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Alzheimer's Disease and the Role of the Physician

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ALZHEIMER'S DISEASE AND THE ROLE OF THE PHYSICIAN

A Thesis

Presented to

The Faculty of the Department of Sociology
The College of William and Mary in Virginia

In Partial Fulfillment

Of the Requirements for the Degree of
Master of Arts

by

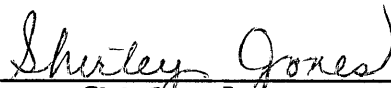
Shirley Jones

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APPROVAL SHEET

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the requirements for the degree of

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ABSTRACT

It is the purpose of this study to address the following; the sociological implications involved in determination of a positive diagnosis of Alzheimer's Disease, physicians' knowledge of the disease, the problems encountered by Alzheimer caregivers in role interaction with the physicians, inference of physician withdrawal due to lack of knowledge about available community services for Alzheimer's Disease clients and caregiver.

A questionnaire was devised and presented to a group of physicians in the study area. The questionnaire asked direct questions that indicated a physician's knowledge of Alzheimer's Disease, knowledge of community services for dementia patients, and subjective feelings concerning the physician's responsibility to caregiving units and Alzheimer's Disease patients.

Unstructured interviews were carried out with a small group of caregivers to identify possible problem areas that arise during the caregiver's term of duty with the Alzheimer's Disease victim.

Results from the questionnaire, in conjunction with information obtained through the unstructured interview, allowed the inference that physicians do withdraw from the terminal dementia client and caregiving unit because of inadequate knowledge of supportive community services available.

**ALZHEIMER'S DISEASE AND THE
ROLE OF THE PHYSICIAN**

CHAPTER I
INTRODUCTION

Purpose of this Study

"It is the worst of all possible diseases, not just for what it does to the victim, but for its devastating effects on family and friends"...

Lewis Thomas, Sloan Kettering Cancer Center

"If we don't control the disease, it will eventually bankrupt us"...

**Robert Terry, M.D., Alzheimer's Disease Researcher,
Albert Einstein School of Medicine**

"I've become mother to my husband instead of wife. I find it hard to make this role change at this time in my life...I feel I'm not my usual self. I seem to have other thoughts that have taken over...I can't become what my husband needs me to be."

(Powell, p.65, 1983)

Each of these quotes illustrates a different aspect of Alzheimer's Disease. In the past ten years much has been written on the general subject. We know that Alzheimer's Disease is one that has long term effects that reach far beyond its primary victim. Because of the often slow progression of the disease, it is devastating to the victim, the caregiver, and the family unit as a whole. It is a disease that can be detected only after seemingly endless tests and examinations. Due to the nature of the illness, the victim is often hard to control, thus increasing the burden on the caregiver. It is not possible to examine all the issues involved in Alzheimer's Disease in the scope of this thesis, however, it is possible to identify several issues related to this "new" medical mystery. These issues revolve around

medical, economic, social and psychological practices.

The disease which has currently won notice as "The Silent Epidemic", is the fourth leading cause of death in the adult population of the United States today. It is estimated that of those in the population over age 80, twenty percent are stricken with Alzheimer's Disease, and that by 1990, 1.5 million people will have this disease or some other dementing illness. In 1984, Congress appropriated a research budget of 40 million dollars for Alzheimer's Disease, which was an increase of 15 million dollars from 1983. Further, it is estimated that by 1990 it will cost 30 billion dollars a year to care for those patients who already account for 25 billion dollars a year in lost productivity due to Alzheimer's Disease (Medical News).

Alzheimer's Disease is an irreversible form of dementia and a terminal illness which entails loss of intellectual faculties, reasoning power, memory and will as a consequence of organic brain dysfunction. At the present time there is no established cause, treatment, or cure (The Coordinator).

Dementias, which alone count for between 70,000 and 110,000 deaths each year in the United States, increase in probability with advancing age. Organic Brain Syndrome accounts for 75 percent of all first admissions to mental hospitals of persons 65-74 years of age, and 90 percent for those in the over age 75 age category (Strub, 1982). Although Alzheimer's Disease can occur

at almost any age, 96 percent of all cases occur after the age of 40. The female to male ratio of the disease is 2:1 at all ages of onset (Strub, 1981).

While these data indicate that Alzheimer's Disease is a devastating illness for the older age population, they do not reveal the complexity of the diagnosis of this condition. This research project first reviews the diagnostic process and examines the sociological implications involved in the determination of a positive diagnosis of Alzheimer's Disease. The review of the current literature on Alzheimer's Disease focused on two aspects of the disease; (1) the diagnostic process, and (2) the impact of the diagnosis upon the primary caregiver. The review of the literature suggests that a serious problem encountered by caregivers following a positive diagnosis of Alzheimer's Disease is withdrawal of the diagnosing physician.

In order to understand what influences this professional withdrawal, the diagnostic process must be examined, as well as some of the social factors that may influence a more thorough rift to develop between the medical professionals involved in diagnosing Alzheimer's Disease and those identified as primary caregivers to persons afflicted with Alzheimer's Disease. Even though professional withdrawal is suggested throughout literature on Alzheimer's Disease, no substantial evidence exists that supports or refutes such a claim.

In order to prepare programs to alleviate some of the stresses encountered in the caregiving situation, it is essential that we first have evidence of what those stresses are, and if they can be changed. It is essential to obtain information from the physicians themselves concerning whether or not they do participate in the family caregiving situation, to what extent they participate, their knowledge of services available, and their professional knowledge of the disease process itself. This may also help with determining the extent of withdrawal from the situation. Another issue for exploration is the extent of communication between the physician and primary caregiver of the Alzheimer's patient to determine the process by which communication among them is maintained or breaks down. The rationale is, to open up lines of information sharing so that the physician and primary caregiver can understand their own involvement in the situation, to the end that effective health care plans can be devised for the patient.

It is the purpose of this study to address: the sociological implications involved in the determination of a positive diagnosis of Alzheimer's Disease, physician knowledge of Alzheimer's Disease symptomology, the problems encountered by Alzheimer's caretakers in role interaction with physicians, inference of physician withdrawal in lack of knowledge about available community service for Alzheimer's Disease victims and caregivers, caregiver responses to physicians, functional

adequacy/inadequacy of community support groups for Alzheimer's Disease clients and caregivers. The methods for this undertaking will be presented in the following chapter.

CHAPTER II

LITERATURE REVIEW

THE DISEASE

Alzheimer's Disease is a devastating illness of long standing, but it has been the target of major research efforts only recently. Alois Alzheimer first described the disease in the early 1900's (Powell, 1981). From around 1902 to 1960, the general assumption was that senile dementia was caused by arteriosclerosis. In 1960, two English pathologists, Corselles and Evans, studied the brains of both demented and non-demented patients and found approximately the same amount of arteriosclerotic changes in both groups (Strub, 1982), thus putting an end to the above mentioned assumption and opening up an entirely new area of inquiry as to the etiology of this disease.

Systematic research on a large scale has been undertaken only in the last twenty years. The term used to identify Alzheimer's disease is SDAT or Senile Dementia of Alzheimer's Type. Dementia is a descriptive term used to describe a group of brain disorders in which the patient suffers progressive

deterioration in intellectual and adaptive functions (Strub,1982).

