	4	5.4	0	0	4	10.8	
OCCUPATION							
Homemaker	28	37.8	17	45.9	11	29.7	2.956 p = .398 NS
Clerical/Sales/Service	24	32.5	12	32.4	12	32.4	
Professional/Management	17	23.0	6	16.2	11	29.7	
Laborer	5	6.8	2	5.4	3	8.1	
ABILITY OF INCOME TO SATISFY NEEDS							
Very well	16	21.6	7	18.9	9	24.3	1.583 p = .663 NS
Adequately	48	64.9	26	70.3	22	59.5	
With some difficulty	6	8.1	3	8.1	3	8.1	
Not very well	4	5.4	1	2.7	3	8.1	
EDUCATION LEVEL							
Elementary/Some h.s.	26	35.1	15	40.5	11	29.7	2.628 p = .453 NS
Completed high school	17	23.0	9	24.3	8	21.6	
Some post-secondary	26	35.1	12	32.4	14	37.8	
Bachelor's degree	5	6.8	1	2.7	4	10.8	

NS = not significant

The participants reported a mean of 3.4 (SD= 2.2) health conditions with a range of 0 to 11 conditions. For the total sample, the most frequently self-reported health conditions were arthritis and eye trouble with 35.1% of participants reporting these conditions. Health conditions which were common to

at least 10% of the entire sample included: heart trouble (31.1%), high blood pressure (31.1%), breathing problems (21.6%), back problems (21.6%), foot problems (20.3%), ear trouble (20.3%), dental problems (16.2%), incontinence (12.2%), diabetes (10.8%), stomach problems (10.8%), and skin problems, osteoporosis, and Parkinson's disease (9.5%). Health conditions in the other category include cancer, circulation problems, emotional/ mental problems, thyroid condition, stroke, allergies, asthma, cleft palate, diverticulosis, multiple sclerosis, and post polio. See Table 2 for a breakdown of the self-reported health conditions for the entire sample, as well as the control and intervention groups.

Tests of significant differences between the control and intervention groups for each health condition were not performed as health condition variables could not be collapsed, and several cells had numbers too small to be analyzed. However, there were no significant differences between the two groups for the number of health conditions per participant ($z = -1.372$, $p = .170$). Control group members had a mean of 3.0 health conditions, and intervention group members had a mean of 3.7 health conditions. (The Mann-Whitney U test was used due to the non-normal distribution of the continuous test variable).

Table 2

Frequencies of Self-Reported Medical Conditions (n = 74)

Medical Condition	Entire Sample		Control		Intervention	
	N	%	N	%	N	%
Arthritis	26	35.1	13	35.1	13	35.1
Eye trouble	26	35.1	10	27.0	16	43.2
Heart trouble	23	31.1	10	27.0	13	35.1
High blood pressure	23	31.1	9	24.3	14	37.8
Breathing problems	16	21.6	9	24.3	7	18.9
Back problems	16	21.6	10	27.0	6	16.2
Foot/ limb	15	20.3	7	18.9	8	21.6
Ear trouble	15	20.3	6	16.2	9	24.3
Dental	12	16.2	5	13.5	7	18.9
Incontinence	9	12.2	4	10.8	5	13.5
Diabetes	8	10.8	4	10.8	4	10.8
Stomach	8	10.8	5	13.5	3	8.1
Skin problems	7	9.5	3	8.1	4	10.8
Osteoporosis	7	9.5	2	5.4	5	13.5
Parkinson's	7	9.5	3	8.1	4	10.8
Other	32	43.2	12	32.4	20	54.0

Self-rated health: Responses to the single item question on self-rated health

suggest that the older adults in this study rated their health positively.

Specifically, 78.5% (n= 58) of older adults rated their health as “good” , “very good” or “excellent” (see Table 3). These findings are consistent with previous studies which indicate that most community samples of older adults tend to rate their health optimistically (Idler & Kasl, 1991; Mossey & Shapiro, 1982). There were no significant differences between the control and intervention groups, when self-rated health was collapsed into two categories: poor (including the poor and fair responses), and good (including the good, very good, and excellent responses) ($\chi^2 = 1.276$, $p = .259$). The cells were collapsed due to small cell sizes in the poor and excellent categories, according to the recommendation of

Wolinsky & Arnold (1988), as discussed previously in Chapter 4. The collapsed self-rated health categories were used for both bivariate and multivariate analysis.

Table 3

Responses to Single Item on Self-Rated Health

Response	Entire sample n = 74		Control group n = 37		Intervention group n = 37	
	N	%	N	%	N	%
Poor	1	1.4	0	0	1	2.7
Fair	15	20.3	6	16.2	9	24.3
Good	40	54.1	21	56.8	19	51.4
Very good	13	17.6	6	16.2	7	18.9
Excellent	5	6.8	4	10.8	1	2.7
Total	74	100.0	37	100.0	37	100.0

Perceived control: Responses to the single item question on perceived control suggest that the older adults in this study perceive that they have a great deal of control in their life (perceived ability to influence outcomes/events in the environment) (Chipperfield & Greenslade, 1999). Using a visual analogue scale from 1 to 10, with 1 indicating a perception of being out of control and 10 indicating a perception of being totally in control, 28.4% (n= 21) of the participants rated their perceived control as 10, while 89.4% (n= 66) rated their perceived control as 7 or greater. The mean rating of perceived control was 8.4 (SD = 1.6).

Social Support: The social support experienced by the older adult participants (including examination of family networks, friends networks, confidante relations, helping others, and living arrangements) was measured by the Lubben Social Network Scale (LSNS). Scores from the ten items are summed and can range

from 0 to 50, and scores below 20 qualify as a cutoff point for screening those elderly who are at greater risk of social isolation (Lubben, 1988). There was one missing case for the LSNS, and this case was excluded from analysis. In this study, the mean score on the LSNS was 30.47 ($SD = 7.60$), indicating a moderate degree of social support experienced by this sample.

The Cronbach's coefficient alpha for the LSNS in this study was .67, which is slightly less than the alpha of .70 reported by Lubben (1988). The Cronbach's alpha for the LSNS in the control group was .50, while the alpha for the LSNS in the intervention group was .74. In order to increase the alpha to .70 (to match that of Lubben, 1988), the SPSS program function providing reliability analysis when items are deleted from a scale was used. This function displays summary statistics comparing each item to the scale composed of the other items. These statistics include scale mean and variance if the item were deleted from the scale, correlation between the item and the scale composed of the other items, and the Cronbach's alpha if the item were deleted from the scale (SPSS Version 10.0). Deletion of one item from the LSNS increased the Cronbach's alpha to .70 (.59 in the control group and .76 in the intervention group). The item removed was the question: "Do you live alone or with other people?" The resulting scale was called the "Lubben9". Deletion of additional items did not increase the alpha beyond .70.

A possible explanation for the lower alpha for the LSNS in this study compared to that of Lubben (1988) probably relates to lower interitem correlations between specific items for this sample (r values between .103 and

.190). For example, although a majority of participants ($n = 48$) lived alone, they nevertheless reported that they had large numbers of friends and/or relatives with whom they had contact on a frequent basis.

Perceived benefits and barriers to completing an AD: The 12 item Living Will Barriers and Benefits Scale developed by VandeCreek and Frankowski (1996) was used in this study. The barrier subscale consists of seven items. Each of the items are scored along a four point Likert-type scale ranging from strongly disagree to strongly agree. Total scores in the barrier subscale can range from 7 to 28 and higher scores indicate higher levels of perceived barriers to the completion of an AD. In this study, scores in the barrier subscale ranged from 7 to 24 with a mean score of 15.60 ($SD = 3.56$).

The benefit subscale consists of five items. Again, each of the items was scored along the same four-point scale as the barrier subscale. Total scores in the benefits subscale can range from 5 to 20 with higher scores indicating higher levels of perceived benefits to completing an AD. In this study, scores in the benefit subscale ranged from 10 to 20 with a mean score of 16.49 ($SD = 2.36$).

In this study, the Cronbach's alpha for the barriers subscale was .81 (.80 for the control group and .83 for the intervention group). The Cronbach's alpha for the benefits subscale was .95 (.94 for the control group and .96 for the intervention group). These are much higher scores than those reported by VandeCreek and Frankowski (1996). These subscales demonstrated strong internal consistency for this study, given that when making group level comparisons, coefficients in the vicinity of 0.70 are usually sufficient (Polit &

Hungler, 1995). As well, strong negative correlations ($r_s = -.361$, $p < .01$) were found between the benefits and barriers subscales.

However, it must be noted that a few older adults had difficulty responding to one item in particular in the barriers subscale. Four participants did not respond to the statement "I do not need to complete an advance directive because I believe that I will live a lot longer". Several participants asked the researcher about this particular question, saying "Who knows how long they will live, you could die tomorrow". Three other items (one in the barrier subscale and two in the benefit subscale) had one missing case each. This may reflect some difficulty in interpretation of these questions by some participants. As stated previously, all cases with missing values were not included in statistical analysis. As a result, analysis using the barrier subscale had an $n = 69$ and analysis using the benefit subscale had an $n = 73$.

Completion of Advance Directives: Advance directives were completed by 25.7% ($n = 19$) participants in the total sample ($n = 74$). This translated into 18.9% ($n = 7$) in the control group and 32.4% ($n = 12$) in the intervention group. Conversely, ADs were not completed by 74.3% ($n = 55$) of the participants. These findings are consistent with completion rates found in the literature.

Discussion of Advance Directives: Discussion about advance directives occurred in 69.4% ($n = 50$) of the participants who provided an answer to this question ($n = 72$). (Upon administration of Questionnaire #2, two participants (one from each of the control and interventions groups) clearly did not understand what the researcher was asking, and therefore were excused from

further questioning.) Discussion occurred in 59.5% ($n = 22$) of the control group participants, and in 75.7% ($n = 28$) of the intervention group participants.

Bivariate data analysis

In the following section, the results of the bivariate data analysis are presented. Each of the research hypotheses in this study is discussed individually. Although the relationship with discussion of ADs was not included in some of the original hypotheses, these relationships will be discussed given that discussion of ADs is one of the dependent variables. Please refer to Appendix N for an operationalization of the variables.

Hypothesis #1:

- a) The intervention group (those who attend the educational session and receive a follow-up phone call to offer information and assistance to complete an AD) is more likely to complete ADs compared with the control group (those who attend the education session but receive no reminder phone call).**
- b) The intervention group is more likely to have discussions with significant others about ADs compared with the control group.**

When the intervention phone call was made, the most frequent response ($n = 23$) was that the education session was thorough and informative and that the participant had no further questions. Several of the participants mentioned that they had all the information (handouts) at hand, but had just not yet had the time to take a look at it or discuss it with anyone. Others stated that they appreciated the information, but really did not need to complete an AD at this

time, because “I’m pretty healthy right now”, or “Things are going well for me”.

In the intervention group, 12 (32.4%) participants completed an AD, while 7 (18.9%) participants completed an AD in the control group. Discussion of ADs occurred in 59.5% ($n = 22$) of the control group participants, and in 75.7% ($n = 28$) of the intervention group participants.

To determine whether being in the control and intervention groups had any impact on either completion or discussion of ADs, Chi-square tests were used to analyze the data. This nonparametric test was chosen given the non-normal distribution of the variables and their nominal (categorical) level. No significant differences between the groups were found for completion or discussion of ADs (see Table 4a).

Table 4a

Relationship between Dependent Variables and Type of Group

Variable	X^2 value	p value	Significance
Completion of AD ($n = 74$)	1.770	.183	NS
Discussion of AD ($n = 72$)	2.356	.308	NS

In addition, the relationship between being in the control or intervention groups and any of the other independent variables in this study (age, gender, marital status, education, income, self-rated health, perceived control, level of social support, confidante relationships, and perceived barriers and benefits of completing an AD) were examined. Chi-square tests (X^2 statistic) were used for variables that were categorical, and Mann Whitney U tests (z statistic) for those variables that were continuous. Again, no significant relationships were found. Please refer to Table 1 for the results pertaining to sociodemographic variables.

See Table 4b for the results pertaining to the other variables.

Table 4b

Relationship Between Study Variables and Type of Group (n = 74 unless otherwise indicated)

Variable	Statistic		p value	Significance
	χ^2	z		
Self-rated health status	1.276		.259	NS
Perceived control		-.226	.821	NS
Social support (n =73)		-1.111	.267	NS
Confidante relationships	2.056		.152	NS
Perceived barriers (n =69)		-.175	.861	NS
Perceived benefits (n = 73)		-1.464	.143	NS

NS = not significant

Given the finding that being in the control or intervention group produced no difference in the completion or discussion of ADs, all further analysis was completed using the entire sample.

Hypothesis #2:

Completion of ADs is directly related to various demographic characteristics:

Completion of ADs is directly related to older age.

Completion of ADs is directly related to being female.

Completion of ADs is directly related to being married.

Completion of ADs is directly related to having higher levels of education.

Completion of ADs is directly related to having adequate income.

To determine whether significant relationships existed between completion of ADs and the demographic variables of age, gender, marital status, educational level, and satisfaction with income, Chi-square tests were used for these categorical variables. For specific coding of the variables, see Appendix N.

For the total group ($n = 74$), no significant relationships were found between completion of ADs and the demographic variables of age, gender, marital status, educational level, and satisfaction with income (see Table 5). The variable of marital status was analyzed using various combinations of married, widowed, divorced/separated, and single. The original categories were further collapsed to 'single, married, widowed', 'married and other', and 'single and other' due to small cell sizes. However, none of these combinations revealed any significant relationships.

It is interesting to note, however, that although the group was too small for bivariate analysis ($n = 4$), single or never married individuals appear to complete ADs at a much higher rate than any other of the marital status groups. For example, of the 4 single individuals in this study, 75% ($n=3$) completed an AD.

Table 5

Relationship between Demographic Variables and Completion of ADs ($n = 74$)

Variable	X^2	p value	Significance
Age	1.338	.720	NS
Gender	1.857	.173	NS
Marital status			
four categories	5.676	.177	NS
three categories	2.183	.336	NS
married vs. other	.872	.350	NS
single vs. other	1.919	.166	NS
Education	1.780	.619	NS
Income	3.585	.310	NS

NS = not significant

Percentages and n's for specific categories are available in Table 1.

Discussion of ADs was examined against the demographic variables of age, gender, marital status, education, and income. Again Chi-square tests were

used for these categorical variables. For the total group ($n = 74$), no significant relationships were found between discussion of ADs and the demographic variables of age, gender, marital status, education, and satisfaction with income (see Table 6).

Table 6

Relationship between Demographic Variables and Discussion of ADs ($n = 74$)

Variable	X^2	p value	Significance
Age	3.226	.780	NS
Gender	.299	.584	NS
Marital status			
four categories	1.285	.733	NS
three categories	3.268	.514	NS
married vs. other	2.199	.333	NS
single vs. other	.451	.798	NS
Education	2.345	.504	NS
Income	2.129	.546	NS

NS = not significant

Percentages and n's for specific categories are available in Table 1.

Hypothesis #3:

Completion of ADs is inversely related to self-rated health status.

To compare self-rated health status with the completion or discussion of ADs, the Chi square test was used, as self-rated health was dichotomized into the poor and good health categories as described previously. For the total group ($n = 74$), no significant relationships were found between self-rated health status and the completion of ADs ($X^2 = 1.496$, $p = .221$) or between self-rated health status and the discussion of ADs ($X^2 = 2.648$, $p = .104$).

Hypothesis #4:

Completion of ADs is directly related to perceived control.

To test the relationship between perceived control and the completion or

discussion of ADs, Mann-Whitney U tests were used, because perceived control is a continuous variable measured at an interval level. For the total group ($n = 74$), no significant relationships were found between perceived control and the completion of ADs ($z = -.669$, $p = .504$) or between perceived control and the discussion of ADs ($z = -.530$, $p = .596$).

Hypothesis #5:

a) Completion of ADs is related to the presence of family and significant others (social support).

To test the relationship between level of social support and the completion or discussion of ADs, Mann-Whitney U tests were used, given that this variable is continuous and measured at the interval level. The Lubben9 scale was used for analysis, given its acceptable alpha value of .70. For the total group ($n = 73$), excluding the one missing case, no significant relationships were found between social support and the completion of ADs ($z = -.176$, $p = .860$) or between the level of social support and the discussion of ADs ($z = -.143$, $p = .886$).

b) Completion of ADs is directly related to the presence of close confidante relationships with family or significant others.

