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COGNITIVELY IMPAIRED ELDERLY INDIVIDUALS
AND DURABLE POWERS OF ATTORNEY
FOR HEALTHCARE

A Thesis
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
In
Health Services Administration

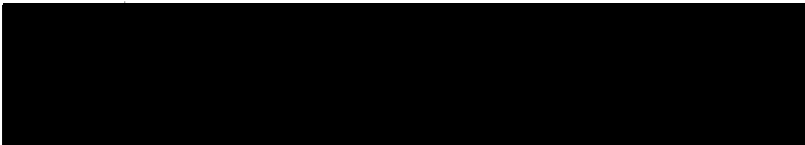
by
Nicole Rae Newman
September 1999

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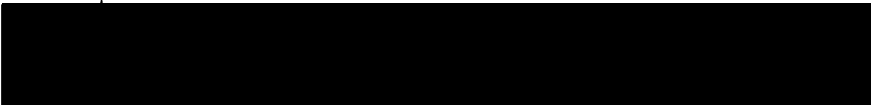
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ABSTRACT

The purpose of this thesis was to develop a profile of both cognitively impaired elderly individuals who do have a Durable Power of Attorney of Health Care (DPAHC) in place and those who do not. A Chi-Square Automatic Interaction Detection analysis was conducted on data previously obtained from five Alzheimer's Disease Diagnostic and Treatment Centers (ADDC) located in California. From this analysis, classification trees were developed which visually depicted the various significant predictors of a patient either having or not having a DPAHC in place. The results of the analysis showed that annual income and ethnicity were significant predictors of a patient either having or not having a DPAHC. Non-demographic characteristics such as health service utilization patterns, and caregiver characteristics and behaviors were also shown to be significant predictors of DPAHC implementation, or lack thereof. A limitation of the study is the barrier of generalizing the findings beyond cognitively impaired elderly individuals who reside in California, as the study's population was a convenience sample taken from the California ADDC sites.

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CHAPTER ONE: STATEMENT OF THE PROBLEM

Patient healthcare rights in the United States have attracted the attention of ethicists and health policy planners alike. One issue is increasing support for patient autonomy, which is a principle that asserts the rights of individuals to make informed decisions about their medical care (Blackhall, Murphy, Frank, Michel, & Azen, 1995). Patient autonomy includes mechanisms to maintain control of terminal treatment even after loss of decision making capabilities.

In 1990, the Supreme Court upheld the Patient Self Determination Act (PSDA) to enhance and preserve patient autonomy. The Court ruled that a written document, now known as an Advance Directive, is convincing evidence of a patient's healthcare treatment preferences (Greco, Schulman, Lavizzo-Mourey, Hansen-Flaschen, 1991). Under this law, health care facilities are obligated to: advise a patient of the right to accept or refuse treatment and complete an Advance Directive, honor a patient's Advance Directive, have policy and procedure regarding the Patient Self Determination Act in place, and train staff and educate the public about Advance Directives (Kirmse, 1998).

An Advance Directive is a legal document that is concerned with the choices that are to be made in the event

that a patient loses decision making capabilities. Decisions about future care are made while the patient possesses the mental capacity to decide, and these decisions can then be implemented at a later date when the patient no longer has this capacity. Advance Directives enhance patient autonomy, reduce the chance that a patient will receive undesired care and increase the chance that the patient will receive desired care (Murphy, 1990).

There are two forms of Advance Directives: the Living Will and the Power of Attorney. The living will gives specific treatment directions concerning healthcare and appoints a proxy to make decisions in case of terminal illness. The Power of Attorney is a legally binding written instrument in which an individual (the principal) gives decision-making authority to another person (the attorney). The validity of this document is based on the fact that the principal must be legally competent at the time the document is executed (Demi, 1989). The Durable Power of Attorney continues to be in effect even after the principal dies or becomes incompetent. A study by Demi (1989) found these advance planning measures to be effective in ensuring that autonomous decisions of the patient are enforced if the patient becomes incompetent.

There are several positive outcomes associated with the implementation of Advance Directives. Kirmse (1998) reported that such positive results included compliance with patient preferences and encouraging patient discussions about end-of-life decisions. Increased patient-provider discussion regarding the patient's healthcare preferences benefits both the patient and the provider. The patient gains more information upon which to base his or her decisions and the provider gains a greater understanding of the patient's wishes (Gamble, McDonald, & Lichstein, 1991). In addition, LaPuma, Orentlicher, and Moss (1991) found that this type of discussion minimizes disagreements between health care providers and families.

Cost containment is another debatable positive outcome associated with the completion of Advance Directives. Two studies (Chambers, Diamond, Perkel, & Lasch, 1994; Scheiderman, Kronick, Kaplan, Anderson, & Langer, 1992) have found that patients without Advance Directives have significantly higher terminal hospital charges than those with Advance Directives. In contrast, Emanuel and Emanuel (1994) reported that none of the individual studies on end-of-life cost savings associated with Advance Directives are definitive.

The importance and significance of Advance Directives is even greater in certain populations, such as Alzheimer's Disease patients. Data obtained by Evans et al. (1989) suggests that clinically diagnosed Alzheimer's disease is a common condition and it will have an increasing public health impact with the increasing longevity of the population. More specifically, Alzheimer's Disease affects one of every three families and is the fourth leading cause of death among adults (Larson, Lo and Williams, 1986). It is estimated that by the year 2050, as many as 10 million Americans will be affected by the disease (Dukoff and Sunderland, 1997). Alzheimer's targets the cognitive abilities such as memory, judgment, comprehension, and reasoning. As a result, individuals are affected cognitively, functionally, behaviorally, socially and physically. With a mentally incapacitated patient, decisions regarding the initiation, withholding, or withdrawal of life support present a dilemma.

According to Levine and Lawlor(1991), patients with Alzheimer's Disease are deemed incompetent when they are judged to be "impaired to the extent that they lack sufficient understanding or capacity to make or communicate responsible decisions." Unfortunately, decisions regarding life-sustaining medical care are often times made after

patients have lost the capacity to make such decisions for themselves due to acute illness or progressive dementia (Meier et al., 1996). After such mental incapacity occurs, the options for decision making are more limited (Steinburg, Fitten, and Kachuck, 1986). The cognitive and physical decline seen in many Alzheimer's patients force family members to make difficult decisions concerning life sustaining treatment (High, 1988). It is important, therefore, for Alzheimer's and otherwise cognitively impaired patients to provide advance knowledge regarding their medical treatment desires through the establishment of legal actions such as the Durable Power of Attorney. The Durable Power of Attorney also allows for research participation for subjects with Alzheimer's disease at all stages. The key point, however, is that the Durable Power of Attorney should be assigned in the early-to-moderate stages of the disease, before the subjects lose the capacity to make informed decisions (Dukoff and Sunderland, 1997).

Despite the obvious need and purpose behind the implementation of Advance Directives, the use of Living Wills and Durable Powers of Attorney is still rather limited (Goldstein et al., 1990; Gamble et al., 1991). There does, however, seem to be an accepting attitude toward the idea of Advance Directives among many elderly patients. Shmerling,

Bedell, Lilienfeld, and Delbanco (1988) found that elderly outpatients wish to participate in Advance Directive discussions with their physician while they are healthy, and Smucker et al. (1993) reported that elderly patients responded favorably to provider initiated discussions regarding Advance Directives.

Unfortunately, an accepting attitude does not appear to be a large enough incentive for individuals to physically implement Advance Directives. Lo, McCleod, and Saika (1986), found that more than 70% of elderly said they would refuse intensive care, cardiopulmonary resuscitation and feeding tubes if they were mentally incapacitated with no chance of recovery, yet only 6% had discussed life-sustaining treatment with their physician. While patients and physicians generally agree on the value of Advance Directives as the most effective way to preserve patient autonomy, completion rates for any form of Advance Directive remains low (Robinson, DeHaven and Koch, 1993). In fact, studies estimate that only 5-20% of Americans have formal Advance Directives in place (Kirmse, 1998; Reilly et al., 1994). Furthermore, rates of Advance Directive completion among the elderly appear to be little to no higher than those for the overall population (High 1993; Finucane, Shumway, Powers, & D'Allesandri, 1988; Zweibel and Cassel,

1989). Thus, one must assume that other factors, or barriers, are affecting the implementation of Advance Directives.

Several potential barriers to Advance Directive completion have been identified in previous studies. These include: lack of patient knowledge about Advance Directives (Roe, Goldstein, Massey, & Pascoe, 1992), lack of provider knowledge about Advance Directives (Goldstein, Valone, & Pascoe, 1991; Dubler, 1991), unwillingness to initiate end-of-life discussions (Kohn and Menon, 1988; Murphy, 1990), and demographic characteristics such as race (High, 1992; Eleazer et al., 1996; Caralis, Davis, Wright, & Marcial, 1993; and Blackhall et al., 1995), education (Blackhall et al., 1995, Duffield and Podzamsky, 1996; and High, 1988) and age (Duffield and Podzamsky, 1996; and Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). These and other yet-to-be defined barriers to completion need to be realized and fully understood by members of the health care field.

Due to the increase in diversity seen in U.S. sociodemographics, the increasing elderly population (Zweibel and Cassel, 1989), and the increasing litigation associated with healthcare, it is essential that healthcare workers and administrators understand the basis behind the differences in completion rates of Advance Directive among

particular individuals and the influence of culture and society on these differences. Knowing more about who uses Advance Directives may help explain their limited use. By gaining this knowledge, healthcare professionals can begin to make the changes and interventions necessary to decrease the differentials seen in completion rates, and increase the overall number of individuals who implement Advance Directives. It is vital that we answer the question: What are the differences in sociodemographic characteristics between individuals who complete legal actions and those who do not?

CHAPTER TWO: REVIEW OF THE LITERATURE

Past research has identified several factors that influence a person's health care wishes and decisions regarding Advance Directive completion. The first is lack of knowledge. A study by Goldstein et al. (1991) examined health care professionals' knowledge, attitudes, and encouragement for use of the Durable Power of Attorney for Health Care. They surveyed 215 physicians, nurses and social workers at a Veterans Affairs Medical Center. The results demonstrated that all of the respondents had favorable attitudes toward patient autonomy and the use of Advance Directives. On a scale from 0 to 9 (9=greatest autonomy), the average score for all professions was a 5.96 (Std. Dev.=1.6). However, the results also showed that 36% of the physicians and nurses had never heard of the Durable Power of Attorney for Health Care, and an additional 20% had no experience with the document. In addition, of those who had heard of the directive, the mean knowledge score about the directive was 6.35 (Std. Dev.=1.9) out of a possible 10 (5 predicted by chance). These results demonstrate that even though health care providers had a positive attitude regarding Advance Directives, they had limited knowledge and exposure to them.

Furthermore, a study by Roe et al. (1992) was conducted to determine how, when and why the Durable Power of Attorney for health care is used. They surveyed 59 senior citizen participants from the same San Francisco Bay area suburb. Seventy-six percent of the participants were women, and only four were nonwhite in ethnic origin. In addition, the group had a high education level, with only four having less than a high school diploma and 46 having attended college. Volunteers for the survey were recruited through announcements made in the dining rooms and classrooms, and through flyers posted at the centers. The results found that 38 of the 59 subjects did not have a Durable Power of Attorney for health care in place and the most commonly cited reasons for this nonuse were: lack of awareness of the form and difficulty choosing a proxy. In addition, the researchers found that 29% of senior center participants did not understand the basic mechanism of a proxy appointment.

Another study by Morrison, Morrison, and Glickman (1994), attempted to determine the relative impact of five proposed barriers to physician usage of Advance Directives. The researchers sent questionnaires concerning physician attitudes about Advance Directives, their usage, and potential barriers to the discussion of Advance Directives with their patients, to 460 internal medicine residents and

attending physicians at a large New York City teaching hospital. There was a 60% response rate. Multivariate regression was used in the statistical analyses of the data obtained. The results found that physician lack of understanding, as well as their erroneous beliefs about the appropriateness of discussions, were significant barriers to Advance Directive discussions and completion. In addition, physician's lack of knowledge, time constraints, and lack of comfort significantly affected physician initiated discussions.

There is also a general unwillingness of both the patient and the physician to initiate the discussions regarding end-of-life decisions. A 1988 study by Kohn and Menon examined factors that influence elderly patients' and health care providers' decisions regarding life-prolongation. The researchers collected data via an "intensive interview" process.

This process included a guided conversation whose goal was to elicit from the interviewee rich, detailed material that could be qualitatively analyzed. The research subjects were comprised of two groups. The first group consisted of 26 elderly ambulatory outpatients. The second group consisted of 23 professionals, including physicians, nurses, a technician and a behavioral scientist, who were

responsible for providing care to the participants of Group One. The data was analyzed through content analysis. The results of this analysis found that both groups agreed that prior communication was necessary when making decisions regarding life prolongation. Most respondents also felt that physicians should be responsible for initiating such discussions. However, the researchers found that while participants from both groups had discussed their wishes and concerns about life prolongation with family members, none had done so with their physicians. In addition, the physician or health care provider who wished to avoid crisis situations also was reluctant to bring the issue up because they feared that it would unnecessarily alarm or compromise the defense mechanisms of the patient.

Furthermore, Murphy (1990) suggested in his review article on Advance Directives that lack of reimbursement for the time spent discussing Advance Directives was a disincentive for physicians initiating end-of-life discussions. Discussing various scenarios with patients and family members and their choices regarding which actions to be taken in the event of such scenarios, can be very time consuming. As a result, physicians may be reluctant to devote time and energy to this service if they know that they will not be reimbursed for it.

Other studies have identified demographic factors to be related to an individual's health care wishes and Advance Directive completion. Such characteristics included: race/ethnicity, gender, education, age, religion, and income.

First, in a study by Sugarman et al. (1992), the researchers explored the concerns of 70 randomly selected ambulatory veterans regarding living wills. The participants were interviewed for ten minutes regarding health care utilization, religion, health status, knowledge of Advance Directives and intent to sign or not to sign a Living Will. The results of the statistical analyses found that only 4% of the subjects had a Living Will, 33% intended to sign a Living Will, 54% were undecided about whether to sign, and 9% did not want a Living Will. Those who intended on signing a Living Will were significantly more likely to be white, to self report lower health status, to know someone with a Living Will and to have previously discussed the topic. In addition, undecided participants were significantly more likely than those who intended on signing a Living Will to report that religious beliefs affected their decision. No significant differences were seen between the groups in terms of age, or education. One important limitation to this study is the small size of its sample,

which could have prevented other differentiating factors from being seen.

In another study conducted by High (1993), the effects of various education interventions and demographic characteristics on Advance Directive completion were examined. This study was conducted in Lexington-Fayette County, Kentucky, which was identified as one of the five places in the U.S. closest to the overall American demographics as measured by the 1990 census. A total of 431 participants were recruited from eight different senior congregate houses, a volunteer research pool at the Sanders-Brown Center on Aging, and two geriatric outpatient clinics. A telephone interview follow-up was conducted four months after the completion of the educational intervention. The results of the study found both education and race to be related to familiarity and use of Advance Directives. More specifically, the results showed that only 70% of those participants with less than twelve years of education were familiar with Living Wills compared with 90% of those with a high school education or more. Likewise, familiarity with appointment of a health care proxy was 23% compared with 42%. Completion rates of Advance Directives were also significantly higher for those who had a high school education or more. Twenty one percent of those with less

than a high school education had completed a Living Will, compared with 34% of those with a high school education or more. In addition, health care proxy completion rates were 7% for those with less than a high school education and 16% for those with a high school education or more.

Significant differences were also seen in familiarity and use between races. Familiarity with the Living Will was 85% for whites and only 62% for blacks. Also, for designation of a health care proxy familiarity was 40% and 17% respectively. Finally the results found that 35% of whites had completed Living Wills, while only 2% of blacks had done the same.

Next, a study by Haas et al. (1993) examined the patient characteristics that were associated with the desire to discuss life-sustaining care. This was accomplished by conducting a structured patient interview with 289 persons with AIDS at various settings including: a HMO, an internal medicine group practice and an AIDS clinic. The results of the interviews were analyzed using univariate odds ratios, and stepwise logistic regression. The results of the analyses showed that non-white patients were significantly less likely to have discussed preferences for life-sustaining care than white patients. The same was found to be true for those of lower pre-illness income.

Caralis et al. (1993) furthered this research by conducting a study that examined the influence of race and ethnicity on the knowledge, and attitudes of patients concerning advance directives and life-prolonging therapy. The study subjects consisted of 139 patients who were scheduled for the general medicine continuity clinic at the University of Miami Medical School. These patients were interviewed in their standard language using a standardized instrument. Demographic questions as well as questions about health data and experiences with advance directives were asked. The validity of the survey instrument was tested via pilot test and retest with a trial group. The chi-square method was used to compare the frequencies of responses among African American, Hispanic and non-Hispanic white respondents.