The word "dementia" literally means "deprived of mind" (AHCA Journal, p. 36). The demented patient exhibits changes in several areas of function; intellect, judgment, and affect or personality. There are many similarities between Alzheimer's Disease, Picks Disease and Multi-infarct dementia. However, as the diseases progress, variations among them appear. The clinical and pathological findings for these disease entities are identical with the only substantial difference being the arbitrary assignment of one label to those patients under age 65 (Alzheimer's pre-senile dementia), and another to those persons in senium (Ibid).

Alzheimer's Disease can occur at almost any age - the youngest on record being a six year old child. This implies that Alzheimer's Disease (AD) may mimic Down's Syndrome in younger patients that are afflicted. Alzheimer's Disease is a form of Senile Dementia. Words like "senile", "pre-senile", and "senility" help perpetuate the myth that mental decline is a normal part of aging (AHCA Journal, p.36). Unfortunately, in the case of Alzheimer's Disease, this mental decline is a fact. The easiest way to define what Alzheimer's Disease is, is to define what it is not. It is not a normal part of the aging process: it is not the aftermath of a stroke (although strokes do cause Multi-Infarct dementia): it is not brought on by alcoholism or

depression, and, it is not a communicable disease. It is a progressive, age related, chronic, cognitive brain dysfunction. Behavioral impairments along with loss of cognitive abilities do occur, however, the nature of these impairments depends on the stage to which the disease has progressed. At the onset of the illness the average survival period is 2.6 years for males as compared to 8.7 years age matched for males that do not have a dementing illness. The survival period for females is 2.3 years as compared to 10.9 years age matched for females that do not have a dementing illness (Schenick, 1982).

The symptoms are many and vary from patient to patient. The easiest way to break down the symptomology is to categorize symptoms according to stage of progression of the disease.

There are four stages in the progression of Alzheimer's Disease. It is the initial stage that is hardest to define. Being very insidious, the person and his family are not sure anything is wrong (Rosen, 1984, Strub, 1982, Schenick, 1982). The symptoms gradually become apparent, but in some cases may become manifest during periods of stress. It is the following initial symptoms that the clinician must learn to recognize. They include: loss of interest in work, family, vocation, increased level of irritability, hypochondriasis, depression, anxiety, feelings of restlessness, fatigue, lack of accustomed initiative, subtle emotional changes, and difficulty forming new memories. General problem solving ability wanes as does comprehension and

expression of complex ideas. The patient develops problems with abstract thinking and the making of critical judgments. Mistakes made in carrying out simple functions that utilize arithmetic are very common in the early stages of Alzheimer's Disease (Strub 1982, Schenick 1982, Rosen 1984, Reisberg 1981).

During the second stage of the disease, the patient is less able to manage personal and business affairs due to an increase of failing memory and lack of initiative. The patient increasingly becomes unable to meet the demands of any challenge. Language which had previously been normal now becomes broken and tangential. The Alzheimer's patient becomes very upset at night and may wander about the house and neighborhood. This occurs because of changes in the brain's physiology in the area of the hippocampus cells. The patient often retains enough insight into his/her condition to develop anxiety and depression (Strub 1982, Schenick 1982, Rosen 1984).

During the third stage of the disease, the patient begins to exhibit aphasic speech. General intellectual abilities have declined, spontaneous speech has decreased, and the patient's comprehension has been greatly reduced. The patients exhibit significant anomia and seem not to recognize previously familiar objects. Disastrous accidents in this stage often precipitate admission to the hospital. The limbs of the patient may begin to resist passive movement and urinary and fecal incontinence usually appear. Patients may sit for hours and talk to them-

selves, a behavior common in organically psychotic patients. The ability to shift their attention to novel stimuli allows Alzheimer's patients to appear brighter than they really are. Memory of the distant past is remarkably clear, however, the ability to form recent memory continues to decline. The patients tend to become withdrawn during this stage of the disease (Strub 1982, Rosen 1984).

The fourth and final stage of the disease completely disables the patient both intellectually and physically. The victims become very uncommunicative, uttering only short phrases or mumbling to themselves. They exhibit involuntary emotional expression and may wander aimlessly if physically able to do so. The patient carries out little meaningful social interaction and may, in fact, become peevish if bothered. They become delusional and apathetic, finally becoming completely withdrawn. Twenty-two percent of the Alzheimer's patients will experience generalized seizures during this last stage of the disease process. If the patient becomes bedridden, he/she may experience flexion of the lower extremities causing their legs to become fixed in the fetal position (Strub, 1982).

These are the textbook symptoms of Alzheimer's Disease and must be treated as such. The important thing to remember is that the rate of progression of the disease and the severity of symptoms experienced vary from patient to patient. A positive relationship exists between rate of onset of the disease and

severity of the symptoms experienced.

THE DIAGNOSTIC PROCESS

The basic problem associated with the diagnosis of Alzheimer's Disease is related to the fact that it is so very similar to many other forms of dementia. In fact, Gwyther (1982) has stated that Alzheimer's Disease may mimic up to one hundred other diseases (Gwyther, 1982), making positive diagnosis difficult at best. Because of the nature of the illness, diagnosis is a process of excluding what the suspect patient does not have. An extremely thorough physical, psychological, and neurological examination is called for when a clinician suspects that his patient might have Alzheimer's Disease.

The physical examination includes the taking of a complete social history. This history is usually taken from a spouse or relative since the patient is likely to confuse facts. This process includes discounting the following disorders as possible causes of the dementia: cardiovascular disease, presence of seizures, parkinsonism, presence of brain tumor, aftermath of thyroid surgery, Vitamin B12 deficiency, old or recent head trauma, history of venereal disease, cancer, medication abuse, or heavy use of alcohol (Strub 1982, Schenick 1982). These possible causes of the dementia must be ruled out before the clinician should entertain the possibility of forming a diagnosis of Alzheimer's Disease.

Along with the physical examination, a complete psychological workup is carried out on the suspect patient. The utility of this lies in the ability of the psychologist to rule out severe depression as a cause of the symptomatology. Several things are looked at during this phase of the examination. These include looking for behavioral changes and changes in emotional and socioemotional behaviors. Also looked for are significant changes in the intellectual ability of the patient. Patients are observed to see if any change in overall personal appearance occurs, such as becoming sloppy in dress or slack in personal grooming habits, because Alzheimer's patients do lose interest in their personal appearance over time. This is directly related to the fact that Alzheimer's patients forget the internalized norms of society regarding good grooming habits.

The psychologist also looks for changes in organically based behavior, and notes such indicators as lack of insight, euphoria, atrophy, secondary depression, and inappropriate social behavior (Strub, 1982). The psychologist observes the attention of the suspect patient, because with time, the Alzheimer's patient's powers of concentration fail. This is illustrated by the ease with which the Alzheimer's patient is distracted by extraneous stimuli. They are also able to rivet their attention to novel stimuli, becoming unable to shift their attention from that object (Ibid).

Three methods of assessment are employed by the psycholo-

gist. These are the mental status questionnaire, the memory for digits test, and the misplaced objects test (Powell, p.122). The mental status questionnaire is simply a way of ascertaining how well the patient is oriented to time, place and person. Such questions as "What is today's date?", "What year is this?", and "What is your full name?" are asked. With the misplaced objects test, the patient is asked to place pictures of familiar objects within representations of typical rooms in order to determine the patient's ability to recognize and segregate familiar objects. The memory for digits test is frequently used in assessments of suspect Alzheimer's patients. During this test the patient is told a list of numbers and then asked to repeat it forwards and backwards (Powell, 1983). This is a useful test as one of the manifest symptoms of Alzheimer's Disease is the inability to deal rationally with numbers.