To test this hypothesis, the single item from the LSNS, "When you have an important decision to make, do you have someone you can talk to about it?", was used. Lubben (1988) suggests that this item is an indicator of confidante relationships. The item was dichotomized into yes or no categories from the original scoring of always, very often, often, sometimes, seldom, and never. Always, very often, and often were collapsed into the yes category, and

sometimes, seldom, and never were collapsed into the no category. For the total sample ($n = 74$), there were 81.1% ($n = 60$) who did have a close confidante relationship with someone, and 18.9% ($n = 14$) of participants who did not have a close confidante relationship. Chi-square testing was performed to determine significance of relationships between the presence of close confidante relationships and the completion and discussion of ADs. For the total group ($n = 74$), no significant relationships were found between the presence of close confidante relationships and the completion of ADs ($X^2 = .637$, $p = .425$) or between the presence of close confidante relationships and the discussion of ADs ($X^2 = .446$, $p = .504$).

Hypothesis #6:

a) Completion of ADs is directly related to perceived benefits of ADs.

To test the relationship between the completion of ADs and the perceived benefits of ADs, Mann-Whitney U tests were performed given the interval level and continuous nature of the independent variable. For the total group ($n = 73$), excluding the one missing case, no significant relationships were found between the perceived benefits of ADs and the completion of an AD ($z = -1.112$, $p = .266$).

To test the relationship between the discussion of ADs and the perceived benefits of ADs, Mann-Whitney U tests were again performed. For the total group ($n = 73$), no significant relationships were found between the perceived benefits of ADs and the discussion of ADs with someone ($z = -1.675$, $p = .094$).

b) Completion of ADs is inversely related to perceived barriers of ADs.

To test the relationship between the completion of ADs and the perceived barriers of ADs, Mann-Whitney U tests were performed given the interval level and continuous nature of the independent variable. For the total group ($n = 69$), excluding the five missing cases, completion of ADs and perceived barriers of ADs were found to be significantly inversely related ($z = -2.726$, $p = .006$). The higher the perceived barriers of ADs, the less likely participants were to complete an AD.

To determine if items in the barrier subscale were related to the completion of an AD, the responses to these items were dichotomized into agree/ disagree answers (from strongly agree, agree, disagree, and strongly disagree) and Chi-square testing performed. The particular items of the barrier subscale which proved significant in relation to whether an AD was completed were: "The many other concerns in my life prevent me from considering how I want my last days managed" ($X^2 = 10.754$, $p = .001$); "It is difficult to complete an AD because I don't think about my death very much" ($X^2 = 7.920$, $p = .005$); "It is difficult to complete an AD now because I will probably change my mind when I become seriously ill" ($X^2 = 7.325$, $p = .007$); and "I do not need to complete an AD now because I believe that I will live a lot longer" ($X^2 = 6.058$, $p = .014$). For a listing of all the barrier items, see Appendix L. These findings indicate a present (versus future) orientation, a tendency toward procrastination, and a reluctance to think about one's death.

To test the relationship between the discussion of ADs and the perceived barriers of ADs, Mann-Whitney U tests were again performed. For the total group

($n = 69$), there was a significant inverse relationship found between the perceived barriers of ADs and the discussion of ADs with someone ($z = -2.405$, $p = .016$). The higher the perceived barriers of ADs, the less likely participants were to discuss ADs with someone.

To determine if items in the barrier subscale were related to the discussion of an AD, the responses to these items were dichotomized into agree/disagree answers (from strongly agree, agree, disagree, and strongly disagree) and Chi-square testing performed. The particular barrier items that proved significant in determining whether an AD was discussed with someone were: "I do not need to complete an AD now because I believe that I will live a lot longer" ($X^2 = 11.074$, $p = .001$); "It is difficult to complete an AD because I don't think about my death very much" ($X^2 = 4.396$, $p = .036$); and "It is difficult to complete an AD because nobody knows how they will respond to the threat of death until that time comes" ($X^2 = 4.396$, $p = .036$). These findings are similar to those for completion of an AD, and generally indicate a present orientation and an unwillingness to think about death at the present time.

Completion and Discussion of ADs: Although a research hypothesis was not generated regarding the relationship between the two dependent variables, completion and discussion of ADs, this relationship was tested. A significant positive relationship was found between discussion of an AD with someone and subsequent completion of an AD ($X^2 = 11.357$, $p = .001$). In fact, all 19 participants who completed an AD had talked to someone about it (see Table 7).

Table 7

Comparing Completion and Discussion of ADs (n =72)

		Did you complete an AD?		Total
		no	yes	
Did you talk about the AD with anyone?	no	22	0	22
	yes	31	19	50
Total		53	19	72

Note: Total does not equal 74 because of missing values.

Multivariate analysis: Multivariate analysis included a logistic regression modeling process to analyze the relationships between selected independent variables and the outcome variables of AD completion and AD discussion. The dichotomous nature of the dependent variables and the goal of predicting or examining the impact of various independent variables on the likelihood of completion and discussion of ADs led to selection of a logistic regression model. A complete description of the procedures used in logistic regression is provided in Chapter 4. The findings are presented here.

Model Building: As discussed in Chapter 4, the selection of independent variables for inclusion in the two regression models: Model A--Completion of ADs and Model B--Discussion of ADs, was based on both statistical ($p \leq 0.15$) and theoretical significance. The resulting independent variables were: perceived barriers, perceived benefits, age and gender for Model A, and perceived barriers, perceived benefits, self-rated health, age and gender for Model B.

For Model A--Completion of ADs, the independent variables added to the logistic estimation of AD completion were perceived barriers, perceived benefits, age, and gender. Perceived barriers was chosen because of its significant

relationship to AD completion ($z = -2.726$, $p = .006$) in bivariate analysis.

Perceived benefits was chosen because of its close conceptual relationship to perceived barriers and its correlation with perceived barriers ($r_s = -.361$, $p < .01$).

Both these variables are also major components of the Health Belief Model and Advance Directives (Appendix B and C). Although not statistically significant in bivariate analysis, age and gender were chosen due to their importance as factors related to AD completion in the literature review. Demographic variables are one of the key modifying factors in the conceptual framework, and these two variables were the ones identified by the most studies as being significantly related to AD completion. Gender was identified by ten studies (Ali, 1999; Bradley & Rizzo, 1999; Colenda et al., 1998; Luptak & Boulton, 1994; Lynn & Teno, 1993; Silverman, Tuma, Schaeffer, & Singh, 1995; Singer et al., 1993; Stetler et al., 1992; Stolman et al., 1990; Suri et al., 1999). Age was identified by nine studies (Ali, 1999; Bradley & Rizzo, 1999; Elpern et al., 1993; Emanuel et al., 1991; Gordon & Shade, 1999; Havens, 2000; Orlander, 1999; Singer et al., 1993; Suri et al., 1999).

For Model B--Discussion of ADs, the independent variables added to the logistic equation were perceived barriers, perceived benefits, self-rated health, age, and gender. Perceived barriers was chosen because of its significant relationship to AD discussion ($z = -2.405$, $p = .016$) in bivariate analysis. Self-rated health was entered also because of its p value ($X^2 = 2.648$, $p = .104$). Perceived benefits, age, and gender were chosen for the reasons outlined in the previous paragraph.

Findings from Multicollinearity Testing: Using the Spearman's rho

correlation matrix of the five independent variables chosen, none of the relationships between variables were found to be multicollinear (using a coefficient of greater than 0.80 to indicate multicollinearity) (see Table 8).

Table 8

Spearman's rho Correlations Between Variables (n = 74 unless otherwise stated)

Variable	Age	Gender	Self-rated Health	Barriers	Benefits
Age	1.000				
Gender	-.075	1.000			
Self-rated Health	** .332	.123	1.000		
Barriers (n = 69)	.110	.029	.159	1.000	
Benefits (n = 73)	-.071	.023	-.026	** -.361	1.000

**Correlation is significant at the .01 level (2 tailed)

In the second method of testing for multicollinearity, linear regression modeling, each independent variable becomes the dependent variable and is regressed on all the other independent variables (Norusis, 2000). Collinearity statistics including the tolerance value are produced. Tolerance measures the strength of the linear relationship among the independent variables. A tolerance of less than 0.20 raises the possibility that multicollinearity exists (Menard, 1995). For this sample, there was no evidence of multicollinearity as the tolerance values are all greater than 0.80 for the independent variables (see Table 9).

Table 9

Collinearity Statistics for Independent Variables in Both Models

Variables	Model A (AD completion) Tolerance	Model B (AD Discussion) Tolerance
Barriers	.859	.864
Benefits	.854	.841
Self-rated health	---	.916
Age	.973	.937
Gender	.981	.940

Multivariate findings:

As mentioned, two regression models were developed: Model A--Completion of ADs, and Model B--Discussion of ADs. The four independent variables of perceived barriers, perceived benefits, age, and gender were used in Model A. The five independent variables of perceived barriers, perceived benefits, self-rated health, age and gender were used in Model B. Each of the independent variables was entered into the models using a stepwise approach. Initially, a backward approach was chosen, due to the advantage of backward elimination having less risk of failing to find a relationship when one exists (Menard, 1995). However, in the final analysis, both forward and backward approaches were used in order to verify the findings. Both approaches yielded the same findings for both models respectively. Independent variables were entered into the equation in one block.

To describe the results of the logistic regression model overall, the -2 times the log of the likelihood (-2LL) and the improvement in the Chi-square were examined. To examine the influence of each of the independent variables on the dependent variable, the Beta (B) and the significance are reported.

The results of the logistic regression model for Model A--Completion of ADs are presented in Table 10. The model Chi square of the first step of variables (perceived barriers) is significant, suggesting that perceived barriers contributed to the goodness-of-fit of the model to the data. In successive steps, the entry of additional independent variables did not result in significant Improvement Chi square values, indicating that the addition of each of the other independent variables did not contribute significantly to the model. However, the model X^2 remained significant for the first three steps of the model when taking into account all the independent variables added to the model up to that point. Only the association between perceived barriers and completion of ADs remained significant ($p < .05$) throughout all steps of the model. The significance value for perceived barriers in the final step ($p = .030$) indicates that those participants with greater perceived barriers were less likely to complete an AD.

Table 10

Stepwise logistic regression for Completion of ADs (Model A)

Independent variables	Step 1 B	Sig.	Step 2 B	Sig.	Step 3 B	Sig.	Step 4 B	Sig.
Barriers	-.196	.023						
Barriers			-.189	.026				
Gender			1.105	.181 NS				
Barriers					-.194	.024		
Gender					1.203	.154 NS		
Age					.034	.383 NS		
Barriers							-.208	.030
Gender							1.192	.157 NS
Age							.033	.391 NS
Benefits							-.050	.726 NS
-2LL	72.806		70.688		69.916		69.791	
Model X ²	5.792		7.909		8.681		8.806	
df	1		2		3		4	
p	.016		.019		.034		.066 NS	
Improvement	5.792		2.117		.772		.125	
df	1		1		1		1	
p	.016		.146 NS		p = .379 NS		.724 NS	

NS= not significant
Variable entered on step 1: barriers
Variable entered on step 2: gender
Variable entered on step 3: age
Variable entered on step 4: benefits

The *B* value, the significance, and the odds ratio for the independent variables in Model A are presented in Table 11. The only significant factor in AD completion is perceived barriers. The odds ratio of .812 for perceived barriers indicates that when perceived barriers increase, there is less likelihood of AD completion.

Table 11

Odds Ratios for Completion of ADs (Model A)

Variables	<i>B</i>	Significance	Odds Ratio
Barriers	-.208	.030	.812
Benefits	-.050	.726 NS	.951
Age	.033	.391 NS	1.034
Gender	1.192	.157 NS	3.294

NS = not significant

The results of the logistic regression model for Model B--Discussion of ADs are presented in Table 12. The model Chi square of the first step of variables (perceived barriers) is significant, suggesting that perceived barriers contributed to the goodness-of-fit of the model to the data. In successive steps, the entry of additional independent variables did not result in significant Improvement Chi square values, indicating that the addition of these other independent variables did not contribute significantly to the model. However, the model X^2 remained significant for the first three steps of the model when taking into account all the independent variables added to the model up to that point. Only the association between perceived barriers and discussion of ADs remained significant ($p < .05$) throughout all steps of the model. The significance value for perceived barriers in the final step ($p = .044$) indicates that those participants with greater perceived barriers were less likely to discuss an AD.

Table 12

Stepwise logistic regression for Discussion of ADs (Model B)

Independent variables	Step 1 B	Sig.	Step 2 B	Sig.	Step 3 B	Sig.	Step 4 B	Sig.	Step 5 B	Sig.
Barriers	-.213	.018								
Barriers			-.195	.032						
Health			-.986	.241 NS						
Barriers					-.196	.033				
Health					-1.165	.202 NS				
Age					.023	.606 NS				
Barriers							-.181	.042		
Health							-1.225	.187 NS		
Age							.028	.548 NS		
Benefits							.065	.622 NS		
Barriers									-.180	.044
Health									-1.166	.217 NS
Age									.024	.601 NS
Benefits									.065	.621 NS
Gender									-.267	.702 NS
-2LL	76.014								73.775	
Model X ²	6.551		74.440		74.169		73.924		8.790	
df	1		8.125		8.396		8.641		5	
p	.010		.017		.039		.071 NS		.118 NS	
Improvement	6.551		1.573		.271		.245		.149	
df	1		1		1		1		1	
p	.010		.210 NS		.602 NS		.620 NS		.700 NS	

NS = not significant

Variables entered: on step 1: barriers, on step 2: self-rated health, on step 3: age, on step 4: benefits, on step 5: gender

For Model B, the *B* value, the significance level, and the odds ratios for the independent variables in Model B are given in Table 13. The only significant factor in AD discussion is perceived barriers. The odds ratio of .836 indicates that with increased perceived barriers, there is less likelihood of AD discussion.

Table 13

Odds Ratios for Discussion of ADs (Model B)

Variables	<i>B</i>	Significance	Odds Ratio
Barriers	-.180	.044	.836
Benefits	.065	.621 NS	1.068
Self-rated Health	-1.166	.217 NS	.312
Age	.024	.601 NS	1.025
Gender	-.267	.702 NS	.766

In summary, the overall results of the logistic regression analysis indicate that perceived barriers remains the only significant variable associated with AD completion and discussion. That is, as perceived barriers to AD completion increase, there is less likelihood of AD completion or discussion.

Content Analysis:

Basic content analysis was used to examine the responses to the open-ended questions in Questionnaire #2. Basic content analysis is the quantification of narrative, qualitative material, and the method of content analysis has been described in Chapter 4. During administration of Questionnaire #2, the researcher telephoned each participant and asked him or her a series of ten open-ended questions. As the participant answered each question, their responses were recorded on the questionnaire form by the researcher.

Once the interview was completed, the researcher transcribed the

responses to a master response sheet where all the participants' responses to each question were recorded. The specific steps of basic content analysis, as described in Chapter 4, were used. The unit of analysis was determined to be "phrases" as most of the answers provided by the participants were recorded as phrases or short sentences. Category definitions (and subcategories, if warranted) were developed by the researcher based on the key words or ideas noted after reading all the responses to each question. The researcher then returned to the master response sheet and color-coded the responses for each of the pre-determined categories. The number of responses in each category (each a different color) was then counted. Finally, inter-rater reliability was established with the thesis advisor, who independently counted the responses for each category according to the category definitions.

Each of the ten questions was analyzed independently. Responses to each of the questions were divided into two groups, depending on whether the participant had completed an AD or had not completed an AD by the end of the study period. Findings related to the categories determined for each question will now be presented, comparing these two groups. Findings indicate both the count of the number of times each category appeared in the responses (absolute frequency) and the percentage of the sample (relative frequency) providing each category of responses. Tables are used to present the data when this is more feasible.

Question #1: Why did you complete an advance directive? (for those participants who completed an AD). or **If not, why not?** (for those participants

who had not completed an AD).

For those participants who had completed an AD ($n = 19$), the responses were grouped into six categories (see Table 14). The most common reason for completing an AD related to wanting to be in control of this decision. The second most common category included wanting others (family, friends, or health care providers) to know the type of care desired. Other categories of reasons for completing an AD included: wanting to decrease burden on family members, having no alternate decision maker, witnessing an illness or death in the family, and the education session increasing awareness of ADs.

Table 14

Reasons AD was Completed (n = 19)

Category	Category Definition	Subcategories	Absolute frequency	Relative frequency
Want to be in control	Contains words or phrases indicating a desire or wish to be in control of specifying one's own wishes regarding type of care desired.	Want to decide for myself, Want to be in control, Believe that it's important to do, Know the type of care want/ don't want, Want wishes in writing, Want things settled	10	52.6%
Wanting others to know the care I want	Contains words or phrases referring to others (family, friends, doctor) knowing wishes for care	--	6	31.6%
Decrease burden on family	Contains words or phrases indicating some type of decreased burden for family if wishes known	--	3	15.8%
No alternate decision maker	Contains words or phrases indicating a lack of individuals to rely on to make decisions for them	No family, No relatives	2	10.5%
Trigger	Contains words or phrases indicating a trigger which prompted completion	Illness or death in family	2	10.5%
Awareness	Contains words or phrases indicating that something increased their awareness of issue	AD educational session	1	5.3%
Total			24	

Note: Total equals 24 because some participants provided more than one response.