The results found that a significantly larger number of African Americans (63%) and Hispanics (62%) than non-Hispanic whites (39%) wanted to have discussions with their physicians regarding life-prolonging treatment ($p=.03$). In addition, African Americans were more likely to feel they would be treated differently and cared for less if they had a living will in place ($p=.004$). Finally, more African Americans (37%) and Hispanics (42%) compared to non-Hispanic whites (14%) wanted their physicians to keep them alive regardless

of how ill they were, while more non-Hispanic whites (89%) agreed to stop life-prolonging treatment under some circumstances compared to African Americans (63%) and Hispanics (59%) ($p < .01$).

Garrett et al. (1993) conducted a study to identify patient characteristics associated with the desire for life-sustaining treatments in the event of terminal illness. The researchers interviewed 2,536 patients aged 65 and older who were continuing care patients of internal medicine and family practice offices enrolled in Medicare. Statistical analyses included multivariate analysis and fitting logistic regression models. The subsequent results found that patient race and education were significantly associated with treatment preferences. More specifically, Black patients were almost three times as likely as White patients to want more treatment, and Whites were almost two-and-a-half times as likely as Blacks to want less treatment. Those patients with greater than 12 years of education were twice as likely to desire less treatment as those with one to eight years of education. In addition, patients who desired more treatment rated religion as very important in their lives. The results of the multivariate analysis found that female gender was independently associated with wanting less treatment.

Another study, by Blackhall et al. (1995), examined the relationship between attitudes toward patient autonomy and demographic factors, including age, religion, level of education and income. They surveyed 200 subjects aged 65 years and older who identified themselves as being from one of four ethnic groups: European American, African American, Korean American, or Mexican American. This sample was taken from thirty-one senior citizen centers within Los Angeles County, California. The researchers included an equal number of men and women within each group and maintained similar distribution across all four groups using a stratified quota technique. Data was analyzed using analysis of variance or χ^2 procedures, and logistic regression analyses.

The logistic regression analyses demonstrated differences in attitudes toward patient autonomy among ethnic groups. Compared to European Americans, Korean Americans and Mexican Americans were significantly less likely to favor telling the truth about diagnosis and prognosis and less likely to choose the patient as primary decision maker. In addition, the oldest subjects were significantly less likely to believe that the patient should be told the truth about a terminal prognosis than were the youngest subjects.

Furthermore, within-group analyses found socioeconomic status to be related to attitudes about patient autonomy in only the Korean American and Mexican American groups. Mexican Americans with at least seven years of education were significantly more likely to believe that the patient should be told the diagnosis or prognosis. The same was true for Mexican Americans who had annual incomes of at least \$10,000. Korean Americans with at least seven years of education were more likely to believe that the patient should make decisions about the use of life support. This within-group analyses also showed that among European Americans, Protestants were significantly more likely than non-Protestants to believe that the patient should be told about a terminal prognosis. The same was found to be true for Jewish subjects and Buddhists.

Cugliari, Miller, and Sobal(1995) also conducted a study to explore the factors the might influence the use of Advance Directives, including demographic variables. They interviewed 419 randomly selected patients who were admitted for a planned admission to two tertiary care, teaching hospitals. Statistical analyses of the data included bivariate comparisons, and multivariate logistic regression analyses. The results of the multivariate analysis found two demographic factors to be weak significant predictors of

proxy completion. Married patients and those with children were significantly more likely to complete a proxy ($p < .03$ and $p < .04$).

The next study by Duffield and Podzamsky (1996) identified individual characteristics of patients who complete Advance Directives compared with those who do not. The subjects included 195 patients ranging in age from 21 to 88, who visited a private family practice office in a rural Illinois community during a 1 month period. Patients with a developmental delay or dementia were not asked to participate. The participants completed a consent form and questionnaire while waiting in the exam room for their provider. The T-TEST and chi-square statistical tests were used to compare the characteristics of subjects who returned a completed Advance Directive with those subjects who did not.

The results found that the only statistically significant differences between the two groups were age, length of time in the practice, and level of education. Older patients who had been patients longer and had not graduated from high school were more likely to return Advance Directives. In addition, those patients who were married, single, separated or divorced were more likely to

return the completed Advance Directive than those who were widowed.

It should be noted that the results of this study concerning level of education conflict with the results of the prior studies. These unexpected results could be due to the fact that the study was conducted in a rural, private primary care office, where patients had close rapport with their providers. This rapport could mean that the less educated patients trusted their providers and assumed that completing the Advance Directive was an appropriate and necessary action.

Another study, conducted by Eleazer et al. (1996), assessed the relationship between ethnicity and health care wishes among frail older persons enrolled in PACE, the Program For All Inclusive Care Of The Elderly. These researchers defined the term "health care wishes" to include Living Wills, Durable Powers of Attorney and verbally expressed wishes about end-of-life decisions. The purpose behind using PACE participants was that a close relationship developed between participants and caregivers, which created an environment more conducive to addressing the sensitive issue of end-of-life decisions. A retrospective chart review was conducted on 1193 participants, of whom 385 were

non-Hispanic Whites, 364 were Black, 156 were Hispanic, and 288 were Asian.

After controlling for confounding variables such as age, education, and marital status, the results of the study found there to be significant ethnic effects in the recording of health care wishes and in the use of a Durable Power of Attorney and health care proxies. Asians were 6.48 times more likely than Whites and Blacks and nearly 50 times more likely than Hispanics to have documented their health care wishes. Whites were five times more likely than Hispanics, ten times more likely than Blacks, and twenty-eight more times likely than Asians to have a Durable Power of Attorney in place. In addition, patients with living children were nearly twice as likely to have a Durable Power of Attorney than those without children.

Finally, Morrison et al. (1998) examined barriers to completion of health care proxies for different ethnic groups. Participants in the study included 197 patients aged 65 and older who identified themselves as African American, Hispanic, or non-Hispanic white, and attended a geriatric and internal medicine outpatient clinic of a large New York City teaching hospital. These subjects were administered a questionnaire that was developed via focus groups who examined the understanding of Advance Directives,

their reasons for non-completion, and their understanding of how decisions are made when patients lose decisional capacity. Statistical analyses included: analyses of variance, x^2 and multiple logistic regression analyses. The results found that African Americans and Latinos were significantly less likely to have completed a health care proxy. In addition, positive predictors of health care proxy completion included: knowledge of health care proxies, availability of a proxy, older age, and health status perceived as fair to poor.

In contrast to the aforementioned research, the results of one study found no evidence of demographic factors correlating to the completion of Advance Directives. A study by Mansfield, Droge, and Billig(1991) examined factors correlated with the decision to execute a Durable Power of Attorney for Health Care (DPAHC). The researchers interviewed 97 patients in a 500 bed university hospital who were over 65 years of age, admitted to the internal medicine department, and judged to be able to participate in the study by their unit's charge nurse. Informed consent was obtained from the subjects and they received brief verbal information about the DPAHC. They were then given a questionnaire, and mental status and depression levels were measured through reliable tests. Content analysis was

applied to the reasons given for wanting or not wanting a DPAHC.

The results found that execution of a DPAHC was significantly associated with higher levels of cognitive functioning. On the other hand, the results also found that occupation, age, birthplace, race, marital status, having children, education, religious affiliation, number of medical diagnosis and depression were not significantly associated with having or wanting a DPAHC. It is possible the small sample size used in this study did not allow for the detection of such associations with sociodemographic factors as seen in the prior research.

Until now, most of the research that has examined the factors associated with the completion of advance directives has focused solely on the demographic characteristics of individuals, such as race, economic status and education. On the other hand, the sociodemographic characteristics of individuals, such as living arrangement, current relationship, residence, and payment mechanism, have been virtually ignored. In fact, Cugliari et al. called for further research to explore the role of race, ethnicity and other demographic factors on influencing attitudes toward and completion of advance directives. In addition, to this date, researchers interested in the completion of advance

directives have looked at a limited number of specialized populations, such as the elderly. Unfortunately, there has also been a lack of research in this area with regard to particularly high-need populations, such as Alzheimer's Disease patients and other cognitively impaired individuals.

Statement of Purpose

The purpose of this study is to identify the sociodemographic characteristics associated with Alzheimer's Disease and other cognitively impaired patients who complete Durable Powers of Attorney of Health Care, as opposed to those who do not complete Durable Powers of Attorney of Health Care. This research will make a distinctive contribution, as it will examine a greater number of sociodemographic characteristics within a specific high-need population.

CHAPTER THREE: METHODOLOGY

Description of the Data

The data used in this study was previously obtained from the five Alzheimer's Disease Diagnostic Treatment Centers (ADDTC) located in California. These centers were established by the California State Department of Health Services, and the University of California San Francisco Institute for Health and Aging. The ADDTC's data set includes baseline, follow-up, and autopsy data on Alzheimer's disease and related disorders patients in the state of California. Patients were either referred to the various sites or sought treatment on their own merit. The data collection instruments were multidisciplinary in content and were used to gather information on the aspects of ADDTC program operations. (See Measurement Instrument, Appendix A)

In addition, the data provided insight into the facets of the lives of Alzheimer's disease and related disorders patients.

The questions used in the data collection fall into three categories. (1) **Rigorous research questions**, which are well known standardized tests that require consistency in how the questions are asked, interpreted, and scored. Examples of this type of question include the Blessed

Orientation Concentration Test, and the Mini-Mental Status Exam; (2) **Judgments about clinical problems and needs**, which reflect the judgments of the multidisciplinary team based on clinical data gathered during the patient's diagnostic work-up; and (3) **Basic descriptive data**, which constitute the major content of the data set. A large emphasis is placed on this type of question because the State of California Department of Health Services is required, by the legislation that established the ADDTC sites, to provide an annual report regarding the operations of the program and characteristics of the patients seen.

Areas of data collection include: procedural data, referral/intake data, patient demographic data, caregiver data, diagnostic information, care plan/action plan information, and autopsy information.

The dependent variable used in this study is the implementation of a Durable power of Attorney for Health Care (DPAHC). Establishing a DPAHC indicates that as a direct response to the patient's presenting illness, a patient's friend, spouse or other relative obtained the power to make decisions regarding the patient's medical treatment only when the patient becomes incompetent.

The independent variables used in this study were named and operationally defined as follows:

- Reason for referral: indicates the reasons for the patient's referral to the ADDTC as stated by the patient and/or informant.
- Primary source of referral: indicates the source for the patient's referral to the ADDTC as stated by the patient and/or the informant. This source is defined as the person who suggested that a dementia work-up be done.
- Patient's date of birth: indicates the patient's date of birth, which was obtained from the patient's medical record or a reliable source. If two sources provided conflicting information, then a third source was sought to corroborate one of the other sources. Possible alternative sources include Medical cards, driver's licenses, or passports.
- Ethnicity: indicates the patient's ethnicity/race, which in most cases was obtained from the patient's medical record. If the information was not available from the patient's medical record, then the patient was asked directly which ethnic group he or she considered him or herself to belong to.
- Current Marital Status: indicates the patient's current marital status as reported by the patient or the informant.

- Living Arrangement: indicates with whom the patient lives at his or her principle residence, as indicated by the patient or informant. The different values for this variable include: living alone, living in a household with spouse only, living in a household with spouse equivalent only, living in a household with spouse and others, living in a household with spouse equivalent and others, living in household with relatives, living in a household with non-relative(s) only, living in a health-related facility, living in group quarters other than a health-related facility, and other. The **Living alone** value is not applicable if the patient resides in a health-related or non-health related facility. The **Living in Household with Relatives** value applies if the patient lives in a household with one or more relatives, but not with a spouse or spouse equivalent.
- Nature of Current Residence: indicates the kind of place in which the patient lives, as reported by the patient or informant. The values for this variable include: house/condominium/apartment/mobile home, rented room (hotel/house), senior residential facility, nursing facility, other, and not determined. The **Senior Residential Facility** value

is used when the patient lives in a residence solely designed for elderly persons. This category of residence offers a less protected environment than a residential care facility, but is more protected than an apartment or hotel with mixed occupancy.

Senior Residential Facilities are characterized by recreational programs, congregate meals, and/or housekeeping, but are not licensed as residential care facilities. **Residential Care Facilities** are licensed by the State of California, and **Nursing Facilities** includes intermediate care or skilled nursing facilities licensed by the State of California.

- **Education:** indicates the number of school years completed by the patient, as reported by the patient or informant. This number includes primary grades, secondary grades, trade school, business school, and all college attended, even if no degree was received. GED was coded as 12 years, an AA degree as 14 years, a BA as 16 years, an MA as 18 years, and a doctorate as 20 years. Credit was given for trade school up to a maximum of 14 school years completed.
- **Primary Occupation:** indicates the occupation that the informant or patient considers to be the

patient's primary occupation throughout life. (See Occupation Codes, Appendix D)

- Income: indicates the combined income of the patient and their spouse or spouse equivalent, as reported by the patient or informant. This includes all sources of income, such as pensions, salaries, and dividends.
- SSI: indicates whether or not the patient receives Supplemental Security Income, as reported by the patient or informant. This variable helps in the indication of the patient's economic status, and was only answered with **Yes** if the patient was receiving SSI at the time of the interview.
- Health Care Coverage: indicates all health care payment mechanisms that the patient had at the time of the interview, regardless of whether any of them were to be used to pay for the ADDTC services, or if the patient pays a share of the cost. These payment mechanisms include: Medicare Part A, Medicare Part B, Medical, Employer Insurance Plan, Health Maintenance Organization, Veterans Administration, Retirement Health Plan, Medigap Supplemental Insurance, other and none. The **Employer Insurance Plan** option applies even if the patient has retired but is still covered by the employer's medical

insurance plan. The **Retirement Health Plan** option applies if the patient has any type of private insurance plan that is derived from his or her previous employer's retirement benefits package, or if the patient is covered by his or her spouse's retirement benefits package.

- Patient Drives: indicates if the patient is currently operating a motor vehicle on a fairly regular basis (several times a week) as reported by the patient or informant. It does not refer to the patient's capability of driving.
- Patient's Primary Caregiver: indicates the primary informal source of patient assistance for Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs) as reported by the patient or informant. ADLs include the following types of tasks: transportation out of walking distance, walking, stair climbing, wheelchair assistance, transfers in and out of bed/chair, grooming, bathing, dressing, eating, using the toilet, and dealing with bowel/bladder accidents. IADLs include the following types of tasks: meal preparation, shopping, routine housework, managing money, laundry, medications, telephone, heavy chores, and home maintenance. Formal caregivers such as paid

attendants or staff at a nursing home are not included in this variable.

- Secondary Caregiver: indicates who, if anyone, informally assists the primary caregiver in caring for the patient, as reported by the patient or informant.
- Prior Service Utilization: indicates each service that the patient and/or the primary caregiver has received in the twelve months prior to ADDTC contact. These services include:
 - Counseling, which involves individual or group counseling to identify psychological problems such as, assessment of social and emotional factors related to health status, assistance in coping with disease processes, supportive counseling in regard to diagnosis, prognosis, and limitations imposed by the illness, or counseling for similar problems. The counseling may have been provided by psychologists, psychiatrists, LCSW or other appropriate providers.
 - Family/Marital Counseling Education, which addresses difficulties engendered by the patient's problems, such as, assessment of social and emotional factors related to health status, assistance in coping with disease processes,

supportive counseling in regard to diagnosis, prognosis, and limitations imposed by the illness, or counseling for similar problems. The counseling may have been provided by psychologists, psychiatrists, LCSW or other appropriate providers. This form of counseling only applies if family members are included in the counseling of the patient.

- Community Support Group includes services provided by a community support group, such as the Alzheimer's Association.
- Outpatient Psychotropic Medication Management, which includes the services provided by a psychiatrist, neurologist, or other medical specialists.
- Substance Abuse Treatment includes treatment utilized for alcohol and/or drug abuse problems.
- Primary Care or Other Physician Services includes the services of the individual's primary care physician or those of a specialist in solo or group practice.
- Case Management Services include individualized assessments of patients and planning to coordinate community based services.

- Transportation Services include taxi, van or escort services because of certain inability to use other modes of transportation. Emergency uses are excluded.
- Congregate Meals are defined as nutritional meals served in a centrally located social setting.
- Home Delivered Meals are defined as nutritional meals that were brought to the patients home on a regular basis.
- Home Health Services include:
 - Skilled nursing services aimed at treatment, prevention, health protection, promotion, or early detection of problems.
 - Personal care services such as assistance with hygiene, self-care, ambulation and transfers, nutritional and dietary needs, and the maintenance of a safe and sanitary environment.
 - Physical therapy services such as skilled evaluation and treatment of functioning in areas such as range of motion, strengthening, endurance, muscle tone, pain, balance, transfers, and mobility to increase level of function in daily activities.

