

A SCREENING TOOL FOR ADVANCE DIRECTIVE  
KNOWLEDGE IN PRIMARY CARE

Scholarly Project for the Degree of M. S. N.

MICHIGAN STATE UNIVERSITY

LINDA C. TREFTZ

1999

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**A SCREENING TOOL FOR ADVANCE DIRECTIVE  
KNOWLEDGE IN PRIMARY CARE**

**By**

**Linda C. Treftz**

**A SCHOLARLY PROJECT**

**Submitted to  
Michigan State University  
in partial fulfillment of the requirements  
for the degree of**

**MASTER OF SCIENCE IN NURSING**

**College of Nursing**

**1999**

## ACKNOWLEDGMENTS

I would like to thank the members of my Scholarly Project Committee, Linda Keilman, Georgia Padonu, and Celia Wills, for their advise and guidance throughout the writing of this project. Special thanks and heartfelt gratitude to Celia Wills, Chairperson, whose encouragement and confidence helped me through the many challenges and obstacles encountered. Thank you also to my husband, Fred, and my mother, Janet Hamilton, who gave a helping hand in research, critiquing and editing of this project, and for giving me encouragement along the way. Their help was invaluable to the completion of this project.



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## INTRODUCTION

The Patient Self Determination Act (PSDA) was enacted by Congress in October, 1990 and went into effect December, 1991. The PSDA requires all health care centers receiving federal aid to inform patients of their right to accept or refuse medical treatment. Further, the PSDA requires such centers to provide information about advance medical directives such as living wills and durable powers of attorney (Cox & Sachs, 1994). The intent of this act is to give people greater autonomy, by clarifying their preferences in advance about decisions related to life-prolonging interventions for a future time when they may be unable to make health care decisions (Berrio & Levesque, 1996). In addition to providing greater individual autonomy, the PSDA was implemented to help encourage adults to complete written advance directives (ADs) (Mezey, Evans, Golub, Murphy, & White, 1994).

### Statement of Problem

Despite implementation of the PSDA, many people die undignified, painful deaths. As a result of fear, lack of empowerment, insufficient information, or various functional limitations, many people do not clearly communicate their wishes to those who may be making medical decisions for them. Those making the decisions usually include peoples families or their primary care providers (PCPs) (Madson, 1993).



Overall, with an 85% non-participation rate, the PSDA is falling far short of its original objectives (Haynor, 1998). Advance directives are not being completed by many patients, despite the significant possibility of prolonged and unnecessary suffering in the process of dying. Although ADs may prevent suffering, even healthy people could benefit from using them as a proactive means of promoting individual health and well being.

One reason ADs are underutilized is that discussions often do not occur among the family and the patient, or between the patient and PCP. A second aspect of the problem is that the written text of a completed AD may not be sufficiently specific to clearly convey the person's wishes to another. The patient could be fearful that without verbal clarification to the family and the PCP, the AD may be misinterpreted by both parties. Also the family and the PCP may have contradictory interpretations of the AD (Teno et al., 1997-a). Thirdly, aside from potential misinterpretation of the document, there is an important attitudinal component. Many families and practitioners alike feel that any withholding of life prolonging treatment constitutes the withholding of desirable care. This component may inhibit the successful implementation of the AD. When discussing ADs it is clinically useful to treat dying as a process of living.

It is a legal right for a competent person to make an informed choice about proposed medical treatment, and the

right to refuse that treatment. Given the difficulty accompanying the determination of an incompetent person's wishes, it is helpful if those wishes are clearly expressed prior to the need to institute life sustaining treatment. One approach to this issue has been the use of ADs (Garwin, 1998).

Ott and Hardie (1997) discussed that there must be increased communication and collaboration among physicians, nurses and patients in order to meet the objectives of the PSDA. Patient education concerning ADs is best done in an outpatient setting before a patient is seriously ill, but such education often does not occur. The role of the Advance Practice Nurse (APN) as a facilitator will help patients prepare for the best level of health. Despite the perceived challenges of AD implementation, there are documented means of overcoming these difficulties. Johns (1996) stated that implementation of the PSDA in the primary care setting rather than in an acute care setting will encourage discussions among patients and their primary care providers (PCPs). In depth discussions of medical diagnosis, probable course of disease and expectations of treatment among patients and PCPs are vital (Ott & Hardie, 1997).

Kelly-Powell (1997) pointed out that "the right of patients to make decisions and choose treatment according to their own values and goals, and the responsibility of health care providers to respect those rights, have long been

affirmed by many authors and policy makers" (Kelly-Powell, 1997, p. 219). Decisions about the treatment of a potentially life threatening illness often are made during the acute stages of the disease, which is why the PSDA would be better implemented in a primary care setting prior to the acute illness (Kelly-Powell, 1997).

#### Purpose

The purpose of this scholarly project is to develop a screening tool to determine patients' knowledge of and readiness to implement an Advance Directive. The tool will be developed for use within the primary care clinic setting, focusing mainly on the Medicaid population within managed care. However this tool is potentially applicable to any population in any type of primary care setting.

The target population for this project includes a variety of racial and age groups, with many considered to have low income and low literacy levels. The rationale for choosing the Medicaid managed care population is that this group has a need for support for both the consideration and implementation of ADs. An additional reason for focusing on this group is that they have not typically been involved in health promotion or planning. The lowest percentage of those completing ADs includes those with low-income, and low-literacy levels (Hanson & Rodgman, 1996). By focusing on patients in the inner-city, this will increase the exposure that ethnic minorities receive regarding end of life options.

The screening tool will be based on Prochaska's Transtheoretical Model and Stages of Change (1997), with a focus on patients' knowledge of and readiness to implement an Advance Directive. The tool will also provide information about each patient's knowledge of his or her health concerns. Such content will enable patients to be aided more efficiently in obtaining education appropriate for their individual circumstances. An overall goal of this project is to address ADs in a non-confrontational manner within the primary care setting. Through determining the person's interest/readiness to implement an AD, APNs can focus their interventions on the patient's stage of change, in order to reach the final objective of helping the patient determine if an AD is right for them.

Through the use of this screening tool, it is the author's hope that the patient's wishes will be more accurately and effectively conveyed to the APN and family members. Such enhanced communication can lead to fewer misinterpretations of the patient's wishes in the context of life prolonging medical treatment. Enhanced communication is vital to determining patient's wishes, not only to avoid misunderstandings, but to remind patients that ongoing communication is necessary prior to and during a health crisis. Both APNs and patients must recognize that preferences for health interventions may change frequently, especially during a health crisis. During periods of relative health, patients may believe they do not want life

sustaining procedures performed. However, they may change their minds when an acute health crisis actually arises (Ryan, 1996).