Another factor taken into account is language usage since the language capabilities of the patient are affected even in the early stages of the disease. Initially, there is a decrease in the amount of language output. As the disease progresses, spontaneous speech tends to become repetitive, concrete, and tangential. The patient experiences word finding pauses and begins to make mistakes when naming objects. This is one of the very frustrating aspects for the patient who becomes very upset at not being able to find the correct name of a previously familiar object. The caregiver may often "put words in the patient's mouth" in an effort to figure out what the patient wants. For both the

patient and the caregiver this is an aggravating situation, and one that can only become worse as the disease progresses.

Using the methods outlined above, psychologists can determine the mental status of the patient, which is of great assistance in supporting or rejecting a diagnosis of Alzheimer's Disease. The next step in the diagnosis procedure is the neurological examination. This part of the process entails the use of state of the art medical technology in determining the status of the patient. The Electroencephalogram (EEG) is the most frequently employed method in the neurological examination: however, its primary utility lies in its ability to rule out other causes of dementia such as tumors, metabolic disorders, and the presence of a hematoma, rather than in providing a clear diagnosis of Alzheimer's disease. The problem with using the EEG for this purpose is that subtle abnormalities in the EEG occur with increasing frequency in the normal elderly patient. This may result in an EEG that appears normal in the Alzheimer's patient (Strub, 1982, Wells, 1977). The Computerized Axial Tomography, or CAT scan is another diagnostic tool used. In this case, the atrophy looked for in the Alzheimer's brain is hard to find because it is difficult to differentiate from the 15-30 percent atrophy already present in the normal elderly patient (Strub, 1982).

The most useful method available for the purpose of diagnosing Alzheimer's disease is the pathological examination of brain

tissue from the suspect patient. Microscopic examination of the tissue can reveal the single, most obvious sign of Alzheimer's Disease, the neurofibrillary plaques and tangles. The degree of dementia is highly correlated with the number of plaques and tangles found in the brain tissue (Strub, 1982).

All the procedures mentioned above must be carried out before a positive diagnosis for Alzheimer's Disease can be made. No step or procedure can be deleted, because all other forms of dementia must be ruled out. Such rigorous examinations are carried out because the implications of a positive diagnosis are numerous and very serious in nature.

THE STRESSES OF CAREGIVING

The problems most often encountered by various family caregivers are: (1) making personal sacrifices to keep the ill individual from being institutionalized, (2) doing everything possible for the patient yet still feeling some guilt, (3) embarrassment at the patient's often bizarre behavior, (4) financial insecurity, (5) quitting a job to become caregiver, (6) anticipatory mourning, (7) unmet sexual and companionate needs, and (8) total absorption into the role of caregiver (Barnes, et al. 1981, Clark, et al. 1983, Gwyther, 1982, Eisdorfer, 1981).

These problems encountered encompass social, psychological, and environmental factors. Alzheimer's Disease causes many dis-

turbances in the victim's mind that are ultimately manifested in their behavior. The caregiver is consumed by the activity of caregiving: an activity that only increases as the disease progresses. The caregiver must make sure that a certain quality of life is made available to the patient. He/she is often faced with the problem of trying to figure out what the patient wants. The caregiver must also make sure the patient does not wander from home. He/she must feed, dress, and cleanse the patient. Because of all the work necessary in "proper" caregiving, the job does not end at 5:30 p.m. every day. It is an around-the-clock, seven day a week job, that if improperly managed, can take a tremendous toll on all involved. Because so many problems do exist for the patient and the caregiver, Clark, et al. (1983) developed a summary of the main problem areas of the patient and caregiver. These are divided into four broad categories and include:

- 1). direct care of the impaired family member,
- 2). intrapersonal task, concerns, and difficulties faced by the caregiver and the patient,
- 3). interpersonal ties with other family members, and
- 4). interaction of the caregiver with the broader societal and health care networks.

(Clark, et al. 1983).

As one consequence of the many stresses encountered in the process of caregiving, support groups for the families of Alzheimer's Disease victims have developed. Many of the most extensive of these support networks have been established in conjunction with major research hospitals such as Duke University and Johns Hopkins University. Several consistent themes are characteristic of these groups regardless of their size and location.

The primary contribution that a support group offers to the participants include: providing emotional support to the family, help in planning and directing future action, help in gaining greater understanding of the process of aging, help in understanding the processes of the disease itself, help in locating resources, help in understanding role relationships and assistance in venting pent up feelings of anger, resentment, and guilt (Clark, 1983, Hartford, et al. 1982, Crossman, 1981, Lazarus, et al. 1981). The single most important function of the support group is to alleviate some of the overbearing feelings of isolation felt by the caregiver which are a function of both social and psychological processes.

PROFESSIONAL WITHDRAWAL

When a diagnosis of Alzheimer's Disease is made a variety of consequences may follow. If a family has an extensive support system already in place, members of this system might rally

around the family caregiving unit providing both emotional and physical support during the afflicted family's trial. The family caregiving unit may also be fortunate enough to have a health care professional involved that is capable of making referrals to appropriate community services. Having a support network that includes family and friends as well as concerned health professionals provides the much needed supportive atmosphere that can make any given caregiver's experience a less stressful one.

While in the ideal caregiving situation all family caregivers would have such an extensive support network, literature on the subject indicate that perhaps the opposite situation occurs more frequently.

The family caregiving situation most frequently described in the literature includes one in which friends, neighbors, co-workers, and even family members may withdraw, leaving the primary caregiver and disease victim alone and without emotional support. As the disease progresses, the felt isolation may reach high proportions because it becomes almost impossible for the caregiver to get away from the caregiving situation. The literature also suggests that health care professionals involved may withdraw leaving the caregiver without a source of accurate information about the disease and what to expect as it progresses.

One of the reasons cited for professional withdrawal from the situation is related to the difficulty of the diagnostic

process (Barnes et al. 1981). During the early phase of the disease, both the spouse and the victim know something is wrong, but it is nothing that can be easily identified. Physicians are often unable to explain the subtle early manifestations of the disease (Barnes et al., 1981, NIMH, 1979, Eisdorfer et al., 1981, Wells, 1977). Because of this high degree of uncertainty, emotions begin to run high even in the early stage of the diagnostic process. By the time a final diagnosis is made (a process that can take up to two years), families are often distrustful of and angry with physicians. After the diagnosis is made, many family members and spouses complain that the physician did not explain the disease to them (Barnes et al., 1981, Archbold, 1982). The stricken family needs support and information from the physician or other supportive health care professionals in order to plan an adequate program of care for the patient. Unfortunately, many caregivers have found health care professionals to be insufficiently informed about Alzheimer's Disease, its development, its ultimate consequences, and/or to be uninterested, and rejecting to their needs (Gwyther, 1982).

In the community as a whole, many health care delivery systems are so disorganized and with access points being so diffuse, that even involved professionals have difficulty knowing what services are available and under what circumstances people qualify for these services (Archbold, 1982).