- Occupational therapy services such as evaluation and instruction in communication, language, voice intelligibility, comprehension, and cognitive rehabilitation.
- Homemaker/chore Services include assistance with IADLs and general home maintenance.
- Adult Day Care includes services that provide unlicensed recreational and activity programs which are more organized and structured than senior center programs.
- Adult Day Health Care includes services that are licensed by the State of California. These services provide recreational and activity programs which are more organized and structured than senior center programs.
- Alzheimer Day Care Resource Centers (ADCRCs) include day care services specifically targeted to meet the needs of cognitively impaired patients and their families.
- Caregiver Resource Centers (CRCs) include family consultations and planning for the care of the patient, family support groups, legal and financial consultations, respite care, and training.

- Other Respite Care includes services other than social/adult day health care or ADCRC services.
- Financial Assistance may be related to cash or in-kind benefits such as Supplemental Security Income (SSI) or food stamps, or service benefits such as Medi-Cal In-Home Supportive Services (IHSS).
- Nursing Home (SNF, ICF) services are characterized by residential care in a group arrangement with 24 hour nursing coverage.
- Residential Care (RCF) services include a group arrangement that provides such services as supervision, meals and homemaking but does not provide specialized medical or nursing services.
- In-patient Hospital Services include those for treatment of acute medical or psychiatric care needs.
- Adult Protective Services which include those services used to address identified problems, such as patient or caregiver neglect or physical and psychological abuse.
- Other Services include any other supportive services not covered in any of the aforementioned service categories.
- Disease Progression: indicates the qualitative type of progression of functional impairment since

dementia-related symptoms were first noted. This information comes from both interviews and medical records, and is rated according to the interviewers judgment, instead of the patient's or caregiver's report. The **Gradual Decline** value is chosen if the patient displays a relatively continuous rate of decline. This choice does not rule out the possibility of other forms of progression. The **Stepwise Decline** value is chosen if the patient displays a course in which there have been two or more discrete drop-offs in functioning without a return to baseline. The **Episodes of Transient Decline** value is chosen if there have been one or more discrete periods lasting at least a day in which cognitive decline with return to baseline occurs due to delirium or other medical or psychiatric problems. The **Stable/Improved** value is chosen when functional capacities have not changed or have improved since the onset of dementia-related symptoms.

The scale of each of these variables was nominal, except for Income which was ordinal and Education which was interval.

Description of Population

A breakdown of the sociodemographic characteristics of the population is provided in Table 1. Of the 4,459 participants in this study, 65% were female, and the ethnic breakdown was as follows: 72% White, 11% Hispanic, 8% African American, 6% Asian, and 3% other, which included American Indian, Alaskan Native, Pacific Islander and Filipino.

The average age was 74.7 years with a standard deviation of 12.4 years.

The average number of years of education was 12 (standard deviation 4.2 years), which included primary grades, secondary grades, trade school, business school and all college.

The average combined income of the participants and their spouse/spouse equivalent was \$15,000-\$19,999 per year. This income included pensions, salaries, and dividends.

The marital states of the participants at the time of the interview were 45% married, 39% widowed, 11% divorced and 4% never married.

The vast majority of the participants (87%) resided in a house, condominium, apartment, or mobile home, while only a small proportion resided in a senior residential facility, residential care facility, or nursing facility (5%, 5%, and 2% respectively).

The living arrangements of the participants were quite varied. Approximately 35% lived in a house with their spouse only, 23% lived in a house with their relatives, and 21% lived alone. The remainder lived in non-health related group quarters, a house with their spouse and others, a house with non-relatives only, or in a health related facility.

The participants' primary occupations were also quite varied: 19% worked in clerical/sales, as technicians or owned little businesses, 17% were machine operators or semi-skilled employees, 17% were business managers, medium proprietors, or lesser professionals, 16% were homemakers and 13% were administrative personnel, small independent business owners, or minor professionals. The remaining 18% were higher executives, large proprietors, major professionals, skilled manual labor, or unskilled employees. A more specific description of the occupation classifications is provided in Appendix A.

The majority of the participants were referred to the ADDTC site by a physician, other health or social service personnel (including social workers, psychologists, nurses, and physician assistants) or by their family (27%, 24%, and 19% respectively). The remaining 30% were referred by a friend, themselves, a community support group, or were unable to identify their source of referral.

Most of the participants were covered by Medicare Part A and Medicare Part B (83% and 78% respectively), while 22% had Medical coverage, and 22% had Medigap Supplemental coverage. Of all forms of health care coverage, 5.5% was HMO coverage, and 4.5% was retirement plan coverage.

The reasons why most participants were referred to the ADDTC site were memory/cognition problems, suspected Alzheimer's Disease, and behavioral change problems (80%, 61%, and 35% respectively). In addition, 84% of the participants' dementia had progressed in a gradual fashion.

Participants were also asked about their utilization of various health services. A large majority of the participants (94%) received primary care or other physician services, while 60% received other services, 18% received homemaker chore services, and 16% received outpatient psychotropic medication management.

Finally, 2,164 of the 4,459 participants had legal actions in place in response to their presenting illnesses at the time of the interview. Of these individuals, 30% had DPAHC, 30% had a general power of attorney, and 22% had estate planning in place. The remaining 18% had representative payees established, Conservatorships in place, or had taken other legal actions.

TABLE 1: POPULATION DESCRIPTION

| | | | |
|-----------------------------------|----------------------------|---|-----|
| <u>Gender</u> | | <u>Primary Occupations</u> | |
| Male | 35% | Clerical/Sales, | 19% |
| Female | 65% | Technicians, Owned Little Businesses | |
| <u>Ethnicity</u> | | <u>Primary Occupations</u> | |
| White | 72% | Machine Operators, | 17% |
| Hispanic | 11% | Semi-Skilled Employees, | |
| African American | 8% | Business Managers, | |
| Asian | 6% | Medium Proprietors, | |
| Other* | 3% | Lesser Professionals | |
| <u>Years of Education+</u> | | <u>Primary Occupations</u> | |
| Average | 12 | Homemakers | 16% |
| Standard Deviation | 4.2 | Administrative Personnel, Small Independent Business, Owners, | 13% |
| <u>Age</u> | | <u>Primary Occupations</u> | |
| Average | 74.7 yrs. | Ore Minor Professionals | |
| Standard Deviation | 12.4 yrs. | Higher Executives, Large Proprietors, Major Professionals, Skilled Manual Labor, Unskilled Employees | 18% |
| <u>Combined Income ++</u> | | <u>Utilization of Various Health Services</u> | |
| Average | \$15,000 - \$19,999/yr. | Primary Care or other Physician Services | 94% |
| <u>Marital State</u> | | <u>Utilization of Various Health Services</u> | |
| Married | 45% | Other Services | 60% |
| Widowed | 39% | Homemaker Chore Services | 18% |
| Divorced | 11% | Outpatient Psych. | 16% |
| Never Married | 4% | Med. Mgmt. | |

Nature of Current Residence

House/condo/apartment/mobile home 87%

Senior residential Facility 5%

Residential Care Facility 5%

Nursing Facility 2%

Living Arrangement

Live in house with spouse only 35%

Live in house with relatives 32%

Live Alone 21%

Other** 21%

Primary Source of Referral

Physician 27%

Other Health or Social Service Personnel 24%

Family 19%

Other*** 30%

Health Care Coverage

Medicare A 83%

Medicare B 78%

Medigap 22%

Reason For Referral

Memory/Cognition Problems 80%

Suspected Alzheimer's Disease 61%

Behavioral Change Problems 35%

* Am. Indian, Alaskan Native, Pacific Islander, and Filipino

+ includes primary & secondary grades, trade school, business school & all college

** includes live-in non-health related group quarters, a house with non-relatives only, or a health related facility

++ combined income of participants and spouse/spouse equiv.

*** referred by a friend, themselves, community support group, or patient was unable to identify primary source of referral

Research Method

Analysis of the data was done using Chi-Square Automatic Interaction Detection (CHAID) software from SPSS. Like multivariate statistics, CHAID identifies statistically significant predictors (at a 95% confidence interval) of an important criterion variable. More specifically, CHAID performs segmentation modeling, which divides a given population into statistically significant groups of predictors based on a given criterion. Once a split occurs, the subgroups that are formed are split even further based on other significant predictor variables. This splitting continues until there are no more statistically significant variables.

CHAID goes beyond other forms of analysis in that it automatically discovers complex interaction effects among predictors. For example, it may detect that income has a different effect on the criterion variable in one age group than it does in another age group. The ultimate goal of CHAID is to find the combination of variables that does the best job of predicting whatever it is you want to predict.

CHAID also provides a classification tree, which visually depicts how the independent variables are associated with the dependent variable. The objectives of the classification tree are to (1) accommodate all of the influences and interactions among the variables, (2)

establish priorities for them, (3) accept non-linear influences, (4) focus on a dependent variable, and (5) end up with homogeneous segments. Each segment in the tree diagram is mutually exclusive and the tree as a whole is exhaustive in its listing of segments.

In this study, the dependent variable that is being predicted is dichotomous; therefore, the CHAID analysis results show what proportion of each population segment consists of cases in the desired category or the dependent variable.

CHAPTER FOUR: FINDINGS

The results of the CHIAD analysis are visually depicted in the classification tree in Appendix B. In addition, portions of this classification tree are presented throughout the text of this section to offer clarification regarding the findings of this study.

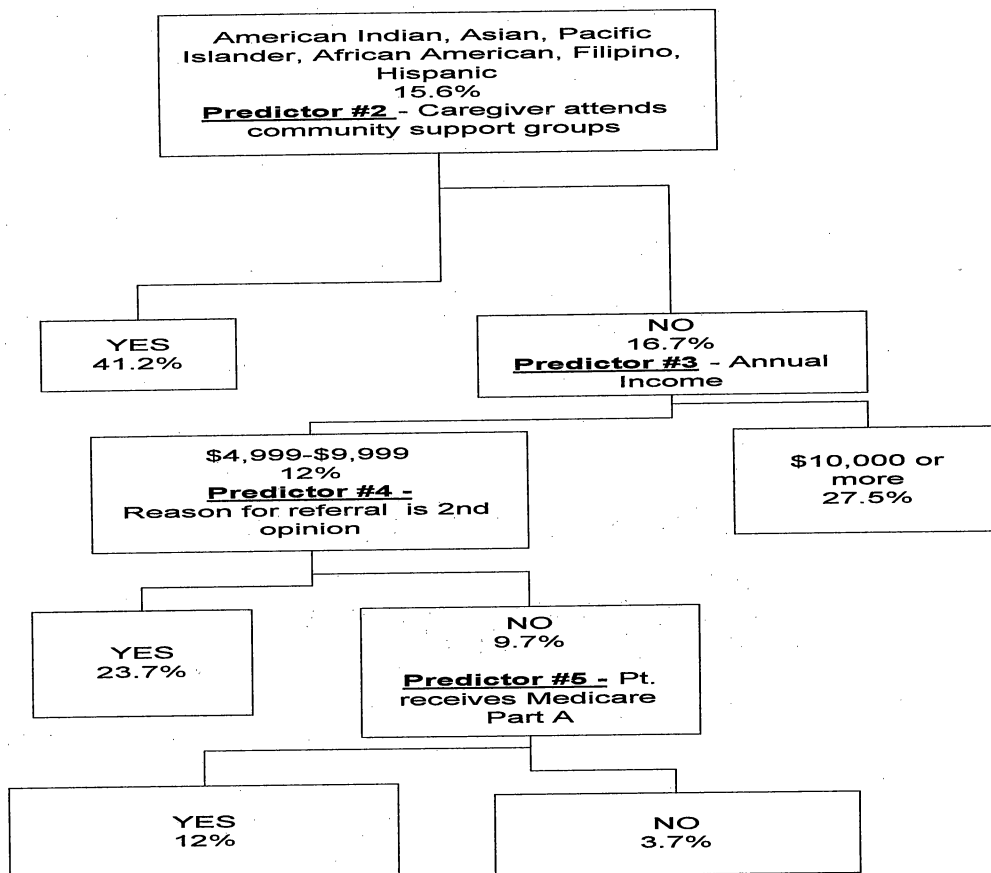
Patients Who Did Have a DPAHC

Strongest Predictor: Ethnicity

The findings showed that the strongest predictor for a patient having a DPAHC in place was ethnicity. Fifteen and half percent of the patients of an African American, American Indian, Alaskan Native, Pacific Islander, Filipino, or Hispanic, descent had a DPAHC in place, while 43% of the patients who classified themselves as White or of another ethnicity not previously mentioned had a DPAHC in place.

The second strongest predictor within the minority ethnicity group was whether the patient's primary caregiver attended community support groups (See Figure One). Forty-one percent of the minority patients whose primary caregivers **did** attend community support groups had a DPAHC in place, while 16% of the minority patients whose primary caregivers **did not** attend community support groups had a DPAHC in place.

Figure One: Minority ethnic groups



This was the final predictor within the group of patients whose caregiver *did* attend community support groups.

The third strongest predictor within the group of minority patients whose primary caregivers did not attend community support groups was income (See Figure One). Twelve percent of those with a combined income of less than

\$9,999 had a DPAHC in place, while 27.5% of those with a combined income of \$10,000 or more had a DPAHC in place.

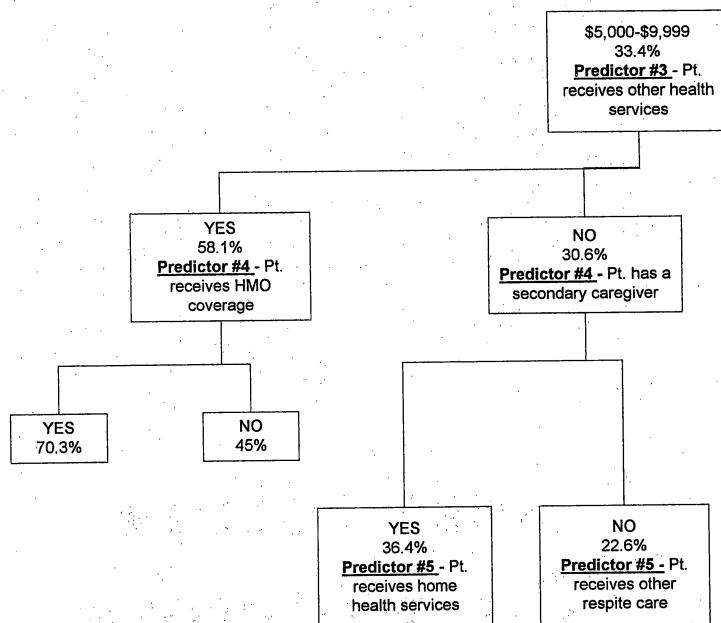
Income was the final predictor within the group of minority patients whose primary caregiver **did not** attend community support groups and whose combined income was \$10,000 or more.

Within the group of patients who classified themselves as White, the second strongest predictor of having a DPAHC in place was income. Eighteen percent of the patients with a combined income of under \$4,999, 33% of those with a combined income of \$5,000 - 9,999, 47% of those with a combined income of \$10,000 - 24,999, and 56% of those patients with a combined income of \$25,000 and greater had a DPAHC.

Income was the final predictor within this group of patients whose combined income was under \$4,999.

The third strongest predictor within the group of patients with a combined income of \$5,000 - 9,999 was whether the patient received other health services (See Figure Two). Fifty-eight percent of those who **did receive** other health services had a DPAHC, while 30.6% of the patients in this group who **did not receive** other health services had a DPAHC.

Figure Two: White ethnic group with an income between \$5,000-9,999



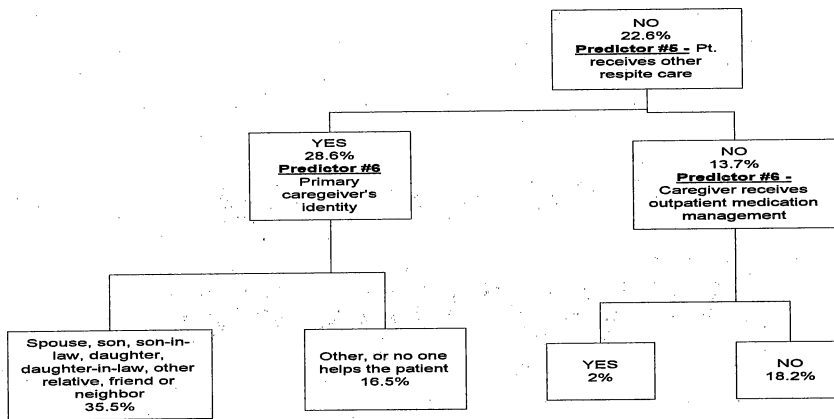
The fourth strongest predictor of whether a patient will have a DPAHC within the group of patients that **did receive** other health services was whether or not they had HMO health coverage (See Figure Two). Seventy percent of those who **did have** HMO coverage had a DPAHC, while 45% of those who **did not have** HMO coverage had a DPAHC.

HMO coverage was the final predictor within the group of patients who **did receive** other health services.

The fourth strongest predictor in the group that **did not** receive other health services was whether the patient

had a secondary caregiver (See Figure Two). Twenty-two percent of the patients who **did not** have a secondary caregiver had a DPAHC, while 36% of those patients who **did** have a secondary caregiver had a DPAHC.