In the absence of ADs, decisions for end-of-life treatment are made by family members and physicians. These surrogates may not know what the patients would have chosen under similar circumstances. The PSDA does not specify that physicians or even health professionals must discuss ADs with patients; in practice this task is often delegated to hospital admitting clerks. The law does little to encourage preparation of ADs before the need for hospitalization or long-term care (Greco, Schulman, Luaizzo-Mourrey, & Hansen-Flaschen, 1991). By targeting this population, the APN can foster improvement in the quality of care and increase decision making opportunities.

### Conceptual Definitions

For the purposes of this project, the author will define ADs as written statements that are intended to govern health care decision making for a patient should he or she lose decisional capacity (King, 1996). ADs allow patients to document preferences regarding health care in the event of impaired decision making capacity in the future (Landry, Kroenke, Lucas, & Reeder, 1997). There are two primary types of ADs currently in use. The first is the living will, a type of Advance Directive in which the patient puts into writing their wishes about medical treatment should they be unable to communicate. State laws may define when

the living will goes into effect, and may limit treatments to which the living will applies. The present use of living wills alone usually is not a viable guideline to ensure the quality of death, and should name a health care proxy to ensure wishes be carried out appropriately (Basta, 1996).

Another important point for this project is that living wills are not legally recognized in Michigan. However, in a case of dispute regarding an individual's health care desires, one's written or oral statements pertaining to healthcare or the withdrawal or refusal of treatment may be used as evidence. These statements could be used in court if the individual is unable to participate in their own health care decisions (State of Michigan, 1996).

The second most common type of AD is a durable power of attorney for health care, also called a healthcare proxy. This type of document enables another person the power to make medical treatment and personal care/custody decisions when the patient is unable to do this for themselves. These decisions are made at a time when patients become temporarily or permanently unconscious from disease, accident or surgery (State of Michigan, 1996). It can specify parameters for the extent of all kinds of medical decisions, and include instructions regarding specific types of treatment that would either be included or excluded in a medical plan of care (Burnell, 1993).

A final concept that is important to this critical issue is that of autonomy or self-determination. The

principle of autonomy/self determination entitles patients to make important decisions regarding treatment choices and outcome goals. This allows the patient to maintain control over their own health care (Schneiderman & Arras, 1985).

### Conceptual Framework

An adaptation of Prochaska's Transtheoretical Model (1997) will be used to guide this project. The change that is being examined in this project is the empowering of a person to exercise autonomy for health care issues via the implementation of an AD. The stages include: precontemplation, contemplation, preparation, action, maintenance and termination.

The stages of change and the time frame in which each stage is used are presented in Figure 1. An example of a health related application of the stages of change model is with smoking cessation. Precontemplation may be when the patient is thinking about quitting, but has no current intention or plan to stop.

While Prochaska's Transtheoretical Model (1997) involves a series of 6 steps/stages, for the purpose of this project only the precontemplation stage will be addressed (Prochaska, Redding, & Evers, 1997). The portion of Figure 2 above the dotted line presents the focus of this project on precontemplation. For detailed information on each stage of change, refer to Appendix A. Precontemplation is the stage in which a person has no intention to take action in the foreseeable future. A person may stay in this stage



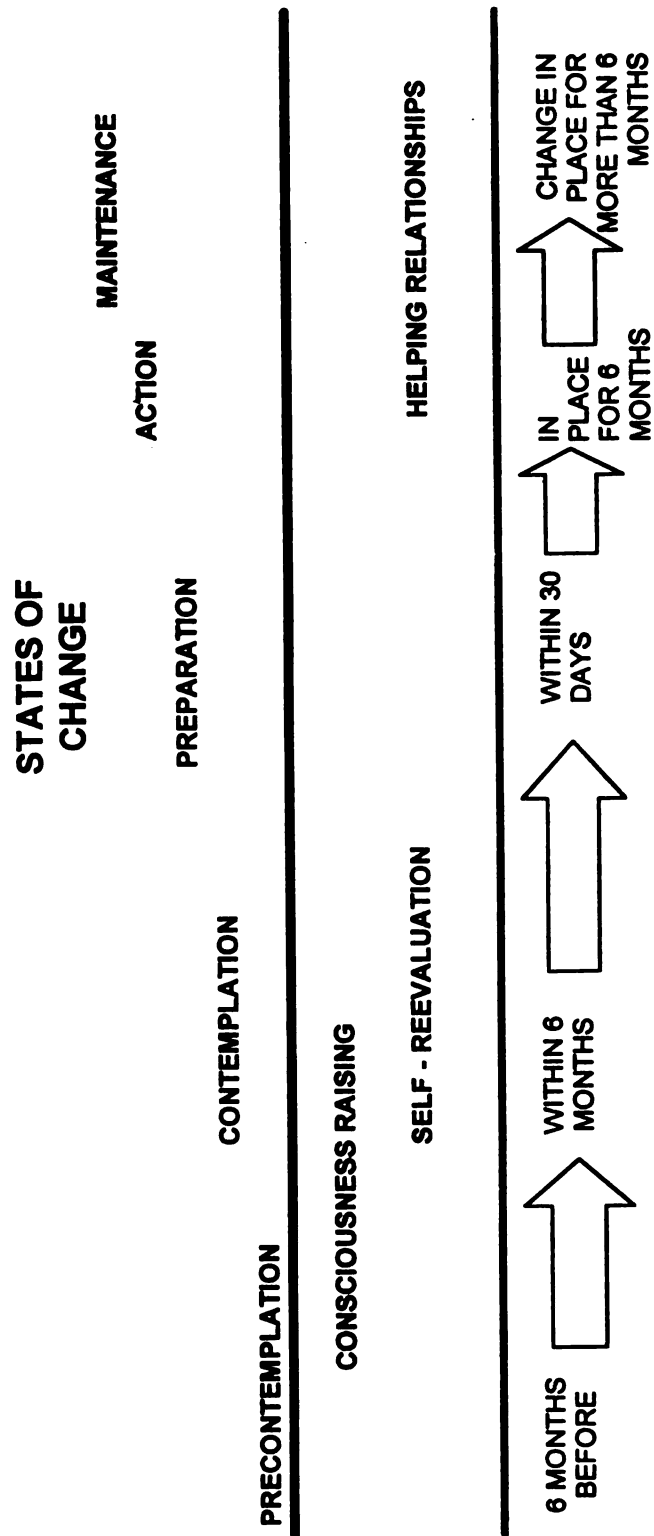
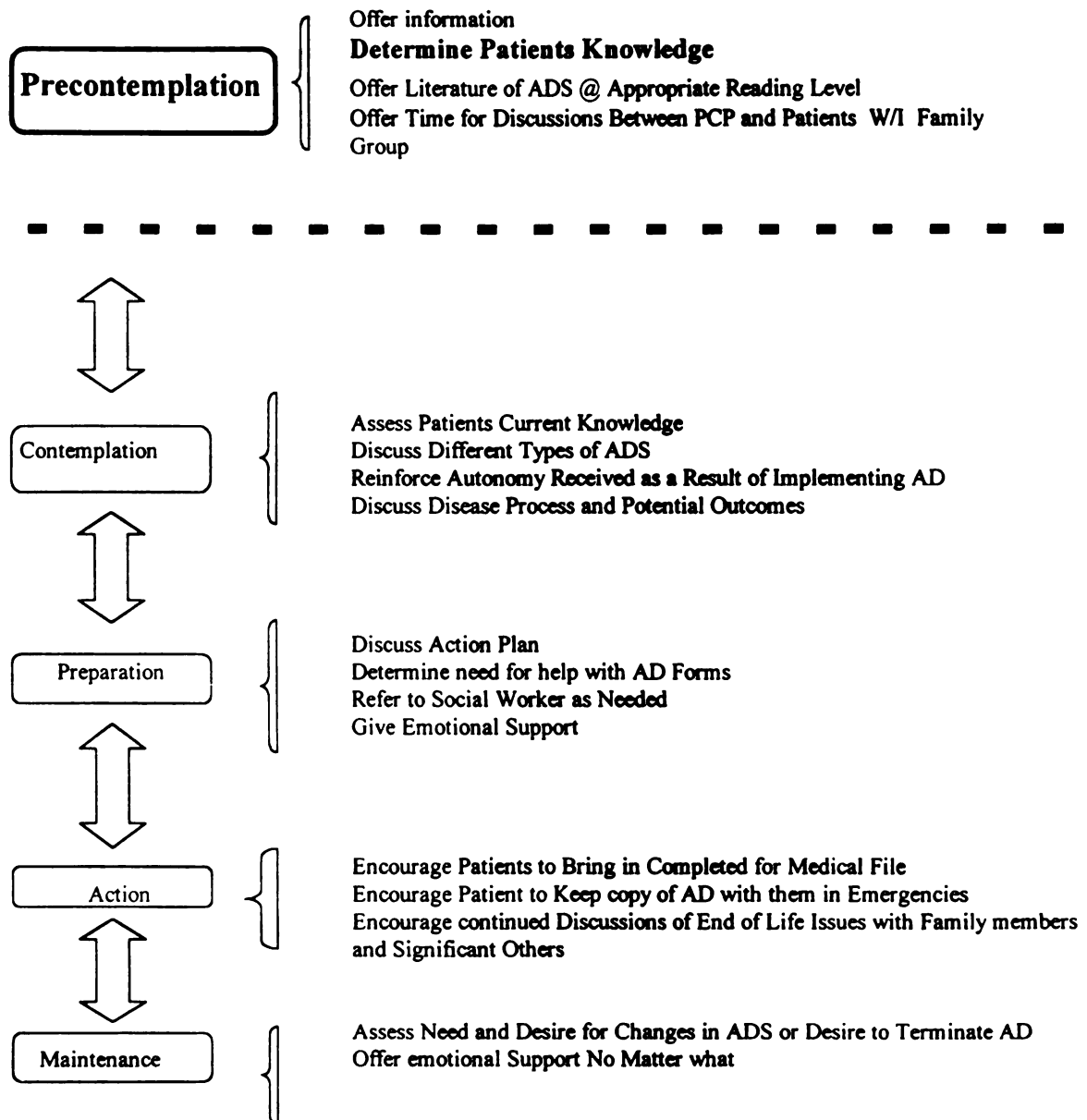