Of the 55 participants who did not complete an AD, the responses were grouped into eight categories. (The n = 53 because two of the participants did not understand what the researcher was asking at this point in Questionnaire #2,

and therefore they were excused from further questioning) (see Table 15).

Overall, the most common reasons for not completing an AD were procrastination or a present orientation to life, reluctance to think about one's future illness or death, trusting others to decide for them, and feeling healthy at the present time. Other reasons for not completing an AD included not knowing what it was, needing more help or information, not being interested in completing an AD, and family being against completion. It should be noted that several participants, 36% (n = 20) reported that they "should do it", "will do it sometime" and "it is a good thing to do" when discussing completion of ADs.

Table 15

Reasons AD Not Completed (n = 53)

Category	Category Definition	Subcategory	Absolute frequency	Relative frequency
Procrastination/ Present orientation	Contains words or phrases indicating a focus on present day living.	Haven't gotten around to it, Procrastination, Not a priority, Not important to me now, Been very busy, No time, Forgot to do	33	62.3%
Reluctance to think about illness or death	Contains words or phrases indicating a desire not to think about planning for own illness or death	Hard to plan for death, Don't believe in planning for illness or death, Don't want to think about illness or death	10	18.9%
Trust others to decide	Contains words or phrases indicating a preference for family/ friends to be involved in decision making	Trust family/ friends/ doctor to decide, Waiting to talk to friends/ family	6	11.3%
Feeling good/ healthy	Contains words or phrases indicating good health at present time and therefore no need to complete AD now	--	6	11.3%
Don't know what it is	Contains words or phrases indicating that the participant does not know to what the researcher is referring	--	4	7.5%
Need more help/ information	Contains words or phrases indicating a need for more information or help before can complete AD	--	3	5.7%
Not interested	Contains words or phrases indicating a lack of interest in completion of ADs	--	1	1.9%
Family against completion	Contains words or phrases indicating family does not agree with completion	--	1	1.9%
Total			64	

Note: Total is 64 because some participants provided more than one response.

Question #2: Tell me about filling out the advance directive (for those participants who had completed an AD). or **What would help you complete the advance directive? What did you do with the advance directive when you took it home?** (for those participants who had not completed an AD).

For the participants who had completed an AD ($n = 19$), the process of filling out the AD comprised four categories. These included: rereading the AD handouts and then simply sitting down and completing an AD ($n = 13$, 68.4%), completing the AD after the intervention phone call when their questions were answered ($n = 3$, 15.7%), seeking help to complete the form ($n = 2$, 10.5%), and getting sick and deciding not to delay any longer ($n = 1$, 5.2%).

The responses of participants who did not complete an AD ($n = 53$) as to what would help them complete an AD reflected five categories (see Table 16). The five categories are: taking the time to sit down and complete the AD, needing help to complete the AD, not being ready to complete it now, trusting family to make decisions for them, and "don't know" reasons.

Table 16

Factors that Would Assist AD Completion (n = 53)

Category	Category Definition	Sub-category	Absolute frequency	Relative frequency
Take time to do	Contains words or phrases indicating a temporal element related to completion	Need to take time to think about and complete it, Huge decision, Have to sit down and do it, Have been too busy, Will do it later	21	39.6%
Need help	Contains words or phrases indicating a need for help from someone else to complete the AD	Need help to put into words, Need to talk to my family/ doctor, It's pretty complicated to do by myself	13	24.5%
Not ready yet	Contains words or phrases indicating a lack of readiness or need to complete	Not ready to do yet, Too young/ healthy	9	17.0%
Don't know	Contains words or phrases indicating a lack of a specific reason	Don't know, Nothing	6	11.3%
Trust family to decide	Contains words or phrases indicating trust in family members	--	5	9.4%
Total			54	

Note: Total equals 54 because one participant provided more than one response.

When asked what they did with the AD information when they took it home, the participants who had not completed an AD (n = 53) replied according to the four following categories: kept it with other important papers (n = 23, 43.4%), nothing or can't remember (n = 15, 28.3%), reread the information for

possible use later (n = 8, 15.1%), and showed it to my family (n = 7, 13.2%).

Question #3: Did you talk about the advance directive with someone? Of the 72 participants who responded to this question, 50 (69.4%) discussed ADs with someone. All of the participants who had completed an AD (n = 19) talked to someone about their AD. Of the 53 participants who had not completed an AD, 58% (n = 31) talked to someone about the AD.

Question #4: If discussion occurred, with whom did you discuss the advance directive? Categories of persons with whom an AD was discussed included spouse, children, friends, siblings, parents, doctor and lawyer (see Table 17). The two largest categories were spouse and children. Of the 19 participants who had completed an AD, 57.8% (n = 11) had spoken to their spouse and 26.4% (n = 5) had spoken to their children. Of the 31 participants who had not completed an AD but who had talked to someone about it, 54.8% (n = 17) had spoken to their children and 29.0% (n = 9) had spoken to their spouse. Overall, this indicates that those older adults who complete an AD are more likely to have talked it over with their spouse, while those who did not complete an AD are more likely to have talked to their children about it.

Table 17Persons with whom AD discussed (n = 50)

Category of person with whom AD discussed	AD not completed (n = 31)		AD completed (n = 19)	
	n	%	n	%
Spouse	9	29.0	11	57.8
Children	17	54.8	5	26.4
Friends	2	6.5	0	0
Siblings	2	6.5	0	0
Doctor	0	0	2	10.5
Parents	1	3.2	0	0
Lawyer	0	0	1	5.3
Total	31	100	19	100

Question #5: How would you describe your relationship with that person(s) with whom you discussed the advance directive? There emerged three categories of relationships with the person(s) with whom the AD was discussed. These included: not that close, 'good/close/pretty close', and 'very close/excellent'. Of the participants who completed an AD (n = 19), 68.4% (n = 13) indicated that they had a "close", "pretty close", or "good" relationship with the person(s) with whom they discussed the AD. Of the participants who did not complete ADs (n = 31), 93.5% (n = 29) indicated that they had a "close", "pretty close", or "good" relationship with the person(s) with whom they discussed the AD. Twenty-six percent (n = 5) of participants who completed an AD described their relationship as "very close" or "excellent", compared to 6% (n = 2) of the participants who did not complete an AD. Only one of the participants who completed an AD indicated that their relationship was "not that close" to the doctor with which they discussed their AD.

Question #6: Tell me about the conversation/ discussion you had with that

person(s). Did they help you complete your advance directive? When asked to describe the type of conversation/ discussion that they had with their confidantes, there were some differences between the participants who completed an AD and those who did not.

Of the participants who completed an AD ($n = 19$), 73.6% ($n = 14$) indicated that they simply told their confidantes their wishes and/ or gave them a copy of their completed AD. Just over twenty-six percent ($n = 5$) stated that they completed their AD with the help of their confidante.

Of the participants who did not complete an AD ($n = 31$), 90.3% ($n = 28$) indicated that although they had talked with someone who felt that completing an AD was a good thing to do and/or who agreed with their wishes, the AD had not yet been completed. Almost ten percent ($n = 3$) indicated that their confidante knew their wishes and so there was no need to complete an AD.

These findings suggest that those older adults who decided to complete an AD went ahead and did so, often without consulting someone until after the AD was completed. Those older adults who did discuss the AD or their wishes with someone tended to put off completing the AD.

In response to this question, it is interesting to note that many of the participants described in detail their wishes for end of life care, which often involved "no heroic measures", and "not living like a vegetable".

Question #7: If discussion did not occur with someone, why not? For those participants who did not discuss the AD with someone, 22 of the 53 participants who did not complete an AD, four categories emerged. The main reasons for not

discussing the topic were not interested or not ready ($n = 15$, 68.2%), don't know who to talk to ($n = 3$, 13.6%), afraid of confidante's reaction ($n = 2$, 9.1%), and want to discuss the topic in person ($n = 2$, 9.1%).

Question #8: Is there anything about your medical condition that influences the way you think or feel about advance directives? Tell me about it.

Of the 19 participants who completed an AD, 42.1% ($n = 8$) stated that their medical condition did influence their decision to complete an AD. All of these participants said that because they currently have a variety of health problems, they know what can happen to them, and want to be prepared for end of life decision making. Several of these participants stated "you have to face death sometime".

Of the 53 participants who did not complete an AD, 39.6% ($n = 21$) replied that their medical condition did influence the way they felt about ADs, even though they had not actually yet completed an AD. Responses from these participants fell into two juxtaposed categories. There were 42.8% ($n = 9$) who said that they felt really healthy and therefore did not need to worry about completing an AD at this time. The others, 57.2% ($n = 12$), however, indicated that because they did have medical or health problems, they were aware that anything could happen to them and so would like to have some control over their end of life decisions and have others know their wishes.

Overall, these responses from both groups indicate that having a number of medical conditions or health problems prompted participants to think more about completing an AD. Those participants who felt very healthy did not see the

need to complete an AD at the present time.

Question #9: Is there anything in your family or cultural background that has influenced your decision about the advance directive? Tell me about it. Fairly large proportions of both those participants who completed ADs, 73.7% (n = 14), and those who did not complete ADs, 43.4% (n = 23), indicated that family or cultural background did influence their decisions about ADs. The reasons given for both groups are fairly similar and are summarized in Table 18. Five categories emerged as being family or cultural influences on participants' decisions about ADs. These are having experienced the suffering or death of a loved one, specific religious or cultural beliefs, trusting family to decide, making it easier on loved ones if wishes are written down, and having no family to decide for them.

Table 18

Reasons why family or cultural background influenced decision to complete AD (n = 37)

Category	Category definition	Frequencies	
		No (n = 23) n (%)	Yes (n = 14) n (%)
Experienced suffering/ death of loved one	Contains words or phrases referring to the suffering/ death of a loved one	7 (30.4%)	7 (50.0%)
Specific religious/ cultural beliefs	Contains words or phrases referring to religious faith/ cultural beliefs about death	6 (26.1%)	1 (7.1%)
Trust family	Contains words or phrases indicating trust in family to decide	5 (21.7%)	--
Easier for family	Contains words or phrases indicating will be easier for family if wishes known	4 (17.4%)	4 (28.6%)
No family	Contains words or phrases indicating a lack of family to make decisions	1 (4.3%)	2 (14.3%)
Total		23 (100%)	14 (100%)

It is important to note that all four of the single individuals in the study, three of whom did complete an AD, cited a lack of family as a major reason for wanting to or having completed an AD. When asked why they wanted to complete or had completed an AD, responses tended to emphasize the fact that they had no family, wanted their wishes to be known before they couldn't speak for themselves, and had no one but themselves to rely on to make these decisions. It is also important to note that in spite of not yet completing an AD, a number of non-completers provided both medical and family/cultural reasons why they would like to complete one.

Question #10: For members of the intervention group: Did my phone call a couple of months ago influence your decision to complete an AD? Of the total of 37 intervention group members, there were 12 participants who completed an AD, 24 participants who did not complete an AD, and one participant who did not answer this question.

Of the participants who completed an AD, 91.6% ($n = 11$) stated that the intervention phone call did influence their completion of an AD. There were three categories of reasons given. The reasons given were that it encouraged them to ask for help to complete it ($n = 4$, 36.4%), it answered questions that they had so that they were able to complete the AD ($n = 4$, 36.4%), and it reminded them to complete the AD ($n = 3$, 27.3%). Only one participant said the phone call did not influence their decision to complete an AD, and this was because they had completed the AD before they received the phone call.

Of the participants who did not complete an AD, 41.6% ($n = 10$) stated

that the intervention phone call did influence them in some way. Of these, 70.0% (n = 7) said it kept the idea on their mind even though they hadn't yet gotten around to completing an AD, and 30.0% (n = 3) said the phone call prompted them to talk to someone about an AD. Conversely, 58.3% (n = 14) of the participants said that the phone call did not affect their decision to complete an AD. The four categories of reasons given included that they were not ready to complete an AD (n = 5, 35.7%), they hadn't gotten around to it (n = 4, 28.6%), their family would decide for them (n = 3, 21.4%), or they gave no reason (n = 2, 14.3%).

Summary of the Findings: There are a few key findings in this study.

Perceived barriers to AD completion are a major reason ADs are not completed or discussed. The main reasons ADs were not completed in both kinds of analysis related to factors such as procrastination, a present orientation, being busy, and a reluctance to think about declining health or death. Trusting others to decide, feeling healthy, and needing more help or information emerged as other factors in content analysis. In this population of active community dwelling older adults there did not seem to be the time or inclination to want to stop and think about mortality, much less to write down one's wishes. As some participants stated to the researcher: "I'm not going to die, am I"?

A great deal of discussion with significant others about ADs took place in this sample. Specifically, 69.4% (n = 50) of the participants said that they discussed ADs with someone. A significant relationship between discussion of ADs and subsequent completion of ADs was found in bivariate analysis. Indeed,

all participants who completed an AD had discussed the AD with someone. In content analysis, the completion of ADs was associated with a closer relationship with the confidante, and also a marital versus a parent-child relationship. Several participants stated that discussion with someone occurred to the point that they were confident that their loved one(s) could competently make health care decisions for them, and so they did not feel the immediate need to complete an AD. Both statistical and content analysis revealed that single individuals (i.e., those without a spouse or children) tended to complete more ADs, citing a lack of significant others to decide for them as a major reason for their wanting to make their wishes known.

A finding that emerged in content analysis that was not demonstrated statistically, was that individuals who believed that they had a number of medical conditions either wanted to complete or had completed an AD. These individuals felt that "anything could happen to them" and so they wanted to be prepared. Likewise, those individuals who had witnessed the suffering or death of a loved one indicated that this was one of the reasons that they had or wanted to complete an AD.

Finally, although the phone call intervention did not prove significant statistically, several of the participants in the intervention group in content analysis indicated that the intervention was helpful. It kept the idea of completing an AD on their minds, it reminded them to complete the AD, and it answered questions that they had about ADs.

Chapter Six

Discussion and Implications

In this chapter, the findings are examined in light of current theory and research on AD completion. The findings of the study are compared to findings from other studies and possible explanations for discrepancies are presented. The use of the HBM as an appropriate conceptual framework is examined. Finally, the limitations of the study, areas for future research, and clinical implications stemming from this study are reviewed.

Explanations for Research Findings:

The intent of this study was to examine factors associated with completion and discussion of ADs in community dwelling older adults. The summary of and explanations for the research findings are presented in terms of each individual hypothesis.

- 1. a) The intervention group (those who attend the educational session and receive a follow-up phone call to offer information and answer questions regarding ADs) is more likely to complete ADs compared with the control group (those who attend the education session but receive no reminder phone call).**
- 1. b) The intervention group is more likely to have discussions about ADs with significant others compared with the control group.**

One of the main tenets of this study was that a cue to action such as a personalized intervention (phone call reminder) would enhance completion and/or discussion of ADs. This tenet was not supported. A probable explanation is

that the cue to action was not intense enough to stimulate action. It may be that a certain threshold of intervention intensity is necessary to promote action on the part of older adults. The designed intervention (phone call reminder) may not have been sufficient to reach that threshold. Additional contacts with participants might have made a difference between the control and intervention groups. A different intervention may have provided a stronger stimulus. For example, a study using computer-generated reminders encouraging physicians to discuss ADs with their patients did increase the rate of discussion and completion of ADs among elderly outpatients with serious illnesses (Dexter et al., 1998). More intensive and ongoing follow-up with participants, including assistance to complete the form, may have encouraged procrastinators to complete an AD. Many of the participants who had not completed an AD had positive attitudes toward ADs and indicated that they wanted to complete one at some time in the future.

2. Completion of ADs is directly related to various demographic characteristics.

Completion of ADs is directly related to older age.

Completion of ADs is directly related to being female.

Completion of ADs is directly related to being married.

Completion of ADs is directly related to having higher levels of education

Completion of ADs is directly related to having adequate income.

The sample in this study appears to be highly homogeneous, and the lack

of variation precludes identifying differences that might be related to completion and/ or discussion of ADs. For example, unlike the vast majority of previous studies which often examined subjects across age groups (Miles et al., 1996), this study dealt with an older adult group (almost 80% of the participants were between 65 and 85 years of age). The sample was similar in other characteristics as well. Overall, participants in this study tended to be predominantly Anglo Saxon, female, widowed, and well-educated with adequate incomes. This homogeneity likely relates to the convenience sample being drawn from older adults who were members of the St. James Assiniboia Senior Centre, Inc., and who volunteered to be participants in this study. In addition, the categorical nature of the demographic variables may have been less sensitive to the measurement of mean differences between groups.