Figure Three: White ethnic group with an income between \$5,000-9,999 who do not receive other health services and have no secondary caregiver



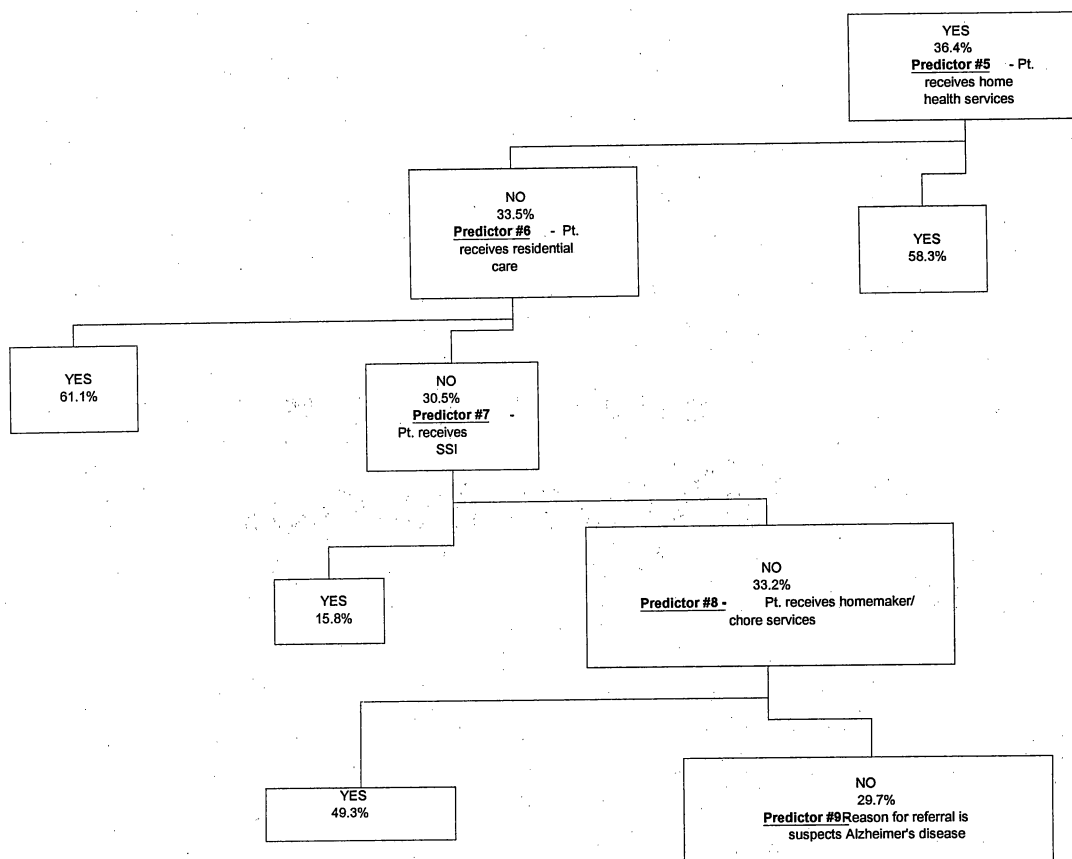
The fifth strongest predictor in the group of patients who did not have a secondary caregiver was whether or not the patient received other respite care (See Figure Three). Twenty-eight percent of those patients who did not have a secondary caregiver, but **did** receive other respite care had a DPAHC, while 13.7% of those patients who did not have a

secondary caregiver and **did not** receive other respite care had a DPAHC.

The sixth and final predictor in the group of patients who did receive other respite care was the relationship of the primary caregiver to the patient (See Figure Three). Thirty-five percent of the patients whose primary caregiver was one of the following: spouse, son, son-in-law, daughter, daughter-in-law, other relative, friend, or neighbor, had a DPAHC. Sixteen percent of the patients who had a primary caregiver that was related to them in another way or was not related at all had a DPAHC.

The sixth and final predictor in the group of patients who did not receive other respite services was whether the caregiver received outpatient psychotropic medication management (See Figure Three). Two percent of the patients that **did** receive these outpatient services had a DPAHC, while 18% of the patients that **did not** receive these outpatient services had a DPAHC.

Figure Four: White ethnic group with an income between \$5,000-9,999 who do not receive other health services and do have a secondary caregiver



The fifth strongest predictor in the group of patients who **did have** a secondary caregiver was whether the patient received home health care services (See Figure Four). Fifty-eight percent of those patients that **did** receive home health services had a DPAHC, while 33% of those patients in

this group that **did not** receive home health services had a DPAHC.

This was the final predictor within the group of patients who **did** receive home health services.

The sixth strongest predictor in the group of patients who **did not** receive home health services was whether the patient received residential care (See Figure Four). Sixty-one percent of the patients who did receive residential care had a DPAHC, while 30% of the patients who did not receive residential care had a DPAHC.

This was the final predictor within the group of patients who **did** receive residential care.

The seventh strongest predictor of whether the patient had a DPAHC in place in the group of patients who **did not** receive residential care was whether they received Supplementary Security Income (See Figure Four). Sixteen percent of the patients who **did** receive SSI had DPAHC, while 33% of those that **did not** receive SSI had a DPAHC.

This was the final predictor among the group of patients who **did** receive SSI.

The eighth strongest predictor in the group of patients who **did not** receive SSI was whether the patient received homemaker/chore services (See Figure Four). Forty-nine percent of the patients who **did** receive homemaker/chore

services had a DPAHC, while 30% of the patients who **did not** receive homemaker/chore services had a DPAHC.

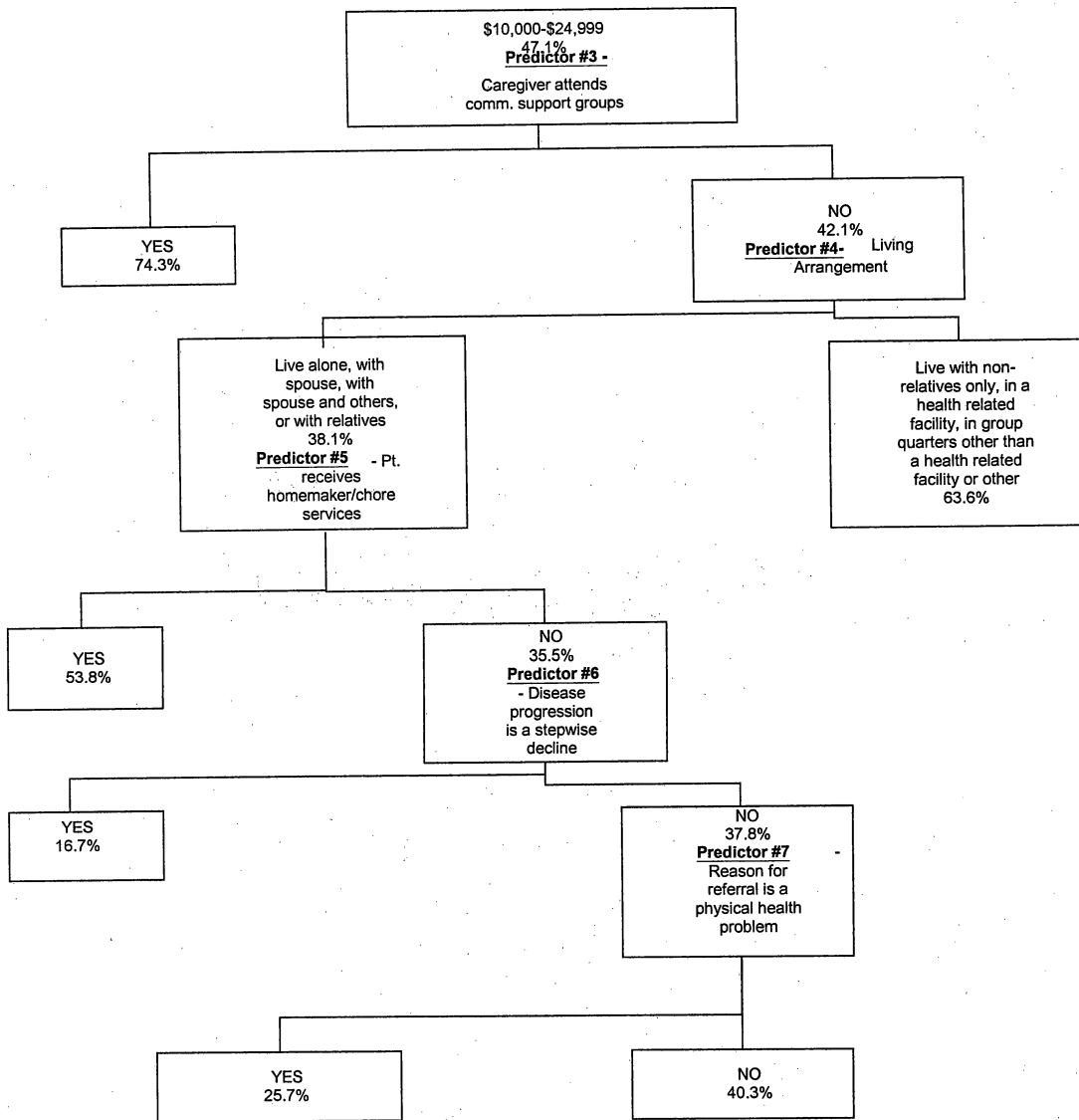
This was the strongest predictor among those patients who **did** receive homemaker/chore services.

The ninth and final predictor in the group of patients who **did not** receive homemaker/chore services was whether the patient was referred to the ADDTC site because it was suspected that they suffered from Alzheimer's Disease or other dementia (See Figure Four). Thirty-five percent of the patients who were referred because of the suspected Alzheimer's disease had a DPAHC, while 19% of those that were not referred due to suspected Alzheimer's disease had a DPAHC.

The third strongest predictor of having a DPAHC within the group of patients who classified themselves as White, and who had a combined income of \$10,000 - 24,999, was whether the caregiver attended community support groups (See Figure Five). Seventy-four percent of the patients whose caregivers **did** attend community support groups had a DPAHC, while 42% of those patients whose primary caregivers **did not** attend community support groups had DPAHC.

This was the final predictor among the group of patients whose primary caregiver **did** attend community support groups.

Figure Five: White ethnic group with an income between \$10,000-24,999



The fourth strongest predictor in the group of patients whose caregivers **did not** attend community support groups was

the living arrangement of the patient (See Figure Five). Thirty-eight percent of the patients who either lived alone, lived in a household with their spouse only, lived in a household with their spouse and others, or lived in a household with relatives, had a DPAHC. Sixty-three percent of the patients who had some other living arrangement other than those previously mentioned had a DPAHC.

This was the final predictor in the group of patients who had a living arrangement other than living alone, with a spouse, with a spouse and others, or with relatives.

The fifth strongest predictor in the group of patients who lived alone, with their spouse only, with their spouse and others, or with relatives, was whether the patient received homemaker/chore services (See Figure Five). Fifty-three percent of the patients who **did** receive homemaker/chore services had a DPAHC, while 35% of those that **did not** receive these services had a DPAHC.

This was the final predictor in the group of patients who **did** receive homemaker/chore services.

The sixth strongest predictor in the group of patients who **did not** receive homemaker/chore services was whether the patient's disease was progressing in a stepwise decline (See Figure Five). Seventeen percent of the patients whose disease was progressing in a stepwise fashion had a DPAHC,

while 38% of the patients in this group whose disease was not progressing in a stepwise fashion had a DPAHC.

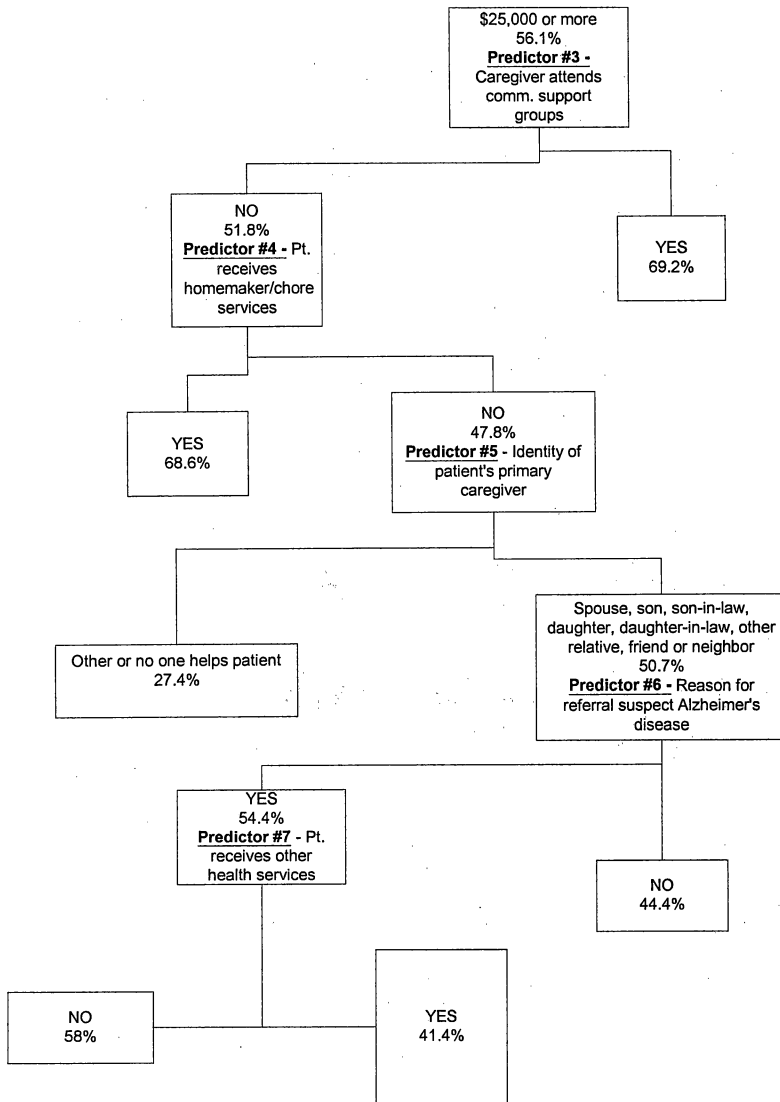
The third strongest predictor of having a DPAHC within the group of patients who classified themselves as White, and who had a combined income of \$25,000 and above was whether the patient's caregiver attended community support groups (See Figure Six). Sixty-nine percent of the patients whose caregivers **did** attend community support groups had a DPAHC, while 52% of the patients whose caregivers **did not** attend community support groups had a DPAHC.

This was the final predictor in the group of patients whose primary caregiver **did** attend community support.

The fourth strongest predictor of whether a patient would have a DPAHC in place among the group of patients whose caregivers **did not** attend community support groups was whether the patient received homemaker/chore services (See Figure Six). Sixty-nine percent of the patients who **did** receive homemaker/chore services had a DPAHC, while 48% of the patients who **did not** receive homemaker/chore services had a DPAHC.

This was the final predictor among the group of patients who **did** receive homemaker chore services.

Figure Six: White ethnic group with an income of \$25,000 or more



The fifth strongest predictor within the group of patients who **did not** receive homemaker/chore services was the relationship of the patient's primary caregiver (See Figure Six). Fifty-one percent of the patients whose primary caregiver was one of the following: spouse, son,

son-in-law, daughter, daughter-in-law, other relative, friend, or neighbor had a DPAHC. Twenty-seven percent of the patients who had a primary caregiver that was related to them in another way or was not related at all had a DPAHC.

This was the final predictor among the group of patients whose primary caregiver was not their spouse, son, son-in-law, daughter, daughter-in-law, other relative, friend or neighbor.

The sixth strongest predictor within the group of patients whose primary caregiver was their spouse, son, son-in-law, daughter, daughter-in-law, other relative, friend, or neighbor was whether they were referred to the ADDTC site because they were suspected to be suffering from Alzheimer's Disease or other dementia (See Figure Six). Fifty-four percent of the patients who **were referred** due to suspected Alzheimer's Disease had DPAHC, while 44% of the patients in this group who **were not referred** due to suspected Alzheimer's Disease had a DPAHC.

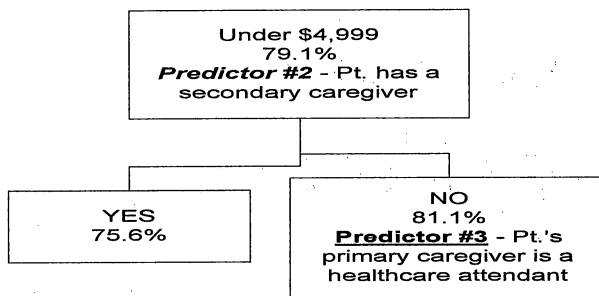
Patients Who Did Not Have a DPAHC

A CHAID analysis was also run to determine the predictors of a patient not having a DPAHC in place. The results of the CHIAD analysis are visually depicted in the classification tree in Appendix C.