Figure 1. States of Change, Process and Timeline



**Figure 2. Stages of Changes with Specific Interventions to Guide Patients from One Stage to Another in Implementing Advance Directives**

because they are uninformed or underinformed about consequences of their behavior. Both uninformed and underinformed groups of people tend to avoid reading, talking or thinking about certain issues (Prochaska et al., 1997).

### **Application to Current Project**

This project focuses on screening for basic knowledge and interest in ADs. However after screening patients there are many interventions which can be followed by APNs (see Figure 2). The portion of Figure 2 below the dotted line represents these interventions. Many of these interventions may potentially be used to improve the quality of care. In addition the target population may benefit from increased participation in their own health care decision making.

There are seven critical assumptions about the nature of behavioral change and the interventions that can best facilitate such change (Prochaska et al., 1997). This project will focus on two of Prochaska's seven critical assumptions that drive the Transtheoretical Model and Stages of Change practice:

1. Behavioral change is a process that unfolds over time through a sequence of stages.
2. Without planned interventions, populations will remain in the early stages of change.

These two critical assumptions will form the backbone of the interventions and implications for Advanced Practice Nurses which will be discussed later.

Within the context of this project, the ill-health condition is chronic suffering and undignified death. If a person is considering implementing an AD, he or she theoretically moves through the precontemplation, contemplation and preparation phase in order to implement a change. For the purpose of this project the focus will remain on precontemplation. However, if one's intent is to help the patient move through the stages of change to prepare a patient for the ill-health condition, the APN can support the patient's decision to: 1) move forward; 2) develop an AD; or, 3) not make any changes at that time. The APN can focus interventions on supporting the person in the way that s/he wishes to be supported, depending on the stage of change the person is currently in. See Figure 2 for a summary of nursing interventions for each specific stage of change.

Within the context of this project, the behavior addressed is choosing whether or not to implement an AD. There are a variety of activities that may be utilized by the APN in an effort to initiate a new behavior. One of these activities is self-reevaluation. Self reevaluation combines both cognitive and affective assessments of one's self-images, with or without a particular behavior (Prochaska et al., 1997). By using self-reevaluation the

APN would focus on encouraging the patient to imagine what end-of life care will be like without the implementation of an AD, compared to having one. An additional factor included in self-reevaluation for this project is clarifying patient's values.

Another critical activity that may be utilized in promoting the precontemplation of change is that of a helping relationship. Prochaska (1997) describes this as combining caring, trust, openness and acceptance as well as support for the change. It includes such things as rapport building, and therapeutic alliances. A strong rapport and therapeutic alliance would assist in developing feelings of caring, trust and supportiveness for the patient which will work to foster movement from one stage to another. The development of a helping relationship is vital during the precontemplation stage. If a strong rapport is not established between the APN and the patient, it is unlikely the proposed behavior would be seriously considered by the patient.

Finally, the action of social liberation is vital to the goal of this project. This action requires an increase in social opportunities or alternatives especially for people who may be deprived or oppressed (Prochaska et al., 1997). Advocacy, empowerment procedures and appropriate social policies can assist in meeting the overall goal of increasing AD implementation, especially for the described target population.

## **Review of Literature**

The proceeding review of literature will discuss the current use of ADs in primary care. The barriers affecting patient decisions to implement ADs will also be examined. Additionally the limitations of current efforts to increase the use of ADs will be reviewed. Furthermore societal factors both inhibiting and enhancing AD implementation will be addressed.

