The Medicalization of Senile Dementia: From "Normality" to “Pathology”

Rosamond Robbert
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THE MEDICALIZATION OF SENILE DEMENTIA:  
FROM "NORMALITY" TO "PATHOLOGY"

by

Rosamond Robbert

A Dissertation
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Doctor of Philosophy
Department of Sociology

Western Michigan University
Kalamazoo, Michigan
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THE MEDICALIZATION OF SENILE DEMENTIA:
FROM "NORMALITY TO "PATHOLOGY"

Rosamond Robbert, Ph.D.
Western Michigan University, 1989

Once considered an uncommon presenile condition, Alzheimer's disease is today claimed to be one of the major causes of death in older persons. This study examines the process of changing definitions that led to this reconstruction. The method employs both unstructured non-quantitative and structured quantitative content analysis. The data base includes journal articles, media reports, government documents, professional manuals and conference proceedings. Alzheimer's disease is treated as a putative condition and all statements concerning the condition are treated as claims. Focusing specifically on the years 1970 to 1985, we show that cognitive impairment in older persons, once claimed to be a concomitant of the aging process, came under the control of the medical profession. A specialized group of physicians were involved in promoting new medical claims. Shortly thereafter non-medical claims makers were co-opted and willingly promoted the new disease designation. The analysis indicates that the strategies of this loose coalition achieved the
institutionalization of Alzheimer's disease as an accepted category of the official order. In effect this was a political rather than a scientific achievement.
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Robbert, Rosamond, Ph.D.

Western Michigan University, 1989

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Rosamond Robbert
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CHAPTER I

INTRODUCTION AND STATEMENT OF THE PROBLEM

Introduction

Sometime in the mid 1970s I read a report of a presentation by Dr. Robert Butler discussing a disease that was unfamiliar to me. I was certainly familiar with the terms senility and dementia but Alzheimer's disease was a new phenomenon for my lexicon. Why had I never heard of such a apparently major illness of the elderly before? What Butler had to say stirred my interest and curiosity and indeed initiated a direction for me within my studies in gerontology that developed into various forms of activities including teaching and numerous public presentations culminating in the present study.

During the period of my graduate studies in sociology Peter Conrad and Joseph Schneider published a monograph entitled Deviance and Medicalization: From Badness to Sickness (1980). This work provided me, not only with a theoretical direction, but also with a challenge to embark on this dissertation. The authors approach social problems as being outcomes of activities of interest groups. They point to the changing nature of specific social phenomena...
over time such as homosexuality or alcoholism, and most importantly, show how the medical model has been used in the social construction of the reality of social problems. Having laid out a sequential model of the medicalization of deviance they conclude their work with a short section entitled "Hunches and hypotheses: notes for further research." Here they mention, in passim, senility as a topic appropriate for extending their theory of medicalization. This brief suggestion finally crystallized a number of directions and tensions with which I had been wrestling since completing my master's degree and embarking on my doctoral work. Lastly, Gusfield's (1980) introduction to Conrad and Schneider's (1980) work included a consideration of sociological irony. This discussion appealed to me and impressed me as an interesting role for the sociologist noting Gusfield's challenge: "The implications of sociological irony for public problems are vastly significant" (p.viii).

Sociological Irony

Sociological irony represents a stage of consciousness and, according to White (1973), presupposes a "realistic" perspective on reality and emphasises critical thought:

... characterizations of the world cast in the ironic mode are often recognized as intrinsically sophisticated and realistic. They appear to signal
the ascent of thought in a given area of inquiry to a level of self-consciousness on which a genuinely . . . self-critical conceptualization of the world and its processes has become possible. (White, 1973, p. 37)

An ironic approach brings moral choices to the fore (Gusfield, 1980). It "unmasks" social norms and raises questions of alternative practices or beliefs. Merton (1957) asserts that a prime characteristic of sociological knowledge is an eye for paradox, contradiction, and reversals that are latent beneath the more obvious manifest content of action:

The distinction between manifest and latent functions serves further to direct the attention of the sociologist to precisely these realms . . . where he can most fruitfully apply his special skills . . . It is precisely the latent functions of a practice or belief that are not common knowledge, for these are unintended and generally unrecognized social and psychological consequences. As a result, findings concerning latent functions represent a greater increment in knowledge than findings concerning manifest functions. They represent also greater departures from "common sense" knowledge about social life. (Merton, 1957, p. 65)

Irony in sociology is not confined to any one theoretical perspective. Exemplars of sociological irony abound. Gans (1973) points to the functions of poverty and concludes that specific aspects of poverty are necessary for the function of contemporary society. In a study of human interaction, Glaser and Strauss (1965) bring an ironic approach to the practice of medicine and show what
appears to be humane treatment of dying persons may often be seen as a mask for organizational efficiency. Daniel Bell (1960) examines how organized crime fulfills a demand for numerous services.

Gusfield (1980) points to the public faith and belief that science brings solutions to numerous human problems and acknowledges that Conrad and Schneider are indeed challenging the authority of the technical and therapy professions. In an ironic perspective, the role of the sociologist is one of an "unmasker." In this role the sociologist is not a moral leader but rather a questioner of social norms. Visions of alternative realities and other ways of inventing human institutions are offered. Ultimately, an ironist will seek to reveal chaos in what appears to be order (Brown, 1977).

Before introducing our theoretical approach, we will further consider the role of the sociologist and our particular involvement in this study.

The Role of the Sociologist

The sociologist him or herself also brings personal experience to social theory. Whatever their differences all sociologists seek to study social phenomena they take to be real:

Whatever their philosophy of science, they seek to
explain it in terms of something that they feel to be real. Like other men, sociologists impute reality to certain things in their social world . . . In important part, their conception of what is "real" derives from the domain assumptions they have learned in their culture. (Gouldner, 1970, p. 41)

Gouldner suggests that there are two types of reality with which sociologists must come to terms. The first is what he terms role realities. These are what they learn as sociologists; what they believe to be "facts" yielded by previous research. These facts are assigned high value setting them above mere opinions or prejudices. There is an obligation to examine critically and to defend oneself against attacks on factual beliefs:

To assign factuality to a belief is a self-involving commitment; the person makes a claim upon the credence of another, or himself lends credence to the claim of another. In these . . . ways, the factual becomes part of the sociologist's personal reality. (Gouldner, 1970, p. 42)

A second conceptual order consists of reality that is personally real. These are imputations or assumptions about the social world not developing as a result of "evidence" or "research" but rather on the basis of what the sociologist has heard, seen and attended to. Personal realities and role realities together shape theory and the treatment of both logically devolves from those realities that the sociologist treats as paradigms.

The author of this study has not approached the subject
as an outside observer. We indeed played a role, albeit minor, in the claims making activities we seek to describe and analyze. Throughout the time period under scrutiny we witnessed many of the events and activities we are now treating as data. In essence many of the characteristics of our data were broadly known to us prior to embarking on this study. Through educational efforts we the investigator contributed to changes in attitudes and beliefs about confused older persons. This involvement was a vital part of the investigator's life and a central part of the experience that shaped our personal reality. Indeed it was this personal reality that became the starting point for this study. The choice of theory and indeed method was grounded in personal experience.

Theoretical Perspective of This Study

The study of social phenomena can be broadly divided into two perspectives namely objectivist and subjectivist. In the objective approach the concern is with causality, and remedy. Issues of distribution and magnitude are stressed and the ultimate goal is cure or at least control. The condition is objectively real and can be potentially understood and ameliorated by science and the scientific method.

The subjectivist or social constructionist approach is
less concerned with issues of causality but rather focuses on the social processes of defining a condition as problematic. Social issues or conditions are seen as products of collective activity based on particular interests and world views. Here the concern lies in the changing definitions of social phenomena. The central problem is to understand how categories of social problems and conditions are "produced" or emerge. Thus meanings are important. W.I. Thomas's dictum provides a base: "If men define situations as real, they are real in their consequences" (Thomas & Thomas, 1928, p. 572). The emphasis is not on the cause of the problem itself, but rather on the meanings attached to the problem and the consequences of the application of such conceptions to human affairs (Freidson, 1970a).

Applications in Medicine

The preference for a subjectivist theoretical approach to the study of a disease can contain several distinct dynamics. Obviously the study of a disease entity, in and of itself, presents certain restrictions to the social scientist who cannot gaze through microscopes, study CT scans, search for viruses or administer experimental medications. Therefore, an etiological approach is usually confined to epidemiologic methods, sometimes known as sociology in
medicine since the epidemiologist often works in collaboration with members of the medical profession (Mechanic, 1978).

Much of the study of disease can be subsumed within the objectivist tradition. Medical researchers tend to limit their concept of disease by focusing on pathological conditions and concentrating their studies on the etiology of organ malfunctioning and the treatment thereof. Clinical explanations are developed with the use of technology. Disease is treated technically and becomes the focus rather than the whole person. As a result of scientific fragmentation the mind and body are seen as separate entities (Wolinsky, 1980). Yet as Conrad and Schneider (1980) point out, medical controversies as to what is "healthy" or "unhealthy" abound. We have only got to look at the debate concerning what is normal and abnormal in blood pressure readings or the normality of menopause (McCrea, 1981) to realize that absolute standards for healthy functioning can be problematic. Despite the dominance of the objectivist approach in medicine, researchers are increasingly recognizing the importance of subjective meanings and the linkage of psychological stress to changes in body conditions (e.g. Antonovsky, 1979, 1987; Selye, 1956). A very few are concerned with the experience of illness questioning how
people deal with disease and make sense of it as a part of themselves (e.g., Schneider & Conrad, 1983). Others focus their research on the changing definitions of behavior and point to the phenomenon known as the medicalization of social problems (e.g., Fox, 1977; Pfohl, 1977). They note that a condition can be identified as problematic at different times in a society and that the same phenomena is subject to various explanations. We posit that these approaches can be subsumed within the subjectivist tradition.

Diseases are both new and old. AIDS can currently be defined as a new disease apparently caused by a virus new to the human race. Other pathologies such as cancer are probably as old as the human race. Some conditions can exist unrecognized perhaps for millions of years defined in non-disease terms and eventually become re-molded in the disease model.

Alzheimer's disease is one such condition and invites the sociologist to examine its social context. The last twenty years has witnessed a major change in attitudes toward and beliefs about older persons suffering loss of memory and crucial bodily functions; a condition often termed senility and historically attributed to normal degeneration due to the process of aging. Senility has, in large part today, been re-conceptualized as a disease af-
flicting a significant portion of the elderly population now generally termed Alzheimer's disease. As a disease its claim to the label is relatively weak. According to Klass (1985) it meets none of Koch's postulates for a disease, yet is claimed to be such.¹ Klass notes: "... there is no particular biochemical or physiologic difference in (the brains of Alzheimer's victims) that is crucial in pointing to disease rather than to degeneration" (p. 3). In this study we will concern ourselves with the collective efforts involved in this re-framing of cognitive loss in the elderly from one of assumed normality to a disease entity.

Utility and Focus of This Study

The reader may question the utility of studying such matters. Is not the clinical and scientific approach of more importance? How can studying social definitions ease the burden of families and victims of Alzheimer's disease?

As already discussed, Gusfield (1980) notes that the implications of sociological irony are important. The intrusion of science into human life requires examination. Faith in science is strong and can blanket inquiry, cause alternative realities to be ignored and discourage the questioning of authority. Sociological irony can reveal special interests and activities by piercing the sheet of
universalistic science (p. ix). The balance of priorities in collective action can be revealed. Questions as to the impact of medicalization on the daily lives of families and individuals can be asked. Is grandfather better off now that his confusion is attributed to disease rather than old age? How has the medicalization of grandmother's confusion changed the behavior of those who care for her?

We suggest that the addition of the variable of old age is crucial to our understanding of the social forces (or the lack thereof) surrounding many of the physiological conditions that threaten the quality of life for the elderly. We need to recognize that ageism is as powerful a force as either sexism or racism impacting on the lives of people most especially in the area of health and illness. If, for example, AIDS or cancer were largely confined to the elderly population would the social response be different? Is the natural history of disease definitions different when members of stigmatized populations are the victims?

Sociological irony invites such questions. Availability of data, methodological restrictions, and the demands of logic restrict the researcher's ability to provide answers to some. At least visions of other realities can be induced and alternatives considered.
**Foci of This Study**

This dissertation has two foci which are inextricably related. First, our intent is to apply existing theory to our data. Here the intent is to expand already developed models rather than formal theory testing. Specifically we will consider our data in the light of the work of those theorists who have developed sequential or natural history models of collective and individual action by actors in the furtherance of their ideological goals.

Second, we intend to examine the phenomenon of Alzheimer's disease as a social condition rather than an individual issue. Within the burgeoning literature on Alzheimer's disease there is a body of reports concerned with the alleviation of suffering for the victim by therapeutic intervention as well as numerous attempts to describe and categorize individual symptoms through behavioral assessment. Our focus is different. We are sensitive to the suffering for those afflicted by the condition. However, in this dissertation our intent is to gain an understanding of Alzheimer's disease as a social phenomenon. By examining the organization of social forces and what people do in the furtherance of their goals we aspire to mutually illuminate existing theory and the condition known as Alzheimer's disease.
Issues of Terminology

As we will demonstrate, efforts to describe and classify mental or cognitive problems in the elderly have, both historically and currently, led to further confusion both in lay and professional usage. Nineteenth century attempts included various modifications of the term dementia. Senility is another term that has experienced both changing and loose usage over the years both as a descriptor and a diagnostic category. Brain failure has been utilized in this century and brain fog was a common term in the nineteenth century. Organic brain syndrome was chosen as the first classification of the American Psychiatric Association in 1952. The term confusion itself is seen on occasion in the nursing literature (e.g. Wolanin & Phillips, 1981). Since the 1970s Alzheimer's disease has emerged as a major classification and has recently been modified to senile dementia of the Alzheimer type. Clinically and colloquially attempts to describe confused behavior and to attribute a cause or causes to the same behavior have resulted in a variety of nomenclatures. Jarvik (1982) in apparent frustration developed her own term:

I propose the term paraskepsia to describe the cognitive impairment independent of etiology. Derived from the Greek words para, meaning "alongside," and skepsia, meaning "thought." Paraskepsia means thought which is at the end of, or alongside, ordinary thought. Paraskepsia does not imply etiology and, even more significantly, it
does not imply that the thought processes are inadequate for all life situations. Calling someone a paraskeptic would not have the perjorative connotation of calling that person demented. (Jarvik, 1982, p. 106)

It is evident that various and sundry terms have been used to describe cognitive loss in the elderly over time and even in the present decade there is little agreement among researchers and medical practitioners. Thus each tends to choose a descriptor according to his or her preference. However, the issue arises on how we are to refer to this condition in this particular study. We do not intend to add to the Tower of Babel and invent our own term, but rather, following current usage, we will utilize whatever term appears to make our meaning clear in the context of a particular discussion.

Claims Making Activities

In this study we will be focusing on the process by which members of society came to define Alzheimer's disease as a medical problem. This process we suggest, following Conrad and Schneider (1980) is one of claims making activities on the part of a variety of actors including researchers, medical practitioners, lay persons, journalists, newspaper editors and families with a member suffering from Alzheimer's disease. We see the use of terminology as a human activity which we also define as a claim.
Our meaning, to be expanded upon later, is couched in Webster's Third International Dictionary (1971) definition: "(To claim) is to assert especially with conviction and in the face of possible contradiction or doubt" (p. 141). In this dissertation we will study the written claims made by a variety of actors and groups. Thus, for example, reports written by biomedical researchers and social scientists are part of our data. In addition published information reporting the activities of individuals or groups comprises another part of our data. Here self-reports or interviews with specific actors, group meetings such as congressional hearings and professional conferences are of interest.

In order that the reader may have a basic understanding of Alzheimer's disease, we offer, in the following section, an overview of the condition and briefly describe some of the current efforts to further understand and treat cognitive impairment in the elderly. It is important to note that the information presented here is treated in this study as claims. However the following material appears to be generally accepted knowledge. We emphasize that our problem is not Alzheimer's disease in and of itself but rather the process by which cognitive impairment of elderly persons came to be viewed as a medical condition.
Overview of Claims

This dissertation is a study of the organization of social forces which are contributing to the remolding of attitudes toward and beliefs about loss of cognitive ability in old age. Within a broad sweep of history, our imagery suggests that attitudinal changes in this respect can be visualized as moving from assumptions of normality to those of pathology. In an historical analysis we will document that until recently most mental health and cognitive problems of the elderly were largely assumed to be an integral part of the aging process. Today the proposition is favored that mental illness in old age is a pathological condition and is caused by specific underlying disease processes. Alzheimer's disease is now suggested to be a major cause of organic deterioration in the brains of aged persons.

In this study we will offer a historical background for contextual reasons. We consider medical and lay attitudes toward old age from Greco-Roman times through the Enlightenment to the present century. However, our major time period is from the 1960s to the 1980s and the concern is with Alzheimer's disease which is now claimed to be a major cause of cognitive loss in old age.
Characteristics and Magnitude of Alzheimer's Disease

In this section we will briefly characterize the illness as currently understood and consider the claimed magnitude of the problem.

Alzheimer's disease is a term that refers to a progressive irreversible change in mental capacity and only recently has it been claimed to be a significant social and public health problem.

Historically, cognitive and memory loss that would be seen as catastrophic in young persons, were tolerated in the elderly since such decrements were thought to be normal and expectable in the aging process. Thus, until recently, there has been little effort to treat mental deterioration in the elderly. This has been a major theme in the history of medical practice. Demented older persons have not been the recipients of aggressive diagnostic and treatment efforts (Mahrendra, 1984).

Major Characteristics

In a recent report the Office of Technology indicates that physicians and researchers generally agree on a basic set of symptoms for describing Alzheimer's disease. However, the Report notes that there is disagreement on the causes of the disease, the treatability of the symptoms, and the stages of decline (Office of Technological Assess-
ment, [OTA] 1987 p.60). Since conflicting claims and estimates of magnitude are, in part, the data base for our study we will confine ourselves here to a short outline of the symptoms of Alzheimer's disease in order to provide the reader with a brief vignette.

Persons suffering from Alzheimer's disease experience a gradual decline in intellectual functioning, characterized by impairment of and decline in memory. Other impairments which may also be present include:

- Impairment of abstract thinking
- Impairment of judgement
- Impairment of other complex capabilities such as language use, ability to perform complex physical tasks, ability to recognize objects or people, or to construct objects; and
- Personality change

(OTA 1987, p. 60)

In addition, impairment in temporal judgement and understanding is often symptomatic. All of these symptoms are presented in a state of unclouded consciousness, although wide individual variation in the severity and consistency of symptoms and indeed the course of the disease is typical. In general the disease is characterized by irreversible decline, increasing severity of symptoms and the addition of new symptoms, such as incontinence, apraxia, and aphasia, during the disease process. The ultimate outcome is death.
Pathology

The pathology of Alzheimer's disease is characterized by abnormal loss of nerve cells or neurons in the brain. Both the size and the weight of an affected brain are significantly reduced. In addition a large number of lesions known as tangles and plaques are present. The former termed neurofibrillary tangles are made up of nerve filaments wrapped in a helix formation and are different from any other filaments in normal brain cells (Cohen & Eisdorfer, 1986). Senile plaques are abnormal clusterings of proteins. Both neurofibrillary tangles and senile plaques appear to be present in the brains of non-demented persons but are much less frequent (Blessed, Tomlinson & Roth, 1968; Price, Whitehouse & Struble, 1986).

Magnitude

In 1984 conservative estimates suggested that dementing illnesses constituted one of the leading causes of death among the elderly, ranking perhaps fourth or fifth in the United States (U.S. Department of Health and Human Services, 1984). The cost of care for victims in 1983 was estimated to be more than 38 billion dollars per annum (Huang, Hu & Cartwright, 1986). Of the various dementias, Alzheimer's disease is considered to be the most common.
It purportedly affects 1.5 to 2 million largely elderly Americans causing a progressive, irreversible and fatal dementia for which, as yet, there is no known cause or cure (Kolata, 1982).

Epidemiological data suggest an increase in absolute numbers of cases of dementia in the last decade, most notably Alzheimer's disease. By the end of the 1970s some described the prevalence of this particular form of dementia as an epidemic (Butler, 1984a).

Epidemiological knowledge of Alzheimer's disease is particularly confounded by the problems of diagnosis.

**Diagnosis**

The diagnosis of Alzheimer's disease was characterized by Wells in 1979 as diagnosis by default:

Demented patients in whom no specific cause...can be found should, then, generally be considered to have Alzheimer's disease. (Wells, 1979 p. 519)

Despite efforts to develop a definitive diagnostic instrument or protocol, Wells' admonition still remains valid.

The diagnostic process requires investigating other illnesses and conditions which may be the major causal factor. These conditions are often referred to as *pseudo-dementias*. For example, numerous studies warn against confusing a true dementia with a potentially reversible
condition. Roth (1981), points to the critical issues of differentiating depression from dementia. (See also Caine, 1981; Kral, 1983; Reifler, Larson & Hanley, 1982). Environmental factors such as physical relocation are receiving attention (Coffman, 1983). However, the plurality of studies of pseudodementias are concerned with ruling out physiological pathologies that are potentially reversible (Gilhooly, Zarit & Birren, 1986).

Reports of error rates in diagnosis vary considerably. However several behavioral factors have been suggested that contribute to diagnostic error:

- ageism (neglect caused by expectations that a patient is "just senile");
- failure to use strict diagnostic criteria;
- insufficient time devoted to obtaining a history or examining patients;
- absence of a policy of searching for remediable causes of confusion;
- inadequate recourse to special tests; and
- incompatibility between the diagnostician and the patient (due to cultural, educational, or ethnic background. (Gurland & Toner, in OTA 1987, p. 88)

Without accurate diagnostic data, the epidemiological data base remains unreliable. In general, epidemiological knowledge of Alzheimer's disease, as noted by Butler (1984a), is crude and inexact:

... we do not have the data, epidemiological or otherwise, to support most of our presently held notions, including how many persons are suffering from senile dementia of the Alzheimer's type and the degree to which the disease curbs life. While we call it the number four or five cause of death
and are increasingly convinced of its commoness, the epidemiological data base remains too poor to provide an accurate portrait of the incidence and prevalence of psychopathology in late life. (Butler, 1984a, p. 87)

Despite these problems he notes that the United States is in the midst of a wave of enthusiasm related to senile dementia.

Indicators of Social Interest

The reflection of an increasing public and professional interest can be noted through the literature. Publications demonstrate new research efforts, innovative medical approaches, an increased concern on the part of nursing and other helping professions, popular press articles, monographs, and books written especially for family members.

In general the literature can be characterized as reflecting a medical approach to the problem. Issues of etiology, the use of technology, the role of genetics, and the use of drugs in treatment are areas of primary focus. In addition psycho-social concerns emerge; problems of behavior, family stress, coping strategies, questions with respect to institutionalization, and the costs of care both to families and the nation are characteristic.

Interest Group

The Alzheimer's Disease and Related Disorders Associ-
ation (ADRDA) was formed in 1980 and has been the primary organization for families and promoting advocacy. The mission of the Association is broad. The goal is to combat the disease in four major arenas. First, research to identify the cause(s), to prevent the disease, and to improve diagnostic capabilities. Second, to enhance the education of medical professionals, to share information about the diagnosis, treatment, and management of patients. Third, to provide education for lay persons and to assist caregivers to cope with the practical details of daily living. Finally by functioning in an advocacy role to inform governmental and social service agencies about the long-term needs of the affected population (Stone, 1982). Thus ADRDA targets both families and professionals, develops public education, and acts in an advocacy role. Additional actors include federal agencies, especially the National Institute on Aging, members of the research community, key family members, and private foundations.

Research Initiatives

Research on Alzheimer's disease has burgeoned. New etiological hypotheses are being tested in growing numbers of studies. Investigations are focusing on factors such as chemical deficiencies in the brain, immune dysfunctions, slow viruses, toxins, trauma, and genetic abnormalities.
The significance of advancing age in the development and progress of the disease has not been clarified and is not systematically understood. In addition the impact of psychosocial antecedents or concommitants such as occupation, diet, medical care, socioeconomic status, depressive conditions, and environmental stress is little understood (U.S. Department of Health and Human Services. [DHHS], 1984).

Conclusion

The emergence or "discovery" of Alzheimer's disease provides an opportunity to examine certain changing definitions concerning old age. The approach taken in this study is social constructionist. We are concerned with the meanings that people attach to phenomena and the activities of individuals and groups in educating or persuading others to support their perspectives.

We will treat Alzheimer's disease as a condition that is alleged to exist. We do not deny that there are numerous older persons experiencing symptoms of memory or cognitive loss, however it is the assertions or claims made about them that are of interest to us. "Pains and complaints are the lot of the human (and other) species. But diseases are inventions" (Hughes, 1971, p. 246). In other words we focus on claims or reactions that
impute mental disease rather than reactions to mental disease. Neither is the reliability, validity or even veracity of these assertions of concern; indeed in many cases a social scientist is not able to make these judgements. Variations in terminology used to describe the symptoms of cognitive loss, such as dementia or organic brain syndrome are also treated as claims.

Our data are the claimsmaking activities associated with Alzheimer's disease thus enabling us to ask questions of the nature of the activities, how they are organized and how they change over time. The central problem of this research is: How and why has cognitive loss in the elderly come to be re-defined as a pathological condition rather than a normal concomitant of old age? What are the temporal and social forces that have led to this change?
CHAPTER II
THEORETICAL CONSTRUCTS

Introduction

In this chapter we will lay out those theoretical positions in the literature that focus on assumptions, constructs, models and phenomena closely related to the central concern of this study. That is we will outline selected existing theories that seek to explain the process by which social problems come to be recognized as such. In our case we are examining in depth the process by which cognitive loss in the elderly came to be recognized as a problem.

We have organized our discussion in terms of three levels of specificity. Thus paradigms as broad assumptions for the guidance of research are our starting point. We will present an overview of two major paradigms in sociology namely social facts and social definitional or construction. In addition we consider our discussion of the social construction of reality as being at a similar level of abstraction as paradigms. We deem theoretical orientations and models to be the next level. Here we focus on the work of selected theorists of social problems within
the social construction paradigm. Sequential models of social change will be examined. At this level the unit of analysis can be broadly described as collective behavior. Lastly we include the micro level of individual action and consider the role of moral entrepreneurs and claims-making activities.

Paradigms

According to Ritzer (1980) sociology is a multiple paradigm science. His analysis is based on Thomas Kuhn's The Structure of Scientific Revolutions (1962) in which Kuhn developed the concept of the paradigm generally applying it to the natural sciences. A paradigm achieves ascendancy in a science and is developed during a period of normal science which, according to Kuhn, is characterized by puzzle-solving. As researchers, however, are confronted by increasing numbers of anomalies a crisis emerges during which the paradigm is questioned. Should the crisis be sufficiently serious a new paradigm may emerge which is seen as able to explain the existing anomalies and deal with the issues handled by the original paradigm. Thus scientific knowledge progresses, not smoothly or steadily, but through a series of discontinuous leaps from one paradigm to another. Since the publication of Kuhn's important work in 1962, the paradigmatic status of
sociology has become of increasing interest to sociologists (Friedrichs, 1970; Phillips, 1973). According to Ritzer (1980) Kuhn never succeeded in defining the concept of paradigm adequately. Ritzer's definition is based on Masterman's (1970) critique of Kuhn in which she posits four different types of science namely: (1) paradigmatic, (2) nonparadigmatic, (3) dual paradigmatic, and (4) multiple paradigmatic. Assuming the latter type, Ritzer (1980) developed the following definition of a paradigm to be applied to the social sciences:

A paradigm is a fundamental image of the subject matter within a science. It serves to define what should be studied, what questions should be asked, and what rules should be followed in interpreting the answers obtained. The paradigm is the broadest unit of consensus within a science and serves to differentiate one scientific community (or subcommunity) from another. It subsumes, defines, and interrelates the . . . theories, and methods and tools that exist within it. (Ritzer, 1980, p. 189)

According to Ritzer (1980), the multiple paradigms of sociology are in conflict within the discipline, thus normal science is almost impossible in sociology because disciples of each paradigm are constantly having their basic assumptions questioned by those who accept other paradigms (p. 189). In the following section we will characterize Ritzer's conceptualization of two major paradigms namely social facts and social definitional or construction.
Social Facts

Traditionally, students of social problems and deviance have focused on questions of etiology. In this approach, social problems or deviant behaviors exist as objective conditions, seen as harmful or pathological, within a healthy society. Thus the traditional task of the sociologist has been to analyze the condition, identify the cause and propose solutions. In general we may categorize this approach as residing within the social facts paradigm whose assumptions and research foci lie within the Durkheimian tradition of sociology (Ritzer, 1980). Phenomena such as groups, norms, and values are seen as social facts that are external to, and in varying degrees, coercive on the individual. Thus behavior and social conditions are largely determined by social structures and institutions. Sociologists in this tradition generally treat problematic behaviors and social problems as objective conditions, hold the norms and values of society constant, and regard any divergence from these standards of behavior as non-normative (Rubington & Weinberg, 1978). Theorists within this approach seek to explain social problems and apply their findings to efforts of prevention and correction. The methods employed by social factists tend to be questionnaires and interviews.
Social Construction

According to Ritzer (1980) the exemplar for the social definitional or constructionist paradigm is a specific aspect of the work of Max Weber namely his analysis of social action. In addition symbolic interactionism and phenomenology are included within the paradigm. In the following discussion we focus on the commonalities within the three theories.