Strongest predictor: Income

The strongest predictor for a patient not having a DPAHC in place was income. Seventy-nine percent of those with a combined income below \$4,999, 75% of those patients with a combined income of \$5,000-9,999, 59% of those with a combined income of \$10,000-14,999, 50% of those with a combined income of \$15,000-29,999, and 41% of those with a combined income of \$30,000 or more did not have a DPAHC.

Figure Seven: Income less than \$4,999



The second strongest predictor within the group of patients with a combined income of less than \$4,999 was whether the patient had a secondary caregiver (See Figure Seven). Seventy-six percent of the patients that **did not** have a secondary caregiver also did not have a DPAHC, while 81% of those patients who **did** have a secondary caregiver did not have a DPAHC.

This predictor was the final predictor in both patients **with** and **without** a secondary caregiver.

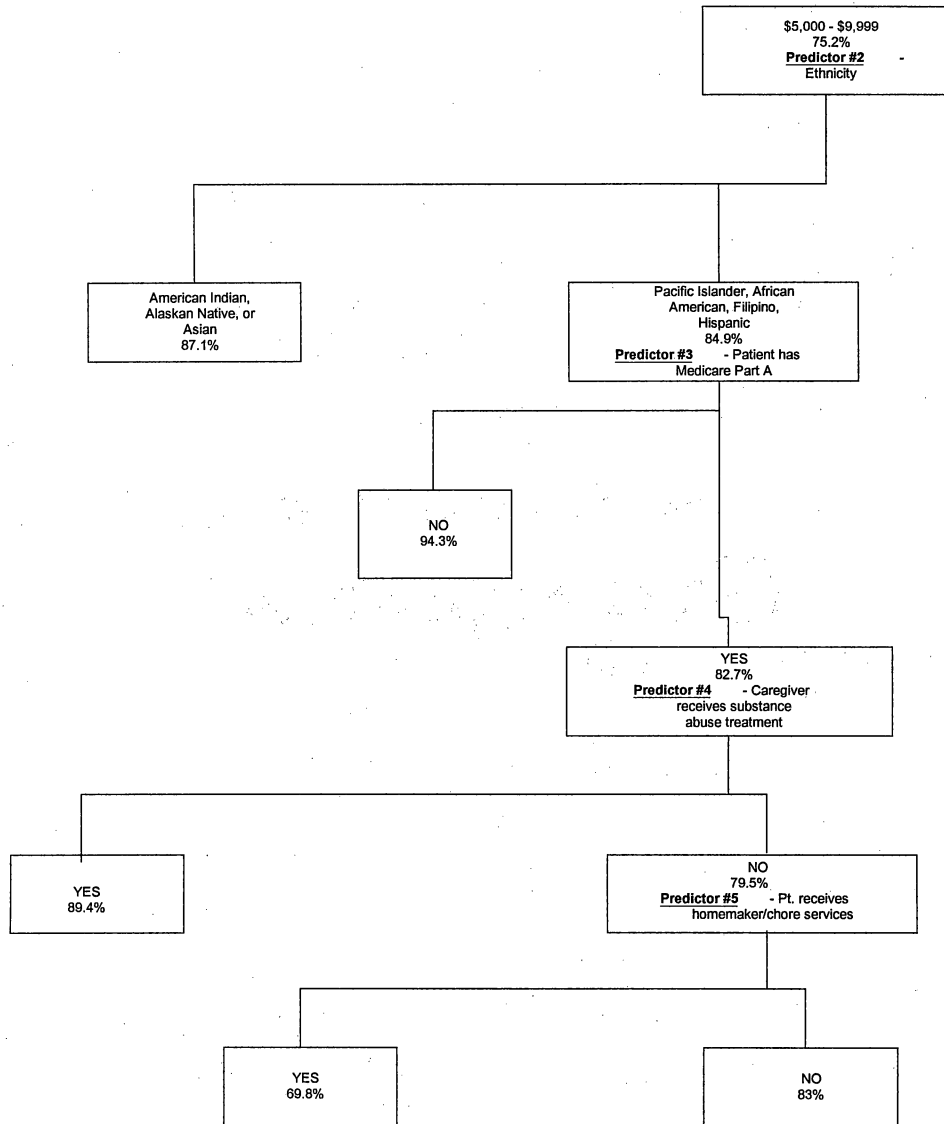
The second strongest predictor within the group of patients with a combined income of \$5,000-9,999 was ethnicity (See Figure Eight). Eighty-seven percent of the patients within this group who were of American Indian, Alaskan Native or Asian descent, 85% of those who were of Pacific Islander, African American, Filipino or Hispanic descent, and 64% of those who were White or of another ethnicity not previously mentioned, did not have DPAHC.

Ethnicity was the final predictor within the group of patients of American Indian, Alaskan Native, or Asian descent.

The third strongest predictor within the Pacific Islander, African American, Filipino or Hispanic group was whether the patient received Medicare Part A (See Figure Eight). Eighty-two percent of these patients who **did** receive Medicare Part A did not have a DPAHC, while 94% of those who **did not** receive Medicare Part A did not have a DPAHC.

Receipt of Medicare Part A was the final predictor within the group of patients who **did not** receive Medicare Part A.

Figure Eight: Income between \$5,000-\$9,999



The fourth strongest predictor for a patient not having a DPAHC in place among the Pacific Islander, African American, Filipino or Hispanic group who **did** receive

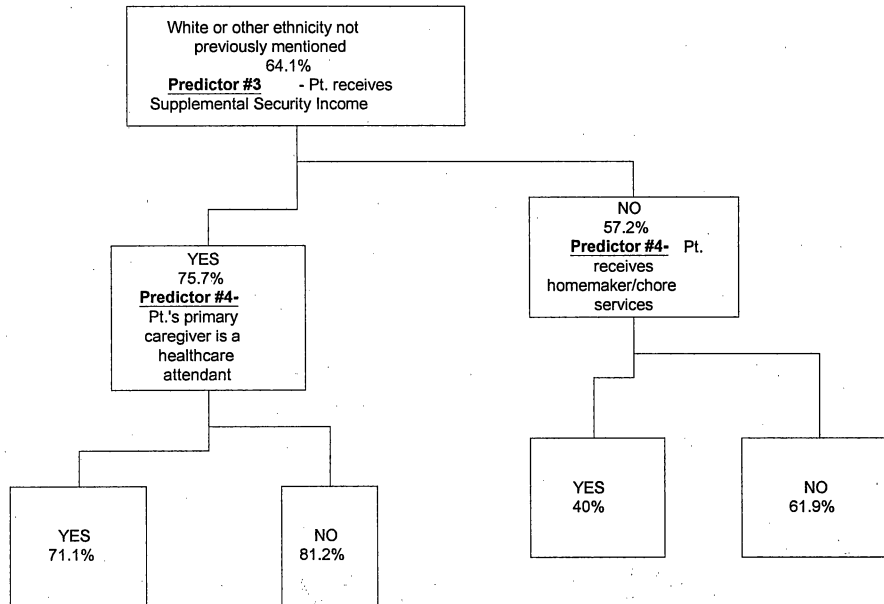
Medicare Part A was whether the patient's caregiver received substance abuse treatment (See Figure Eight). Eighty-nine percent of the patients whose caregivers **did** receive substance abuse treatment did not have DPAHC, while 80% of those whose caregivers **did not** receive substance abuse treatment did not have a DPAHC.

This was the final predictor within the group of patients whose caregiver **did** receive substance abuse treatment.

The fifth strongest predictor within the group of patients whose caregivers **did not** receive substance abuse treatment was whether the patient received homemaker/chore services (See Figure Eight). Seventy percent of these patients who **did** receive homemaker/chore services did not have a DPAHC, while 83% of the patients in this group who **did not** receive homemaker/chore services did not have a DPAHC.

The third strongest predictor within the White group of patients whose income was between \$5,000 and \$9,999, was whether the patient received Supplemental Security Income (See Figure Nine). Seventy-six percent of the patients who **did** receive SSI did not have a DPAHC, while 57% of the patients within this group who **did not** receive SSI did not have a DPAHC.

Figure Nine: Income between \$5,000-9,999 and White Ethnic Group



The fourth strongest predictor among the group of patients who did receive SSI was whether the patient's caregiver was a healthcare attendant (See Figure Nine). Seventy-one percent of the patients whose caregiver **was** a healthcare attendant did not have a DPAHC, while 81% of those whose caregiver **was not** a healthcare attendant did not have a DPAHC.

This was the final predictor among both group of patients.

The third strongest predictor within the group of patients who **did not** receive SSI was whether the patient received homemaker/chore services (See Figure Nine). Forty

percent of the patients in this group who **did** receive homemaker/chore services did not have a DPAHC, while 62% of the patients within this group who **did not** receive homemaker shore services did not have a DPAHC.

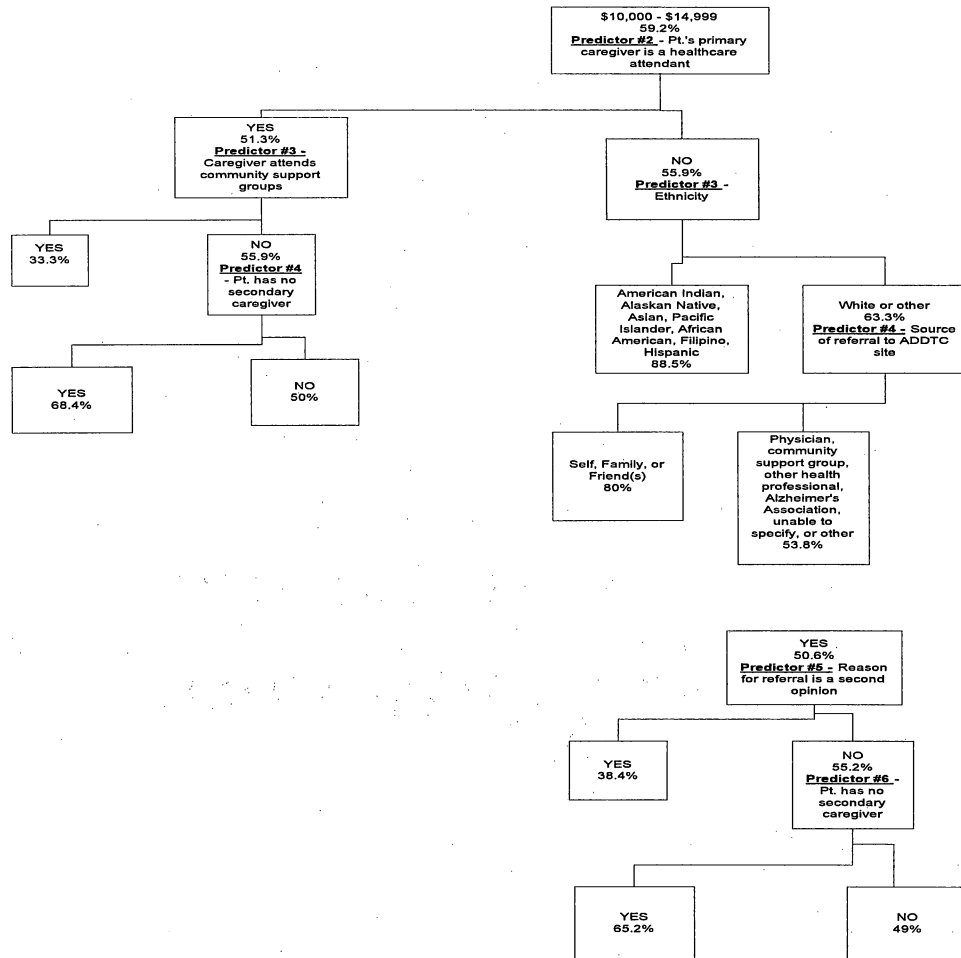
This was the final predictor among both patients who **did** and **did not** receive homemaker/chore services.

The second strongest predictor within the group of patients with a combined income of \$10,000-14,999 was whether the patient's primary caregiver was a healthcare attendant (See Figure Ten). Fifty-one percent of the patients whose primary caregiver **was** a healthcare attendants did not have a DPAHC, while 70% of the patients whose primary caregiver **was not** a healthcare attendant did not have a DPAHC.

The third strongest predictor within the group of patients whose primary caregiver **was** a healthcare attendant was whether the primary caregiver attended community support groups (See Figure Ten). Thirty-three percent of the patients whose primary caregivers **did** attend community support groups did not have a DPAHC, while 56% of the patients whose primary caregivers **did not** attend community support groups did not have a DPAHC.

This was the final predictor among the patients whose caregiver **did** attend community support groups.

Figure 10: Income between \$10,000-14,999



The fourth strongest predictor within the group of patients whose primary caregiver **did not** attend community support groups was whether the patient had a secondary caregiver (See Figure Ten). Sixty-eight percent of the patients who **did not** have a secondary caregiver also did not

have a DPAHC, while 50% of the patients who **did** have a secondary caregiver did not have a DPAHC.

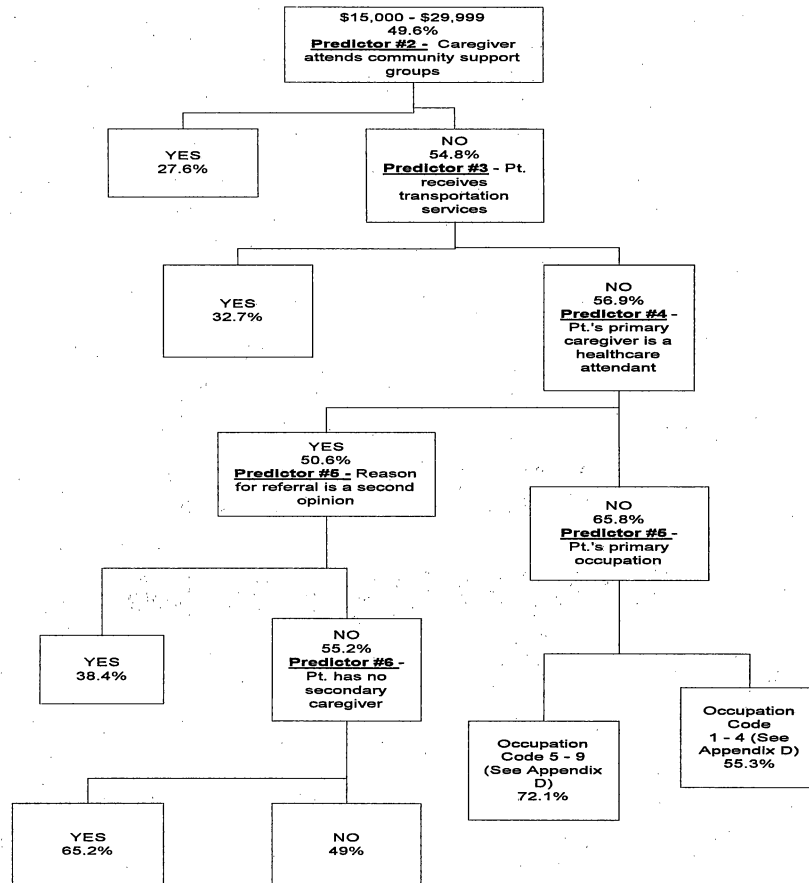
This was the final predictor among both groups of patients.

The third strongest predictor within the group of patients whose combined income was between \$10,000 and \$14,999 and whose primary caregiver was not a healthcare attendant was ethnicity (See Figure Ten). Eighty-nine percent of the patients who were of American Indian, Alaskan Native, Asian, Pacific Islander, African American, Filipino or Hispanic origin did not have a DPAHC. Seventy-eight percent of the patients who were White did not have a DPAHC.

This was the final predictor among patients who belonged to a minority ethnic group.

The fourth strongest predictor within the group of patients who were White was the source of referral (See Figure Ten). Eighty percent of the patients who were referred by themselves, family or friends did not have a DPAHC. Fifty-four percent of the patients within this group who were referred by a physician, a community support group, another health or social service professional, the Alzheimer's Association, another source of referral not mentioned here, or those who were unable to specify their source of referral did not have a DPAHC.

Figure Eleven: Income between \$15,000-\$29,999



The second strongest predictor within the group of patients with a combined income of \$15,000-29,999 was whether the patient's caregiver attended community support groups (See Figure Eleven). Twenty-eight percent of patients whose caregiver *did* attend community support groups did not have a DPAHC, while 55% of the patients in this

group whose caregivers **did not** attend community support groups also did not have a DPAHC.

This was the final predictor among patients whose primary caregiver **did** attend community support groups.

The third strongest predictor within the group of patients whose caregivers **did not** attend community support groups was whether the patient received transportation services (See Figure Eleven). Thirty-three percent of the patients who **did** receive transportation services did not have a DPAHC, while 57% of the patients who **did not** receive transportation services did not have a DPAHC.

This was the final predictor among patients who **did** receive transportation services.