The primary case prompting the development of the PSDA was the Nancy Cruzan Case focusing on the issue of the 'Right to Die' (Haynor, 1998). Cruzan, the victim of an auto accident, remained in a persistent vegetative state for four years. Her parents petitioned the Missouri court system for the removal of her feeding tube, but were denied. The case was eventually appealed to the U.S. Supreme Court which upheld the constitutional right of a patient to refuse medical care. The court maintained that states could require clear and convincing evidence that cessation of medical treatment was in agreement with the patient's wishes. To facilitate such evidence, ADs were developed.

Notwithstanding the Cruzan ruling, the implementation of the PSDA, and the opportunity for ADs, only 15% of American adults have prepared ADs (Haynor, 1998). The current policies for facilitating the development of ADs are producing few actual directives. Most ADs include only standard content which would not be expected to effectively

individualize care to people's preferences (Teno et al., 1997-b).

#### ADs in Primary Care

There are a variety of things that patients are looking for and expect in regard to the implementation of ADs. Schlenk (1997) pointed out that discussions regarding ADs take time and need to be discussed with PCPs so questions and issues can be adequately clarified. An ongoing, trusting relationship which is most likely to be developed in a primary care setting fosters such a discussion. Without proper recognition and documentation, an individual's wishes regarding the use of life-sustaining medical interventions may not be carried out (Schlenk, 1997). Schlenk (1997) cited a study where investigators found that 93.9% of outpatients preferred to preserve a good quality of life rather than to have an extended life without regard to quality. Because of the therapeutic relationships that develop between patients and APNs, APNs are in an ideal situation to counsel patients regarding ADs.

Studies have shown that patients want the subject of end of life decisions discussed with them. The primary care setting is an excellent environment for such discussions (Schlenk, 1997). This can be seen through a study (Schlenk, 1997) in which the effectiveness of physician initiated counseling within a primary care setting on the rate of healthcare proxy appointments was determined. By the distribution of educational materials by the physician, the



healthcare proxy appointment rate rose to 31.5%, compared to a rate of 2.3% for those not receiving the intervention (Schlenk, 1997).

Edinger and Smucker (1992) studied outpatients who had not previously discussed ADs with their PCPs. A majority of the subjects (68%) wanted the physician to initiate the discussions, and (45%) stated that it was very important to make decisions about life prolonging treatment while they were well. Schlenk (1997) stated that discussion of end of life issues when patients are physically and/or emotionally stressed, such as with illness or in preparation for surgery, may result in hasty decisions. She further stated that under such conditions as admission to the hospital, comprehensive education about ADs cannot take place due to the multitude of factors in the forefront of the acute medical crisis. Information on ADs at this point may seem like another overwhelming sheet of paper to the individual. Also, in this environment, some people may perceive ADs as a threatening experience when discussed at this time (Schlenk, 1997). Given that APNs work predominantly in primary care settings, the possibility of AD discussion being perceived as a threatening experience could be minimized by the non-acute care situation.

When discussing ADs with patients, PCPs must remember that the primary reason behind establishing ADs is the expectation that they will be associated with positive results (Johns, 1996). An assumption is that even during

situations when patients are unable to make their own decisions, they nonetheless will have a means of retaining their authority and autonomy regarding their health care. Specifically, this control will be maintained through the use of ADs.

ADs coupled with well informed surrogate decision makers probably represent the best method of protecting patient autonomy when the patient no longer has a voice (Arenson et al., 1996). Haynor (1998) pointed out that the need for family discussions is very important. If family members or health care proxies disagree with the patients' AD instructions, they may overturn the AD when the patient can no longer assert their wishes. Haynor (1998) stated it is far better for patients to have their wishes in writing than to spend their final hours with their families agonizing over what should be done; instead they could focus on saying goodbye. The focus of the APN will include the whole family, not just the patient, thus fostering family discussions.

Discussions regarding end of life issues should be held in a quiet environment with minimal interruptions for the allotted discussion time. These discussions should be held in an outpatient office during periods of relative health rather than during health crises. Language should be simple, kind and direct with questions encouraged, and understanding checked. Interested family members/friends should be encouraged to be present if desired (Arenson et

al., 1996). For the purposes of this project this overall approach will be utilized. However, as the identified target group usually presents to primary care for an acute illness, they could be anticipated to be in a state of less-than-optimal health at the time of AD discussions.

Landry et al. (1997) used a randomized controlled trial to demonstrate that mailed information on the subject of ADs can increase the number of ADs produced. It was also found by Landry et al. (1997) that simple educational seminars can double completion rates of ADs. Hare and Nelson (1991) increased completion rates from 0% to 12% through distributed information and physician-initiated discussions.

The process of completing ADs is more complex than just filling out a form; it includes appropriate introduction of the issues and their integration into a longitudinal patient and PCP relationship (Landry et al., 1997). Furthermore, completion of an AD is not enough to ensure patient's wishes are honored. Despite the intervention taken in Landry's et al. (1997) study, less than 20% of patients told their PCP that they had an AD, and less than 50% placed the AD in their medical record. However, it was also found that when the AD is recognized, it influences treatment decisions in 86% of the cases. Landry et al. (1997) explained that as a result of this, more emphasis should be placed on encouraging patients to inform their PCPs about their ADs, and PCPs should routinely ask whether such directives have been established. Research demonstrates that discussion

with PCPs about ADs increases the likelihood that a patient will complete one, but patients seldom initiate this topic (Haynor, 1998). In implementing ADs, PCPs must remember that patient preferences regarding end of life may change over time; therefore, ADs need to be periodically reviewed (Arenson et al., 1996).

### Barriers and Limitations

The PSDA currently focuses on patients sufficiently ill to require hospitalization. This does not foster discussions between patients and PCPs about advance care planning (Gramelspacher, Zhou, Hanna, & Tierney, 1997). Other problems with ADs were demonstrated in a recent study that revealed both the infrequency of their use and the inadequacy of their formulation (Kolata, 1997). Garwin (1998) cited a multi-center study involving 4800 terminally ill patients. Fewer than 700 had a written AD; of those who had an AD, only 22 had directives explicit enough to help guide their medical care. Haynor (1998) stated that three in four physicians were unaware of their patients' ADs, even though they were a part of the patient's medical record. Given the outcome of these studies, it is evident that there are many barriers to the appropriate implementation of ADs. As a result of therapeutic alliances developed between APNs and their patients, APNs are in an ideal role to meet these challenges.

One of the primary weaknesses of the current method of informing patients about ADs is that much of the literature

and the documents themselves are above reading levels recommended for patients (Ott & Hardie, 1997). Ott and Hardie (1997) concluded that, "Patients must be able to read and understand advance directive documents before signing them. Refinement of documents is recommended to support patient understanding and autonomy in end of life care" (p. 54). A patient's inability to understand ADs may explain why so few have signed the documents (Ott & Hardie, 1997).