Without information regarding the disease process, possible

genetic involvement, stress management, and services available, the caregiving family may not be able to function adequately. Poor management of a chronic illness such as Alzheimer's Disease has severe ramifications that reach far beyond simple emotional stress. The patient may actually suffer from inadequate care caused by lack of understanding on the part of the caregiver. The caregiver in turn may suffer from having to take on sole financial responsibility for the family, role reversal, inadequate legal aid, and from dealing with a patient who has a stigmatized illness.

Of course not all the problems experienced by the caregiver can be alleviated by support from the family physician, but the literature indicates that much of the disease process could be explained in a way that would help the caregiver understand what he/she is up against. A solid information base would ultimately help the caregiver develop a more effective health care plan for the patient. Eisdorfer et al., has outlined twelve functions that a physician could carry out that would help the caregiver maintain a reasonable level of functioning. These twelve functions are listed in Appendix B.

The main utility of continued involvement with the irreversible dementia patient and his/her family is to provide support and information about the disease to both parties with the hope of creating a more effective caregiving unit for the patient. While this is an ideal typical physician - caregiver - patient

relationship, it nonetheless is one that can be utilized for discovering the discrepancies between what should exist and what does exist for persons in this situation. Because one of the central problems associated with caregiving is the lack of adequate information about the disease (Wells 1977, Eisdorfer 1981, Archbold 1982, Barnes et al., 1981, Gwyther 1982, Lazarus et al., 1981, Powell 1983, Mace and Rabins 1981) and the withdrawal of health care professionals once the diagnosis is made, a relevant research question is: Why do health care professionals withdraw from the Alzheimer's Disease patient and family caregiving unit?

THE MEDICAL ENVIRONMENT

Because of the recency of the development of research in the area of Alzheimer's Disease it is here suggested that some physicians may lack adequate knowledge of the disease. This is not the only reason, however, for this suggestion. A careful look at the structure of the medical profession makes it evident that there are several barriers related to physician care of the terminal demential patient. The foremost of these barriers is related to the training of the physician who most frequently is taught that the main goal of medicine is to cure, rather than to maintain, a patient. They are not taught to deal with ambiguous diseases such as Alzheimer's, primarily because while the disease is organically based, it is manifested more as a mental illness than a physical one. Many General Practitioners and Family Prac-

tioners may, therefore, feel that this is one illness that is beyond their level of expertise, which may ultimately lead to withdrawal from the case. The second suggestion arising from this is that those professionals in the area of neurology, psychiatry, and psychology would have a much wider knowledge of Alzheimer's Disease for several reasons. First, it is a disease of the brain, and each of the health care professionals mentioned should have extensive knowledge of brain physiology. It is an organically based illness with manifestations that closely resemble that of a mental illness. Because of this fact alone, psychiatrists and psychologists perhaps may be more informed on the current research on Alzheimer's Disease. As described earlier psychologists are instrumental in determining the true mental status of the patient through various tests. This in conjunction with the ability of a psychiatrist to differentiate between a true dementia and a pseudo-dementia, place these professionals at the top of the list for potential involvement with patients suspected of having Alzheimer's Disease. Thus, a third suggestion becomes: neurologists, psychiatrists, and psychologists may have a more extensive knowledge of Alzheimer's Disease than will other medical specialists. There still exists, however, the problem of professional withdrawal. One assumption behind the suggestion that health care professionals withdraw is a prevailing assumption these professionals, regardless of background, do not have a clear idea of what the disease entails; and, they are not trained to provide supportive services to the family of the demented patient. Even after a definite diagnosis is made, since there is no

explicit therapy available, this further complicates the dilemma of the physician who is socialized to perform a curative rather than caretaking role.

It is the main purpose of this study to examine the issues that may facilitate a physician's withdrawal from the patient and family once a clear diagnosis of Alzheimer's Disease is made.

When the issue of professional withdrawal is addressed, several things need to be taken into account in order to understand fully the physician's position in the caregiving situation. These include: the doctor-patient relationship and how it is defined, the organizational setting in which this therapeutic relationship exists, the educational background of the physician, and the general medical model in which the profession is enmeshed.

The Physician-Patient Role Relationship
and Professional Withdrawal

Keeping in mind that the relationship being examined by this particular study is that between the primary physician and the primary caregiver to the Alzheimer's patient, it is important to examine the defining characteristics of the doctor-patient relationship when discussing the issue of professional withdrawal.

The initial stage in the development of patienthood in general is the pre-patient stage in which the person begins to recognize that something is wrong and consequently begins to seek pathways to a cure (Wilson, 1963). These pathways to better health often involve the seeking out of a medical doctor. Thus, the patient has initiated the relationship and has the greater or lesser voice in its course or termination. However, the practitioner has a nearly exclusive monopoly on psychological and social leverage (Ibid).

Once the patient has sought out medical treatment in the form of a diagnosis and a therapy plan for the illness, he/she has the social right to assume the "sick role". However, since the sick role has been defined as a deviant role, this prevents multitudes of people from engaging in the role simply to escape responsibility. As a consequence of the sick role definition, the patient becomes the deviant and the physician, the primary mode of social control (Wilson, 1963). By normative status definition, the physician is charged by society with the job of returning the sick person to full functioning and of reversing the tide of withdrawal (Wilson 1963). The issue is the process of defining who the patient is. If the patient is defined as the person in direct contact with the helping agency (Wilson 1963) then the primary caregiver could be a plausible candidate for involvement in the doctor-patient relationship. If, however, the patient is defined singularly as the person presenting the symptomatology,

i.e., the person with the illness, then the caregiver may no longer be privy to the physician's medical expertise. Another assumption of this thesis is that as noted previously, obtaining a thorough social history on a suspected Alzheimer's Disease patient is largely dependent upon the caregiver's input, thus compelling the physician to involve the caregiver in the therapeutic setting from the beginning; no longer disallowing caregiver involvement due to textbook definition of what constitutes the doctor-patient relationship. Medical professional withdrawal from such a situation is dependent upon more than how we choose to define who the patient is.

We must also examine the type of education the medical professional receives and how this impacts upon his/her perceptions of exactly what constitutes the responsibilities of a practicing physician. One of the most widely discussed teachings of medical schools is that of "affective neutrality". The medical student is socialized in how to be interested in the patient without becoming emotionally involved with the patient. Affective neutrality is the vital distancing mechanism that prevents the practitioner from becoming the patient's colleague in the illness, from entering an emotional contract whose mute provision would destroy his objective judgment along with his therapeutic and educational leverage (Ibid). Ideally then, the physician must remain separate from the emotionality of dealing with the Alzheimer's patient.

Another consideration in this problem area is the organiza-

tional setting in which the practice of medicine and caregiving take place. Most caregiving takes place in the home of the victim or the caregiving relative. For the physician, the home environment is the most limited and the least advantageous, for it is a setting controlled by the patient and the family (Wilson 1963). In this unfamiliar structure, the physician must cope with various individuals in a setting where he is seemingly on trial as to his medical abilities and technical capacity (Ibid). It is an environment in which the management of the interaction is out of the physician's hands (Ibid). On the other hand, if the physician cares for his patient in a medical environment such as the office setting, then the physician is the controlling individual. The M.D. is clearly in control as he determines lighting, timing and spatial arrangement, and inclusion or exclusion of third parties in the examining room. The patient must wait for the physician to initiate the relationship in this particular setting (Ibid). It becomes clear in this circumstance that the connotations of being a doctor include being one's own boss, being in control, and of having a great deal of professional autonomy. For this to exist, the physician must be in control, work alone, and have no long term obligations to his clients (Ibid); that is, he can terminate the relationship with a patient who does not concur with his diagnosis or treatment of Alzheimer's Disease. These factors help to explain, in part, the process of medical withdrawal from the caregiving situation.

