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**The Relationship Between the Classification of Dementia and
Social Policy and Consequent Delivery of Services**

Brigitte Pennington

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**The Relationship Between
the Classification of Dementia and Social Policy
and Consequent Delivery of Services**

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Abstract

The American population is getting older, and with the aging of the population the prevalence of chronic illnesses will increase. Current social policies that are intended to assist elderly persons and their families in case of illness are no longer sufficient to meet that need, and will decline further as the number of older persons increases. This is especially true for patients who have developed dementia, including Alzheimer's disease, because dementias are still considered that "peculiar disease of the cerebral cortex" described by Alois Alzheimer in 1907 that seems not to fit any current classification.

This study was designed to explore how the classification of dementia has influenced the social policies that govern a variety of institutions and systems, and the ultimate outcome for the provision of care for dementia patients and their care givers. Its purpose is to describe the current reality faced by dementia patients and their families.

The focus of the study was an exploration of written policies, rules, and regulations that govern existing systems, and how such written rules affect the patients based on the classification of their disorder. After an exploration of written material and description of the resulting services, interviews were conducted to complement the previously mentioned material with the experiences of those who are charged with the delivery of care based on such rules.

The findings from this study lend support to the following conclusions: 1) the classification of dementias as mental illness can lead to involuntary psychiatric hospitalization or reduced reimbursement if treated on an outpatient basis; 2) the classification as deterioration with aging that requires support only results in lack of

formal support outside of institutionalization and almost no reimbursement by Medicare or Medicaid for treatment and care in home setting; 3) the seldom used classification as a physical illness allows for most but still insufficient support. All classifications frequently lead to the impoverishment of the patient which in turn often leads to institutionalization.

It is concluded from this study that the classification and the social policies based on such classification have become dysfunctional for the original population of older and ill persons and their families, but have become functional for new industries, professions, and bureaucracies. Further studies should investigate how the policies can again become functional for the intended population, and whether re-evaluation of the classification for dementia can be a first step in that direction.

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Chapter 1 - Introduction

The American population is growing older, and many people age without significant health or economic problems. However, a proportion of the aging population will develop one or more chronic illnesses, some that are considered physical and others that are considered psychological. It is the segment of the chronically ill that will be discussed, specifically those elderly persons who develop dementia, especially of the Alzheimer's type. It is the purpose of this study to explore how the classification of dementia has influenced social policies that govern a variety of institutions and systems, and the ultimate outcome for the provision of care for dementia patients and their care givers.

Obviously, people have always aged, some of the aged needed assistance, and families and communities had to find ways to provide that assistance. However, the introduction of Medicare and Medicaid in the mid 1960s, as well as the entry of a large number of women into the workforce, may have forever changed how elder care is provided in our society. Furthermore, never before in American history did people have a life expectancy as long as they have now, and never before in American history were the elderly the fastest growing segment of our population, a trend termed "the graying of America."

The Effects of the Graying of America on National Financial Resources

The postwar period of the 1950s was marked by unbound optimism in the future (Holstein, 1993). One indication of this optimism was the increased birthrate in the country during that period, resulting in the "baby boom" generation. While the birthrate

during the Depression of the 1930s was at 75.8 births per 1,000 women of childbearing age, during the 1950s it soared to 122.7 births, and began to drop in the 1960s until it had declined to 67.0 births in 1990 (Popenoe, 1993). At the same time, life expectancy was increasing continuously. Obviously, high birthrates and low mortality will result in an older population. Table 1 demonstrates this trend from 1970 to the year 2050.

Table 1 - Population by Age 1970 - 2050
(in thousands)*1993 - 2050 projected (middle series)

Year	Total	65-74 years	75-84 years	85 years
1970	203,235 (100%)	12,443 (6.1%)	6,122 (3.0%)	1,408 (0.7%)
1980	226,546 (100%)	15,581 (6.9%)	7,729 (3.4%)	2,240 (1.0%)
1990	248,710 (100%)	18,045 (7.3%)	10,012 (4.0%)	3,021 (1.2%)
1993*	257,927 (100%)	18,650 (7.2%)	10,628 (4.1%)	3,315(1.3%)
2010*	300,431(100%)	20,978 (7.0%)	13,157 (4.4%)	5,969 (2.0%)
2030*	349,993 (100%)	37,429 (10.9%)	23,348 (6.7%)	8,843 (2.5%)
2050*	392,031(100%)	34,628 (8.8%)	26,588 (6.8%)	18,893 (4.8%)

Source: U.S. Bureau of the Census, Current Population Reports, p. 25-1104

Evidently, the aging population is occupying an ever increasing percentage of the total population. The cohort of Americans aged 65-74 increased from 6.1% in 1970 to 7.3% in 1990, and is expected to represent 8.8% of the population by the year 2050. For the cohort 75-84, the increase was from 3% in 1970 to 4% in 1990, and is projected to be 6.8% by 2050. For the 85 and over cohort, the increase is from 0.7% in 1970 to 1.2% in 1990 to projected 4.8% in the year 2050. This means that the first group may increase by 2.7%, the second by 3.8%, and the oldest group by 4.1% over a period of 80 years.

The fastest growing cohort, age 85 and over, is the group with the highest prevalence of chronic illness, including dementia. Currently, only 1% of people in the age group from under 65 to 74 years are diagnosed with severe dementia. This increases to

7% for the group age 75 - 84, and to 25% for those over 85 years (Coleman, 1994).

According to data released by the Alzheimer's Association (1992), approximately four million Americans have Alzheimer's disease and, unless a cure is found, more than 14 million Americans will be afflicted by the middle of the next century. Alzheimer's disease is the most common type of senile dementia, representing over half of all dementia cases (Alzheimer's Association, 1992). The pathologic changes in the brain, while less marked in other senile dementias than in Alzheimer's disease, are identical and thus, "the distinction between senile dementia and Alzheimer's disease is ... arbitrary" (Guenther, 1983). Since Alzheimer's disease is a type of senile dementia, the terms dementia and Alzheimer's disease will be used interchangeably throughout this study.

Today, Alzheimer's disease costs society approximately \$90 billion a year. This means that the cost for the year 2050 could be estimated at \$315 billion excluding any increase in health care cost. A report by the Alzheimer's Association (1994) states, "A new report that Alzheimer's disease will cost this country \$1.75 trillion is further evidence that this disorder is an urgent public health issue requiring immediate attention ... Alzheimer's disease is draining the resources of this country, and its citizens, at a great rate" (1). Even if we assume that the cost estimated by the Alzheimer's Association, an advocacy group, is on the high side, cost for dementia care may become tremendous when we consider the following expenditures. The national health care expenditures for 1991 were 13.2% of the Gross Domestic Product (GDP) with \$751.8 billion. Compared to the 1960 expenditures of \$27.1 billion (5.3% of the GDP), this represents an increase of 7.9% and \$724.7 billion over the last thirty-one years. Considering the rate of health care cost

increases from 1960 to 1991, together with the population and dementia prevalence projections, proactive policies are absolutely necessary. Summarizing the impact Alzheimer's disease will have not only on fiscal resources, but on all aspects of society, Scinto (1995) writes: "Today Alzheimer's disease is poised to become the plague of the next century" (2).

Dementia: A Topic for Sociological Investigation

It appears that the study of health care issues related to aging should be the arena of health care professionals and fiscal and insurance policy makers, not of sociologists. Some sociologists, including Habermas and Foucault, warn against sociologists becoming social engineers or providing the blueprints for social engineering. However, Farganis (1993) illustrates how sociology can investigate a topic without getting involved in social engineering. He writes, "For Weber, scientific analysis was a tool for understanding social reality and not an appropriate instrument for social change" (107). Furthermore, as Sudnow (1967) noted when studying dying, biological events such as dying or illness occur within a social context and have social consequences; thus they are an appropriate topic for sociological investigation. It is the role of sociology, and was the intent of this study, to increase the understanding of social reality, that is, what factors are contributing to the dilemma society is facing in providing adequate support for dementia victims and their families.

Obviously, the issues of an aging population and how to provide adequate health care for that population are complex. When analyzing how dementia care is provided and paid for, it becomes apparent that care and payment for such care by the main insurance

carriers for senior citizens, Medicare and Medicaid, is related to how the disease is classified. Classification is explored in greater detail in the following chapters. Some consider dementia a mental illness, others see it as a physical illness, and yet other perceive dementia as a human state of deterioration requiring custodial care only. Depending on how dementia is classified, different systems may be accessed to assist the dementia patients and their families. Consequently, different sociological concepts may be useful in understanding society's dilemma when dealing with dementia. The concepts of deviance, labeling, function and dysfunction, and bureaucracies were utilized as they apply to the different concepts and systems.

Method of Investigation

To explore how the classification of dementia influences social policy and outcome, a variety of research methods were used. The study was mainly exploratory with some descriptive components. The units of analysis were the various institutions and systems, with a focus on their policies, that provide services to patients and their families. This included the mental health system and the legal system as it relates to the mental health system, the nursing home, adult residence, and home health industries, social service and social security agencies as well as private insurance carriers and primary health care providers.

According to Babbie (1992), exploratory studies are useful to determine whether a more careful study of the topic is feasible and what methods should be employed in a more extensive study. Answers from an exploratory study also "suggest ways in which ... complexities could be tapped in a more structured questionnaire to be administered to a

much larger sample” (91). Therefore, before exploring detailed components and utilizing a larger and more representative sample of persons involved in dementia care, the current study explored what systems are in place, why they are in place, and how the classification of dementia influences their function.

As a first step, secondary sources in form of a literature search were used to determine how and why certain systems have developed and whether classification plays a role in these systems. Because of the various systems and their respective jurisdiction, natural and social science literature were used such as medicine and nursing, and respectively, sociology, psychology, gerontology, and social work. Additionally, the legal literature and material from advocacy groups were used, together with material from government sources and the health care industry. Special attention was paid to the exploration of policies governing Medicare and Medicaid, the main sources of payment for health care of dementia patients. The focus of the search was a) on antecedents for present policies and systems and b) whether those policies are still useful or functional for the intended target population.

Although policies and regulations do exist, often times there is a gap between the ideal and the real. Therefore, to understand the real world of care, unstructured direct and telephone interviews were conducted with key staff from various agencies. Key staff are those that are responsible for development of policies or that have major responsibility for implementation of these policies. Typically they are in administrative/managerial roles, and they usually have the best understanding of their organization’s policies, regulations, and programs. In addition, some field staff were interviewed to explore whether written

policies and implementations are consistent with each other, and how well these policies and practices fulfill their purpose for dementia victims and their formal or informal care givers. Field staff are those who work directly with either the patient or the care giver and are typically social workers, nurses, or others in service providing roles, including physicians. The field research method is appropriate for the interviews because “field research can reveal things that would not otherwise be apparent” (Babbie, 1992, p. 286), thus validity of qualitative field research is usually superior to that of quantitative methods.

The unstructured interview, according to Lofland and Lofland (1995), is “a guided conversation whose goal it is to elicit from the interviewee ... rich, detailed materials that can be used in qualitative analysis” (18). The investigator in this study worked for approximately twelve years in the field of gerontology and has developed good rapport with key staff and field workers in various organizations. While not a full participant in most organizations, she was a partial participant-as-observer, and in one organization, the mental hospital that will be explored, a full participant-as-observer. Lofland and Lofland (1995) suggest that the researcher should not be overly concerned with the contamination of data due to the closeness of the participant-as-observer to the study topic and the unit of analysis. However, they find a tension between “distance and closeness in the researcher” beneficial to the richness of data. The researcher in this study was not directly involved in patient care services, yet was close enough to the systems to gather honest data from the interviewees. Of course, this raises some ethical concerns. But before discussing the ethical concerns, some shortcomings of the exploratory field research must be addressed.

Field research in the form of interviews is usually less objective than quantitative methods. The interpretation of the material is subject to the researcher's position on a topic, especially when the information provided is reported in a descriptive manner. A comparative analysis, when possible, will increase reliability (Babbie, 1992). Replication, while increasing reliability, is usually difficult since the interview will be largely unstructured, and thus the interaction between the researcher and the informant may not be replicable.

Obviously, the problem with reliability also leads to a problem with generalizability of the collected data. While field research may give the investigator a more in-depth understanding of the research topic, the sampling techniques required to generalize data are usually not met (Babbie, 1992). A generalizability problem specific to this study is the unit of analysis. The organizations studied are state agencies of the Commonwealth of Virginia or organizations that are regulated by the state as, for instance, the nursing and adult homes. While the issues in all states are somewhat similar, they are still different enough to prevent generalization. A comparative analysis of the policies and programs of all fifty states, as it was recently conducted (and federally funded) in the field of elder abuse, may be necessary but was beyond the scope of this study. Nevertheless, as previously discussed, this is an exploratory study and the results may be useful in the development of more in-depth studies that can employ methods better suited to meet more rigorous reliability and generalizability requirements.

Ethical Considerations

Finally, ethical considerations must be addressed. It is necessary that no harm,

either physically, psychologically, or socially will result from a study for those who participate in it. While physical danger was very unlikely to participants in this study, job security could have become an issue for an informant. Therefore, anonymity and confidentiality, as well as voluntary participation in the study, were essential. All interviewees were notified of the intent of the conversation with the assurance that their identity would not be revealed in reporting data or for any other purposes, unless they agreed to have their names disclosed. In addition to protecting the interviewees, this practice also increased the likelihood that they were revealing issues beyond the official policies.

An additional ethical consideration specific to this study was the possible effect of the results on dementia victims and their families. As previously mentioned, this study attempted to increase the understanding of social reality, that is, whether the classification of dementia is contributing to the dilemma of providing adequate support for dementia victims and their families. While improvement in the provision of services is always desirable, further intensive studies should be the basis for social policy and programmatic changes. This exploratory study should only be a first step and was by no means intended to provide a blueprint for social change.

Organization of the Project

With this introductory chapter having defined the research topic, its relevance to society, why it should be investigated from a sociological perspective, and methods and ethical considerations, the following chapters will present the findings and conclusions.

As a basis for better understanding dementia, chapter two will explore common

definitions and classifications of dementia, and then describe what dementia of the Alzheimer's type is, based on current knowledge. It will also cover how dementia patients enter the treatment and care system, and how the classification of their disorder will affect the consequent course of care.

Chapters three and four will explore the treatment and care system available to the patients and their families. The discussion in chapter three will cover the role of institutional inpatient psychiatric care when dementia is classified as a mental illness. This will include the involuntary commitment process. The focus in chapter four will be on the consequences when dementia is not classified as a mental illness. Institutionalized care for patients in non-mental health settings such as nursing homes and adult care residences will be discussed, and care in a private home together with community options for the patients and home care providers.

Chapter six will explore how payment for treatment and care is based on classification, thus how social policies governing payment are driven by classification. Also, the function and dysfunction of social policies and of classification will be discussed. The advantages and disadvantages of bureaucracies to administer policy-driven systems will conclude that chapter.

With the previous chapters having covered the treatment and care options and the payment for treatment and care, chapter six will attempt to show how societal values may influence these topics and the ethical dilemma they present. To explore some alternatives, a brief discussion will be given of the social policies some other countries have implemented to address the problem of caring for the chronically ill, with a special focus

on the German model. The conclusion of that final chapter is intended to encourage a re-evaluation of our present thinking about the classification of dementia based on current knowledge.

It is hoped that the research will increase awareness of the difficulties facing dementia patients, their care givers, and society, and how classification may have contributed to care in systems that are not be in the best interest of the elderly population and their families. Furthermore, it is hoped that a comprehensive understanding of the present reality and how it developed will lead to future research into better methods to generate social policy that fulfills the needs of the individual patient, the care givers, and society within the constraints of dwindling resources for health care.

Chapter 2 - Definition and Classification

To provide a basis to better understand why the definition and classification of dementia is problematic, this chapter will explore how dementia is defined and classified, and what dementia actually is, based on current knowledge. Furthermore, how classification influences the entrance of the patient into various health care or custodial settings, and how the setting entered may influence the patient's future care, will be discussed.

The definition and classification of dementia varies with disciplines. The linguistic, legal and general medical definition and the psychiatric classification will be explored.

Definitions

Linguistically, the term "dementia" is derived from *dement*. Dement is defined in the Oxford English Dictionary (1971) as "... out of one's mind." The American Heritage Dictionary, Second College Edition, (1982) gives a more precise definition as follows: "Dementia ... 1. Irreversible deterioration of intellectual faculties with accompanying emotional disturbance, resulting from organic brain disorder ..." and "Dement ... [Lat. *dementare*, Lat. *demense*, mad: *de-*, from + *mense*, mind]."

Black's Law Dictionary - 1st edition, published in 1891, gives the following legal definition of dementia: "Senile Dementia - That particular decay of the mental faculties which occurs in extreme old age, and in many cases much earlier, whereby the person is reduced to second childhood, and becomes sometimes wholly incompetent to enter into any binding contract, or even to execute a will. It is the recurrence of second childhood by mere decay." The 6th edition, published in 1990, separates the terms senile and dementia,

thus offering the following two definitions: “Dementia: Form of mental disorder in which cognitive and intellectual functions of the mind are prominently affected; impairment of memory is early sign; total recovery is not possible since organic cerebral disease is involved.”

“Senile: Quality of being senile; an infirmity resulting from deterioration of mind and body experienced in old age. Feebleness of body and mind incident to old age; and an incapacity to contract arising from the impairment of the intellectual faculties by old age.”

A medical definition is provided by the Stedman’s Medical Dictionary (1989) in the chapter on *neurological* [italics added] disorders as follows: “Dementia [L. Fr. De-priv. + mens, mind] ... a general mental deterioration due to organic or psychological factors; characterized by disorientation, impaired memory, judgement, and intellect, and a shallow labile affect.” Harpers Collins Medical dictionary (1993) offers: “Dementia Deterioration of intellectual function due to organic factors; formerly used to denote madness or insanity.”

When analyzing the three types of definitions, some inconsistencies become apparent, especially in the impression the definitions create. The first linguistic definition is the most neutral one; it makes no medical claim. “Out of one’s mind” is the most widely accepted translation, but as can be seen later, the term was originally applied to a different illness: to Schizophrenia. The definition does not give the reader a clue that the meaning of the definition has changed. The second linguistic definition is also misleading. Not all illnesses termed dementia or that present with dementia symptoms are irreversible. Medication problems, metabolic disorders, nutritional deficiencies, trauma, delirium, or

depression, to name just a few, also can create dementia type illnesses, yet they are reversible if detected early. Nevertheless, the impression, even in part of the medical community, that dementia is irreversible and a “normal” process occurring with aging deprives many patients of appropriate diagnosis and treatment, medically and socially (Hirsh, 1990; Scinto, 1995). It is noteworthy that the second definition attributes dementia to organic brain disorder.

The latter legal definition also attributes dementia to organic disorder, but clearly labels it as mental disorder. While the language in the sixth edition is less reductionistic than in the first edition, it still allows some inferences why the legal system is involved with several aspects in a dementia patient’s life, but mainly with treatment decision when a patient is entering the mental health system on an involuntary basis. Considering the early definition, together with the longstanding historical involvement of the legal system with mentally ill persons, the paternalistic approach to the “disposal” of dementia patients becomes more understandable. Additionally, the definition seems to suggest that patients with senile dementia are incapable to contract from the moment of diagnosis and are not able to make any binding decisions for themselves. However, such incapacity is only true for later stages of the disease, but the impression of early incapacity is common and can lead to decisions that may not be in the best interest of the patient.