The fourth strongest predictor within the group of patients who **did not** receive transportation services was whether their primary caregiver was a healthcare attendant (See Figure Eleven). Fifty-one percent of the patients whose primary caregiver **was** a healthcare attendant did not have a DPAHC, while 66% of the patients within this group whose primary caregiver **was not** a healthcare attendant did not have a DPAHC.

The fifth strongest predictor within the group of patients whose primary caregiver **was not** a healthcare attendant was the patient's primary occupation (See Figure

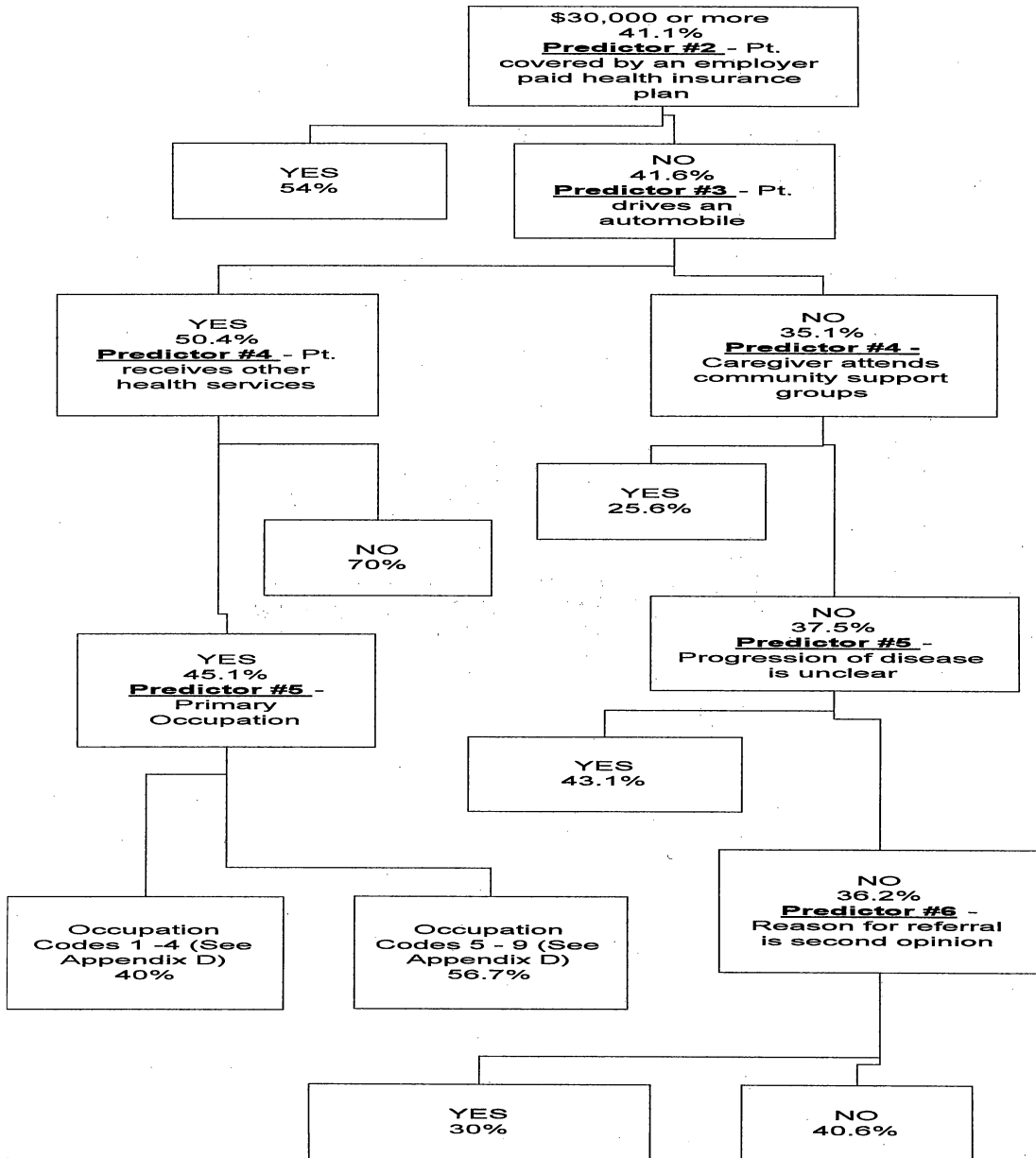
Eleven). Fifty-five percent of the patients whose primary occupations were higher executives, proprietors of large concerns, major professionals, business managers, proprietors of medium sized businesses, lesser professionals, administrative personnel, small independent businesses, minor professionals, clerical and sales workers, technicians or owners of little businesses did not have a DPAHC. Seventy-two percent of the patients whose primary occupations were skilled manual employees, machine operators, semi-skilled employees, unskilled employees, homemakers or those who did not have a primary occupation did not have a DPAHC.

This was the final predictor among this group of patients.

The second strongest predictor within the group of patients with a combined income of \$30,000 or more was whether they were covered under an employer paid insurance plan (See Figure Twelve). Fifty-four percent of the patients who **were** covered by an employer paid insurance plan did not have a DPAHC, while forty-two percent of the patients who **were not** covered by an employer paid insurance plan did not have a DPAHC.

This was the final predictor among the patients who **were** covered by an employer paid insurance plan.

Figure Twelve: Income of \$30,000 or more



The third strongest predictor within the group of patients who **were not** covered by an employer paid insurance plan was whether the patient drove a vehicle (See Figure

Twelve). Fifty percent of patients who **did** drive a vehicle did not have a DPAHC, while 35% of those who **did not** drive did not have a DPAHC.

CHAPTER FIVE: DISCUSSION

Patients With a DPAHC in Place

The strongest predictors of a patient having a DPAHC in place were being White, having an annual combined income of \$25,000 or more, and having a primary caregiver who attends community support groups. A portion of these results confirm prior studies' findings that demonstrated a correlation between ethnicity and socioeconomic status, and the implementation of Advance Directives (High, 1993; Morrison, 1998; Haas, 1993; and Blackhall; 1995).

In addition, the findings of this study go further in that they introduce the likelihood that a primary caregiver's actions, a patient's participation in and exposure to health services, and variables other than patient demographics, are also related to the implementation of a DPAHC. Variables such as: the primary caregiver attending community support groups, the patient receiving homemaker/chore services, patient living arrangement, identity of the patient's primary caregiver, the patient having a secondary caregiver, the patient receiving other health services, and the patient receiving home health services, were shown to be significantly associated with the patient having a DPAHC in place.

These results suggest that social support networks, such as those provided by receiving homemaker/chore services, home health services, or other health services, are an important aspect in the implementation of Advance Directives. The relationship of increased social support with Advance Directive completion has been absent from the published research on Advance Directive implementation. Patients who receive homemaker/chore services, home health services, other health services, and/or have a primary caregiver who attends community support groups, are presumably less socially isolated than those who do not. As a result, they do not benefit from the learning and exposure gained from social interactions with others. In fact, empirical evidence has substantiated the importance of social networks and support to health and well-being among the elderly (Rubenstein and Lubben, 1994).

Specific variables associated with the caregiver have also been shown to be positively associated with the implementation of a DPAHC. For instance, the identity of the primary caregiver being a family member, friend or neighbor, as well as the presence of a secondary caregiver, were shown to be positively associated with the implementation of a DPAHC. These findings further imply the impact of social support on Advance Directive

implementation, especially the level of support received by those who work closest with the patient, namely the caregivers.

Patients Without a DPAHC in Place

The strongest predictors of a patient not having a DPAHC in place were having an annual combined income below \$4,999, and having a secondary caregiver. Again, the correlation between lower economic status and lack of Advance Directive implementation found in the previous literature was corroborated.

However, the results regarding the presence of a secondary caregiver being positively associated with the absence of a DPAHC, seem to contradict the results of the analysis on the group of patients with a DPAHC in place. Having a secondary caregiver was a significant predictor of a patient having a DPAHC in place, only if that patient was White and had an annual combined income of \$25,000 or more. On the other hand, having a secondary caregiver was a significant predictor of a patient not having a DPAHC in place, if that patient had an annual combined income of less than \$4,999. This clarification of the results demonstrates how a specific variable or characteristic can have a very different influence on or association with an individual and

their actions, depending on their other characteristics and unique circumstances.

The difference seen in the example given above may be attributed to the fact that the caregiver to the individual with a lower income may have less knowledge and experience regarding Durable Powers of Attorney of Health Care, or Advance Directives in general, than the caregiver to the individual with a higher income. The caregivers' incomes, levels of education, and degrees of community support could also play a role in the use or non-use of Advance Directives.

Other significant predictors of a patient not having a DPAHC in place included: being a member of an ethnic minority, receiving Supplemental Security Income, not having Medicare Part A health care coverage, having a primary caregiver who is not a healthcare attendant, having a primary caregiver who does not attend community support groups, not receiving transportation services, and being covered by an employer paid health insurance plan.

These results offer more support to the prior literature regarding the positive association between being an ethnic minority and of lower economic status, and the absence of an Advance Directive. In addition, these results further substantiate the claims that caregiver

characteristics and actions, as well as the level and content of social support a patient receives, can also be associated with the presence or absence of an Advance Directive.

Conclusion

The results of this study were successful in providing a profile of both those cognitively impaired elderly individuals who do have a DPAHC in place, and those who do not. This profiling information more clearly defines the areas of importance and significance with regards to the presence or absence of a DPAHC. Such information can be utilized by health educators, health care administrators, social workers and healthcare providers who recognize the importance and value of Advance Directive implementation, and therefore, seek to identify those individuals who are faced with the most barriers to implementation, as opposed to those with the fewest barriers.

Furthermore, these results demonstrate that the strongest predictors of a patient not having a DPAHC in place are not necessarily the opposite of the strongest predictors of a patient having a DPAHC in place. For example, the strongest predictor of a patient having a DPAHC in place was being White; however, the strongest predictor of a patient not having a DPAHC in place was not being a

member of an ethnic minority, but having an annual combined income of less than \$4,999.

The results of this study have some limitations. First, the population used in this research was a convenience sample of persons arriving at one of the five Alzheimer's Disease Diagnostic and Treatment Centers. Therefore, all of the participants in this study were suffering from some form of cognitive impairment or dementia. Second, more than 99% of the participants resided in the State of California. Again, a random sample was not taken from the nationwide elderly population.

As a result of these limitations, there are certain boundaries on inference and generalizability. The findings of this study cannot be applied or generalized to the entire elderly population within the nation. In fact, these results can only be generalized to those elderly individuals who are California residents and suffer from some form of cognitive impairment. Nevertheless, the results of this study did highlight several significant variables associated with Advance Directive completion that have been overlooked in previous research on the subject.

In conclusion, these findings indicate the need for further research on the effects of social support, isolation and caregiver characteristics and actions on the

implementation of Advance Directives among the elderly. It is recommended that future studies on Advance Directive implementation examine a nationwide sample of elderly individuals. In addition, particular attention should be focused on the following variables: 1) caregiver demographics, behaviors, and utilization of health services, 2) patients' personal use of health services, 3) source and level of social support for the patient, and 4) geographic location of the patient. By increasing healthcare professionals' knowledge regarding the variables associated with Advance Directive implementation, or lack thereof, they can begin to tear down the less obvious, and perhaps more significant barriers associated with Advance Directive implementation.

APPENDIX A: MEASUREMENT INSTRUMENT

ADDTC MINIMUM UNIFORM DATA SET - PART 1 OF 2

Elements and Coding of Initial Patient Assessment Data

I. PROCEDURAL DATA

- | | | |
|---|-----------|------|
| 1. ADDTC code/Patient ID number: ___/___-___-___ | (1-7) | |
| 2. Date of patient's first clinic/home visit: ___/___/___ Month Day Year | (8-13) | |
| 3. Date diagnostic work-up completed (ENTER 99/99/99 IF THE DIAGNOSTIC WORK UP WAS <u>NOT</u> COMPLETED): ___/___/___ Month Day Year | (14-19) | |
| 4. Date of family/caregiver conference (ENTER 99/99/99 IF NO FAMILY/CAREGIVER CONFERENCE WAS CONDUCTED): ___/___/___ Month Day Year | (20-25) | |
| 5. Relationship of informants to patient (CIRCLE "YES" OR "NO" FOR EACH): | | |
| | Yes No | |
| a. Spouse..... | 1 2 | (26) |
| b. Spouse equivalent..... | 1 2 | (27) |
| c. Son..... | 1 2 | (28) |
| d. Son-in-law..... | 1 2 | (29) |
| e. Daughter..... | 1 2 | (30) |
| f. Daughter-in-law..... | 1 2 | (31) |
| g. Other relative(s)..... | 1 2 | (32) |
| h. Friend..... | 1 2 | (33) |
| i. Neighbor..... | 1 2 | (34) |
| j. Self..... | 1 2 | (35) |
| k. Caseworker..... | 1 2 | (36) |
| l. Other..... | 1 2 | (37) |

II. REFERRAL/INTAKE DATA

6. What are the main reason(s) for bringing the patient to the center? (CIRCLE "YES" OR "NO" FOR EACH. CIRCLE "NO" IF CATEGORY DOES NOT APPLY):

| | Yes | No | |
|--|-----|----|------|
| a. Suspected Alzheimer's disease or other dementia..... | 1 | 2 | (38) |
| b. Second opinion on pre-existing Alzheimer's disease or other dementia diagnosis..... | 1 | 2 | (39) |
| c. Patient becoming unmanageable at home..... | 1 | 2 | (40) |
| d. Memory/cognition problem..... | 1 | 2 | (41) |
| e. Physical health problem..... | 1 | 2 | (42) |
| f. Behavioral change/problem..... | 1 | 2 | (43) |
| g. Other | 1 | 2 | (44) |

7. Who primarily referred the patient to the center (i.e., who suggested that the evaluation be done)?

| | | |
|---|---|------|
| Self..... | 1 | (45) |
| Family..... | 2 | |
| Friend(s)..... | 3 | |
| Physician..... | 4 | |
| Community support group (not Alzheimer's Assoc.)..... | 5 | |
| Other health/social service professionals..... | 6 | |
| Alzheimer's Association..... | 7 | |
| Unable to specify primary source of referral..... | 8 | |
| Other..... | 9 | |

III. PATIENT DEMOGRAPHIC DATA

8. Patient's date of birth (CODE 99/99/99 IF NOT DETERMINED):

___/___/___
 Month Day Year

(46-51)

9. Zip code of patient's principle place of residence (CODE 99999 IF UNKNOWN, 00000 IF INTERNATIONAL):

(52-56)

10. Patient's gender:

Male..... 1
 Female..... 2

(57)

11. What is the patient's ethnicity/race? (FROM MEDICAL RECORDS OR BY SELF-IDENTIFICATION; CIRCLE ONE CATEGORY ONLY):

- American Indian or Alaskan Native..... 1 (58)
- Asian..... 2
- Pacific Islander..... 3
- African American (not Hispanic)..... 4
- Filipino..... 5
- Hispanic origin..... 6
- White (not Hispanic)..... 7
- Other..... 8
- Not determined..... 9

12. What is the patient's current marital status? (CIRCLE ONE CATEGORY ONLY):

- Never married..... 1 (59)
- Married..... 2
- Widowed..... 3
- Divorced..... 4
- Separated..... 5
- Living together (unmarried spouse equivalent).... 6
- Not determined..... 9

13. With whom does the patient live at his/her principle residence?

- Living alone..... 01 (60-61)
- Living in a household with spouse only..... 02
- Living in a household with spouse equivalent only 10
- Living in a household with spouse and others..... 03
- Living in a household with spouse equivalent and others..... 11
- Living in a household with relatives..... 04
- Living in a household with non-relatives only.... 05
- Living in a health-related facility..... 06
- Living in group quarters other than a health-related facility..... 07
- Other..... 08
- Not determined..... 09

14. In what kind of place does the patient live?

- House/Condominium/Apartment/Mobile Home..... 1 (62)
- Rented room: Hotel/House..... 2
- Senior Residential Facility..... 3
- Residential Care Facility (Board & Care)..... 4
- Nursing facility (SNF/ICF)..... 5
- Other..... 6
- Not Determined..... 9

15. How many years did the patient go to school?
 (INCLUDE PRIMARY, SECONDARY, TRADE AND BUSINESS
 SCHOOLS AS WELL AS ANY COLLEGE ATTENDED)

(63-64)

16. What was the patient's primary occupation
 throughout life?

_____ / _____

(65)

17. Does the patient currently receive Supplemental
 Security Income (SSI)?

Yes..... 1 (66)
 No..... 2
 Not Determined..... 9

18. What is the combined annual income of the patient
 and his or her spouse/spouse equivalent?

Under \$4,999..... 1 (67)
 \$5,000 - \$ 9,999..... 2
 \$10,000 - \$14,999..... 3
 \$15,000 - \$19,999..... 4
 \$20,000 - \$24,999..... 5
 \$25,000 - \$29,999..... 6
 \$30,000 - \$34,999..... 7
 \$35,000 and above..... 8
 Not determined..... 9