Other factors must be taken into account in the examination

of the theoretical model by which the medical profession proceeds. The basic premise of the bio-medical model is that a specific biological cause is at the root of each symptom presented. In this medical approach the physician attempts to identify clusters of signs and symptoms that are causally related and that may be indicative of some underlying disorder (Mechanic, 1974). The identification of such clusters entails the use of the basic scientific knowledge and clinical research to obtain information on the etiology of the cluster, its likely course, and a possible treatment. Once the physician has identified the patient's problem, he can utilize the existing knowledge concerning the disease (Ibid).

All these factors impact heavily upon the caregiver and the situation in which they find themselves. It is a situation controlled by the caregiver and the severity of the symptoms experienced by the victim. The caregiver may indeed know more about the patient's condition than the physician. The elusive nature of Alzheimer's etiology, its variant course of development, and its similarity to other disease entities present the physician with a dilemma in diagnostic and therapeutic decisions. In this situation, the physician can do little except refer the patient and the family caregiving unit to supportive services that may be available within the community. It is also a situation that progresses largely in the home environment which has far different expectations than those in the structure of the medical office and medical decision making. It is an emotionally charged situation

in which information sharing between the caregiver and physician, not the physician and patient, is of primary importance. With all these intervening factors arising, it is reasonable to assume that health care professionals do exhibit a tendency to withdraw from the family caregiving unit once a diagnosis of Alzheimer's Disease is placed upon the patient.

CHAPTER III

METHODOLOGY

To obtain data on the existence of professional withdrawal from caregiving situations of diagnosed Alzheimer's cases by physicians, a questionnaire was administered to a sample population of forty-eight local physicians whose names and phone numbers were taken from the community phone directory. Although psychologists are also instrumental in the diagnosis of Alzheimer's disease, they are not included in the sample so as to limit it to the primary physician, who is the most likely candidate for contact with the Alzheimer's patient. The specialties of medical doctors included in the sample range from General Practitioner to Reconstructive Surgeon. No particular group of physicians was targeted simply because any physician, regardless of specialty, faces the possibility of having to deal with the Alzheimer's patient at some point. The questionnaire was designed to measure withdrawal indirectly. The rationale for this is simple. To ask the physician directly whether or not he/she knows about a given service, or about Alzheimer's Disease (given that such knowledge is considered to be a physician's professional responsibility), is to invite a socially desirable answer. By asking the same questions in an indirect manner which does not threaten the physician's status, it was expected that a more accurate reflection of the physician's knowledge of Alzheimer's Disease could be obtained as well as their perceptions of professional responsibility to Alzheimer's patients and their care-

givers.

The questionnaire consisted of four sections. Section One asked for general background information on the respondent. Items included the number of years of practice, medical school graduated from, medical specialty, and whether or not the respondent is currently treating any patients with Alzheimer's Disease. The assumption was that each of these items would impact upon how the physician deals with the terminal dementia patient. Section Two was designed to assess the respondent's knowledge of Alzheimer's Disease. The questions were based on facts taken from various sources ranging from medical textbooks on neurological disorders to articles targeted to the family caregiver. All the items listed were designed to test the general knowledge base of the respondent concerning Alzheimer's Disease. Section Three was designed to test for knowledge of community services available to the respondent and his/her clientele. The central question asked was, "would you refer the dementia patient and/or their caregiver to any of the following services?" A list of services was given to which the respondent answered "yes", "no", or "unfamiliar with service". In this manner, it was possible to determine what services were known to the physician. The list of support services in the Tidewater, Virginia, area was taken from information provided by the Dementia Center of Hampton Roads and from the Services Directory provided by Mental Health Services. Section Four was designed to determine what the physician felt was his/her professional responsibility to the terminal dementia patient and/or the

caregiving unit. The central question asked was, "as a physician, do you consider it your professional responsibility to carry out the following functions when dealing with a terminal dementia patient?" A list of twelve functions was taken from an article by Carl Eisdorfer, M.D., (1981), in which he outlines twelve functions an involved physician can carry out which would help alleviate some of the stress placed on the family caregiver.

As stated earlier, the questionnaire was designed to obtain evidence to test the claim in the literature that professional withdrawal is one of the most serious problems faced by caregivers to Alzheimer's Disease patients. Secondly, if the evidence demonstrates that withdrawal does occur, then some tentative probable sources of the withdrawal within the context of the disease and available services, could be generated. Overall, the goal was to establish what is communicated from physician to caregiver in order to assess what the possible problem areas are. If this investigation can establish the nature of the problem area, whether it is lack of knowledge of the disease, of services, or a combination of both; or if it simply does not fall into the realm of the physician's professional responsibility, then some preliminary recommendations can be made as to how to alleviate the problem(s). It is anticipated that the holistic research design with its inclusion of the structure of caregiving and the processes involved, will provide a perspective and information useful to improve the treatment of those afflicted with Alzheimer's Disease. This

project also builds on the questionnaire data gleaned from physicians by considering the roles of the primary caregiver, most often members of the Alzheimer's Disease patient's family. The views of the primary caregiver must be obtained in order to establish what has or has not been communicated about the disease, what to expect, and how to prepare a health care plan.

To gain this information, unstructured interviews were carried out with five local caregivers. These people were contacted through word of mouth referral through the local support group. The process involved was to ascertain what the caregiver thinks the physician knows in relation to this particular situation, what the caregiver knows, what communication goes on between physician and caregiver, and from what source the primary family caregivers receive their initial information about services that are available in the community.

The combined use of the questionnaire and unstructured interviews is aimed at obtaining an interactional view of what it is we need to know about the caregiving situation. Two things occur when this situation is examined. The first, of course, is that a diagnosis is made. This is a process that demands considerable expertise of all health care professionals involved. It also involves the use of knowledge from a wide range of sources and demands interaction between the various health care professionals and lay persons involved. It is a process that ultimately calls

for the role of the family caregiver to be assigned. The second thing that arises as a direct result of the diagnostic process is the adaptation of the caregiver to a new and demanding role. Is the adaptation achieved on a trial and error basis that demands a great deal of time and is often ineffective, or is it a somewhat easier process that is aided by careful guidance of the primary physician involved? These were the root issues to be examined with the hope of discovering what happens between the physician and the family caregiver toward the end of learning how to improve lines of communication between the two primary parties involved in the caregiving situation of Alzheimer's Disease clients.

CHAPTER IV

FINDINGS

The sources of the data presented below are questionnaire responses from unstructured interviews with local caregivers to Alzheimer's patients.

Forty eight questionnaires were sent, by mail, to physicians in the study area. The mailing yielded eighteen usable returns. Of these, seventeen respondents were male, one was female. The mean age of the respondents was 46 with the most commonly indicated number of years in practice being 5 to 10 years. Eight of the respondents had diagnosed a total of 148 patients as afflicted with Alzheimer's Disease, while the remaining 10 respondents indicated that they had never diagnosed a patient as being afflicted with Alzheimer's Disease.