Social Action

Weber's work focused on how individuals define their social world and the consequences of such definitions. This Ritzer asserts is the basic subject matter of the social definitional paradigm and the crucial object of study is intra and inter subjectivity and the resulting action. Social action, according to Weber, is all human behavior when subjective meanings are attached to it:

Action in this sense may be overt, purely inward or subjective; it may consist of positive intervention in a situation, of deliberately refraining from such intervention, or passively acquiescing in the situation. Action is social insofar as by virtue of the subjective meaning attached to it by the acting individual (or individuals) it takes account of the behavior of others and is thereby oriented in its course. (Cited in Ritzer, 1980, p. 85)

Thus Weber sees sociology as a science that seeks to under
understand interpretive understandings (Verstehen) (Ritzer, 1980, p. 27).

**Symbolic Interaction**

Ritzer notes that of all the schools of theory, symbolic interaction is the most difficult to summarize, however, he distinguishes a major theme. In general he suggests that the key to the symbolic interaction position lies in the process of interpretation. Humans attempt to interpret each other's actions rather than merely reacting. This response is based on the meanings that individuals, collectivities, and organizations attach to such actions. The imagery is one of voluntarism rather than coercion. Humans are active creators of their social world rather than responding to norms or cultural expectations. Thus processes of interpretation and orientation are of interest. Changing meanings can occur at the individual level but also in large and complicated clusters.

**Phenomenology**

The work of Alfred Schutz provides the base for phenomenological sociology. His interest is particularly with subjective analysis and therefore he stands in opposition to the social factist tradition. One form of subjectivity is of particular interest namely inter-subjectivity. Rit-
Zer (1980) describes Schutz's approach:

(Intersubjectivity) refers literally to shared subjective states, or simply the consciousness common to a particular social group . . . It is subjectivity that makes social intercourse possible, for the patterning of interaction depends on the knowledge of rules that are shared, yet experienced subjectively. (Ritzer, 1980, p. 112)

Thus groups of people interpret the world similarly and without such mutual understandings cooperation would not be possible. Language and language categories provide ordered meanings by which both the self and social life is experienced. As Zer (1980) notes, Schutz's primary question is global and basic to social science: How is society possible?

In general these three theories assume that people are active creators of their social world and not coerced by static social facts. Social change is thus studied in terms of process. The focus is on social definitions, interpretations, and perspectives, how they emerge and how they influence social interaction and self-perceptions. Behavior is not seen as a stimulus response phenomenon but rather as a result of an evaluative process conducted by the individual or individuals. The changing and varying definitions of phenomena is the subject of inquiry.
Conclusion

In this study we are interested in the changing interpretation of cognitive loss in the elderly. Our own involvement in the social forces that led to new definitions produced a personal sense of the reality of the situation. That is, the re-interpretation of this condition was not a product of a collective unconsciousness, but rather, deliberate action on the part of individuals and groups in cooperative action. In this action shared common knowledge of senility was examined and evaluated. Meanings and shared realities were changed. Theory developed within a social constructionist paradigm allows us to examine meanings that actors construct both individually and collectively. In addition we can develop explanations for changes in meanings. This is our interest and therefore social construction is the approach taken in this study.

However, if we are to study process then the dynamics of such require examination. The work of Peter Berger and Thomas Luckman offers a dialectical approach to social change.

The Social Construction of Reality

In order to study process subjective meanings cannot be ignored. Berger and Luckman (1967) posit that reality is
socially created by means of a dialectical interplay between subjective human consciousness and objectified social facts. Thus in this approach to social reality the statements: "Society is produced by consciousness," and "Consciousness is a social product," are both simultaneously true. What is crucial, in Berger and Luckman's view, is the knowledge that people have of their social world, and how they perceive the institutions and structure of their society. They propose three simultaneous moments in this continuing dialectical process (Glennon, 1974).

Externalization is defined as the outpouring of human consciousness, whether material or non-material, social, structural, cultural and physical, ideas about human nature, and knowledge. Objectification is the moment where externalized products take on a reality of their own, becoming independent of the people who created them. To Berger and Luckman language is an example: "I encounter language as facticity external to myself and it is coercive on me" (Berger & Luckman 1967, p. 38). Internalization is similar to the process of socialization whereby the objective social facts are introjected into subjective consciousness thus formulating an individual's expectations, definitions, values and norms. Thus objective social reality, which has its origins in human consciousness acts back on consciousness and thus subjective knowledge,
as developed, produces a new reality (Glennon, 1974). Berger and Luckman (1967) point out that different interest groups hold varying definitions of reality. This is explained in part by what they term the *social distribution of knowledge*: definitions vary by, for example, age, social class, occupation, sex, religion, and ethnicity. The meanings held by these groups will be related to their social interests which have become for them an integral part of their definition of reality (Berger & Luckman, 1967).

If knowledge as a social product becomes reality when acted upon, then the interests contained within knowledge itself must be recognized.

**Habermas**

Habermas (1968) sees knowledge as existing at the objective level while human interests are subjective phenomena. He posits three systems of knowledge and suggests the interests lying within each type. *Analytical science* is the first type of knowledge. The interest within such knowledge is technical control which can be applied to the environment, people within society, or other societies. Scientism, according to Habermas, is increasingly becoming the decision basis in all spheres of society and takes on the appearance of independent, neutral legitimations for maintaining the social system and for ensuring economic
growth. **Humanistic knowledge** seeks to understand the world. By an understanding of history we can better understand our present. This type of knowledge is not oppressive but, on the other hand it is not liberating. **Critical knowledge** has human emancipation as its primary interest (Ritzer, 1983).

The fact that people are motivated by their own interests has been noted by theorists as diverse as Karl Marx and Adam Smith. Collective interests can motivate individuals to action, and conversely individuals can motivate collective behavior.

**Conclusion**

Berger and Luckman's (1967) view of society is one of constantly changing realities in a dialectical process. We suggest that their construct has application to knowledge about Alzheimer's disease. In the first moment, externalization, the notion that confused behavior is probably not caused by the aging process but rather can be a symptom of a disease is new knowledge. A new interpretation of reality is proposed. The concept becomes objectified into a new reality namely, Alzheimer's disease causes cognitive loss in the elderly. Lastly, the "objective facts" about Alzheimer's disease become internalized in the collective consciousness of a society and a new social norm is pro-
duced. This process is guided by interested parties and the particular knowledge that they produce. This in essence is the subject matter of our study. In the following section we will describe Blumer's challenge to students of social problems who have, he claims, been unable to detect social problems before a society recognizes them as such. If sociologists are ever able to do so they must understand the process by which recognition and ultimately internalization occurs. This then leads us to consider models of process (sometimes called the natural history of social problems) by which social problems become recognized and/or re-defined. Our intention is to consider these stage models of social change and ultimately apply them to our data.

Natural History Models of Social Problems

Blumer's Critique

Herbert Blumer, a leading exponent of symbolic interactionism and originator of the name, stressed the importance of studying the process by which individuals and groups create and change their social worlds, and criticized the failure of sociologists to recognize social problems:

Current sociological theory and knowledge, in themselves, just do not enable the detection or
identification of social problems. Instead, sociologists discern social problems only after they are recognized as social problems by and in a society. Sociological recognition follows in the wake of social recognition . . . if conventional sociological theory is so decisively incapable of detecting social problems, it would seem logical that students of social problems ought to study the process by which a society comes to recognize its social problems. Sociologists have conspicuously failed to do so. (Blumer, 1971, pp. 299-300)

Blumer describes specific social problems as "veering in the winds of . . . public identification" (1971, p. 299). Poverty, racial injustice, and the status of women are all examples of conditions that have either emerged, disappeared, or re-emerged according to the focus of public concern at specific times. He critiques the conventional sociological approach asserting that it treats social problems as objective conditions in a society:

Sociologists treat a social problem as if its being consisted of a series of objective items, such as rates of incidence, the kind of people involved in the problem, their number, their types, their social characteristics, and the relation of their condition to various selected societal factors. It is assumed that the reduction of a social problem into such objective elements catches the problem in its central character and constitutes its scientific analysis. (1971, p. 300)

In his judgement, this is an erroneous assumption. Social problems, according to Blumer, exist primarily in terms of how they are defined. Societal definitions give social problems their characteristics, lay out how they are to be approached, and shape what is to be done about them. This,
he asserts, is the decisive influence. Thus the objective makeup of a social problem is decidedly secondary.

An extension of Blumer's critique suggests that sociologists may note what they consider to be negative conditions, but if a society ignores the presence of such conditions they will not exist as social problems regardless of sociological analysis.

In the following section we move away from paradigmatic assumptions and enlarge on the concept of process. We will examine those theorists who have developed specific sequential models of the career of social problems. But first we briefly review the debate within sociology regarding the relationship between social problems and social movements.

Social Problems as Social Movements

Mauss (1975) takes the position that social movements themselves generate social problems. No condition however regrettable is inherently problematic. Thus social problems and social movements are interdependent:

Since . . . a social problem is dependent on a social movement for its very existence and is, practically speaking, coterminous with it, we might say that a social problem is simply a kind of social movement. (Mauss, 1975 p. xvi)

Both Blumer and Mauss point to a tension within soci-
ology namely, the connection between social problems and social movements. More specifically there is little agreement within sociology upon the definition of a social problem. Indeed Spector and Kitsuse (1977) posit that all attempts have been inadequate: "There is no adequate definition of social problems within sociology, and there is not and never has been a sociology of social problems" (p. 1).

Two major approaches within social problems theory provide the bases for the disagreement. One position suggests that social problems have objective reality and collective action is generated as a result of the noxious condition. The other group posits that social problems themselves are generated by the collective action of interested parties. The former approach is subsumed within the social facts paradigm and scholars in this tradition concern themselves with the cause and treatment of an objectively given problem. The latter position is characterized by Blumer (1971) who, although clearly concerned with human suffering, sees social problems as emerging and disappearing according to collective action (or the lack thereof). Mauss (1975) extends Blumer's position and suggests that since a social problem is so closely connected with collective action it is therefore a type of social movement and thus logically it may be stated that
social movements generate social problems.

We now turn to five specific models sometimes referred to as career or sequential models of social problems. We will first lay out each one and then briefly comment on their application to the subject matter of this study.

**Sequential Models**

Drawing on empirical data obtaining to the rise of trailer camps in Detroit Fuller and Myers (1941) developed one of the earliest natural history models of the development of social problems. Their three stages were: (1) awareness of the problem, (2) policy determination, and (3) reform. Compared to the subsequent work of Blumer (1971) and Spector and Kitsuse (1977) theirs was a rudimentary model, yet it generated replication efforts and criticism (Lemert, 1951). The work of Fuller and Myers can be described as sensitizing later sociologists to the need for further refinement in developing theoretical constructs for the study of social problems.

**Herbert Blumer**

Herbert Blumer was one of the originators of the natural history model of social problems. He posited a five stage model: (1) the emergence of a social problem, (2) the legitimation of the problem, (3) the mobilization of
action with regard to the problem, (4) the formation of an
official plan of action, and (5) the transformation of the
official plan in its empirical implementation (Blumer,
1971).

Blumer's substantive description of these stages is
brief. In his discussion of the first stage he notes the
lack of research:

We have scarcely any studies, and pitifully limi-
ted knowledge of such relevant matters as the
following: the role of agitation in getting rec-
ognition for a problem; the role of violence in
gaining such recognition; the play of interest
groups who seek to shut off recognition of a
problem; the role of other interest groups who
forsee material gains by elevating a given con-
dition to a problem . . . the role of political
figures in fomenting concern . . . and putting a
damper on concern with other conditions; the role
of powerful organizations and corporations . . .
the impotency of powerless groups to gain attention
. . . the role of the mass media in selecting
social problems; and the advent of adventitious
happenings that shock public sensitivities. (1971,
p. 302)

**Legitimacy** is an essential stage in the development of
a social problem. It must acquire social endorsement and
respectability without which it is doomed. As in emer-
gence this is a selective process about which, according
to Blumer, we know very little. It is a complicated pas-
sage which is not necessarily attributed to the gravity of
the problem.

If a social problem achieves legitimacy it enters the
third stage, that of *mobilization*. It is now an object of discussion, claims (exaggerated and otherwise), distorted depictions, and advocacy. How the problem is defined, and how it is influenced by power struggles depends largely on this process.

The **formation of a plan** for action represents the decision of a society with regard to a specific problem. The plan is developed in committees, legislative chambers, and executive boards. It is a product of bargaining and accommodation and Blumer describes it as a concentrated process of re-defining and refining that has telling significance on the fate of the specific problem.

**Implementation of the plan** is not identical to its formation. In this last stage a whole new process of collective definitions is ushered in. It sets the stage for new lines of action for those involved in the problem and those who are affected by the plan. For Blumer, it is essential for sociologists who wish their studies to produce improved social conditions to understand the process of collective definitions.

*Spector and Kitsuse*

Spector and Kitsuse (1977) posit that there never has been a sociology of social problems and that theoretical development in this area is non-existent. Despite the ex-
treme nature of their statement they do acknowledge the earlier work of Fuller and Myers and the more recent formulations by Blumer and Mauss, but criticize these efforts as being conceptually ambiguous and claim that "no one has ever attempted to pursue the implications of (the definitional approach) singlemindedly to their logical conclusion" (1977, p. 6).

Spector and Kitsuse (1977), sharing the features of models proposed by others developed a natural history or sequential model for the study of social problems. Their four stage model goes beyond the implementation stage and includes the emergence of dissatisfaction with established procedures and the creation of alternative responses:

Stage 1. Group(s) attempt to assert the existence of some condition, define it as offensive, harmful, or otherwise undesirable, publicize these assertions, stimulate controversy, and create a public or political issue over the matter.

Stage 2. Recognition of the legitimacy of these group(s) by some official organization, agency, or institution. This may lead to an official investigation, proposals for reform, and establishment of an agency to respond to those claims and demands.

Stage 3. Reemergence of claims and demands by the original group(s); or by others, expressing dissatisfaction with the established procedures for dealing with the imputed conditions, the bureaucratic handling of complaints, the failure to generate a condition of trust and confidence in the procedures and lack of sympathy for the complaints.

Stage 4. Rejection by complainant group(s) of the agency's or institution's response, or lack of response to their claims and demands, and the de-
velopment of activities to create alternative, parallel, or counter-institutions as responses to the established procedures. (Spector & Kitsuse, 1977, p. 142)

Theirs is a hypothetical construct, not empirically derived from individual case histories, but, in the opinion of the authors, an outline for such studies.

Armand Mauss

Mauss (1975) developed a sequential model of a social movement. His concern is with the activity of interest groups:

No social condition, however deplorable or intolerable it may seem to social scientists or social critics, is inherently problematic. It is made a problem by the entrepreneurship of various interest groups, which succeed in winning over important segments of public opinion to the support of a social movement aimed at changing that condition. (1975, p. xvi)

In addition Mauss includes the possibility of demise in his processual five stage model of the development of social problems.

The first stage, incipiency, is characterized by people "who have begun to feel a mild threat to the preservation or realization of certain vital interests" (1975, p. 61). Meetings, letters to and articles in the media, and organization of ad hoc committees are all examples of activities at this stage. In the second stage,
coalescence, formal and informal organizations begin to develop among sympathisers. Caucuses spring up, alliances are formed, and organization at the regional level emerges. The third stage, institutionalization, is characterized by collaboration with the state and other established institutions to work out a series of coping mechanisms. In this stage the movement (as opposed to the program) is institutionalized which implies that the movement is still mobilizing to get its program adopted. The movement is society wide, there is an extended division of labor within the organization, the media are attentive, politicians vie for its favor, and legislation begins to be passed. This stage, according to Mauss, is the period of greatest power for the movement.

The last two stages of Mauss's model focus on decline. Fragmentation, the fourth stage, typically occurs after a period of success and respectability. Those in the movement argue amongst themselves over strategy and tactics for the future; some will call for the modification of the original plan while others will advocate developing entirely new goals and objectives. The final stage is demise which, according to Mauss, is not usually perceived:

Within the movement, the demise is seldom recognized. Instead, this stage might be defined by the movement as "success" since most of its goals may have been accomplished . . . or it might be defined as a temporary setback for an otherwise still vital
movement. (1975, p. 65)

The first three stages of Mauss's model are derived from the work of others, while the last two stages are novel formulations not considered by other theorists. He posits several reasons for the demise of a social movement:

In our zeal to solve problems through laws, we often pass laws that do not have sufficient support in the traditional norms of the society, so that enforcement is an awesome burden. (In addition) . . . the laws that are passed and enforced around a given social problem are likely to be a reflection more of the interests of politicians . . . than of the imperatives of the "problem situation." (1975, p. 70)

In conclusion Mauss notes that the putative conditions that generated the original activity in the first place are often left unchanged or even worse as a result of collective behavior.

We next consider another sequential model developed by Conrad and Schneider (1980) with particular reference to the role of medicine and medical values in social definitions. Their model is exemplified by changing definitions of specific behavior such as alcoholism or insanity into medical conditions rather than the more general concern with social problems in the sequential models described above. Spector and Kitsuse (1977) however see a parallel situation between the process of defining social conditions and deviance:
The theoretical problem is to account for how categories of social problems and deviance are produced, and how methods of social control and treatment are institutionally established. (1977, p. 72)

Thus the theoretical problem in both cases is generally the same.

The Medicalization of Deviance

The medicalization of deviance tends to be a phenomenon of American society. Deviant behaviors that were at one time defined as evil or criminal are increasingly being re-labeled within the medical arena, seen as disease entities, and treated as such. The implications for the imputation of responsibility, social control, medical dominance, and social policy have been examined by scholars of deviance in both historical and contemporary contexts. Hyperkinesis in children, child abuse, alcoholism, and drug addiction are all examples of behaviors that have been re-appraised within the context of medicine.

Conrad and Schneider (1980) stress that theory within the social constructionist paradigm views deviant behavior as socially produced:

. . . the labeling-interactionist perspective views deviance as relative to time, place, and audience and as an attribute that is conferred on people by others . . . (This) approach turns the analysis away from the individual and the "causes" of his or her behavior, which have so long preoccupied the sociologist, to the "societal reaction." Rather

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than being viewed as an objective condition, deviance is regarded as a social product . . . (p. 18)

Thus interest is focused on the macro level of analysis, namely collective definition, rather than micro concerns such as deviant careers or stigmatized identities.

Conrad and Schneider (1980) offer a sequential model of the medicalization of certain deviant behaviors. Their construct is largely based on case studies of certain behaviors that have experienced changing definitions. For example, through documentary analysis they demonstrate that homosexuality or same-sex conduct has been defined historically in three different manners; from "sin" to "sickness" to one of "life-style." They posit a five stage model (1980, pp. 266-270).

**Definition of behavior as deviant.** In general the activity or behavior must be defined as deviant before medical definitions emerge. Thus attitudes are essential precursors to explanations.

**Prospecting: Medical discovery.** The "discovery" of a medical explanation is made in a professional journal, at a conference, or possibly in a monograph. The explanation is made in the form of a new diagnosis, a newly discovered syndrome or disease, or a proposal for a medical etiology for the deviant behavior. The articles are usually the work of a limited number of physicians or researchers.
who are specializing in the problem. Conrad and Schneider (1980) note that many such "claims" are made but few become ammunition for claims-making activities. When this does occur the third stage is reached.

**Claims-making: medical and nonmedical interests.** This is a critical stage in the model. Organized interests begin to emerge, champions and moral entrepreneurs start to make claims for the new definition. Conrad and Schneider specifically note the special characteristics of the medical interests:

The medical professional interests involved . . . . usually comprise a specialized group. They are either medical researchers of a specific problem . . . or are administratively involved . . . By "administratively involved" we mean that these physicians either operate a special clinic treating the behavior in question or are attached to an institution mandated to deal with the problem. (1980, p. 267)

The usual rank and file physicians are rarely involved at this stage other than receiving information about claims-making through professional journals and other channels. Non-medical claims-makers are also involved:

Usually drawing on already-made professional claims, nonmedical champions and vested interests play an important role in the promotion of new medical deviance designations . . . These groups, in different ways, promote new designations by engaging in publicity campaigns, lobbying in legislatures, and supporting litigation and judicial challenges. (1980, p. 268)

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These lay claims-makers are vital in the process of medicalization. Because of their non-medical status they may be less constrained in promoting their position. Ultimately, both groups will probably appeal to the state for legitimation and thus the fourth stage is entered.

**Legitimacy: securing medical turf.** The arena of activity changes to legislatures, federal bureaucracies, courts, or special committees. Hearings may be instituted, special investigations conducted, and legal challenges mounted. "Victories" may be seen as legislation being enacted that is supportive of the new designation, favorable reports from investigatory committees, official recognition by professional bodies such as the American Medical Association or the American Psychiatric Association, or, where needed, increased funding from private and public sources. When significant victories are achieved, the claim is seen as being successfully staked and becomes an accepted category.

**Institutionalization of a medical deviance designation.** In this last stage the medical interpretation becomes a fixity and semi-permanent in the social order and thus institutionalization is achieved:

When a deviance designation is codified, it becomes an accepted part of the official medical and/or legal classification system. It is written into law, supported by court decisions, or is included as an official diagnosis in official manuals such
as the American Psychiatric Association's *Diagnostic and Statistical Manual*. This provides both a symbolic and instrumental acceptance of deviance as a medical category. (Conrad & Schneider, 1980, p. 270)

Bureaucratization is a form of institutionalization. Large social control agencies are developed that provide institutionalized support for medicalization:

... they are bureaucratic "industries" with large budgets and many employees, that depend for their existence on the acceptance of a particular deviance designation. They become "vested interests" in every sense of the term. (Conrad & Schneider, 1980, p. 270)

Despite institutionalization of the new definition, the authors note that public support lags behind professional and bureaucratic support. The public remains skeptical, especially when anomalous data become available, thus they provide a source for new challenges and claims to the medical designation.

**Summary**

In this section we have been concerned with collective activity and have laid out five models of the natural history of social problems. Although Fuller and Myers' model is the simplest in terms of stages, we note that each one of their three stages is also included in the other four models. Thus awareness for Fuller and Myers is variously seen as emergence, assertions, incipiency, or
definition. We particularly note Blumer's complaint that there are few studies of this stage.

Each model also contains a stage of legitimation whether it be policy development, a plan or institutionalization within social structures. Lastly social change is posited namely: transforming the plan into action, fragmentation and reform. Rejection of the plan and demise are variations developed by Spector and Kitsuse and Armand Mauss respectively. In general the models are similar to one another with variation being provided in each case on the basic themes as set out by Fuller and Myers. Each contributes additional rather than alternative perspectives.

In this study we seek to apply these sequential models to the emergence of Alzheimer's disease. In broad terms we will examine the collective activities of individuals and groups in re-defining cognitive loss in the elderly as a disease entity. The activity of an elite group of physicians, particularly Dr. Robert Butler, the emergence of a national interest group from several small self-help groups, the use of the media and the burgeoning interest in Alzheimer's will all be considered in light of the combined characteristics the of the sequential models described above.

In all the models delineated above claims-making by interest groups is either implicit or explicitly dis-
cussed. We now expand upon the meaning of this activity.

Claims Making Activities

Spector and Kitsuse (1977) have suggested that the sociology of social problems should be concerned with the social process of definitions. If, as Mauss and others have proposed, social problems are a kind of activity therefore sociologists should analyse or describe the claims-making activities of groups asserting their views of reality which are often guided by visions of future realities. Spector and Kitsuse's definition of social problems focuses upon process:

... we define social problems as the activities of individuals or groups making assertions of grievances and claims with respect to some putative conditions. (Spector & Kitsuse, 1977. p. 75)

Thus the central problem for students of social problems is to account for the emergence, nature, and maintenance of claims-making and responding activities.

The micro level of analysis involves claims made by individuals or moral entrepreneurs and interest groups. Claims are the activities that interested parties take part in or produce either collectively or individually and are based on varying and changing perceptions of reality. Views of alternative realities often guide these activities. The analysis of claims making activities can re-
veal how activities are organized rather than suggest why people get involved in action in the first place.

Claims-making always takes place in interaction. Spector and Kitsuse (1977) provide examples of various claims:

A letter from a constituent to a member of congress urging support for some measure is a claim. So is a petition to the city council to fix potholes in the streets. So, also, is a resolution of a professional body for the end of a war in Indochina. Mundanely, claims-making consists of demanding services, filling out forms, lodging complaints, filing lawsuits, calling press conferences, writing letters of protest, passing resolutions, publishing exposes, placing ads in newspapers, supporting or opposing some governmental practice or policy . . . (Spector & Kitsuse, 1977, pp. 78-79)

Claims, therefore, are made through normative means of communication and are interactions (whether they be direct or indirect) between parties wherein some demand or appeal is made. Furthermore, a claim carries the implication that the claimant has a right to be heard but not necessarily satisfied.

The key for the sociologist in defining a claim as such lies in mutual interpretation by actors:

Usually it is not difficult for the sociologist to recognize and classify activities . . . as claims because they are so recognized and interpreted by members as well. That is, claims are a common-sense category, understood by members of a society and often associated with such terms as demands, complaints, gripes and requests. (Spector & Kitsuse, 1977, p. 79)
In addition, the choice of a forum for the claim must be seen as appropriate. "When the choice of a forum is grossly inappropriate people making claims will not be treated as claimants . . ." (Spector & Kitsuse, 1977, p. 81). The imagery of a claims-maker is that of a crusader making demands for social reform concerning a putative condition and utilizing accepted methods and channels of communication.

Putative conditions are those that are alleged to exist. The sociologist is not expected to verify the existence of the condition nor question the veracity of the claims made about the same condition. The challenge is to develop a theory of claims-making activities not a theory of conditions. By focusing on claims-making activities the sociologist can develop questions that ask how people organize their activities rather than inquire why participants become involved in activities. Researchers can consider issues related to vested interests, who benefits from the activities, varying claims as to the cause of the putative condition and the role of specific actors in the activities (Spector & Kitsuse, pp. 82-83). Thus the analysis may consider collective action by interest groups or individuals.
Summary

In this section we have described five stage models of social problems. As we have already noted the five models share commonalities. All appear to posit an early stage of activity which is characterized by assertions on behalf of selves or others. In addition a group with a collective sense of threat or awareness of their situation is essential. Legitimation is also a common theme among the models. Social endorsement, state collaboration and recognition by professional bodies are all typical of this stage. Spector and Kitsuse (1977) suggest that dissatisfaction with proposed solutions can lead to alternative institutions for addressing the problem. Mauss (1975) posits a similar situation, fragmentation, in which dissatisfaction and argument emerge. This can lead to demise of the movement which may or may not be recognized as such. Conrad and Schneider's model (1980) is more specific than the other four. Their interest lies in the role of medicine in defining social problems. However, within this approach they also posit stages that are broadly similar to those of the other four models with the exception of fragmentation or demise. We suggest that the broad stages outlined in the models cannot be explained without considering claims making activities. These are the dynamic interactions between groups or individuals that provide
the impetus for change.

In this study we will consider the process of changing definitions of cognitive loss in the elderly as compared to these stage models in combination. Thus, for example, we will describe early efforts of claims makers to define Alzheimer's disease as a legitimate problem of hitherto unrecognized magnitude. We will also examine the activities to achieve a broad based constituency to legitimize the definition and the efforts to develop a national policy. Our intention is to support and refine existing theoretical models with our data.

Interest Groups and Moral Entrepreneurs

In the discussion of claims making activities we have already indicated that claims are made on the basis of specific interests or concerns. Claims can be made by collectivities such as professional organizations. They can also be made by individuals. In this section we examine typologies of interests and discuss the characteristics of individual rule makers or moral entrepreneurs. The latter are persons who, through their ability to influence others contribute to social change. We conclude by discussing self-help groups as a type of interest group with particular strategies.
Interest Groups and Publics

In the study of collective action the interest group is an important unit of analysis. It is a public in a particular sense. This latter term is generally used in two senses: in the first it may be defined as a scattered number of people who share an interest in a particular topic. Thus there is a football public, a classical music public and many others. In the second usage a public is defined as a number of people who are concerned over, divided upon, and/or in discussion about an issue. Thus motivation for collective action may be present. The latter definition is of interest in this study.

According to Mauss (1975), it is from this issue-specific public that interest groups emerge. Interest groups are largely made up of persons who have the most to gain or lose from the putative condition or situation that is the focus of their concern. They are loosely organized and become pressure groups when they engage in lobbying and other political activities and organise a highly structured bureaucracy.

These groups tend to have six types of interests which may or may not be mutually exclusive: (1) economic, (2) political, (3) occupational, (4) moral, (5) psychological, and (6) scientific.

Economic interests can be given concrete expression or
"remain rather vaguely defined as the property of amorphous public . . . " (Mauss, 1975, p. 14). Political interest groups seek to acquire and/or exercise power and, as noted above, are likely to become pressure groups in their search to affect social change. Occupational interests may overlap political and economic interests but are clearly distinguishable as separate organizations. Examples would include the American Medical Association and numerous trade unions organized to support and enhance specific occupations. Similarly moral interests and political interests can often be synonymous. Some are religiously motivated and are based on ideals that "are seen as having ultimate, or even eternal, importance . . . because they were handed down by God" (Mauss, 1975, p. 16).

Mauss defines a psychological public in terms of personal characteristics and affect:

A psychological public . . . is a collection of individuals having certain psychological or emotional needs and dispositions that make them ready recruits for interest groups and movements. (1975, p. 16)

However, these individuals are depicted broadly as dogmatic, hyper-patriotic, uncomfortable with ambiguity, and possessing narrow views of right and wrong, thus conforming to the authoritarian personality described by Adorno, Frenkel-Brunswick, Levinson, and Sanford (1950). In addi-
tion Mauss includes those who are suffering deprivation in this category. Any of these states can account for an individual's participation in a social movement and his or her zeal in commitment to the cause.

Scientific publics are characteristic of advanced societies with economic surpluses where knowledge is highly specialized:

... Thus we have the "theoretical life" with its luxurious proliferation of specialized bodies of knowledge, administered by specialists whose social prestige may actually depend upon their inability to do anything but theorize ... (Berger & Luckman, 1967, p. 81)

Although Mauss directs his discussion of scientific publics to the social sciences, he notes that any field of science is applicable to the construct and that all scientific theory can be viewed as reality construction.