The finding that single individuals (i.e. those without a spouse or children) tended to complete more ADs has been previously supported in larger studies. The literature does indicate that being childless and having few living family members or friends can be a significant predictor of AD completion (Moore and Sherman, 1999; VandeCreek, Frankowski, & Johnson, 1995).

3. Completion of ADs is inversely related to self-rated health status.

Failing to find a significant relationship between self-rated health and the completion and/ or discussion of ADs could be related to the fact that the older adults in this sample rated their health very positively. AD completion has been most often associated with poorer health status (High, 1990; Moore & Sherman, 1999; Suri et al., 1999). The single item self-rated health scale seemed to

provide information in a concise and parsimonious way. However, this single-item scale may not have been sensitive enough to measure subtle differences among those who rated their health positively. Variability in health status was not achieved. That is, the single item scale was not able to differentiate between those older adults who rated their health positively when they had no or few health conditions and those older adults who rated their health positively even when they had several health conditions.

4. Completion of ADs is directly related to perceived control.

The lack of a significant relationship between perceived control and AD completion could be related to one of the fundamental assumptions that guided the study. A common assumption associated with studies of AD completion is that the general public wants to be more involved in decision making regarding their health care, i.e., they want more personal control (Molloy et al., 1991). This assumption held for some participants in the study, but not for others. In content analysis, it was evident that although most participants wanted to be more involved in decision making about their health care, some participants did not want to be involved in AD decision making and indicated that they trusted their families or doctors to make the appropriate decisions for them. This desire for wanting family to decide is also consistent with the findings of High (1994). The lack of a significant relationship between perceived control and AD completion and/ or discussion could also exist because some older adults may find the idea of completing an AD as threatening and perhaps a relinquishing of some of their control (Rye et al., 1985). Also, many participants may not have felt an urgent

need to complete an AD as a result of the educational session, and so perceived control may not have been a key factor in their decision making process (Colenda et al., 1998).

5. a) Completion of ADs is directly related to the presence of family and significant others (level of social support).

b) Completion of ADs is directly related to the presence of close confidante relationships with family or significant others.

Failing to find relationships between social support and/ or confidante relationships and AD completion could be related to the findings that older adults in this sample had fairly high levels of social support, as well as close confidante relationships. They therefore may have trusted family or friends to make decisions about end of life issues for them (Colenda et al., 1999; High, 1994). Because many of the participants had discussed ADs with family or friends (69.4%), this discussion of their wishes may have been more important than actual completion of an AD (Hines et al., 1999; Kapp, 1991).

6. a) Completion of ADs is directly related to perceived benefits of ADs.

Failing to find a significant relationship between perceived benefits of ADs and either the completion or discussion of ADs probably relates to the fact that perceived barriers outweighed perceived benefits of AD completion for this sample. This is consistent with the Health Belief Model which indicates that if perceived barriers outweigh the perceived benefits of a proposed health action, then it is unlikely that the behavior will be undertaken (Rosenstock, 1974; Rosenstock & Kirscht, 1974).

b) Completion of ADs is inversely related to perceived barriers of ADs.

The significant inverse relationships found between perceived barriers and the completion and discussion of ADs are similar to those found by VandeCreek & Frankowski (1996) and Sam & Singer (1993). The findings are also consistent with the Health Belief Model which postulates that a preventive health behavior will not occur until barriers are overcome (Rosenstock, 1966).

Discussion of ADs: Although not a hypothesis in this study, the relationship between discussion and completion of ADs was examined. A great deal of discussion with significant others about ADs took place in this sample. Specifically, 69.4% ($n = 50$) of the participants said that they discussed ADs with someone. These relatively high rates of discussion about ADs are similar to the findings of Martin, Singer, & Thiel (1999) and Orlander (1999). In a study examining the use of ADs by health care workers and their families, Orlander (1999) found that younger subjects (mean age of 44.7 years) engaged in discussions with their parents half the time, and three fourths of married subjects had AD-related discussions with their spouses. In the current study, a significant positive relationship was found between the discussion of an AD with someone and subsequent completion of an AD. In fact, all 19 participants who completed an AD had talked to someone about it. This relationship between discussion and completion of ADs has not been tested in previous studies.

Use of the HBM as a conceptual framework:

For this study, the disease or condition to be prevented is a "bad death", defined broadly as a death in which one's medical treatment wishes are not

honored. This might include death after prolonged, unwanted life support, or survival for an indefinite amount of time in a dependent or incapacitated state (Basile, 1998). If a bad death is a disease to be prevented, then the completion of an AD is a preventive health behavior. Health beliefs are fundamental to advance directive completion (Bradley et al., 1998). In the HBM, health beliefs include the perceived severity (or consequences) of a bad death, and the perceived benefits and costs of completing an advance directive. With regard to ADs, various personal (demographic), psychological, and interpersonal factors, as well as beliefs about the benefits of planning for end of life care, likely combine to create a readiness to act. However, beliefs are not directly translated into behavior. Instead, barriers exist to deter the completion of an AD, including the action being inconvenient, time-consuming, unpleasant, or upsetting. A cue or trigger to trip off appropriate action may be necessary, such as providing information or assistance with completion, or a phone call reminder (Rosenstock, 1966). According to the HBM, completion of ADs occurs as an interaction of certain motivators (cues and beliefs) and barriers, and this behavior is reached only after the barriers are overcome. (See Appendix C).

Some aspects of the HBM seem pertinent for the current study, or at least for some of the participants in the study. For those participants who did complete an AD, the fear of a “bad death” was an expressed paramount concern in content analysis. These participants often indicated that they had witnessed the “bad death” of a friend or loved one, and simply did not want to die in the same manner. For one of these participants, their beliefs were so strong, that a

reminder was not necessary. For the others, the reminder (cue) may have been the final push into action.

Although demographic and health factors were not associated with completion or discussion of ADs in the statistical analysis, the perception of being in poor health or having a variety of health conditions emerged as a common reason for the completion of ADs in the content analysis. Interpersonal factors, such as trust in others to make a proxy decision, emerged as a common reason for noncompletion of ADs. Barriers to the completion of ADs as identified in both the statistical and content analysis included a present orientation, procrastination, being busy, and the belief that completing an AD was not necessary at this time because “I’m very healthy”, or “I’m going to live a lot longer”. In addition, some participants indicated that they did not want to think about their own mortality or decline in health.

Overall, this study demonstrated, as did VandeCreek and Frankowski (1996) that perceived barriers to living wills (ADs) are stronger than perceived benefits. Of all the independent variables that were examined, only the barriers measure was statistically significant in relation to completion and discussion of an AD in both bivariate and multivariate analysis.

Although the HBM provided adequate guidance for this study, other theoretical models might also prove useful. For example, the Transtheoretical Model (TTM) of behavior change has been presented as an effective model for promoting healthy lifestyle changes in older adults (Burbank, Padula, & Nigg, 2000). Havens (2000) used the TTM in a study to examine factors related to the

process of execution or nonexecution of ADs in community dwelling adults. The TTM model is based on the premise that individuals engage in a dynamic process of change when adopting a new behavior (see Table 19). An assumption of the model is that individuals in different behavioral stages require different information, tailored to their specific stage, to motivate them to proceed in the change process (Havens, 2000). In the current study, participants seemed to be involved across all five stages of possible change. Future studies might begin with an assessment of the individual's stage of change related to AD completion, followed by individualized interventions that fit his or her stage of change. For example, if an individual is in the precontemplation stage, the simple provision of information about ADs e.g. in pamphlet form or an invitation to an educational session would be appropriate. In the contemplation stage, provision of ongoing education or reminders would be appropriate. In the preparation stage, an offer of assistance to complete an AD might be most effective (Havens, 2000).

Table 19

The Transtheoretical Model Stages of Change

Stage of change	Behavior
Precontemplation	no intention to change behavior in the foreseeable future or denial of need to change
Contemplation	intention to change within the next six months
Preparation	serious intention to change within the next 30 days
Action	engaged in behavioral change
Maintenance	sustaining behavioral change for 6 months or more

Limitations of the Study:

The study had both strengths and limitations. Strengths of this study include the randomized design, pilot testing of Questionnaire #1, the comprehensiveness of the education session and handout package, and the paucity of missing responses. However, there were also several limitations. These limitations relate to sample size, selection bias, length and intensity of follow-up, measurement tools, and use of telephone interviews.

One limitation of this study relates to its small sample size. Because only a small number of total participants completed an AD, it was difficult to make comparisons within this group. For example, of interest is the finding that most of the participants who were childless and did not have a spouse (three out of four) completed an AD. However, the actual number is too small to conduct further analysis.

A second limitation is the self-selection bias that comes into effect when an intervention involves aspects of volunteerism. A sample of older adults who chose to attend an advertised educational session suggests similar baseline interest level, motivation and the wherewithal to attend. It is difficult to assess how this selection bias may have affected the results.

Another limitation could be the length of the follow-up period. In intervention studies to date, follow-up periods have ranged from one month to two years. Some studies suggest that a shorter follow-up period does not allow sufficient time for the participant to digest the information, think about the issues, talk to others (family and physicians), and complete an AD (Luptak & Boulton,

1994; Molloy, Russo, & Pedlar, 2000; Richter et al., 1995). In the final phone call to all participants, several indicated that they would complete an AD in the near future, i.e., “today”, “this summer”, or “soon”. Perhaps a second or more follow-up phone calls at graduated periods would have found that individuals completed ADs as time progressed.

This last point raises another possible limitation of the study—the need for more intensive follow-up versus only a phone call reminder. Several participants ($n = 24$) in the intervention group, both those who completed ($n = 11$) and those who did not complete an AD ($n = 10$), indicated that the intervention phone call influenced their decision to complete an AD in some way. Common responses were that the phone call kept the idea of ADs on their minds, or that it prompted them to talk to someone about an AD, or that it answered questions that they had so that they were able to complete the AD. Additional phone calls may have prompted more participants to complete an AD. The most intense intervention would have been the offer of direct assistance to complete the AD.

Although the measurement tools chosen for this study had proven psychometric properties, there are some potential drawbacks regarding the use of some of the tools in this study. As mentioned previously, the single item self-rated health scale may not have been sensitive enough to measure the intended concept in this study. The LSNS did not achieve expected reliability when used in its full form. This could have been related to low interitem correlations between some items of this scale for this study population (r values between .103 and .190). For example, although a majority of participants ($n = 48$) lived alone, they

nevertheless reported that they had large numbers of friends and/or relatives with whom they had contact on a frequent basis. Further use of the LSNS, complemented with the use of additional social support measures, is warranted in future studies of AD completion with older adults. The VandeCreek and Frankowski Living Will Barriers and Benefits Scale had only been used in one previous study on AD completion, but proved to be useful in relation to the completion and discussion of ADs in this study. However, modifications had to be made in wording after pilot testing and some participants indicated problems with a few of the items. Further testing of this tool in studies of AD completion among older adults would seem to be indicated.

Finally, using a telephone interview format for Questionnaire #2 may also be a limitation. In this study, telephone interviews permitted the asking of only a few simple questions, and did not allow for the participant to expand greatly on the responses. It is difficult to interview and transcribe simultaneously and some information from the participants may have been lost. Selective recording might also have introduced a bias.

Implications for Future Research:

This study suggests several implications for future research. First, further research in this area must be cognizant of the need for larger and more diverse samples of older adults in order to determine significant factors related to AD completion or noncompletion. Research focussing on older adults without children or spouses is worthy of future study, as is research on the influence of cultural and religious beliefs and the completion of ADs (Vaughn, Kiyasu, &

McCormick, 2000). Given that several participants in the current study indicated that the death experience or suffering of a loved one influenced their decision about ADs, future research could explore the relationship between personal experience with the lingering death of a relative or friend and the presence of an AD (Havens, 2000). Research using more comprehensive measurement tools might produce more significant results.

Locating the present research findings within the HBM clearly identifies future directions for research on the completion of ADs. The current study focused primarily on beliefs related to the perceived benefits and barriers to completion of an AD. In future studies, this could be expanded in that other elements of the HBM could be studied in more detail. For example, the perceived threat of a "bad death" could be explored further. As well, the effectiveness of educational materials and other interventions designed to promote the completion of ADs could be assessed. Future work might include designs that allow for several groups of participants with various lengths of follow-up and various intensities of interventions (from phone call reminders to assistance to complete the form). These designs could accommodate questions related to the threshold or intensity of the intervention (cue to action) needed to promote the completion of ADs.

This study, as well as the work of Martin, Thiel & Singer (1999), has indicated the importance of discussion of ADs with significant others. Future research could focus on the decision making process in relation to discussion with significant others. Although the participants in the study who completed ADs

generally conveyed a sense of well-being at having completed an AD, future research could examine the psychological impact of AD discussion and completion on variables such as mood, depression, uncertainty, and satisfaction with decision making (Patterson et al., 1997). Future research needs to show that enhanced communication/ discussion about advance care planning not only extends the autonomy of the individual patient, but also improves patient care at the end of life (Dexter et al., 1998).

Although this study focussed on a community setting, future research must include institutional settings. Nursing homes will play an increasingly important role in the care of the dying (the proportion of deaths in the United States occurring in nursing homes is expected to be 40% by 2020). Therefore, research that focuses on the completion of ADs in long-term care is needed (Teno, 2000).

Implications for Clinical Practice:

The findings of this thesis highlight the importance of perceived barriers in influencing the discussion and completion of ADs. In both bivariate and multivariate statistical analysis, the only variable associated significantly with AD discussion and completion (in an inverse relationship) was perceived barriers to completion of an AD. The main reasons ADs were not completed in both statistical and content analysis related to factors such as procrastination, a present orientation, being busy, and a reluctance to think about declining health or death. Trusting others to decide, feeling healthy, and needing more help or information emerged as other factors in content analysis. Therefore, nurses in a

variety of clinical settings may undertake several roles in an attempt to overcome some of these barriers. These roles could include education, more intensive follow-up, and promotion of AD discussion with significant others.

Education: For any older adult, but especially those who indicate an interest in ADs, education would be an important beginning role of the nurse (Dimond, 1992; Wold, 1992). In order to make truly autonomous decisions about end of life care and whether to complete an AD, individuals and their families must be well-informed (Eriksen et al., 1995; Murphy, 1994). Clinical experience and research indicate that individuals are receptive to nurses' teaching about ADs and end-of-life treatment planning, but seldom initiate this topic of conversation (Dunlap, 1997; Haynor, 1998).

Nurses can educate individuals about ADs in the community, hospital, and long-term care facilities. Education might include discussing the competent adult's right to accept or refuse medical treatment; describing the effects of various life-prolonging interventions; encouraging people to discuss thoughts about end of life care with their families and health care providers, and the provision of specific AD information, including forms (Perrin, 1997). Teaching packages could be given to newly admitted patients in hospitals and primary care practices. The education session provided in this study was well received by the participants, and encouraged several of them to want to complete or to complete an AD.

The study findings indicate that it might also be helpful for nurses to target specific individuals for education about ADs i.e., individuals who have recently

experienced the suffering or death of a loved one, individuals with no spouse or children, and individuals with a number of medical conditions. For example, Havens (2000) found that individuals who completed ADs had more personal experiences with the terminal illnesses or critical injuries of relatives or friends compared with those community dwelling adults who had not completed ADs. Therefore, nurses could use the time of death of a loved one as an opportunity to introduce the topic of ADs to family members and friends (Havens, 2000).

More intensive interventions and follow-up: For those individuals who have received education about ADs and indicate a desire to complete an AD, but then procrastinate for a variety of reasons, the nurse might provide more intensive follow-up in order to try to overcome these barriers. Although education about ADs is important in its own right, this study has demonstrated that education alone (or coupled with modest follow-up) will not encourage most individuals to complete an AD. Other studies have demonstrated that it is feasible to systematically implement ADs with older adults, given more intensive interventions including one-on-one follow-up and assistance to complete the form if necessary (Molloy, Russo, & Pedlar, 2000; Patterson et al., 1997). Colenda et al. (1998) and Gordon & Shade (1999) suggest that systematic, repetitive contacts with individuals are one way to overcome barriers to AD completion.

Several participants in the intervention group in this study indicated that the phone call intervention influenced their decision to complete an AD because it kept the idea on their minds, answered their questions, and encouraged them

to complete an AD (even if they hadn't already done so). Repeated phone calls may have prompted more participants to complete an AD. For some participants, assistance to complete the form would have been ideal as the participants were interested and motivated, but could not sit down to write an AD by themselves. They expressed a need for help from a health professional or family member to interpret the forms, clarify options, and simply sit down and do it.