TABLE I

**Number Of Alzheimer's Disease Diagnosed Patients
According To Medical Specialty**

Medical Specialty	Number	Number Patients Diagnosed
General Practice	2	2
Family Practice	2	17
External Medicine	1	6
Neurology	1	103
Psychiatry	2	20
Other Specialty	10	0
Total	18	148

Neurology was the leading diagnostic specialty where Alzheimer's Disease was concerned. Psychiatry and Family Practice were second, and third respectively, with Internal Medicine and General Practice making the fewest number of diagnoses.

When the respondents were asked to identify the medical specialty to which they would refer the suspect patient, fifteen of the eighteen responded. Of those fifteen, eleven indicated that they would refer the suspected Alzheimer's Disease patient to a neurologist, two would refer to an internal medicine specialist, one would refer to a psychiatrist, and one respondent indicated that referral would depend on the patient's primary physical problem. Seventeen respondents answered the question concerning the point in time at which such a referral would be made. Eight indicated they would refer the patient to the appropriate specialist upon their first suspicion that the patient may have Alzheimer's Disease; one indicated that he would always refer the patient but gave no time frame; one stated this disease was not within his field to diagnose and therefore no referral would be made; one indicated that rapid onset of symptoms would prompt referral; four indicated that diagnostic conferences were necessary in all suspect patients; one indicated that timing of the referral would depend upon the problems the patient was experiencing; and two respondents did not answer this question.

Section II of the questionnaire deals with the physician's knowledge of Alzheimer's Disease. See Appendix A for presenta-

tion of questions. Table 2 provides the medical specialty of each of the 18 respondents, the total number of questions concerning Alzheimer's Disease answered correctly, incorrectly, and the number of questions to which "Don't know" was the response.

TABLE 2

Frequency Responses On Knowledge Of Alzheimer's Disease
By Specialty Of Respondent

Specialty	Number of Respondents	Correct Answers	Incorrect Answers	Don't Know	Total Responses
ENT	1	8	2	0	10
Psychiatry	2	14	3	0	17
Family Practice	2	12	13	5	30
Gen. Practice	2	11	4	5	20
Ortho Surgery	1	6	2	2	10
Surgery	3	13	10	7	30
Neurology	1	6	4	0	10
OB/GYN	1	5	3	2	10
Int. Med.	1	4	4	2	10
Ophthalmology	1	4	5	1	10
Dermatology	1	3	2	5	10
Pediatrics	1	0	0	10	10
Urology	1	0	0	10	10
Total	18	86	52	49	187

There were some slight patterns indicated by these scores. Family Practitioners, Neurologists, Psychiatrists, and General Practitioners gave more correct responses. Questions number (1), (2), and (7) were the questions to which "Don't Know" was the most frequent response. Question One is stated as follows: "The sex ratio of the incidence of Alzheimer's Disease is 1 male per 2 females". It is understandable that some physicians may not be aware of the demographics of a disease as elusive in nature as Alzheimer's Disease is. Question Two read: "Neurofibrillary plaques and tangles are the most obvious physiological signs of Alzheimer's Disease". Eight of the respondents answered "Don't Know" to this question, indicating two things; (1). the wording of the statement was confusing, and (2). these respondents may have been unaware of these two major characteristics of this disease. It was pointed out by two respondents that plaques and tangles are not physiological in nature, but are pathological changes that are anatomical in nature. This indicates the remaining six respondents may have been aware of the significance of neurofibrillary plaques and tangles regardless of their nature. Question Seven also had eight responses of "Don't Know". The question read: "Alzheimer's Disease progresses through two distinct stages". Actually, the disease process progresses through four stages. More accurate, less misleading wording of this statement may have produced different results.

According to the results in Table 2, the best overall scores on Knowledge of Alzheimer's Disease were presented by those

professionals in the fields of ear, nose and throat medicine, neurology, and psychiatry; upholding one of the primary assumptions of this thesis; that those health care professionals in the fields of neurology and psychiatry would exhibit a higher general level of knowledge of Alzheimer's Disease. The total "Don't Know" answers by Pediatricians and Urologists and relatively high number of incorrect answers presented by the Opthomologist are a reflection of their various specialties and the lack of emphasis placed on diseases so elusive in nature as Alzheimer's Disease.

Section III of the questionnaire concerned the knowledge of community services available and whether or not the physician would refer the patient and family caregiving unit to these services. This was perhaps the most enlightening area explored within the confines of this study. The central question was "would you refer the dementia patient and/or family caregiving unit to any of the following services?" A list of twelve services (see Appendix B) was provided to which the respondents replied, "yes", "no" or "unfamiliar with service". As Table 3 indicates, unfamiliarity with community services is a serious problem for those professionals in a position to make frequent use of these services. Of eighteen total responses concerning referral to the Dementia Center, sixteen marked "unfamiliar with service" as their response. Ten of the eighteen respondents were unfamiliar with the local support group meetings for Alzheimer's patients and caregivers. Overall, almost one half of all the respondents included "unfamiliar with service" indicating a serious break in the gener-

al health care referral system. In conjunction with this, the question "what are your best sources of information about community services available in the Tidewater, Virginia, area for dementia patients?" was asked. Nine respondents indicated they had no good source of information concerning community services for these patients. Four respondents listed Williamsburg Community Hospital as their primary source of community service information; two listed "professional consultants", and one respondent each listed Community Home Health Care of Williamsburg, Eastern Virginia Medical School, and Eastern State Mental Hospital as their information source for available community services.

TABLE 3
Physician's Knowledge Of Service Organizations
And Incidence Of Referral

Service	Would Refer		Unfamiliar with
	YES	NO	Service/No Response
Dementia Center Norfolk General	2	1	16
Colonial Services	4	4	7
York Co. Home Health Care	6	3	9
Peninsula Agency on Aging	5	3	8
Williamsburg Commu- nity Home Health Care	8	3	6
ADRDA of Hampton Roads	8	1	7
Hancock Geriatric Center/ESH	10	2	5
Public Health/ Home Care	9	2	6
Patrick Henry Care Center	7	3	5
Hampton Support Group	2	1	11
Williamsburg Support Group	7	1	10
Peninsula Evening Support Group	2	1	11

Total Respondents = 18
(Some respondents did not mark each question)

Section IV of the questionnaire concerned what the physician felt was his/her professional responsibility to the terminal dementia patient. See Appendix C for the list of services. Five respondents stated that none of the responsibilities listed were their own as they were not primary care physicians. However, of the remaining thirteen respondents, a high percentage felt that all but making home visits was their professional responsibility as a physician. One respondent stated that he would arrange for a home health care nurse to make continuing home visits for the Alzheimer's Disease patient. Only two respondents felt that all twelve functions listed in Section IV were the responsibility of the physician; the medical specialties of these respondents were family and general practice.

A variety of closing comments were made by the respondents in the space provided at the end of the questionnaire. These are stated below.

- 1). "All too often dementia seems to equal Alzheimer's Disease. Granddad is forgetting=dementia=Alzheimer's Disease. M.D.s must evaluate each patient closely to rule out reversible forms of dementia. The recent media stress on Alzheimer's Disease sadly neglects this fact."

(Psychiatrist)

- 2). "Many families are aware of the facts, information sources, and referral groups prior to discussion of dementia."