The medical definitions do not use the term “irreversible,” but attribute the disease to organic deterioration. The Stedman definition offers a possible psychological explanation, which may be applicable to, for instance, depressions that present with dementia symptoms. It is noteworthy that the Harpers definition clearly states that

dementia was “formerly used to denote madness or insanity.”

Obviously, depending on the source of the definition, different impressions can arise regarding reversibility, and whether dementia is a physical or mental illness. As will be shown, true dementias such as Alzheimer’s disease are irreversible and have a somewhat predictable course. However, whether the disease is to be classified as a physical or mental illness, or perhaps just aging, is not clear yet, but has considerable impact on the patient, the family, and the care that is available.

Classification

The term “dementia” appears in the first attempt to classify psychiatric illnesses. Emil Kraepelin, who published the first true classification system in 1883, identified two mental diseases: dementia praecox [early], now termed schizophrenia, and manic depressive psychosis (Davison & Neal, 1990). Old-age or senile dementia is not mentioned. However, it is notable that Alois Alzheimer, the German neurologist who described for the first time in 1907 the neuropathology of the brain named after him as Alzheimer’s disease, was a colleague of Kraepelin (Chenitz, Stone and Salisbury, 1991; Meyer, 1994). As previously discussed, Alzheimer’s disease is the most common type of dementia as the term is used today.

The American Psychiatric Association (APA), in the latest edition of the *Diagnostic and Statistical Manual of Mental Disorder*, the DSM-IV, clearly includes dementia as a mental illness. Dementias, among other disorders, are classified among those disorders that are known to be caused by brain impairment, either permanent or transient. According to Laura Queeny from the APA (personal communication, April 1995), the first

edition of the manual, the DSM I, published in 1952, already included the dementias in the diagnostic category of "Chronic Brain Disorder" which was often associated with Syphilis. Additionally, Chronic Brain Syndrome, a subcategory, was associated with senile brain disease, mild, moderate or severe, manifesting itself with childish emotionality, with or without psychosis. It was suggested that the disease may progress to a vegetative state, and in severe cases institutionalization was recommended. Subsequent editions of the manual, the DSM II (1968), the DSM III (1980), the revised version the DSM III-R (1987), and the latest version the DSM IV (1994) included dementias, even though revisions and changes in terminologies were made. Treatment recommendations, including institutionalization, are no longer made in the manual.

The Diagnostic Criteria for Dementia of the Alzheimer's Type in the DSM IV requires that "the development of multiple cognitive deficits manifested by both memory impairment and cognitive disturbances must be present and cause significant impairment in social or occupation functioning" (142). Additionally, other central nervous system conditions or systemic conditions must be ruled out.

It is recognized in the diagnostic requirement that dementia is based on an organic illness, but it is still clearly defined as a psychiatric illness. As shall be seen in the next chapter, this can have enormous consequences for the patients.

Scinto (1995) perhaps most clearly states what Alzheimer's disease is, based on current knowledge. He writes:

Alzheimer's disease is a neurodegenerative disorder of the central nervous system. The disease is characterized by progressive memory loss and the decline of other higher cognitive functions such as attention. This cognitive decline is presumably

the consequence of the synaptic loss and extensive neuronal cell death that occur in regions of the brain involved in cognition and memory. The presence of amyloid deposits and neurofibrillary tangles are required for the definitive diagnosis of the disease, but can only be detected upon microscopic examination of the brain, usually at autopsy (3).

A similar classification of Alzheimer's disease as a physical/neurological disorder is offered by pharmaceutical manufacturers. Parke-Davis, who markets tacrine hydrochloride (Cognex®) to patients with mild-to-moderate dementia, states that Alzheimer's disease is "a progressive, neurodegenerative disorder" (1993). And Georgia Sargeant (1994) writes: "... the deadly brain disease called Alzheimer's has only been recognized for about a decade. Before then, cases of 'senile dementia' and 'hardening of the arteries' were usually chalked up to normal aging" (12).

While newer research obviously moves Alzheimer's disease into the category of biological illnesses, others interpret these findings as confirmation that Alzheimer's disease is "normal" aging. Cutler (1993) reports that researchers at Duke University Medical Center found

that the normal process by which cholesterol is transferred in and out of the blood stream also deposits a fatty substance known as 'beta amyloid' into the brain. The lifetime accumulation of beta amyloid produces the brain 'plaques' that are likely cause of Alzheimer's disease. These results suggest that Alzheimer's disease is a part of 'normal aging,' i.e., something that eventually develops in all humans. For most people the accumulation of amyloid deposits in the brain is so slow that death from other causes precedes the onset of Alzheimer's disease. Some people have a particular gene that ... speeds up the amyloid deposits, which may explain why some people get Alzheimer's and others do not (34).

It is interesting that the same processes that are believed to cause cardiovascular diseases are also believed to cause Alzheimer's disease. Cardiovascular disease is clearly a biological illness, and insurance companies, private or public, readily cover patient

treatment. Cardiovascular disease has an effect on patients' behavior. Their activity level may be greatly impaired, they may have limitations on their life style, and their social life may change.

Although the biological processes may be similar for both diseases, the behavioral outcome with dementia patients whose brain is affected is different. When the cardiac patient grabs his chest in agony during angina pain or a heart attack, it is understandable and measures to assist the patient are usually known. Alzheimer's disease patients, on the other hand, may display behaviors that are both incomprehensible and frightening. They may become aggressive, so forgetful that they do not recognize loved ones or their own image in a mirror, and may even forget how to bathe, groom, dress, and even eat. Sometimes in the process they become paranoid, delusional, or otherwise psychotic. Considering that as the disease progresses every moment in the patient's life is a new experience, responses such as paranoia, aggression, and psychosis are not surprising. However, as a psychiatrist pointedly stated: "If they [the patients] just wouldn't behave so strange, they wouldn't bother anyone." And the private insurance spokesperson said: "Frankly, between us ... they frighten us, that's why we can't deal with it."

Mental illness is a social and psychological construct. It cannot be measured by blood tests, seen on x-rays, or felt during manual examination. While definite testing for Alzheimer's disease is currently only feasible after death, medical advances allow us to test for the disease with some accuracy. With Computer-Assisted Tomography (CAT scan) changes can be detected in the later stages of the disease, especially atrophied (shrunken) brain with tissue indentations and enlarged fluid-filled chambers. Newer types of

equipment such as Positron Emission Tomography (PET scan), Single Photon Emission Computerized Tomography (SPECT), as well as Magnetic-Resonance Imaging (MRI), can show changes in the brain of a patient with possible Alzheimer's disease relatively early in the disease process. The National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) work group has developed criteria for a diagnostic workup that includes neuroimaging and other neurological and psycho-neurological testing. Other tests that can detect physical changes and that may assist in accurately diagnosing dementias are developed rapidly. For instance, experiments using eye drops that result in a different reaction in Alzheimer's patients than in non-patients have shown promising results in laboratory tests (National Institutes of Health, 1994).

Even though some (Cutler, 1993) still may consider Alzheimer's disease a "normal" part of aging, that notion is put to rest by current scientific knowledge. For instance, a pamphlet of the National Institutes for Health (NIH, 1994) states: "Alzheimer's disease is the term used to describe a dementing disorder marked by certain brain changes ... is not a normal part of aging--it is not something that inevitably happens in later life" but, "the main risk factor for Alzheimer's disease is increased age" (1). So Alzheimer's disease is not normal aging, and Alzheimer's disease does not fit cleanly into the mental illness category. It appears that the physical illness category allows for a better fit. Perhaps the director of an aging association put it best: "It's age related, but it is not normal aging, it's a quasi mental illness with a foot in each compartment ... the causes are physical but the treatment is mental" (personal communication, September 1995).

Although, it seems that the physical nature of the illness is accepted by most, treatment does not reflect such medical explanation. Except for some pharmaceutical interventions, treatment is usually supportive or custodial, and in the best instances behavioral/supportive. But even though we can presently not cure or reverse Alzheimer's disease, we can alleviate symptoms and suffering (NIH, 1994). According to Thelma Bland, the Commissioner of the Virginia Department for the Aging, the most important way to accomplish that task is family education and support (personal communication, September 1995). Since families are usually not medical professionals, such statements remove dementia from the medical realm and place it in the custodial area, often times in one where care and "treatment" are provided by family members without financial compensation.

Nevertheless, regardless whether dementia is categorized as a biological or mental illness, there is agreement among general medicine, neurology, and psychiatry about the outcome of the illness. Guenther (1983) writes "Only nonspecific supportive therapy is available. The patient usually dies 5 to 10 years after the onset of illness, usually from respiratory infections" (515). Others allow 6 to 8 years, or in some instances as little as 2 years or as much as 20 years from onset of the illness to death (NIH, 1994). But what happens to the patient and his or her family from the beginning of the disease until death is greatly influenced by a) classification of the disease and b) social policy that is driven, among other things, by the classification.

Clinical Features of Dementia

Before exploring the treatment and care options available to the patients within the

current social policy climate, the course of Alzheimer's disease will be briefly covered. The course is often described in stages; some use four stages, others use seven, and yet others use up to ten stages. In every phase, symptoms are not unique to Alzheimer's disease, so it is important that other diseases that are often less serious, and more importantly usually reversible, are ruled out.

The onset of Alzheimer's disease is usually gradual. The first signs noticed may be memory problems, especially problems with short term memory. A patient may repeatedly forget to turn off a stove or forget to take medicine. As the disease progresses, abstract thinking and intellectual functioning will become impaired. Recently performed tasks such as balancing a check book or organizing daily activities may become increasingly difficult for the patient. The patient may also become irritable and neglect self care. Still later in the disease process, confusion and disorientation are common. The patient may forget time and place, may wander away from home, and become lost. Familiar objects and persons become unfamiliar and conversation becomes less and less possible as language and cognitive skills deteriorate. The patient may become even more inattentive, have erratic mood swings, and lose bladder and bowel control. In the very late stages, the patient becomes completely incapacitated, sometimes even unable to swallow food and may live in a near vegetative state until death. Rate and severity of decline vary with each patient. Some patients function at an acceptable level for a long time and need only some assistance while others may need much assistance early on. While the functioning levels of patients may vary widely, patients are still in need of interpersonal relationships, of loving, and caring (NIH, 1994). They also still have a right to as much self-determination as

possible and being treated with dignity. How much self-determination a patient can maintain is linked to the time when the problems are brought to the attention of someone in the systems that will be involved with the patient, mainly the various health care systems and the legal system.

Entering the Systems

Early memory problems are frequently attributed to the normal aging process and will be ignored. Frequently, people jokingly will say: "I'm getting old and forgetful," or "I must be getting Alzheimer's disease," or more frequently "Old-timer's disease." Old-timer's sometimes is linked to difficulties in the pronunciation of the German word Alzheimer's, but more frequently to a general acceptance that old-timers become forgetful and somewhat "senile." Using such serious illness in a joking manner is an indicator that general education about the disease is far behind that of other diseases. No one would say, "I must have AIDS," because most people know what a serious disease AIDS is. Yet, Alzheimer's disease is not any less serious and has a similar outcome. Even medical professionals may attribute forgetfulness to the normal aging process. A senior case manager in a community mental health clinic found it to be her experience that "general practitioners may try medications when older persons come in confused, but most of them don't get tests, most doctors assume that's how it is when people get old" (personal communication, September 1995). However, as physicians become more educated about dementing illnesses or those that appear like dementing illnesses, more accurate and early diagnosis can be expected, with consequent better treatment (Hirsh, 1990).

Later stages bring a patient more likely into contact with a system. The first

contact may be with a family doctor who, hopefully, carefully rules out other diseases and prescribes appropriate neurological testing. One interviewed physician stated that, in their community practice, they will refer confused patients to neurologists for appropriate testing if the patients have the financial means, otherwise they attempt some testing themselves (personal communication, September 1995). A nurse practitioner in a rural health care clinic stated that they have written instructions to refer anyone presenting with possible mental problems to an affiliated psychiatrist or to the community mental health clinic. So the confused patient, or the patient presenting with some irritable or aggressive behavior, may now enter the mental health system which could result in inpatient or outpatient treatment. The wandering patient who becomes lost could enter a system via the police, and the person who forgets to pay bills may end up in court. "Strange" behavior can also lead to intervention from social service agencies and to being admitted to a nursing or other residential facility.

Obviously, there are many ways a patient can enter a variety of systems. The official or professional in the system that the patient initially enters has decision making power that may have immense practical implication for the patient. Sudnow (1967) when exploring the social organization of dying recognized that natural states (in his instance death, in this instance dementia, an illness) are "the product of organizationally prescribed, practical decision-making" (8). In quoting Sudnow, the word dementia will be substituted for death. He writes:

... biological "happenings" are "discovered," "recognized," "named," and "treated"--and these activities occur in an organized social world--by persons who have established rules of certification allowing certain of them to make officially

valid designations, who premise institutionalized courses of action on the basis of their knowledge of their own and others' states. In fact, the very recognition and naming of such biological locatable events as dementia [death in original] occurs as social activities: social in that they require special achieved competence, in that the propriety of the names given is determined by a cultural tradition, in that the correctness or incorrectness of a designation is a matter of immense practical concern to others [cites the ground-breaking work of Harold Garfinkel in focusing on practical actions, procedural definitions, and common sense knowledge] (9).

This practical concern for others will be explored in-depth in the remaining chapters.

To summarize, while the various definitions of dementia present some inconsistencies, the classifications point toward a biological or medical illness with psychiatric manifestations. This leads to inclusion of dementias into the nomenclature of mental disorders, but also to inclusion into the medical illnesses category, especially as it relates to medical/neurological testing and pharmacological interventions. Others exclude dementias as an illness altogether, but simply relate it to "normal" aging. All agree that dementia follows a predictable course of progressive mental and physical deterioration leading to death within two to twenty years. Depending on how dementia is viewed by the agents of the system the patients enter when they first seek help, treatment may be medical/pharmacological, psychiatric/behavioral, or custodial/supportive. The treatment based on classification has implications for the patients that will be explored in the following chapters.

Chapter 3 - Dementia as a Mental Illness

As previously discussed, dementia is included in the classification of mental disorders. Therefore, psychiatric treatment for dementia patients, including inpatient care, is one of the options for patients and their families. In this chapter the long-standing difficulties of society to deal with the concept of mental illness will be explored. This will be followed by an analysis of admission procedures for psychiatric inpatient care, including how America has arrived at the current standards for admission to psychiatric facilities and the involvement of the legal system to involuntary commit patients. Finally, the safeguards that are supposed to protect patients from inappropriate involuntary admission to psychiatric facilities will be examined as they apply to dementia patients.

Schulz (1985) quotes Butler who wrote in 1975, "The tragedy of old age is not the fact that each of us must grow old and die but that the process of doing so has been made unnecessarily and at times excruciatingly painful, humiliating, debilitating and isolating"(192-193). An example of that tragedy may be a dementia patient who is displaying difficult behavior, and is for that reason detained by police, handcuffed, and delivered to a community mental health clinic or a mental hospital to be incarcerated. Such a person may never have had any involvement with the police or the legal system. The only offense committed is not meeting any longer the expectations of society because one is growing old and has the bad fortune of having a brain that is deteriorating from disease. The second bad fortune is that we still classify dementia as a mental illness; thus the legal system through the civil commitment process can be invoked to commit a person with or without consent to a mental hospital. All it takes is that we deem the person's behavior

dangerous to others or self, or that a person is substantially unable to self-care for reasons of mental illness.

Even though the admission director at a geropsychiatric facility stated that it is the behaviors that bring dementia patients into the mental health system not the diagnosis per se, it is still a fact that the admission criteria requires that the behaviors are due to mental illness. And the presence of mental illness depends on a diagnosis of such illness which is based on classification. Of course, as the senior case manager from a community mental health clinic stated, "The problem with mental illness is that we can't measure it, so we don't understand it" (personal communication September, 1995). This lack of understanding has a long history and has led to much debate in the last forty years.

A Controversial Concept: Mental Illness

Different periods attached different meanings to behaviors that are beyond the general understanding. Since ancient Babylonian times the pendulum swung back and forth between a supernatural and natural explanation for out-of-norm behavior, with the psychiatric or medical model currently dominating the thinking about mental illness (Davison and Neal, 1990).

In the 1960s, a sociological, and rather antipsychiatric, model emerged. Thomas Szasz argues for about the past thirty years that mental illness is a myth, that it does not exist (Holstein, 1993). He writes, "If mental illness is a metabolic or neurological disease, then it is a disease of the body, not of the mind; and if mental illness is behavior, then it is behavior, not disease" (Szasz, 1989, p. 558). Furthermore, he argues that "psychiatry is a religion, not a science, a system of social controls, not a system of treating illness" (Szasz,

1990, p. 557).

Similar thinking was expressed by Scheff in 1966 who applied Becker's labeling theory to the concept of mental illness. According to this theory

deviance is not a quality of the act the person commits, but rather a consequence of the application by others of rules and sanctions to an "offender." The deviant is one to whom the label has been successfully applied; deviant behavior is behavior that people so label. (Becker, 1963, p. 9, cited in Holstein, 1993).

Scheff appears to make the argument that mental illness has social not medical reasons, and consequently, the societal reaction not the pathological states of an individual must be studied.

Obviously, such revolutionary thinking did not go unchallenged. Gove, in a rebuttal, argued that it was not societal reaction but a person's psychiatric condition and behavior that were important in determining whether one was identified and treated as mentally ill. An ongoing heated and public exchange between Scheff and Gove dominated the major sociological publications for well over a decade in the 1970s and 1980s (Holstein, 1993).

Gove's view is in line with the previously discussed opinion of the admission director of a psychiatric facility. However, other clinicians in the same facility believe that too many patients are admitted for social problems. This seems to support the argument of Scheff and Szasz, that is, the label of mental illness is affixed to misbehavior and social problems, not to brain disease.