Promotion of Discussion: As many study participants engaged in discussion about ADs with their significant others or else expressed an interest in their families deciding for them, the encouragement of discussion about ADs with significant others could be another role of the nurse. In this study, discussion about ADs occurred in 69.4% of the sample, when participants were encouraged to go home and discuss ADs with significant others after the educational session. Although a significant relationship existed between discussion and subsequent completion of ADs, many participants in this study were satisfied that discussion with family members ensured that their wishes were known and would be followed, even though the process had not been formalized. Therefore, discussion about end of life care is beneficial to all involved and should be valued and promoted for these positive effects, if not actual completion of a written document (Miles et al., 1996; Teno, Stevens, Spornak, and Lynn, 1998). If the ultimate goal in advance care planning does not focus solely on AD completion, but rather on the beliefs, values, and wishes of individuals, then perhaps barriers to discussion will not be so great (Martin, Thiel, & Singer, 1999). It is important to remember, however, that when individuals indicate that they do

not want to complete a written AD or are not ready to discuss or think about these issues, then their wishes should be respected.

Conclusion:

This research study has contributed to the knowledge base of the use of advance directives by examining relationships between the use of an individualized intervention, as well as various characteristics of older adults, and their subsequent discussion and completion of ADs. Results of data analysis showed that only perceived barriers of AD completion were significantly inversely related to AD completion and discussion. More research is needed to understand older adults and their desire to complete and discuss advance directives, and how some of these barriers might be overcome. Nursing, because of its proximity to older adults in both the community and institutional settings, has important roles to play in the area of advance care planning and the promotion of autonomy in older adults.

References

Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1987). Appraisals of control and predictability in adapting to chronic disease. Journal of Personality and Social Psychology, 53, 273-279.

Agresti, A. & Finlay, B. (1986). Statistical Methods for the Social Sciences (2nd. ed.), San Francisco, Dellen.

Aikman, P., Thiel, E., Martin, D., & Singer, P. (1999). Proxy, health, and personal care preferences: Implications for end-of-life care. Cambridge Quarterly on Healthcare Ethics, 8 (2), 200-210.

Ali, N. (1999). Promotion of advance care planning in the nonhospitalized elderly. Geriatric Nursing, 20 (5), 260-262.

Annas, G. (1995). How we lie. Hastings Center Report 25, Special Supplement (6), S12-S14.

Baker, J. (1989). Breast self-examination and the older woman: Field testing an educational approach. The Gerontologist, 29 (3), 405-407.

Bandman, E. L., & Bandman, B. (1979). The nurse's role in protecting the patient's right to live or die. Advances in Nursing Science, 1 (3), 21-35.

Basile, C. M. (1998). Advance directives and advocacy in end of life decisions. Nurse Practitioner, 23 (5), 44, 46-47, 57-60.

Bayer, R., Callahan, D., Fletcher, J., Hodgson, T., Jennings, B., Monsees, D., Sieverts, M., & Veatch, R. (1983). The care of the terminally ill: mortality and economics. New England Journal of Medicine, 309, 1490-1494.

Bedell, E., & Delbanco, T. (1984). Choices about CPR in the hospital: when do physicians talk with patients? New England Journal of Medicine, 310, 1089-1092.

Berelson, B. (1971). Content analysis in communication research. New York: Hafner Publishing Company.

Berwick, D. (1995). The SUPPORT project: Lessons for action. Hastings Center Report 25, Special Supplement (6), S21-S22.

Bjorner, J., & Kristensen, T. (1999). Multi-item scales for measuring global self-rated health. Research on Aging, 21 (3), 417-439.

Bradley, E., & Rizzo, J. (1999). Public information and private search: Evaluating the Patient Self-Determination Act. Journal of Health Politics, Policy

and Law, 24 (2), 239-273.

Bradley, E., Walker, L., Wetle, T., & Horwitz, S. (1998). Advance directives and the role of health beliefs. Journal of Mental Health and Aging, 4 (3), 379-392.

Burbank, P., Padula, C., & Nigg, C. (2000). Changing health behaviors of older adults. Journal of Gerontological Nursing, 25 (3), 26-33.

Callahan, D. (1995). Once again, reality: Now where do we go? Dying well in the hospital: The lessons of SUPPORT. Hastings Center Report 25, Special Supplement (6), S33-S36.

Campbell, D. T., & Stanley, J. C. (1963). Experimental and quasi-experimental designs for research. Chicago: Rand McNally Company.

Caralis, P., Davis, B., Wright, K., & Marcial, E. (1993). The influence of ethnicity on attitudes towards advance directives, life-prolonging treatments, and euthanasia. Journal of Clinical Ethics, 4, 155-165.

Carmel, S., Shani, E., & Rosenberg, L. (1996). Skin cancer protective behavior among the elderly. Educational Gerontology, 22 (7), 651-668.

Chambers, C., Diamond, J., Perkel, R. & Lasch, L. (1994). Relationship of advance directives to hospital charges in a Medicare population. Archives of Internal Medicine, 154, 541-547.

Chipperfield, J. & Greenslade, L. (1999). Perceived control as a buffer in the use of health care services. Journal of Gerontology: Psychological Sciences, 54B (3), P146-P154.

Christie, B., Skinner, B., & Weatherill, S. (1997). What's new for the old. Canadian Healthcare Manager, Oct/Nov, 23-28.

Clark, P. (1987). Individual autonomy, cooperative empowerment, and planning for long-term care decision making. Journal of Aging Studies, 1 (1), 65-76.

Clark, P. (1996). Communication between provider and patient: Values, biography, and empowerment in clinical practice. Ageing and Society, 16, 747-774.

CNA Joint Statement on Advance Directives. [Http://www.cna-nurses.ca/pages/policies/advance_directives.html](http://www.cna-nurses.ca/pages/policies/advance_directives.html).

Cochran, D. (1999). Advance elder care decision making: A model of family planning. Journal of Gerontological Social Work, 32 (2), 53-64.

Cohen, J. (1988). Statistical Power Analysis for the Behavioral Sciences (2nd ed.) London: Lawrence Erlbaum Associates.

Cohen-Mansfield, J., Droge, J., & Billig, N. (1991a). The utilization of durable power of attorney for health care among hospitalized elderly patients. Journal of the American Geriatrics Society, 39, 1174-1178.

Cohen-Mansfield, J., Rabinovich, B., & Lipson, S., Fein, A., Gerber, B., Weisman, S., & Pawlson, G. (1991b). The decision to execute a durable power of attorney for healthcare and preferences regarding the use of life sustaining treatments in nursing home residents. Archives of Internal Medicine, 151, 289-294.

Colenda, C., Jensen, M., Foster, J., Kendrick, B., Mewhinney, K., & Messick, C. (1998). Variables predicting the completion of an advance directive by older adults. Annals of Long-Term Care, 6(3), 83-91.

Cotton, P. (1993). Talk to people about dying: they can handle it, say geriatricians and patients. Journal of the American Medical Association, 269, 32-322.

Cugliari, A., Miller, T., & Sobal, J. (1995). Factors promoting completion of advance directives in the hospital. Archives of Internal Medicine, 155, 1893-8.

Danis, M., Southerland, L. I., Garrett, J. M., Smith, J. L., Hielema, F., Pickard, C. G., Egnor, D. M., & Patrick, D. L. (1991). A prospective study of advance directives for life-sustaining care. New England Journal of Medicine, 324, 882-888.

Davidson, K, Hackler, C., Caradine, D., & McCord, R. (1989). Physicians' attitudes on advance directives. Journal of the American Medical Association, 262, 2415-2419.

Dexter, P., Wolinsky, F., Gramelspacher, G., Zhou, X., Eckert, G., Waisburd, M., & Tierney, W. (1998). Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms: A randomized, controlled trial. Annals of Internal Medicine, 128, 102-110.

Diers, D. (1979). Research in nursing practice. Toronto: J. B. Lippincott Company.

Dimond, E. P. (1992). The oncology nurse's role in patient advance directives. Oncology Nursing Forum, 19 (6), 891-6.

Doukas, D. (1999). Advance directives in patient care: If you ask, they will

tell you (editorial). American Family Physician, 59 (3), 530-533.

Doukas, D., & McCullough, L. (1991). The Values History: The evaluation of the patient's values and advance directives. The Journal of Family Practice, 32 (2), 145-153.

Dunlap, R. (1997). Teaching advance directives: The why, when, and how. Journal of Gerontological Nursing, December, 11-16.

Edinger, W., & Smucker, D. (1992). Outpatients' attitudes regarding advance directives. Journal of Family Practice, 35, 650-653.

Egan, E., Snyder, M., & Burns, K. (1992). Intervention studies in nursing: Is the effect due to the independent variable? Nursing Outlook, 40 (4), 187-190.

Eisendrath, S., & Jonsen, A. (1983). The living will-help or hindrance? Journal of the American Medical Association, 249, 2054-2058.

Eleazer, G., Hornung, C., Egbert, C., Egbert, J., Eng, C., Hedgepeth, J., McCann, R., Strothers, H., Sapir, M., Wei, M., & Wilson, M. (1996). The relationship between ethnicity and advance directives in a frail older population. Journal of the American Geriatrics Society, 44, 938-943.

Elpern, E., Yellen, S., & Burton, L. (1993). A preliminary investigation of opinions and behaviors regarding advance directives for medical care. American Journal of Critical Care, 2 (2), 161-168.

Emanuel, L. (1995). Structured deliberation to improve decision making for the seriously ill. Hastings Center Report 25, Special Supplement (6), S14-S18.

Emanuel, L., Barry, M., Stoekle, J., Ettelson, L., & Emanuel, E. (1991). Advance directives for medical care: a case for greater use. New England Journal of Medicine, 324, 889-895.

Emanuel, L., Danis, M., Pearlman, R., & Singer, Peter, A. (1995). Advance care planning as a process: structuring the discussions in practice. Journal of the American Geriatrics Society, 43 (4), 440-446.

Emanuel, L. & Emanuel, E. (1989). The medical directive: a new comprehensive advance care document. Journal of the American Medical Association, 261, 3288-93.

Emanuel, L., & Emanuel, E. (1994). The economics of dying. New England Journal of Medicine, 330, 540-544.

Emanuel, L., Emanuel, E., Stoeckle, J., Hummel, L., & Barry, M. (1994). Advance directives: stability of patients' treatment choices. Archives of Internal

Medicine, 154, 209-217.

Eriksen, J., Rodney, P., & Starzomski, R. (1995). When is it right to die? The Canadian Nurse, September, 29-34.

Fade, A. (1993). A right-to-die update. American Bar Association Experience, 4, 35-42.

Fairchild, B. (1996). Why Advance Directives? Discovering motivating factors through grounded theory. Master's thesis. University of Delaware, Wilmington, Delaware, United States of America.

Fairchild, B. (1998). Why advance directives? Image: Journal of Nursing Scholarship, 30 (1), 90.

Finucane, T., Shumway, J., Powers, R., & D'Alessandri, R. (1988). Planning with elderly outpatients for contingencies of severe illness: A survey and clinical trial. Journal of General Internal Medicine, 3, 322-325.

Fried, T. & Gillick, M. R. (1994). Medical decision-making in the last six months of life: choices about limitation of care. Journal of the American Geriatric Society, 42 (3), 303-307.

Gamble, E. R., McDonald, P. J., & Lichstein, P. R. (1991). Knowledge, attitudes, and behavior of elderly persons regarding living wills. Archives of Internal Medicine, 151, 277-280.

Gillick, M., Hesse, K., & Mazzapica, N. (1993). Medical technology at the end of life: what would physicians and nurses want for themselves? Archives of Internal Medicine, 153, 2542-2547.

Gleeson, K., & Wise, S. (1990). The do-not-resuscitate order. Still too little, too late. Archives of Internal Medicine, 150, 1057-60.

Glick, K., Mackay, K., Balasingam, S., Dolan, K., & Casper-Isaac, S. (1998). Advance directives: Barriers to completion. Journal of the New York State Nurses Association, 29 (1), 4-8.

Goold, S., Arnold, R., & Siminoff, L. (1993). Discussions about limiting treatment in a geriatric clinic. Journal of the American Geriatrics Society, 41 (3), 277-281.

Gordon, M., & Singer, P. (1995). Decisions and care at the end of life. Lancet, 346 (8968), 163-166.

Gordon, N., & Shade, S. (1999). Advance directives are more likely among seniors asked about end-of-life care preferences. Archives of Internal Medicine,

159, 701-704.

Greco, P., Schulman, K., Lavizzo-Mourey, R., & Hanse-Flaschon, J. (1991). The PSDA and the future of advance directives. Annals of Internal Medicine, 115, 639-643.

Grossberg, G. (1998). Advance directives, competency evaluation, and surrogate management in elderly patients. The American Journal of Geriatric Psychiatry, 6 (2), S79-S84.

Hackler, C., Moseley, R., & Vawter, D. (Eds.) (1989). Advance directives in medicine. New York: Praeger.

Haisfield, M., McGuire, D., Krumm, S., Shore, A., Zabora, J., & Rubin, H. (1994). Patients' and health care providers' opinions regarding advance directives. Oncology Nursing Forum, 7, 1179-1187.

Hallal, J. (1982). The relationship of health beliefs, health locus of control, and self-concept to the practice of breast self-examination in adult women. Nursing Research, 31, 137-142.

Hammes, B., & Rooney, B. (1998). Death and end of life planning in one midwestern community. Archives of Internal Medicine, 158, 383-390.

Hare, J., & Nelson, C. (1991). Will outpatients complete living wills? Journal of General Internal Medicine, 6 (1), 41-6.

Hare, J., Pratt, C., & Nelson, C. (1992). Agreement between patients and their self-selected surrogates on difficult medical decisions. Annals of Internal Medicine, 152, 1049-1054.

Havens, G. (2000). Differences in the execution/ nonexecution of advance directives by community dwelling adults. Research in Nursing and Health, 23, 319-333.

Haynor, P. (1998). Meeting the challenge of advance directives. American Journal of Nursing, 98 (3), 27-32.

Heffner, J. E., Brown, L. K., & Barbieri, C. A. (1997). Publications in subspecialty journals on end-of-life ethics. Archives of Internal Medicine, 157 (6), 685-90.

Helgeson, V. (1992). Moderators of the relation between perceived control and adjustment to chronic illness. Journal of Personality and Social Psychology, 63, 656-666.

Henderson, M. (1995). Facilitating a "good death" in patients with end stage

renal disease. ANNA Journal, 22 (3), 294-300.

Hesse, K. (1995). Terminal care of the very old. Changes in the way we die. Archives of Internal Medicine, 155, 1513-1518.

Hibbard, J., Neufeld, A. & Harrison, M. (1996). Gender differences in the support networks of caregivers. Journal of Gerontological Nursing, 22, (9), 15-23.

High, D. (1990). Who will make health care decisions for me when I can't? Journal of Aging and Health, 2 (3), 291-309.

High, D. (1993a). Advance directives and the elderly: A study of intervention strategies to increase use. The Gerontologist, 33 (3), 342-9.

High, D. (1993b). Why are elderly people not using advance directives? Journal of Aging and Health, 5, 497-515.

High, D. (1994). Families' roles in advance directives. Hastings Center Report (Dec. Special suppl), S16-18.

Hines, S., Glover, J., Holley, J., Babrow, A., Badzek, L., & Moss, A. (1999). Dialysis patients' preferences for family-based advance care planning. Annals of Internal Medicine, 130 (10), 825-828.

Hofmann, J. C., Wenger, N. S., Davis, R. B., Teno, J., Connors, A. F., Desbiens, N., Lynn, J., & Phillips, R. S. (1997). Patient preferences for communication with physicians about end-of-life decisions. Annals of Internal Medicine, 127 (1), 1-12.

Hooker, K., & Siegler, I. (1992). Separating apples from oranges in health ratings: Perceived health status includes psychological well-being. Behavior, Health, & Aging, 2 (2), 81-92.

Hughes, D., & Tartasky, D. (1996). Implementation of a flu immunization program for homebound elders: a graduate student practicum. Geriatric Nursing, 17 (5), 217-221.

Idler, E. L., & Kasl, S. (1991). Health perceptions and survival: Do global evaluations of health status really predict mortality. Journal of Gerontology, 46 (2), S55-S65.

Janofsky, J. S., & Rovner, B. W. (1993). Prevalence of advance directives and guardianship in nursing home patients. Journal of Geriatric Psychiatry and Neurology, 6 (4), 214-216.

Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade

later. Health Education Quarterly, 11, 1-47.

Johns, J. (1996). Advance directives and opportunities for nurses. Image:Journal of Nursing Scholarship, 28 (2), 149-153.

Johnston, S. C., Pfeifer, M. P., & McNutt, R. (1995). The discussion about advance directives: patient and physician opinions regarding when and how it should be conducted. Archives of Internal Medicine, 155, 1025-1030.