Research indicated that many people read below the level of their completed formal education (Meade & Wittbrot, 1988). Glazer-Waldman, Hall, and Weiner, (1985) showed 40% of adults tested at a Texas hospital read below the 6<sup>th</sup> grade level. Miller and Brodie (1994) found 100 patients sampled at a VA hospital read at a 5.6 grade level despite having completed an average of 11.6 grades. Written materials given to patients should not be above a 6<sup>th</sup> grade level (Ott & Hardie, 1997). It is imperative that any tool used to elicit patients wishes be readable and comprehensible by the patients. It is important for APNs to realize that only one of every five people know what ADs are, leaving 80% uninformed, even after being given information on ADs (Haynor, 1998).

Grant (1992) discussed that physicians' approach to soliciting ADs may constitute an ethical issue. Physicians may be perceived to be intimidating, even though their demeanor may be intended to comfort. "The desire to please the physician by signing an AD during an acute

hospitalization may constitute duress...this would be incompatible within the principles of informed consent and patient autonomy" (Grant, 1992, p.46). There are a variety of factors reported as to why physicians frequently shy away from discussions regarding ADs. Morrison, Olson, Mertz, and Meier (1995) cited discomfort with the topic, fear of eliminating patients' hope for recovery and time constraints as barriers to physician initiated discussion of ADs in the outpatient setting.

Schwarz (1992) stated that one of the biggest problems with current ADs is that they are often comparatively simple, frequently make use of clinically vague terminology such as: 'rejection' of 'heroic' or 'extraordinary measures' when all hope is gone. The problem of vagueness in ADs is not rectified easily. However, if one attempts to be specific about how care is to be provided then one may define the directive so narrowly that it is applicable to very few circumstances. It is rare for anyone to foresee and specify all possible critical conditions as well as therapeutic modalities they may or may not want for their conditions (Garwin, 1998). Despite these problems, the APN as an educator could function as a translational unit for the terminology. Furthermore the APN can advocate these discussions not be held during periods of duress.

Current wording of living wills may impede decision making and lead to decisions contrary to patients true preferences. In a study by Hammes and Rooney (1998), there

are cited instances where patients have requested not to be hospitalized but their wishes had not been honored. This resulted in patients undergoing treatments that they would not have chosen. Additionally, in this study, there are inconsistencies between the patient's documented preferences and treatment decisions. The study included seven instances in which decedents' preferences stated that CPR should be attempted but was not. In four cases the decedents' appointed agent revised the CPR status in the final stages of terminal illness. Two of the patients were found dead and CPR was not attempted. In one case CPR was attempted resulting in a poor outcome, and a do not resuscitate order was subsequently written. Johns (1996) stated that in a study of nursing home patients where ADs were placed in patient records, care was consistent with preferences in 75% of instances.

Despite the fact that patient preferences regarding end of life decisions often are not assessed, a number of research articles make it clear that health professionals are most likely not following what the patient would have wanted. In one study, the authors sought to describe resuscitation preferences of patients hospitalized with exacerbation of congestive heart failure compared to physician's perceptions of the patients wishes. The physician's perceptions were not accurate in about one quarter of the cases (Krumholz et al. 1998). Physician misperceptions resulted in misaction both when resuscitation



was preferred as well as in cases when it was not wanted. However, it was more likely to occur when the patient did not want to be resuscitated. This occurred in 14% of the cases studied (Krumholz et al., 1998). The presumption in favor of preserving life by whatever means necessary conflicts with most peoples wishes in cases of terminal illness or permanent loss of cognitive function (Greco et al., 1991).

Emanuel, Barry, Stoeckle, Ettelson, and Emanuel, (1991) reported that the two most frequent barriers to writing ADs were the expectations of patients that the physicians should take the initiative to discuss the matter, and the belief that such issues are only relevant to older people or to those in poor health. Other reasons ADs may not be implemented may include potential negative outcomes such as the stereotyping of patients who have ADs, resulting in undertreatment and inferior care or the refusal of health care providers to follow ADs even when they are well understood (Johns, 1996). Other barriers to the completion of ADs include: dependence on family for decision making, it is a difficult topic to discuss, belief a lawyer is needed to complete an AD, fear of signing one's life away, and fear of not being treated (Berrio & Levesque, 1996).

Despite the number of research articles currently published on the PSDA and ADs, there are still a variety of barriers to ADs which are incompletely understood. Haynor (1998) discussed several important issues, such as how many

people have openly discussed their AD with their PCP, and how to best educate the public, physicians, and nurses. Still another issue is whether patients or proxies really want their ADs to be followed in a crisis. Furthermore, it is unclear what needs to be documented in an AD to ensure adequate pain control and comfort (Haynor, 1998).

Johns (1996) further cited examples of limitations for current research pertaining to ADs. She stated that there are relatively few research articles by nurses, suggesting nurses are not heavily involved in this type of research. She also pointed out that ethnic issues are not adequately addressed in the literature. Finally, the number of studies regarding effectiveness of ADs is relatively small and results are often contradictory (Johns, 1996). This gives APNs the opportunity for future research on this important health care topic.

#### Social Factors and ADs

There are a variety of social factors that need to be considered when discussing ADs, including ethnicity, education, income, and age. One area that requires special attention is the response to AD discussions of members of minority populations (Arenson, Novielli, Chambers & Perkel, 1996). African American and Hispanic patients may be more likely to avoid signing an AD for fear it will lead to poor care and may lead them to desire more rather than less intervention. Therefore, it is necessary to emphasize that the main intent of ADs is to preserve rather than limit

patient autonomy and choices (Arenson et al., 1996).

Several authors suggest including a discussion of patients' underlying values and reasons for choosing or declining treatment options. A discussion of health care values might include asking the patient to rank in relative importance: survival at any cost, freedom from pain, ability to communicate, and burdening of family (Arenson et al., 1996).

De Palma (1996), through a retrospective chart review, assessed 1193 elders for their life support preferences (no code, basic or conditional life support, or full code) and whether they had documented preferences in an AD. Of the 1193, 385 were Caucasian, 364 were African American, 288 Asian American, and 156 were Hispanic. De Palma (1996) found that African American patients were significantly more likely to select aggressive interventions and less likely than Caucasian or Hispanic patients to have documented end of life wishes. Caucasian patients were significantly more likely than all others to have a written AD, selected "no code" more than Hispanic or African Americans, but less than Asians, who were most likely to have selected the less aggressive intervention of "no code". It also was found that Asians were less likely to designate a proxy or to have an AD than any of the other groups. Cultural characteristics that explain these differences include the importance of religion and close family ties in African American and Hispanic communities, and a belief among many Asian cultures that talking about death can bring bad luck.