(Family Practice)

- 3). "The treatment and course with each family is so different, it makes questionnaire difficult." and "information about support services not well known to me."

(Internal Medicine, 5-10 years practice)

- 4). "The questionnaire is inappropriate for me, should be directed to primary care physician."
- 5). "Practicing a surgical specialty, I have very little opportunity to diagnose, treat, or refer patients with Alzheimer's Disease. My answers to this questionnaire should be considered in that light."
- 6). "I am not a primary care physician. Patients are treated by me for special surgical problems and released from my care. However, I have treated some Alzheimer's Disease patients."

In summary, the information gleaned from these questionnaires supports the main assumption of this thesis. As expected, neurologists and psychiatrists had the best scores on the questions concerning knowledge of Alzheimer's Disease. However, no one respondent achieved a perfect score. The second assumption of this thesis, that physicians in general are poorly equipped to

provide supportive services to caregiving families, was strongly supported. Even though the majority of the respondents felt that referral to community services was the responsibility of the physician, the results show that a high percentage of these professionals were unaware of what community services were available.

If those in a position to make frequent referrals have little knowledge of services available, then referrals simply cannot be made, which creates a situation in which the physician is induced to withdraw from the caregiving situation. If this should occur, it reduces information sharing between physician and caregiver and renders caregivers bereft of professional information needed to care for their loved ones.

A third assumption, that the home environment in which most family caregiving takes place, is considered off-limits by physicians was supported to some extent. When asked if they felt it was their professional responsibility to make home visits for the Alzheimer's patient, the most frequent response was "no".

A fourth and final assumption of this thesis was that physicians may tend to view Alzheimer's Disease as one that is not part of their particular medical expertise. Five respondents took the time to write personal comments whose consistent theme was, "This questionnaire is inappropriate for me, as I am not a primary care physician".

The information gleaned from unstructured interviews with five family caregivers in the area elaborated on some of the information gained from the questionnaires. All five participants were female, with their age range being from 42 - 75 years of age. Two were caregivers to their husbands, and three were caregivers to their aged mothers. The focus of the interview was to identify the range of knowledge the caregiver had of services available, whether or not they participated in a local support group, and to determine if they felt that their physician had provided them with enough information to work with when engaged in the activity of caregiving.

Each respondent exhibited a reasonable level of knowledge of the disease. The book, The Thirty Six Hour Day (Mace and Rabbins, 1981), was mentioned by each respondent.

Of the list of services mentioned (the same list on the questionnaire), all caregivers were familiar with the Hampton Roads ADRDA Organization, Williamsburg Home Health Care Co., Patrick Henry Health Care Center, and its day care program, and the local support group. Only one respondent could identify the source of her information, the local newspaper, concerning the services available. Each had participated in the local support group but had dropped out. The universal reason given for this was that while information sharing was adequate, not one of the participants felt they had received any emotional support during the meetings. One participant characterized the meetings as a

lecture session during which the "students" were allowed only to listen but not draw people into a sharing experience. The local support group lacked the key ingredient of the ideal support group, the knowledge on the part of the participants that these meetings are places where they could come for emotional reinforcement and support in conjunction with information sharing.

Each respondent had the same answer to the question, "Do you feel like your diagnosing physician fulfilled his responsibility to you as a concerned family member, upon the diagnosis of the illness?", and each said "yes". The response that each of these participant's physicians had given them was in one way or another, "get your affairs in order, get a lawyer, and start looking for nursing home placement possibilities".

Each participant felt that his/her physician had carried out his primary responsibility in the diagnostic process itself; however, each voiced the desperate need for further information concerning what to expect in the future, and where to begin the search for information.

Three of the participants had very well organized family support systems, such that the ill individual spent six months with one caregiver, six with another. They had family members who sent newspaper clippings concerning drug testing, information on the disease itself, and coping mechanisms for caregivers. These clippings helped the caregivers devise effective methods of

care delivery. The other two caregivers, bereft of these support mechanisms, simply proceeded by trial and error. Each had effective plans and arrangements for the moment and felt it was their sole responsibility to care for the affected family member.

In closing, the descriptive hypothesis presented in this study received limited support based upon the observations gleaned from the surveys. One glaring new finding is that primary health care professionals do not possess adequate knowledge of community services available to terminal dementia patients. Given the media attention on the disease itself and the heavy emphasis upon the need for supportive services, one must pose the question as to why a breakdown exists between those in the community service field and those in the medical profession.

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

Several caveats must be made concerning this study. First, the sample size was small and limited to the Williamsburg, Virginia area disallowing generalizations from outside this area. Although forty-eight questionnaires were mailed out with two follow up reminders, only eighteen usable questionnaires were returned, lessening the impact of the information gleaned from these surveys. Another problem related to the questionnaire itself, was that even on those questionnaires that were usable, not every question was answered. This made scoring the items difficult at best and also impacted on interpretation of the data itself.

A second problem with this study centered around the unstructured interview. Only five family caregivers were available for participation in the interview and these were chosen by word of mouth referrals. These two facts alone may indicate that those selected may be somewhat less than representative of the general caregiver population at large. The names of the participants were obtained from the Williamsburg Alzheimer's support group roster. The fact that each participant had at one time or another been a part of the support group, but had subsequently "dropped out", further clouds the utility of the information

obtained during the unstructured interview.

Even with these problems surrounding the actual data from the questionnaire, one very important piece of information was gained from this study.

The data indicate that physicians manifest a serious lack of information concerning availability of community resources. It was not the intent of this study to place blame upon physicians or to imply that medical professionals do not adequately perform this job. It was the intent to identify where a breakdown exists within the information system of those professionals involved with Alzheimer Disease patients. This study has provided one very important bit of information, that is, that physicians have very limited knowledge of community resources available.

Without adequate knowledge of what a particular community can offer, a physician cannot fulfill what he/she views as one of their primary responsibilities, that of referring families to appropriate community treatment resources. Without the referral, families often are unable to cope with the excessive demands of caregiving, nor can they devise effective health care plans for the individual for whom they are principal or only caretaker.

An end result of this barrier to solid referrals is the misuse and/or lack of use of services available to people within a given area. Thus, the problem is not one faced solely by the

primary physician, but one that runs throughout the human service and health care delivery systems. Although this study did not try to locate exactly where a breakdown in communication occurred, it would appear that a community service delivery system must publicize its services and qualifications to provide effective service to the public. Recent employment within both the community service system and health care delivery system has taught me that not only does duplication of services exist, but also that many community service workers are aware of only the particular service they deliver. A plausible solution to this situation might be to place service specialists within the professional associations of primary care physicians to act as links among the physician, the patient-family, and community services. Most major acute care facilities do employ social workers for just that purpose, but this does not include those persons who are not within the acute care setting, those persons who leave their doctor's office in need of meals on wheels, food stamps, or some other supportive community service.

With all the changes occurring within the health care delivery system today, it is crucial to make community resources more available to those in the community they are supposed to serve. One suggested solution to this dilemma is the appropriate placement of social workers within the present health care delivery system which include: doctor's offices, home health care organizations, acute care facilities and long term care facilities. This should be instituted along with better planning

of services to the community than currently exists. An interim procedure would be to make known the community services available for Alzheimer's patients. Colonial Services in Williamsburg has a Handbook which serves as an excellent example of the sort of information which should be made widely available. Such a services handbook should be made available to all physicians and area health care organizations. Perhaps the ultimate outcome of such an endeavor would be the reduction in felt physician - patient - family withdrawal in terminal cases such as Alzheimer's. A service manual would be an invaluable tool for a physician who has no real treatment for his/her Alzheimer's patients.