Kapp, M. (1991). Health care decision making by the elderly: I get by with a little help from my family. The Gerontologist, 31 (5), 619-23.

Kaufman, S. (2000). Senescence, decline, and the quest for a good death: Contemporary dilemmas and historical antecedents. Journal of Aging Studies, 14 (1), 1-23.

Kelner, M. (1995). Activists and delegates: Elderly patients' preferences about control at the end of life. Social Science Medicine, 4, 537-545.

King, N. (1991). Making sense of advance directives. London: Kluwer Academic Publishers.

Kohn, M., & Menon, G. (1988). Life prolongation: views of elderly outpatients and health care personnel. Journal of the American Geriatrics Society, 36, 841-844.

Kohut, N., Sam, M., O'Rourke, K., MacFadden, D., Salit, I., & Singer, P. (1997). Stability of treatment preferences: Although most preferences do not change, most people change some of their preferences. Journal of Clinical Ethics, 8 (2), 124-135.

Krippendorff, K. (1980). Content analysis: An introduction to its methodology. Beverly Hills, California: Sage Publications, Inc.

Landry, F., Kroenke, K., Lucas, C., & Reader, J. (1997). Increasing the use of advance directives in medical outpatients. Journal of General Internal Medicine, 12, 412-419.

LaPuma, J., Orentlicher, D., & Moss, R. (1991). Advance directives on admission: clinical implications and analysis of the PSDA of 1990. Journal of the American Medical Association, 266, 402-405.

Layson, R., Adelman, H., Wallach, P., Pfeifer, M., Johnston, S., & McNutt, R. (1994). Discussions about the use of life-sustaining treatments: A literature review of physicians' and patients' attitudes and practices. The Journal of Clinical Ethics, 5 (3), 195-203.

Leinonen, R., Heikkinen, E., & Jylha, M. (1999). A path analysis model of self-rated health among older people. Aging Clinical Experimental Research, 11 (4), 209-220.

Lo, B. (1995). End-of-life care after termination of SUPPORT. Hastings Center Report 25, Special Supplement (6), S6-S8.

Lo, B., McLeod, G. A., & Saika, G. (1986). Patient attitudes to discussing life-sustaining treatment. Archives of Internal Medicine, 146, 1613-1615.

Loewy, E., & Carlson, R. (1994). Talking, advance directives, and medical practice. Archives of Internal Medicine, 154, 2265-67.

Lubben, J. E. (1988). Assessing social networks among elderly populations. Family and Community Health, 11, (3), 42-52.

Lund, M., & Wei, F. (1990). Speaking out on ethics. Geriatric Nursing, September/ October, 223-227.

Luptak, M., & Boulton, C. (1994). A method for increasing elders' use of advance directives. The Gerontologist, 34 (3), 409-412.

Lynn, J., Arkes, H., Stevens, M., Cohn, F., Koenig, B., Fox, E., Dawson, N., Phillips, R., Hamel, M., & Tsevat, J. (2000). Rethinking fundamental assumptions: SUPPORT's implications for future reform. Journal of the American Geriatrics Society, 48, S214-S221.

Lynn, J., & Teno, J. M. (1993). After the patient self-determination act: The need for empirical research on formal advance directives. Hastings Center Report, 23 (1), 20-24.

Lynn, J., Teno, J., Phillips, R., Wu, A., Desbiens, N., Harrold, J., Claessens, M., Wenger, N., Kreling, B., & Connors, A. (1997). Perception by family members of the dying experience of older and seriously ill patients. Annals of Internal Medicine, 126, 97-106.

Maiman, L., & Becker, M. (1974). The health belief model: Origins and correlates in psychological theory. In M. H. Becker (Ed.), The health belief model and personal health behavior (pp. 9-26). Thorofare, NJ: Charles B. Slack, Inc.

Manitoba Association of Registered Nurses. (1994). Information sheet for registered nurses on the Manitoba Health Care Directives Act. Winnipeg, Manitoba: Manitoba Association of Registered Nurses.

Manitoba Law Reform Commission. (1991). Self-determination in health care (Living wills and health care proxies). (Report #74). Manitoba. Law Reform Commission.

Markson, L., Fanale, J., Steel, K., Kern, D., & Annas, G. (1994). Implementing advance directives in the primary care setting. Archives of Internal Medicine, 154, 2321-2327.

Marshall, P. (1995). The SUPPORT study: Who's talking? Hastings Center Report 25, Special Supplement (6), S9-S11.

Martin, D., Thiel, E., & Singer, P. (1999). A new model of advance care planning: Observations from people with HIV. Archives of Internal Medicine, 159 (1), 86-92.

Mason, R., Lind, D., & Marchal, W. (1991). Statistics: An introduction (3rd ed.). Toronto: Harcourt Brace Jovanovich College Publishers.

Measuring quality of care at the end of life: a statement of principles. (1997). Journal of the American Geriatric Society, 45, 526-527.

Mebane, E., Oman, R., Kroonen, L., & Goldstein, M. (1999). The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision making. Journal of the American Geriatrics Society, 47, 579-591.

Meier, D., Fuss, B., O'Rourke, D., Baskin, S., Lewis, M., & Morrison, S. (1996a). Marked improvement in recognition and completion of health care proxies: a randomized controlled trial of counseling by hospital patient representatives. Archives of Internal Medicine, 156, 1227-1232.

Meier, D., Gold, G., Mertz, K., Taylor, B., Cammer-Paris, B., Seckler, A., & Mulvihill, M. (1996b). Enhancement of proxy appointment for older persons: Physician counseling in the ambulatory setting. Journal of the American Geriatrics Society, 44, 37-43.

Menard, S. (1995). Applied Logistic Regression Analysis. Thousand Oaks, CA: Sage Publications.

Menec, V., & Chipperfield, J. (1997b). The interactive effect of perceived control and functional status on health and mortality among young-old and old-old adults. Journal of Gerontology: Psychological Sciences, 52B, P118-P126.

Menec, V., Chipperfield, J., & Perry, R. (1999). Self-perceptions of health: a prospective analysis of mortality, control, and health. Journal of Gerontology: Psychological Sciences, 54B (2), P85-P93.

Miles, S., & Gomez, C. (1989). Protocols for elective use of life-sustaining treatments. New York: Springer Publishing Company, Inc.

Miles, S., Koepp, R., & Weber, E. (1996). Advance end-of-life treatment planning. A research review. Archives of Internal Medicine, 156, 1062-1068.

Molloy, D., Guyatt, G., Alemayehu, E., & Mcilroy, W. (1991). Treatment preferences, attitudes toward advance directives and concerns about health care. Humane Medicine, 7 (4), 285-290.

Molloy, D., Guyatt, G., Russo, R., Goeree, R., O'Brien, B., Bedard, M., Willan, A., Watson, J., Patterson, C., Harrison, C., Standish, T., Strang, D., Darzins, P., Smith, S., & Dubois, S. (2000). Systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. Journal of the American Medical Association, 283 (11), 1437-1444.

Molloy, D., Russo, R., Pedlar, D., & Bedard, M. (2000). Implementation of advance directives among community-dwelling veterans. The Gerontologist, 40 (2), 213-217.

Moore, C., & Sherman, S. (1999). Factors that influence elders' decisions to formulate advance directives. Journal of Gerontological Social Work, 31 (1/2), 21-39.

Moran, S. (1993). In medical choices, a will doesn't always mean a way. Insight, 2, 10-35.

Mor-Barak, M., & Miller, L. (1991). A longitudinal study of the causal relationship between social networks and health of the poor frail elderly. The Journal of Applied Gerontology, 10,(3), 293-310.

Morrison, R., Morrison, W., & Glickman, D. (1994). Physician reluctance to discuss advance directives. An empiric investigation of potential barriers. Archives of Internal Medicine, 154, 2311-18.

Morse, J., & Field, P. (1995). Qualitative research methods for health professionals. Thousand Oaks, CA: Sage Publications, Inc.

Moskowitz, E., & Nelson, J. (1995). The best laid plans. Hastings Center Report 25. Special Supplement (6), S3-S6.

Mossey, J. M., & Shapiro, E. (1982). Self-rated health. A predictor of mortality among the elderly. American Journal of Public Health, 72 (8), 800-808.

Munro, B. H. (1997). Statistical methods for health care research. (3rd. Ed.). New York: Lippincott-Raven Publishers.

Murphy, D. (1990). Improving advance directives for healthy older people. Journal of the American Geriatrics Society, 38, 1251-1256.

Murphy, P. (1994). The nurse's role in end-of-life decisions. Journal of Burn Care Rehabilitation, 15, 84-85.

Nazerali, N., Ska, B., & Lajeunesse, Y. (1998). A new health care directive for long-term care elderly based on personal values of life. Canadian Journal on Aging, 17 (1), 24-39.

Ney, C. A. (1989). Living wills: The ethical dilemmas. Critical Care Nurse, 9 (8), 20-40.

Norusis, M. (2000). SPSS 10.0: Guide to Data Analysis. Upper Saddle River, New Jersey: Prentice-Hall.

O'brien, L. A., Grisso, J. A., Maislin, G., Lapenn, K., Krotki, K. P., Greco, P., Siegert, E., & Evans, L. L. (1995). Nursing home residents' preferences for life-sustaining treatments. Journal of the American Medical Association, 274, 1775-1779.

Orentlicher, D. (1990). Advance medical directives. Journal of the American Medical Association, 263, 2365-2367.

Orlander, J. (1999). Use of advance directives by health care workers and their families. Southern Medical Journal, 92 (5), 481-484.

Palker, N. B., & Nettles-Carlson, B. (1995). The prevalence of advance directives: Lessons from a nursing home. Nurse Practitioner, 20 (2), 7-21.

Patterson, C., Molloy, D., Guyatt, G., Bedard, M., North, J., Hassard, J., Willison, K., Jubelius, R., & Darzins, P. (1997). Systematic implementation of an advance health care directive in the community. Canadian Journal of Nursing Administration, 10, 96-108.

Perrin, K. (1997). Giving voice to the wishes of elders for end-of-life care. Journal of Gerontological Nursing, March, 18-27.

Polit, D., & Hungler, B. (1995). Nursing research: principles and methods. Philadelphia: J. B. Lippincott Company.

Quadrel, M., & Lau, R. (1989). Health promotion, health locus of control, and health behavior: Two field experiments. Journal of Applied Social Psychology, 19, 1497-1521.

Rabeneck, L., Viscoli, C., & Horwitz, R. (1992). Problems in the conduct and analysis of randomized clinical trials: Are we getting the right answers to the wrong questions. Archives of Internal Medicine, 152, 507-512.

Reilly, B. M., Wagner, M., Magnussen, R., Ross, J., Papa, L., & Ash, J.

(1994). Can we talk? Inpatient discussions about advance directives in a community hospital. Archives of Internal Medicine, 154, 2299-2308.

Richter, K., Langel, S., Fawcett, S., Paine-Andrews, A., Biehler, L., & Manning, R. (1995). Promoting the use of advance directives: an empirical study. Archives of Family Medicine, 64, 609-615.

Rimer, B. K. (1990). Perspectives on intrapersonal theories in health education and health behavior. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), Health behavior and health education (pp. 140-158). San Francisco, CA: Jossey-Bass.

Rodriguez, G. S. (1990). Routine discussion of advance health care directives: are we ready? An opposing view. Journal of Family Practice, 31 (6), 656-9.

Rosenstock, I. M. (1966). Why people use health services. Milbank Quarterly, 44, 94-127.

Rosenstock, I. M. (1974). The health belief model and preventive health behavior. In M. H. Becker (Ed.), The health belief model and personal health behavior (pp. 27-59). Thorofare, NJ: Charles B. Slack, Inc.

Rosenstock, I. M. (1990). The health belief model: explaining health behaviour through expectancies. In K. Glanz, F. M. Lewis, F. M., & B. K. Rimer (Eds.), Health behavior and health education (pp. 39-62). San Francisco, CA: Jossey-Bass.

Rosenstock, I. M., & Kirscht, J. (1974) The health belief model and personal health behavior. Health Education Monographs, 2, 470-473.

Rosenstock, I. M., & Kirscht, J. (1979). Why people seek health care. In G.C. Stone, F. Cohen, & N. E. Adler (Eds.), Health psychology-a handbook (pp. 161-188). San Francisco, CA: Jossey-Bass.

Rubin, S., Strull, W., Fialkow, M., Weiss, S., & Lo, B. (1994). Increasing the completion of the durable power of attorney for health care: A randomized controlled trial. Journal of the American Medical Association, 271, 209-212.

Rubinstein, R., Lubben, J., & Mintzer, J. (1994). Social isolation and social support: an applied perspective. Journal of Applied Gerontology, 13, (1), 58-72.

Rye, P., Wallston, K., Strudler Wallston, B., & Smith, R. (1985). The desire to control terminal health care and attitudes towards living wills. American Journal of Preventive Medicine, 1, 56-60.

Sachs, G., Stocking, C., & Miles, S. (1992). Empowerment of the older patient: a randomized, controlled trial to increase discussion and use of advance directives. Journal of the American Geriatrics Society, 42, 269-273.

Sam, M., & Singer, P. (1993). Canadian outpatients and advance directives: poor knowledge and little experience but positive attitudes. Canadian Medical Association Journal, 148 (9), 1497-1502.

Sandelowski, M. (1996). Focus on qualitative methods: Using qualitative methods in intervention studies. Research in Nursing and Health, 19, 359-364.

Sansome, P., & Phillips, M. (1995). Advance directives for elderly people: worthwhile cause or wasted effort? Social Work, 40 (3), 397-401.

Saultz, J., & Rodriguez, G. (1990). Routine discussion of advance health care directives: Are we ready? Journal of Family Practice, 31, 656-659.

Saultz, J. (1990). Routine discussion of advance directives: An affirmative view. Journal of Family Practice, 31 (6), 653-6.

Sawchuk, P., & Ross-Kerr, J. (2000). Older adults and advance care directives. Canadian Nurse, 96 (7), 16-20.

Scanlon, C. (1993). Safeguarding a patient's right to self-determination. The American Nurse, 20-21.

Schmerling, R. H., Bedell, S. E., Lilienfeld, A., & Delbanco, T. L. (1988). Discussing cardiopulmonary resuscitation: a study of elderly outpatients. Journal of General Internal Medicine, 3, 317-321.

Schneiderman, L., Kronick, R., Kaplan, R., Anderson, J., & Langer, R. (1992). Effects of offering advance directives on medical treatment and cost. Annals of Internal Medicine, 117, 599-606.

Schonwetter, R., Walker, R., Solomon, M., Indurkha, A., & Robinson, B. (1996). Life values, resuscitation preferences, and the applicability of living wills in an older population. Journal of the American Geriatrics Society, 44, 954-958.

Silverman, H., Tuma, P., Schaeffer, M., & Singh, B. (1995). Implementation of the PSDA in a hospital setting. Archives of Internal Medicine, 155, 502-510.

Singer, P., Choudhry, S., & Armstrong, J. (1993). Public opinion regarding consent to treatment. Journal of the American Geriatric Society, 41 (2), 112-116.

Singer, P., Choudhry, S., Armstrong, J., Meslin, E., & Lowy, F. (1995). Public opinion regarding end-of-life decisions: Influence of prognosis, practice, and

process. Social Science and Medicine, 41 (11), 1517-1521.

Singer, P., & Lowy, F. (1992). Rationing, patient preferences and cost of care at the end of life. Archives of Internal Medicine, 152, 478-80.

Singer, P., Martin, D., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. Journal of the American Medical Association, 281 (2), 163-168.

Singer, P., Martin, D., Lavery, J., Thiel, E., Kelner, M., & Mendelssohn, D. (1998). Reconceptualizing advance care planning from the patient's perspective. Archives of Internal Medicine, 158 (8), 879-884.

Singer, P., Thiel, E., Naylor, C., Richardson, R., Llewellyn-Thomas, H., Goldstein, M., Saiphoo, C., Uldall, P., Kim, D., & Mendolssohn, D. (1995). Life-sustaining treatment preferences of hemodialysis patients: Implications for advance directives. Journal of American Society of Nephrology, 6, 1410-1417.

Slavenas, J., Karuza, J., & Katz, P. (1990). Ethical perspectives and attitudes towards advance directives by nursing home residents and their families. Journal of the American Geriatrics Society, 38 (8), 12.

Solomon, M., O'Donnell, L., Jennings, B., Guilfooy, V., Wolf, S., Nolan, K., Jackson, R., Weser, D., & Donnelley, S. (1993). Decisions near the end of life: Professional views on life-sustaining treatments. American Journal of Public Health, 83 (1), 14-23.