Obviously, dementia is a brain disease. Following the arguments of Szasz and

Scheff, dementia patients should not be committed to a mental hospital. When needed, they should receive treatment in a "regular" hospital just like patients with other physical diseases. So why are they admitted, frequently involuntarily, to mental hospitals? It is the classification of these persons as mentally ill, a pre-condition for admission to a mental hospital, that allows that difficult behaviors are managed in a psychiatric inpatient setting. Wexler (1981) writes that a "concept such as 'abnormality' has many possible meanings-- including statistical deviation, improper biomedical functioning, ideological deviations, and less than optimal psychological adjustment" (15). He cites Livermore who writes:

One need only glance at the diagnostic manual of the American Psychiatric Association to learn what an elastic concept mental illness is. ... Obviously, the definition of mental illness is left largely to the user and is dependent upon the norms of adjustment that he employs. (15)

It is interesting that the DSM IV now includes, identifies, and classifies approximately 280 mental illnesses; the classification system has come a long way from the two conditions originally identified and classified by Emil Kraepelin in 1883. And dementia, as we know it today, seemed to be included by default or perhaps by a survival mechanism. Dr. Warren Strittmatter, an Alzheimer's disease Researcher from the Division of Neurology, at Duke University Medical Center in Durham, North Carolina, (personal communication, April 1995) attributes the inclusion of senile dementia into the mental illness category to history. He maintains that even Charcot (1825-1893), a French neurologist who was a proponent of the somatogenic view but later became more interested in non-biological causes of mental disorders, realized that some mental illnesses, as for instance senile dementia, had clearly an organic cause. However, confinement of

those with out-of-norm behavior was already well established, and confinement required a reason such as mental illness. Furthermore, older dementia patients, based on relatively short life expectancies, were still too few to be concerned with. Additionally, yet another view was emerging with the neurologist, Sigmund Freud (1856-1939), who is by many considered the founder of modern abnormal psychology. Freud removed the domain of mental disorders from general medicine and neurology into psychology and psychiatry--a course followed for many years. (Abbott, 1988, in *The System of Professions* gives a thorough account of the processes involved in the division of jurisdictions among different professions.) Senile dementia, recognized as a brain deterioration, and thus clearly a physical illness but with mental symptoms, simply was left in the domain of mental disorders, perhaps for a lack of a more appropriate place. Also, the mental hospital industry was growing in Europe as well as in America, so there was a place for these patients, and a cure was not yet in sight.

Then as now it is this classification of dementia as a mental illness that allows the involuntary commitment of some older people through the legal system. The next segment will explore the historical and current role of the legal system in committing patients to treatment.

Treatment of the Mentally Ill in Hospitals

Not only did different periods attach different labels to behaviors that are beyond the general understanding, the label also affected the treatment of those considered deviant. During periods when out-of-norm behavior was attributed to the supernatural, the clergy of the respective institution was in charge of treatment. However, with the loss of

church dominance in Europe, municipal authorities began to take on some of the former church responsibilities, including the care of the sick. In the mid-fourteenth century, English law allowed that the dangerously insane and the incompetent could be confined to a hospital. The purpose statement of the Holy Trinity Hospital in Salisbury, England, specified that the "mad are kept safe until they are restored of reason" (Davison & Neal, 1990). Furthermore, it was the right of the Crown to be the guardian of the lunatic's estate (Neugebauer, 1979). The formal legal system was now involved with the mentally ill. Nevertheless, mental hospitals or asylums did not begin in earnest until the late fifteenth and early sixteenth centuries when former leprosariums became asylums for mentally disturbed people, for beggars, and for others society wanted to control (Davison & Neal, 1990).

In early America, perception and treatment of deviant behavior, including mental illness, was closely tied to European beliefs. Generally, dependent people such as the insane, beggars, vagrants, the elderly, and handicapped received various treatment by local officials. Some received financial support in exchange for care from their own or other families, others were in poor- or almshouses, and others were imprisoned. The Pennsylvania Hospital was the first hospital with a separate ward for insane patients in America, admitting "lunaticks" beginning in 1752. In 1760, four to five mentally disturbed persons were imprisoned in the Williamsburg Public Goal (jail). Other colonies similarly imprisoned the insane. The first hospital in the United States, solely dedicated to the care and treatment of the mentally ill, was founded in Williamsburg, Virginia, on October 12, 1773, initiated by Francis Fauquier, the royal governor of the colony of Virginia. Fauquier

rationalized that the "poor unhappy set of People who are deprived of their senses and wander about the Country, terrifying the Rest of their Fellow Creatures" (Zwelling, 1985, p. 18) needed to be legally confined in a hospital for troubled people who cannot help themselves.

The history of the Williamsburg Hospital (Zwelling, 1985) gives a vivid account of the ups and downs of treatment approaches, and society's waning interest in the mentally ill when other issues became more pressing. Treatments, more or less human, were tried, failed, and made room for another approach, depending on the current thinking about mental illness. It also reflects how social interest changes with changing times.

Interestingly, the original mission of the Williamsburg Hospital was the treatment of acute mental conditions with the goal of a cure. But by 1884, a little over 100 years after its founding, the hospital held 451 patients and officially became a long-term care facility. Custodial care had won over active treatment and over the goal to cure the patients and return them to the community. Thus, society had increased social control and had devised ways to keep those who were different out of sight. Fauquier's statement that those who "terrify the rest of their fellow creatures" must be confined was carried out to the fullest extent.

The establishment of more mental hospitals raised the issue of legal admission criteria. So far, most states required a petition from a family member and certification by a physician. But cases emerged in about the mid-nineteenth century where such a system led to abuse and courts began to make decisions in favor of persons deemed mentally ill. Statutes began to change in favor of more judicial commitment, abandoning the "common-

law assumption that family and friends would always act in the best interest of a patient,” (Holstein, 1993, p. 23). Thus, the State began taking a paternalistic role, and removing decisions for the care of the mentally ill from the family.

In the early twentieth century, the Progressive Era began in America, with an expansion of scientific discovery and technological development (LaFond and Durheim, 1992). Even though the Depression of the 1930s and two World Wars stifled progress for a certain period of time, by the 1950s America had unbounded optimism in the future. In this climate, an acceptance of individual differences developed. Additionally, scientific advances resulted in a trust that science could correct many ills, including mental illness. It is noteworthy that in this climate the first DSM was published in 1952; the *Zeitgeist* was right for it. The concepts of custody and punishment made room for the concept of rehabilitation. Furthermore, a belief in the benevolence of the state developed. Therefore, enlarging the power of public offices to “treat” the mentally ill and criminals was not only accepted but encouraged; after all, rehabilitation was the goal and the end justified the means. Stays in mental hospitals were long, and discharges were up to the hospital superintendent. LaFond and Durheim (1992) write:

The reforms of the Progressive Era resulted in an overwhelmingly paternalistic system of social control. Experts “diagnosed” what was wrong with each individual; the state decided what “treatment” was best ... A system which presumed only the best intentions for the care and rehabilitation of each individual had little need to respect the wishes or safeguard the rights of prisoners or patients (5).

Economic success of each individual was an assumption of the Progressive Era, but was not available to all. This resulted in disillusionment and a time of intense social

upheaval. The 1960s and 1970s, described as the Liberal Era by LaFond and Durheim, focused on individual freedom, even at the expense of the community, but also on achieving equality for all. To create the "Great Society" envisioned by Americans, government was broadened. However, the courts' roles were no longer limited to social control of persons displaying deviant behavior; they were now expected to protect the individual rights of these persons. In previous periods, few if any safeguards were in place to protect individuals from commitment to mental institutions. This changed with the Mental Health Study Act in 1955 resulting in the implementation of newer mental health laws in the 1960s and 1970s. The safeguards of the mental health laws resulted in the stipulation that only those persons who are either dangerous to themselves or to others for reasons of mental illness can be involuntarily committed. Individual state laws include these stipulations but they may vary slightly in other conditions. Some states allow the need for treatment as a condition, others, including Virginia, consider substantial inability to care for self a reason for commitment. Parry, Turkheimer and Hundley (1989) capture these changes as follows:

Although much of the reform to civil commitment statutes was informed by a shift from a *parens patriae* to a police power basis for commitment, at least 30 states also allow for involuntary commitment if a person is so gravely disabled as a result of mental illness as to be unable to care for his or her own needs. The grave disability standard entitles the state to protect persons who are unable to care for themselves, while the dangerousness standard authorizes the state to confine individuals for the prevention of harm to the community. (1)

These limitations on commitment laws, confirmed by a number of Supreme Court decisions, resulted in massive releases from mental institutions. Additionally, the

development of powerful antipsychotic drugs in the 1950s allowed persons who could previously only be managed in an institutional setting to live in the community (Romano, 1994). Also, state mental health budgets were reduced, thus states had additional incentives to move the mentally ill out of state hospitals. Bonnie (1993) believes that “de-institutionalization would have occurred even without the libertarian developments” (3) that prompted the mental health laws; the time was simply ripe for it. However, the de-institutionalization movement of the last three decades resulted in other problems. The mental hospitals either no longer committed the mentally ill or “dumped” them into the community because they no longer met commitment criteria. For instance, in the 1950s state mental hospitals had almost half a million patients; this population had dropped to about 130,000 by the late 1980s. However, community programs could not keep pace with the onslaught of mentally ill persons because, according to Davison & Neal (1990), “There is not an unlimited supply of money, and care of the mentally ill has never been one of government’s high priorities” (618). The mentally ill once again became visible to society in the form of the homeless and in reports of deplorable conditions in nursing homes and boarding houses. They also entered the legal system, the very same system that set out to protect them with civil commitment laws, but this time they entered the system under criminal law. Society had returned to the “criminalization of mental illness.”

The current trend to deal with the problem is toward increased institutionalization or incarceration of deviants (LaFond & Durham, 1992; Wexler, 1981). However, as a society we still seem to have reservations about the state’s paternalistic power. Stuart Mill (cited in Wexler, 1981) suggested that “society ought to interfere with an individual

against his or her will only to protect others, not to protect the individual personally” (39). This suggestion would preclude anyone not presenting an imminent danger to others from interference by the legal system and possible commitment to a mental hospital. The underlying assumption is that the state may not know what is best for an individual and that the individual’s dignity may be offended by the state’s interference. These considerations should weigh heavy when elderly persons, diagnosed with dementia-type illnesses, are considered for placement in mental hospitals.

Interaction Between Legal and Mental Health Systems

As shown previously, the various legal systems have long been invoked to confine those who display unacceptable behavior that is attributed to mental disorders. However, societies used different standards to determine the presence of mental disorder, and one can suspect that mental disorder was often used to incarcerate those who were uncomfortable to those in power. The implementations of the Mental Health laws in America in the 1970s, and consequent limitations on civil commitments are considered a safeguard against such abuse. A diagnosis of mental illness is a pre-condition for any civil commitment, or as Holstein (1993) writes, “Mental illness provides a rationale for depriving persons of their freedom in order to promote their well-being” (3).

Invoking the Legal System

Today involuntary commitment is based on civil law which has its theoretical basis in the criminal justice system. The modern criminal justice system is a combination of Beccaria’s free will theory, and Ferri’s deterministic crime theory. According to Wexler (1981), classical criminology is “a blending of Kantian retributive justice and the

utilitarianism of Cesare di Beccaria and Jeremy Bentham” (11) which proposes that persons have a free will and, therefore, should be held accountable for their actions. However, classical criminology was criticized as overlooking differences between individual offenders such as biological, environmental, and psychological factors. Consequently others, including Enrico Ferri, proposed a deterministic criminology that advanced the abolition of personal responsibility and moral guilt as a basis for criminal law. He writes:

When an individual has been found to have committed an act harmful to society, the law should not be concerned with questions of guilt and its degrees nor with measuring a fit punishment, but should *humanely* [italics added] apply whatever measures are necessary to protect society from further transgressions by the same individual. (cited in Wexler 1981, p. 12)

The application of the criminal justice system did not fit all offenders, such as persons addicted to alcohol or drugs, sexual deviants, or the mentally ill. Since it was deemed that their behavior was not necessarily a product of free will, but also not always predetermined, another legal framework was needed to deal with these offenders. The civil commitment law provided this framework. Conveniently, psychiatry already had delineated such behaviors as mental disorders in need of therapeutic interventions. The United States Supreme Court in *Robinson v. California* confirmed the civil law when it argued that holding a person criminally responsible for an illness of addiction was cruel and unusual punishment. However, the court held that it would be constitutionally proper to “confine addicts involuntarily for the express purpose of treatment” (Wexler, 1981, p. 13). Civil commitment laws were refined over time and strengthened by several court cases; an excellent account of this development is given by LaFond and Durham (1992). The basic

implications of civil commitment laws are clear. Whether free will was present or not may be the determining factor with criminal insanity defenses and today also with some substance abuse issues. However, in cases of dementia where, according to current knowledge, free will is not present, the civil commitment laws give the legal authority for involuntary commitment to the courts.

To explore how the civil commitment law is applied in an actual setting, the admission records of a 210-bed geropsychiatric hospital serving about half of the Commonwealth of Virginia were examined for the year 1994. About 43% of the patients admitted had a diagnosis of dementia, mainly Alzheimer’s type, and another 10% had Organic Mental Disorder (see table 2).

Table 2 - Admission Diagnosis 1994

DSM-III-R Diagnosis	N	Percent
Various Dementias (mainly Alzheimer’s disease and Related Disorders)	57	42.6
Organic Mental Disorder NOS (not otherwise specified)	13	9.7
Delirium	9	6.7
Various Forms of Schizophrenia	24	17.9
Mood Disorders	18	13.4
Others	13	9.7
Total	134	100

Only two of the total admissions were voluntary; for two data was not available, and the remaining 130 arrived through the court system. A Temporary Detention Order (TDO) was used in nearly one-third of the admissions. Forty-six percent of the patients were involuntarily committed during the commitment hearing in the community or in the hospital, and 17% were already involuntarily committed in other facilities and then

transported to the hospital (see table 3).

Table 3 - Type of Admission 1994

Type of Admission	N	Percent
Committed	62	46.27
TDO	42	31.34
Committed Transfer	23	17.16
Court Order Transfer	2	1.49
Court Order	1	0.75
Voluntary	2	1.49
Data not available	2	1.49
Total	134	100.00

While some contend that the trend in the United States is toward voluntary admission (Winick, 1991), this trend obviously does not hold true for the examined geropsychiatric hospital and for public hospitals in general. This may be related to the screening procedure and to the preferences of medical staffs, but also to the patients' perceived inability to make decisions and his or her family's cooperation with the process. The senior case manager (personal communication, September 1995) explained that families bring dementia patients into the community mental health clinic asking to "Put them somewhere. They don't know what they are asking for, they just ask that something be done." In other instances, according to the interviewee, physicians "work" the system until they get their patient admitted to a psychiatric facility, because they think this is the appropriate place, but they do not know or do not care about the legal commitment criteria.

The commitment process for the Commonwealth of Virginia is outlined by state law, in the *Code of Virginia*, sections 37.1-67.1 et. seq. All state laws are somewhat

similar, so the procedure for Virginia will be repeated verbatim for accuracy as covered in House Document No. 77. (Commonwealth of Virginia, 1995)

According to the statute, any person having probable cause to believe that an individual is mentally ill and in need of emergency evaluation for hospitalization may request a magistrate or judge to issue an emergency custody order for that individual. The emergency custody order requires that the detainee be taken into custody and evaluated within a four-hour period by a mental health professional designated by the community services board in that region. A law enforcement officer may take a person into emergency custody directly, without an ECO, if there is probable cause. The person shall remain in custody until a temporary detention order is issued, or until the person is released. If it appears from all available evidence that the person is mentally ill and in need of hospitalization, the judge or magistrate may then issue a temporary detention order on the individual.

Before issuing a TDO, a magistrate or special justice is required to receive the advice of a mental health professional who has conducted an in-person evaluation of the individual. The magistrate may omit the evaluation if the individual has been examined in the last 72 hours by a mental health professional or if contact with the individual would pose a significant risk to those involved.

After a TDO is issued, a law enforcement officer is required to execute the order. The order may be executed by the law enforcement authority in any area of the Commonwealth and is valid for 24 hours after it is issued. If it is not executed in that time, it expires and a new order must be issued. Individuals detained under a TDO are taken to an inpatient hospital for evaluation.

Generally within 48 hours of the issuance of a TDO, the patient must accept voluntary admission or be given a commitment hearing. If a TDO is issued during a weekend or holiday, the time limit may be extended to 96 hours.

The commitment hearing is usually conducted by a special justice. Prior to the commitment hearing, a special justice must notify the individual of the right to obtain counsel or have one appointed, the right to apply for voluntary admission, and the right to a commitment hearing and other due process and procedural details. The notification constitutes the preliminary hearing. The commitment hearing follows the preliminary hearing.

During the period between the preliminary hearing and the commitment hearing, the detainee is to be interviewed by legal counsel. This period is to be used by the detainee and legal counsel to prepare a case based upon the detainee's wishes. The special justice requires that a licensed psychiatrist or psychologist

perform an evaluation on the detainee. Additional independent psychological evaluations may be performed at the expense of the detainee.

At the commitment hearing, the special justice hears evidence from numerous sources concerning the mental state of the detainee and various treatment or disposition options. The psychologist or psychiatrist requested by the court to perform an evaluation presents the evaluation either orally or in a written report. Additional reports by a mental health professional contracted by the detainee may also be reported in the hearing. The community services board in the home region of the detainee is requested to submit a report on the individual. Finally, counsel for the detainee presents the detainee's wishes.

At the conclusion of the commitment hearing, the special justice renders a judgment. *If the special justice decides that the individual, as a result of mental illness, presents an imminent danger to self or others, or is incapable of self care, and alternatives to involuntary confinement and treatment have been deemed unsuitable and there is no less restrictive alternative, an order for involuntary inpatient commitment is issued* [italics added]. Inpatient commitment may be for no longer than 180 days and must be to a facility designated by the community services board that serves the political subdivision of the detainee. Involuntary outpatient commitment may also be ordered if less restrictive treatment alternatives exist and are suitable.

All patients have a right to appeal the outcome of their commitment hearings. These appeals can be made to either a jury or a judge at the circuit court level. The appeal must be filed within 30 days of a commitment ruling.

If at the end of 180 days of inpatient treatment an individual is still thought to be in need of involuntary care, a petition may again be filed, and a recommitment hearing is conducted. Recommitment hearing procedures are the same as the initial hearing with the exception of the preliminary hearing. No preliminary hearing is held in the recommitment process (2-5).

In addition to the above procedures, an individual must be age 65 or over to be considered for admission to the geropsychiatric facilities in Virginia. While it appears that the procedures are protective of individual rights, exploration of individual components demonstrate that the practice is often different.

Does the Civil Commitment Process Work?

Bonnie (1993) writes:

There are only two jurisprudential predicates for confinement in our legal system: (i) arrest and conviction for criminal conduct; and (ii) therapeutic commitment under the mental health system based upon findings of mental illness and *imminent* (italics added) dangerousness, and on the presumed connection between the two ... our law does not permit purely preventive confinement outside of the criminal justice system (20-21).

The dangerousness criterion was implemented to protect patients from unjust hospitalization. However, research suggests mixed results when evaluating involuntary hospital admissions (Parry et al., 1989). One report indicates that 94% of admitted patients display behaviors conforming to dangerousness standards, while two comparable studies found only 31% and, respectively, 36% meeting these standards (Segal, 1989).

Admission staff and nurses in the observed geropsychiatric hospital rationalized that patients wander away from their places of residence, and therefore represented danger to themselves. Other reasons for admission were an inability to self-care. For instance, patients may have lived in deplorable physical environments, may not have eaten properly, had forgotten to turn off stoves or other heat producing appliances, or had forgotten to turn the heat on when needed. A social worker from a local Social Services Department stated after initiating admission to the hospital, "You wouldn't believe how he lived, in a shack I wouldn't have for my dog. And he was drinking too. It all happened after his wife died." Obviously, some behaviors can endanger a person while others are only an annoyance to others.