19. What forms of health care coverage does the patient
 have? (CIRCLE "YES," "NO" OR "N/D" FOR EACH):

| | Yes | No | N/D | |
|---|-----|----|-----|------|
| a. Medicare Part A..... | 1 | 2 | 9 | (68) |
| b. Medicare Part B..... | 1 | 2 | 9 | (69) |
| c. Medi-Cal (MediCaid)..... | 1 | 2 | 9 | (70) |
| d. Employer insurance plan..... | 1 | 2 | 9 | (71) |
| e. Health Maintenance Organization..... | 1 | 2 | 9 | (72) |
| f. Veterans Administration..... | 1 | 2 | 9 | (73) |
| g. Retirement health plan..... | 1 | 2 | 9 | (74) |
| h. Medigap supplemental insurance..... | 1 | 2 | 9 | (75) |
| i. Other..... | 1 | 2 | 9 | (76) |
| j. None..... | 1 | 2 | | (77) |

20. Is the patient driving at this time? |
 |
 Yes..... 1 | (78)
 No..... 2 |
 Not Determined..... 9 |

IV. CAREGIVER DATA

21. Who is the patient's primary informal caregiver |
 (i.e., ADLs OR IADLs)? |
 |
 09 |
 10 | (79-80)
 Spouse 01 |
 Spouse equivalent..... 13 |
 Son..... 02 |
 Son-in-law..... 03 |
 Daughter..... 04 |
 Daughter-in-law..... 05 |
 Other relative(s)..... 06 |
 Friend..... 07 |
 Neighbor..... 08 |
 Other..... 11 |
 No one helps patient (SKIP TO Q. 23)..... 12 |

22. Who are the patient's secondary informal caregivers? |
 (CIRCLE "YES," "NO," OR "N/D" FOR EACH. CIRCLE "NO" |
 IF THE CATEGORY DOES NOT APPLY): |
 |
 Yes No N/D |
 a. Spouse..... 1 2 9 | (81)
 b. Spouse equivalent..... 1 2 9 | (82)
 c. Son..... 1 2 9 | (83)
 d. Son-in-law..... 1 2 9 | (84)
 e. Daughter..... 1 2 9 | (85)
 f. Daughter-in-law..... 1 2 9 | (86)
 g. Other relative(s)..... 1 2 9 | (87)
 h. Friend..... 1 2 9 | (88)
 i. Neighbor..... 1 2 9 | (89)
 j. Blank..... - - - | (90)
 k. Other..... 1 2 9 | (91)
 l. Patient has no secondary caregiver..... 1 2 | (92)

V. PREVIOUS SERVICE UTILIZATION

23. Indicate services that the patient and the primary informal caregiver received in the past twelve months. (CIRCLE "YES," "NO," OR "ND" FOR BOTH THE PATIENT AND CAREGIVER TO INDICATE IF THE SERVICE WAS RECEIVED BY EACH PERSON. CIRCLE "NO" IF THE CATEGORY DOES NOT APPLY)

| TYPE OF SERVICE | RECIPIENT OF SERVICE | | | | | | |
|--|----------------------|----|----|----------------------------|----|----|-----------|
| | Patient | | | Primary Informal Caregiver | | | |
| | Yes | No | ND | Yes | No | ND | |
| a. Counseling (individual or group format)..... | 1 | 2 | 9 | 1 | 2 | 9 | (93-94) |
| b. Family/marital counseling-education..... | 1 | 2 | 9 | 1 | 2 | 9 | (95-96) |
| c. Community support group..... | 1 | 2 | 9 | 1 | 2 | 9 | (97-98) |
| d. Outpatient psychotropic medication management..... | 1 | 2 | 9 | 1 | 2 | 9 | (99-100) |
| e. Substance abuse treatment..... | 1 | 2 | 9 | 1 | 2 | 9 | (101-102) |
| f. Primary care or other physician services... | 1 | 2 | 9 | - | - | - | (103) |
| g. Other health practitioners (e.g. Dental, PT, ST, OT)..... | 1 | 2 | 9 | - | - | - | (104) |
| h. Case management services..... | 1 | 2 | 9 | - | - | - | (105) |
| i. Transportation services (Non-emergency).. | 1 | 2 | 9 | - | - | - | (106) |
| j. Congregate meals..... | 1 | 2 | 9 | - | - | - | (107) |
| k. Home delivered meals..... | 1 | 2 | 9 | - | - | - | (108) |
| l. Home health care services..... | 1 | 2 | 9 | - | - | - | (109) |
| m. Homemaker/chore services..... | 1 | 2 | 9 | - | - | - | (110) |
| n. Adult day care..... | 1 | 2 | 9 | - | - | - | (111) |
| o. Adult day health care..... | 1 | 2 | 9 | - | - | - | (112) |
| p. Alzheimer Day Care Resource Centers..... | 1 | 2 | 9 | - | - | - | (113) |
| q. Caregiver Resource Centers..... | 1 | 2 | 9 | 1 | 2 | 9 | (114-115) |
| r. Other respite care (e.g. Overnight, Volunteer Companion)..... | - | - | - | 1 | 2 | 9 | (116) |
| s. Financial assistance..... | 1 | 2 | 9 | 1 | 2 | 9 | (117-118) |
| t. Nursing home (SNF/ICF)..... | 1 | 2 | 9 | - | - | - | (119) |
| u. RCF (board & care)..... | 1 | 2 | 9 | - | - | - | (120) |
| v. In-patient hospital services..... | 1 | 2 | 9 | - | - | - | (121) |
| w. Adult protective svcs..... | 1 | 2 | 9 | 1 | 2 | 9 | (122-123) |
| x. Other services..... | 1 | 2 | 9 | 1 | 2 | 9 | (124-125) |

24. Have any of these legal actions been necessitated by the patient's presenting illness. (CIRCLE "YES," "NO" OR "ND" FOR EACH):

| | <u>Yes</u> | <u>No</u> | <u>N/D</u> | |
|---|------------|-----------|------------|-------|
| a. Power of attorney established..... | 1 | 2 | 9 | (126) |
| b. Durable power of attorney for health care established..... | 1 | 2 | 9 | (127) |
| c. Representative payee established..... | 1 | 2 | 9 | (128) |
| d. Conservatorship established..... | 1 | 2 | 9 | (129) |
| e. Estate planning..... | 1 | 2 | 9 | (130) |
| f. Other legal action..... | 1 | 2 | 9 | (131) |

VI. MEDICAL/DIAGNOSTIC INFORMATION

A. Medical/Family History

25. Patient's age at dementia symptom onset:

___ ___ ___ years (+/- 5 YEARS) (132-134)
 Not determined..... 999

26. How did the patient's symptoms begin:

| | | | | |
|----------------------------|---|--|--|-------|
| Gradually/Insidiously..... | 1 | | | (135) |
| Suddenly..... | 2 | | | |
| Unclear..... | 3 | | | |
| Not determined..... | 9 | | | |

27. What were the first symptoms noted? (CIRCLE ALL THAT WERE PRESENT):

| | <u>Yes</u> | <u>No</u> | <u>N/D</u> | |
|---|------------|-----------|------------|-------|
| a. Memory problems..... | 1 | 2 | 9 | (136) |
| b. Language problems..... | 1 | 2 | 9 | (137) |
| c. Visuo-spatial or perceptual problems..... | 1 | 2 | 9 | (138) |
| d. Other cognitive/intellectual problems..... | 1 | 2 | 9 | (139) |
| e. Behavior/personality change..... | 1 | 2 | 9 | (140) |
| f. Depressed mood..... | 1 | 2 | 9 | (141) |

28. How has the patient's dementia progressed? (CIRCLE "YES," "NO" OR "N/D" FOR EACH):

| | Yes | No | N/D | |
|--|-----|----|-----|-------|
| a. Gradual decline (Progression of dementia has been gradual)..... | 1 | 2 | 9 | (145) |
| b. Stepwise decline (Plateaus with two or more discrete episodes of decline)..... | 1 | 2 | 9 | (146) |
| c. Episodes of transient decline (i.e., delirium)... | 1 | 2 | 9 | (147) |
| d. Stable/Improved (No decline of functioning or improved functioning since onset of dementia symptoms)..... | 1 | 2 | 9 | (148) |
| e. Unclear (It is not clear whether dementia has progressed gradually or in a stepwise fashion). | 1 | 2 | - | (149) |

29. What was the patient's age when dementia was first diagnosed prior to ADDTC contact? (FIRST DIAGNOSIS WILL NOT NECESSARILY BE THE DEFINITIVE OR PRIMARY DIAGNOSIS)

| | | |
|-------------------------|-----|-----------|
| _____ years | | (150-152) |
| No prior diagnosis..... | 888 | |
| Not determined..... | 999 | |

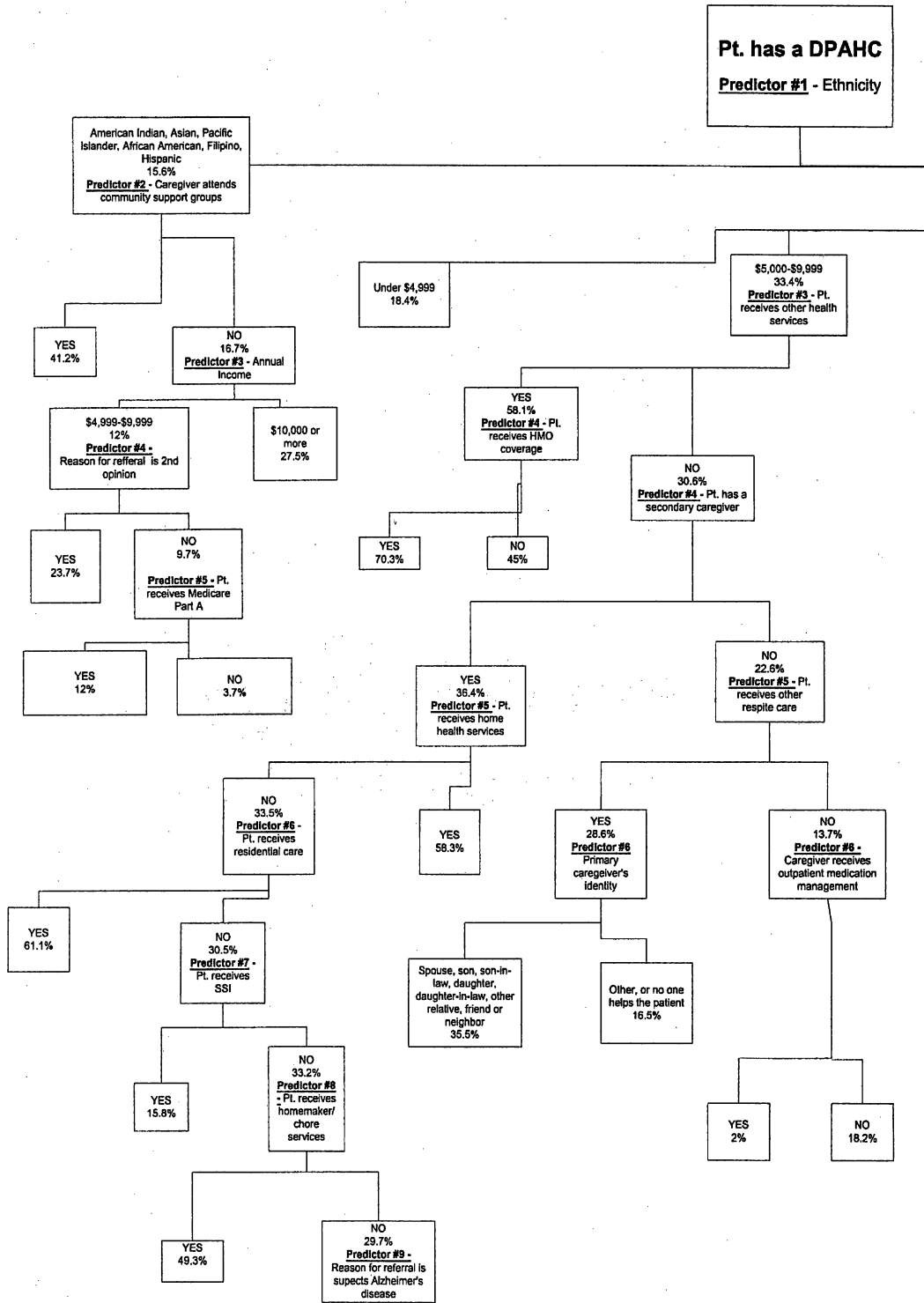
30. Patient's height : _____ inches (ROUND TO THE NEAREST INCH)

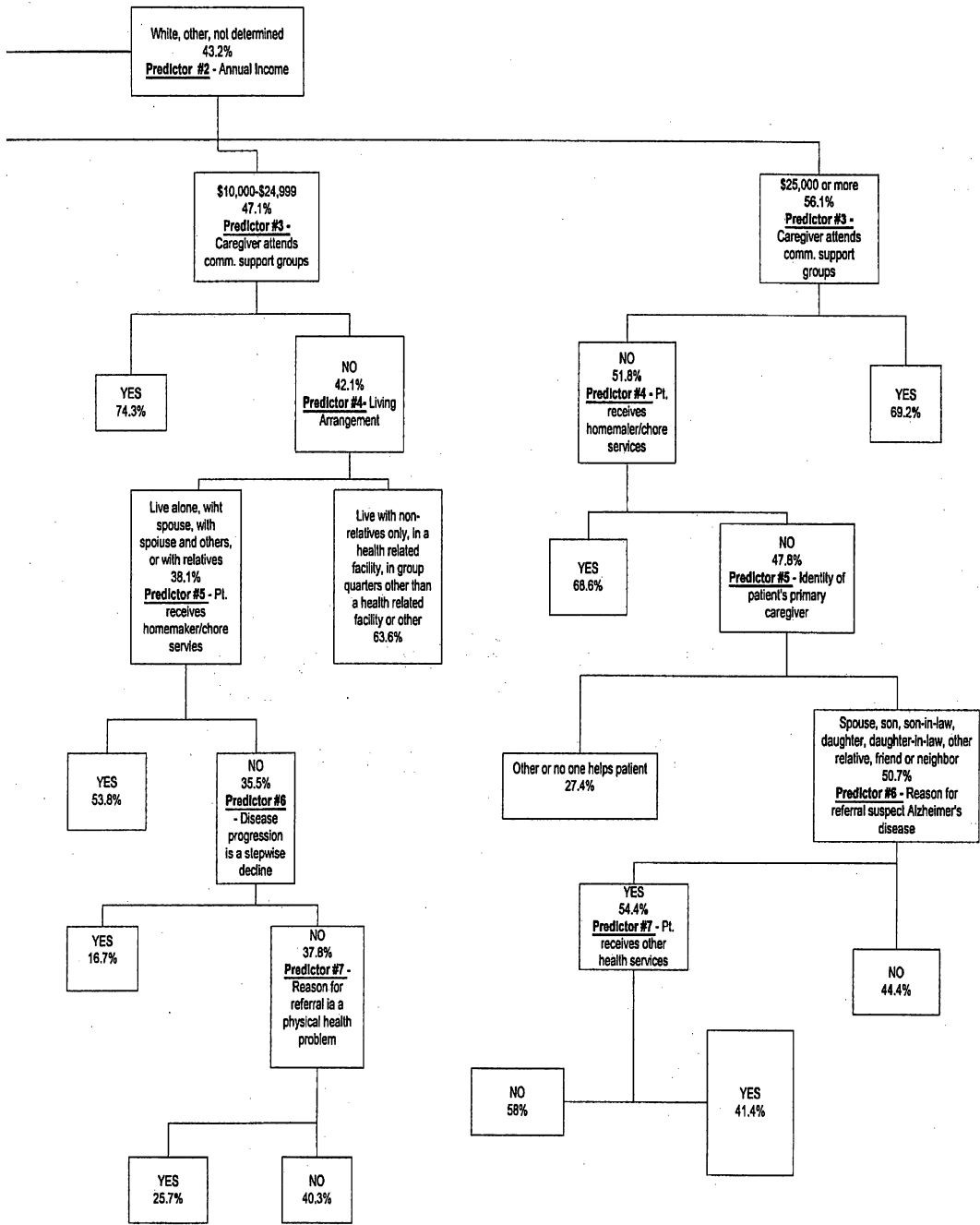
| | | |
|---------------------|----|-----------|
| Not determined..... | 99 | (153-154) |
|---------------------|----|-----------|