The typology of interest/pressure groups discussed above has generally been developed at the macro level of analysis where collective knowledge and action is of interest. Action by individuals, or micro level concerns are not explicit in these constructs. Collectivities are, however, made up of individuals interacting either directly in face-to-face encounters or indirectly through, for example, mass communication systems. Becker, (1963) confronts this problem:

Sociologists agree that what they study is society,
but the consensus persists only if we don't look into the nature of society too closely. I prefer to think of what we study as collective action. People act . . . together. (1963, pp. 161-182)

Micro and macro levels of analysis are symbiotic constructs. Individual decisions for action are taken with an eye to what others have done or may do. The result is collective action which may conform to or oppose normative expectations. According to Becker, the problem is theoretical:

We can construct workable definitions either of particular actions people might commit or of particular categories of deviance as the world . . . defines them. But we cannot make the two coincide completely, because they do not do so empirically. They belong to two distinct, though overlapping, systems of collective action. (1963, p. 185)

The first system consists of the people who cooperate to produce the act in question. The second consists of the people who cooperate in the "discovery" or re-definition of the act. Both these systems are subsumed under the rubric of collective behavior. It is the task of the sociologist to select and develop the theoretical perspective for the study of a specific problem.

Moral Entrepreneurs

According to Becker (1963) all social groups and societies make rules and attempt to enforce them. Social rules define situations and the behaviors appropriate to
them. The term **moral crusade** is broadly used in the sociology of deviance to describe concerted efforts to shape or change social rules. **Moral entrepreneurs** are those individuals who, through their own initiatives, produce rules. Becker (1963) posits two types of moral entrepreneurs: (1) rule creators and (2) rule enforcers.

The imagery of the former is reformist:

The prototype of the rule creator . . . is the crusading reformer. He is interested in the content of rules. The existing rules do not satisfy him because there is some evil which profoundly disturbs him. He feels that nothing can be right in the world until rules are made to correct it. (Becker, 1963, pp. 147-148)

Becker (1963) conceives rule creators as fervent and often selfrighteous. However, he notes that there are other characteristics such as humanitarian motivations.

A successful crusade will lead to the development of a new set of rules. Rules often require enforcement and so a new set of agencies and officials is established. With the establishment of these agencies the crusade becomes institutionalized. Becker (1963) draws examples of rule enforcers from the legal system and specifically the role of the police as such. He notes that rule enforcers need to justify their enforcement activities and the existence of rules provide them with an occupation and a raison d'etre. In addition they must win and maintain the respect of those
they deal with. The rule enforcers face a double problem; in order to justify their positions they must demonstrate to others that the problem still exist, and that the rules that they are supposed to enforce have purpose since infractions are occurring. Secondly, they must show that their efforts at enforcement are effective and worthwhile. Thus enforcement organizations simultaneously make opposing claims especially when requesting funds:

First, they say by reason of their efforts the problem they deal with is approaching solution. But in the same breath, they say that the problem is perhaps worse than ever (though through no fault of their own) and requires renewed and increased effort to keep it under control. (Becker, 1963, p. 157)

Such activities are increasingly becoming professionalized. McCarthy and Zald (1973) note the rise of professional social movements and social movement entrepreneurs. They note the expanded definition of certain careers:

Ministers, community organizers, public relations directors, membership and development specialists, lawyers, doctors, and engineers are some of the occupations from which the professional movement organization attracts its cadres. They are distinguished from their colleagues in these professions largely by their rejection of traditional institutional roles, careers, and reward structures. . . . We suspect . . . that they define their opportunities less in terms of the use of professional skills, and more in terms of social change objectives. (1973. pp. 23-24)
In addition they point to two developments in education and professional literature:

The first is the beginning of routinized training for such positions in the form of training institutes for social movement personnel . . . The second is the growth of a literature that attempts to systematize the knowledge required for success at such activity. (McCarthy & Zald, 1973, p. 24)

McCarthy and Zald (1973) conclude that there has been a significant increase in professional social movement activity. This is largely due to several secular trends: the growing importance of the mass media, the increase in both discretionary money and time, the growth of foundations, and the development of career alternatives. Thus social movement analysis must include the infra-structure of funding, the media, and the interaction between professional entrepreneurs, or elites, and the aggrieved participants, those who are actually experiencing the putative negative condition.

Self-Help Groups

Aggrieved parties either attempt to remediate their situation by individual action or participate in collective action. Self-help groups are a particular form of collective action in that they emerge from the recognition of mutually shared unmet needs. People turn to self-help groups for many reasons. Back and Taylor (1976) sug-
gest that one major reason for motivating people to turn
to or establish a self-help group is the belief that pro-
fessionals have failed them:

They find that a lay group better helps them in
dealing with the immediate problem . . . From re-
ports of self-help groups, one senses that there is
a clear agreement among members concerning their
intolerance of the claim that professionals are
omnipotent. (Back & Taylor, 1976, p. 298)

Self-help groups tend to be a characteristic of the
twentieth century. Pillemer (1980) estimates that over
500,000 of such groups, involving 15,000,000 persons,
currently exist in the United States.

Katz and Bender (1976) note the optimistic reports of
the success of self-help groups in both the media and
professional journals:

... large gains seem to be present not only for
the stigmatized, dispossessed, and 'disadvantaged'
but for society as a whole. New group identifica-
tions allow the forging of new identities, which in
turn enlarge the sense of self and the possibil-
ities of contributing to and altering the social
order. (p. 7)

Pillemer (1980) however cautions that, despite the
optimism, one area is of concern namely the relationship
between self-help and social structure. He raises two
fundamental questions regarding self-help. First, does the
so-called aprofessional character of self-help consti-
tute a basic challenge to the power structure? Second,
have self-help groups the ability to develop far reaching political goals over time? (Pillemer, 1980, p. 3).

The literature on self-help characterizes mutual aid in two ways: typologies and stages. Sagarin (1969) posits two typologies. The first emphasizes reform of deviant behavior and conformity to social norms. The second includes groups who desire to change the norms and expectations of their society. Examples of the former include Alcoholics Anonymous, and of the latter Gay action groups are an exemplar. Gussow and Tracy (1976) offer a typology that also posits two categories of self-help. Type I provides services and assistance to members directly, while Type II is more activist and involved in lobbying, sponsoring research and public education. Katz and Bender (1976) lay out four types:

1. Groups that are primarily focused on self-fulfillment or personal growth.

2. Groups that are primarily focused on social advocacy.

3. Groups whose primary focus is to create alternative patterns for living.

4. "Outcast haven" or "rock-bottom" groups such as halfway houses, and Synanon-style therapeutic communities. (Cited in Pillemer, 1980, p. 25)

As Pillemer points out, these typologies are static and as such cannot include a developmental perspective. Spiegel (1976) studied three self-help groups with different needs
and noted that they all tended to become more politically active as they developed. Back and Taylor (1976) broadly utilize Blumer's five stages described above to posit that self-help movements also can follow a regular sequence in their development. First, there is agitation and a general unrest among people who feel that their needs are not being met. Their aspirations have been aroused and are not being fulfilled. Second, a group comes together and develops esprit de corps. In the third stage the development of an official plan is characteristic. According to Back and Taylor (1976) the development of morale is important in this stage "since the defining characteristic of the group is essentially negative in value" (p. 299). In the fourth stage the acceptance of a general ideology such as anti-professionalism, is characteristic. In the last stage the mutual aid organization may become a political movement. It is probable that during this stage persons other than the original aggrieved parties may become involved and, as Back and Taylor (1976) suggest, the end result may be that the social effects of the groups may have little to do with the original problem.

Summary

The micro level of analysis involves claims made by individuals or moral entrepreneurs and interest groups.
Claims are the activities that interested parties take part in or produce either collectively or individually and are based on varying and changing perceptions of reality. Views of alternative realities often guide these activities. The analysis of claims making activities can reveal how activities are organized rather than suggest why people get involved in action in the first place.

Self-help groups are a specific type of organized action. Their goals may include accommodation to the status quo thus assisting individuals to adapt to social norms or they may also include social change as a primary or additional goal.

Conclusion and the Research Questions

This chapter has outlined the conceptual framework that informs this study. We introduced our discussion by referring to two approaches to studying social phenomena namely social factist and social constructionist. Our perspective espouses the latter. The basic concern is rooted in questioning how a social phenomenon comes to be seen as a problem in the first place. We agree with Blumer that "... social problems are fundamentally products of a process of collective definition ..." (1971, p. 29). Thus we assume that human behavior is based in interaction and interpretation and not merely reactive to social in-
stitutions and social structures. The out-pourings of hu-
man consciousness are the products of mutual understand-
ings and interpretations or evaluation.

Our intention is not to develop new theory nor to test
existing theory but rather to accept the challenge of
Blumer and Conrad and Schneider and attempt to refine or
add to existing theoretical models and knowledge. We make
certain assumptions based in part on our personal reality,
gestalt or world view. We assume that humans are active in
creating their social world, therefore social change is
brought about by interaction which may be cooperative or
antagonistic. Interaction is based on the process of in-
terpretation thus meanings that people bring to their ac-
tivities become of importance. Behavior is not seen as
reactive, but rather, following Parsons' concept of human
action, a creative, active and minded process (Parsons,
1937, p. 77).

We examined specific theories (Blumer, 1971; Conrad &
Schneider, 1980; Fuller & Myers, 1941; Mauss, 1975;
Spector & Kitsuse, 1977) all of which focus on the process
by which a social phenomenon comes to be recognized as a
social problem and, in specific cases, recast into a medi-
cal interpretation. The varying models that they posit
form the theoretical framework that we will apply to our
data. We will consider our data specifically in terms of
data. We will consider our data specifically in terms of these existing models.

Within these models, human activity and interaction is seen as claims making. In this study we treat cognitive impairment in elderly persons as a putative condition; historically this condition was viewed as a normal and expected concomitant of the aging process; it is currently alleged to be a disease. Both these positions we view as claims within the context of our theory. Thus our data are claims made over time concerning cognitive loss in old age. We will examine very specific claims, namely only those that are written. However, we view claims-making activities in two distinct ways. First, the products of individual actors are seen as claims. Thus, for example, reports by individual scientists, medical practitioners and social scientists regarding the etiology, diagnosis and treatment of Alzheimer's disease we consider to be claims-making activity. Second, since claims-making is defined as a form of interaction between parties, organizational activities are also so defined. Here the initiation of conferences and professional forums or workshops are examples of collective activity that we see as organized claims-making. For example, we will describe conferences and congressional hearings on Alzheimer's disease and analyze the strategies therein.
We posit that Alzheimer's disease is being claimed as a social and medical problem by aggrieved parties, interest or pressure groups, politicians and medical professionals to name but a few. Using the sequential models of social change reviewed above as a basis we will analyze the claims-making activities of actors and groups involved in legitimating Alzheimer's disease as a social and medical problem.

Our research questions are concerned with change over time, strategies of the parties involved and the characteristics and extent of claims making activities by the same parties. Our overall research question focuses broadly on social change:

1. How has senility come to be re-defined as a pathological condition of old age?

The specific research questions are subsumed within this general question and are as follows:

2. What were the historical antecedents that gave impetus to the emergence of claims?

3. What was the extent of claims making?

4. What were the characteristics of the claims?

5. What were the strategies for pressing claims?
CHAPTER III

METHODS

The literature on Alzheimer's disease is characterized by studies of distribution and extent, causal hypotheses, reports of treatment experiments, analyses of family stress, and service delivery needs and systems. Most researchers attempt to illuminate one particular aspect of the problem and describe its elements. Much research on disease conditions is characterized by gathering data on biological processes and treatment experiments. In this study we attempt to consider Alzheimer's disease in a broad and different perspective. Our concern is not with causality but rather with process, and thus our data gathering is directed at reports of human activities. We are interested in what people report they do in the process of deciding that a problem exists and subsequently addressing themselves to solving the putative condition. Our actors are medical researchers, physicians, social scientists, journalists, family members, and many others. Our data are the documents that they have produced. By using this particular data source we may also examine trends over time.

In this chapter we first describe documentary analysis
as a particular form of content analysis. Positive and negative aspects of documentary analysis will be considered. In the first part we will consider issues of validity, the development of analytical categories and the time period of the documents under consideration. In the second section we focus on our study specifically and describe the operation of the research questions together with the data sources utilized for addressing each question separately.

Content Analysis Method: An Overview

Content analysis is a multipurpose research method developed specifically for the analysis of communication. It is a method of observation. Rather than observing behavior directly or asking people to respond to scales the content analyst utilizes communications that people have already produced (Kerlinger, 1964). Content analysis has been further described as a process of analyzing data as symbolic entities. Writing in 1963 Danielson and Bryan noted a trend in content analysis toward hypothesis testing rather than descriptive research. Thus the researcher formulates theory, research questions, and hypotheses.

The purposes of content analysis are as broad as those encompassed by other methods. Holsti (1969) lists seven
broad purposes classified by basic questions:

What?
To describe trends in communication content. To relate known characteristics of sources of messages they produce. To audit communication content against standards.

How?
To analyze techniques of persuasion. To analyze style.

To Whom?
To relate known attributes of the audience to messages produced for them.
To describe patterns of communication. (Holsti, 1969, p. 43)

Examples of units of communication examined by content analysts include textbooks, advertising messages, newspaper editorials, and campaign speeches. The data base for this study is broad. It includes documents such as professional journal articles, media sources, classificatory manuals, government documents and conference proceedings.

Advantages and Disadvantages of Documentary Analysis

Documentary analysis has certain basic advantages over other methods such as survey research and experiments. First, it is an unobtrusive technique. Since the source of the data is non-reactive the investigator has no concern that the behavior of the subjects under investigation may contaminate the findings. Second, problems of access can be minimal. Most documents are in the public domain and thus accessible through libraries and on-line search services.
Third, costs can be relatively low. Fourth, the concept of time is of increasing interest to content analysts. Retrospective studies over long periods of time are well suited to documentary analysis. Issues of hindsight and memory are of no concern. The data are unchanging over time and are an excellent source for trend analysis. (We note however, that interpretations of words may change over time).

Disadvantages of content analysis include the following concerns. First, bias is inherent in most documents. The goals, objectives and purposes for which they were written can be sources of bias. Many are written for the purpose of making money (Bailey, 1982). Publication in scholarly journals is often required for career enhancement. What is both included and excluded is a value judgement on the part of the author, editor and/or publisher. Second, certain documents may not be available to the researcher. They may have been destroyed or classified. In some cases the information may not have been recorded (Bailey, 1982). Third, the researcher is entirely dependent on the verbal ability of the author. In the case of highly technical language the services of a consultant may have to be sought. Fourth, due to the extreme variability in format and content of documents coding may be quite problematic. Bailey (1982) suggests that the analysis of open-ended
questions by survey researchers provides a similar problem (p.306). Fifth, since content analysis can include potentially large volumes of data it can quickly exceed what a single analyst can do (Krippendorff, 1980, p. 31).

**Types of Documentary Analysis**

Documentary analysis can be classified into two broad typologies namely: unstructured non-quantitative and structured quantitative content analysis. Unstructured non-quantitative studies are organized to develop a theoretical point generally with a descriptive narrative. The classic study of Thomas and Znaniecki (1918) serves as an example. Personal letters of Polish immigrants residing in the United States were analyzed as to their content and a taxonomy developed. A main purpose of this study was to provide an understanding of all phases of life and insight into the subjects' inner mental life (Phillips, 1971).

Krippendorff (1980) describes structured content analysis as the "objective, systematic, and quantitative description of any symbolic behavior" (p. 10). Thus method is important. Sampling, codification and issues of reliability and validity must be addressed. Analytical constructs are developed and projections of future trends can be appropriate. Durkheim's pioneering study of suicide (1897/1951) is an example of active and rigorous explor-
ation of archival sources. He related suicide rates to religion, time of day, season of the year, race, sex, education and marital status. These variables were obtained from available archives and their systematic manipulation presaged the "morass of cross-tabulations that were later to appear in sociological research" (Webb, Campbell, Schwartz, Sechrest, & Grove, 1981, p. 93).

**Sampling**

As in most research the investigator must utilize some form of sampling strategy in order to make the task executable. The universe of available raw data can be overwhelming (Krippendorff, 1980). In documentary analysis sampling occurs in two broad stages. Krippendorff (1980) outlines the stages of decision making:

... (the content analyst) has to make two kinds of decisions. First, he has to employ all knowledge he can possibly obtain to distinguish relevant and irrelevant material. ... Second, if, after exhausting all available knowledge, the volume of relevant material is still too large, he has to employ random methods to select a sample that is large enough to contain sufficient information and small enough for analysis. (p. 65)

The selection of communication sources is the first strategy. Which newspapers, journals, and other documents should be selected as being representative of the universe? If there is no a priori knowledge of the phenomena then a
simple random sample can be drawn. If, however, the researcher is well acquainted with the subject matter, then Holsti (1969) suggests that a purposive sample may be drawn "to reflect qualitative or quantitative aspects of the sources which are deemed important" (p. 130).

Stratification on the basis of geography may be appropriate. Thus the data base may be limited to one particular country, state or other geographical unit.

Sampling within documents may be necessary if the investigator wishes to reduce the data further. Thus every "nth" page of a document could be selected or newspaper content might be restricted to the front page (Holsti, 1969, p. 132).

Sampling decisions will vary according to the type of documents utilized and the overall purpose of the study. Kaplan (1964) concludes:

... sampling is not a simple uniform procedure but one which varies from problem to problem in a way that permits and even demands correspondingly different ... treatment (Cited in Holsti, 1969, p. 132).

Thus sampling strategy varies by the size of the universe, the prior knowledge of the investigator, the types of documents selected, the broad purpose of the study and the questions to be answered.
**Development of Categories**

Bailey (1982) writes that categories must be adequate for the purpose of the study. In addition they should be exhaustive, mutually exclusive and independent. Categories are not constructed in a vacuum but rather originate by examining the documents:

Only by letting the categories emerge from the documents to be analyzed can the goals of mutual exclusiveness and exhaustiveness be met. Categories constructed without prior inspection of documents would no doubt exclude many important categories and include many that are superfluous or unnecessary. (Bailey, 1982, p. 316)

Thus the researcher, having confidence in his/her sampling strategy develops categories from a close inspection of the selected document.

Categories, however, should not be developed without reference to the researcher's theory and hypotheses or research questions. As Holsti (1969) warns: "aimless 'fishing expeditions' into documentary data are not likely to prove rewarding" (p. 94). Without theory the analyst is without guidance in category development "... unless he can state explicitly why he is analyzing documents, he cannot intelligently work out a plan on how to do it" (Holsti, 1969, p. 94). Most particularly Holsti stresses that categories must clearly reflect the investigator's research questions.
Holsti (1969) points out that there is no single unit of analysis for a given set of documents. Thus there may be several different recording units. The single word is generally the smallest unit to be considered. It is most often utilized in studies of style and literary detection. If the data contain many lengthy documents there may be too many words for the investigator to manage. On the other hand the single word is a discrete category with clear boundaries (Bailey, 1982, p. 317).

The theme or single assertion of a subject is, according to Holsti (1969), the most useful unit of content analysis. Coding may be time consuming and boundaries less clear than those of the word. Reliability can be a problem if the structural characteristics of the theme are not clearly delineated.

The character as a unit of analysis is limited to documents such as scripts for movies and plays. It has limited use and is only used in specific types of documents (Bailey, 1982).

The sentence or paragraph is better used for illustrative purposes since their use as a unit of analysis is problematic. Each written form may contain more than one topic and thus neither is mutually exclusive.

Holsti (1969) recommends the item as having utility as a unit of analysis. It is of use when many documents are
compared. In general the item characterizes an entire document whereas a theme may refer to a small part of the same document. Holsti (1969) suggests that the item can be a useful unit of analysis:

When used in conjunction with well-formulated categories that permit reliable judgements about major attributes of (the document), item analysis can yield interesting results . . . (p. 117).

The selection of the unit of analysis is clearly bound by the topic, type of questions or hypotheses, and characteristics of the documents under consideration. Other categories may be appropriate. Particularly in historical studies the presence or absence of an item or theme may be of interest. This type of observation invites qualitative data analysis. In addition the frequency of appearance of a certain item or theme may enable the investigator to point to the emergence of themes or to make assertions with respect to priorities or relative importance of the topic.

Reliability and Validity

Reliability

In content analysis opportunities for improving reliability are usually limited to issues of coders and category improvement. Bailey (1982) points out that the documentary analysis "... is often a rather subjective pro-
cess" (p. 328). The construction of categories, determination of the unit of analysis, and even the definition of the universe under consideration are all choices that involve subjective decisions. In addition Holsti (1969) considers the lack of consensus amongst content analysts concerning the establishment of standard categories to be a major indicator of subjectivity:

Reasons for the absence of standard categories are not hard to find. The premium on "originality" and the concomitant reluctance of analysts to adopt the categories of others--tendencies clearly not limited to content analysis research--is probably a contributing factor. A more basic reason, however, is that there are few areas of social inquiry in which there is sufficient consensus on theory to inform the selection of categories. . . . Finally, many of the most interesting content analyses will probably always depend on categories developed especially for the data at hand. (Holsti, 1969, p. 102)

Thus we conclude that the analyst must pay attention to the pooled judgements of coders. Intercoder reliability should focus on the boundaries of units coded, the categories developed and the assignment of data to the same categories.

**Validity**

Bailey (1982) claims that documents tend to have face validity since they are first-person accounts by the author(s) of the document. However, validity tends to be
damaged by the motives of the authors for example in making the results favorable to themselves. In addition the biases of the publishers of the documents may have an impact. Clearly the larger the sample the less the probability of systematic error and the greater confidence in making valid inferences from the data analysis.

Method of Study

This study employs both unstructured non-quantitative and structured quantitative content analyses as the two principal methodologies. Our analysis of the extent of claims will utilize quantitative methods whereas the characteristics and strategies of claims and claims makers will be reported using descriptive narrative.

Units of Analysis

In general, our unit of analysis is the item. That is each entire document will be examined and assigned a particular overall characteristic. Since we are not interested in literary style or character development, it is obvious that neither the word, sentence nor the character as units of analyses are appropriate. However, in cases of multiple topics within one single document the unit of analysis was considered to be a theme within the overall item. (Coding decisions regarding these documents will be
addressed in a subsequent section).

Limitations

The volume of documents on Alzheimer's disease is formidable and the universe is of unknown size. Following Holsti (1969) our strategy was one of purposive sampling. That is with a priori knowledge we selected key sources to access professional publications, media coverage, and state and private sector interest in Alzheimer's disease. In the following we discuss further sampling strategies and then discuss each data source in some detail.

The documents to be studied are limited in several specific aspects. First, our analysis is confined to documents written in English and published in the United States. Translations from other languages are excluded. Second, unpublished documents are also excluded. Thus personal documents, dissertations and theses are not included in the quantitative data base. (We note however, that some unpublished documents will be used for descriptive purposes). Third, for both our structured and unstructured analyses the time period is broadly limited to the fifteen year period between 1970 and 1985. Prior knowledge of the subject matter suggests that the quantity and variety of topics started to develop in the early 1970s. However, we will not focus exclusively on this time
period since the examination of documents published as early as 1806 allows us to discuss the historical background of our subject matter.

Sources of Data

This study uses a variety of data sources. Broadly these include, newspapers, professional journal articles, specific indices, government documents, popular magazine articles, books and monographs. The following section describes the specific data sources and discusses issues of coding where appropriate.

The New York Times

This study uses the New York Times as an important source of data. It was chosen since it is the major newspaper of the United States. Schwartz & Leitko (1977) suggest the newspapers are an appropriate source for examining the manifesting of social problems:

... even though [newspapers] are less popular than television [they] are major daily information sources for a sizable portion of the adult population...particularly for elites. ... they contain the problem manifesting activities, in symbolic form, of a number and a variety of social groups ... Newspaper items are the symbolic products of the activities of individuals and groups. (pp. 428-429)

In this study we use the New York Times in two ways. First we will quantify the articles by year. Secondly we will
consider two specific characteristics of the articles. As we examined the documents in the New York Times, it became evident that there were two types of articles published on Alzheimer's disease that had temporally different patterns of appearance. The typology broke down into documents that were primarily feature articles that were not generated by a specific event and those that were reports of events. For example, reports on specific research findings were considered to be news items whereas articles such as "Did Alzheimer's Afflict Ravel?" (New York Times, 25 December 1984) were clearly feature items. Those articles whose editorial genuses appeared to be National Alzheimer's Month were considered primarily on their content and then so assigned to either category. Our second foci considers the characteristics of terminology utilized in the titles to the documents published by the New York Times. By confining our unit of analysis to a single phrase we could examine changes in popular usage of terminology as reflected in the media. At a minimum titles need to (a) communicate a common shared meaning between the reader and the author and (b) encourage the reader to peruse the article. Here we examined only those titles that focused directly on cognitive loss in the elderly and excluded those that did not reflect the topic in their content despite the fact the subject matter was addressed in the body of the article.
Thus, for example, "Medicare's Broken Promise" (New York Times, 17 February 1985) was eliminated as was "Mt. Sinai Names Head of New Geriatric Unit" (New York Times, 28 February 1982) since neither article conveyed any substantive information about Alzheimer's disease.

**Magazine Index**

The Magazine Index was selected because it accesses popular literature and thus provides an indication of media and public interest. This index provides a full reference to each article; abstracts, however, are not available. The unit of analysis was the name of the magazine that published the article. Classification by content was found to be problematic since many articles could be characterized as overviews in that they offered information on both medical research and caregiver issues. The search of the Magazine Index yielded several references to the journal Science. It was decided to eliminate these items from the count since we do not consider Science to be a popular magazine. On the other hand, Science (Year) was included since it is available on news stands and generally couches its reports in less technical terms than those published by Science.
Professional Journal Articles

Professional journal articles are a major source of data for this study. In order to access this data base specific indices of published literature and electronic searches were utilized. Index Medicus was a major source of data specifically accessed through Medline a national electronic search system.

Index Medicus

Index Medicus published monthly and annually as the Cumulated Index Medicus by the National Library of Medicine is the major means of accessing the bio-medical literature in both journals and monographs. We searched Index Medicus for the years 1969 to 1985 utilizing five major key words namely: dementia, senile dementia, pre-senile dementia, senility and Alzheimer's disease. Abstracts were reviewed as the primary basis for categorization and in cases where they were not available the original article was obtained. All documents were discarded from the analysis that did not have a major focus on the topic. As already noted, only articles in English and those published in American journals were utilized.
Development of Categories

In this section we provide a description of the development of categories from the analysis of Index Medicus and provide examples of coding decisions.

Following Bailey (1982) fifty-one categories were developed by examining the documents rather than setting an a priori coding scheme. Many articles could be easily coded into categories since they were issue specific as, for example, the use of medications in enhancing memory. Some, however, covered several topics; in these cases the relative balance of information within each topic was considered. For example, if it was decided that each sub-topic was equally balanced the document was considered to be an overview of current knowledge. In other cases of multiple topics within one document the coding decision was made by deciding which topic was of major import and which of lesser weight.

Categories were developed according to the content of the journal article. Thus, for example, articles on neurochemical studies of Alzheimer brain tissues were coded as pathology. Research on specific etiology such as a virus, aluminum and genetic hypotheses was separated from pathology initially however the logic of maintaining this category became problematic. After some deliberation, the
separate categories were maintained since the researcher decided that by so doing subsequent analysis would not be affected and indeed the comparison of each of these items over time might potentially be of interest.

Medical diagnosis was differentiated from psychological testing and similarly drug therapy was separated from behavioral therapy such as reality orientation and validation therapy. Descriptions of behaviors with reference to crisis intervention were also separated from behavioral therapy and research reports describing the results of environmental manipulation were assigned a separate category. Certain behaviors such as depression, inappropriate sexual conduct and speech were categorically separated in order to maintain the richness of the data for descriptive purposes if needed.

Nursing care as a professional skill was a distinct category from social care. For example an article on skills for handling incontinence would be coded as the former whereas a piece advocating the need for community services would be coded as social care. Articles that recognized the unit of care to be the family were distinguished from those that considered the victim of Alzheimer's disease alone.

Articles about the use of technology fell into two categories: reports of the results of using, for example,
CT scans as compared to those authors that discussed of the method of use of the equipment itself. The former was coded as pathology whereas we developed a separate category for the latter (See Appendix A for a complete listing of the categories).

Reliability

In order to address reliability, two coders, in addition to the investigator, examined the many documents in Index Medicus. Both coders were professional nurses and graduate students in a MA nursing program. One held an undergraduate degree in Social Work while the other a bachelor's degree in Sociology with an emphasis in Gerontology. Both had some familiarity with the literature on Alzheimer's disease and, as medical professionals, had knowledge of the type of terminology they would encounter in their review of the documents. Both were instructed to develop their own categories independently of each other and the investigator, and, in the case of a multiple topic document to use the criteria described above for allocation to categories. In the case of disputes the investigator acted as final arbiter. Out of the 1539 documents considered, the coders disagreed on 151, or 9.8 percent.