It appears that the imminent danger criteria is stretched from the original intent to

protect the individual from suicide and society from homicide. One of the hospital executives stated that most patients are admitted because they are resistant to care and cannot self care. This is confirming the findings of Parry et al. (1989), who write that according to some studies, the basis in 95% of all committed cases, and nearly in all cases of recommitment, is the inability to self-care without any findings of danger to self or others. It is ironic that such patients often are admitted from nursing homes or other residential facilities where they lived because they could not self-care, and where they may spend their life savings, usually to the point of reaching the poverty level, and nearly every penny of their social security. Obviously, law does permit purely preventive confinement outside of the criminal justice system once the mental illness criteria is met. And, according to Wexler (1981), “ ... the diagnostician has the ability to shoehorn into the mentally diseased class almost any person he wishes, for whatever reason ...” (15).

All patients admitted to the hospital must be prescreened by their respective community mental health clinic. The senior case manager remembers the instance of a 78 year old man who was a “wanderer.” The prescreeners did not think he needed hospitalization because the mental illness criteria was not met, but the physician who attended to the patient assumed dementia, convinced the family that psychiatric care was needed, and “worked” the system until the patient was admitted. The hospital evaluation and a series of tests showed that the patient had a recent fall with a head injury, resulting in some irrational behavior, including wandering which is often present in dementia patients. The evaluation and testing in the psychiatric hospital, together with some treatment, allowed the head injury to heal and the patient was discharged. This patient

should not have been admitted to a mental hospital, but to an acute care hospital.

While it is not known how that particular patient had arrived at the hospital, most patients arrive via the sheriff's department, often restrained by handcuffs. Restraining usually depends on the circumstances and the compassion level of the transporting officer. Nevertheless, transportation of mentally ill patients is the responsibility of sheriff and/or local police departments according to the *Code of Virginia*. In fiscal year 1993, 125 sheriffs representing 91% of the sheriffs statewide, reported to have transported nearly 16,000 mental health patients or an average of 140 transports per department at a cost of \$1.4 million. This does not include those patients being transported by local police departments other than sheriff's departments. Of these transports, only 10% were related to forensic patients. Forty-eight percent involved transporting a TDO patient to a hospital; 18% involved transporting an ECO patient to a hospital; 12% were conducted to transport a TDO patient to a private acute care facility for medical clearance and then transporting the patient to a public psychiatric hospital for admittance; and 11% involved transporting a committed patient from one hospital to another hospital (Commonwealth of Virginia, 1995).

In a survey conducted by Joint Legislative and Audit Commission (JLARC), 75% of the responding sheriffs felt it was their duty to transport mentally ill persons, and it is, according to the Code of Virginia. However, 78% of them reported a problem with staffing and funding for these transports. They also seemed to relate the appropriateness of their duty directly to the dangerousness of the patient. On the other hand, mental health staff perceive the sheriff's involvement as problematic. Concerns include the

criminalization of the mentally ill as well as problems with determination of dangerousness, use of restraints, and lack of training for law enforcement officers in the area of mental illness (Commonwealth of Virginia, 1995). Obviously, being arrested, possibly handcuffed, and taken to several places for interrogation are not the most therapeutic ways to begin “treatment” for an illness. The “series of abasement, degradations, humiliations, and profanations of self” (14) addressed by Goffman (1961) begin long before a person enters an institution. Alternative options could be ambulances, privatization of the transportation function, or the utilization of community mental health staff or family. Recommendations in this direction were dismissed by the previous mental health commissioner because of the impact such changes could have on other entities. The transportation issue seems to serve systems better than it serves the patients. However, transportation is continuously addressed by mental health advocates and actually resulted in a change as of July 1, 1995. Now the committing judge has the option to recommend that other transportation means be explored. However, while the change has been in place for about four months now, most patients still arrive in a police vehicle at the hospital.

When the client enters the mental hospital, after prescreening by community mental health professionals, an evaluation by the hospital physician takes place. However, this evaluation is mainly conducted to ensure that the patient is not presenting with a physical illness such as delirium and to arrive at an initial diagnosis. Most referred patients are deemed to be appropriate for admission once they are transported. As an additional safeguard, as of July 1995, a physician with any financial interest in a psychiatric hospital or ward cannot prescreen a patient in the community and then initiate commitment to that

hospital. Obviously, this only holds for private sector hospitals.

Additional safeguards are in place in the form of mandatory legal counsel for the patient and the commitment hearing. Legal counsel may consist of offering the option of voluntary commitment, explaining procedures and treatment options, and other legal issues. Parry et al. (1989) write about the attorneys' role in the civil commitment process:

In general, studies have reported low levels of preparation and activity on the part of attorneys representing mental patients. Attorneys rarely call witnesses, object to the admission of evidence, explore the use of least restrictive alternatives (LRA's), or question the conclusions of the clinical examiner. Furthermore, most appear to have limited experience of mental health law and frequently defer to the opinions and recommendations of mental health professionals, functioning more as guardians *ad litem* or as mere bystanders. (1)

Additionally, patients are often too unresponsive or too impaired to even understand the concept and consequences, and family members are relieved to have the problem taken off their hands. Also, families usually are not allowed to make the decision because legal incompetence is not assumed when a person enters the mental health system. Furthermore, many families and their advocacy groups would like to see the involuntary commitment process simplified, regardless of the patients' wishes (LaFond & Durham, 1992). The assumption of the mental health law that families and friends do not always have the best interest of the patient in mind may be true. However, the parental power has only moved from families and friends to the state, and it appears that we cannot guarantee that the state has the patients' best interests in mind.

The judge presiding over the hearing usually accepts the recommendation of the mental health professionals who evaluated the patient. LaFond and Durheim (1992) write:

... the courts--traditional mainstay of individual rights--have by and large ratified formal and informal legal reforms permitting expanded involuntary detention. They have also indicated greater willingness to defer both to legislative and executive initiatives and to psychiatric expertise. As a result, more and more citizens considered mentally ill will likely be confined to psychiatric institutions in the years to come (116).

The usual acceptance of psychiatric opinion by judges is confirmed by Parry et al. (1989) who additionally found that judges frequently take the role of attorneys and that they often fail to advise respondents of some or all of their rights.

Patients are usually committed, but sometimes discharged, based on the psychiatrist's professional opinion. By the time the institutional physician sees the patients, they may already have experienced the "arrest" and transportation by police in the community, as well as extensive "interviewing." So even if the patient is discharged because he or she was not deemed mentally ill, the series of degradations has already occurred.

Some proponents of the practice to accept clinical judgement feel that this does not represent a weakening of the safeguards. Lidz, Mulvey, Appelbaum, and Cleveland (1989) offer the following conclusion:

Involuntary commitment is a legal institution designed to facilitate psychiatric treatment. As such, it involves a unique power in our society to deprive an individual of liberty. ... the mental health professions have a major interest in seeing that the power is not abused...By and large, clinicians believe that patients are committable only when they have the characteristic which the law specifies as making them committable. Moreover, clinicians are fairly reliable in their judgements of committability. (180)

Others, led by Szasz, hold that the involuntary commitment should be abandoned once and for all because it unjustly deprives people of their freedom, and commitment

safeguards and treatment are nothing but a farce.

Taking all of the above into consideration, many dementia patients are not appropriate candidates for admission to a psychiatric hospital using the involuntary commitment procedures. First, it can be argued that dementia is not a mental but a physical illness and as such does not meet commitment criteria for a psychiatric facility. Current psychiatric and official legal thinking, as well as the thinking of some advocates for dementia patients, does not concur with this view. Thus, dementia is classified as a mental illness and the classification is used to detain victims.

Second, danger to self or others must be imminent; a condition rarely met by the frail elderly because they simply do not have the physical capacity to carry out dangerous actions. Additionally, dementia patients, by the very nature of their illness, do not have the mental capacity to plan such acts. Dangerous behavior is usually accidental, unintentional, and not pre-planned.

Finally, substantial inability to self care is a vague concept wide open for interpretation and social judgement. Many patients come from long-term care settings or from families who care for them. It is the care setting's inability, often in spite of best intentions, to care for the geriatric dementia patient; it is not the patients' inability to care for themselves that brings patients to psychiatric hospitals. They may receive the best possible care in the psychiatric settings, but it should not be argued that they are there because they meet legal commitment criteria. The psychiatric hospital is certainly not the least restrictive alternative (LRA) required by law. In fact, it is estimated that in 55% of the cases LRAs are not explored, and even when they are considered, they are rarely used

(Parry et al., 1989).

The changes of the 1960s and 1970s in the commitment procedure, using the legal system to safeguard mentally ill persons' rights, do not fulfill that function for dementia patients. The system may be used because there seems to be no better alternative to bring patients into a setting that may benefit them, but it does not safeguard their rights. So commitment procedures may be interpreted as acts of rationalized compassion, but they should not be interpreted as legal safeguards.

Holstein (1993) suggests that

commitment proceedings might be framed as a contemporary 'rationalization' of compassion. According to Giddens (1979), rationalization is the process of explaining why we act as we do by giving reasons for our conduct...Providing motives or reasons for action rationalizes it, making it a meaningful and understandable feature of everyday life. Commitment proceedings thus rationalize the confinement of selected persons by showing how detention and care result from the court's organized expression of compassion. (183)

Additionally, Holstein (1993) offers the Weberian concept of "formal rationality," that is, systems act according to principles and rules based on institutionalized procedures and, therefore, promote the predictability of bureaucracies. Thus, "commitment proceedings are bureaucratic manifestations of the desire to rationalize compassionate intervention" (183). They require increased reliance on expert authority, but reduce the importance of nonrational factors such as emotions and caring for others. "Abstract laws and formal procedures, it appears, may eliminate some forms of arbitrariness, but in exchange they introduce an impersonal monopoly over how compassion, concern, and control are asserted into people's lives" (Holstein, 1993, p. 184).

While we may lament the passing of those days when parents took care of their

children, and children in turn took care of their parents as they aged, we can most likely not bring back those days, and compassion cannot be legislated or mandated. However, by using bureaucratic systems, based on legal authority, to rationalize our society's inability to take care of the most vulnerable, and by dehumanizing the process by invoking the legal system, we may have moved further into the "iron cage" of bureaucratic rationalization leading to the "polar night of icy darkness" predicted by Weber. We may be closer to the modern individual that is "a passionless, coldly calculating, and instrumentally rational actor" (Farganis, 1993, p. 105).

In summary, society has struggled over the centuries to understand out-of-norm behavior, and treatment of persons considered mentally ill was closely tied to the thinking of any particular era, but usually included confinement that was sanctioned by the legal authority of that time. To this date, we have no consensus about the meaning of the construct of mental illness, especially when illnesses like dementia are involved that clearly have organic causation but include psychiatric symptoms. Several safeguards have been implemented over the years to protect victims from detention based on an abuse of the involuntary commitment process. Currently, most states require in one form or another that patients must present imminent danger to themselves or to others, or are substantially unable to self care, all for reasons of mental illness, before the civil commitment process and the state's police power can be invoked to confine victims. However, analysis of the literature and of the admissions of one geropsychiatric hospital revealed that mental illness and the admission safeguards are subject to elastic interpretation by mental health and legal professionals. Furthermore, most dementia patients by the nature of their illness may

not meet these safeguard criteria, even if we accept a classification of mental illness. Many of these patients seem to be detained because they represent social problems, not because they meet the commitment criteria, thus the safeguards do not work for these patients.

However, if we conclude, based on the previous discussion, that many dementia patients are not meeting requirements for mental illness and the involuntary commitment process then what are the alternatives? The following chapter will explore settings outside of the mental health system, that is, settings that cannot invoke the legal system to commit elderly persons.

Chapter 4 - Dementia, *Not* as a Mental Illness

While some dementia patients are institutionalized in mental hospitals, many live in other settings. In this chapter institutionalization in nursing homes will be explored, as well as other living arrangements such as adult residential homes. With many patients and families preferring care at home, barriers to such care will be discussed, together with some suggestions to minimize these barriers.

Alternatives to the Mental Hospital

The de-institutionalization movement did not escape the geriatric population in America. The rate of Americans over age 65 residing in public mental hospitals dropped between 1972 and 1987 from 374.6 per 100,000 to 67.6 per 100,000, an 82% decrease. In 1972, 8% of all admissions to public mental health hospitals were over age 65, but in 1987 only 4.5% were in that age group. Nevertheless, 20,000 elderly persons remained in public mental hospitals in 1987 which constitutes about one-fifth of all residents in such facilities, at a cost of over \$1 billion annually (Fogel et al., 1993). Additionally, the graying of America, together with a renewed emphasis on institutionalization of deviants, may reverse the previous trend of de-institutionalization. Of those ever being admitted to a geropsychiatric hospital, an average of 50 to 70% of the patients carry a dementia diagnosis (Fogel et al., 1993) which concurred with the data from the examined hospital.

However, we may conclude that the recent reduction of patients in the psychiatric state hospitals not only protects dementia patients from the involuntary commitment procedures by sheer reduction in number, but also that considerable savings in health care cost are realized. This would hold true if all of these patients either were miraculously

cured and returned to an independent life, or if they went back to families who provided unpaid, comprehensive care for them. However, neither of these conditions are met.

The Current Status of Non-Hospital Based Care

As previously discussed, beginning with the progressive era, a strong belief in the benevolence of the state developed, and public officials were encouraged to care for persons deemed in need. This resulted in an explosive admission of geriatric patients to mental hospitals. In fact, elderly persons were admitted four times faster than younger persons. Most of these patients were admitted for medical, social, and economic reasons; only a few were severely mentally ill. A lack of alternative places to provide care for the cognitively impaired and frail elderly, and a belief that they needed mainly custodial care, led to a “dumping” of geriatric patients into state hospitals (Fogel et al., 1993).

However, the Mental Health laws that resulted from the Mental Health Study Act in 1955 and the inception of Medicaid in 1965 gave rise to increased numbers of nursing homes. Many of the patients that were discharged from psychiatric hospitals actually were transinstitutionalized to nursing homes that provided few, if any, mental health services. New institutionalization of elderly dementia patients or discharges were made into nursing homes. Geropsychiatric hospitals or units dramatically decreased their census, and private and non-federal general hospitals increased their admissions of these patients only minimally (Fogel et al., 1993). Today, when the term “institutionalization of the elderly” is used in the literature, nursing home placement is meant, not psychiatric hospital placement. This transinstitutionalization was most likely not an intended outcome of the de-institutionalization movement. However, Community Mental Health Centers

(CMHCs), even though required by a Congressional Amendment in 1975 to provide specialized services for the elderly and other groups (including children), largely failed to comply. The funds to meet the amendment requirements were never allocated, and the implementation of block grants in 1980 under the Alcohol, Drug, and Mental Health Administration removed the requirements to serve special populations, such as the elderly. Presently, only 45% of CMHCs offer any type of geriatric services, and the effectiveness of the offered programs is unknown (Fogel et al., 1993). The service area of the examined geropsychiatric hospital includes 13 community services boards (CSBs); only two have a designated geriatric program, and only one has an active outreach program for the older population. Admissions from these two areas are extremely low, even though they serve the largest concentration of elderly persons. The CSB with the outreach program, serving a city of about 200,000, had only four admissions to the geropsychiatric hospital in 1994. The program of that CSB will be discussed later.

Nursing Homes

The discharge of the elderly from the mental hospitals without appropriate community support resulted in the admission of many patients to nursing homes that lacked specialized programming and appropriate staffing to serve that population. The nursing homes became the new back wards for the elderly dementia patients.

To remedy the deplorable conditions in nursing homes, congress passed the Nursing Home Reform Act, under the Omnibus Budget Reconciliation Act (OBRA) in 1987. One provision of the act was the requirement for pre-admission screening and annual resident review (PASARR) for the presence of mental illness and mental

retardation, and a requirement that such patients would be sent to specialized treatment facilities when needed. Specialized treatment was also required for those who did not need psychiatric hospital care, but who had a mental illness, *other than dementia*. However, funding again did not accompany that requirement (Fogel et al., 1993). Amazingly, dementia type illnesses were excluded from this requirement. Thus, for all practical purposes, PASARR declassified dementia as a mental illness and, at the same time, allowed nursing homes to admit these patients freely, but not provide specialized care for dementia victims, not even for those who needed psychiatric treatment. Dementia effectively had been classified as a consequence of aging, requiring custodial care only--a very similar view to the state of mental hospitals prior to the introduction of the Mental Health Act. This classification was not based on newer medical knowledge, but purely on policy that served the needs of the nursing home industry. To complicate matters for legislators, providers, care givers, and patients, dementia and mental illnesses such as depression frequently coexist, requiring diagnosis and treatment for all conditions. Recognizing these complicating factors and prompted by litigations, the original PASARR requirement underwent several changes. As of 1990, the law stipulated that only persons with *serious* mental illnesses are covered by PASARR, and those with secondary diagnosis of dementia are excluded as long as they do not have a primary diagnosis of serious mental illness (Fogel et al., 1993). However, Judith Riggs, Director of Federal Policy, Alzheimer's Association, made an official statement submitted to the Department of Health and Human Services on January 4, 1993, stating the following:

The Association objects strongly to language in the proposal which

excludes from the definition of adults with serious mental illness ‘Alzheimer’s-related dementias unless they co-occur with another diagnosable disorder.’ The effects of this exclusion will be to deny access to the mental health system, arbitrarily, for persons with Alzheimer’s disease and related disorders -- because of their diagnosis, regardless of their need for mental health services ... The exception to the exclusion for Alzheimer’s-related dementias that ‘co-occur with another diagnosable disorder’ is not adequate to protect persons who need mental health services. The reality is that persons with Alzheimer’s disease who have psychiatric and behavioral symptoms do not always receive psychiatric diagnoses of co-occurring disorders, because clinicians have come to expect these symptoms as part of the primary illness. (Copy of the memo is available from Ms. Riggs.)

Ms. Riggs (personal communication, April 1995) argues that a declassification of dementia as a mental illness, while decreasing stigma, would also decrease needed services to the patients and their families. This argument of the Alzheimer’s Association seems to suggest that the availability of mental health services, regardless where they are offered, outweighs the stigma and other negative effects. In response to such concerns expressed by advocates, several states have programs under development that would provide state-funded services that “wrap around” nursing home care, thus, beginning a continuum of care.

In addition, OBRA required that the psychosocial and behavioral needs of patients are met, again without providing funding for the requirement. OBRA also required that the chemical restraints provided by psychotropic medications must be justified with a psychiatric diagnosis. However, psychotropic medications and the wide usage of physical restraints, together with the negative effects of relocation and institutionalization on psychological well being, actually seem to increase the prevalence of mental illness in nursing home patients (German et al., 1992) and thus justify the use of these medications.

The latest plans by the current Republican congress propose that as an outcome of the Medicare/Medicaid reform “Medicaid patients in nursing homes would lose federal protection against being overmedicated or forcible restrained” (Richmond Times Dispatch, September 24, 1995, p. A15). One can only imagine what will take place in many nursing homes if these plans materialize. Nursing homes could effectively play the same role in dementia care that mental hospitals played prior to the Mental Health Act of 1955, with conditions so deplorable that advocacy and litigation may be necessary to protect the most vulnerable in our society.