So far as the problems encountered by participants in the local support group are concerned, several suggestions can be made. 1). Have the support group leader contact the Tidewater ADRDA for help in reorganizing the structure of the group so that the caregiver needs are more fully met; 2). publicize the meeting with weekly reminders in the local newspaper; 3). above all, remember that the caregivers are there for emotional support as well as information.

APPENDIX A

APPENDIX A

ALZHEIMER'S DISEASE AND THE ROLE
OF THE PHYSICIAN

This section is designed to obtain general background information on the respondent. Please answer each question in the space provided, or place an "X" in the appropriate set of ().

Section I
GENERAL BACKGROUND INFORMATION

- 1). Gender: () Male, () Female
- 2). Age: _____
- 3). Number of years in practice:
 less than 5
 5 to 10
 11 to 15
 16 to 20
 over 20
- 4). Medical school graduated from: _____
- 5). Medical specialty:
 GENERAL PRACTICE
 FAMILY PRACTICE
 INTERNAL MEDICINE
 NEUROLOGY
 PSYCHIATRY
 OTHER, please specify: _____
- 6). Number of patients you have ever diagnosed as having Alzheimer's Disease: _____
- 7). Are you currently treating any patients with Alzheimer's Disease? () yes () no
7A). If yes, how many: _____
- 8). Number of patients with Alzheimer's Disease symptoms that you have referred to a specialist: _____
- 9). Please indicate if and at what point you would refer an Alzheimer's patient to a specialist:

- 10). To what type of medical specialist would you refer the Alzheimer's patient? _____

**ALZHEIMER'S DISEASE AND THE
ROLE OF THE PHYSICIAN**

**Section II
Knowledge of Alzheimer's Disease**

Please place an "X" in the appropriate column for each of the following items.

	AGREE	DIS- AGREE	DON'T KNOW
11). The sex ratio of the incidence of Alzheimer's Disease is 1 male per 2 females.	()	()	()
12). Neurofibrillary plaques and tangles are not the most obvious physiological sign of Alzheimer's Disease.	()	()	()
13). Alzheimer's Disease may mimic Down's Syndrome symptoms in younger children.	()	()	()
14). The EEG is not conclusive in diagnosing Alzheimer's Disease.	()	()	()
15). The brain biopsy does not provide a conclusive diagnosis of Alzheimer's Disease.	()	()	()
16). One frequent initial symptom of Alzheimer's Disease is the inability to deal with numbers.	()	()	()
17). Alzheimer's Disease progresses through two distinct stages.	()	()	()
18). The Alzheimer's Disease patient loses past memories but can form new memories.	()	()	()
19). As the disease progresses, the Alzheimer's Disease victim often experiences word finding pauses.	()	()	()
20). Alzheimer's Disease and Senile Dementia are two separate disease entities.	()	()	()

What are your best sources of information about Alzheimer's Disease?

**ALZHEIMER'S DISEASE AND THE
ROLE OF THE PHYSICIAN**

Section III

Please place an "X" in the appropriate column for each of the following items.

Would you refer the Dementia patient and/or their caregiver to any of the following services?

	YES	NO	UNFAMILIAR WITH SERVICE
21). The Dementia Center	()	()	()
22). The Colonial Services	()	()	()
23). York County Homemaker/ Health Aide Service	()	()	()
24). Peninsula Agency on Aging	()	()	()
25). Community Home Health Care of Williamsburg	()	()	()
26). The Alzheimer's Disease and Related Disorders Association of Hampton Roads	()	()	()
27). Hancock Geriatric Center Eastern State Hospital	()	()	()
28). Public Health Dept. Home Care Division	()	()	()
29). Patrick Henry Health Care Center	()	()	()
30). The Following Support Group Meetings:			
Hampton Satellite Group	()	()	()
Williamsburg Satellite Group	()	()	()
Peninsula Evening Support Group	()	()	()

What are your best sources of information about community services available in the Tidewater, Va., area for Dementia patients?

**ALZHEIMER'S DISEASE AND THE
ROLE OF THE PHYSICIAN**

Section IV

This section of the survey is designed to identify what you, as the physician, define as your professional responsibility to the Alzheimer's Disease patient and his/her family caregiving unit. Please place an "X" in the appropriate column for each item.

As a physician, do you consider it your responsibility to carry out the following functions when dealing with a terminal dementia patient?

- | | YES | NO |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|-----|
| 31). Provide the family with specific information about the nature and course of the dementing illness. | () | () |
| 32). Provide primary medical and psychiatric care to maximize the level of independence of the patient and the family. | () | () |
| 33). Refer families to appropriate medical specialists. | () | () |
| 34). Assist the family in dealing with the decision of institutionalization. | () | () |
| 35). Alert the family to the need for acquiring proper legal aid in dealing with financial and other personal business matters. | () | () |
| 36). Refer the family to appropriate community and social services where they exist. | () | () |
| 37). Provide counseling or psychotherapy where personal, marital, or family problems become manifest. | () | () |
| 38). Make home visits to understand the patient's living conditions and involve consultants to help eliminate physical barriers and help maximize the independence of the patient in his/her environment. | () | () |

ALZHEIMER'S DISEASE AND THE

ROLE OF THE PHYSICIAN

- | | YES | NO |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|-----|
| 39). Obtain ongoing psychological and cognitive assessments to monitor the patient's strengths and weaknesses, and to provide a basis for helping the family work effectively with their ill relative. | () | () |
| 40). Work with the family or caregiver to develop therapeutic strategies and to cope effectively with the stress of caregiving. | () | () |
| 41). Refer the patient and family to self help groups in the community. | () | () |
| 42). Provide medication as needed. | () | () |

Please use the following space for any additional comments you want to make on any aspect of the physician's role regarding Alzheimer's Disease patients and their care:

APPENDIX B

FUNCTIONAL ASSISTANCE BY PHYSICIANS TO CAREGIVERS

- 1). Provide the family with specific information about the nature and course of the dementing illness,
- 2). Provide primary medical and psychiatric care to maximize the level of independence and functioning of the patient and family,
- 3). Refer families to appropriate medical specialists,
- 4). Refer the family to appropriate community and social services where they exist,
- 5). Assist the family with the decision of institutionalization,
- 6). Alert the family to the need of acquiring proper legal aid in dealing with financial and personal business matters,
- 7). Provide counseling or refer to psychotherapy where personal, marital, or family problems become manifest,
- 8). Make home visits to understand the patient's living environment and involve consultants to help alleviate physical barriers and help maximize the independence of the patient in his/her environment,
- 9). Obtain ongoing psychological assessments to monitor the patient's strengths and weaknesses, and to provide a basis for helping the family work effectively with the ill individual,
- 10). Work with the family or caregiver to develop therapeutic strategies and to cope effectively with the stresses of caregiving,
- 11). Refer the patient and family to self help groups in the community,
- 12). Provide proper medication as needed without sedating the patient or inducing drug dependence.

(Eisdorfer, et al, 1981).

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