Some problems encountered in the coding were as follows:
a tendency to assign some documents which were general in
nature to the category of pathology since they contained a
discussion of contemporary (for the year under scrutiny)
information on pathology, or structure and function of
brain tissue obtained on autopsy. It became clear that the
category of pathology was quite broad. Therefore, after
discussion, this category was reexamined. It was noted that
there were clearly two major differences between these
documents as follows: one group clearly reported new
knowledge whereas the second series of documents provided
reviews of the current status of knowledge. It was decided
that if the latter documents provided a review of
pathological knowledge exclusively they were coded as
pathology. If, however the documents referred to pathology
in the context of other issues they were evaluated for
potential coding as overview as discussed above. Another
problem encountered in the coding involved some overlap
between the category of medical diagnosis and psychological
assessment. Some documents included discussion of both in
terms of an overall diagnostic effort. Here it was decided
that when the medical diagnosis was the primary content it
was so assigned. Similarly when psychological testing was
the major content it was coded as such. Lastly, it was
agreed to separate other particular conditions such as
Downs, Korsakoff’s, Parkinson’s and Creutzfeld-Jacob.\footnote{2}
Secondary Analysis

In order to examine trends in claims making, the various topics were collapsed into four major categories. The first we termed etiology. This variable includes all those documents that were considered to be directly related to research on finding a cause of Alzheimer's disease. For example, documents on pathological changes and abnormalities in the brain were included in this variable as were other conditions thought to be related such as Creutzfeld-Jacob, Downs syndrome or Parkinson's disease. Documents reporting research on the presence of aluminum in the brains of victims were also included. In addition, epidemiological research was included under the category of pathology. The second major category we named assessment. This contained all those topics relating to medical diagnosis, psychological assessment and the reliability and validity of instruments. Papers on the use of technology were placed in this category as were publications attempting to differentiate between a "true dementia" and other conditions such as depression. Our third collapsed variable contained those articles that reported efforts to treat persons with Alzheimer's disease. This was entitled treatment. All documents containing reports on drug trials and treatment efforts were included as were considerations
of the use of vitamins or certain foods as therapeutic agents. Articles on behavioral and environmental manipulation were placed in this category. The use of shunts, nursing care and electro-convulsive shock treatment are examples of topics also included in this category. Lastly, we developed a category which we named social. Herein were placed documents relating to family caregivers, social support, issues relating to nursing homes as alternatives to home care, legal concerns and support groups. These four categories were examined in order to elucidate any differences between them over the time period of interest namely 1970 to 1985.

Several coding decisions require explanation. First, after deliberation, three categories were omitted from the analysis since it was agreed between the researcher and the coders that these specific documents could not be placed in any of the four categories. These included: documents describing the historical background, articles that provided a broad overview of multiple issues and lastly, ethical considerations. One hundred and fifty one such documents were omitted. Thus the secondary analysis included 1383 documents. Second, categories of medical practice were assigned to the broad variable treatment since the content of each document fell clearly within this domain. Third, documents dealing with the use of
electroencephalography (EEG) as a diagnostic technique were coded as assessment. Fourth, documents concerned with epidemiology were included in the category etiology. Lastly one article on a special clinic for Alzheimer's patients was coded as treatment since that was the prime activity of the proposed clinic (See Appendix B for a listing of topics by each category).

Analysis of New Topics

Upon inspection of the raw data it was noted that new sub-topics on Alzheimer's disease appeared to be introduced in a patterned manner between 1970 and 1985. It was therefore decided to break down our data by the number of sub-topics introduced for each year.

Social Sciences Citation Index

A quantitative (non-electronic) analysis of the Social Sciences Citation Index (SSCI) was performed. Here the number of items recorded from 1970 (the first year of publication) to 1985 relating to Alzheimer's disease was of interest. In addition the development of multiple categories related to Alzheimer's disease within the SSCI was recorded. The keywords utilized were as follows: dementia, senile, senility, pre-senile, Alzheimer's disease. Care was taken to avoid repetition and to identify unique
articles only. Only those articles indexed under a primary term with a solid arrowhead (indicating a unique article) in front of the authors' names were counted. Thus the problem of duplication was avoided.

Professional Manuals

Two major professional manuals were selected for examination. The Diagnostic and Statistical Manuals of Mental Disorders published by the American Psychiatric Association are the major source of information on diagnostic categories and strategies for professionals in the mental health field. In contrast, the Merck Manual is a resource primarily for physicians to provide information on medical diagnosis and treatment. It was first published in 1899 and has been edited and updated on a regular basis since that time. The most recent edition was published in 1987. For this study we confined ourselves to the eighth through fourteenth editions of the Merck Manual published from 1950 to 1982. Our use of both these professional manuals is for illustrative and descriptive purposes and no structured analysis is proposed.

Government Documents

Specific government documents were examined namely reports of congressional hearings on Alzheimer's disease and
task force reports. These sources were used for illustrative purposes; however, quantification of congressional hearings over time was performed as an indicator of the involvement of the state. In addition the documents provided data on federal expenditures on Alzheimer's disease. Only federal government documents were included in this study. Since many states in the union have, or are considering, some policy initiative it was considered impossible to include state documents in the analysis.

Private Funding

The Foundation Grants Index provides information about the funding interests of 400 major foundations in the United States. This index was searched in order to develop an indicator of private sector interest in Alzheimer's disease. The data were quantified by annual expenditures. A subsequent analysis was performed in order to examine differences in targeted goals by the foundations who granted funds to Alzheimer's disease.

The Research Questions

The overall research focus of this dissertation is on changing definitions.

1. How has senility come to be re-defined as a pathological condition of old age? In order to address
this question we will next discuss our method in relation to each research question.

2. What were the historical antecedents that gave impetus to the emergence of claims making activities? Here we describe attitudes toward aging and mental incapacity in old age from both medical and lay perspectives from the time of Hippocrates to the twentieth century. We will utilize monographs and journal articles mainly taken from secondary sources such as histories of medicine and historical attitudinal studies. In addition reference will be made to demographic data and vital statistics.

3. What are the strategies for pressing claims? We will consider conferences, activities of particular actors, the state, and self-help groups as well as media utilization. In this section we examine and describe conference proceedings, reports of congressional hearings and publications by key actors. Essentially the methodology is non-structured and descriptive.

4. What are the characteristics of the claims? Our operationalization of this question involves content analysis of medical and social science literature and the New York Times from 1965 to 1985. Broad categories will be developed and subsequently refined. Inter-coder reliability will be addressed. We will examine changes in professional classification manuals such as Merck's Manual and
the *Diagnostic and Statistical Manual of the American Psychiatric Association*.

5. What is the Extent of Claims Making? The method here is a structured quantification of scientific publications referenced in *Index Medicus* and the *Social Sciences Citation Index*. We will develop categories according to the item and quantify the number of items within each category. Media reports are included as is an analysis of financial support from public and private sources between 1970 and 1985.

Conclusion

This retrospective study is both descriptive and analytical. In order to make the task executable major indices of the literature were utilized. While the absolute numbers of documents published each year on Alzheimer's disease are unknown we posit that by utilizing the sources in these indices in their entirety rather than drawing samples from each, we may be reasonably confident that systematic error is minimized.
CHAPTER IV
HISTORICAL BACKGROUND

The interactionist perspective seeks to explain meanings or socially constructed realities. Thus questions concerning the etiology of meaning are of interest. According to Conrad and Schneider (1980), the only way to answer such questions is "... to locate their origins in history and identify the social groups and activities that generate and support them" (p. 20). This chapter is designed to place the twentieth century approach to mental incompetence in old age in a historical context. Our goal is to identify general patterns of social attitudes, professional practice and debate with respect to elderly incompetent persons. We will highlight themes that will be picked up later and applied to our findings. The overall intent of this chapter is to answer first research question namely: What were the historical antecedents that gave impetus to the emergence of claims making activities? (The next three chapters address each of the subsequent research questions in turn).

Madness has probably co-existed with the human race throughout history. However the concept of madness has varied widely ranging through supernatural possession,
witchcraft to one of illness. Conrad and Schneider (1980) have carefully documented the historical development of mental illness from the era of the Old Testament through the classical Greek and Roman period, the middle ages, the Enlightenment and the rise of science to the medical model. They conclude that although physicians, psychiatrists and clinical psychologists had no theories or treatments that would make madness ipso facto a medical model the medical profession by the end of the nineteenth century nevertheless "had a firm dominance over the conception and treatment of madness yet possessed no 'successful' medical treatment and no evidence of organic causes of madness" (Conrad & Schneider, 1980 p. 71). Nineteenth century clinicians, Pinel for example, were humanitarian reformers in the treatment of madness thus their "capture" of madness was less a scientific endeavour rather than a social and political achievement (p. 71). It is with this background that we now turn more particularly to the psychiatry of old age and consider its historical antecedents. Following Cardno's (1968) observation that ". . . (nineteenth century psychiatrists' methods) made it perilously easy to interpret rather than to observe i.e., to apply a stereotype . . . " (p. 605) we also include historical attitudes toward the elderly in our discussion. The general history of psychiatry can be traced to Hippocrates but the geneal-
ogy of the psychiatry of old age remains obscure and ill-defined. The paucity of references to dementia or any mental conditions related to old age in comprehensive histories of medical psychology (Zilborg & Henry, 1941) and psychiatry (Hunter & MacAlpine, 1963) testify to this issue (Alexander, 1972).

Greco Roman Origins

In general the Greeks took a very somber view of old age. They were strongly influenced by the Hippocratic view of medicine and psychiatric problems. This proposes that disease results from an imbalance between hot and cold forces, a view that was further refined by Galen (c.130-200) who posited four humors namely blood, phlegm, yellow and black bile. These elements interact by permutation and combination into a complex system of arrangements for the maintenance of health. Galen generally subscribed to the philosophy of the Stoics who often used the term disease and old age synomously and advocated suicide as a release from protracted illness (Sandbach, 1975). According to both Galen and Hippocrates dementia and imbecility are consequences of rarefaction and diminuition in quantity of the animal spirits and the coldness and humidity of the brain (Zilborg & Henry, 1941 pp. 91-92). Hippocrates wrote that mental deterioration in old age which he called
paranoia was an inevitable, incurable, and a fatal consequence of aging because the veins are empty and the blood scanty, thin and watery (Adams, 1939). A son, if he could prove that his father was incompetent due to paranoia, would be granted a request to have a guardian appointed. This law was considered important enough for Plato to include it in his ideal state (Zilboorg & Henry, 1941). The Greeks saw the danger of relying too much upon experience and the leadership of the elderly.

Aristotle had a particularly negative view of old age. Hall (1922) quotes from his Rhetoric:

He (Aristotle) says in substance that the old have lived many years and been often the victims of deception (thus) they are never positive about anything. They are uncharitable and ever ready to put the worst construction upon everything. . . . they have no strong loves or hates but go according to the precept of bias. (pp. 64-65)

Furthermore Aristotle described older persons as cowards, alarmists, expedient, feeble-minded, self-interested and garrulous. He agreed with Hippocrates and Galen by attributing all the deficiencies of old age to the drying up of the humors in the brain (Hall, 1922).

When we turn to the Romans we have, on the whole, a more complex view of old age. Roman law gave the head of the family dignity and power through the concept of Patria Potestas. Hall (1922) writes:
This term designates the aggregate of those peculiar powers and rights that, by the civil law of Rome, belonged to a head of a family in respect to his wife, children (natural or adopted) and more remote descendants who sprang from him through males only (p. 66).

Furthermore, the Roman Senate, noting the etymology of the word, was a body of elderly men.

Cicero's poem *De Senectute* is a remarkable document. It is a repudiation, though perhaps not intentionally, of much of the Greek view of old age. His view of aging in a social context is positive and the poem abounds with examples of nobility and dignity in old age. He noted that if mental deterioration (which he termed *senilis stultitia*) does occur in the later years it is the result of character disorders which are reversible. However, despite Cicero's eloquence, the broadly negative Greek view of old age prevailed in the practice of medicine (Halpert, 1979).

Alexander (1972) concludes that "... early physicians were more concerned with a quest for the means of obtaining longevity and staving off the ravages of old age so vividly portrayed by their literary contemporaries" (p. 207). Given the inevitability of old age, the search for the fountain of youth appeared to be the only logical direction in which to proceed.
The Dark Ages

After Galen's death a chapter in medical history ended, the effect of which cannot be minimized. "The medical world entered into that twilight that is commonly called the Dark Ages" (Zilborg & Henry, 1941, p. 93). Garrison (1929) noted that after Galen's death European medicine remained level for nearly fourteen centuries. According to Halpert (1979) this period was typified by the absence of medical pronouncements and research on the functioning of the human mind which was placed in the realms of theology and philosophy. By the end of the fifteenth century medical psychology became enmeshed with so many abstract theological questions that physicians of the day retreated from attempting to diagnose or treat insanity:

The physician of the time reasoned in a manner that his preoccupation with clinical matters might be mistaken for indifference to the questions of sin and virtue. (Zilborg & Henry, 1941, p. 44)

The insane thus fell under the jurisdiction of established religion and belief in free will was brought to "its most terrifying, although most preposterous, conclusion" (Zilborg & Henry, 1941 p. 156). Individuals succumbing to insanity were thought to do so at their own free will and voluntarily accept the command of the Devil (p. 156). The Greco-Roman view that the highest endowment of humans is
the mind was reaffirmed and any deviation seen as sin:

The twenty-seventh verse of the twentieth chapter of Leviticus continued to rule psychiatry: "A man also, or woman that hath a familiar spirit, or that is a wizard, shall surely be put to death (Zilborg & Henry, 1941, p. 165).

The biblical injunction "Thou shalt not permit a witch to live" was noted and reified in the Malleus Maleficarum (The Witches' Hammer) the famous document published in 1487 that initiated and justified the persecution of witches and those believed to practice witchcraft. The Malleus included a section on the methodology of identifying a witch:

The second part is devoted to what we would call today clinical reports. It tells of various types of witches and of the different methods one should use to identify a witch. To use modern terminology, it describes the clinical pictures and the various ways of arriving at a diagnosis. (Zilborg & Henry, 1941 p. 152)

Alexander (1972) observes that records made of trials of witches as a result of the Malleus provided more detailed information of the physical, psychological and behavioral symptoms of senile dementia than any nineteenth century texts (p. 207). He notes that Esquirol (1838) in his publication Traite des Maladies Mentales attempted the first description of psychiatric problems associated with aging. However senile dementia as discussed in the nineteenth century "emerged . . . as a very vague and over-inclusive

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concept, including within its limits a miscellaneous variety of senile disorders" (Alexander, p. 207). In addition the semantic confusion surrounding the definition the definition of dementia has prevailed in psychiatry until the present day (Alexander, 1972). In broad terms Zilborg and Henry (1941) note the slow progress of medical psychiatry and ponder whether it is the inevitable fate of psychiatry always to make slower progress than other fields of knowledge.

The Nineteenth Century:
Vicissitudes of Classification and Terminology

The re-establishment of science in the eighteenth and nineteenth centuries was known as the Enlightenment. In historical terms the Enlightenment signaled the period in which "madness moved once and for all into medical turf" (Conrad & Schneider, 1980 p. 52). By the end of the eighteenth century physicians had become essential to the madhouse despite limited therapeutic ability. They took on a gatekeeping role certifying the need for confinement and some became leaders in humanitarian reform in the treatment of the insane (Conrad & Schneider, 1980). Philippe Pinel (1745-1826) the humanitarian director of the Salpiztre asylum in France was one such reformer. In 1806 he published his Treatise on Insanity. We first
consider the work of three major psychiatrists. Not one of them devoted any significant amount of their writings to the psychiatry of old age therefore our discussion is of necessity quite brief. We begin with the work of Pinel on dementia.

**Pinel, Esquirol and Maudsley**

Nineteenth century physicians, psychiatrists and academicians developed and then grappled with defining numerous forms of mental disease and/or conditions. Cardno (1968) notes that these terms included idiocy, cretinism, depression, weakness, exaltation, dementia, chronic dementia and apathetic dementia. Pinel (1806) using the general category of insanity organized five sub-species of mental derangement namely: melancholia or delirium, mania without delirium, mania with delirium, dementia or the abolition of the thinking faculty, and ideotism or obliteration of the intellectual faculties and affections (Cardno, 1968). Willmuth (1979) suggests that concepts of insanity in the nineteenth century were seen as a causal process. These concepts were:

> . . . strong passions cause melancholic insanity, melancholia is the first stage of all insanity, and chronic insanity degenerates into dementia. (Willmuth, 1979, p. 497)

According to Pinel, dementia was apparently associated
with the aging process and therefore incurable:

May dementia, from an occasional cause, be properly identified with that originating in old age: and are they not equally incurable? All the facts that I am acquainted with appear to countenance this melancholy truth (Pinel, 1806, pp. 200-201).

Idiocy, on the other hand may originate from a variety of causes including intense study, profound sorrow and excessive and enervating pleasures (p. 165). However Pinel, in a later paragraph, appears to suggest that dementia has other causes besides old age:

... Curative measures are ... useless in cases of dementia originating in enthusiasm or any other ecstatic emotions, as Tissot has ably shewn in his "Essay on the diseases of literary and sedentary persons." (Pinel, 1806, pp. 200-201)

Esquirol writing in 1845 attempted to clarify the matter:

Dementia and idiocy differ essentially ... A man in a state of dementia is deprived of advantages which he formerly enjoyed: he was a rich man, who has become poor. The idiot ... has always been in a state of want and misery ... dementia only commences with puberty, increases from year to year, deprives the faculties of energy, though they still exist. (Cited in Cardno, 1968, pp. 598-599)

Thus, according to Esquirol, dementia develops over time whereas idiocy is a condition of birth. Mayo (1838) however clouds the issue:

(Idiocy may be) either congenital or a state supervening upon some noxious influence subsequently applied. Idiocy; when it occurs at a more advanced period it has been called, by French writers, Demence. (Cited in Cardno, 1968, p. 599)
Esquirol, writing in the same year, appears to have little doubt about the relationship between advancing age and dementia:

Senile Dementia results from the progress of age. Man, passing insensibly into old age, loses his sensibility along with the free use of the faculties of understanding, before arriving at an extreme state of decrepitude. Senile dementia is established slowly. It commences with enfeeblement of memory, particularly the memory of recent impressions. The sensations are feeble; the attention at first fatiguing, at length becomes impossible; . . . there are some who, before becoming demented, experience a great sensitiveness, are irritated at the least thing; some are very active, to undertake all sorts of things. Dementia follows closely after this hyperexcitation . . . especially when old people are contrary and unreasonable in their desires . . . (Zilborg & Henry, 1941, p. 552)

Maudsley (1876) however is less convinced that aging alone is the primary cause of dementia:

. . . the natural decline of the mental faculties which in greater or less degree commonly accompanies the bodily decline of old age should be distinguished (italics added) from the greater loss of mental power known as senile dementia. (Maudsley, 1876, p. 254)

Maudsley continues to describe the progress of senile dementia in some detail and concludes that at the end "there is nothing left that we properly call mind" (p. 259). Yet he questions this conclusion:

Surely a mind, even though manifesting itself through broken glimpses of a damaged brain, should not lose its consciousness of personal identity should not be ignorant whose mind it is. (Maudsley,
Toward the end of the nineteenth century the concept of senile melancholia was introduced. Senile melancholia was believed to be the precursor to dementia. "Senile insanity may assume in the first instance the form of mania or melancholia, but essentially ends in dementia" (Bucknill & Tuke, 1879 cited in Willmuth, 1979, p. 497). Similarly Maudsley (1876) supports this view:

when (a person) is gloomy, wretched, and fancies himself ruined or damned, he has melancholia; and when his memory is impaired, his feelings quenched, his intelligence enfeebled or extinct, he is said to be suffering from dementia. (p. 73)

Dementia according to Maudsley is the destruction of mind by disease. However, he expresses his discomfort with this definition:

Much dissatisfaction has been felt with this classification, and many fruitless attempts have been made to supercede it by a better one. It is extremely vague, and obviously teaches us very little concerning the disease; it is in fact a rough classification of certain marked symptoms. (Maudsley, 1876, p. 73)

A superficial examination of the amount of writing by nineteenth century psychiatrists on the psychiatry of old age reveals very little output as compared to the amount of their publications on general psychiatry. Reasons for this can only be surmised however we do note Pinel's claim that dementia results from the aging process both of which...
are incurable. As we now turn to the work of two selected physicians of the late nineteenth and early twentieth century we will see this position more extensively articulated and questioned. In particular we will consider the work of Ignatz Leo Nascher (1863-1944) recognized as the founding father of the speciality of geriatrics (indeed he invented the term geriatrics).

Ignatz Nascher

In his introduction to Thewlis' monograph on geriatrics Nascher relates how he came to see geriatric medicine as a special branch of medicine. He relates an incident during his student days:

... an instructor took a number of students to the almshouse to see cases. An old woman hobbled up to the instructor with some trivial complaint. He afterwards told us she was suffering from old age. "And what could be done for her?" "Nothing." Suffering from old age and nothing could be done to relieve her suffering! Is old age, then, a disease from which those who have reached advanced life were doomed to suffer? (Cited in Thewlis, 1919, p. 11)

In his own monograph also entitled Geriatrics Nascher addresses this question and attributes the cause in part to the general social attitudes of his time toward the elderly:

The cause of this neglect must be sought in the general mental attitude toward the aged. The spirit of veneration of ancestors and the aged, such as
exists in China, does not exist among us. The sentimental interest in the aged is confined to the immediate family of the individual and there the interest is often less sentimental than dutiful. We realize that for all practical purposes the lives of the aged are useless, that they are often a burden to themselves, their family and to the community at large. Their appearance is unesthetic, their actions objectionable, their very existence often an incubus to those who in the spirit of humanity or duty take upon themselves the care of the aged. (Nascher, 1914, p. v)

The physician however must rise above such attitudes:

The physician views the aged from a different standpoint. As a humanitarian it is his duty to prolong life as long as there is life and to relieve distress wherever he may find it. There is, however, a natural reluctance to exert oneself for those who are economically worthless and must remain so, or to strive against the inevitable, though there be the possibility of momentary success, or to devote time and effort in so unfruitful a field when both can be used to greater material advantage in other fields of medicine. Still these objections are paltry when applied to the physician's self-imposed obligation to relieve distress and prolong life. (Nascher, 1914, pp. v & vi)

Nascher emphasizes that only the scientific approach will discover the causes of aging-related changes in human physiology and points to recent advances in knowledge relating to blood pressure.

He is particularly concerned with the analogy between childhood and old age:

Senility is often called Second Childhood. A comparison of the organism in childhood with the organism in old age will show that there is not an organ or tissue, not a function, mental or physical, identical at the two periods of life. . . .
The process of senescence is progressive, not retrogressive . . . (Nascher, 1914, p. 1)

And again some pages later he returns to the subject:

The fancied similarity in the mentality of childhood and old age gives rise to the belief that senility is second childhood. Only in the complete absence of intelligence in the new born and the absolute dement is there any resemblance in their mentality . . . The child's mind is analytical; it wants to know why, and it will take apart, destroy, question. The senile mind is synthetical; it wants to know how, to combine to construct and to restore . . . There are differences in judgement, imagination, the ethical sense, the esthetic sense, sentiment and other mental traits and characteristics between childhood and old age but these differ so widely in individuals at the same age that we cannot make a broad distinction at the two periods of life. (Nascher, 1914, p. 9)

Here it appears that Nascher is using the term "senility" to mean the state of being old and "senile" as an adjective "(being) prefixed to diseases that present different features in senility from those of later life" (p. vii).

He stresses that senescence being the process of aging does not regress but rather progresses in its own unique biological and psychological manner. Senility however has specific characteristics:

The obvious characteristics of senility are evidenced in the appearance, gait, mentality and the tout ensemble of mental and physical decay. The appearance of the senile individual is repellent both to the esthetic sense and to the sense of independence, that sense or mental attitude that the human race holds toward the self-reliant and self-dependent . . . While the dependence of the child arouses sympathy, in the aged the repugnance aroused by the disagreeable facial aspect and the
idea of economic worthlessness destroys the sympathy we bestow upon the child and instills a spirit of irritability if not positive enmity against the helplessness of the aged. (Nascher, 1914, p. 9)

The synthetic mind earlier cited is however characterized by dependence. A dependence that is acceptable in a child and barely tolerated in an aged person. In addition he or she inevitably becomes selfish despite the eloquence of Cicero and others:

The senile changes in mentality are found in temperament, emotions, will, sensations, and intellect. The most prominent mental characteristic in old age is an overwhelming interest in self, a selfishness which gradually subordinates every other interest in life to the welfare of the individual. Notwithstanding all the optimistic platitudes of philosophers from the days of Cicero to Metchnikoff, notwithstanding the inbred resignation of the fatalists, the ready submission to the inevitable of the materialists, notwithstanding the promise of heaven, bliss and light and life everlasting, made by theologians of all ages, man looks forward to death with dread and indignation. (Nascher, 1914, p. 14)

The realization of approaching death inevitably causes a turning inward, a focusing on self rather than others and heightened fear of death itself. Women however can retard aging due to their natural vanity:

The obvious manifestations of senility appear later in the female, for the reason that she makes an effort to remain attractive, the psychic factor factor . . . of the senile slouch in the male being overcome by her vanity . . . Women being more impressionable than men, they are more amenable to religious teachings, they become more readily resigned to the inevitable through their faith . . .

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and being more cheerful they do not present the disagreeable, gloomy appearance of aged men. This as well as their sex brings them the sympathy denied to men. (Nascher, 1914, p. 17)

For both men and women senility appears to be an inevitable state. However Nascher points to a difference between old age and senility:

The term old age should be applied only to such cases as present obvious manifestations or marked subjective symptoms with the progressive organic changes which are due to ageing. The term senility is usually applied to a more advanced old age. It implies pronounced senile changes with the accompanying objective and subjective manifestations, and covers the period from the time when the mental and physical impairment begins to incapacitate the individual, to the complete decrepitude that ends in physiological death. (Nascher, 1914, p. 18)

The transitional period between old age and senility Nascher terms the **senile climacteric**. This is characterized by periods of exaltation followed by depression. Former mental vigor may appear in flashes when the individual may be capable of brilliant work but this work cannot be protracted else **brain fag** will set in. Depression gives way to apathy and the individual is beyond mental stimulation (even with mnemonics) (p. 19). The senile climacteric merges into the **post climacteric period**. Periods of exaltation become less pronounced and less frequent. The aged person becomes garrulous, falls into childish ways, and seeks the company of children. In a few old men sexual desire cannot be controlled and they
may rape little girls (p. 19). Nascher is careful to note that dementia is not inevitable:

After the senile climacteric has passed, there is a uniform decadence of mind and body. The intellectual faculties become gradually weaker, but rarely reach the stage of complete dementia. (Nascher, 1914, p. 21)

What then is senile dementia? How is it different from senility and the senile climacteric? Nascher acknowledges the difficulty of differentiating between normal and pathological aging:

Of the organic changes only one has been found to be invariably due to ageing. This is the progressive increase of interstitial fibers between the pyramids of the kidneys ... Every other senile change in the organism may also be found as a pathological process of maturity, and it is often difficult to determine whether the change is due to ageing or to disease. (Nascher, 1914, p. 17)

Senile dementia according to Nascher in many cases is secondary to other disorders and appears at the terminal stage of mental illnesses that have continued from earlier years. These may include mania, melancholia, and paranoia. Senile dementia is however irreversible and terminal.

We now turn to the work of Alois Alzheimer who combined both behavioral reports and autopsy data on a demented patient at the start of the twentieth century.
Alois Alzheimer (1864-1915)

Alois Alzheimer was born in Bavaria, the son of a government officer. He studied medicine at the universities of Wurzburg, Tubingen and Berlin gaining his MD degree from the University of Wurtzburg in 1887. His thesis was an investigation of the wax-producing glands of the ear. During the next fifteen years Alzheimer worked with Nissl on a systematic research of brain pathology. In 1902 he was called to Heidelberg by Emil Kraepelin, a pioneer in experimental psychiatry and the advocate of a systematic classification of mental disorders. One year later he accompanied Kraepelin to Munich. Here he became director of the anatomical laboratory in the psychiatric clinic which rapidly became a highly regarded center for neuropathology. In 1912 Alzheimer became director of the Psychiatric and Neurological Institute where he continued his clinical practice and research until his death in 1915 (Talbot, 1970).

In 1894 Alzheimer described arteriosclerotic atrophy of the brain which he believed was distinct from senile degenerative processes. Microscopically he reported small aneurisms, capillary bleeding and loss of cells. He concluded that this disease typically affected persons aged 45 to 58 years of age and was not a common condition (Talbot, 1970).
In 1907 Alzheimer reported his clinical and pathological findings in a woman aged 51 who, despite his best efforts, died in a demented condition. Alzheimer described her symptoms:

The first noticeable symptom of illness . . . was suspiciousness of her husband. Soon, a rapidly increasing memory impairment became evident; she could no longer orient herself in her own dwelling, dragged objects here and there . . . she is completely disoriented to time and place. . . . Her ability to encode information is most severely disturbed. . . . Terminally, the patient was totally dulled, lying in bed with legs drawn up, incontinent, and, despite all care, developed decubiti. (Jarvik & Greenson, p. 8)

Upon autopsy Alzheimer reported specific findings namely an atrophied brain and changes in the neurons:

The autopsy reveals a consistently atrophic brain without macroscopic foci. The larger cerebral vessels show arteriosclerotic changes. Preparations stained with Bielschowsky's silver method reveal peculiar changes of the neurofibrils. Inside an otherwise apparently still normal cell, first one or more fibrils stand out prominently . . . Later on, there are many such fibrils lying next to each other, all changed in the same way. These are eventually seen clustering together in thick bundles which gradually emerge at the surface of the cell. (Jarvik & Greenson, 1987, p. 8)

Alzheimer concluded that he was observing evidence of a specific disease process. He presented his findings at a meeting of the South West German Society of Alienists one year earlier than his published report. There was no discussion after his presentation and his research was
basically ignored (McMenemey, 1970). Alzheimer's description of senile plaques was called Alzheimer's disease by Kraeplin. However, the condition came to be categorized as a rare condition of younger (pre-senile) persons.

Achenbaum (1978) noted that between the two world wars, two different views of old age vied for acceptance in the medical profession. The first saw cognitive impairment as a pathological condition, while the second described it as a normal physiological state (p. 120). Despite this dualism in medical practice, little or no advances in the psychiatry of old age were made for the next fifty years. However, during this same period the numbers of older Americans were steadily increasing.