These data make clear that cultural attitudes must be considered when approaching people and families about end of life decisions (De Palma, 1996).

Hanson and Rodgman (1996) analyzed a random sample from the 1986 National Mortality Followback Survey to examine the decedent's use of living wills. They found that patients who were black, poorly educated, underinsured or cognitively impaired were least likely to prepare a living will. Only 15% of adults had completed a living will at all. Only 3.7% of those with a grade school education had completed an AD compared to 22% of those with a college education. Of those surveyed 10.7% of Caucasians completed an AD compared to 2.7% of African Americans. Only 13.8% of those with private insurance compared to 6.3% of those with Medicaid had completed one. Only 7.5% of those whose family income was less the \$5,000 compared to 14.6% of those whose income was over \$25,000. The authors pointed out that another survey of primary care patients over age 65 found that, regardless of whether they had a living will, those who were black or lower educated wanted more aggressive treatment in the event of terminal illness. Reasons for this may be that patients did not know that they have the right or ability to develop an AD, or may not have trusted a written legalized form of communication (Hanson & Rodgman, 1996).

The last social factor to be considered is age, which has been found to be an important variable in who is likely to complete an AD. Fairchild (1998) found in her study that

69% of people over the age of 55 had an AD, while 27% of those less than 33 years had implemented an AD. Gamble, McDonald, and Lichstein, (1991) identified that elderly subjects lacked knowledge about ADs, lacked communication between themselves and their PCP regarding ADs, and had a preference for proxy decision making by a family member. Garwin (1998) cited a study in which 93% of those asked desired ADs. Interest was expressed equally by those who were young and healthy, and those who were older and in fair to poor health.

Fairchild (1998) discussed that little is actually known about the prevalence of ADs or about how and why people prepare them. She further points out that little is known about initiating factors, facilitating factors or personal objectives for implementing ADs. Few studies have examined whether the rate of AD use in practice can be improved through educational intervention (Lynn & Teno, 1993). It is not yet well-understood why some people choose to complete a formal directive and others do not (Lynn & Teno, 1993).

### Summary

By addressing ADs in primary care rather than the acute care setting, APNs can initiate AD discussion with all patients despite their level of health. Taking into consideration the past difficulties with AD implementation, the primary care APN is in a perfect role for education and implementation of ADs. Despite the many challenges of

current AD implementation, from the preceding review of literature it is evident that the public desires a better means of AD implementation.

#### **Project Implementation**

For the design of this project, the APN will administer a screening tool containing twelve questions regarding patients' existing knowledge of ADs. This tool will also determine, in accordance with Prochaska's Transtheoretical Model and Stages of Change (1997), where the patient falls in his or her readiness to implement an AD. In addition, the tool will determine the patient's knowledge of their current health status. In order to assure reading and content appropriateness, the tool will be reviewed by an expert panel that includes a social worker, lawyer, reading specialist and a variety of APNs. By having this tool reviewed by an expert panel, this gives a means of assessing content validity. The tool will also be assessed for face validity. Assessing face validity will give the APN insight as to how favorably this tool will be received by patients. Patients representative of the target population will be administered the tool and asked to provide feedback, including an assessment of whether any portion of the tool could be construed as negative.

Implementing the PSDA in a primary care setting will encourage discussion between patients and their APN. Subsequently, the APN will have a greater understanding of patient preferences than is obtained by merely completing a

standard living will. If APNs can facilitate this type of proactive discussion, disagreements between families and healthcare providers may be reduced. Research has shown that patient education is a key element in initiating ADs and is a focus of the PSDA. However, many patients are reticent to initiate discussions of ADs preferring that the provider be the one to do this (Johns, 1996).

#### Design

The screening tool will be administered as part of a primary care visit. This may be a health promotion visit, or part of an intake assessment for new patients. For the target population, discussion is more likely to take place during an acute care visit, as this is when these patients usually present for primary care. In an effort to help prevent any embarrassment for those patients who are illiterate, all patients will sign in, be given a clipboard with the tool, and asked to fill out what they can. They will be told in advance that if they have any problems completing the tool, the Medical Assistant will provide any help needed. Most of the patients within the identified target group will likely require direct questioning to adequately complete the tool. After the tool is completed, although it is outside the scope of this project, it would be reviewed and discussed with the APN. Before giving a patient the screening tool, they would be asked if they currently have an AD or a living will. If the answer is "yes", this screening tool would not be administered.

In the design of this tool, it was kept in mind that primary care visits are very limited in terms of time, especially in managed care settings where most Medicaid recipients are seen. Primary care visits have been documented to last an average of 16.5 minutes, with a standard deviation of 5.7 minutes, and included discussion of a median of 3 patient concerns, with a range of 1-12 concerns (Levinson, Roter, Mullooly, Dull, & Frankel, 1997). With these time constraints in mind, the screening tool was developed to keep questions short and readily responded to by patients.

The questions in the screening tool (see Appendix B) are developed based on the interpretation of need from the literature review. Questions are designed to elicit a simple "yes/no" or "true/false" for most of the questions. The questions in this tool are designed to assist the APN in determining which stage of change a patient is in. For example, questions 1 and 2 determine the patient's existing knowledge of ADs. This enables the APN to determine if the patient falls into the precontemplation stage of change, or into another stage. Although it is not within the scope of this project, if the patient has existing knowledge, the APN would further assess the level of that knowledge through a detailed discussion to determine which stage of change the patient is in. If the patient has no existing knowledge, the patient will be considered to be in the precontemplation



stage, and interventions would be directed accordingly (see Figure 2).

The wording in questions 1 and 2 was chosen to determine patients' existing knowledge based on Fairchild's (1998) determination that only 3 out of 80 people know what an AD is. Questions 3-7 are included to give the APN an idea of the accuracy of information that the patient has regarding ADs and treatment options. Questions 8 and 9 give the APN a means of determining if patients are interested in maintaining control of their care during a health crisis. Question 10 gives the APN an opportunity to assess factors that may hinder the patient from wanting to develop a written AD. Question 11 is used to determine the patient's understanding of their current health status. Finally, question 12 is used to enable the APN to determine whether or not the patient is interested in discussing their rights and options. Altogether, these questions allow the APN to determine whether or not to use interventions focused toward increasing the patients knowledge on the issue of advance planning.

Family members, friends or significant others will be encouraged to take part in the discussion unless the patient wishes otherwise. After discussing a patient's wishes on this issue, it will be determined which phase of Prochaska's Transtheoretical Model and Stages of Change the patient falls under. Decisional support and guidance for the actual AD development, or refusal of development will be given to

all patients. Although beyond the scope of this project, nursing interventions would be focused on helping the patient move through the stages of change if it is determined they are interested in developing an AD. Reassessment of patients' end-of-life choices will be done periodically.