Considering the combination of all factors, including the impact of OBRA on nursing homes, it is not surprising that many nursing homes are reluctant to admit persons with an existing or future chance of a mental illness diagnosis (Estes and Swan, 1993; Mosher-Ashley et al., 1991). Further complicating is the fact that once a nursing home has a patient, it may be difficult for them to discharge a patient, even if they cannot meet the patient’s needs any longer. As of 1990, only eight states have specific statutory and/or program responsibility for persons with Alzheimer’s disease: California, Florida, Maryland, Michigan, Oregon, South Carolina, Virginia, and Washington (Fogel et al., 1993; Mosher-Ashley et al., 1991). When dementia and mental illness co-exist, it seems to be a matter of convenience which diagnosis is primary and which is secondary. If a person with a primary diagnosis of dementia lives in a nursing home and develops a secondary mental illness such as severe depression, they may not be admitted to state mental hospitals in most states. On the other hand, if the person has primary depression and secondary dementia, psychiatric care in state hospitals is possible, but the nursing home

has that patient counted against them for PASARR purposes and is required to provide specialized services until hospitalization is necessary and possible. Nursing homes in Virginia often bitterly complain that they cannot get patients into the mental health system once they feel that such patients are too disruptive. Community mental health, as previously discussed, places low priority on the geriatric population; the state psychiatric hospitals attempt to admit only patients that meet the legal admission criteria (and the patients must be pre-screened by community mental health); and private psychiatric units or hospitals may not want those patients because they are often unable to pay for services. OBRA, while intending to protect the elderly, actually may have created a no-care zone as coined by Estes and Swan (1993).

Nevertheless, there is still a large population of dementia patients who represent a lucrative market for the nursing home industry. In response, many nursing homes have developed specialized Alzheimer's units. Presently, about 10% of nursing homes have such special care units (Cotter, 1995). Although some of these units are staffed adequately with well-trained persons and provide a desirable conducive environment for dementia patients, many are simply blocked off areas with locked doors. The admission director of a nursing home, operated by a large chain, explained that their specialized unit has to be locked because the facility is so close to a busy street. Staff working on the unit get special training consisting of one hour of instruction for two weeks which totals ten total training hours. They rotate all staff every six months off the unit as a stress-reduction strategy for staff, even though they know that such abrupt staffing changes add to the confusion of the patients, and may result in adverse or even catastrophic patient reactions. (A catastrophic

reaction is a clinical term used to describe extreme confusion and aggression or resistance in patients, that may lead to psychiatric treatment on various levels.) The admission director said, “It’s bad, we know it is bad to change all staff at the same time; they should do it gradually, but they won’t listen to me.” But the patients have a nice large courtyard where they can walk, and the unit is in subdued colors so external stimulation is reduced. Eating is done in shifts so staff can pay more attention to patients and the dining room is less busy, and “the activity person for that unit is really good and caring” (personal communication, September 1995). Obviously, while there is some effort to provide a therapeutic environment for the dementia patients, the high expense of losing staff and having to replace them, supersedes the residents’ needs.

Although other means than locking units are available, they are costly. For instance, some nursing homes equip patients that are known to wander with special wristbands that set off an alarm when the patient leaves a designated area. But it requires staff to return a patient to a safe area, and staff is expensive, more expensive than a lock on a door. While some nursing homes are excellent, and others are good, many nursing homes have become other places of involuntary confinement and they have become the new back wards in the community (Mosher-Ashley et al., 1991). However, the “involuntary” confinement is based on coercion from family members, or simply a lack of alternatives; it is not invoking the legal system. Such confinement may be supported by the patient’s physician. One interviewed physician stated that, in general, he advises families not to attempt to provide home care once a patient is not easily controlled any longer; that is, obeys the care giver, and when the patient is incontinent. He said that it is his

experience that families cannot last as care givers under these conditions (personal communication, September 1995). There was no mentioning of advice or referral to community resources, even though many projects have shown that community resources can prevent institutionalization, which will be discussed later in this chapter.

Obviously, while attempts were made to regulate the nursing home industry and protect patients, funding and enforcement did not follow the policies, and thus high quality nursing home care still depends on the organizational philosophy of the individual homes and the dedication of staff. Presently, it appears that nursing homes are not the best solution to the problem of caring for an ever increasing population of dementia patients, even though they are one of the options. The following will explore some other options.

Adult or Boarding Homes and Other Assisted Living Options

Currently, approximately 32,000 board and care homes are licensed in the United States, with an additional unknown number of non-licensed facilities. The licensed facilities provide room and board and various levels of assistance to about 500,000 older persons (Clemmer, 1994).

Adult or rest homes (adult care residences is the current appropriate term in Virginia) are widely utilized by the mental health system as a discharge setting for the mentally ill, and they are also often the first institutional setting for elderly persons when they leave their own home. Rest homes are long-term care facilities that care for persons who are aged or mentally or slightly physically disabled, but do not require nursing or medical care. Traditionally, nursing homes care for the more physically impaired, while adult homes care for those persons less physically but more mentally impaired. Adult

homes are a much less restrictive environment than psychiatric hospitals or nursing homes, but consequently also provide less “treatment” or programming. Many rest homes are small family-operated facilities. In Virginia, the administrator is only required to have a high-school diploma, and no nursing staff is required. Legislative attempts to require at least one nurse on staff has so far successfully been avoided in Virginia by lobbyists for the adult home industry. Many of these homes are licensed so they meet minimum safety, staffing, and training requirements. A licensing official called the rest home “a home away from home,” thus, residents cannot be required or forced to do anything they could not be forced to do at home. Of course, if residents become too difficult to manage, transfer, often to a mental hospital, is always a possibility.

Obviously, this type of residential setting provides more of a home-like atmosphere, together with some assistance and supervision when needed. However, governmental reports confirm reports from the popular media and advocacy groups that this industry is “plagued with allegations of abuse and low quality of care” (Clemmer, 1995, p. 3).

The rest home may be an appropriate and often successful alternative for the early stages of dementia when supervision is the main concern and care at home is not possible. They do not provide any treatment for dementia patients, only custodial care, thus the disease is in the realm of “normal” aging. Transfer to a nursing home or psychiatric facility often occurs in the later stages of the illness when symptoms become less manageable.

Adult homes in Virginia that admit persons with mental illness from psychiatric facilities have an agreement with their local CSB or a private mental health professional

for the provision of mental health services. Mental health services may include screening for admission to a psychiatric facility, but also staff training and consultation as to avoid other levels of institutionalization.

Assisted living or congregate housing arrangements are a yet less restrictive living environment, focusing on preservation of residents' autonomy. They usually offer room and board, social and recreational activities, assistance to persons needing help with personal care and medications, monitoring and protective oversight, and 24-hour help when needed. However, over half of the persons living under these arrangements move into nursing homes or hospitals when their needs increase. Some states also limit the level of help that can be provided in such facilities (Clemmer, 1994). These programs are often highly individualized toward the needs of the residents, and are a valid option for the early stage patient when in-home care is not available. However, they are not widely available and are expensive, and often are not a lasting alternative for dementia patients as the disease progresses and the patients' needs move beyond the capability and mission of these facilities.

Home Care

Institutionalization, regardless on which level, is costly on a financial and personal level, but often it is the only solution for elderly dementia sufferers who have no family and can no longer function independently in their homes. But for those who have a caregiver, staying at home may be the best solution. Most elderly persons, including dementia sufferers, want to stay at home as long as they can express their preferences, and we do not know once they cannot express their wishes any longer. As the director of an aging

association stated, recalling a personal experience from her family, "They [the elderly] want to stay home, they want to stay on the farm" (personal communication, September 1995).

Most families want to provide care at home, too, and often make truly heroic efforts to avoid institutionalization. Additionally, some studies have supported that care at home is cheaper than institutional care (Estes and Swan, 1993). For instance, Coughlin and Liu (1989) found that the annual cost for nursing home care for cognitively impaired persons was \$22,300, and for community care \$11,700. However, it was not disclosed how comprehensive the home care was, so these figures need to be regarded with caution. The *Medicare Alzheimer's Disease Demonstration* that was contracted by congress to explore whether comprehensive community services, including intensive case management and family education, would delay institutionalization allowed a direct cost of \$300.00 per client/per month and, respectively, \$500.00 per client/per month for a control group (Manning, 1993). This seems much cheaper than institutional care, but does not include the extensive support staff required to administer such a program, nor does it include costs for physicians and medications. Nevertheless, with community care preferred by the patients and their families and possible cost benefits available, why are millions still institutionalized in mental hospitals, nursing homes, and rest homes?

Several studies have attempted to explore which factors affect the decision to institutionalize elderly dementia patients (Cohen et al., 1993; Coughlin and Liu, 1989; Knopman et al., 1988; Lieberman and Kramer, 1991; Severson et al., 1988) resulting in a wide variety of conflicting findings. However, in general it appears that spouses may opt

for in-home care as long as their own health will allow it, while children, other relatives, or non-family informal care givers may opt for institutional placement of the patients (German et al., 1992; Lieberman and Kramer, 1991; Mittleman et al., 1993). Troublesome behavior, such as aggressive behavior and incontinence, was not always predictive of consequent institutionalization and neither was the availability of community resources. However, community-based resources were helpful when they carefully focused on the specific needs of the care givers. Mittleman et al. (1993) found that specific, individualized counseling for care givers, together with intensive case management, delayed institutionalization significantly and often avoided it altogether. Especially in the middle stage of Alzheimer's disease, when patients display the most disturbing behaviors such as wandering, delusions and hallucinations, the counseling was very effective. Family members understood the transitional nature of these behaviors and waited out that stage of the disease. The non-placement of patients could also be explained by the reluctance of nursing homes to accept such difficult patients, and the state mental hospitals in New York (where the study was conducted) will no longer admit dementia patients. The Mittleman study is noteworthy, because it offers an effective model how community interventions could be structured. They maintain that "it is essential to provide care givers with sufficient support to mitigate the emotional and physical toll of caring for Alzheimer's disease patients in order to extend the time that home care remains an option, without jeopardizing the well-being of the care giver or the patient" (739). The *Medicare Alzheimer's Disease Demonstration* (Manning, 1993) arrived at similar conclusions even though as we shall see later, Medicare will not pay for these services.

The effectiveness of focused community support and intensive case management is also demonstrated by the previously mentioned geriatric component of a community services board serving a city of 200,000 in Virginia. The director of that program stated in a personal communication (April 1995) that case management provides for coordination of services in that city. Once a dementia patient enters their caseload, they utilize private psychiatric hospitals, usually on a voluntary basis, for short-term treatment to stabilize acute episodes of behaviors that care givers cannot handle and that qualify for psychiatric treatment. The 190 day lifetime limit for inpatient treatment of mental illnesses allowed by Medicare is deemed sufficient for the management of acute episodes, for those dementia patients who enter the mental health system usually for the first time. After stabilization of the acute episode, services such as adult day care and home health care, often from religious non-profit organizations, are secured. Referral to other private or public resources is coordinated, based on the clients' ability to pay for services, and arrangements for financial services will be made when needed. When caregiving at home is not possible, adult homes specializing in dementia care may be utilized. These efforts are designed to keep the patient in the community, ideally in his or her own home. It must be noted that the director of the program attributes their success in keeping clients out of institutions to his thorough understanding of dementia-type illnesses and his ability to effectively network among the widely fragmented services, and to the case managers' dedication and willingness to go far beyond their required duty to ensure the well-being of their clients. He also recognizes that many services are only available in urban areas and that the same coordination may represent a much bigger problem in rural areas.

The case management approach was not as unconditionally supported by Thelma Bland, the Commissioner of the Virginia Department for the Aging (personal communication, September 1995). Among the community services administered by this department are the local area agencies on aging (AAAs) that provide a variety of programs for the elderly, such as assistance with housekeeping, shopping, personal care, and meal preparation. Some AAAs provide adult day care, respite services for care givers, home repairs to ensure safety, legal assistance, and meal sites for the elderly. While Commissioner Bland believes that some barriers that keep elderly persons from receiving available services are 1) a lack of knowing about it, 2) reluctance to accept a “handout,” and 3) long waiting lists for services, she still thinks that it is absolutely necessary that families and patients participate actively in their own care. “They need education and information, so they don’t rely entirely on case management.” Education of policy makers, family members, insurance carriers, and the general public was suggested by her to raise awareness for the plight of dementia patients and their families.

Returning to the services of community mental health, one city rarely is using the option of the inpatient mental hospital, while a neighboring city with similar services is one of the largest users of the geropsychiatric facility. The Clinical Director of that CSB stated in a personal communication (February, 1995) that they cannot serve dementia patients because they a) do not consider them seriously mentally ill; thus they are not required to serve them, and b) they do not have the necessary resources to serve the seriously mentally ill younger population in their community. The availability of the geropsychiatric hospital and the involuntary commitment procedure seem to bring patients from that area

to the hospital, not the lack of community resources outside of the mental health clinic.

However, according to the Senior Case Manager (personal communication, September 1995) community mental health clinics are in a dilemma. To provide case management on a reimbursable basis, the client must meet the serious mentally ill criteria that stipulates that the clients must (1) have had more than one psychiatric hospitalization in the past, (2) be on some kind of disability or public support, and (3) must have had more inpatient than outpatient treatment and care in the past. Most dementia patients may not meet these requirements and, therefore, may not be able to get the case management that brings community resources within their awareness and reach. Therefore, even if the client could be assisted in the community, psychiatric hospitalization may be required to meet the hospitalization and inpatient treatment requirements. Once the patient meets these requirements, community assistance, including case management, can be offered and is reimbursable. This is a vicious cycle for the client and community mental health, creating a segment of dementia patients that may be hospitalized so that they can be labeled as seriously mentally ill for no other reason than to receive community support that was designed to prevent institutionalization. So it is not the mental health directors' opinion that dementia is not considered a serious mental illness; the dementia patients simply do not fit the requirements under normal circumstances and may not get the services they need and that may be available.

But even when community resources are available and adequate, and case management can be provided to coordinate the widely fragmented services, the question still remains who will provide home care and how can families provide it. It is very

possible that adult children have responsibility for two sets of parents because longevity has increased. Additionally, many families also have some responsibility for children who return home, often with their children, while aging parents also need care. The term “Sandwich Generation” is often used for that middle-aged group that provides support for parents and children. It is usually women who fulfill the “filial duties” of providing day-to-day care for elderly relatives (Martin and Post, 1992). And these women, who have at great sacrifice provided about 70 to 80% of the informal care to aging parents, are often in the workforce (Estes and Swan, 1993; Manning 1993).

Disregarding all these problems, community care is promoted by both progressive and conservative forces, but for different reasons. Conservatives may see the benefit of community care in the cost savings for the public sector, especially when the free labor is provided by women. In addition, caregiving restores the traditional role of women in the patriarchal family. On the other hand, progressives see social policy which provides community care as a mechanism to a) increase public responsibility for entitlement for much needed long-term care, b) redress the unequal burden currently carried by women, and c) empower care givers and care recipients. Estes and Swan (1993) write:

Lloyd characterizes the two major positions on community care in terms of conflict and consensus discourse. The consensus discourse represents gatekeeping and the distribution of community-care resources as benign and unproblematic...the conflict discourse emphasizes the ‘structural contradictions and conflicts of individual interests, oppositions’ inherent in social situations (Lloyd, 1991, p. 129). The conflict discourse attend to the participation and power concerns of older persons faced with the increasingly bureaucratized and rationalize structures of service delivery and the professionalization of geriatric assessment and case management. (260)

The bureaucratized and rationalized structure of service delivery is not only problematic for the older persons but also for their care givers. Presently, it is complicated to understand the rules and regulations that allow persons to utilize any resources. Additionally, the gatekeeping bureaucrats often do not understand that their systems are not as clear to potential clients as they are to them, and they do not always refer to other services available. Of course, they may also not be aware of all other and frequently overlapping services, or they do not understand or do not trust resources from other systems, or they may have some other reasons not to acknowledge other services. It often becomes too difficult for care givers to “work the system,” so they do without resources or elect to institutionalize the care recipient. Even though case management is another step in the bureaucratization, at least a dedicated case manager can coordinate all services, and relieve the care giver from that burden. It is unfortunate that the sheer luck of place of residence, the personal dedication of case workers, and the financial ability of the patients or their families determines whether a dementia victim can stay at home as long as possible, thus maintaining as much life satisfaction and dignity as possible.

Adult Day Services

Among the many barriers to home health care is a lack of respite for care givers and the out-of-home employment of the primary care giver. Recognizing this, a new option is emerging with adult day services, formerly called adult day care. The number of such centers has increased from less than 15 only twenty years ago, to over 3,000 in 1994. The Robert Wood Johnson Foundation, technically supported by The Bowman Gray School of Medicine in Winston-Salem, North Carolina, carried out the first national four-

year demonstration project (1988-1992) that focused on day centers and respite services for persons with dementia. Results of this project suggest that such centers can provide effective day care for dementia patients, even for those that display behavior problems considered dangerous to self and others. Specific programming targeting the needs of the patients and families and focused marketing increase visibility of these programs and make them valuable resources for dementia patients and their care givers (Cox and Reifler, 1994). According to Nancy Cox, one of the program managers, the encouraging results of the program prompted the Foundation to announce a successor in 1992 that will include even more day centers (personal communication, September 1995).

Programs that support home care seem to validate dementia as an illness that can usually be managed at home with some assistance, but in special circumstances requires institutionalized care on various levels. This is similar to most other illnesses that are managed at home with the assistance of a physician, a nurse, other family members, or friends, and that require institutional care only in the worst of circumstances. Dementia, as a long-term illness takes a special toll on care givers, and home care is not the best solution for everyone, but when dementia is removed from the area of “normal” illness and moved into custodial care or mental illness categories, institutionalization is the routinely preferred treatment option.

To summarize, the Mental Health Study Act resulted in widespread deinstitutionalization that included elderly dementia patients. However, communities were not prepared to absorb and care for these patients, so many were transinstitutionalized into nursing homes. Deplorable conditions in many nursing homes resulted in federal

regulations that were intended to provide adequate care for dementia patients, but actually resulted in declassification of dementia as a mental illness and unofficial re-classification as aging deterioration that is not an illness at all. Consequently, some nursing homes provide excellent care to dementia patients while others are “warehouses.” Alternatives to nursing homes are adult or boarding homes or assisted living communities that provide more of a home-like atmosphere, but often lack appropriate staffing and programming for dementia patients. Therefore, they usually discharge dementia patients into nursing homes or psychiatric hospitals when care becomes too difficult.

Most patients and families prefer that the patient is cared for at home, just like it is customary in most other illnesses. Studies show that barriers to such care can be overcome through supportive measures, including intensive case management that includes coordination of available resources, and programs that provide respite for care givers such as adult day care services. However, these services are presently reserved for those who can find and afford them, thus institutionalization of dementia patients for custodial care is often an alternative.

As can be seen from the previous chapters, the classification of dementia as a mental illness or not as a mental illness has implications on what system can be evoked. All systems, including home care by non-family members, are regulated and driven by social policy. While individual value systems play a role, it is ultimately societal values reflected in social policy and consequent funding, or lack thereof, that decide the outcome for those affected. Therefore, the next chapter will address how services are funded, and how this funding is reflected in the care decisions made by family members and the public sector.