Sonnenblick, M., Friedlander, Y., & Steinberg, A. (1994). Dissociation between the wishes of terminally ill parents and decisions by their offspring. Journal of the American Geriatrics Society, 41 (6), 599.

Statistics Canada. (1997). A portrait of seniors in Canada. (Catalogue no. 89-519-XPE). Statistics Canada, Ottawa, Ontario.

Steinberg, M., Cartwright, C., MacDonald, S., Najman, J., and Williams, G. (1997). Self-determination in terminal care. A comparison of GP and community members' responses. Australian Family Physician, 26 (6), 703-7.

Stelter, K. L., Elliott, B. A., & Bruno, C. A. (1992). Living will completion in older adults. Archives of Internal Medicine, 152, 954-959.

Stolman, C. J., Gregory, J.J., Dunn, D., & Levine, J. L. (1990). Evaluation of patient, physician, nurse, and family attitudes toward do not resuscitate orders. Archives of Internal Medicine, 150, 653-58.

Storch, J., & Dossetor, J. (1994). Public attitudes toward end-of-life treatment decisions: Implications for nurses, clinicians, and nursing administrators. Canadian Journal of Nursing Administration, 7 (3), 65-89.

Strain, L. (1993). Good health: What does it mean in later life? Journal of Aging and Health, 5 (3), 338-364.

Suri, D., Egleston, B., Brody, J., & Rudberg, M. (1999). Nursing home resident use of care directives. Journal of Gerontology: Medical Sciences, 54A (5), M225-M229.

Swarz, R., & Perry, E. (1993). Advance directives are associated with good deaths in chronic dialysis patients. Journal of the American Society of Nephrology, 3, 1623.

Task Force on Canada in 2030. (1996). Beginning the Dialogue. Ottawa, Ontario: Task Force on Canada in 2030.

Task Force on Ethics of the Society of Critical Care Medicine. Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill. (1990). Critical Care Medicine, 18, 1435-1440.

Teno, J. (2000). Advance directives for nursing home residents: Achieving compassionate, competent, cost-effective care. Journal of the American Medical Association, 283 (11), 1481-1482.

Teno, J., Kim, R., Knaus, W., Wenger, N., Phillips, R., Wu, A., Layde, P., Connors, A., Dawson, N., & Lynn, J. (1995). Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resources use. Journal of General Internal Medicine, 10, 179-186.

Teno, J., Nelson, H., & Lynn, J. (1994). Advance care planning: priorities for ethical and empirical research. Hastings Center Report, 24 (Special suppl), 32-36.

Teno, J., Spornak, S., & Lynn, J. (1998). Role of written advance directives in decision-making: Insights from qualitative and quantitative data. Journal of General Internal Medicine, 13, 439-446.

Thibodaux, L., & Shewchuk, R. (1988). Strategies for compliance in the elderly. Topics in Geriatric Rehabilitation, 3 (3), 21-33.

Uhlmann, R., Pearlman, R. & Cain, K. (1988). Physicians' and spouses' predictions of elderly patients' resuscitation preferences. Journal of Gerontology, 43, M115-21.

University of Toronto Centre for Bioethics.
[Http://www.utoronto.ca/jcb/end_of_life.htm](http://www.utoronto.ca/jcb/end_of_life.htm)

VandeCreek, L., & Frankowski, D. (1996). Barriers that predict resistance to

completing a living will. Death Studies, 20, 73-82.

VandeCreek, L., Frankowski, D., & Johnson, M. (1995). Variables that predict interest in and the completion of living wills. The Journal of Pastoral Care, 49 (2), 212-213.

Vaughn, G., Kiyasu, E., & McCormick, W. (2000). Advance directive preferences among subpopulations of Asian nursing home residents in the Pacific Northwest. Journal of the American Geriatrics Society, 48 (5), 554-557.

Virmani, J., Schneiderman, L., & Kaplan, R. (1994). Relationship of advance directives to physician-patient communication. Archives of Internal Medicine, 154, 909-913.

Vladeck, B. (1993). Beliefs versus behaviors in health care decision making. American Journal of Public Health, 83, 13-14.

Wallston, K., Maides, S., & Wallston, B. (1976). Health-related information seeking as a function of health-related locus of control and health value. Journal of Research in Personality, 10, 215-222.

Weber, R. (1990). Basic content analysis. Series: Quantitative applications in the social sciences. Iowa City: Sage Publications, Inc.

Wetle, T. (1995). Individual preferences and advance directives. Hastings Center Report, 24, Special Supplement, (6), S5-S8.

White, P. (1997). The role of the critical care nurse in counselling families about advance directives. Critical Care Nursing Clinics of North America, 9 (1), 53-57.

Wold, J. L. (1992). The living will: legal and ethical perspectives. Journal of Neuroscience Nursing, 24 (1), 50-53.

Wolinsky, F. & Arnold, C. (1988). A different perspective on health and health services utilization. In G.L. Maddox & M.P. Lawton (Eds.), Annual Review of Gerontology and Geriatrics, Volume 8 (pp. 71-101). New York: Springer.

Zweibel, N., & Cassel, C. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. The Gerontologist, 29, 615-621.

Appendix A**Provincial Advance Directive Legislation**

<u>Province</u>	<u>Legislation</u>
Alberta	Personal Directives Act
Manitoba	Health Care Directives Act
Newfoundland	Advance Health Care Directives Act
Nova Scotia	Medical Consent Act
Ontario	Substitute Decisions Act
Prince Edward Island	Consent to Treatment and Health Care Directives Act
Saskatchewan	Health Care Directive and Substitute Health Care Decision Makers Act

(Source: University of Toronto Joint Centre for Bioethics Website, 1999)

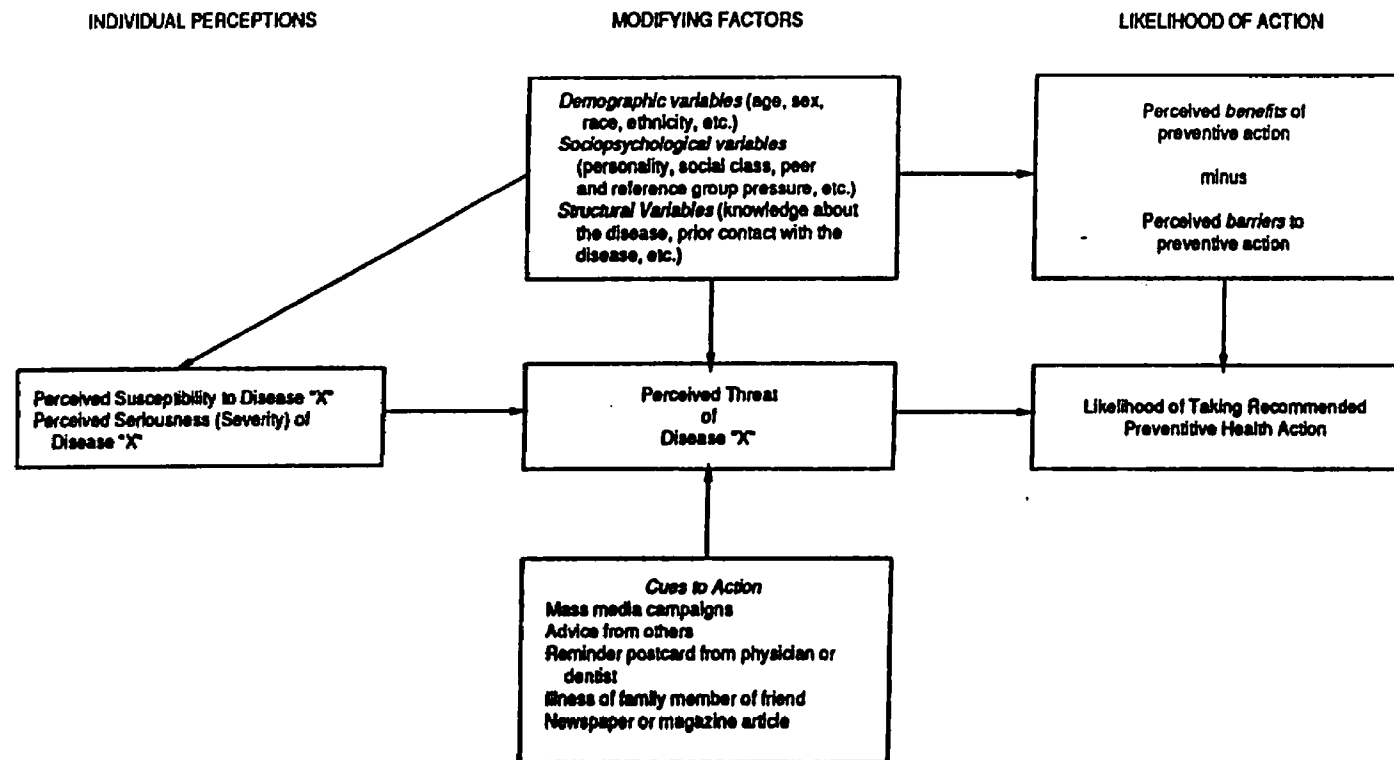
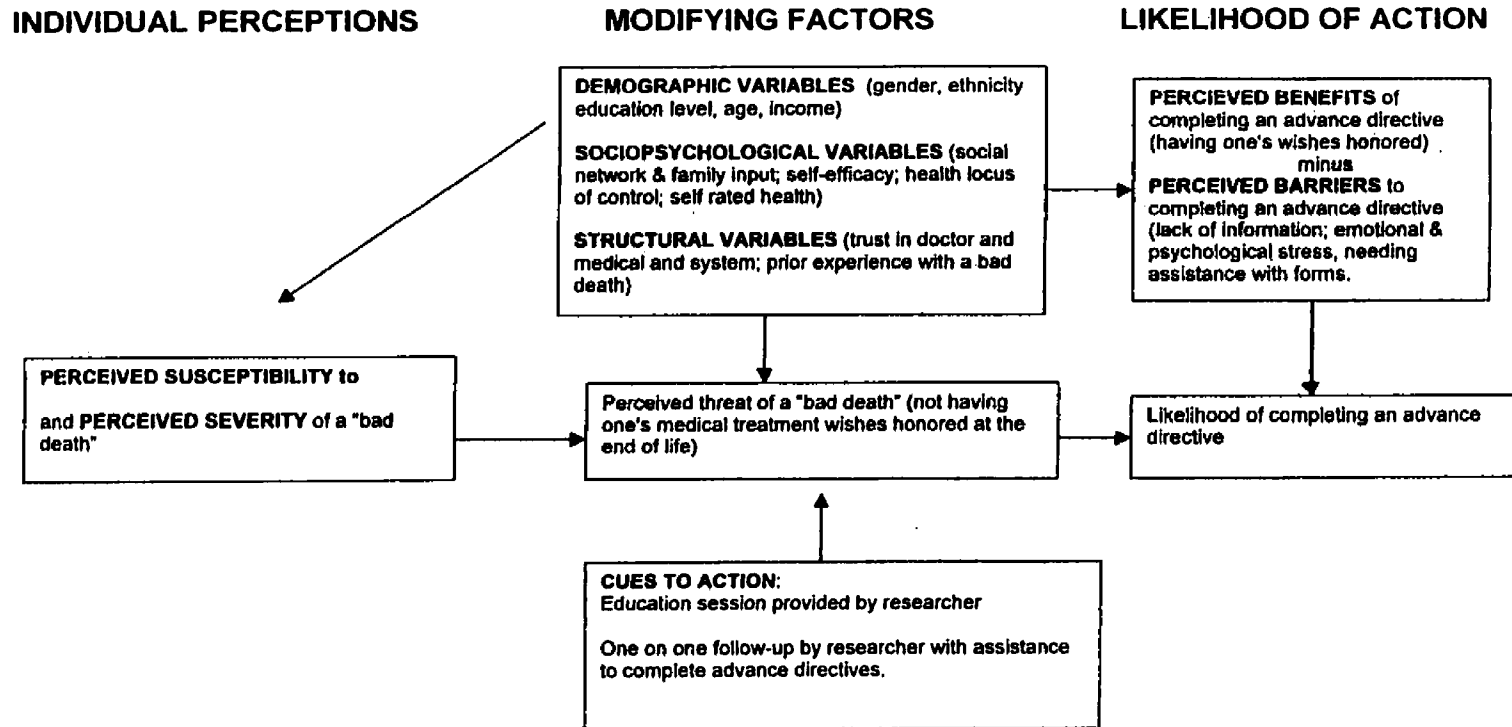


Fig 1. The Health Belief Model. Reprinted with permission from Becker MH: The health belief model and sick role behavior. *Health Educ Monogr* 1974;2:7.

The Health Belief Model and Advance Directives



(C. Hamel, 1999)

Appendix D - Disclaimer

You are invited to take part in a research study dealing with advance directives. The study is being conducted by Carole Hamel, a student in the Master of Nursing program at the University of Manitoba.

All interested adults over the age of 50 who live in the St. James Assiniboia area, and who attend an educational session on advance directives at the St. James Senior Center are invited to participate in this study. The study has been approved by the University of Manitoba Faculty of Nursing Ethical Review Committee. The St. James Senior Centre Board of Directors has allowed me to provide this educational session and to ask you to participate in this study.

If you wish to participate in the study, please fill out your name and phone number below, and complete the attached questionnaire. Participants will then be randomly divided into two groups. Carole Hamel will telephone one group in one month and both groups in 3 months to ask you a few more questions and offer assistance.

All of the information collected will be kept strictly confidential. The information will be grouped to avoid identifying individuals. Your name will not be used on any reports about the study or in future publications. Only Carole Hamel and her thesis advisor, Dr. Lorna Guse, will have access to the information. The researcher will keep all information secured in a locked file cabinet in her home.

There are no benefits to participate in the study, other than learning more about advance directives. The findings of the study may be published so that health care professionals and others may gain a better understanding about the use and completion of advance directives. There are no risks to participate in the study, unless you feel uncomfortable discussing issues surrounding end of life treatment decisions. Participation in the study is completely voluntary. You are under no obligation to participate and you may withdraw from the study at any time.

If you have any questions, please feel free to contact the researcher, Carole Hamel at 275-1204, or her thesis advisor, Dr. Lorna Guse at 474-6220.

Please complete the following:

I, _____ (name--please print);

_____ (phone number), agree to participate in the above study, and give permission to the researcher to call me at home and ask me several questions. I do not have to answer all questions if they make me feel uncomfortable.

Date: _____

Signature: _____

Appendix E - Advance Directive Questionnaire

Please read each question carefully and complete all questions by either filling in the blanks or by checking off (✓) the appropriate box. Thank you.

1. Year of birth: _____

2. Birth place: city/town _____ province/country _____

3. Gender: Male ☐ Female ☐

4. Marital status:
 Single/ Never married ☐ Married ☐
 Divorced/ Separated ☐ Widowed ☐ Other (specify) _____

5. Number of children: _____

6. Do you consider yourself a member of a particular religious group?
 No ☐ Yes ☐ If yes, which denomination? _____

7. Do you consider yourself a member of a particular ethnic group?
 No ☐ Yes ☐ If yes, which ethnic group? _____

8. What was your major occupation in life? _____

9. How well does your household income currently satisfy your needs?
 Very well ☐ Adequately ☐ With some difficulty ☐
 Not very well ☐ Totally inadequate ☐

10. Education:

What was the highest level of schooling or education that you completed?

11. Please indicate which of the following health conditions you have, if any:

- | | |
|---------------------------------------------------------------|-----------------------------------------------------|
| <input type="checkbox"/> Heart trouble (heart attack, angina) | <input type="checkbox"/> Dental problems |
| <input type="checkbox"/> Stroke | <input type="checkbox"/> Emotional/ mental problems |
| <input type="checkbox"/> High blood pressure | <input type="checkbox"/> Foot/ limb problems |
| <input type="checkbox"/> Other circulation problems | <input type="checkbox"/> Skin trouble |
| <input type="checkbox"/> Kidney trouble | <input type="checkbox"/> Arthritis or rheumatism |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> Eye trouble |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Ear trouble |
| <input type="checkbox"/> Breathing problems | <input type="checkbox"/> Incontinence |
| <input type="checkbox"/> Palsy | <input type="checkbox"/> Other bladder problems |
| <input type="checkbox"/> Thyroid trouble | <input type="checkbox"/> Back problems |
| <input type="checkbox"/> Stomach trouble | <input type="checkbox"/> Osteoporosis |

Other: _____

12. Would you say your health in general is:

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐

.....

Please answer some questions about your relatives and friends.

Relatives:

13. How many relatives do you see or hear from at least once a month?

14. How often do you see or hear from the relative with whom you have the most contact?

15. How many relatives do you feel close to? That is, how many of them do you feel at ease with, can talk to about private matters, or can call on for help?