#### Implications for APNs

After completing an extensive review of literature on the subject of ADs it is apparent that there are many implications for APN clinical practice. Through their comprehensive and holistic health care emphasis, APNs are in a position well-suited for meeting the challenges of AD implementation. As educators, APNs must pay attention to understanding the perceptions of particular treatments and options given to the patients, from the viewpoint of the patient, involving patients in collaborative decision making. When discussing the subject of ADs, the APN must remember that the attitudes of health care providers are a very important signal to patients, as patients make their own decisions.

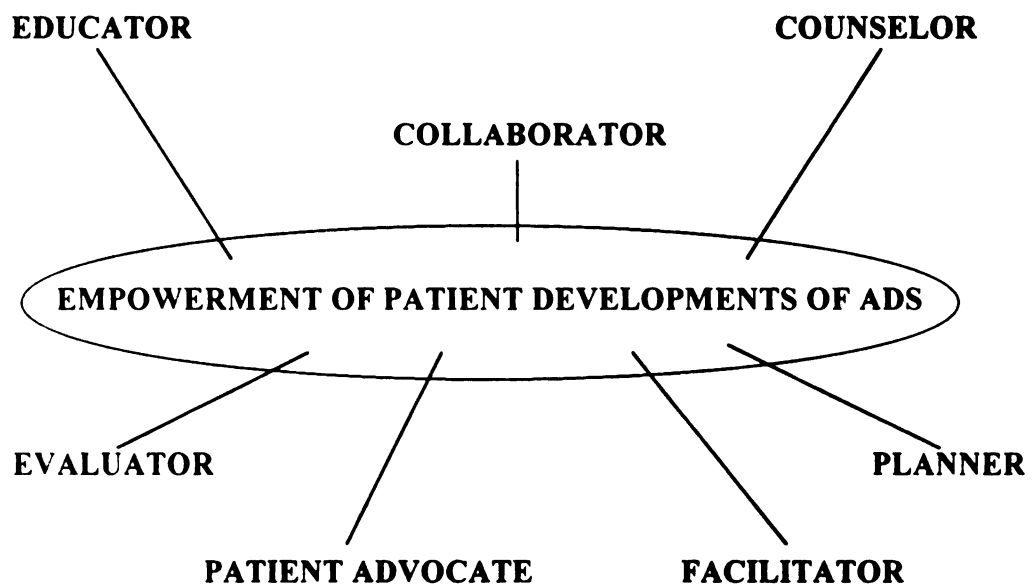
It is best to present information and treatment options honestly, not to deny hope but not to give false hope, and to always remember that the patients have placed their trust in that provider (Kelly-Powell, 1997). APNs can facilitate this process by aiding the patient in clarifying and identifying unrealistic goals, alternatives, and potential

outcomes. APNs must also teach and reinforce self-help skills required for behavioral implementation.

One way APNs can be sure of helping patients best live a healthful and proactive life, including management of chronic disease or coping with unexpected life events, is through early discussion of ADs. When trying to counsel patients about decision making, the APN must remember that decisions are not simply cognitive issues. Patient decisions are grounded in feelings of faith, trust, love, support, values, and beliefs that come from individuals' lives, as well as unique life events that have occurred to those with whom patients have personal relationships.

The American Nurses Association (1992) has stated that nurses have a responsibility to ensure patients have access to the knowledge necessary to make treatment decisions. This includes giving patients a thorough understanding of ADs and the treatment options they have regarding end-of-life decisions. Figure 3 presents a variety of roles the APN can use in aiding patients in the development of ADs.

Ott and Hardie (1997) pointed out that one of the nursing roles in education of the PSDA includes having an awareness of the patient's reading skills. APNs can also encourage consumer advocacy groups to develop supportive educational materials for the PSDA at low reading levels. In addition, they can lobby legislators to require good readability for PSDA documents. Those involved with patient education can evaluate the readability of the materials



**Figure 3. Roles of APNs in Developing Patient's Advance Directives**

given to patients. Also, the use of larger size print for older adults should be considered (Ott & Hardie, 1997).

Greco et al. (1991) encouraged outpatient discussions of ADs. Educating the public about ADs is crucial. Successful public education campaigns such as smoking cessation and bicycle helmet use suggest that a long-term, multifaceted approach that includes the mass media can change behavior. Unfortunately, no funds were allocated by Congress with the PSDA for this. Idemoto, Daly, Eger, Lombardo, Matthews, Morris, and Younger (1993) stated that of all disciplines, nursing perhaps seems best suited to carrying out the PSDA's mandate to encourage advance planning.

APNs may find it difficult to discuss this emotional topic with patients. Helping patients think about their preferences regarding life sustaining treatment is a very important role for the APN. If patients communicate their preferences adequately it will enable them to play an important role in their care and increase their end of life autonomy.

Schlenk (1997) pointed out that many APNs currently practice within a primary care setting, which is ideal for discussions regarding ADs. APNs possess the opportunities and skills to discuss ADs with their patients, while keeping in mind that end of life discussions are health care decisions that require information and reflection (Schlenk, 1997). APNs can assist their patients to develop ADs

through education and patient advocacy prior to catastrophic or life-threatening illnesses (Schlenk, 1997).

In implementing this screening tool, there are a variety of barriers that the APN must remain cognizant of for the identified target group. One of these barriers is that low income people often do not use primary care services. Glick and Thompson (1997) cited Padgett and Brodsky, (1992). Padgett and Brodsky concluded that members of racial and ethnic minority groups and those of low socioeconomic status often depend on Emergency Rooms as a regular source of care. It is well documented that community based primary care centers are an appropriate means of optimizing the availability and accessibility of services that focus on the unique needs of various populations while relieving hospital Emergency Rooms of inappropriate and costly demands for care. It is this author's hope that as more accessible community based primary care centers are developed, more people from the identified target group will be reached by the goals of this project.

It is clear from the literature that the issue of ADs is here to stay. Although ADs have been a formal part of health care since 1991, the average person still does not understand how an AD can benefit them. APNs play an integral role in increasing the use of ADs. As a result of APNs caring view of patients as holistic beings, the role of the APN is best suited to meet these challenges.

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## **APPENDIX A**

## Appendix A

In the Transtheoretical Model and Stages of Change, behavioral change is conceptualized as a process involving a series of 5 steps (Prochaska, Redding, & Evers, 1997):

- 3) Pre-contemplation: The stage in which a person has no intention to take action in the foreseeable future. A person may stay in this stage because they are uninformed or underinformed about consequences of their behavior. Both uninformed and underinformed groups of people tend to avoid reading, talking or thinking about certain issues.
- 4) Contemplation: The stage in which a person intends to make a change within the next 6 months. He or she is aware of pros of making a change, but is also acutely aware of the cons.
- 5) Preparation: The stage in which a person intends to take action within the immediate future. The person has typically already taken some significant action in the past year, and often has an action plan.
- 6) Action: The stage when a person has made specific overt modifications in his/her lifestyle within the past 6 months.
- 7) Maintenance: The stage in which a person works to prevent a relapse of a previous behavior.
- 8) Termination: The stage in which a person has no temptation to return to a previous behavior and has achieved 100 percent self efficacy.