Chapter 5 - Payment for Dementia Care

As shown in chapters three and four, dementia patients and their families have a variety of treatment and care options, from keeping the patient at home and perhaps utilizing available services to support home care, to institutional placement in nursing or rest homes and psychiatric long-term hospitals. But how are those services paid and what are we doing as a society to support persons who are needy based on illness?

This chapter will explore the social policy in America that is the basis for Medicare and Medicaid, the main payor for health care services for the elderly population. Furthermore, how this social policy has become dysfunctional for the original population but has become functional for others, will be discussed. The chapter will conclude by exploring the role of bureaucracy in that particular social policy.

The question of payment may not be of utmost importance to those who are wealthy. We may never hear that one of the famous victims of Alzheimer's disease, former President Reagan and his family, will have to struggle to pay for his care, even though their emotional struggle may not be less than that of any other family. However, payment for services becomes of utmost importance to most patients and families, and, unless a patient or family has sufficient funds to pay for treatment and care, social policy based on social security laws governs how reimbursement can be obtained.

Social Policy in America

According to the Social Security Bulletin (1987), industrialized countries recognized that the agrarian era support system for the needy, consisting mainly of families, charity, and local government, was insufficient to meet the needs of more and

more urban and industrialized societies. However, each country tailored social public policy programs to its specific situation. The American program was influenced by the size of the nation, ethnic diversity, and a tradition of self-reliance based on frontier experiences. Beginning with their introduction, social programs were pragmatic and incremental, based on specific needs not necessarily on values and philosophies. Policies and programs appear to be reactive rather than proactive. Additionally, American social programs are characterized by decentralization and by a large involvement of the private sector in the administration of such programs.

Beginning in the 1920s, government realized that social insurance principles would best meet the needs of a progressively more industrialized nation. This means that risk is pooled and premiums paid by employer and/or employees could be used when a need for assistance arises through old age, illness, unemployment, disability, or death. Based on this system of contribution, benefits are paid as an *earned right not as a charity*. As early as 1908, federal law was enacted that protected workers from disability incurred on the job. The depression of the 1930s prompted additional federal action.

In January 1935, President Franklin D. Roosevelt proposed to congress long-range economic security recommendations embodied in the report of a specially created, Cabinet-level Committee on Economic Security. Identical legislation was introduced in the House and Senate and there followed the passage of the Social Security Act, signed into law on August 14, 1935 (Social Security Bulletin, 1987, p. 7).

During the depression, private health insurance began to emerge, with Blue Shield partially covering doctor bills, and Blue Cross covering hospitalization. However, this coverage was mainly available through employee plans or to those who could pay for it. The elderly and poor were often unprotected (Popenoe, 1993).

Medicare and Medicaid - Security for the Old and the Poor

In reaction to arising needs, the basic program of Social Security was amended, and Medicare was established in 1965, providing medical insurance for nearly everyone aged 65 or older. Similar to the private insurance that provided the model for Medicare, inpatient and outpatient care were separated, with Part A partially covering hospitalization, and Part B covering outpatient services. At the same time, title XIX of the Social Security Act instituted Medicaid. That state-operated program provides federal matching funds to states to help offset the cost of medical care to the indigent population. For the poorest segment of the population, congress replaced in 1972 a previously existing program for the needy aged, blind, and disabled with the Federal Supplemental Security Income (SSI) program (Social Security Bulletin, 1987). It is noteworthy that these programs had their roots in the Progressive Era, where the state not the community or the individual decided what was best, and evolved into the Liberal era with its dream for the "Great Society." Government was for the first time deeply involved in providing health care for a segment of the population; taking care of the needy in a community was no longer the major responsibility of individuals or charities. It seems that social policy is not only a reaction to a need, but is still a reflection of societal values and beliefs at a given time. At first glance, it appears that all is well for dementia patients because they are usually over age 65, and Medicare should cover their illness. Yet, a closer look will show that only illnesses that are traditionally considered "physical" and "curable" are partially covered by Medicare. As a representative from the Health Care and Financing Administration (HCFA), who administers Medicare and Medicaid stated: "These programs

are meant to be a financial protection against acute short-term illnesses--and they do that very well" (personal communication, October 1995).

Medicare - Part A - Inpatient Care and Beyond

Table 4 will demonstrate which services are partially covered under Medicare Part A, followed by an exploration how this relates to the care for dementia patients.

Table 4 - Medicare Part A: 1995

Services	Benefit	Medicare Pays
HOSPITALIZATION Semiprivate room and board, general nursing and other hospital services and supplies.	First 60 days	All but \$716
	61st to 90th day	All but \$179 a day
	91st to 150 day ¹	All but \$358 a day
	Beyond 150 days	Nothing
SKILLED NURSING FACILITY CARE Semiprivate room and board, skilled nursing and rehabilitative services and other services and supplies. ²	First 20 days	100% of approved amount
	Additional 80 days	All but \$89.50 a day
	Beyond 100 days	Nothing
HOME HEALTH CARE Part-time or intermittent skilled care, home health aide services, durable medical equipment and supplies and other services.	Unlimited as long as patient meets Medicare conditions.	100% of approved amount; 80% of approved amount for durable medical equipment.
HOSPICE CARE Pain relief, symptom management and support services for the terminally ill.	For as long as doctor certifies need.	All but limited costs for outpatient drugs and inpatient respite care.
¹ This 60-reserve days benefit may be used only once in a lifetime.		
² Neither Medicare nor private Medigap insurance will pay for most nursing home care		

Adapted from: Your Medicare Handbook, 1995. Department of Health and Human Services

Hospitalization

Medicare Part A will help to pay for a maximum of 190 days inpatient care in a psychiatric hospital in a lifetime on the same level as it will pay for any other hospital. Psychiatric care in a non-psychiatric hospital is not subject to the 190 day lifetime limit. The help during the 190 days may very well be sufficient for dementia patients who have some savings and require only stabilization of an acute episode of unmanageable behavior to be returned to a care giver at home. Of course, if the patient has a coexisting physical

illness that requires hospitalization in conjunction with psychiatric treatment, Medicare will help out longer, and the hospital days will not count toward the 190 days inpatient lifetime limitation for psychiatric hospitalization. However, because dementias, especially of the Alzheimer's type, are not recognized as physical illnesses per se, patients are usually not hospitalized for the treatment of their dementia, unless, as previously mentioned, they present with a coexisting physical illness. To complicate matters, Alzheimer's patients are usually diagnosed with less chronic or acute physical illnesses than non-dementia patients. Some (Hirsh, 1994) suspect that perhaps these patients are simply under-diagnosed and under-treated because physicians view them as terminally ill anyway.

One of the interviewed physicians had additional explanations for the decreased prevalence of illness in dementia patients (personal communication, September 1995). According to him, dementia patients in advanced stages cannot communicate their symptoms, or if they express them in an unusual manner, they may be dismissed as confused. Those in institutional settings such as hospitals have a better chance to be diagnosed during routine examinations. Furthermore, since dementia is a terminal illness, patients simply may not live long enough to be diagnosed. However, there may be a more serious reason. Physicians, based on their own professional ethics and personal value system, may decide that a diagnosis leads to a requirement of treatment. The physician may find such treatment useless based on his or her judgment of quality of life, especially when late-stage dementia patients are involved. The interviewed physician usually recommends to the family of late-stage dementia patients who develop serious illness that no active treatment but only comfort measures be implemented. If the family insists on

treatment, the physician “will do as little as possible” within the family’s wishes. There also appears to be some networking among physicians so they support each other in “doing as little as possible.” Dementia patients frequently die of secondary infections, often respiratory. Healthcare professionals’, and often families’, disengagement with those patients who are considered beyond hope, especially if they are institutionalized, was explored by Sudnow (1967) and by Glaser and Strauss (1968) within the framework of social death, which will be discussed in the next chapter.

With Medicare paying only under very limited circumstances for psychiatric hospitalizations, many patients end up in state-operated facilities. One physician suspected that the private hospitals “pack their [the patients] bags once Medicare or private insurance runs out.” Even those patients who have some savings usually spend down very fast to Medicaid eligibility. And the state-operated hospital that charges on a per-diem rate of only \$200.00 per day for comprehensive care, can “help” patients to spend down very quickly. Payment in the state-operated hospital is completely nontransparent, even for those who attempt to understand it. The reimbursement officer makes decisions on an individual basis, even though some rules seem to apply. However, most patients who enter that hospital are already Medicaid eligible, and Medicaid is the major payor for that facility.

Nursing Facilities

The next option on the list of Medicare Part A are skilled nursing facilities. As the footnote in Table 4 clearly states, Medicare will not pay for most nursing home care, and the partial payment is limited to 100 days, surely not enough for the dementia patient

under most circumstances. When Medicare pays for part of nursing home care, only skilled care is covered, and only few nursing homes are certified as skilled nursing facilities. Custodial care is not covered.

Skilled vs. Custodial Care

Interestingly, custodial care has never been defined by congress, and thus the concept led to litigation. The United States Court of Appeals, District of Columbia Circuit, decided on May 15, 1987, in *Barnett v. Weinberger* that CHAMPUS, the civilian insurance for the military, was required to pay for care that the insurance carrier considered “custodial.” Rachael Barnett, a 10-year old military dependent, was “the victim of a disabling and incurable neurological condition ... she is generally comatose, severely retarded, incontinent, and unable to dispose of bodily secretions that may collect in her throat ... as a result, Rachael must be fed, dressed, exercised, and cleansed by an attendant” (818 Federal Reporter, 2d Series, pp. 954-955). Rachael’s conditions sounds very much like a late-stage Alzheimer’s patient’s, except for the age factor. The insurance carrier maintained that “Rachael’s disorder is incurable, no rehabilitative or other treatment to improve her condition has been prescribed ... hospitalization supplied only ‘custodial care’” (p. 955), and therefore, CHAMPUS benefits should cease. CHAMPUS is a statutorily-authorized military-dependent care system, just like Medicare is a statutorily-authorized care system for the aged. Both programs exclude domiciliary or custodial care, and so do private insurance carriers. For the previously mentioned case, both parties attempted to define custodial care. The insurance carrier defined custodial care as rendered to a patient

(i) who is disabled mentally or physically and such disability is expected to continue and be prolonged and (ii) who requires a protected, monitored or controlled environment whether in an institution or in the home, and (iii) who requires assistance to support the essentials of daily living, and (iv) who is not under active or specific medical, surgical, or psychiatric treatment that will reduce the disability to the extent necessary to enable the patient to function outside the protected, monitored, or controlled environment. The regulation provided that it is not the condition itself that is controlling, but whether the care being rendered falls within the definition of custodial care ... and the determination of custodial care in no way implies that the care being rendered is not required by the patient; it only means that it is the kind of care that is not covered under the basic program (p. 959).

The court decided for Rachael Barnett based on previous cases involving the Social Security Act and, consequently, cases involving senior citizens. While congress completely failed to define custodial care, the courts usually interpreted this type of care as “provided by a lay person *without special skills* [italics added] and not requiring or entailing continued attention of trained or skilled personnel” (p. 968). However in *Ridgely v. Secretary of the Department of Health, Education and Welfare*, the United States District Court, D. Maryland, decided on July 5, 1972, for Ms. Ridgely who filed for the estate of her mother, Mrs. Hape. Mrs. Hape, at age 86, was transferred to a nursing home after hip surgery for convalescence care. Medicare paid for care from April 1, through June 10; payment ceased on June 11, because Medicare determined that her care was only custodial in nature. Her attending hospital physician had requested nursing home care, because the patient was *confused* [italics added] which could lead to interference with the healing of her hip fracture. Mrs. Hape was not able to understand or follow the instructions given to her by the physician and care givers. She was also *incontinent* [italics added] and had hearing loss. Mrs. Hape could not recuperate at home because of her

confusion (345 Federal Supplement). Mrs. Hape displayed the symptoms and problems of dementia patients, but had the “good luck” to also have a broken hip which allowed the case to go to court. Chief Judge Northrop, who preceded over this case, rejected the idea that the exclusion of custodial care was meant to reduce benefits. He concluded:

Indeed, it appears to this Court that the purpose of the custodial care disqualification in § 1395y(a) (9) was not to disentitle old, chronically ill and basically helpless, bewildered and confused people like Mrs. Hape from the broad remedy which congress intended to provide for our senior citizens. Rather, the provision was intended to stop cold-blooded and thoughtless relatives from relegating an oldster who could care for him or herself to the care of an ECF [Extended Care Facility] merely so that oldster would have a place to eat, sleep, or watch television. But when a person is sick, especially a helpless old person, and when those who love that person are not skilled enough to take care of that person, congress has provided a remedy in the Medicare Act, and that remedy should not be eclipsed by an application of the law and findings of fact which are blindly bureaucratic economics to the purpose of the congress (345 Federal Supplement, p. 993).

The other case used as a precedence in the Barnett case involved *Kuebler v. Secretary of Health and Human Services* that was decided in favor of Kuebler, the Plaintiff, on February 7, 1984, in the United States District court, E.D. New York. Mrs. Kuebler, a 71-year old patient, was transferred from a hospital, after a back injury resulting from a fall, to a nursing home with

progressive cerebral arteriosclerosis with brain atrophy ... suffered from periods of confusion during which she did not recognize her husband and did not know her name. She also had episodes of agitated, assaultive and abusive behavior and a history of wandering about, both at her home and at San Simeon [the nursing home]. Such wandering occasioned the fall that caused the back injury Haldol, a psychotropic drug, was prescribed as needed to control agitation (Federal Supplement 579, p. 1438)

Based on *Ridgely v. Secretary of HEW* and other similar cases, the court in this case decided that

Mrs. Kuebler's condition shows progressive deterioration to the point where she was a danger to her own well-being and needed skilled care ... Although many specific services rendered to Mrs. Kuebler were routine and seemingly unskilled, in the aggregate they were treatment of her medical condition. And also taken singly Mrs. Kuebler's ailments might not seem to require skilled nursing care, taken together they made her a chronically ill, disabled old woman in need of monitoring ... To contend that her care was merely custodial and therefore could have been provided by a lay person is to ignore the fact that a lay person, in the form of her husband, was unable to provide adequate care (pp. 1439-1440).

Mrs. Kuebler was most likely a dementia patient in the middle to late stage of the illness. In fact, her dementia produced the fall that allowed her to be reimbursed for part of her nursing home care.

The court in the Barnett case concluded that

To suggest that a victim of a catastrophic illness ... is receiving 'custodial care' simply because the 'primary' portion of her attendants' time is spent providing for her elemental needs is patently misguided ... Indeed, further extension of the perverse logic advanced by the Department would reveal that the more debilitating the ailment affecting a claimant, the more likely the care will be termed 'custodial,' since even the simplest bodily task will require assistance and supervision (818 Federal Reporter, 2d series, p. 969).

Following the logic of the previously explored decisions, dementia patients should freely have access to Medicare reimbursement for their nursing home care. Even though all discussed cases had a physical illness element, the care included the type of care that traditionally may be termed custodial. Ironically, because dementia is not considered the right kind of illness (only physical illnesses are reimbursable) it has always been excluded from Medicare payment. Therefore, patients and families have no grounds to open litigation even if, based on the previously discussed cases, they may have a chance that the courts would decide in their favor.

Medicare considers care custodial "when it is primarily for the purpose of helping

the patient with daily living or meeting personal needs and could be provided safely and reasonably by people without professional skills or training. For example, custodial care includes help in walking, getting in and out of bed, bathing, dressing, eating and taking medicine” (Department of Health and Human Services, 1995, p 7).

However, the term “skilled care” still needs exploration. The previous cases provide some guidelines by maintaining that such care could not be provided by a lay person, and the Medicare definition of custodial care also has the professional skills or training component without defining what professional training is. Without any training and education, most untrained lay persons could not provide care for an Alzheimer’s disease patient. One needs to learn how to construct an environment that reduces confusion and that is safe for the patient who, for instance, may eat houseplants; feed a person as to prevent choking from aspiration (food entering the airways); develop a toileting or changing schedule that prevents dangerous skin breakdown and recognize breakdown when it occurs; give medication to a perhaps resistant patient; recognize coexisting illnesses in a non-communicative person; or adapt their own behavior as to prevent catastrophic reaction. This list covers only a very few of the skills the care giver must learn; a care giver with these skills is no longer an untrained lay person and should be able to be reimbursed. Additionally, much of the care is medically necessary because the patient may, for instance, not eat without being fed and thus starve to death.

Obviously, for legal and practical purposes it is a gray area whether care is skilled or custodial. For insurance carriers, skilled care is traditional medical care such as nursing services provided by licensed staff, physical, occupational or speech therapy, drug therapy,

etc. And the few skilled nursing facilities certified by Medicare are closer to acute care hospitals than they are to traditional nursing homes. They are closer to the traditional curative treatment model of the hospital than they are to the care model of nursing homes. However, with a growing aging population and consequent increased prevalence of dementia, perhaps these concepts need to be reevaluated. For instance, is a shot more treatment than a comforting hug, is intravenous feeding more nourishing than careful feeding or prompting to self-feed, and is a catheter better treatment than regular toileting or changing?

The skilled nursing principles that were previously discussed also apply to Home Health Care. The issues are similar, but care is provided in a private home rather than in a nursing home. Medicare may pay for some physician prescribed services such as part-time skilled nursing, physical and speech therapy, and home health aides. However, the service must be related to a covered illness, and dementias are usually not a covered illnesses. The director of a home health agency stated that Medicare or private insurance will pay when it is demonstrated that skilled care is provided mainly by a nurse or under a nurse's supervision. She said "things like wound care and injections are paid; prevention like with Alzheimer's disease families is not allowed or encouraged" (personal communication, July 1995). With very careful documentation, the home health care agency may be able to provide some initial education for families, but reteaching when the condition progresses into another stage is not reimbursable. "In essence," she said "Chronic conditions are not fixable, improvement is the key -- constantly show improvement. Have a start and an end."

Hospice Care

There is a clear end to dementia, death. Yet, whether Hospice Care is reimbursed by Medicare or not is unclear and decided on an individual basis. Physical, terminal illnesses are covered once the physician certifies that the patient has only a very limited life expectancy (according to the HCFA representative about six months). Because many late stage dementia patients are in nursing homes, hospice care is not often considered as an option for the family. And since pain relief, symptom management, and supportive services to terminally ill patients are the key components for reimbursement by Medicare, and a strict medical model is usually applied, it appears that reimbursement for dementia patients and their families may be doubtful.

It appears that the “benevolent legislative purpose” of congress with the introduction of Medicare (*Kuebler v. Secretary of Department of Health and Human Services*) has made room for a cold, rational bureaucratic approach as feared by Weber (Farganis, 1993). While some litigation seems to question Medicare practices, as a whole dementia patients are usually not reimbursed for hospital, nursing home, home health, or hospice care because their illness is considered either a condition requiring only “custodial” care, whatever that may be, or a mental illness for which care is only reimbursable on a very limited basis. However, should dementia ever be classified as the bona fide physical illness it appears to be, reimbursement through Medicare may become easier.