Friends:

16. How many friends do you see or hear from at least once a month?

17. How often do you see or hear from the friend with whom you have the most contact?

18. How many close friends do you have (with whom you feel at ease, can talk to about private matters, or can call on for help)?

19. When you have an important decision to make, do you have someone you can talk to about it?

Always ☐ Very often ☐ Often ☐ Sometimes ☐ Seldom ☐
Never ☐

20. When other people you know have an important decision to make, do they talk to you about it?

Always ☐ Very often ☐ Often ☐ Sometimes ☐ Seldom ☐
Never ☐

21. Does anybody rely on you to do something for them each day? For example, shopping, cooking dinner, doing repairs, cleaning house, or providing child care.

No ☐ Yes ☐

22. If yes, how often do you perform these activities?

Very often ☐ Often ☐ Sometimes ☐ Seldom ☐ Never ☐

23. Do you live alone or with other people?

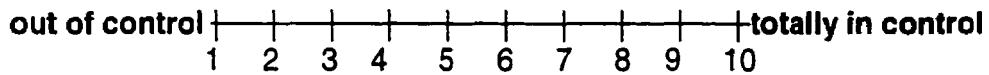
Live with spouse ☐ Live with other relatives or friends ☐

Live with other unrelated individuals (e.g. paid help) ☐ Live alone ☐

24. How much control do you feel you have in your life?

Thinking about life in general, some people feel out of control and helpless, while others feel in control and able to cope.

Please **X** the number that best describes how you feel.



Please indicate how strongly you agree or disagree with the following:

25. It is difficult to complete an advance directive because nobody knows how they will respond to the threat of death until that time comes.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

26. It is difficult to complete an advance directive because I don't think about my death very much.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

27. The many other concerns in my life prevent me from considering how I want my "last days" managed.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

28. I do not want to complete an advance directive because the doctors will probably not follow my wishes when I become seriously ill.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

29. It is difficult to complete an advance directive now because I will probably change my mind when I become seriously ill.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

30. I do not need to complete an advance directive now because I believe that I will live a lot longer.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

31. I think my doctor might be against my completing an advance directive.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

32. Completing an advance directive will benefit my family by making it easier for them when I become seriously ill.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

33. An advance directive will help those around me to know what my wishes are for medical treatment.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

34. My "last days" will be more comfortable for me if I have an advance directive.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

35. An advance directive will give my doctors guidelines on how to care for me when I become seriously ill.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

36. I want my doctors to know how I want to be cared for when I become seriously ill.

Strongly Disagree ☐ Disagree ☐ Agree ☐ Strongly Agree ☐

Appendix F**Questionnaire #2: Follow-up**

The last time I talked with you was when 1) you took part in a session that was designed to introduce you to advance directives, or 2) I called to offer you assistance with completing your advance directive. That was a few months ago and I am very interested in knowing what has happened since. Are you willing to answer some more questions?

I want to understand whether advance directives make a difference and, if they do, what difference they make. I don't really know about your experiences and what goes through your mind. That is why I am so grateful for your time and help. For that reason, I am going to ask you a few questions about your experiences, thoughts and feelings about the completion of advance directives. Please feel free to be open and honest. I am not here to judge your experiences or your thoughts, but to listen and learn from you.

Do you have any questions before we begin?

After the educational session, did you complete an advance directive?

Yes ☐ No ☐

If yes:

Why did you complete an advance directive?

Tell me about filling out the advance directive. For example, what did you do with it when you took it home? Then what?

Did you talk about it with anyone? Who? How would you describe your relationship with "X"?

Tell me about that conversation. What else? Anyone else?

Did "X" help you to complete your advance directive?

Is there anything about your medical condition that influences the way you think or feel about advance directives? What else?

Is there anything in your family or cultural background that has influenced your decision about the advance directive? Tell me about it.

If member of intervention group: Did my phone call a few months ago influence your decision to complete an advance directive?

If no:

Why not? Tell me more about it?

What could help you overcome that? What needs to happen before you can fill it in?

What did you do with the advance directive when you took it home?

Did you talk about it with anyone? Who? How would you describe your relationship?

Tell me about that discussion. What else?

Is there anything about your medical condition that influences the way you think or feel about advance directives? What else?

Is there anything in your family or cultural background that has influenced your decision about the advance directive? Tell me about it.

If member of intervention group: Did my phone call a few months ago influence your decision to complete an advance directive?

Appendix G - Lubben Social Network Scale

Family networks:

1. How many relatives do you see or hear from at least once a month?

zero = 0 one = 1 two = 2 three or four = 3 five to eight = 4
nine or more = 5

2. How often do you see or hear from the relative with whom you have the most contact?

< monthly = 0 monthly = 1 a few times a month = 2 weekly = 3
a few times a week = 4 daily = 5

3. How many relatives do you feel close to? That is, how many of them do you feel at ease with, can talk to about private matters, or can call on for help?

zero = 0 one = 1 two = 2 three or four = 3 five to eight = 4
nine or more = 5

Friends networks:

4. How many close friends do you have? That is, friends with whom you feel at ease, can talk to about private matters, or can call on for help?

zero = 0 one = 1 two = 2 three or four = 3 five to eight = 4
nine or more = 5

5. How many friends do you see or hear from at least once a month?

zero = 0 one = 1 two = 2 three or four = 3 five to eight = 4
nine or more = 5

6. How often do you see or hear from the friend with whom you have the most contact?

< monthly = 0 monthly = 1 a few times a month = 2 weekly = 3
a few times a week = 4 daily = 5

Confidante relationships:

7. When you have an important decision to make, do you have someone you can talk to about it?

always = 5 very often = 4 often = 3 sometimes = 2 seldom = 1
never = 0

8. When other people you know have an important decision to make, do they talk to you about it?

always = 5 very often = 4 often = 3 sometimes = 2 seldom = 1
never = 0

Helping others:

9.a. Does anybody rely on you to do something for them each day? For example, shopping, cooking dinner, doing repairs, cleaning house, providing child care.

If no, go on to Question 9. b.

If yes, score 5 and skip to question 10.

9. b. If no, how often do you perform these activities?

very often = 4 often = 3 sometimes = 2 seldom = 1 never = 0

Living arrangements:

10. Do you live alone or with other people?

live with spouse = 5 live with other relatives or friends = 4

live with other unrelated individuals (e.g., paid help) = 1 live alone = 0

Scoring:

The total LSNS score is obtained by adding up scores from each of the ten individual items. Thus, total LSNS scores can range from 0 to 50. Scores on each item were anchored between 0 and 5 in order to permit equal weighting of the ten items. (Lubben, 1988).

Appendix H - Intervention Protocol

The following script will be read to subjects in the intervention group who will be called by the researcher one month after the education session has taken place. The one on one follow-up and /or reminder provided by this script is the intervention in this study.

Hello, Mr. or Mrs. X. My name is Carole Hamel and I am the nursing student who presented the education session on advance directives at the St. James Senior Center about one month ago. At that time you agreed to participate in my study on advance directives. Are you still willing to answer a few questions? If not, what would be a good time to call you back?

1. Do you have any questions about the education session or advance directives in general?
2. Do you require more information about advance directives and how to complete one?
3. Do you require any assistance to complete an advance directive?

The researcher will attempt to provide simple answers to any questions raised in Item #1. For Item #2 , the researcher will offer to send out additional reference material and refer the subject to the Grace Hospital Educational Resources (837-0346). For Item #3, the researcher will encourage the subject to speak to their family doctor or family members.

Appendix I – Ethical Approval Letter

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number #99/46

Proposal Title: "Promoting Advance Directive Completion in Community Dwelling Older Adults"

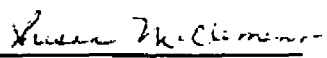
Name and Title of
Researcher(s): Carole Hamel

Date of Review: December 6, 1999

APPROVED BY THE COMMITTEE: January 6, 2000

Comments: With changes and clarification in your letter of January 3, 2000.

Date: January 6, 2000


Susan McClement, Associate Chair

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Appendix J – Advance Directive Educational Sessions

Date	Session	Location
Tuesday, February 22nd, 2000	Coffee Talk	St. James Senior Centre
Wednesday, March 1st, 2000	Easy Breathers	St. James Senior Centre
Tuesday, March 7th, 2000	EPH*	125 Carriage Road
Wednesday, March, 8th, 2000	Parkinson's Group	St. James Senior Centre
Thursday, March 16th, 2000	EPH	90 Sinawik Bay

*EPH= Elderly Persons Housing

Please note that 125 Carriage Road and 90 Sinawik Bay are outreach sites of the St. James Senior Centre.

All educational sessions were advertised within the St. James Senior Centre and the two EPH's, as well as at various community sites, via posters, in the St. James /Assiniboia Center newsletter, and via public service announcements in various community papers and television stations.

Appendix K – Letter from St. James-Assiniboia Senior Centre, Inc. Program Committee

St. James-Assiniboia Senior Centre, Inc.

Corner of 2109 Portage Ave. & Duffield, Winnipeg, MB R3V 0G

Phone: (204) 987-8850 Fax: (204) 987-8856

February 25th, 2000

Carole Hamel,
75 Rutgers Bay,
Winnipeg MB. R3T 3C9

Dear Carole,

On behalf of the St. James-Assiniboia Senior Centre Inc. and the Program Committee, I would like to thank you for a most interesting presentation regarding 'Living Wills'.

The Centre is not always as fortunate as the Coffee Talk group in having a presenter who is so pleasantly open and easily heard when relaying information and answering questions. Food for thought for all of us Carole, which of course is why you were there, and very timely for the age bracket of our members.

You mentioned giving a presentation to the Easy Breathers group on Wednesday March 1st. As an asthmatic I try to attend as many of these meetings as possible. Unfortunately the timing conflicts with the Program Committee meetings so I miss more than I attend, and will not be at the March 1st meeting. Please accept our good wishes in your course Carole.

Sincerely,

Name withheld for confidentiality purposes,

Program Committee/Publicity.

Appendix L**Schedule of Questionnaire and Intervention Administration**

Q#1 Date	# resp.	Corrected # *	Interv.Date	# interv. subjects	Q#2 Date	# resp.
Feb. 22	23	21	March 20 – 22	11	May 15 – 17	21
March 1	18	17	April 1 – 3	8	May 27 – 29	17
March 7	10	10	April 4 – 6	5	June 1 – 3	10
March 8	18	16	April 4 – 6	8	June 1 – 3	16
March 16	10	10	April 13 – 15	5	June 5	10
Totals	79	74		37		74

- Corrected number randomly excludes one spouse if both husband and wife responded to the initial questionnaire.

Appendix M

Modifications made to VandeCreek and Frankowski's Barriers and Benefits Scale

Original Statement	Modified Statement
BARRIER: One obstacle to completing a living will is the fact that nobody knows how they would respond to the threat of death until that time comes.	BARRIER: It is difficult to complete an advance directive because nobody knows how they will respond to the threat of death until that time comes.
BARRIER: One difficulty with making a living will is that I don't think about my death very much.	BARRIER: It is difficult to complete an advance directive because I don't think about my death very much.
BARRIER: The many other concerns in my life prevent me from considering how I want my "last days" managed.	No change.
BARRIER: I am not so excited about making a living will because doctors who would take care of me in the hospital probably would not follow my wishes.	BARRIER: I do not want to complete an advance directive because the doctors will probably not follow my wishes when I become seriously ill.
BARRIER: Completing a living will now is difficult because I would likely change my mind about how I want to be managed during terminal illness.	BARRIER: It is difficult to complete an advance directive now because I will probably change my mind when I become seriously ill.
BARRIER: I am not very interested in a living will because I believe that I will live a lot longer.	BARRIER: I do not need to complete an advance directive now because I believe that I will live a lot longer.
BARRIER: I think my physician might be against my completing a living will.	BARRIER: I think my doctor might be against my completing an advance directive.
BENEFIT: Completing a living will benefits my family by making it easier when I become terminally ill or permanently unconscious.	BENEFIT: Completing an advance directive will benefit my family by making it easier for them when I become seriously ill.
BENEFIT: One advantage of a living will is that those around me will know my wishes concerning how I want to be managed.	BENEFIT: An advance directive will help those around me to know what my wishes are for medical treatment.
BENEFIT: My "last days" will likely be more comfortable for me if I have a living will.	BENEFIT: My "last days" will be more comfortable for me if I have an advance directive.
BENEFIT: One benefit of a living will is that it gives my physicians guidelines under which to manage my care.	BENEFIT: An advance directive will give my doctors guidelines on how to care for me when I become seriously ill.
BENEFIT: I want my doctors to know how I want to be medically managed if I become terminally ill or permanently unconscious.	BENEFIT: I want my doctors to know how I want to be cared for when I become seriously ill.

Appendix N - Operationalization of the Variables

Variable name	Variable label	Level	Type	Coding
Age	Age in groups	Ordinal	Categorical	0 = less than 65 1 = 65 - 74 years 2 = 75 - 84 years 3 = 85 and over
	Exact age	Ratio	<i>Continuous</i>	<i>Age as specified</i>
Gender	Gender	Nominal	<i>Categorical</i>	0 = male 1 = female
Marital status	Marital status divided into groups	Nominal	Categorical	0 = single/ never married 1 = divorced/ separated 2 = married 3 = widowed
Education	Educational level divided into groups	Ordinal	Categorical	0 = elementary/ some high school 1 = completed high school 2 = some post-secondary 3 = Bachelor degree
Income	Ability of income to satisfy needs along a five point scale	Ordinal	Categorical	0 = totally inadequate 1 = not very well 2 = with some difficulty 3 = adequately 4 = very well
Occupation	Type of occupation divided into groups	Nominal	Categorical	0 = homemaker 1 = clerical/ sales/ service 2 = professional/ management 3 = laborer

Self-rated health	Rating of health divided into two categories	nominal	<i>Categorical</i>	<i>0 = poor 1 = good</i>
Perceived control	Visual analogue scale from 1 to 10	Interval	Continuous	Value from 1 to 10.
Level of social support	Total score on LSNS from 0 to 50	Interval	Continuous	Total score from 0 to 50.
Confidante relationship	Presence or absence of relationship	Nominal	Categorical	<i>0 = no 1 = yes</i>
Perceived barriers	Subscale ranging from 7 to 28	Interval	<i>Continuous</i>	<i>Total score from 7 to 28.</i>
Perceived benefits	Subscale ranging from 5 to 20	Interval	<i>Continuous</i>	<i>Total score from 5 to 20.</i>
Completion of AD	Yes or No	Nominal	<i>Categorical</i>	<i>0 = no 1 = yes</i>
Discussion of AD	Yes or No	Nominal	<i>Categorical</i>	<i>0 = no 1 = yes</i>

Italicized measurement values indicate the coding of variables for multivariate analysis.

Appendix O--Pearson's Skewness Coefficients

Variable	Skewness Statistic
Age	.012
Gender	-1.407
Marital status	-1.082
Satisfaction with income	.942
Education	.518
Self-rated health	.414
Number of illnesses per participant	1.274
Level of social support	-1.206
Confidante relationship	.425
Perceived control	.818
Perceived barriers	-.279
Perceived benefits	.385
Completion of AD	1.137
Discussion of AD	-.862



UNIVERSITY
OF MANITOBA

Faculty of Nursing

THESIS ORAL DEFENSE

CAROLE F. HAMEL

**Room 475 Riverview Health Centre (Princess Elizabeth Building)
Thursday, November 16th, 2000
0900 hrs.**

Thesis Committee Members: Dr. Lorna Guse - Chairperson
Dr. Pamela Hawranik - Member
Dr. John Bond - External Member

"Discussion and Completion of Advance Directives Among Community Dwelling Older Adults"

Abstract

Advance directives (ADs) in Manitoba are documents that allow competent individuals to set forth their medical treatment wishes and to name a health care proxy in the event that they lose the capacity to make or communicate these decisions at some time in the future. Despite the benefits of such documents and widespread support for advance planning, very few people have completed an advance directive. Using the Health Belief Model as a conceptual framework, this post-test only experimental study examined whether or not an individualized intervention (phone call reminder) given to half of the older adults who attended an AD educational session increased the discussion and/ or completion rate of ADs. Two questionnaires (self-administered and telephone) were administered to a convenience sample of 74 older adults living in a large midwestern Canadian city, who had been randomly assigned to control and intervention groups. Of the 74 participants, 25.7% (n = 19) completed an AD. There were no significant differences between control and intervention groups on the discussion and/ or completion of ADs. Both bivariate and multivariate analysis suggested a significant relationship between AD discussion and completion and perceived barriers associated with ADs. Overall, the study findings indicate a positive attitude toward advance directives and their completion, but significant barriers to discussion and completion included a present orientation, procrastination, busy lifestyles, and not thinking about one's own death. Future research is needed to explore factors influencing completion and non-completion of ADs.