Growth of the Older Population

The growth of the older population, both proportionately and in absolute numbers, is one of the most significant demographic trends of the twentieth century. At the turn of the century, four percent of the population was over the age of 65. Eight decades later, in 1980, the Bureau of the Census reported that 11.3% of the population was aged 65 and older. This trend is expected to continue into the next century. Census projections suggest that one out of four persons is expected to be over the age of 65 in 2050 (U.S. Senate, Special Committee on
Aging, 1985).

Within the older population (65 and older), changes are also occurring. With increases in the number of people surviving into the upper age ranges, the elderly population itself is growing older:

In 1980, the young old (age 65 to 74) outnumbered the oldest old (age 75 or older) by three to two. By the turn of the century, half of the elderly population are expected to be age 65 to 74 and half will be age 75 or older. (U.S. Senate, Special Committee on Aging, 1985, p. 14)

The 85 plus age group is currently the fastest growing segment of the American population. This age group is expected to triple in size between 1980 and 2020 and experience a seven fold increase between 1980 and 2050 (U.S. Senate, Special Committee on Aging, 1985).

Life Expectancy

Life expectancy at birth has increased steadily during this century. In 1900 life expectancy at birth was 47.3 years and by 1983 it had risen to 74.7 years. Similarly, life expectancy at age 65 was 11.9 years in 1900 and had risen to 16.8 years in 1983 (National Center for Health Statistics [NCHS], 1986).

Differences in life expectancy by sex were evident during this century, the data displaying an increasing advantage to women. A woman born in 1900 had a life
expectancy of 48.3 years whereas a man born in the same year had a life expectancy two years less, namely 46.3 years. By 1980 life expectancy at birth for women was 77.4 years and for men 70.0 years. Similarly, the data on life expectancy at age 65 shows that women had a small advantage over men in 1900 namely 11.5 years for men and 12.2 years for women. By 1980 however, men could expect on the average to live 14.1 years and women 18.3 years (NCHS, 1986). In 1982 women aged 65 and older outnumbered elderly men in the same age category by three to two. In 1984 the Census Bureau reported that there were 81 men aged between 65 and 69 for every 100 females in the same age group and 40 men aged 85 and over for every 100 women in the same age category (U.S. Senate, Special Committee on Aging, 1985).

Mortality and Morbidity

Mortality. Mortality rates have declined throughout the twentieth century. Rabin and Stockton note:

In early decades improvements were concentrated among younger age groups. In the 1940's and 1950's substantial mortality declines continued, with the changes spread more evenly across the age spectrum. From 1955 to 1967 mortality rates remained relatively constant; in recent years the downward trend has resumed for all age groups, including the extreme elderly. (Rabin & Stockton, 1987, p. 52)

Data from the National Center for Health Statistics show
differences in mortality rates for men and women. The age-adjusted death rate in 1940 for men was 22 percent higher than that of women and by 1978 the rate was 78 percent higher (NCHS, 1986).

Morbidity. Chronic conditions are relatively rare in young persons but today account for the majority of disabilities in the elderly. This pattern however, was not characteristic for the entire twentieth century:

The pattern of illness and disease has changed in the past 80 years. Acute conditions were predominant at the turn of the century, chronic conditions are now the most prevalent health problem for elderly persons. (U.S. Senate Special Committee on Aging, 1985, p. 66)

Self-reported morbidity has increased since 1957 (Verbrugge, 1984) however, data suggest that the majority of older persons view their own health positively:

According to the results of the 1982 Health Interview Survey conducted by the National Center for Health Statistics, 65 percent of elderly persons living in the community describe their own health as excellent, very good, or good compared with others of their own age; only 35 percent report that their health is fair or poor. (U.S. Senate Special Committee on Aging, 1985, p. 63)

It has been argued that the increase in life expectancy and decline in mortality rates represents the failures of success (Gruenberg, 1977). Advances in medical technology have been instrumental in arresting acute conditions leaving the nation facing a rising pandemic of chronic
conditions (Kramer, 1980). These conditions include mental disorders and associated disabilities. With specific reference to dementia Kramer (1982) calculated the effect of population changes in the United States into the year 2005 on the prevalence of dementia. He concluded that the percent increase in the prevalence rates of senile dementia for white persons over the age of 65 will be 43.9 percent and for non-whites of similar age, he estimated an increase of 72.2 percent.

Conclusion

Historically, the psychiatry of old age has been a neglected area of both research and practice. The influence of Hippocratic medicine on medical practice with the elderly has been persistent over the centuries. Three inextricably related themes emerge from our historical review. First, originating perhaps with Hippocrates, normal aging and dementia were closely, if not causally, associated therefore, it was generally concluded that neither research nor treatment would serve any purpose. Second, negative attitudes toward the elderly appeared to be related to lack of interest by the medical profession. Third, problems of nomenclature abound. During the nineteenth century cognitive loss in elderly persons was variously termed senility dementia (which may have originated
from idiocy), senile dementia, senile melancholia and brain fog.

Despite the work of Ignatz Nascher and others, interest in geriatric psychiatry, medicine and research languished during the first half of the twentieth century. Not until the 1970s did the medical community begin to demonstrate a growing interest in mental problems of older persons. However, it is the differences in interpretation of cognitive dysfunction that forms the basis for the specific issues to be considered in the next chapters.
CHAPTER V

FINDINGS

Extent of Claims 1970 to 1985

In this chapter we will examine the distribution of claims made by medical researchers, physicians, psychologists, social workers and nurses as documented in Index Medicus and the Social Sciences Citation Index. In addition we will document the changing interest of the media as evidenced by popular magazines and the New York Times. In conclusion we will present data on both federal and private support for both research and social needs. These data are included as a measure of changing public concern.

We begin by examining Index Medicus since this set of data provide us with the best available measure of the medical community's interest in Alzheimer's disease.

Index Medicus

Our analysis of Index Medicus from 1970 to 1985 yielded 1539 journal articles which were then coded into 51 separate categories. As already described, these categories were independently developed by the researcher and two coders. In addition a secondary analysis was performed on these data. The categories were subsequently analysed by
(a) the number of items per annum, and (b) the number of new topics per annum. An additional analysis was executed which will be laid out in the following chapter.

Figure 1 is a count of all documents published each year as recorded in Index Medicus from 1970 to 1985. We note a range from a low of three documents in 1970 to a high of 334 in 1985. Between 1970 and 1975, Index Medicus referenced a total of 48 documents on Alzheimer's disease. However, during the next five years the numbers of documents rose steadily. We note a doubling in quantity between 1976 and 1977. In 1982 the number of documents fell from 215 in 1981 to 112, however the subsequent year showed an increase of more than double. Thus, with the exception of 1982, the Figure generally shows a steady increase in the number of documents published in the decade starting in 1975 as recorded in Index Medicus.

Figure 2 graphically presents the number of new sub-topics about Alzheimer's disease introduced each year as recorded in Index Medicus. For the seven years between 1970 and 1976 we observe that a total of twelve new sub-topics were introduced yielding a mean of 1.71 per annum. After 1976 we note a substantial increase in the number of sub-topics with a range from zero to eleven. Between the years 1977 and 1985 41 documents containing new sub-topics were published with a mean of 4.5 per annum. No new sub-
Figure 1. Numbers of Documents on Alzheimer's Disease
   *Index Medicus* 1970-1985
Figure 2. Numbers of New Sub-topics on Alzheimer's Disease *Index Medicus* 1970-1985
topics were introduced in 1982 and we note 1977 as having the largest number of publications (N=11).

Social Sciences Citation Index

Between 1970 and 1985, 1477 documents on Alzheimer's disease were indexed in the Social Sciences Citation Index. In examining Figure 3 we observe that during the years 1970 to 1976 the number of articles per annum was relatively low ranging from 28 in 1970 to 33 in 1976. The mean number of articles for these years was 27.3. We note that after 1976, with the exception of 1979 to 1980, the slope rises sharply with a particularly steep slope between 1982 and 1985. From 1976 to 1985 the mean number of documents published per annum was 143. The range over this total time period shows a low in 1970 of 28 to a high in 1985 of 353. In broad terms we note slightly more than a twelve fold increase in the number of articles from 1970 to 1985.

An increase in items over the same time period is also observed in the number of primary terms utilized in the SSCI. In Appendix C we note that in 1970 the SSCI had developed three primary terms. However, by 1985 the subject matter had been categorized into 14 primary terms. We notice, however, that no actual new terms were introduced during this time period, but rather modifications of two
Figure 3. Numbers of Documents on Alzheimer's Disease
Social Sciences Citation Index 1970-1985
terms namely *dementia* and *Alzheimer's disease* accounted for the increase in the number of primary terms.

**Documents in the Media and Popular Press**

**The Magazine Index**

Figure 4 presents in graphic form the numbers of documents published in popular magazines and periodicals. No articles on Alzheimer's disease were published in popular magazines prior to 1979. Between 1979 and 1982 a total of 4 articles were published, with none in 1980. However, starting in 1983 the number of articles steadily increased with a total of 74 documents being published in three years.

As we review the magazines recorded in Appendix D we can see that three major national weeklies namely *Time*, *U.S. News and World Report*, and *Newsweek* published articles on Alzheimer's disease quite regularly between 1983 and 1985. Indeed *Newsweek* printed a short article in 1979. In December 1984 the same publication printed four separate pieces on Alzheimer's disease in one number and devoted its cover page to the topic. It is clear that after 1982 media interest as measured by magazine articles burgeoned with publications as diverse as *Good Housekeeping*, *Consumers Digest*, and *Jet* taking editorial interest.
Figure 4. Numbers of Articles on Alzheimer's Disease

Magazine Index 1979-1985
In this section we will examine the number of articles published by the New York Times on Alzheimer's disease between 1970 and 1985. Figure 5 displays the number of articles on Alzheimer's disease published by the New York Times between 1977 and 1985. No articles between 1970 and 1976 were directly related to Alzheimer's disease. On May 4, 1976 the appointment of Robert Butler to be Director of the National Institute on Aging was reported. However, within this time period (1970 to 1985), the first article on cognitive impairment in the elderly was published on May 8, 1977 entitled "Senility is not always what it seems to be." Figure 5 shows us that between 1977 and 1982 articles on the subject were regularly published annually but at very low rates. For the six years between 1977 and 1982 the New York Times published a mean of 1.5 articles per annum. In 1982, however, there was more than a three fold increase the number of items published over the previous year year. Between 1983 and 1985 the mean number of articles was 11 per annum.

In the following section we document sources of financial support for biomedical research on Alzheimer's disease as well as funding for the needs of families with a member suffering from Alzheimer's disease.
Figure 5. Numbers of Articles on Alzheimer's Disease
Private and State Support

Foundations

The Foundation Grants Index provided data on grants made to private agencies, universities and Chapters of the Alzheimer's Disease and Related Disorders Association (ADRDA). Table 1 shows the number of grants by year, total amount donated and average amount per grant.

Table 1
Number, Amount and Average Grant for Alzheimer's Disease by Foundations 1980 - 1985

<table>
<thead>
<tr>
<th>Year</th>
<th>N</th>
<th>$</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980</td>
<td>2</td>
<td>23,700</td>
<td>11,850</td>
</tr>
<tr>
<td>1981</td>
<td>4</td>
<td>271,704</td>
<td>67,926</td>
</tr>
<tr>
<td>1982</td>
<td>7</td>
<td>1,193,500</td>
<td>170,500</td>
</tr>
<tr>
<td>1983</td>
<td>14</td>
<td>1,333,300</td>
<td>95,235</td>
</tr>
<tr>
<td>1984</td>
<td>23</td>
<td>1,194,657</td>
<td>51,941</td>
</tr>
<tr>
<td>1985</td>
<td>19</td>
<td>1,077,791</td>
<td>56,726</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL $5,094,652</td>
<td></td>
</tr>
</tbody>
</table>

No grants for Alzheimer's disease were made prior to 1980. From 1980 until 1985 a total of $5,094,652 was
granted by private foundations for research, family support and therapeutic programs for patients. We notice an increase in monies granted between 1980 and 1982 together with a concomitant increase in the average amount donated per grant. The data show that, for this time period, 1983 was the year of greatest donations ($1,333,300) by foundations. However the number of grants approved in the same year doubled from 1982 thus reducing the average amount of each grant to $95,235 from a high of $170,500 in the previous year. In both 1984 and 1985 we note a reduction in overall grant monies together with a reduction in the average amount of each grant.

Figure 6 portrays graphically a comparison between grants made for social support and those for medical research between the years 1980 and 1985. No grants for these or other purposes related to Alzheimer's disease were identified prior to 1980.

Starting in 1980 two grants were awarded for social and organizational needs. The General Mills Foundation of Minnesota gave a $5,000 grant to the Bloomington, MN Chapter of the ADRDA for establishing a program for families of victims of Alzheimer's disease. The Bremer Foundation, also in Minnesota, donated $18,700 to underwrite a position of family counselor. Subsequent to 1980 Figure 6 shows an escalation of grant support. In 1981 three grants
Figure 6. Amounts of Foundation Grants for Alzheimer's Disease by Purpose 1980-1985
totaling $271,704 were made. These included the first private grant for medical research from the MacArthur Foundation of Illinois to McLean Hospital, Belmont MA for biological investigation of the senile brain with Alzheimer's disease. As our figure shows the total monies from this grant superceded the amounts of the two other grants in that year for social purposes. This trend continued until 1985 when combined grants for medical purposes were superceded by those for social, humanitarian and organizational purposes. We note that in 1985 grants for social needs or purposes exceeded those for medical research by a ratio of more than seven to one.

Federal Support

In this section we will consider federal support for Alzheimer's disease. Between 1976 and 1985 the federal government has supported basic biological and clinical research on Alzheimer's disease. Three federal agencies are primarily responsible to providing support for biomedical research on Alzheimer's disease: the National Institute on Aging (NIA), the National Institute on Neurological and Communicative Disorders and Stroke (NINCDS), and the National Institute on Mental Health (NIMH). Figure 7 displays the funding provided by each agency between 1976 and 1985. NIA support remained low between 1976
Figure 7. Federal Support for Research on Alzheimer's Disease by Agency 1976-1985

Source: U.S. Congress Office of Technology Assessment (1987)
and 1981. In 1976 $857,000 was allocated to research on Alzheimer's. This figure rose to $5,196,000 in 1981. However, in the next four years (1982-1985) funding increased substantially as compared to the previous six years. The 1983 allocation represents a more than 80% increase over the previous year while the 1985 budget shows a three fold increase over 1982. Overall the NIA provided more than $88 million for biomedical research on Alzheimer's disease between 1976 and 1985 with more than half this amount being allocated between 1984 and 1985.

For the first three years (1976-1978) NINCDS funded Alzheimer's research at a higher level than NIA for each year ranging from $2,314,000 in 1976 to $2,422,000 in 1978. After 1981, however, NIA funding exceeded that of NINCDS for each subsequent year. In every year funding by NIMH was consistently lower than either NINCDS or NIA.

Conclusion

In this chapter we have demonstrated that claims about Alzheimer's disease not only increased in numbers over time, but also changed their characteristics. Documents analysed in the Social Sciences Citation Index, and Index Medicus, as well as items in the New York Times and popular magazines clearly demonstrate an increase in numbers over the time period of interest. The analysis of Index
Medicus also revealed a burgeoning interest in a variety of subjects as indicated by the increase in reports on new sub-topics between 1970 and 1985, but most particularly between 1977 and 1985. In 1982, the literature on Alzheimer's disease as recorded in Index Medicus declined in numbers as did the new sub-topics for the same year; in fact none was recorded for that year. However, data from the Social Sciences Citation Index revealed a contrary trend with the numbers in 1982 increasing from the previous year. Data presented on federal and private support yielded a similar trend namely, a steady increase in the amount of monies being granted to support medical research and social needs.

In this chapter we have generally reported the extent or distribution of claims making activities. In the next chapter we will consider the characteristics of the same claims in order to provide a more in-depth analysis. We will utilize two data sources already examined in this chapter namely the Index Medicus and the New York Times. In addition we will also examine professional manuals and describe specific organizational activities.
CHAPTER VI

FINDINGS

Characteristics of Claims

This chapter starts with a further analysis of documents in *Index Medicus* and the *New York Times*. We then consider changing terminology as applied to, and the conceptualization of, cognitive loss in the elderly. Here we will utilize the *Merck Diagnostic Manual* and the *Diagnostic and Statistical Manuals* published by the American Psychiatric Association. Finally we report specific conferences and congressional hearings as examples of collective claims making.

*Index Medicus*

*Analysis of Topics*

In Figure 8 we examine the documents in *Index Medicus* between 1970 and 1985 by amount and characteristic. As previously described the data were collapsed into four main categories namely (1) documents focusing on etiology and pathology, (2) documents containing information on medical diagnosis and psychological assessment, (3) documents relating to reports on drug trials and other
forms of treatment, and (4) documents concerned with social issues, policy development and caregiver needs. These four categories are termed (1) etiology, (2) assess-

Table 2

<table>
<thead>
<tr>
<th>Year</th>
<th>Etiology %</th>
<th>Assessment %</th>
<th>Treatment %</th>
<th>Social %</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td>1970</td>
<td>67.0</td>
<td>0</td>
<td>33.0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>1971</td>
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<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>1972</td>
<td>71.0</td>
<td>0</td>
<td>29.0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>1973</td>
<td>67.0</td>
<td>33.0</td>
<td>0</td>
<td>0</td>
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<tr>
<td>1974</td>
<td>27.0</td>
<td>9.0</td>
<td>64.0</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>1975</td>
<td>72.0</td>
<td>14.0</td>
<td>14.0</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>1976</td>
<td>80.0</td>
<td>10.0</td>
<td>10.0</td>
<td>0</td>
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</tr>
<tr>
<td>1977</td>
<td>40.0</td>
<td>24.0</td>
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<tr>
<td>1978</td>
<td>59.0</td>
<td>22.0</td>
<td>15.0</td>
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<tr>
<td>1979</td>
<td>58.0</td>
<td>12.0</td>
<td>26.0</td>
<td>4.0</td>
<td>84</td>
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<tr>
<td>1980</td>
<td>69.0</td>
<td>12.0</td>
<td>12.0</td>
<td>7.0</td>
<td>88</td>
</tr>
<tr>
<td>1981</td>
<td>50.0</td>
<td>21.0</td>
<td>23.0</td>
<td>6.0</td>
<td>185</td>
</tr>
<tr>
<td>1982</td>
<td>56.0</td>
<td>23.0</td>
<td>14.0</td>
<td>7.0</td>
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<tr>
<td>1983</td>
<td>57.0</td>
<td>19.0</td>
<td>17.0</td>
<td>7.0</td>
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</tr>
<tr>
<td>1984</td>
<td>53.0</td>
<td>25.0</td>
<td>13.0</td>
<td>9.0</td>
<td>231</td>
</tr>
<tr>
<td>1985</td>
<td>53.0</td>
<td>18.0</td>
<td>19.0</td>
<td>5.0</td>
<td>308</td>
</tr>
</tbody>
</table>

Total N 781 270 254 79 1384 (56%) (19%) (18%) (7%)
ment, (3) treatment and (4) social respectively. Because certain topics were eliminated from this analysis the total number of documents in this secondary analysis was reduced to 1384 from a grand total of 1539. (See Appendix B for a listing of sub-topics by categories). Table 2 lays out the numbers and percentages of documents in each year by our four categories. We note that documents relating to concerns of etiology have a proportional advantage over the other three categories combined. In every year under consideration, with the exception of 1974 and 1977 when documents relating to etiology represent twenty seven and forty percent respectively and 1981 when equal proportions are reported, this category out numbers each of the other three categories. In 1982, there is a decline in absolute numbers (N = 103) from the previous year (N = 185). Documents relating to etiology are recorded for every year. We see, however, for documents on assessment and treatment the first years of record are 1973 and 1970 respectively. Documents concerning social and family issues (Category 4) range from a low of 4% of the total in both 1978 and 1979 to a high of 9% in 1984. Figure 8 graphically depicts the same data. Once again we note the decrease in numbers of documents in all categories for the year 1982. We can also compare the slopes. Here we observe that Category 1 (with the exception of 1982) shows a steady rise from 1970 to
Figure 8. Numbers of Documents on Alzheimer's Disease by Selected Characteristics |Index Medicus| 1970-1985

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1985 with a particularly steep slope starting in 1977.

Categories 2 and 3, while reflecting a similar decline in 1982, display a series of declines and subsequent gains while maintaining, in general, a direct relationship between time and numbers of documents in each category. Category 4 (social) contains the smallest number of documents with the first four being recorded in 1977.

Using the same data, Table 3 shows the mean number of documents published for the years 1970 to 1977 and 1978 to 1985 in each category. As we compare the two eight year time periods for each category, we note that the mean number of documents has increased in every case. For Category 1 the increase is more than eleven fold (11.40).

Table 3

Mean Number of Documents in Index Medicus
by Category

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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</thead>
<tbody>
<tr>
<td>Etiology</td>
<td>7.87</td>
<td>2.25</td>
<td>3.62</td>
<td>0.5</td>
</tr>
<tr>
<td>Assessment</td>
<td>89.75</td>
<td>31.50</td>
<td>28.12</td>
<td>9.37</td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Category 2 shows a fourteen fold increase, Category 3 more than a seven fold rise (7.77) and in Category 4 we see the greatest increase in the mean number of documents as slightly more than eighteen fold (18.74).

In conclusion we reiterate that the major finding from this analysis shows a distinct numerical advantage between 1970 and 1985 for those documents that contain reports on pathological and etiological research on Alzheimer's disease. Indeed, overall, this category represents 56% of the total documents. Categories 2 (Assessment) and 3 (Treatment) contain 19% and 18% respectively with Category 4 (Social) comprising 7% of the total number of documents.

In the following section we return to our data from the New York Times and consider some of the characteristics of the documents published between 1970 and 1985.

The New York Times

As reported in Chapter V, The New York Times published 43 documents concerning cognitive loss in the elderly between the years 1970 and 1985 with the first article on the subject appearing in 1977. In this section we will explore these data in somewhat more depth and consider three specific characteristics. The first concerns the characteristics of the documents themselves.
Characteristics of Articles

Figure 9 depicts the distribution of the 43 articles in the New York Times by type namely news items and feature articles. Between 1977 and 1978 no news reports were published, the first being in 1981. Indeed for the time period between 1977 and 1981 five feature articles were published as compared to a single news event. In 1982 and 1983 feature articles were in the majority (N=8) as compared to seven news reports. However, in 1983 and 1985 equal numbers of feature articles and news reports were published. Of the total number of items on Alzheimer's disease (N=43), 44% (N=19) were news items and 56% (N=24) were feature items. The major characteristic of this table is the lack of news items until 1981 and the subsequent increase in numbers of these reports that eventually outnumbered the feature articles in 1984 and 1985.

Terminology

Table 4 contains a listing of the titles of articles on Alzheimer's disease published in the New York Times between 1977 and 1985. As already described, only those that contained direct reference to cognitive loss in the aged were included in this analysis. Between the years 1977 and 1980 the terminology of choice to describe cognitive loss in the elderly was senility. In 1981 Alzheimer's disease
was used for the first time. We note however that this piece was a small insert at the bottom of a page devoted entirely to issues of biological aging and life span. In

Table 4

Titles of Articles on Senility and Alzheimer's Disease 1970-1985

New York Times

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1977</td>
<td>Senility is not always what it seems to be</td>
</tr>
<tr>
<td>1978</td>
<td>Exposing the myth of senility</td>
</tr>
<tr>
<td>1979</td>
<td>Research attempts to fight senility</td>
</tr>
<tr>
<td>1980</td>
<td>The doctors' world: Perceptions hinder treatment of senility</td>
</tr>
<tr>
<td>1981</td>
<td>New center fights big killer of the aged</td>
</tr>
<tr>
<td></td>
<td>Alzheimer's disease: Seeking chemical clues</td>
</tr>
<tr>
<td></td>
<td>Mystery of memory that fails in old Age</td>
</tr>
<tr>
<td>1982</td>
<td>Three schools given $675,000 to study a disease of the aged</td>
</tr>
<tr>
<td></td>
<td>Mysterious brain disease attracting wider interest</td>
</tr>
<tr>
<td></td>
<td>Coping with the travail of Alzheimer's disease</td>
</tr>
<tr>
<td>1983</td>
<td>Alzheimer's disease month</td>
</tr>
<tr>
<td></td>
<td>Aid on Alzheimer's</td>
</tr>
<tr>
<td></td>
<td>Families describe toll of Alzheimer's disease</td>
</tr>
<tr>
<td></td>
<td>New clue in mystery of Alzheimer's disease</td>
</tr>
<tr>
<td></td>
<td>Alzheimer's disease afflicts families, too</td>
</tr>
<tr>
<td></td>
<td>How a single disease has become a political cause</td>
</tr>
<tr>
<td></td>
<td>Alzheimer's disease deaths put at 120,000 a year in U.S.</td>
</tr>
<tr>
<td></td>
<td>Another name for madness</td>
</tr>
<tr>
<td></td>
<td>Substance tied to Alzheimer's in coast study</td>
</tr>
</tbody>
</table>
Table 4—Continued

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
</tr>
</thead>
</table>

the same year "big killer of the aged" and "mystery of memory" were utilized as headline descriptors of Alzheimer's disease. Similarly, of the three articles published in 1982 Alzheimer's disease was the term of
choice in one of three article titles, the others utilizing "a disease of the aged" and "mysterious brain disease." In the years 1983 through 1985 the use of the term Alzheimer's disease was typical of the document titles and senility was no longer utilized.

Professional Manuals

In this section we will provide descriptions of two professional manuals in terms of their content concerning cognitive loss in the elderly. We will consider the Merck Manual and the Diagnostic and Statistical Manuals of the American Psychiatric Association. The former was selected since it generally is a resource for physicians and allied medical practitioners for information on medical diagnosis and therapy. It was first published in 1899 and has been edited and updated on a regular basis since that time. The most recent edition was published in 1987. In contrast the Diagnostic and Statistical Manuals can be very broadly characterized as providing information for mental health professionals and practitioners. The first manual (DSM I) was published in 1952 with two subsequent editions following in 1968 (DSM II) and 1980 (DSM III). A revision of DSM III was published in 1987 however this document will not be included in this study since the time period of this study concludes in 1985. In examining these documents we
will provide descriptive quotations only and confine ourselves to the conceptualization of cognitive loss in the elderly as reflected in these manuals. Examples of diagnostic advice will also be included. With respect to these documents, we will examine only those editions that were published between 1950 and 1985 since the 1950s was a period that saw the initiation of efforts to better describe a variety of mental illnesses including those of elderly persons.

The Merck Manual

In 1950 the eighth edition of the Merck Manual described Alzheimer's disease as a presenile psychoses and notes that it is a relatively rare form of dementia which may occur during the 40s. Arteriosclerotic dementia tends to occur during the 50s and senile dementia is rarely observed below the age of 60. Age is a major indicator for the diagnostician. Similarly the 1956 manual categorizes Alzheimer's disease as a pre-senile condition: "In an individual exhibiting symptoms of dementia during the 40's, this disease should be suspected" (Merck Manual, 1956, p. 1273). However a further encompassing category was introduced in 1956. Alzheimer's disease remains a presenile psychosis however it is now categorized with other conditions, such as arteriosclerosis, as an organic brain
syndrome. Since it remains defined as a rare presenile disease, little space is devoted to a description. Senile dementia, occurring in persons over 60, has however several clinical types: simple, delirious and confused, depressed and agitated, and paranoid. Readers are advised that transition from normal aging to senile dementia is gradual. If a patient can no longer find satisfactions to replace those he or she once had a tendency toward regression is likely (Merck Manual, 1956, p. 1274).

The 1961 Merck Manual provided a more in depth definition of an organic brain syndrome than did the 1956 edition which generally listed the impairments of persons so diagnosed:

A group of disorders due to some agent or process usually producing diffuse brain lesions, with associated impairment of cerebral tissues function. Organic disturbances of the brain seem mainly to undermine the ego function. This is a striking but poorly understood phenomenon that affects habits, knowledge, or skills most recently acquired far more than it does longer established or more instinctive behavior. (Merck Manual, 1961, p. 1197)

Alzheimer's disease is classified as a presenile dementia that begins between the ages of 40 and 60. It has no known etiology and progresses to death within 5 to 10 years. Diagnosis is only made post mortem which will reveal diffuse cortical atrophy (Merck Manual, 1961, p. 1201).

The Merck Manual of 1966 contained little or no modi-
fications relating to Alzheimer's disease or organic brain syndromes. However advice to the physician in assisting families is offered:

The family should be made to understand that the patient's behavior is not directed consciously at angering them, and reassured that they have not caused the patient's condition. By working patiently with the family, the physician may be able to save them needless expense in further, fruitless diagnostic studies and also may help them arrange for custodial care. When considering the desirability of this provision, one must assay available finances, inability of the family to care for the patient adequately at home, and the possible disruption of family life by a severely demented person, especially as it affects children in the home. (Merck Manual, 1966, p. 1163)

The 1972 Manual is basically similar to the previous edition. Alzheimer's disease remains classified as a presenile dementia appearing under the age of 60. Reference to the family is reduced: "... familiar supportive family members in attendance often helps ... The family should be counseled and should encourage the patient in activities which promote a sense of participation and accomplishment" (p. 1408).

In the Merck Manual of 1977 Alzheimer's disease remains a presenile dementia however a new classification is added namely simple presenile dementia. The overall classification is changed; Organic Brain Syndrome is replaced by the term Functional Syndromes in Cerebral Disease. A behavioral description of dementia is expanded and
characterized as "more painful to the beholder than to the patient" (p. 1542). The physician is warned that in certain cases "... dementia should not be regarded as a hopeless condition to be diagnosed and then ignored. Each case requires careful consideration and the most appropriate investigations should be selected for each patient" (p. 1544).