Medicare - Part B - Outpatient Care and Beyond

While the dementia patient in need of institutional or other extended care fares

badly under Medicare Plan A, Medicare Part B that covers outpatient treatment is a little friendlier to those patients, at least in the beginning. Table 5 will show what is covered under this plan which is based on premium contributions from beneficiaries.

Table 5 - Medicare Part B: 1995

Services	Benefit	Medicare Pays
MEDICAL EXPENSES Doctor's services, inpatient and outpatient medical and surgical services and supplies, physical and speech therapy, diagnostic tests, durable medical equipment and other services.	Unlimited if medically necessary.	80% of approved amount (after \$100 deductible). Reduced to 50% for most outpatient mental health services.
CLINICAL LABORATORY SERVICES Blood tests, urinalyses, and more.	Unlimited if medically necessary.	Generally 100% of approved amount.
HOME HEALTH CARE Part-time or intermittent skilled care, home health aide services, durable medical equipment and supplies and other services.	Unlimited as long as patient meets Medicare conditions.	100% of approved amount; 80% of approved amount for durable medical equipment.
OUTPATIENT HOSPITAL TREATMENT Services for the diagnosis or treatment of illness or injury.	Unlimited if medically necessary.	20% of billed amount (after \$100 deductible).

Adapted from: Your Medicare Handbook, 1995. Department of Health and Human Services

Based on the strict traditional medical interpretation of health care, Medicare Part B may pay for doctor visits, diagnostic tests, and treatment of physical illnesses as Medical Expenses. However, it “will not pay for most routine physical examinations, and tests directly related to such examinations” (Department of Health and Human Services, 1995, p. 14), and according to the HCFA representative, after the initial diagnosis most care for dementia patients is considered routine. As previously discussed, such routine examinations may discover coexisting physical illnesses in dementia patients who can no longer communicate their symptoms in an appropriate manner. Consequently, patients may not be diagnosed for a currently bona fide physical illness and not receive treatment or extended care that may be reimbursable under the skilled care criteria.

Furthermore, it is noteworthy that once dementia is diagnosed as a mental illness and treated by a mental health professional such as a psychiatrist, reimbursement is heavily reduced.

Many general practitioners refer dementia patients to psychiatrists. The psychiatrist usually diagnoses and prescribes medications for dementia patients. The psychotherapy and counseling that can be provided by some psychiatrists, psychologists, and clinical social workers, and that is partially reimbursable by Medicare, is usually not an option for dementia patients because of their cognitive impairment. However, care givers may greatly benefit from it, but only direct care to the patient is reimbursable. Because of low reimbursement rates, many psychiatrists will not provide care to dementia patients that may benefit from their treatment and that may help families to prevent institutionalization.

A worker in a community medical center found it to be her experience that general practitioners may delay the diagnosis of dementia, even if they are fairly sure, to protect the patient. They also can refer to a neurologist, who is not considered a mental health professional, and thus reimbursement criteria changes. The care and testing provided by a neurologist may be very appropriate and helpful for the patient. An insurance representative stated that Blue Shield, whose payment policies are similar to those of Medicare, pays for dementia followed by neuromedicine but not followed by psychiatry (personal communication, August 1995). A interviewed physician, who usually refers those patients who can pay to a neurologist for testing and treatment, noted that those patients who cannot be referred because they lack the financial means often require a "very long" time until all other illnesses are ruled out and a diagnosis of dementia must be made

(personal communication, October 1995). So treatment and support is provided on an acute not routine basis. Although this sounds like compassion, Hirsh (1990) points out that physicians may be subject to litigation if they misdiagnose dementia that may stigmatize the patient and prevents him or her from obtaining more appropriate treatment.

Outpatient care is similar to reimbursement for medical expenses with the reduced reimbursement of 50% for mental illnesses. Reimbursement criteria for Home Health Care is the same under Part A and Part B and has been discussed previously.

To summarize Medicare reimbursement for dementia patients: It is usually not covered when it exceeds the most basic level and a very limited time frame. Perhaps the private insurance representative captured Medicare's difficulties with dementia when he said, "The problem with dementia is that accurate diagnosis is still difficult, and dementia is not tangible. Dementia and mental illness is still vague and not concrete" (personal communication, August 1995). So how is dementia treatment and care paid for if private funds are not available or exhausted?

Medicaid - Medical Charity

For those who have exhausted their Medicare coverage, are ineligible or are otherwise indigent, Medicaid eligibility may be determined. As previously discussed, Medicaid is jointly financed by federal and state governments to pay health care, including long-term care, for the poorest segment of the American population. Medicaid is not based on the shared risk principle of insurance like Medicare is; it is in essence government charity (or welfare) for those who cannot provide for themselves. Consequently, public policy and assistance will not start until a person is reduced to a certain level of poverty.

However, once a person is Medicaid eligible, most medical financial worries should end. Medicaid pays for “medical care and services through direct payments to suppliers of the care and services,” including premiums for Medicare Part B and long term care in nursing homes (Social Security Bulletin, 1987). According to a report by National Public Radio (NPR) on October 25, 1995, currently 4 million senior citizens have health care through Medicaid, and the nursing home cost is paid by this program for 1.6 million elderly persons.

This relatively comprehensive paid health care, including dementia care, through impoverishment of senior citizens has become such a “popular” option that legal professionals dealing with estate planning advise their clients in planned impoverishment.

Bagge (1990), writes:

An older person or couple attempting to plan for an uncertain future is challenged by the need to navigate between ... adequate health care whose cost can pauperize the affluent and ... premature estate distribution, a self-pauperization which may lead to a loss of autonomy and unexpected denial of public funding for required health care. (46)

Nevertheless, many attorneys advise their clients to pauperize themselves in a planned manner, and the legal literature offers a surprisingly large number of articles on that topic (e.g., Bonnyman, 1990; Buddish, 1990; Gouskos, 1989; Mooney et al. 1988; Simon, 1984). A Legal Aid representative stated that they make all of their clients routinely aware of this option, who then must seek assistance from a private attorney (personal communication, September 1995).

It takes an attorney’s services to understand the eligibility criteria. Because Medicaid is in its basic elements a state’s program supplemented by federal funds, each

state determines its own eligibility criteria and also which services will be covered.

Presently, some minimum federal regulations must be adhered to, but proposed welfare reforms would eliminate these requirements. States would receive block-grants from the federal government for disposal at their own discretion and within their own regulations.

Most persons need Medicaid funds only for either long-term care at home or for nursing home care. In general, to be eligible for nursing home reimbursement, they must spend down all personal property which usually does not take long once a person enters a nursing home. Nursing home costs range from \$20,000 to \$50,000 annually, with Medicaid paying a per-diem rate of 62.22/day in Virginia and a slightly higher rate for special care unit placement. (Private pay rate is substantially higher at \$88.00 per day for room and board and extra charges for many other services in a medium priced nursing home.) About half of those entering nursing facilities in Virginia qualify for Medicaid six months later (Virginia Department for the Aging, 1991). The admission director of a nursing home (personal communication, August 1995) usually admits as private pay those patients who have a minimum of \$20,000.00 available. All others must attempt to become Medicaid eligible. Nursing homes often will not admit those who do not have adequate cash but are not poor enough to be Medicaid eligible.

Buddish (1990) summarized the general rules that apply in most states as follows: non-married persons can keep a personal allowance once they enter the nursing home ranging from \$30.00 - 70.00 per month (\$40.00 in Virginia). In some states, they may also keep funds for health insurance premiums and other medical expenses not covered by Medicaid. To maintain a home, persons are allowed a small allowance averaging \$250.00

per month which ceases when they enter the nursing home permanently.

Assets the person can protect include for a limited time the house they live in, household goods not to exceed a value of \$2,000.00, one wedding and one engagement ring, one car of a value not to exceed \$4,500.00, personal property if the property is income or sustenance producing, cash value of a life insurance not to exceed \$1,500.00, and up to \$1,500.00 for burial costs.

Federal safeguards implemented in September 1989 protect married community spouses against being impoverished. A spouse may keep his or her income, plus a basic living allowance from the nursing home resident's income, capped at about \$1,500.00 per month. The spouse of a nursing home resident also may keep certain assets, including \$62,000 of their combined life savings, and exempted assets similar to those of single persons, including the home as long as the community-based spouse lives in that home. Exempted assets can be protected without limitation on their value. However, current proposed welfare reform would remove that safeguard for married spouses from federal regulation; states would have to come up with their own criteria to protect community spouses from impoverishment. The interviewed Legal Aid representative stated that it must be noted that the nursing home spouse is essentially homeless once he or she becomes eligible for Medicaid, and the community spouse will become homeless once he or she moves out of the home for whatever reason (personal communication, September 1995).

The states protected themselves somewhat against planned impoverishment for Medicaid through transfer of assets. "Transfers of property for less than fair market value

made *within thirty months* [italics in original] of an older person's application for Medicaid generally are not considered valid for transfers for Medicaid purposes" (Buddish, 1990, p 53). Certain exceptions apply to those transfer rules. The reimbursement officer in the geropsychiatric facility sometimes advises spouses to buy that car they always wanted so their institutionalized spouse will become Medicaid eligible (personal communication, August 1995).

Once Medicaid eligibility is determined for a person, comprehensive home health care is reimbursable under Medicaid in many states for those persons who are also nursing home eligible (Fatoullah, 1992; Estes and Swan, 1993). Here too, eligibility criteria and services vary widely by state, and legal advice may be needed. In Virginia, once a person is nursing home eligible, Medicaid pays usually for personal care, adult day care, and respite care as long as the cost of home care is less than that of nursing home care. All services must be provided by authorized agencies; a family care giver cannot be reimbursed. Some Social Service Departments have a very small fund they can use to pay informal care givers for personal care once the patient's nursing home eligibility is determined. In most cases, the payment for home support services, if they can find them, is the patients' or the families' responsibility (Virginia Department for the Aging, 1991).

Medicare, Medicaid, and most private insurance will not pay for adult home care. However, some coverage may be supplied through the Supplemental Security Income (SSI) program that is available to the very poorest segment of our population under certain circumstances. In Virginia, an auxiliary grant can help indigent persons to pay for adult home care. After they have depleted all of their assets and income, the grant pays

between \$600.00 - \$700.00 per month. A monthly allowance of \$35.00 is granted to pay for personal items, including co-payment for drugs that are not covered by Medicaid (Virginia Department for the Aging, 1991).

Barriers to Care For Dementia Patients

While it appears that for most options (excluding home care by informal care givers) either Medicare, private insurance, Medicaid or other welfare programs will help to pay, the matter is much more complicated in reality. All have very complicated eligibility criteria, and many providers of services will not accept these payment sources as reimbursement in full. It is estimated that elders pay more than 18% of their health cost which may constitute 4.5 months of their annual Social Security income. Older women seem to be worse off with Medicare covering only 33% of health care costs for single older women living alone (Estes and Swan, 1993).

Additionally, many residential long-term care facilities, home health agencies, and similar providers will only serve private pay patients. Many respite and day care programs will not accept patients with difficult behaviors or advanced functional impairments such as incontinence, so they may have to search for more expensive alternatives. The availability of services is market based, and those who can pay for it have the best access to it. Many cannot pay the market price of community care, thus they will become institutionalized. Estes and Swan (1993) coined the lack of access to care the no-care zone. The business director of a nursing home pointed out that a reimbursement system that encourages welfare usually elicits two responses. Her personal experience shows that “when the family finds out that nursing home or adult home can be reimbursed, they’ll

institutionalize” (personal communication, September 1995). The facility is not Medicare certified, and thus only admits private pay or Medicaid patients. The second response is that of families fiercely proud of the fact that they are able to provide for themselves, voicing that mom or dad would have wanted it this way. Mom or dad can still pay their own way. Generally, she finds that “people get upset because they tried to build up some wealth and now they lose it all; they have the same like those who didn’t save anything during their younger years.” Perhaps the current strong public support for welfare reform reflects that sentiment.

Furthermore, legislation discourages community mental health clinics to serve the elderly as previously discussed. In fact, in Virginia, CSBs have a financial incentive not to commit their clients to state psychiatric hospitals. However, this financial incentive is not available for diversion of geriatric clients, thus, hospitalization in a state facility is indirectly encouraged, even though we know that community care is more desirable and possible.

Dementia patients, who are usually not considered medically ill under current reimbursement standards, will be reduced to poverty and welfare before they can receive some of the care they need or when family members are not willing or able to provide unpaid home care. This care may include involuntary commitment into a public psychiatric hospital; private hospitals utilize the involuntary commitment process less often. Informal care givers often must provide unpaid care and make tremendous personal sacrifices either out of economic necessity or compassion. What went wrong with social policy in America? Two sociological concepts may provide some answers: Function and

dysfunction as described by Merton (1964) and bureaucracy as described by Weber (translated and re-published, 1978).

Function and Dysfunction of Social Policy

It was the purpose of the Social Security Act and consequent introduction of Medicare to assist senior citizens that have made a considerable contribution to the wealth and well-being of America. As a group, those age 65 and over were the first to have national health insurance. No other subgroup of the American population has public health insurance to this date. The purpose of the Medicaid component that protects older persons was to provide a safety net for those who were not Medicare eligible or when Medicare did not cover necessary medical services. Obviously, that social policy fulfilled a function for the older population. It provided health insurance for medical care usually more needed by older persons than by a younger population, because older persons always had more illnesses than younger persons, and they may no longer have any health insurance provided by their employers during their working years. The system was based on a pooled risk. Medicaid fulfilled the same function on a smaller basis, except the risk was with the government. Persons could age in dignity and peace and their children, mainly the males in the family, could take their place being the productive members of society. Additionally, they did not need to provide a substantial amount of money to assist their parents to pay medical bills. Many women provided unpaid care for the children and the elderly who needed assistance in the family.

However, Medicare has not change considerably since its implementation in 1965. These last 30 years have brought considerable changes to America. The birthrates and

increased life expectancies produced an ever-increasing older population while medical costs experienced more inflation than any other commodity in America. At the same time, more women--the traditional unpaid care givers--entered the workforce for a variety of reasons, but often for economic ones. It is difficult to expect from women who were not able to stay at home to raise their own children, to make the sacrifice of giving up an often hard earned career to care for their aging family members. The cries of crisis that we hear today result from a failure to adapt Medicare to changing economic and social conditions. The original Medicare concept had survived even though it was no longer fulfilling the needs for the elderly, thus it became partially dysfunctional.

The changing conditions also changed the original intent of Medicaid. Medicaid was meant as a last resource, a final safeguard, but it became the primary resource for health care for many elderly persons, especially for those with chronic illnesses such as the dementias. It too had survived but became dysfunctional for the original population.

Furthermore, a lack of adaptation to the changing family that is no longer routinely available to provide care to older family members increased institutionalization of elders who lost the ability to live independently. The whole system had become dysfunctional for those it was originally intended for, primarily the elderly and secondarily their families.

However, Merton realizes that concepts or systems become often functional for another population when they become dysfunctional for the original one. And this did happen precisely with Medicare and Medicaid. Whole industries have developed around these systems. With public geropsychiatric hospitals perhaps declining, private hospitals open geropsychiatric units on an ever expanding basis. Medicare will pay a substantial

amount for 190 days which can be lucrative business. Nursing and boarding homes, adult day care programs, and home health care agencies spring up everywhere, even though their lobbyists complain loudly about inadequate reimbursement, which allows many of the facilities to also offer inadequate services to ensure profits. The graying of America is good business for health care and long-term care industries, and social policy provides much of the funding, thus social policy has become functional for that industry.

Function and Dysfunction of Classification

The concept of function and dysfunction can also be applied to the classification of dementia. Dementia occurring in old age, at the prevalence level we have today and anticipate in the future, is a relatively new phenomenon beginning in the late 19th and early 20th centuries. With increasing life expectancies, we did see more and more old people displaying the behavioral symptoms of dementia, and they also showed the physical decline associated with old age. Two concepts were available to explain such problems: mental illness that required “managing” and old age that required supervision and help with everyday tasks. Both classifications also had people and locations to manage and supervise those elders: the mental health profession with its various in- and outpatient clinics, and the home where women provided unpaid care. Thus, the classifications fulfilled the functions to a) place the dementia sufferers in some location from the poorhouse to the mental hospital or the care of family, and b) give those around them the peace of mind that they provided the most “appropriate” care and management for the elderly who became “senile,” thus relieving our collective responsibility. After all, our Judeo-Christian heritage tells us that we must honor and provide for our elders (Post, 1990); the classification

provided a convenient tool to shift this responsibility from the collectivity of society to selected groups.

However, the physical sciences developed better methods to view the human body, including the brain, and tests were developed to search for biological causes for illnesses, including dementia. Such research showed that many illnesses, including dementia, were not an illness of the mind but of the body. Yet the classifications survived. But the classification no longer served primarily to provide *appropriate* care and placement in location. So neither the patients nor society benefitted any longer, especially as the provision of care put an ever increasing fiscal burden on Americans. Yet, the classification is still alive and well; as one physician stated, “You need to take that up with the APA” (American Psychiatric Association). While this may be a hopeless undertaking, he may be right.

The Function for Psychiatry

Psychiatry has since its beginning struggled for full recognition as a medical science and constantly had to restructure its cultural jurisdiction. As an outgrowth of the prestigious discipline of neurology, psychiatry has a history from being the keepers of the asylums, over the psychoanalytical school of thought with “talk-therapy,” to its present pharmacological model. Abbott (1988) gives an excellent history of the changing cultural jurisdictions of psychiatry and the invasion of other professions, such as psychology, social work, and counseling, into the arena of psychiatry. With a renewed focus on biological triggers for mental illnesses, and personal problems well under the control of mental health professions other than psychiatry, psychiatrists are compelled to include illnesses into their

jurisdiction that could just as well be served by neurology. Romano (1994) is only partly right when he laments, “We [psychiatrists] have lost the demented patients and others with organic brain disease to the neurologists because of our negligent attention to biological matters” (89). Dementia is firmly included as a mental illness and in the jurisdiction of psychiatry, and thus serves the function to further strengthen the role of psychiatry, especially as the population ages and prevalence of dementia increases. While the pharmacological advances have brought great relief to patients with certain mental illnesses, and some dementia patients definitely benefit from treatment by psychiatry, such treatment can have devastating economic and social consequences for the patients, as previously discussed. Thus, the classification is mostly dysfunctional for the dementia patient. The controversy over the entire concept of mental illness has been discussed in chapter three.

The Function for Society

The American society as a whole was another beneficiary of the classification system, regardless whether dementia is seen as a mental illness or simply as a deterioration. As previously mentioned, care of the dementia patient has been delegated to a variety of jurisdictions because once we accept either classification, it only confirms our history that such patients must be kept safe. We then can argue that this safe-keeping is best carried out in specially designed facilities. Thus, the ever increasing number of facilities and consequent need to fill those facilities shows how caring we are, while at the same time making true the nightmare of many older persons, including dementia patients, that of being put into a “home.” Accepting dementia as a collective public health issue

perhaps would force us to fund research, treatment, and care accordingly. Even though Moody (1992) maintains that “in the last decade Alzheimer’s disease has moved, in the famous phrase of sociologist C. Wright Mills, from a private sorrow to being understood as a public problem” (98), we are still not willing to expand the public funds necessary to provide the level of care needed to maintain hope and dignity for patients and families; other issues are still more pressing. Although \$280 million was spent in 1992 for Alzheimer’s disease research, four to seven times more funds were spent on research for heart disease, cancer and AIDS (Alzheimer’s Disease and Related disorders Association, 1992).