31. Patient's weight: _____ pounds (ROUND TO THE NEAREST POUND)

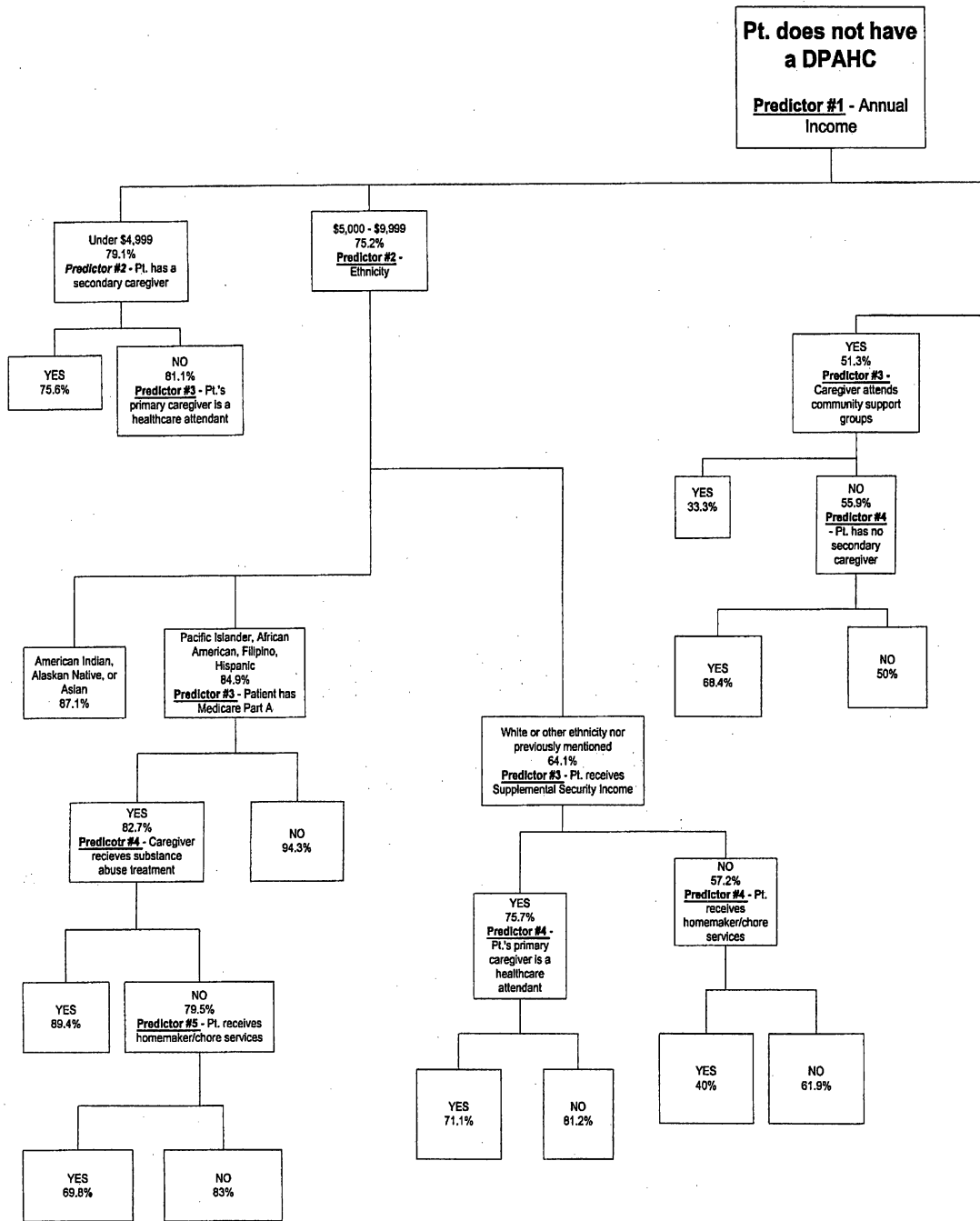
| | | |
|---------------------|-----|-----------|
| Not determined..... | 999 | (155-157) |
|---------------------|-----|-----------|

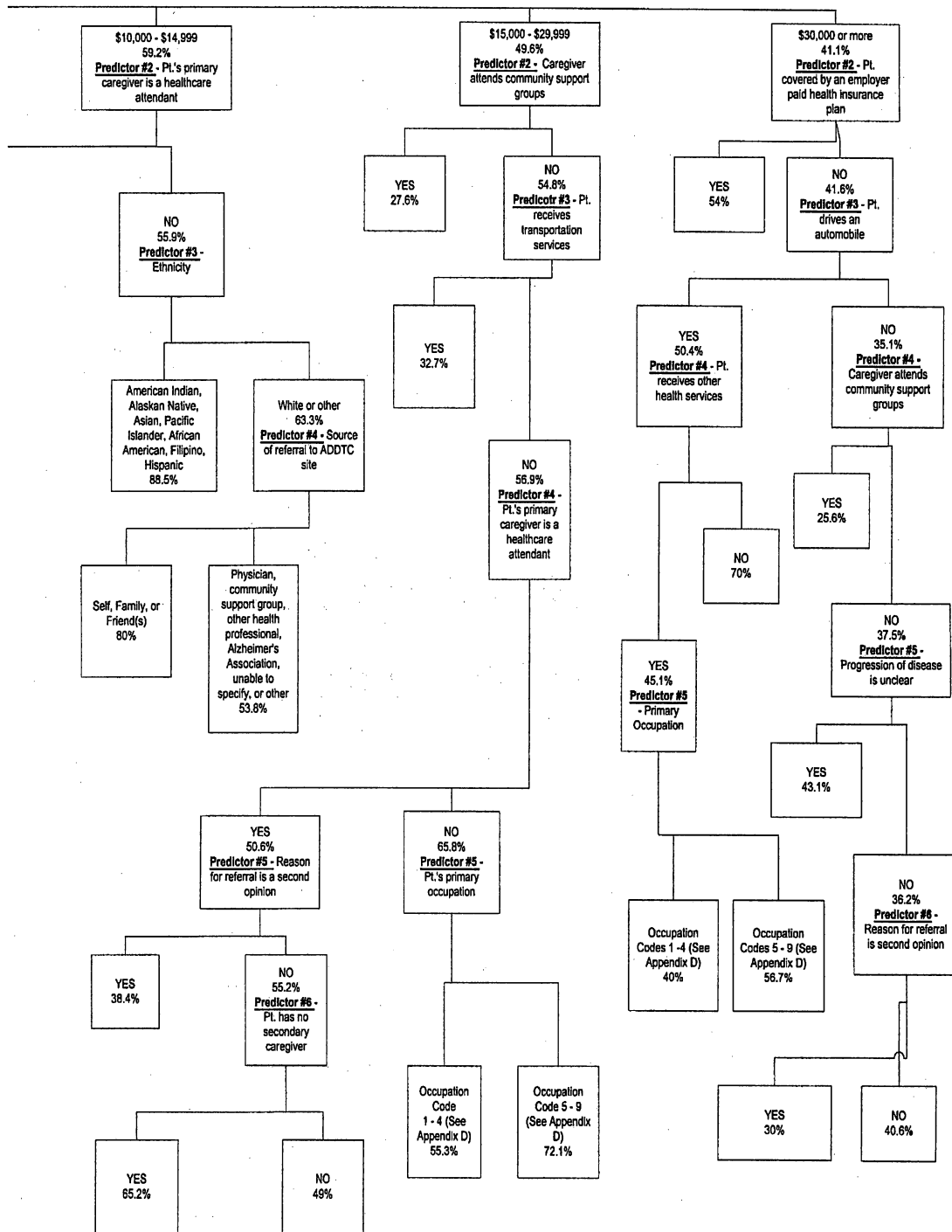
APPENDIX B: CLASSIFICATION TREE FOR
ANALYSIS OF PATIENTS WITH A DPAHC





APPENDIX C: CLASSIFICATION TREE FOR
ANALYSIS OF PATIENTS WITHOUT A
DPAHC





APPENDIX D: OCCUPATION CODES

OCCUPATION CODES/VERSION 1988 ADDTC-MUDS

| <u>CODE</u> | <u>OCCUPATION</u> |
|-------------|---|
| 0 | None |
| 1 | Higher Executives, Proprietors of Large Concerns and Major Professionals |
| | a. Higher executives |
| | Bank Presidents & Vice presidents; Military, Commissioned Officers (Major and above); Judges (Superior Courts); Officials of large businesses, e.g. Directors; Executive Branch of Government; Federal, State, Local, Government Officials |
| | b. Large Proprietors. (Value over \$100,000) |
| | Brokers; Dairy Owners; Contractors; Lumber Dealers |
| | c. Major Professionals |
| | Accountants (CPA); Actuaries; Agronomists; Architects; Artists, Portrait; Astronomers; Auditors; Bacteriologist; Chemical Engineers; Chemists; Clergymen (Professionally |

trained); Dentists; Economists;
Engineers (College Grad.); Foresters;
Geologists; Lawyers; Metallurgists;
Physicians; Physicians, Research;
Psychologists, Practicing, Symphony
Conductor; Teachers, University,
College; Veterinarian (Veterinary
Surgeons)

2 Business Managers, Proprietors of Medium
Sized Businesses, and Lesser Professionals.

a. Business Managers in Large Concerns

Advertising Directors; Branch Managers;
Brokerage Salesmen; District Managers;
Executive Assistants; Executive
Managers, Government; Farm Managers;
Office Managers; Personnel Managers;
Police Chief, Sheriff; Postmaster;
Production Managers; Sales Engineers;
Sales Managers, National Concerns;
Sales Managers (Over \$100,000)

b. Proprietors of Medium Businesses (Value
\$35,000 - \$100,000)

Advertising Owners; Clothing Store

Owners; Contractors; Express Co.

Owners; Fruits, Wholesale; Furniture

Business; Jewelers; Labor Relations

Consultant; Manufacturers

Representative; Poultry

Business; Purchasing Managers; Real

Estate Brokers; Rug Business; Store

Owners; Theater Owners

c. Lesser Professionals

Accountants (not CPA); Chiropodists;

Chiropractors; Correction Officers;

Directors of Community Houses;

Engineers (not college grad.); Finance

Writers; Health Educators; Librarians

(full-time); Military, Commissioned

Officers; Musicians (Symphony

Orchestra); Nurses; Opticians;

Pharmacists; Public Health

Officers (MPH); Research Assistants,

University; Social Workers; Teachers

(Elementary and higher)

3

Administrative Personnel, Small Independent

Businesses, and Minor Professionals

a. Administrative Personnel

Advertising Agents; Chief Clerks;
Credit Managers; Insurance Agents;
Manager, Department Stores; Passenger
Agents; R.R.; Private Secretaries;
Purchasing Agents; Sales
Representatives; Section Heads,
Federal, State, and Local
Government Offices; Section Heads,
Large Businesses and Industries;
Service Managers; Shop Managers; Store
Managers (Chain); Traffic Managers

b. Small Business Owners (\$6,000 - \$35,000)

Art Gallery; Auto Accessories; Awnings;
Bakery; Beauty Shop; Boat Yard;
Brokerage, Insurance; Car Dealers;
Cattle Dealers; Clothing; Cigarette
Machines; Cleaning Shops; Coal
Business; Contracting; Convalescent
Homes; Decorating; Dog Supplies; Dry
Goods; Engraving Business; Food; Finance
Co., Local; Fire Extinguishers; 5 & 10;
Florist; Food Equipment; Food Products;

Foundry; Funeral Directors; Furniture;
Garage; gas Station; Glassware;
Grocery, Hotel Proprietors; Instructor
of Music; Jewelry; Machinery Brokers;
Manufacturing; Monuments; Package Store
(Liquor); Painting; Plumbing; Poultry
Producers; Publicity and Public
Relations; Real Estate; Records and
Radios; Restaurant; Roofing Contractor;
Shoe; Signs; Tavern; Taxi Company; Tire
Shop; Trucking; Trucks and Tractors;
Upholstery; Wholesale Outlets;
Yardmasters

c. Semi-Professionals

Actors and Showmen; Army M/Sergeant;
Navy CPO; Artists, Commercial;
Appraisers; Clergymen (not
professionally trained); Radio, TV
Announcers; Concern Managers; Deputy
Sheriffs; Dispatchers, R.R. Train;
Interior Decorators; Interpreters,
Court; Lab Assistants; Landscape
Planners; Morticians; Oral Hygienists;

Photographers; Physio-therapists; Piano
Teachers (Trained); Reporters, Court
and Newspaper; Surveyors; Title
Searchers; Tool Designers; Travel
Agents; Yardmasters R.R.

d. Farmers and Farm Owners (\$25,000 -
\$35,000)

4 Clerical and Sales Workers, Technicians, and
Little Businesses (Value under \$6,000)

a. Clerical and Sales Workers

Bank Clerks and tellers; Bill
Collectors; Bookkeepers; Business
Machine Operators, Offices; Claims
Examiners; Clerical or Stenographic;
Conductors, R.R.; Employment
Interviewers; Factory Store Keeper;
Factory Supervisor; Post Office Clerks;
Route Managers; Shipping Clerks;
Supervisors, Utilities, Factories; Toll
Station Supervisors; Warehouse Clerks

b. Technicians

Dental technicians; Draftsmen; Driving
Teachers; Expediter, Factory;

Experimental Tester; Instructor,
Telephone Co.; Inspector, Weights,
Sanitary; Inspector, R.R., Factory;
Investigators; Lab technicians;
Locomotive engineers; Operators PBX;
Proofreaders; Safety Supervisors;
Supervisors of Maintenance Factory;
Technical Assistants; Telephone Co.
Supervisors; Time Keepers; Tower
Operators, R.R.; Truck dispatchers;
Window trimmers

c. Owner of Little Businesses (%3,000 -
\$6,000)

Flower Shop; Newsstand; Tailor Shop

d. Farm Owners (\$10,000 - \$20,000)

5 Skilled Manual Employees

Auto Body Repairs; Bakers; Barbers;

Blacksmiths; Book Binders;

Boilermakers;

Breakmen, R.R.; Brewers; Bulldozer

Operators; Butchers; Cabinet Makers;

Carpenters; Casters (Founders); Cement

Finishers; Cheese Makers; Chefs;

Compositors; Dye Makers; Diesel Engine
Repair and Maintenance (trained);
Diesel Shovel Operators; Electricians;
Electrotypists; Engravers;
Exterminators; Fitters, Gas, Steam;
Firemen, City; Firemen, R.R.; Foremen,
R.R., Construction, Dairy; Gardeners,
Landscape (trained); Glass Blowers;
Glaziers; Gunsmiths; Gauge Makers;
Hairstylists; Heat Treaters;
Horticulturists; Installer, Electrical
Appliances; Linemen, Utilities;
Linoleum Layers (trained); Linotype
Operators; Lithographers; Locksmiths;
Loom Fixer; Machinist (trained);
Masons; Massears; Mechanic (trained);
Millwrights; Moulders; Painters;
Paperhanger; Patrolmen, R.R.; Pattern
and Model Makers; Piano Builders; Piano
Tuners; Plumbers; Policemen, City;
Postmen; Printers; Radio, TV,
Maintenance; Repairmen, Home Appliance;
Rope

Splicers; Sheet Metal Workers
(trained); Shipsmiths; Shoe Repairmen
(trained); Stationary Engineers
(licensed); Stewards, Club; Switchmen,
R.R.; Tailor (trained); Teletype
Operators; Tool makers; Track
Supervisors, R.R.; Tractor-Trailer
Transit; Typographer; Upholsterers
(trained); Watchmakers; Weavers;
Welders; Yard Supervisors,
R.R.; Small Farm Owners (under
\$10,000); Tenants who own farm equ.

6 Machine Operators and Semi-Skilled Employees

Aids, Hospital; Apprentices,
Electrical, Printers; Steamfitters,
Toolmakers; Assemblyline Workers;
Bartenders; Bingo Tenders; Building
Superintendents (Custodian); Bus
Drivers; Checkers; Coin Machine
Fillers; Cooks, Short Order;
Deliverymen; Dressmakers, Machine;
Elevator Operators; Enlisted men,
Military Services; Filers, Benders,

Buffers; Farmers:Smaller Tenants who
own Little Eqt.; Foundary Workers;
Garage and Gas Station Assistants;
Greenhouse workers; Guards,
Doorkeepers, Watchmen; Hairdressers;
Meatcutters and Packers;
Meter Readers; Operators, Factory
Machines; Oiler, R.R.; Practical
Nurses; Pressor, Clothing; Pump
Operators; Receivers and Checkers;
Roofers; Set-Up Men, Factories;
Shapers; Signalmen, R.R.; Solderers,
Factory; Sprayers, Paint; Steelworkers;
Stranders, Wire Machines; Strippers,
Rubber Factory; Taxi Drivers; Testers;
Timers; Tire Moulders; Trainmen, R.R.;
Truck Drivers, General; Waiters-
Waitresses; Weighers; Wleders, Spot;
Winders, Machine; Wiredrawers, Machine;
Wine Bottlers; Wood Workers, Machine;
Wrappers, Stores and Factories

7

Unskilled Employees

Amusement Park Workers (Bowling Alleys,

Pool Rooms); Ash Removers; Attendants,

Parking Lots

8 Homemakers

9 Missing-DNA

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