In 1982 the overall classification is changed to *Neuropsychiatric Syndromes in Organic Cerebral Tissue*. Alzheimer's disease as a category is changed to *Alzheimer-type dementia*. In addition the term Alzheimer's appears to apply to both presenile and senile onset dementias:

Alzheimer-type dementia is due to a degenerative process, with a large loss of cells from the cerebral cortex and other brain areas. Clinically, memory loss is the most prominent early symptom. Disturbances of arousal do not occur early in the disease course. The brain shows marked atrophy in wide sulci and dilated ventricles. Senile plaques and neurofibrillary tangles are present. Alzheimer's presenile and senile onset dementias are similar in both clinical and pathological features with the former commonly having its beginning in the 5th and 6th decades and the latter in the 7th and 8th decades, sometimes earlier, rarely later. (Merck Manual, 1982. p. 1306)

Advice to families is similar to the earlier edition as is the broad advice on responsibility in diagnosis.

In general we can say that for the period under consideration Alzheimer's disease has been seen as a condition of those under the age of 60. In the 1950s the age grading
was more precise, that is, Alzheimer's disease generally occurred in persons in their 40s. Over time estimates of age distribution became broader and refinements of categories were added for example simple senile dementia and Alzheimer's type dementia were differentiated from senile dementia and Alzheimer's disease respectively. However, in 1982 we note the first application of the term Alzheimer's disease to both presenile and senile dementia.

We now turn to the Diagnostic and Statistical Manuals published by the American Psychiatric Association and consider the first three editions.

The Diagnostic and Statistical Manuals

DSM I

The first Diagnostic and Statistical Manual (DSM I) was published by the American Psychiatric Association in 1952. In general it was "...(an attempt) to provide a classification system consistent with the concepts of modern psychiatry and neurology" (DSM I, 1952, p. 9). All known mental disorders were divided into two major groups as follows:

(1) those in which there is disturbance of mental function resulting from or precipitated by, a primary impairment of the function of the brain, generally due to diffuse impairment of brain tissue; and (2) those which are the result of a more general difficulty in adaptation of the individual,
and in which any associated brain function disturbance is secondary to the psychiatric disorder. (DSM I, 1952, p. 9)

As the editors noted, the major change in DSM I from previous attempts lay in the handling of disorders with known organic etiological factors (p.9). In these conditions (Group 1 above) five impairments were considered characteristic namely: (1) intellectual functions, (2) memory, (3) orientation, (4) judgement and (5) shallowness of affect. Consistent with the definition of Group 1 these conditions, and variations thereof, were termed organic brain syndromes. This classification was further broken down by acute organic brain syndrome and chronic brain syndrome. The terms acute and chronic refer primarily to the reversibility of the condition with acute organic brain syndrome being considered a potentially reversible condition while chronic brain syndrome implies permanent damage with little or no possibility of reversal. The reader is cautioned that an acute condition may eventually prove to have left permanent damage and thus should be re-classified as a chronic brain syndrome. Acute brain syndrome is characterized with conditions such as infections, drug, alcohol or poison intoxication, circulatory disturbance and neoplasms. Chronic brain syndrome by contrast is associated with congenital defects, syphilis, convulsive disorders and most conditions cate-
gorized as acute that eventually cannot be reversed or controlled.

Two categories in DSM I are of particular interest:

009-79x Chronic Brain Syndrome associated with senile brain disease

This category is designed for the classification of organic brain syndrome occurring with senile brain disease, whether this be mild, moderate or severe. These cases vary from mild organic syndrome with self-centering of interest, difficulty in assimilating new experiences, and "childish" emotionality up to and including those so severely affected by senile brain disease as to require institutional care. Deterioration may be minimal or it may progress to a state of vegetative existence, with or without super-imposed psychotic, neurotic, or behavioral reactions.

009-700 Chronic Brain Syndrome associated with other disturbances of metabolism, growth or nutrition (includes presenile, glandular, pellagra, familial amaurosis).

This category includes the chronic brain syndromes associated with disorders formerly classified separately, such as Alzheimer's disease, endocrine disorders, pellagra, and others of a similar nature. In Alzheimer's disease, the brain pathology is characteristic. Clinically, the disorder may be suspected in severe progressive brain syndromes occurring at a comparatively early age, as in the forties. The degree of brain atrophy, which is generalized, is usually severe, and can be demonstrated by pneumoencephalogram . . .

Both these classifications can be associated with or without psychotic, neurotic or behavioral reactions. (pp. 75-76)

Prior to DSM I, practitioners utilized the Standard Nomenclature of Diseases and Operations as a classifi-
catory resource. In Appendix B of DSM I we note that the third edition of this manual utilized the term *senility* as the major classification for conditions of the elderly. In the subsequent edition (1952) this category was dropped in favor of sub-classifications of various disease entities. Since the editors and committees assigned to the task of developing the new DSM I and coordinating it with the Standard Nomenclature of Diseases and Operations were in close communication and association, the term senility as a classification was not utilized in DSM I.

**DSM II**

DSM I was reprinted twenty times through 1967 and was eventually replaced by DSM II in 1968. The editors and authors of DSM II were particularly concerned to produce a manual that had broader international acceptance and application than DSM I. Thus they worked closely with the World Health Organization in order better to coordinate DSM II with the International Classification of Diseases.

Organic Brain Syndrome as a classification was retained from DSM I however, an additional qualification was added:

**Organic Brain Syndromes (OBS)**

This section is divided into the psychotic and non-psychotic conditions; consequently, the distinction between the acute and chronic forms must now be indicated with a qualifying phrase. A condition is considered a psychosis if the patient is
psychotic at any time during the episode being diagnosed. This principle avoids the necessity for changing a patient's diagnosis from day to day as he slips in and out of a psychosis during one episode; at the same time it permits giving a non-psychotic diagnosis to a patient who has not been psychotic during a particular episode yet has had past episodes of psychosis. (DSM II, 1968, p. 128)

In addition DSM II recognizes eight different types of alcohol brain syndromes including Korsakov's psychosis (p. 129).

Two categories of psychosis associated with organic brain syndrome of interest here:

290 Senile Dementia

This syndrome occurs with senile brain disease, whose causes are largely unknown. This category does not include the pre-senile psychoses or other degenerative diseases of the central nervous system. While senile brain disease derives its name from the age group in which it is most commonly seen, its diagnosis should be based on the brain disorder present and not on the patient's age at time of onset. Even mild cases will manifest some evidence of organic brain syndrome: self-centeredness, difficulty in assimilating new experiences, and childish emotionality. Deterioration may be minimal or progress to vegetative existence. (This condition was called "Chronic Brain Syndrome associated with senile disease" in DSM I). (DSM II, 1968, p. 24)

290.1 Pre-senile Dementia

This category includes a group of cortical brain diseases presenting clinical pictures similar to those of senile dementia but appearing characteristic ly in younger age groups. Alzheimer's and Pick's diseases are the two best known forms, each of which has a specific brain pathology. In DSM I Alzheimer's disease was classified as "Chronic
Brain Syndrome with other disturbances of metabolism. 

When the impairment is not of psychotic proportion, the patient should be classified under Non-psychotic OBS with senile or pre-senile brain disease. (DSM II, 1968, p. 24)

Non-psychotic organic brain syndrome with senile or pre-senile brain disease is to be found in category 309.6 in DSM II with no additional discussion. In general, we see that some main differences between DSM I and DSM II are as follows: a new assignment of numbers to coordinate with the International Classification of Diseases, the introduction of the sub-division of psychotic and non-psychotic, the warning against the use of age as an indicator and the elimination of a specific age group for a pre-senile condition in DSM II, no mention of invasive diagnostic procedures in DSM II, and the introduction of the term dementia (without discussion) in DSM II.

**DSM III**

The third edition of the Diagnostic and Statistical Manual (DSM III) of the American Psychiatric Association published in 1980 differs from the two previous editions both in depth and content. The editors of DSM III note that since the publication of DSM II there has been a growing recognition of the importance of diagnosis in clinical practice and research. Thus DSM III devotes considerable attention to diagnostic criteria and provides a
multiaxial approach to evaluation. In addition "much expanded descriptions of the disorders and many additional categories (some with newly-coined names) . . . (are included)" (DSM III, 1980, p. 1). Finally, DSM III stresses the importance of data as a basis for understanding mental disorders.

In DSM III a distinction is made between organic brain syndromes and organic mental disorders. The latter replacing the former as the generic or major classification. Organic Brain Syndrome is however retained as a sub-category and nine separate syndromes are recognized. The editors observe:

Although this manual provides a classification of mental disorders, there is no satisfactory definition that specifies precise boundaries for the concept "mental disorder" (also true for such concepts as physical disorder and mental and physical health . . . In DSM III each of the mental disorders is conceptualized as a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is typically associated with either a painful syndrome (distress) or impairment in one or more important areas of functioning (disability). In addition, there is an inference that there is a behavioral, psychological, or biological dysfunction, and that the disturbance is not only in the relationship between the individual and society. (When the disturbance is limited to a conflict between an individual and society, this may represent social deviance, which may or may not be commendable, but is not by itself a mental disorder.) (DSM III, 1980, pp. 5-6)

An organic brain syndrome refers to a constellation of psychological or behavioral signs and symptoms without
reference to etiology (for example Dementia) whereas an organic mental disorder designates an organic brain syndrome in which the etiology is known or presumed (for example Multi-infarct Dementia) (DSM III, 1980, p. 101). Despite the above definition of organic brain syndrome the reader is warned that causation is, however, assumed:

As with all Organic Brain Syndromes, an underlying causative factor is always assumed. In certain clinical states, e.g. Primary Degenerative Dementia, however, it may be impossible to show a specific organic factor as to the definitive cause of the disturbance. These conditions may nevertheless be diagnosed as Dementia. (DSM III, 1980 p. 108)

The diagnosis is made on the basis of three co-existing criteria: (1) multifaceted loss of intellectual ability, (2) there is no evidence for any other diagnosis, and (3) an exhaustive search has failed to demonstrate any other organic etiology. By definition Dementia is diagnosed when the loss of function interferes with social functioning. Thus the diagnosis is made up of observable behavioral symptoms and specific laboratory tests and a physical examination.

Dementia occurs primarily in the elderly but certain etiological factors may induce it at any age once the intellectual quotient is stable at approximately 4 years of age. In DSM III the classifications of senile and presenile have been dropped in favor of Primary Degener-
erative Dementia since the final diagnosis is made on the basis of pathological data upon autopsy rather than age as in DSM I:

The Dementias associated with Alzheimer's and Pick's diseases have been referred to as Senile and Presenile Dementias, the former arbitrarily signifying an age of onset over 65. Since nearly all cases of these Dementias are associated with Alzheimer's disease and the identification of Alzheimer's is largely or entirely dependent on histopathological data, it seems more useful to have in a clinical classification of mental disorders a single category that encompasses the syndrome of Primary Degenerative Dementia. (DSM III, 1980, p. 124)

It appears that Alzheimer's disease is reclassified as a Primary Degenerative Dementia with a pathology that is briefly described for the first time in the Manuals. Epidemiological estimates are offered:

**Prevalence.** Between 2% and 4% of the population over the age of 65 is estimated to have Primary Degenerative Dementia. The prevalence increases with increasing age, particularly after 75.

**Sex Ratio.** The disorder is more common in women than in men.

**Familial Pattern.** First-degree relatives are four times more likely to develop the disease than members of the general population. In rare cases, Primary Degenerative Dementia of the Alzheimer's type is inherited as a dominant trait.

**Differential Diagnosis.** The normal process of aging has been associated in a number of studies with certain decrements in intellectual functioning. The nature and significance of these changes are controversial. (DSM III, 1980, p. 125)

The diagnostic criteria for Primary Degenerative Dementia

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of the Alzheimer type are identical to those for Dementia with the addition of two categories: (1) insidious onset with uniformly progressive deteriorating course, and (2) exclusion of all other specific causes of Dementia by the history, physical examination, and laboratory tests.

In conclusion we may note that DSM III differs from DSM II in the following areas. First, Organic Mental Disorders was introduced as the broad classification rather than Organic Brain Syndromes utilized in DSMs I and II. Second, the distinction between acute and chronic Organic Brain Syndromes was dropped in favor of nine different syndromes. Third, the terms presenile and senile dementia are replaced by dementias arising in the senium and presenium. The changes in enumeration and terminology in this category are recorded in DSM III as follows:

<table>
<thead>
<tr>
<th>DSM II</th>
<th>DSM III</th>
</tr>
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<tbody>
<tr>
<td>290 Senile and Presenile Dementia</td>
<td>290.xx Dementias arising in the senium and presenium</td>
</tr>
<tr>
<td>290.0 Senile Dementia</td>
<td>290.xx Primary degenerative dementia, senile onset</td>
</tr>
<tr>
<td>290.1 Presenile Dementia</td>
<td>290.1x Primary degenerative dementia, presenile onset</td>
</tr>
</tbody>
</table>

(DSM III, 1980, p. 372)

In general DSM III affirms that Alzheimer's disease is now
considered an underlying etiology for Primary Degenerative Dementia with a pathology that is briefly described. Its classification as a presenile dementia is clearly dropped from usage.

We will now turn our attention away from professional manuals and consider the role of the state. In the next section we will describe the characteristics of state activities as evidenced in publications of the federal government. More particularly we will consider hearings in both the Senate and the House of Representatives.

Government Documents

Between 1980 and 1985 the United States Congress held twelve separate hearings on Alzheimer's Disease. Table 5 lists the titles of the hearings by date and location.

Table 5

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<th>Year</th>
<th>Title</th>
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</thead>
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<td>1980</td>
<td>Impact of Alzheimer's Disease on the Nation's Elderly. 5 May</td>
</tr>
<tr>
<td>Year</td>
<td>Title</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>1983</td>
<td>Oversight on Treatment of Alzheimer's Disease. 16 May</td>
</tr>
<tr>
<td></td>
<td>Senility: The Last Stereotype. 18 May</td>
</tr>
<tr>
<td></td>
<td>Alzheimer's Disease: A Florida Perspective. May 19</td>
</tr>
<tr>
<td></td>
<td>Alzheimer's Disease. August 3</td>
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<tr>
<td></td>
<td>Alzheimer's Disease: Is there an Acid Rain Connection? August 8</td>
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<td>1984</td>
<td>Alzheimer's Disease Research. August 30</td>
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<td>Alzheimer's Disease and Related Disorders. November 9</td>
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<td>Caring for America's Alzheimer's Victims. May 21</td>
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<td></td>
<td>Alzheimer's Disease: Burdens and Problems for Victims and their Families. October 28</td>
</tr>
<tr>
<td></td>
<td>Alzheimer's Disease: Pennsylvania Perspective November 25</td>
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</tbody>
</table>
Half the hearings were held in Washington DC with the other half in six states namely New Jersey, Maine, Ohio, Florida, Tennessee and Pennsylvania. The first hearing was in 1980 with none being held in either 1981 or 1982. However, there were six separate hearings in 1983, with two and three in 1984 and 1985 respectively. Nine different Committees were involved with the Select Committee on Aging conducting four hearings between 1983 and 1985.

Witnesses

The numbers of witnesses ranged from five for the first hearing on July 15, 1980 to 21 on August 30, 1984. This latter hearing on research needs lasted three days and included in-depth testimony by research physicians and others. The five witnesses at the first hearing were two family members, the executive director of the National Council of Senior Citizens, Dr. Carl Eisdorfer of the University of Washington School of Medicine, and Dr. Robert Butler Director of the National Institute on Aging. With the exception of one hearing on August 3, 1983 on federally funded research, family members testified at all the hearings. Physicians testified at all the twelve hearings.

The witnesses in the hearings came from a variety of backgrounds. In all, eight distinct groups were repre-
presented. These included directors of federal and national agencies such as the Department of Health and Human Services, the National Institutes of Health, the Alcohol and Drug Abuse and Mental Health Administration, the National Institute of Neurological and Communicative Diseases and Stroke, the National Council of Senior Citizens, and the National Institute on Aging. "Key" physicians and medical researchers provided testimony at every hearing. This group included those who were administratively involved in promoting research and soliciting funds for support as well as those engaged in active research. Social and behavioral scientists with a particular interest in developing social policy. Persons who had a family member suffering from Alzheimer's disease fell into two categories; those who were involved in social activism to promote research and raise concern for families caring for a victim of Alzheimer's disease and those who came forward to testify and lend support for their cause yet appeared to be less active at least at state and national levels. Some family members came as representatives of local support groups. Health care professionals were represented by nurses, directors of health care agencies and geriatric centers. Representatives from state units on aging, area agencies on aging and social service agencies offered testimony as did attorneys and,
in the case of regional hearings, local dignatories such as mayors and commissioners of health.

Conclusion

In this chapter we have analyzed documents on Alzheimer's disease indexed in Index Medicus in terms of etiological research, assessment, treatment and family and social issues. We basically found that research into the pathology and etiology of the condition together with diagnostic and treatment concerns dominated the content of the documents. We then considered the characteristics of articles in the New York Times in terms of news reports of events such as research findings and feature articles that sought to inform but did not appear to be precipitated by a specific event. Here we noted a change over time with feature pieces predominating from 1977 to 1983 but with reports of events being in the majority in 1984 and 1985. Next we considered professional manuals noting the changes in definitions of cognitive impairment in the elderly over time. In both the Merck Manuals and the Diagnostic and Statistical Manuals the last editions examined showed a change in definition of Alzheimer's disease from one of a presenile condition to an overarching definition encompassing a broad age range. Lastly we listed the congressional hearings on Alzheimer's disease and provided a
typology of witnesses. In the next chapter we characterize
the testimony of the witnesses in the hearings as well as
other strategies employed by key actors and groups.
CHAPTER VII

FINDINGS: STRATEGIES FOR PRESSING CLAIMS

Introduction

In this chapter we will describe the efforts of selected key individuals and consider the development of specific interest groups and organizations. We will begin by providing an account of the establishment of the National Institute on Aging and the work and strategy of Dr. Robert Butler as its first director. We then describe the activities of individuals with spouses afflicted with Alzheimer's disease as well as actors in the research community. Once again the sources for this chapter are documents which include journal articles, proceedings of conferences, reports of congressional hearings, monographs and unpublished papers.

The National Institute on Aging

During the 1940s and 1950s the needs and problems of older Americans gradually became an important issue. Lockett (1983) suggests that two distinct but parallel interests were developing: "While gerontologists were struggling for funds at NIH during the 1950's, the public
and the social scientists were pressuring for national attention to the welfare problems of the elderly" (p. 49). The latter faction saw the problems of the elderly as mainly psychosocial while biomedical researchers were promoting two specific areas for investigation:

Most biomedical investigators and many laymen felt that if specific diseases were studied and conquered, the elderly could live to a healthy old age. Those who would study aging in order to retard or halt the process have been considered on the fringe of biomedical research, looking for the fountain of youth. More importantly, most researchers see few opportunities for scientific investigation in this area. (Lockett, 1983, p. 5)

The White House Conference on Aging of 1961 generated the first major recommendation for a national institute to promote biomedical research in aging. However "... older Americans had their share of the social programs passed in the 1960's, but the area of biomedical research devoted to the aging process continued to be neglected" (Lockett, 1983, p. 59). The Gerontological Society reported in 1967 that the National Institute of Mental Health invested 3.1% of its budget and had only one professional in charge of the development of programs for the elderly (Lockett, 1983). In 1963 the National Institute of Child Health and Human Development was established. In the Institute provisions were made for a Center for Research in Aging. As Lockett notes "... despite these efforts ... the Center did not fulfill the hopes of
After considerable debate, in May 1974 Congress passed the Research on Aging Act. This Act established the National Institute on Aging within the National Institutes of Health. The mandate of the new institute was to promote research on aging. From the beginning of the debate leading up to the passing of the bill the National Institutes of Health opposed the creation of a separate institute specifically dedicated to aging. The fear of duplicating the work of the National Institute of Child Health and Human Development was raised. New institutes, it was argued, are duplicative and inhibit intellectual exchange. Furthermore, the concern that funding for the Institute might be guided by concern for specific diseases was expressed:

... the political impact of diseases should not be the determining influence of funding, especially when scientific leads were lacking ... (Undersecretary Carlucci) pointed out that in the 92nd Congress, more than 100 bills for particular diseases were introduced and that, had these been enacted, they would have split up research teams; fragmented existing, well-integrated programs; and added more personnel to the federal payroll. (Lockett, 1983, p. 145)

In addition to lack of support from the Administration of the time, disputes concerning research priorities surfaced during the debate. Those supporting biomedical research argued that social and behavioral aspects of aging should not be of any concern of the institute. However, ultimate...
mately Congress saw the need to include research on social issues since they were "the ones that the people could understand and support" (Lockett, 1983, p. 148).

The President signed the bill on May 31, 1974, however it took two years to appoint a director. In the meantime monies had been appropriated for the institute yet there was no research agenda. Dr. Robert Butler was appointed first director of the Institute on May 1, 1976. Lockett (1983) notes that the Research on Aging Act required the National Institute on Aging to publish a research plan by May 1975. Yet, at the time of Butler's appointment no research agenda had been presented to Congress. Finally, in December 1976 the plan entitled Our Future Selves was published and sent to Congress eight months after the appointment of Dr. Robert Butler as director and more than two years after the passage of the act.

Dr. Robert Butler

Presently Dr. Butler holds the Chair of Geriatrics and Adult Development at Mount Sinai School of Medicine. As a practicing psychiatrist he utilized the concept of life review or the progressive return to consciousness of past experiences using reminiscence as a tool in therapy with older clients. However, he emphasized the universality of the process not only in the aged but also in adults of all ages. In 1969 he published his first major piece of social
criticism coining the term "age-ism" to mean discrimination and prejudice against persons on the basis of their age. (Butler, 1969) His publications regularly reflect his concern not only for the practice of medicine but also medical education. His view that much of what he terms medical age-ism is largely generated in medical schools particularly through role models is a recurring theme in his work. Furthermore his concern for the lack of training for medical personnel in the chronic illness moved him to suggest the development of teaching nursing homes as a strategy to bridge the gap between the acute medical care system and the practice of long term care:

This country has about 75,000 community hospitals and 450 teaching hospitals. There are 18,000 nursing homes, but none have the contemplated teaching and research functions and affiliations with medical and other professional schools. One result is that 1.3 million people in these nursing homes are outside the mainstream of academic medicine and nursing. (Butler, 1981, p. 508)

Essentially the teaching nursing home would bring to long term care some of the strategies of the teaching hospital such as on-site research and training.

As an advocate for the elderly his concerns are wide including issues of long term care, the status of older women, the over use of medications, the need to educate geriatricians and ethics. In addition to psychiatry he has expertise in the area of nutrition and aging as well as sexuality and the older individual. With respect to the
latter he co-authored a text which emphasizes physiological, psychological and social aspects of sexuality and aging. He is perhaps best known as the Pulitzer Prize winning author of the book *Why Survive? Being Old In America*, published in 1975, in which he lays out his broad criticism of the experience of aging in America.

**Stewardship of the National Institute on Aging**

In 1975 when the Director of the National Institutes of Health asked Butler to become the director he immediately inquired about the research plan. As he noted:

I wanted to compare my own priorities for developing aging research with the research planning process that I was to complete. I identified 18 priorities among them the dementing disorders of old age. (Butler, 1984b, p. 33)

As we have already noted the research plan was barely formulated at that time. Upon appointment Butler examined grant holdings of the National Institutes of Health: "I found 12 research grants averaging about $60,000, totaling $700,000 devoted to brain disease and aging" (Butler, 1984b, p. 33). This amount he observed was insignificant compared to the social costs of dementing illness in the elderly. In an address to the American Geriatrics Society he discussed the mission of the National Institute on Aging:

The National Institute on Aging (NIA) . . . is dedicated to improving the quality of life of the
old in America through biomedical, social, and behavioral research . . . The NIA will encourage innovative research, but will not support the delivery of health services, as that is the domain of other agencies. In areas of overlap, such as diseases common to the old, the NIA will collaborate with other Institutes. (Butler, 1977, p. 97)

He continued:

We want to collaborate with other Institutes. A good target area for collaboration is senile dementia, the organic brain syndrome which results in a horrifying destruction of personality and memory. (Butler, 1977, p. 99)

Noting the inadequacy of research in aging he described his feelings upon being appointed Director of the National Institute on Aging:

In my appointment as Director of the newly created National Institute on Aging, I feel as if I have been given a mid-life research career development award with an incredible opportunity to do something constructive toward shaping research and training in the field of aging in America. (Butler, 1977, p. 97)

He made a critical decision to promote fundamental research in aging from the biological, medical, psychological and social perspectives as well as focusing on the major illnesses of old age that were receiving scant funding.

In targeting Alzheimer's disease he explained his reasoning:

. . . I tried to conceptualize an evaluative screen to help determine what diseases or topics should be supported. The criteria I developed were: The problem for proposed research needed to be a common
problem. It needed to have a heavy impact upon individuals and families. It needed to cause high social costs. But it should be one for which some promising leads and trained scientists were available. Alzheimer's disease fulfilled these criteria. (Butler, 1984b, p. 33)

The problem then became one of promotion:

The question was, how to make it attractive for members of the appropriations committees in Congress. How do you sell Alzheimer's disease? One public relations expert told me we should change the name. I considered this poor advice. I turned to the director of the information office, Jane Shure, who proved to be extraordinarily imaginative, and working together we developed successive steps to raise public consciousness about "senility" and Alzheimer's disease. It was my judgement that Congress would respond to an increasing popular awareness of the problem, to public testimony and to behind-the-scenes discussions. (Butler, 1984b, pp. 33-34)

His strategies were multifaceted and included working with the research community. To this end, as NIA director, he co-sponsored a conference on Alzheimer's disease which, in his opinion, "proved to be of catalytic importance" (Butler, 1984b, p. 33). A year later a second conference was organized.

The First Workshop Conference

In 1977 the National Institute of Neurological and Communicative Disorders and Stroke, the National Institute of Mental Health and the National Institute on Aging co-sponsored a workshop conference on Alzheimer's disease, senile dementia and related disorders.
The purpose of the conference was not to provide an simplified overview of the state of knowledge relating to the condition, but rather to "share detailed information on the current state of knowledge in each of several aspects of the disorders, as well as to provide a forum for airing conflicting views and criticisms" (Katzman, Terry & Bick, 1978, p. v).

Presentors at the conference included researchers from Europe and Japan as well as the United States. In the Proceedings of the conference, published in 1978, 84 attendee presentors were listed. Topics of presentations and discussions included nosology, epidemiology, etiology and pathophysiology. Several speakers expressed a concern for the need to understand the difference between normal aging and Alzheimer's disease. The following extract is taken from the verbatim report of a discussion considering this issue in relation to the presence of senile plaques (as originally discovered by Alzheimer) in post mortem or biopsied brain tissue:

DR. SOKOLOFF: Are these plaque formations part of the normal aging process?
DR. ROTH: Statistically they are normal.
DR. TERRY: All normal people have a few, but I think we are working at this from the wrong end. We still have to prove that the plaque and the tangle are more than simple labels, that they are causal. They are associated with disease, but we haven't proved that they cause the disease.
DR. GRUFFERMAN: In the absence of dementia, wouldn't you hesitate to diagnose the living patient as having Alzheimer's disease or senile dementia just on the histologic diagnosis?
DR. TERRY: No. If you give us an opportunity to do the histology tests, I certainly wouldn't hesitate for a moment.

DR. SOKOLOFF: Then you would call a lot of normal people demented.

DR. TERRY: No, because we are not counting plaques or tangles in the hippocampus. If you give me a good biopsy, we can be quite accurate on the basis of histology.

DR. SCHEINBERG: The question was whether this is a natural aging process or a disease process.

DR. SOKOLOFF: If it is due to normal aging, we certainly are not going to cure aging.

DR. TERRY: Childbirth is a natural process, and physicians have had an ameliorating effect on it. There is no point in our arguing about this business as to whether it is a disease or normal. It is a process that diminishes the well-being of the public, and if we can have an effect on it, we should do so and not worry about whether it is normal or a disease. (Katzman, Terry & Bick, 1978, p. 265)

Another issue of concern was the difference between Alzheimer's disease and senile dementia. This focused on the question of whether the two conditions are one and the same or whether there are two separate entities.

The Two Disease Question

In an introductory paper to the Proceedings of the conference Dr. Robert Butler briefly addressed the issue of the relationship between Alzheimer's disease and senile dementia.

What exactly is senile dementia? How does it relate to Alzheimer's disease? The two conditions present pictures that are indistinguishable to the clinician, histochemist, and electro microscopist. The only apparent difference between the two is the earlier stages of onset associated with Alzheimer's disease (Butler, 1978, p. 8)
Yet in another presentation entitled "Is Alzheimer's Disease a Major Form of Senile Dementia? Clinical, Anatomical, and Genetic Data", Dr. Jean Constantinidis of Switzerland appears to support the thesis that senile dementia and Alzheimer's disease are one and the same. "Simple senile, Alzheimer's senile and Alzheimer's presenile dementias are forms of the same nosological entity. This unicist concept is corroborated from many clinical, anatomohistological, and genetic data" (Constantinidis, 1978, p. 15).

Writing in 1976 Dr. Robert Katzman included both senile dementia and presenile dementia under one name "Alzheimer's disease." In an editorial in the Archives of Neurology he pointed to his estimate one year previously that the senile form of Alzheimer's disease may rank as the fourth or fifth most common cause of death in the United States. This argument he noted rests on the assumption that Alzheimer's disease and senile dementia are a single process and therefore should be considered a single disease entity. (Katzman, 1976, p. 217) He concluded by pointing out that the two conditions are clinically and pathologically the same.