However, more and more families feel the effects of the aging population and the effects of dementia. Nearly every interviewed person immediately shared a personal experience, either in their family or in the family of friends where the present systems did not meet the needs of those involved. While the classification is dysfunctional for the elderly dementia patients and often for their families at the present time, it is still functional for our social conscious if we are not directly affected. However, classification and resulting social policies may become dysfunctional for society as a whole as more and more families feel the effects of the graying of America.

The Bureaucracy of Social Policy

Social policies are administered in the framework of bureaucracies. Max Weber (1964, 1978 translated versions) describes bureaucracies as having certain characteristics and principles. The principles include that of “*official jurisdictional areas*, which are generally ordered by rules, that is, by laws or administrative regulations” (956).

Classification provides an ideal tool to separate the jurisdictional areas and allows for laws to be applied according to jurisdiction. Once the jurisdiction is established “only persons that qualify ... are employed” (956). This allows jurisdictions, based on classifications, to stay intact and protected, as is exemplified by the classification of dementia as a mental illness. Weber sees this development of systematically patterned bureaucracies as a phenomenon of the modern state. One must agree when we consider that, in the not too long ago past, the extended family took care of their elders, perhaps assisted by a local physician, the church congregation, and the community. Only after these informal means to care for individual elders became less available was the bureaucratic system feasible and needed, resulting in the Social Security Act.

This writer agrees with Weber that there may be no alternative to the bureaucratic structure to administer large scale programs and services to a large segment of the population in a modern society. Ritzer (1992) in quoting Weber writes, “The needs of mass administration make it [bureaucratic structure] today completely indispensable. The choice is only between bureaucracy and dilettantism in the field of administration” (131). The individualized services provided by families or communities are no longer available without any assistance; it is the large scale provision of services that requires the structure bureaucracy has to offer. And even if we could return to these individual services, they would require some regulation as to avoid misuse and abuse. Would we begin to pay families a salary to take care of elderly family members, the administration of this pay would require a structure, as would the provision of services a family cannot provide. Developments in science and technology have made it impossible for the previous family

structure to provide what is available and needed, obviously a development of modern society.

Although bureaucracy seems to be the best alternative we have, not all is well with it. As predicted by Weber--with amazing vision--the rule-boundedness of such a structure facilitates that professions and field workers can rationalize their decisions. Usually, they do what they are supposed to do and can do within the goals and missions of their individual systems. The systems themselves and those who administer them often have become system-serving, thus functional for themselves, not client-serving, and therefore dysfunctional for those they are supposed to serve. Even if a worker clearly sees the needs of a client, he or she cannot provide the services because rules and regulations prevent it. On one hand, this prevents arbitrarily administered services based on the subjective opinion of a worker; on the other hand, it leads to the dissatisfaction of the clientele and non-availability of services for those who need them. The public is usually blaming the bureaucrats for the shortcomings of the system, but it is the structure that promotes the worker to become a cold and calculating rationalizing actor. As previously discussed, Holstein (1993) offers the Weberian concept of "formal rationality;" that is, systems act according to principles and rules based on institutionalized procedures and, therefore, promote the predictability of bureaucracies. The administration of other programs, requiring reliance on expert authority, also reduces the importance of nonrational factors such as emotions and caring for others. "Abstract laws and formal procedures, it appears, may eliminate some forms of arbitrariness, but in exchange they introduce an impersonal monopoly over how compassion, concern, and control are asserted into people's lives"

(Holstein, 1993, p. 184).

To summarize, in 1965 the Social Security Act was amended to provide medical insurance for the elderly based on private insurance principles; that is, the insured contribute through premiums, and benefits paid are an earned right not a charity. However, Medicare is paying only basic benefits for covered illnesses under limited circumstances. Illnesses that require custodial care are usually not covered; they are for all practical purposes a non-illness. What constitutes custodial or skilled care has not been answered completely, but at this point, dementia care is considered custodial for Medicare purposes, and thus excluded from payment. Therefore, elderly dementia patients must reach poverty level before the second safety net that was meant for extreme hardship cases only, Medicaid the medical welfare program, will pay for treatment and care. Medicare and Medicaid will not pay for care by non-approved providers which includes family members that often care for the dementia victim at home. As a consequence, family members often decide to institutionalize the patients because the financial and emotional hardships become too much for them to bear. Thus, it is concluded that the social policies intended to help secure adequate health care for the later years have become dysfunctional for the elderly, but have become functional for the long-term care industries and some professions, mainly psychiatry. Additionally, the bureaucratic systems that administer social policies also have become system-serving rather than client-serving. They, too, have become dysfunctional for the original population but now fulfil a function for themselves.

However, it is not unavoidable that we move into the “iron cage” of bureaucratic rationalization leading to the “polar night of icy darkness” predicted by Weber (Farganis,

1993). Humans are thinking creatures that can use the best of a system, discard the worst, and make a better system. The next chapter will present some alternatives to dementia care that have been explored.

Chapter 6 - Some Alternatives

In an ideal situation, as a society we would accept that some people need help for a variety of reasons. We would pool our resources and provide whatever is needed, regardless of what created the needs. This would require a more equal distribution of the national wealth, and classifications and categorizations would become obsolete. However, we do not exist in an ideal world, jurisdictions are established, and interests of groups are fiercely protected by, among other things, classifications and categorizations.

In this final chapter, some alternatives to the current dilemma of providing care for elderly dementia patients will be offered for the reader's consideration. Rationing of health care, solutions implemented in European countries, and case management to coordinate fragmented systems will be discussed.

Rationing of Health Care

The elderly dementia patients belong to the category of senior citizens by age and are classified either as chronically or mentally ill or simply as senile due to their condition. At the same time, Americans maintain that only limited resources are available for those that need help. One proposed solution is the rationing of health care for the elderly.

As Binstock & Post (1991) argue, the public perceives the underlying thinking of Social Security and consequent health care for those over age 65 in the form of Medicare as favoritism toward one category. They are "exempted from the screening that are applied to other Americans to determine whether they are worthy of public help (1)" Highly publicized reports promoted the idea that greedy older people take a disproportionate amount of public funds and get away with it because they are actually a

politically powerful force based on their sheer numbers and on their relative wealth. As one Social Services Department Director put it, the elderly are too greedy to spend their own money on their own health care; they are politically powerful so they get all the money, and little is left for the children who are our future.

It is true that social policies have reduced poverty levels for older persons and that many older people are not poor. But the elderly, just like any other group, are a heterogeneous group with some being rich and others being poor. However, the elderly have a greater risk of becoming poor due to medical expenses not covered by any program and their increased risk for acute and chronic illness, especially dementia that is not or only very limited covered under Medicare. Additionally, many seem to overlook that the cornerstones of social policy for the elderly, Social Security and Medicare, are based on contributions and are administered under the same principles as private insurance. Of course, some aging programs are charity with the Medicaid component for the elderly taking up the largest part. Ironically, it is the lack of comprehensive coverage for dementias and other chronic illnesses under Medicare and other social programs that often reduce the elderly to becoming Medicaid recipients.

Nevertheless, many have a general picture of our aging population as being less needy than other groups that also want public funds. Thus, the elderly are removed from the “worthy” needy category. Related to health care, such sentiment has effectively shifted the blame for the excess public funds spent on it from “providers, suppliers, administrators, and insurers -- the parties responsible for setting the prices of care -- to the elderly patients for whom health care is provided” (4) and avoids that distribution of

resources is evaluated from the angle of justice between rich and poor (Binstock & Post, 1991). As a solution, some propose rationing of health care based on age. The biomedical ethicist, Daniel Callahan, and the former Colorado governor, Lamm, are famous representatives of this movement, with the latter going so far as stating that older persons “have a duty to die and get out of the way” (Slater, 1984, quoted in Binstock & Post, 1991, p. 5).

Actually, the proponents of age-based health care rationing are perhaps not only the more radical but also the more honest segment of our population. Current social policy already constitutes rationing of health care for elderly persons who are not wealthy enough to make the co-payments or pay for non-covered elements such as medications. Health care is severely rationed for dementia patients because their health care is often considered custodial care that does not fit the focus on “cure” in our current system. Furthermore, the passive euthanasia that is practiced by ignoring the co-occurring illnesses of dementia patients is a radical form of rationing. Whether a health care professional administers the death-bringing treatment or withholds the diagnosis and treatment that can save or prolong a life is irrelevant for the outcome; it only slightly changes the time when the outcome, death, occurs. Battin (1992) argues that withholding treatment is seldom termed “euthanasia” and is permitted by social policy, while the active form is prohibited. However, instead of entering the “slippery road,” as termed by Battin, of social policy permitting active euthanasia for dementia patients in advanced stages, we often elect the more subtle forms of withholding health care for dementia patients. They are classified as needing “custodial care” only which leaves them in the care of care givers who may not be

able to recognize co-occurring illnesses. Furthermore, by withholding Medicare payment for routine doctor visits, it can be rationalized that if we do not know, necessary health care cannot be provided.

When solutions to social problems are contemplated, “worthiness” often becomes an issue. Sudnow (1967) explored how worthiness of receiving health care was subjectively decided by ambulance drivers. Others (Kamerman, 1988; Moody, 1992; Smith, 1992) explore the issue whether dementia patients still experience personhood or identity. This sentiment was expressed by one of the interviewed physicians who believes that “dementia is infancy in reverse.” According to this view, newborn babies gain recognition of their loved ones and appreciation of their surroundings as they get older; dementia patients lose that recognition and appreciation. As infants gain abilities to eat independently, toilet, and groom, dementia patients lose such abilities (personal communication, September 1995). In short, babies progress into personhood and develop an identity, while dementia patients regress into non-personhood and lose their identity. Perhaps it is this sentiment that justifies that very large amounts of health care funds are expended to save infants at risk but prevent the development of social policy to care for dementia patients in the best possible manner. The infant gains recognition, the demented patient has lost recognition and will never gain it, so why spend money on a “hopeless” cause when custodial care will do?

Obviously, the issue of health care rationing spawned many debates, and many different opinions have been heard and will be heard. However, whether society will ultimately decide for or against provision of appropriate care and funding for the elderly,

including elderly dementia patients, is heavily influenced by our values as a society.

The European Alternative

Many European countries have comprehensive health insurance and long-term care insurance for their elderly. The Netherlands have since 1968 mandatory contribution-based long-term care insurance for the chronically ill, regardless of classification or age, in addition to comprehensive national health insurance. Denmark and Sweden provide comprehensive care for the chronically ill from tax revenues. Austria implemented in 1993 a system that provides a safety-net for chronically ill persons before they become welfare eligible. Thus, persons must spend down to pay for long-term care but not to the poverty level. France and Belgium pay for treatment with public funds but require the patients to pay for their own room and board. This cost can be paid from public funds for the indigent. Germany, a country with a longstanding history of comprehensive social programs, did not have long-term care insurance prior to 1995. The “pillars” of the social security system were implemented beginning in 1883 with health insurance, followed by occupational accident insurance in 1884, social security in 1889, and unemployment insurance in 1927. All programs are contribution-based, with employers and employees contributing about half of the cost each, and fee waivers for those who are unemployed or ill. Only the very wealthy are exempted from contribution but also from receiving. Health insurance is comprehensive for all age groups with only minimal co-payments for some assistive devices and medications. However, the cost to provide what Americans may consider “custodial care” was not covered. Increased longevity forced many Germans that required long-term care for chronic illnesses to impoverish themselves so they would

become welfare eligible. In addition, spouses, and at times even adult children, could be held responsible for long-term care. To correct this situation, as of January 1, 1995, Germany implemented the fifth pillar, long-term care insurance, as part of and administered by the health care insurance with the following rationale (translated by the author of this paper from a brochure published by the German Ministry for Labor and Social Order [Bundesministerium für Arbeit und Sozialordnung]):

The need to receive care resulted for care recipients and their families in large physical, psychological, and financial burdens ... the cost was the responsibility of the patients and their families. But the cost is often so great that it exceeds the individual's means. Care recipients are dependent on others for essential activities of daily living ... care givers often must reduce or quit their employment so they can provide care, but as a consequence reduce or lose their own social security ['social security' is meant as a comprehensive protection system, not limited to the American form of income subsidy in old age].

For these reasons, families are less willing to provide care at home and increasingly institutionalize the person in need of care. However, the care recipient and the families are often unable to pay the cost of institutionalized care. Therefore, in the old States [former West Germany] approximately 80 percent of long-term institutionalized persons require welfare (Sozialhilfe) and in the new States [former East Germany] 100 percent require welfare. *Such high percentages of welfare recipients among those in need of long-term care are opposite to the principles of our system of social security.*

Welfare should only subsidize in exceptional cases, to alleviate individual emergencies, when the existing social programs in an individual case fail to provide sufficient protection and the personal means are not sufficient to pay. Welfare should protect from individual risk, but it should not be the rule for those requiring long-term care in institutional settings [italics added]. So far, the care recipients become the recipient of an allowance, even if he, in a full life of employment, paid contribution and taxes for the building and maintenance of our social system. Additionally, those legally responsible for the maintenance of the care recipient can be held liable for the cost.

These processes not only reduce the performance of individual's, they also endanger acceptance of our economic and social order as a whole. Additionally, such unintended financing by welfare leads to increased payments from welfare

which can exceed the means of the carriers of social programs, especially the localities. (It is noteworthy that the proposed welfare reforms in America will shift responsibility for such programs to localities.)

Population trends show an increase in life expectancy and in the population age 75 and over. This age group has an increased risk to become care recipients. Changes in living conditions (or styles) and family relations lead to smaller families and single-person households. This development makes home care more difficult. Therefore, it becomes essential to increase the protection for those that require and provide care.

Beginning January 1, 1995, all persons employed in Germany, and their employers, began contribution to this new insurance; on April 1, 1995, payments began for home care, and on July 1, 1996, payment for institutional care will begin. The payment system is heavily favoring home care by providing payment for family or hired care givers similar to average salaries paid in Germany and by covering the social benefits of the care giver who elects to quit employment to provide care at home. All social programs do not differentiate between mental and physical illnesses even though the classifications do exist, and now "custodial care" is included in the comprehensive health care coverage, thus removing for social policy purposes differentiation based on classification.

It is beyond the scope of this project to explore all details of the German program. It is the purpose of this example to show that other industrialized nations have similar problems regarding health care for the elderly but seem to be able to find workable solutions.

Fragmented vs. Comprehensive Systems of Care

As previously discussed, American implementation of social public policies have been pragmatic and incremental. They seem to address only immediate needs in a reactive

manner, which must lead to fragmentation. Categorization and classification increase that fragmentation. Such fragmentation leads to many different jurisdictions which sometimes results in duplication of services but more often in services becoming unavailable, except for those who have learned to "work the system." Binstock, Post, and Whitehouse (1992) note that a 1990 report by the Office of Technology Assessment found that "the system is so fragmented that even when high quality services are sufficiently available, many patients and families do not know about them and require help in defining their service needs and in arranging for them to be provided" (3). This confirms the opinion of Commissioner Bland of the Department for the Aging (personal communication, September 1995) that many families do not know about the services. The Congressional Research Service reported in 1988 that over eighty federal and many state and locally funded, as well as privately operated, programs exist in America to serve dementia patients. But each program has different service jurisdiction, eligibility criteria, and availability of funds. Under normal circumstances, most dementia patients, as previously discussed, are not eligible for the major funding sources of Medicare and Medicaid (Binstock, Post and Whitehouse, 1992). Actually, a whole new jurisdiction is developing out of the need to work the system--the case managers. Browne and McNeely (1995) describe geriatric case management as "creating a partnership between the individual, their family (loved ones) and the service system." Obviously, this is an attempt to provide comprehensive access to a fragmented system.

Of course, a comprehensive national health insurance system that is not based on classification but based on individual needs would be a desirable solution. An interviewed

physician aptly put it when saying, "I can't understand that a nation that can put man in space is not able to develop a comprehensive health insurance system for its entire population (personal communication, September 1995). The current debate over Medicare and Medicaid can make us believe that we are in an imminent crisis. However, Binstock and Murray (1992) question the politicians' crisis mentalities when asking,

Is there an economic crisis, current or impending, engendered by health care expenditures? Advocates of health care cost containment warn that we cannot economically sustain increasing health care expenditures. Why not? What are the inevitable dire consequences that would ensue for our nation (as opposed to specific health care payers and providers) if health care expenditures continue to grow? (P 157).

They furthermore quote Eli Ginsberg (1990) who writes: "There is nothing inherently bad about the expenditure of \$620 billion on health care services by a \$5 trillion economy. Nor is there any reason a \$6 to \$7 trillion economy should not spend \$1 trillion or even more for its health care" (157). Yet, at least the current trend does not point toward the solution of national comprehensive health care or increased spending for health care. And even if spending would increase, dementia patients still may be left either entirely on their own or receive only limited benefits because of classification. As a first step, if we must adhere to classifications, dementia could be more appropriately included as a physical illness, regardless where care is provided. As a second step, we could re-evaluate a public insurance system that mainly considers "curing" worth paying for and "caring" not worth the investment. Callahan (1992) argues that our current insurance system and entitlement programs for the elderly are heavily biased toward curative medicine; that we expand endless funds toward high-technology in medicine to "endlessly patching up individual

human bodies pulled down by their mortality” (145). As long as we consider caring as being “unskilled” and as being inferior to curing or rehabilitation, we may not be able to alleviate the private sorrow of dementia; we may actually add to it by not alleviating the economic burden on patients and families. Short of preventing or finding a cure for dementias, a major overhaul of our current health care philosophy is required, including rethinking the validity of current classification systems. Perhaps this can be a step in the right direction so it will no longer be true that

The tragedy of old age is not the fact that each of us must grow old and die but that the process of doing so has been made unnecessarily and at times excruciatingly painful, humiliating, debilitating and isolating through insensitivity, ignorance and poverty (Schulz, 1985, pp. 192-193).

Conclusion

Chronic illness in old age, especially dementia, is presenting American society with the dilemma of how to provide care for this segment of the population. It was the purpose of the previous discussion to explore the current systems that came about by a complex net of social and historical forces that helped to classify dementia as a mental illness or as age deterioration but not as the physical illness it appears to be. Alzheimer’s disease, the most prevalent form of dementia, is still perceived as the “peculiar disease of the cerebral cortex” described by Alois Alzheimer in 1907. As Whitehouse (1992) points out: “... the use of an eponym, like Alzheimer’s, to describe an illness usually reflects inadequate knowledge about classification” (27). This inadequate knowledge about classification has tremendous consequences for the victims of the disease and their families. Classification should not be important enough to deprive those in need of dignity, care, and security. We

have created classification, so we can change it as a first step to improve the plight of dementia patients. It is our choice.

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