## **APPENDIX B**

## APPENDIX B

### QUESTIONS ABOUT HEALTH PLANNING

In an effort to best serve all of your health care needs we would appreciate you taking a moment to answer the following questions.

If you need assistance in filling out this questionnaire please see the Medical Assistant.

**PLEASE CIRCLE YES OR NO**

1. Do you know what an **ADVANCE DIRECTIVE** is?

Yes      No

2. Do you know what a **LIVING WILL** is?

Yes      No

**PLEASE CIRCLE TRUE OR FALSE**

1. Health decisions can be made before  
you are too ill to speak for yourself.

True      False

2. It is very important to be kept alive no  
matter what has to be done or how great  
the pain.

True      False

3. Family burden is not an issue if you are  
unable to care for yourself.

True      False

4. It is ok to allow health care providers  
and family members to make medical  
decisions for you if you are not able  
to make those decisions.

True      False

5. If you want to make sure that your wishes  
are followed, you must pay a lawyer to  
prepare the document.

True      False

**PLEASE CIRCLE YES OR NO**

1. Would you like to know more about what you can do to keep control of your healthcare if you cannot speak for yourself?  
Yes No
2. In a life or death situation, would you like to have a form to make sure your wishes are followed  
Yes No
3. What concerns you most about having a written document expressing your wishes regarding your healthcare?

**PLEASE CIRCLE THE LETTER OF ANY THE CONCERNS YOU MAY HAVE**

- A. Fear it is against my religion to do this.
- B. Fear I will receive poor care.
- C. Fear I won't be cared for at all or will receive inadequate care.
- D. Fear I will be unable to change my mind once I have a written document.
- E. Fear family friends or my physician will not follow my wishes anyway.

**PLEASE CIRCLE YES OR NO**

1. Do you understand your current illness and what may happen to your health as a result of it?  
Yes No or No Health Problems
2. Would you like to discuss your healthcare rights and options with your health care provider?  
Yes No

Date Reviewed \_\_/\_\_/\_\_ Reviewed By \_\_\_\_\_



**Educational Model:** An interpretative picture based on specific theoretical presuppositions that infers teaching objectives, teacher qualities, content selection, and organizations. A basic scheme in which the system of teaching can be understood (Casagrnde et al., 1998).

**Older Women:** Persons of the female, ages 60-80, (Younkin, & Davis, 1994).

### **Conceptual Framework**

The Health Belief Model (HBM) [Rosenstock, 1966] was selected to guide this project.

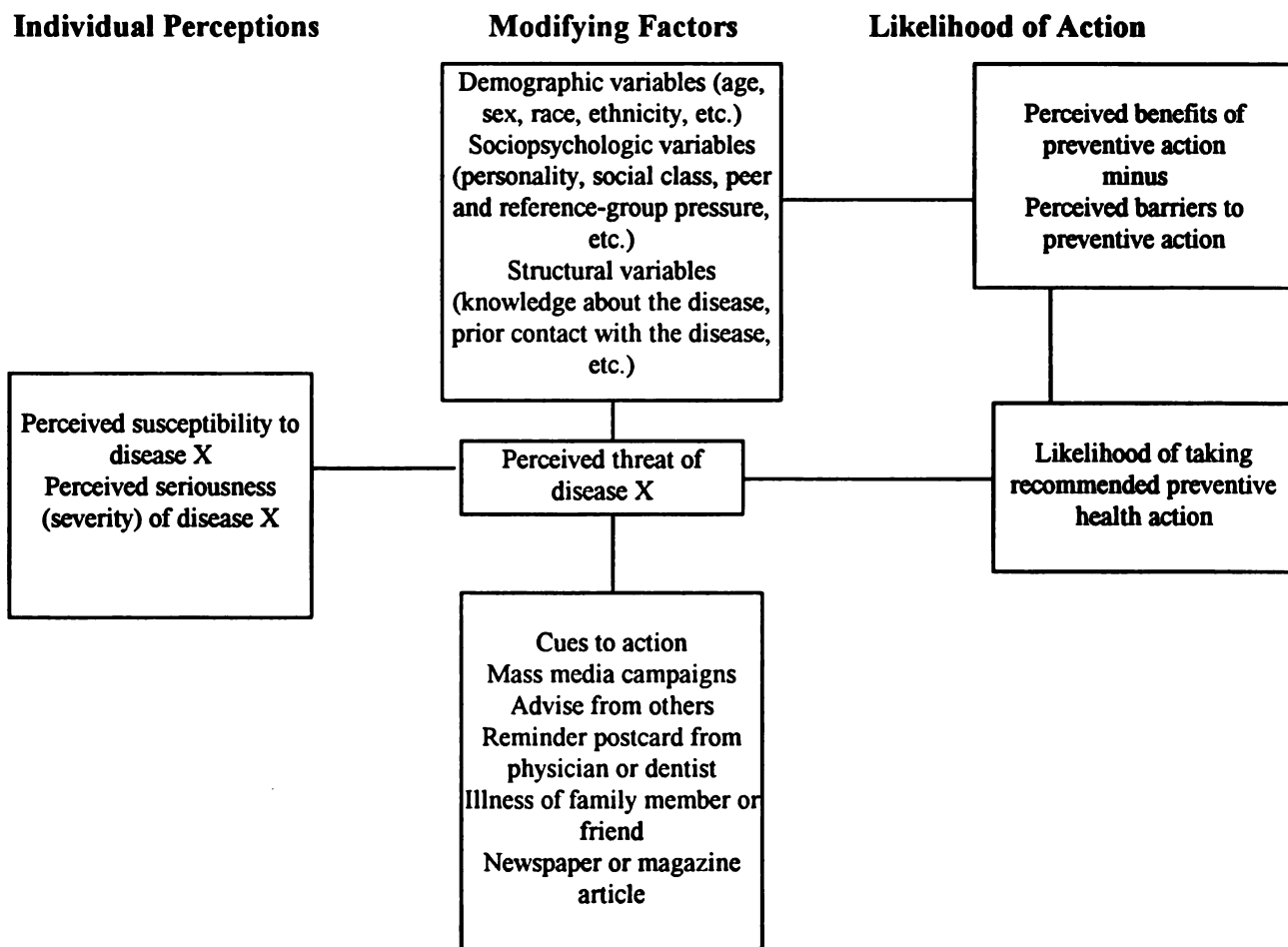


Figure 1: Health Belief Model

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