In an interview in 1985 Katzman commented on his position:

Essentially what I was doing . . . was taking things to their logical conclusion. . . . all I did was say if in fact half of the cases of senile
dementia are due to Alzheimer's disease, and if you project the number of cases of senile dementia on the basis of community studies to our population over 65 today, then it becomes a major public health problem and we gotta start dealing with it. . . (Cited in Fox, 1987, p. 1)

In the First Workshop Conference an effort was made to re-categorize Alzheimer's disease and codify it into the professional literature:

DR. KATZMAN: . . . Dr. Butler tells me that the group that writes the psychiatry diagnostic manual the American Psychiatric Association uses for classifying psychiatric conditions is about to revise their manual. He wants to know if we wish to recommend any changes in terminologies concerning the current classification of these diseases, which I believe are in terms of organic brain disease with psychosis, associated with senile brain disease, and associated with arteriosclerosis. Have we reached this point?

DR. TERRY: Isn't it safe and certain if we call this sort of disorder "senile dementia of the Alzheimer type." In this way we don't necessarily lock ourselves into believing absolutely that the senile Alzheimer is exactly the same as the presenile Alzheimer. All we indicate that it is of the same type. It seems to be a safe neutral diagnosis, and it allows us to add other subtypes of senile dementia.

DR. KATZMAN: Does everybody agree with that?

(Katzman, Terry & Bick, 1978, p. 268)

The Second Conference

The Second International Conference on Alzheimer's Disease and Senile Dementia was jointly hosted by the same agencies. The emphasis of the conference was on clinical research and practice in the assessment, differential diagnosis, care, and treatment of the Alzheimer's patient within a practical and multidisciplinary framework.
Thus more topics that fell within the domain of behavioral and social scientists were considered than were in the first conference. Topics such as institutionalization, minority groups and dementia, reimbursement systems, the effect of relocation, behavioral therapy, service delivery and family needs were presented and discussed.

Concern for the erosion of the social support system was expressed and speakers noted that fewer women were available for caretaking in the home due to the increase in numbers of women working. In several presentations social and behavioral scientists pointed to temporal concerns between the potential for new knowledge from applied medical research and the immediate social and medical needs of families and victims of Alzheimer's disease:

Given data and information available on senile dementia and the helpless aged, it is difficult to assess the impact of a moonshot type of strategy. It is beyond my knowledge to predict possible breakthroughs in etiological research, where I have doubts about outcomes in the immediate future. So there has to be action along several fronts simultaneously. . . . I am by no means sanguine that we are capable - as a society - to manage the increasing pressure of the sick aged gracefully. The social system and the family unit are, in my opinion, being overloaded. (Anderson, 1981, p. 340)

Anderson and others stressed the need for the expansion of existing services and the implementation of new services to meet the needs of an increasingly knowledgeable public.
with respect to Alzheimer's disease. The essential message was one that urged public policy to be developed in a broad and general direction rather than uniquely favoring the clinical and biomedical model of research. Tension between these two areas in the development of policy was of particular concern.

**Working with Families**

In order to develop public support for the National Institute on Aging's declared goal to support research on Alzheimer's disease a constituency had to be developed. Dr. Butler contacted families:

> . . . I learned that support groups for families with an Alzheimer's victim existed in various cities. In 1979 we invited them to Bethesda. Concerned that there not be a splintering of groups competing over precious dollars and incipient public support, we urged the establishment of a national federation. (Butler, 1984b, p. 34)

Jerome Stone takes up the story.

**Forming a National Organization**

As a spouse of an afflicted wife in 1970 Jerome Stone's dissatisfaction with both medical knowledge and social support was a catalyst for his activism concerning Alzheimer's disease. He became a member of a small family support group in New York and through this became acquainted with Dr. Robert Katzman. In 1979 this group was
one of seven that were invited to meet with Dr. Robert Butler and the staff of the National Institute on Aging:

At that meeting I became enthralled by the possibilities of a national organization, but frustrated by the difficulties in having seven disparate groups each trying to mold a national group in their own image. During that day . . . much good will dissipat(ed) into acrimonious debate . . . Fortunately, voices of wisdom prevailed. Eloquent statements by such distinguished educators as Dr. Katzman, Dr. Carl Eisdorfer and Dr. Donna Cohen...Dr. Robert Butler and Dr. Tower of NIH and Dr. Leopold Liss . . . prompted the lay people to set aside prejudices and fears and work towards the common good. (Stone, 1982, p. 39)

According to Fenchak (Cited in Fox, 1987). "The conflict was centered around either promoting biomedical research specifically for Alzheimer's disease or advocating for a broader designation to encompass any disease which may cause dementia" (p. 3).

A year later Jerome Stone as president of the newly formed Alzheimer's Disease and Related Disorders Association testified in the first congressional hearing on Alzheimer's disease:

What have the afflicted done? Family support groups were functioning in San Francisco, Seattle, Pittsburgh, Minneapolis, Columbus, Ohio, and Boston, Mass., and New York City as of the fall of 1979. Representatives of these groups were called to Washington by the National Institutes of Health and Dr. Butler and Dr. Tower, last fall, for a seminar to discuss Alzheimer's disease as laypeople as well as professional people, and also to ascertain the need of a national organization. From that time on, we formed the Alzheimer's Disease and Related Disorders Association. (U.S. Senate, Committee on Labor and Human Resources, 1980, p. 12)
Jerome Stone pointed to six major goals for the Association. First, to stimulate research. Second, to begin a nationwide education program for medical professionals to improve diagnosis and treatment. Third, to educate and inform the lay public. Fourth, to advocate for social change especially in the area of service delivery both medical and social. Fifth, To assist in the formation of family support groups across the nation. Lastly, to gather epidemiological data in order to "assess the incidence of this disease" (U.S. Senate, Committee on Labor and Human Resources, 1980, p. 13).

As well as the formation of a national organization other strategies were developed at the National Institute on Aging.

**Working with Congress and the Media**

We have already described efforts to work with the scientific community as typified by the two conferences. In addition public interest and support was solicited through a deliberate use of the media:

Jane Shure and I used the scientific media and medical journals. We developed hearings in Congress, created publications of the institute, and intensified contact with the radio, TV and print media. We also utilized the airline magazines, since airline passengers tend to include business, professional, academic and political people who influence popular awareness and policy. We made contact with and did programs with "Over Easy" on public television and "20/20" on ABC. There were
Congressional hearings were an important part of the strategy.

**Congressional Hearings**

In the previous chapter we have already described the congressional hearings on Alzheimer's disease and provided a categorization of the interested parties or witnesses. What follows is a brief characterization of the testimony of three of these groups namely directors of major agencies, family members and researchers.

**Directors of Federal and National Agencies**

Testimony by directors of federal agencies typically included reference to epidemiological data with respect to Alzheimer's disease. Testimony by the Secretary of Health and Human Services provides an example:

> Our focus this morning will be on Alzheimer's disease in the elderly, and it is indeed a disease of catastrophic proportions. It affects at least one in every twenty people between 65 and 75 years of age, and two in every 10 over 80 years old. Alzheimer's disease is the cause of serious confusion and forgetfulness . . . in some 1.5 million to 2.5 million elderly persons. (U.S. Senate, Committee on Labor and Human Resources, 1983, p. 21)

These statements were often tied to present or projected demographic trends of the older population:
However, because the number of persons living to age 65 and beyond has increased dramatically in the past decades, the absolute number of persons with some form of cognitive deficit continues to increase. (U.S. House, Select Committee on Aging, 1983 (a), p. 78)

Another very common theme in the presentations included reference to the recent recognition of Alzheimer's disease:

We once thought that senility was the price for old age . . . If you lived long enough, eventually, you would lose the clarity of your mind. Now we know that a dread disease robs us of our mental faculties, as stealthily and silently as any thief. (U.S. Senate, Committee on Labor and Human Resources, 1983, p. 49)

Each agency director provided the committee with an overview of the current status of research. Thus findings in brain chemistry and metabolism were laid out in some depth. Contemporary etiological theories were reviewed and the use of new technology was explained. Testifying on behalf of the National Institute on Aging Dr. Zaven Khachaturian concluded:

The U.S. Public Health Service, of which the National Institute on Aging is a part, has supported a significant proportion of basic biomedical research in this country during the last 30 years. . . . Using knowledge gained from such areas of science as biochemistry, cellular and molecular biology, bioengineering, physics, genetics, recombinant DNA, and cloning technology, it is now feasible to make rapid progress in understanding the cause of Alzheimer's disease . . . (U.S. House, Committee on Science and Technology, 1984, p. 69)

Other commonalities in themes expressed in testimony
included the need for education not only of future medical professionals but also present practitioners most particularly physicians. To this end several pamphlets and brochures had been prepared and were disseminated. For example the National Institute of Mental Health published a fact sheet and the Public Health Services printed a brochure as noted by Dr. James B. Wyngaarden testifying on behalf of the National Institute of Health:

Printed information also has been distributed to physicians and medical institutions across the Nation. One example of this is the PHS brochure entitled "Alzheimer's Disease: A Scientific Guide for Health Practitioners". . . (U.S. House, Select Committee on Aging, 1983 (a), p. 80)

In most testimony reference was made to families and their needs often after a brief review of behavioral symptoms exhibited by persons with Alzheimer's disease.

**Family Members**

In ten out of twelve hearings, persons with a family member with Alzheimer's disease testified on their own behalf. That is they did not represent an organization but voluntarily offered testimony of their personal experience. At the hearing entitled *Senility: The Last Stereotype* Helene Mahaney, a victim of misdiagnosis, described the difficulties she had in obtaining an accurate diagnosis of her own condition which was characterized as decline of memory. Dorothy Kirsten French described to
the Senate Special Committee on Aging in their hearing entitled "Endless Night, Endless Mourning: Living with Alzheimer's" her personal experience in caring for her husband, a neurosurgeon:

My husband has Alzheimer's disease . . . I have enjoyed a beautiful marriage of 28 years with Jack French, and we have both worked very hard in our professions. Our careers separated us much of the time. Now when we could be enjoying our life together, this hellish nightmare is destroying us (U.S. Senate, Special Committee on Aging, 1983, p. 13)

Other individuals also referred to the stress they were experiencing and described the financial problems and the lack of medical insurance to cover their family member. One such witness was Bobbie Glaze who was also a founder member of the national organization known as the Alzheimer's Disease and Related Disorders Association. Her testimony also described her personal experience with her husband's condition. In addition she pointed to a variety of needs that, in her opinion, must be met:

We need guidance and research methods of helping these families find appropriate medical professionals who are knowledgeable about this unique problem . . . We need assistance with the appropriate type of care as the disease progresses . . . We need direction in business matters...Legal affairs may need attention . . . Education for the whole world is a top priority. We need to use every resource possible so that all will know what this strange word, Alzheimer's, is about. The general public needs to know, but most importantly, the medical community needs to know. (U.S. Senate, Committee on Labor and Human Resources, 1980, p. 4)
Physicians provided testimony in all the hearings between 1980 and 1985. They basically fell into two groups. Those who were directors of agencies such as Dr. Robert Butler of the National Institute on Aging or Dr. William Mayer Administrator of the Alcohol and Drug Abuse and Mental Health Administration. These physicians were not actively engaged in clinical research but rather served as advocates for research support and policy development for their specific agencies. We have already characterized their testimony above. The second group of witnesses were those who were directly involved in clinical and biological research. The statements of these persons tended to provide in-depth information concerning the current status of research together with a discussion of the advancement of knowledge in their particular field, the particular problems and future needed directions. The testimony of Dr. Peter Davies of Albert Einstein College of Medicine provides an example.

He first furnished the committee with new evidence that some of the major symptoms of Alzheimer's disease appear to be caused by a deficiency of a neurochemical in the brain and reported the first statistically significant results of attempting to treat the deficiency directly. Dr. Davies then turned to an area that, in his
opinion, Alzheimer's research has been deficient, namely, developing an understanding of the molecular genetics of the disease. Here he suggested that similar efforts to those applied to Huntington's disease be initiated for Alzheimer's. He concluded with a plea for funding of laboratory research:

It is in the laboratory that Alzheimer's disease will be conquered, not in the clinic or the home, laudable as the efforts are in those areas. It is in the laboratory that we will solve this problem. . . . (U.S. House, Committee on Science and Technology, 1984, p. 360)

Social and Behavioral Scientists

Social and behavioral scientists offered testimony that gave the committees an overview of the symptomatology of Alzheimer's disease. In addition demographic data were often provided as a means of projecting the magnitude of the problem into the 21st century. Concern for families was evident. Nancy Mace of Johns Hopkins University expanded this point in 1983:

The tragedy of a dementing illness is not limited to the patient himself. The patient's family suffers as well and has been called the "other victim of dementia." Although any chronic and fatal illness can have a tremendous impact on the family, the very nature of a brain disease adds significantly to the family's burden. Family members report the effects of the almost overwhelming burden of caring for a person with a dementing illness. (U.S. Senate, Committee on Labor and Human Resources, 1983 (b), p. 232)
At a joint hearing in 1983 before the Subcommittee on Health and Long Term Care of the Select Committee on Aging and the Subcommittee on Health and the Environment of the Committee on Energy and Commerce Elaine Brody of the Philadelphia Geriatric Center praised the strength of families and explained the impact of changing demographics on the family:

... for the first time in history, 40 percent of people between the ages of 55 and 59 have at least one surviving parent, as do 20 percent of those between the ages of 60 and 64, and 10 percent of those between 65 and 69. And 3 percent of people who are 70 and over - more than half a million people - have a living parent. (U.S. House, Select Committee on Aging, 1983, p. 102)

Despite these demographics she asserted that family bonds have not eroded across the generations and the commitment to care is as strong as ever; most particularly among women. She concluded by stressing the need to support families in social policy development, not to replace them. Many approaches were needed and many of the needed services can only be developed through entitlements of public policy.

Conclusion

In this chapter we have concerned ourselves with strategy; strategies by interested parties to define their interests and organize action. We have described the establishment of the National Institute on Aging, con-
sidered the development of a research policy for that agency under the directorship of Dr. Robert Butler together with strategies for public information. In addition the characteristics of two key conferences and congressional hearings on Alzheimer's disease have been described. In the following chapter we will consider our findings in terms of the research questions and as applied to the theoretical constructs set out in Chapter II.
CHAPTER VIII

DISCUSSION

The Social Context of Alzheimer’s Disease

In this, the penultimate chapter, we will examine the social context of Alzheimer’s disease as shown from the analysis. Here we review the findings and consider the emergence of Alzheimer’s disease as a social construct. First, the reader is provided with an overview and discussion, organized by year, of the major events and activities involved in the Alzheimer’s initiative. Second, we address the research questions starting with the historical background up to the period when our data demonstrate that claims making activities were initiated.

We begin by considering the historical background and answering the research question: What were the historical antecedents that gave impetus to the emergence of claims making activities? In so doing three themes will be identified and discussed. However, before proceeding a brief comment on the nature of the historical documentation is in order.

The paucity of references to dementia in histories of psychiatry requires consideration. First, for lack of
contrary evidence, we must work with the historical record as if it were correct and trust that we are not subject to the historian's sorting process. We assume that indeed in early records little or no reference was made to dementia as a medical problem. If we believe this assumption to be a correct assumption we can then speculate on several possible reasons. Certainly demography must have had some impact. That is, both the proportions and absolute numbers of old persons were both very low. Therefore it is likely that the patients of early physicians tended to be young. This is, however, speculative since it is also possible that older patients would consult physicians more often than those who were younger.

The nineteenth century also witnessed a similar paucity of publications on cognitive impairment in old age. The publications of Pinel, Esquirol and Maudsley were, in each case, a very small section on specific conditions of old age as compared to the content of the entire document.

1. What were the historical antecedents that gave impetus to the emergence of claims?

In response to this research question, three themes will be discussed that appear to be characteristic of the historical antecedents to the twentieth century reframing of senile dementia.

First, beliefs about the relationship between old age and mental functioning is a pervasive theme. Hippocrates
and his followers believed that paranoia was an inevitable result of the drying up of the humors. This was seen as a natural outcome of the normal process of aging. Such a belief was reflected centuries later by Pinel and Esquirol who both viewed dementia as originating from old age. Maudsley, however, questioned this conclusion and suggests that the natural decline in mental faculties should be distinguished from senile dementia. Nascher acknowledged the difficulty of making such a distinction but also pointed to the need for the medical profession to avoid attributing all conditions of the elderly to old age.

Second, problems of nomenclature and classification were evident. A variety of terms describing cognitive loss in the elderly were used. Thus paranoia, melancholia, mania, idiocy and dementia were attempts to classify mental disease and/or conditions. Applications to the elderly were inconsistent and loose. It seemed that dementia could originate from both enthusiasm and old age; in the latter case the preferred term appeared to be senile dementia. On the other hand idiocy in old age became dementia. Nascher's use of the term senility involves not only mental but also physical decay. However, he noted that it should be applied to persons of advanced old age who have passed through the senile climacteric. In this last stage of life individuals were thought to be susceptible to brain fag if protracted men-
tal vigor was employed. The relationship between brain fag, dementia and senility was not clarified. Twentieth century usage, as indicated in the data for this study, included dementia (senile, presenile and arteriosclerotic), organic brain syndrome (acute and chronic), senility and Alzheimer’s disease.

The third theme that appears to have historical consistency suggests negative attitudes toward elderly persons. Aristotle’s attitudes are reflected by Nascher in the twentieth century. Both reveal powerful negative attitudes toward older persons. Selfishness of the elderly is a shared belief. Fear of death, lack of economical utility and unesthetic appearance are, according to Nascher, characteristics of older persons. Yet, in the practice of medicine all such negative attitudes must be sublimated. The physician must overcome a natural reluctance to treat economically worthless persons. In his discussion, Nascher appeared to recognize broad social attitudes which he deemed to be counter-productive to the practice of medicine.

In sum, these are the themes that have historical consistency: a broad based belief that old age and the loss of mental capacity are related; the use of a variety of terms describing cognitive loss in old age; and ongoing negative attitudes toward elderly persons.

We now return to the work of Alois Alzheimer whose work
was of critical importance to the subsequent initiative.

**Alois Alzheimer**

Alois Alzheimer posited a specific disease process. Despite the fact that the noted clinician Kraepelin agreed with the disease hypothesis and named the condition after Alzheimer, his research did not generate wide interest and little replication. We cannot attribute this lack of interest to Alzheimer's lack of standing as a clinician. He had trained and collaborated with noted researchers of his day. Yet his presentation in November 1906 of his clinical and neuropathological findings did not stimulate any discussion. McMenemy (1970) notes that the presentation was reported by title only in the conference program and the report was published the following year without illustrations perhaps indicating a lack of peer interest in the findings. We can only speculate on reasons for the disinterest on the part of the medical community. Can we suggest that the age of Alzheimer's patient (51 years) had any relevance? In the United States, life expectancy at birth at the beginning of the twentieth century was 48.3 years for women and in the same period a sixty-five year old woman could expect to live another 12.2 years. (National Center for Health Statistics, 1986). Was Alzheimer's patient considered to be old? If so, were notions of social worth contributory? Achenbaum (1978)
suggests that the period between 1865 and 1914 constituted an important transition in the history of ideas about aging (p.39). Elderly persons were increasingly viewed as obsolescent. Two broad cultural underpinnings were contributory. First, industrialization leading to a decline in occupational status of older workers and increasingly obsolescent work skills. Second, Achenbaum suggests that negative opinions of the elderly were consonant with the Social Darwinism of the late nineteenth century. (Nascher's view of social attitudes toward the elderly support this thesis). However, if we posit that Alzheimer's work was generally ignored due to negative attitudes toward the elderly, how then can we explain why the term Alzheimer's disease was generally applied to persons so afflicted who had not yet reached old age. Perhaps Alzheimer's earlier research provides us with a clue. In 1894 he claimed that arteriosclerotic atrophy of the brain was distinct from senile degenerative processes and that the former condition, which he asserted was uncommon, only affected persons aged between 45 and 58. In his later study (1907) he also observed arteriosclerotic changes in the brain tissue as well as the lesions and tangles. In addition the age of his patient (51 years) fell within the parameters he himself had established. It appears that Alzheimer's interpretation of his own data supported the classification of Alzheimer's disease as a presenile de-
mentia. His first claim that arteriosclerotic atrophy in the brain was a rare condition distinct from senile degeneration potentially provided the basis for his later claim that he had found a specific disease process since arteriosclerosis was present in both cases.

As we approach the time period that encompasses the major focus of this study namely 1970 to 1985 we note the following historical trends. The claim that old age inevitably results in mental incompetence has deep roots traceable certainly to Hippocrates and Galen and perhaps earlier. The Enlightenment heralded the rise of both science and medical authority. The debate concerning the inevitability of dementia in old age re-emerged, causal theories were suggested and concerns for categorizing mental incompetence in old age were expressed. The twentieth century witnessed the rise of multiple specialties in scientific knowledge and medical practice and the development of technology to aid diagnosis and treatment of human ailments. Despite this Nascher's plea for geriatric medicine as a special branch of medicine met with resistance, and little or no clinical research on dementia was done after Alzheimer published his findings. The Hippocratic thesis continued however to be debated between its supporters and those who claimed senility to be a pathological condition. Lastly, Alzheimer's disease was considered to be a rare pre-senile condition.
At the same time a demographic revolution was occurring. The United States witnessed the greatest increase in the proportions and absolute numbers of older persons ever especially among those over the age of 75. Census projections claimed a steady increase in the proportions and absolute numbers of older persons until the second half of the twenty first century. In addition noted epidemiologists warned of significant increases in the prevalence of chronic diseases (Gruenberg, 1977) and dementia (Kramer, 1982). The stage was being set.

Claims and Claims Makers 1970 to 1985

The following section is organized to cover the time period from 1970 to 1985. The intent is to discuss the findings in time order. The findings are then summarized in terms of the research questions.

Figure 10 draws together many of the events discussed in this study and relates them to our data from Index Medicus and the Social Sciences Citation Index as reported in Figures 1 and 3. We will use this graphic model to illustrate the following overview of the sequence of events.

1970 to 1975

The establishment of the National Institute on Aging in
Figure 10. Numbers of Documents in *Index Medicus* and *Social Sciences Citation Index* and Events, 1970-1985
1974 provided a structural channel for the development of research on Alzheimer's disease. However, prior to this event research activity was not totally lacking. Our data indicate that reported research on Alzheimer's disease as recorded in *Index Medicus* and the *Social Sciences Citation Index* was sparse but extant. Comparatively few documents were recorded in both these Indices and numbers of new sub-topics on Alzheimer's disease also showed relatively low rates of publication prior to 1974. Robert Butler (1984) reported that few federal dollars were being allocated to brain disease and aging prior to 1976. In sum therefore, the years prior to the establishment of the National Institute on Aging were characterized by few research reports and little or no federal monies for research support. Of the documents that were published the focus was on biomedical research on and treatment of, brain disease in elderly persons (See Figure 8). Our data do not allow us to conclude that this low level of published research was a direct result of lack of funding, nor can we demonstrate that lack of interest on the part of the research community accounts for the low number of research reports. We can however suggest that research claims, as measured by numbers of reports, and levels of funding are associated.

Biomedical research was characteristic of the claims making between 1970 and 1975 albeit at very low levels of
activity. No specific strategies for pressing claims were identified during this time period. However demands for support of aging research in general were ongoing and efforts to establish a federal agency to promote research on aging were escalating.

The Research on Aging Act of 1974 established the National Institute on Aging within the National Institutes of Health. The passage of the Act was not without debate and opposition. Concerns were voiced that the Institute would allow parties interested in specific diseases to guide its research agenda, especially if scientific leads were lacking. Others thought that only clinical and medical projects should be supported thus precluding support for all social and behavioral research. Congress however passed the Act and included language that invited a broad interpretation of the mission of the new Institute. Cressey (1967) observes:

Perhaps social phenomena are extensively perceived as social problems only when some proposal for...change is well publicized and well financed. Thus "mental health" seems to have become a major social problem only after the National Institute of Mental Health was established to improve the nation's mental health. Somewhat as a consequence of the fact that mental health was established as a social problem in this way, social scientists discovered that they are experts on mental health problems. (Cressey, 1967, p. 107)

While the National Institute on Aging was not established exclusively to promote research on Alzheimer's
disease it provided a focus for funding, research and indeed public relations. Certainly research efforts burgeoned after its establishment in 1976 with many new investigators who apparently hitherto had not undertaken research on Alzheimer's disease publishing research findings, many on new sub-topics. Our data indicate a body of experts rapidly emerged to support the emergent claim of Alzheimer's as a major social and medical problem. The decision by Congress to establish a federal agency exclusively for gerontological research provided the forum for the activities which we term the Alzheimer's initiative.

1976

In 1976 Dr. Robert Butler was appointed first Director of the National Institute on Aging. Upon appointment, his first task was to develop a mission statement.

Responding to his own unique vision of aging issues, Butler considered senile dementia as a target for the mission of the National Institute on Aging. By the end of 1976 the National Institute of Aging targeted Alzheimer's disease as a research priority and provided $3,899,000 in funding for research (See Figure 7).

The problem, as defined, required recognition of extensive need, existing but as yet unrecognized social costs and the potential of medical science to provide
promising leads and already trained scientists in the field not yet created. In order to demonstrate these three parameters of the emergent problem multiple strategies had to be developed and a broad basis of support solicited. In 1977, Butler initiated the first major strategy; an international workshop conference which he himself described as being of catalytic importance.

1977-1978

We have described how, during the debate in Congress on the establishment of the National Institute on Aging, a concern was expressed by the Administration of the time that funding for the Institute should not be guided by specific diseases especially when scientific leads were lacking. Given this concern, Butler was faced with a challenging task of gaining political support for the Alzheimer initiative. One of his first strategies was to review and publicize the current status of research both nationally and internationally. This he initiated in 1977 by organizing a major conference on Alzheimer's disease sponsored by the National Institute on Aging in collaboration with the two federal agencies who were already providing some monies for research on brain disease of the elderly.

As we review our description of the 1977 conference on Alzheimer's disease and related disorders co-sponsored by
the National Institute on Aging several strategies are apparent. The conference would assist in demonstrating that ongoing research was indeed occurring and that work in progress held promise for the future. Already made medical claims can provide the basis for new claims. Thus the purpose of the conference was not just to survey the current status of knowledge but also to consolidate new claims. This was promoted in part by providing extensive time for discussion which was carefully recorded and reported in the Proceedings of the conference. Only biomedical topics were discussed during the conference. Two major concerns emerged during the presentations and discussion periods at the conference. The first focused on whether cognitive loss in the elderly was an expected characteristic of the aging process. If indeed this thesis was correct then the role of the physician was potentially less important than that of a laboratory based researcher seeking to understand the parameters of normal as opposed to pathological aging. Yet, it was clear that the organizers of the conference saw the role of the practicing physician as essential to the initiative. Physicians provide direct linkages and perform gatekeeping roles between the medical profession and the public at large. This is the expected role of a physician and not usually that of a biomedical researcher. During the conference, the ongoing problem of the relationship between dementia and normal
aging appeared to be swept away. We sense that strategically this was not considered a fruitful question to pursue since normal aging is not usually seen as being treatable. If indeed the "normality hypothesis" gained support we might conclude that laboratory research on biological processes of aging would be of primary importance and the practice of medicine decidedly secondary. However, the "turf" of practicing physicians could potentially be extended by claiming ability to ameliorate the suffering of the as yet unrecognized masses.

The second concern involved the ongoing medical definition of Alzheimer's disease as an affliction of persons not yet considered to be elderly. As a pre-senile condition it would not affect the elderly but rather younger persons. In addition Alzheimer's disease was considered a rare condition whereas senile dementia appeared to be much more common and was exclusively a condition of elderly persons. Clearly neither high social costs nor extensive family burden can be claimed for a rare condition. This classification of Alzheimer's disease was challenged at the conference as we have described. Presentors generally claimed that in their research the two conditions appeared to be similar if not identical. Support for a new definition of Alzheimer's disease emerged.

If indeed pre-senile and senile dementia were to be
seen as identical conditions, then institutionalized professional support is required for the new claim. The claim must become part of the medical classification system. A new all-encompassing term senile dementia of the Alzheimer type was proposed. It was agreed that the proposed change in terminology be submitted to the American Psychiatric Association for inclusion in their professional manual.

As we have described, Dr. Katzman made a similar claim one year earlier: "our goal is . . . to call attention to our belief that senile as well as presenile forms of Alzheimer's are a single disease . . .." (1976, p. 218). By expanding the disease nomenclature to include the older demented person many more cases could be claimed and the notion of a rare condition removed. Klass (1985) sees this strategy as a focal event:

Some years ago an event occurred which was focal in determining our current conception of a common condition of the elderly. In 1976 Dr. Robert Katzman, in an editorial, included both senile dementia and pre-senile dementia under the same name - Alzheimer's disease. We should note this change in name because that single move constituted a radical redefinition. What was once an unfortunate natural concomitant of aging became a disease. (Klass, 1985, p. 1)

The 1977 Conference was an important strategy for consolidating existing biomedical knowledge and for reframing cognitive impairment in older persons as a disease. Not only a disease but a disease of catastrophic
proportions ranking, according to Katzman (1976), as the fourth or fifth most common cause of death in the United States.

The acceptance of a linguistic category usually indicates the appropriate agent of social control. If senility is a disease then it follows that the medical profession is the legitimate agent of control. However, such a claim must be supported. "Scientific evidence" presented in support of the claim or to refute others is vitally important ammunition. (Conrad & Schneider, 1980, p. 26). Our data indicate a burgeoning number of research reports particularly after 1977.

In 1977 the New York Times published its first article dealing with dementia. The title "Senility is not always what it seems to be" suggests a challenge to the common understanding of the condition as well as an indication that the term senility was generally understood terminology at that time.

The publication of this article in the New York Times can potentially be considered to be the result of the co-opting or public relations strategies initiated by the National Institute on Aging. Although Butler (1984) gives no indication as to when the strategy to "sell" Alzheimer's disease was initiated we can surmise that this activity started in 1977 since the research plan for the Institute was not submitted to Congress until December
1976. The plan entitled "Our Future Selves" targeted Alzheimer's disease as a research priority (See Chapter VII).

Our data indicate a sizable increase in the number of publications recorded in both Index Medicus and the Social Sciences Citation Index during 1977. In the case of the former the number was exactly double that of the previous year. In the same year eleven new sub-topics relating to Alzheimer's disease were recorded in Index Medicus. This was the highest number (N=11) for the entire period (1970 - 1985). We can suggest that increase was a response to the publication of the National Institute on Aging research agenda which in turn may have affected editorial policy for some professional journals; research on dementia, being prioritized by an agency of the federal government could potentially stimulate editorial interest. Butler has clearly stated that he himself "worked with medical journals" (Butler, 1984b, p. 34) presumably to influence policy and encourage a greater interest in brain disease and aging on the part of the editors. We can also suggest that increased federal funds also influenced scientific priorities. Federal grants in 1977 for research on Alzheimer's disease totaled $4,648,000 an increase of $749,000 over 1976.

Documents relating to both assessment and treatment efforts showed a notable increase in numbers in 1977 as
compared to the previous years. This was also the first year that documents pertaining to social and family issues relating to Alzheimer's disease were referenced in *Index Medicus*.

As shown in Figure 10 no specific event occurred in 1978 however the numbers of publications continued to grow. As in previous years biomedical research dominated the reports. New sub-topics continued to be introduced but in fewer numbers (N = 6). Once again the *New York Times* published a single article still utilizing the term "senility" to communicate meaning in the heading.

**1979**

In 1979 the first two articles relating to Alzheimer's disease were published by the popular press. *Science News* reported on choline and Alzheimer's disease whereas *Newsweek* published an article entitled "Epidemic of senility."

Here we see the more scientifically oriented magazine using the term Alzheimer's disease whereas *Newsweek* follows the same mode of communication as the *New York Times* in 1979 namely senility. Once again we can surmise that this first indication of interest in Alzheimer's disease (or senility) by the popular press was as a result of public relations efforts by the National Institute on Aging.

Up to this point in time, the key actors had been physicians and biomedical researchers. In 1979 the
strategy was extended to include the support of the lay community; specifically those persons most affected (apart from the patients themselves) by Alzheimer's disease. The intent was to co-opt persons who had a family member suffering from the condition. Non-medical claims makers, such as families were important in establishing the new disease. They are not so restrained by scientific credibility and "... allow physicians to take the more dignified role as 'experts' rather than overt partisans" (Conrad & Schneider, 1980, p. 269). Non-medical claims makers initiate public relations, lobby legislatures and call on medical practitioners to lend credence to their claims. They are in effect the most ardent supporters of the medical claim (Conrad & Schneider, 1980, p. 269). In 1979 public support and knowledge was not yet established. A national organization was required to involve the non-medical claimsmakers and represent the various interests as they grew. One year later the goal was realized with the establishment of the Alzheimer's Disease and Related Disorders Association.

1980

From the start the Association established broad goals targeting research on etiology and treatment, education of the medical profession and the general public, assistance to family support groups and advocacy for change in ser-
vice delivery. The involvement of families not only broadened the base of support but it also provided a clear rationale for extending the advocacy effort beyond medical research to involve a challenge to multiple social systems. The first hearing in Congress was held in 1980. Family members testified to their needs. The long-term care system was inadequate, the legal system provided no protection for families, the medical profession was ill-informed and the laity needed to be informed. These and other claims constituted a challenge to both the state and the private sector. The process now involved an awareness of a whole range of injustices.

Family members in testimony supported the claims for social change by telling sad tales (Goffman, 1961). Poignant descriptions of mis-diagnosis, family stress and despair, loss of employment and lack of support and assistance are characteristic themes in the sad tales. Sad tales emerged in the press with some written by family members themselves and others narrated to a reporter. The media were responding.

The title of the new organization (Alzheimer's Disease and Related Disorders Association) reflected the earlier discussion in the 1977 Conference regarding the classification of Alzheimer's disease as well as assisting to encode the new definition into the public consciousness. Indeed, the Association provided a forum wherein lay and
medical interests could come together.

It seems that these non-medical champions accepted the new designation of Alzheimer's disease readily. Some disagreement between the medical and non-medical groups occurred at their initial meeting, however, it appeared to concern the advocacy base rather than the new definition (Fox, 1987). In fact the Alzheimer's initiative as presented in this study can be characterized as lacking in disagreement and rancour. (This point will be taken up in the following chapter.)

In the same year the American Psychiatric Association reframed Alzheimer's disease from a pre-senile dementia to a senile dementia for the first time. Medical claims are reflected in part through the use of specific terminology. Conrad and Schneider (1980) point to the acceptance of linguistic categories as an essential stage in medicalization. By devising a category with special connotations and having it accepted is a major victory. The medical perspective becomes institutionalized and the category becomes part of the language of medicine.

Lastly, the second conference on Alzheimer's disease was held. In this conference a multidisciplinary approach was taken. Non-medical claims-makers were invited. Social and behavioral scientists, medical practitioners and biomedical researchers all came together to share their various claims. Social scientists presented new claims.
but did not challenge the emerging medical claims of the physicians and biomedical researchers. By drawing on the medical claims they broadened the political arena and pointed to the need for social policy development in conjunction with biomedical research. The issue was one of achieving and maintaining an equitable balance between medical and social priorities.

During the years between 1974 and 1980 events occurred which were critical to the Alzheimer initiative. As we examine Figure 10 we can see a clustering of events between 1974 and 1980. During these seven years the numbers of events become more dense. Thus, in 1980 the initiative involved not only the support of the National Institute on Aging and its director Robert Butler, but also increasing federal monies from other agencies, the involvement of non-medical claims makers through the establishment of the national Association, the establishment of a series of hearings in Congress, the initiation of ongoing private financial support, growing interest in the media and the acceptance of the new classification for dementia by the American Psychiatric Association.

1981 to 1985

The five years after 1980 are characterized by ongoing activity. No new strategies were introduced. The density of the various events as portrayed in Figure 10 continued.
That is the various initiatives established between 1974 and 1980 were ongoing. Federal support increased steadily with NIA grants showing a sharp increase between 1981 and 1985. Hearings continued to be initiated, foundation monies increased and the numbers of articles on Alzheimer's disease generally increased in the printed media.

At the same time publications in both Index Medicus and the Social Sciences Citation Index burgeoned. Indeed, Figure 10 shows a direct relationship between the increase in the number of events and publication activity as recorded in these indices. After 1980 reports on etiology and pathology still continued to dominate our data base as indicated in Figure 8. However, documents on social and family issues showed an increase between 1981 and 1985.

In general our analysis shows that publications recorded in Index Medicus and the Social Sciences Citation Index steadily increased between 1970 and 1985. However, in 1982 the numbers of documents in Index Medicus fell from 215 in 1981 to 112 subsequently increasing to 228 in the following year. Reasons for this can only be surmised. Index Medicus generally accesses documents from the medical literature. The major area in this literature was biomedical research into Alzheimer's disease. Projects in this domain often require considerable financial support. It may have been that monies were unusually limited for that year. Yet our data show that the numbers of pub-
lished documents in the social domain also declined (See Table 3). We also note that there was no decline in federal monies for research in 1982 (See Figure 7). As far as foundations were concerned monies for medical research were the highest for the entire period during 1982. It is possible that research funded in 1981 or earlier was not yet ready to report in 1982. Whatever the reason, this decline in numbers of publications was only observed in 1982; subsequent years indicated a steady increase as before.

The Research Questions

In the following section the findings discussed above summarized in terms of the research questions. The intent is not to reiterate the discussion above but rather to briefly characterize specific responses to each research question.

1. What was the Extent of Claims? Our findings indicate that claims about Alzheimer's disease burgeoned between 1970 and 1985. Prior to 1976 few medical claims were made. However after the mandate of the National Institute on Aging was established in 1976 these claims increased steadily in numbers. Similarly, the number of new subtopics increased substantially. The analysis reveals that documents relating to social and family issues were first published in 1977 the same year that witnessed a notable
increase in the number of new sub-topics. Federal funds for research on Alzheimer's disease grew more rapidly for the five years between 1981 and 1985 than for the previous five years. At the same time the numbers of research reports in both Index Medicus and the Social Sciences Citation Index also grew rapidly.

In 1980 private foundations supported projects on Alzheimer's disease for the first time. Data on foundation grants for social purposes as opposed to biomedical research, reflect the similar rises in documents on social and family issues in 1980 through 1983. In 1982 private foundations gave $1,035,000 for biomedical research. This was the largest amount donated from this source between 1980 and 1985. The availability of these funds in 1982 may in part explain the relative lack of research reports during the same year since it is unlikely that findings from funded research can be reported in the same year as the initial grant.

With reference to this discussion we reiterate that the data for this study do not allow causal statements between increases in numbers of research publications on Alzheimer's disease and availability of federal and private funds to be made. The conclusions are entirely inferential.

Claims relating to Alzheimer's disease emerged in the mass media later than those reported in professional
journals. The *New York Times* published a feature article on Alzheimer's once a year between 1977 and 1980. Thereafter news items emerged and predominated over the feature articles in 1984 and 1985. The first feature articles potentially reflect editorial interest possibly in response to the publicity efforts of the National Institute on Aging. However, the increase in the numbers of feature articles can also be regarded as indicators of emerging public interest in a putative social and medical problem. At the same time, the growth in the numbers of news articles reflect the increase in claims making activities by biomedical researcher and social scientists.

Interest by popular magazines mirror a broader public interest than the *New York Times* despite the fact that it is a national newspaper. The findings suggest that between 1983 and 1985 both popular magazines and the *New York Times* increased the numbers of their reports on Alzheimer's disease. The effect of the media on public sentiment and opinion about Alzheimer's disease cannot be addressed here. However, we can conclude that the media plays an important role in the dissemination of ideas and information thus contributing to the development of consensual reality.

In sum, absolute numbers of claims, claims makers and new sub-topics increased after the mandate of the National Institute on Aging was established. Claims in the media
emerged later than professional claims.

2. What were the Characteristics of the Claims? Medical and biomedical research topics dominated the claims making activities from 1970 until 1985. Social and family concerns emerged later, were decidedly secondary and constituted a minority of the claims.

Professional manuals changed the classification of Alzheimer's disease from one of an uncommon presenile dementia to include senile dementia. In 1980 DSM III reframed Alzheimer's disease as a Primary Degenerative Dementia. The rationale for change contains the following statement: "The Dementias associated with Alzheimer's and Pick's diseases have been referred to as Senile and Presenile Dementias, . . ." (DSM III, 1980, p. 124). Since neither DSM I nor DSM II classified Alzheimer's disease as such, we can surmise that the authors of DSM III were referring to the initiative emerging from the first Workshop Conference on Alzheimer's Disease. Two years later in 1982 the Merck Manual also changed the classification to include Alzheimer's senile and presenile dementia to be generally known as Alzheimer-type dementia.

The adoption of the new terminology by the public is reflected in the New York Times. Senility was the preferred term until 1981. Then Alzheimer's disease was utilized for the first time being introduced as "a big killer of the aged" (See Table 4). In the following year
the descriptors mysterious brain disease and a disease of the aged were utilized. Finally in 1983 Alzheimer's disease became the term of preference, descriptive modifiers were no longer used and, as our data indicate, media interest burgeoned. The change over seven years in the New York Times in the use of terminology is an indication of the original lack of public knowledge regarding Alzheimer's disease. Once again we see the press educating the public in new terminology.

In sum, the characteristics of claims making activities included the following: a domination of medical claims over those concerned with social issues; the codification of Alzheimer's disease as both a presenile and senile dementia in official medical manuals; and change in media use of terminology from the colloquial senility to the disease entity Alzheimer's disease.

3. What were the Strategies for Pressing Claims? The first major strategy in the Alzheimer's initiative was the development of the mandate of the National Institute on Aging in which Alzheimer's disease was targeted for research initiatives and funding. In order to achieve support for this initiative ongoing research and the availability of trained researchers had to be established. This was achieved through an international conference workshop which provided the forum for reframing Alzheimer's disease as both a senile and pre-senile
dementia and the impetus to the new definition within the language of medicine.

The second conference was a strategy to broaden the definition of the problem and involve both social and behavioral scientists. Furthermore, the co-optation of families as non-medical claims makers was an important strategy in order to develop an advocacy base for social change. These last two initiatives provided the basis for disseminating claims regarding both the social and individual costs of the new definition.

In the last chapter we will return to the theoretical issues laid out in Chapter II, consider them in terms of our findings and provide some further discussion. In addition we will discuss the limitations of this study and make recommendations for further research.
CHAPTER IX

CONCLUSION

This final chapter begins by considering theoretical framework as applied to the data. Next the limitations of the study are discussed and we conclude by suggesting directions for further research.

Relationship of Theory to Findings

The goal of this dissertation has been to explain the changing definition of senile dementia. Through our analysis we have sought to understand the process whereby Alzheimer's disease came to be claimed as the fourth or fifth leading cause of death in elderly persons from its original classification as an uncommon disease. Our interest has focused on how this was achieved. We posit that a new category of illness was created as an outcome of action and the meanings that individuals and collectivities attached to such action. The following discussion is divided into two parts; in the first we will characterize and discuss the action as documented in this study and in the second the temporal aspect of the action will be addressed. That is we will discuss the findings in relation to the sequential models of social problems laid out in
Chapter II.

This study is couched in the social construction paradigm. Within this perspective, reality is seen as a social construction that emerges from social interaction:

The phenomenological perspective views deviance designations as "socially constructed realities," typifications (commonly understood categories or types) that are products of social interaction and central in our interpretation of the world. "Reality" is defined not as something that exists "out there" for the scientist or anyone to discover but as a social construction that emerges from and is sustained by social interaction. (Conrad & Schneider, 1980, pp. 20-21)

The German philosopher Husserl sought to develop a new philosophical method that would bring absolute certainty to a troubled world. In his quest he rejected the common-sense belief that objects exist independently of ourselves and that information about them is reliable. All that we can be certain about is how they appear to us in our consciousness whether we are experiencing an illusion or not. Objects thus are not regarded as things in themselves but as things posited by consciousness (Eagleton, 1983 p. 55). The individual consciousness can be fleeting or it can endure for a life time. The collective consciousness is not usually a fleeting phenomenon but takes time to change. Within the phenomenological approach is the recognition that meaning is not simply something reflected in language; it is actually produced by language (Eagleton-
ton, p. 60). In a similar mode, discussing the phenomenology of human behavior, Conrad and Schneider (1980) point out the social world is both constructed, interpreted and sustained through the medium of language. Language provides ordered meanings and brings meaning to objects and behavior in the social world (p. 21). Meanings as expressed through language are historical and in a continuous state of both being and becoming.

This study has been concerned in some part with the phenomenology of language. In this study we can see that language has reflected ongoing perplexity in the classification and indeed understanding of cognitive impairment in older persons. We have shown that language reflected changes over time in the interpretation of this phenomenon. However, our major concern has been with the origins of these changes. Let us now consider the issue of medicalization and the consequences thereof in the context of this study.

**The Medicalization of Senile Dementia**

In very broad terms we have shown that prior to the 1970s medical attitudes towards confused older persons were equivocal. Some practitioners (such as Nascher's instructor) saw old age as a period of inevitable decline. Medical intervention in this case was useless since aging
was seen as a normal biological process beyond the intervention of medicine. Others were less certain; questions concerning the difference between senile dementia and normal aging were raised as were concerns about the possibility of senile dementia being caused by a disease process as yet unknown. Indeed, Alzheimer himself appeared to be determined that he had evidence of a specific disease.

However, by the last year of our time period (1985), Alzheimer's disease had become accepted language to describe and diagnose confused older persons. In effect senile dementia finally came under the control of the medical profession. A new reality emerged with important consequences for both practitioners and victims of the disease.

Social Consequences

Let us first consider the implications for persons afflicted with Alzheimer's disease. A diagnosis of disease legitimates the individual to take on the status of a patient and enter the sick role. As Parsons (1937) posits the sick role places obligations on both parties, the physician and the patient. The former is expected to treat the patient to the highest level of his or her ability and the patient is expected to comply with the prescribed regimen. In addition the patient is absolved of responsi-
ility for some of his or her normative obligations or, in certain cases, behavior. Recent literature in the medicalization of deviance has pointed to the secondary gain for an individual entering the sick role. More specifically, the sick role legitimizes a certain amount of deviant behavior (Fox, 1977; Conrad & Schneider, 1980; Sigler and Osmond, 1974). Examples in the literature include alcoholism and hyperactivity in children (Conrad & Schneider, 1980). Secondary gain for persons diagnosed as having Alzheimer's disease is more equivocal. A certain amount of seemingly irrational behavior is allowed older persons solely on the basis of their age. A degree of memory disfunction is permitted an older individual, which in a younger persons might be seen as pathological. Indeed increasing age alone absolves most individuals from certain social expectations such as working. But, demented persons cannot generally comply with social norms and expectations.

Implications for Families

Persons suffering from Alzheimer's disease appear to be unaware of their situation and thus cannot cooperate in the obligations of the sick role. Thus a third party, acting on their behalf, must interpret the role for them. In this case, family members usually act as guardians of
the sick role. It is they, not the patient who are respon-
sible for gaining entry in the first place. They are re-
sponsible for seeing that the patient complies with the
physician's orders. By acting as a surrogate for the
patient in some ways, the family itself also enters the
sick role. The targeting and subsequent cooptation of
families into the Alzheimer's initiative was a significant
strategy. It is obvious that persons suffering from
Alzheimer's disease cannot themselves be involved in their
own care except in the early stages of the disease and
thus family members were the logical choice. However, our
point is that this strategy had important consequences for
families and others caring for a victim of Alzheimer's
disease.

Prior to the Alzheimer initiative, persons caring for
an elderly confused individual were in an anomic situ-
ation. Anomie, as originally developed by Emile Durkheim,
(1893/1964) is a condition characterized by the relative
absence or confusion of values both in the individual and
in society when social norms are weak. Persons in this
situation have a feeling of isolation which according to
Young (1952) is the result of a high degree of special-
ization in mass society. We have described how key family
members in the Alzheimer's initiative were dissatisfied
with the lack of support for their situation. The domain
of medicine was not seen as a recourse since physicians could offer little or no assistance. Families had nowhere to turn except within their own personal circle of friends and relatives. By taking on the sick role, albeit as a surrogate, the family acquired some benefits. Their anomic situation was in part ameliorated. The medical profession, as we have shown, took on the condition of senile dementia and reframed it as Alzheimer's disease. In so doing the mantle of medical legitimacy was laid on the condition. Dementia had come under the domain of science thus families were provided with a rationale to turn to the medical profession and also to raise their expectations. Therapeutic ideology suggests that a problem can be alleviated if only the proper treatment is discovered and administered (Conrad & Schneider, 1980, p. 247). As Eliot Freidson (1970a) noted "... when a physician diagnoses a human's condition as illness, he changes the man's behavior by diagnosis: a social state is added..." (p. 223). As a patient the individual now turns to the medical profession in expectation of relief.

Medical Control

According to Illich (1976) medical practice sponsors sickness by supporting a morbid society that encourages people to become consumers of curative and preventive
medicine (p. 33). This he terms social iatrogenesis. In a morbid society the belief prevails that defined and diagnosed disease is infinitely preferable to a negative label or to no label at all. Illich suggests that people want their doctor to act as lawyer and priest:

As a lawyer the doctor exempts the patient from his normal duties . . . As a priest, he becomes the patient's accomplice in creating the myth that he is an innocent victim of biological mechanisms . . . Social life becomes a giving and receiving of therapy: medical, psychiatric, pedagogic, or geriatric. (Illich, 1976, p. 123)

The physician is the official designator of the sick role for a morbid society. Without recourse to the physician the status of patient is difficult to acquire and maintain. In the case of Alzheimer's disease the physician has acquired this gatekeeping role. Within this role the responsibility to accurately diagnose the patient's condition is crucial. A diagnosis admits the patient to the sick role. It is the official legitimation that allows the individual to become a patient. Our data indicate that issues of assessment (N=270) were second to research on the etiology of Alzheimer's disease (N=781) and only exceeding treatment concerns by 16 documents (N=254). Clearly these three categories have a close relationship. That is neither diagnosis nor treatment can be adequately performed if the nature of the pathology is not
The growth of medical control usually involves a concomittant increase in the development and use medical technology. Our data indicate some numbers of documents relating to the use of technology such as CAT scans and EEG. Additionally the use of medications in the treatment of Alzheimer' disease was a major theme. A new illness will often stimulate research for either new pharmaceutical products or new applications of existing medications as the drug industry gains interest in the new illness designation (a classic example of the latter involves the use of Ritalin for hyperactive children).

The discovery of a new disease can potentially invite the development of a world of new experts or expertise. The numbers of sub-topics on Alzheimer's disease is an indicator of growing specialized knowledge. An inspection of Appendices A or B can suggest an array of potential areas for the development of expert knowledge. This expertise could develop in the areas of the law, family counseling and dentistry to name but a few.

How Did It All Happen?

In the previous chapter we provided a basic overview of the "Alzheimer initiative" and discussed the various characteristics and strategies involved. In this section we
will return to this topic and consider specific issues which we consider to be relevant to the emergence of the initiative.

In this study the reframing of senile dementia has been documented. In terms of the natural history models discussed in Chapter II we believe that our data show that Alzheimer's disease has become instituted as a medical classification. (We will return to this point in the following section). We now attempt to explain how this happened.

Scholars of social problems often point to tension or strife between at least two parties or collectivities as the definition of a putative condition emerges. For example Troyer and Markle's (1983) study of smoking showed that there were basically two opposing groups involved in the debate namely the pro and anti smoking forces. In our study the medicalization of senile dementia emerged without apparent tension of this nature. The conclusions of the 1977 conference appeared to be accepted with little criticism by key family members and later by the general public. No documents available to us indicated any generalized opposition to the new illness designation. We have posited that caregivers of demented persons were in an anomic situation. Following this assumption, we further suggest that the Alzheimer's initiative clarified an ambig-
uous situation and offered the potential for a solution through the auspices of medicine. This perception provides a partial explanation for the lack of dissent or organized opposition.

The reframing of confusion in older persons as Alzheimer's disease occurred in an extraordinarily short period of time. In effect the time period was little more than eleven years from 1974 to 1985. Indeed to be more specific, we consider the establishment of the NIA to be a necessary but not sufficient event since the appointment of Robert Butler and his subsequent strategies as its first director provided the primary initiative. Therefore, the time period is in effect less than eleven years since Butler was not appointed until 1976.

Additionally our study did not reveal any more significant events similar to those laid out in Figure 10 after 1980. Thus we consider the years between 1980 and 1985 to be a time of consolidation. The national organization was established and growing, increasing numbers of articles in the press provided an indication of growing public interest during this period, congress was responding and private foundations continued to provide grant monies.

We suggest that the lack of opposition can be explained from two perspectives namely that of the medical community
and that of families.

The Medical Perspective

Some of the characteristics of medical control have already been discussed. As Friedson (1970a) notes:

(Medicine) is active in seeking out illness. The profession does treat the illnesses that laymen take to it, but it also seeks to discover illnesses of which laymen may not even be aware. One of the greatest ambitions of the physician is to discover and describe a "new" disease or syndrome and to be immortalized by having his name used to identify the disease. Medicine, then, is oriented to seeking out and finding illness, which is to say that it seeks to create social meanings of illness where that meaning or interpretation was lacking before. (Friedson, 1970a, p. 252)

Medicine has the authority to define conditions or behaviors as pathological or deviant. It has developed an organization and wide range of specialties and sub-specialties so complex that lay persons without expert knowledge are increasingly less able to challenge medical decisions and classifications.

The medical model is assumed to have a scientific basis thus diminishing competing explanations. Scientific knowledge has historically and even currently engendered much social support. Conrad and Schneider (1980) suggest that "American society has cultivated an extraordinary faith in science, both as a way of making sense of experience and as a source of dazzling and problem-solving technology"
Similarly Illich (1976) characterizes American society as over medicalized and receptive to medical interpretations of social problems and individual behavior; in effect a morbid society. Such confidence provides the medical community with considerable power and the flexibility to extend its boundaries without engendering much opposition as in the case of Alzheimer's disease.

The Family Perspective

Our documents show us that key family members accepted the medicalization of dementia willingly. One year later after the first meeting between families and medical advocates at the National Institute on Aging family members were testifying to Congress concerning their needs and the need for social change. We suggest that this willingness to cooperate with the medical profession originates from their anomic situation. There was nowhere they could turn for assistance. Social agencies failed them and the medical profession could offer no assistance or hope. It is not surprising therefore that when an approach from the medical community it was accepted without significant debate.

Furthermore medical language is assumed to be morally neutral. To call a condition a disease is to deem it to be
be undesirable and therefore provides justification for a crusade to be developed. Such a crusade cloaked in the mantle of science, especially in the case of Alzheimer's disease, would be readily seen as appropriate and timely.

In sum, the medical initiative was broadly accepted by lay family members who provided it with advocacy and support which in turn generated broader public interest. A more micro analysis might have revealed specific tensions and concerns along the way between groups or individuals which our data generally do not reveal.

We will now turn to the role of medical advocates in the initiation of the new label of Alzheimer's disease.

The Role of the Moral Entrepreneur

According to Becker (1963) moral entrepreneurs are those individuals who, through their charisma or specialized knowledge produce social rules. In effect they challenge the status quo in order to create new rules. As noted in Chapter II moral entrepreneurship is a role increasingly assumed by professionals who broaden their interpretation of their role within their profession. Thus, for example, physicians are seen in positions in which they function less in terms of their professional skills and more in terms of promoting social change. In his role as Director of the National Institute on Aging
Robert Butler warrants the title of a moral entrepreneur.

Butler came to the NIA with a broad vision. His mandate from Congress was also broad in that medical and social science research were both permitted to be included in the mission of the Institute. By examining Table 10 we can discuss the influence of Robert Butler as a rule creator. In each one of the events, with perhaps the exception of the foundation grants initiative, we can see his influence. The research mission of the Institute reflected his priorities, which in turn initiated channeling federal monies for research on Alzheimer's disease. It was Butler who elicited the interest of the media. It was Butler as Director of the NIA who invited families to join the Alzheimer initiative which ultimately led to the founding of the national association and it was Butler who initiated congressional hearings. The proceedings of the 1977 conference indicate that Butler suggested the approach to the American Psychiatric Association which proposed altering the classification of Alzheimer's disease. In the introduction to the proceedings of the conference it was Butler who raised the question of the relationship between senile dementia and Alzheimer's disease. In sum we can attribute several rule changes to Butler's strategies as a moral entrepreneur.

His authority for such strategies stemmed from his
position as director of the NIA and his reputation as an authority on gerontological issues. This status gave him ready entree to agencies of the federal government for collaborative enterprises such as the conference in 1977 as well as access to Congress.

The strategy to co-opt families clearly broadened the base of the initiative. The author of this study had originally conceptualized the Alzheimer's initiative as a grass roots movement. That is she attributed the origins of the initiative as starting with key family members who challenged the norms of society and the medical profession by forming a national organization. The documents examined in this study suggest an alternative interpretation. We can perhaps better explain the Alzheimer initiative as originating with a group of elites within the medical profession who mobilized the medical profession and co-opted families to form an advocacy base for the new disease. These physicians were not typical of their profession. For example, Dr. Robert Butler was educated at Columbia and Dr. Robert Katzman received his M.D. at Harvard. They and others came together not to specifically promote a new medical label but rather because of similar professional interests and viewpoints. This loose group of claims makers became increasingly politicized. Medical elites must rely heavily on the influence of their
messages to have effect. They are likely to use education, persuasion, and specialized knowledge to convert others to their viewpoint. This model of activity, we suggest, has potential for explaining the medicalization of senile dementia and the remolding of Alzheimer's disease.

The initiation of strategy by elites also adds additional explanatory power to the acceptance of the medical label by the key family members. As we documented the original families invited to Betheseda were members of support groups. Little is known about these specific groups. However, we must assume that they were characteristic of Gussow and Tracy's (1976) first typology of a support group namely one that provides support and assistance to its members and does not engage in social activism. Lobbying and social advocacy are not typical of this type of group's activities. Spiegel (1976) suggests however that self-help groups have a tendency to become politically active. Perhaps collective consciousness raising is engendered through mutual support which in turn leads to activism in various forms. Whatever the individual or collective motivations within the original support groups contacted by the National Institute on Aging, we have documented that they became part of the Alzheimer initiative with one of them serving as the first president of the National Association.
We will now consider the Alzheimer initiative in the context of the natural history models of social problems.

The Natural History of the Alzheimer's Initiative

As already noted the five sequential models of social problems developed by Blumer (1971) Conrad and Schneider (1980) Fuller and Myers (1941) Mauss, (1975) and Spector and Kitsuse (1977), have more commonalities than differences in their respective stages. We will therefore focus on Conrad and Schneider's model and where appropriate refer to the characteristics of the others.

Conrad and Schneider (1980) suggest that before any medical definitions emerge the condition or behavior must be seen as problematic in the first place. Mauss (1975) characterizes the early stages of a social movement as being made up of people who have begun to feel some kind of threat to their well-being. As a result they take action whether it be writing letters to a newspaper or organizing small meetings. Our data indicate such activity by families caring for a demented individual. However, unlike Mauss who posits essentially a grass roots movement as the initiative for a social movement, our analysis suggests that medical elites were the original source of action. We do not have any documents that demonstrate that the medical community as such was experiencing a
threat to their collective well-being in the mid 1970s as a result of some putative claim regarding senile dementia. We do however have documentation that medical elites such as Dr. Terry considered medicine to be the appropriate discipline to ameliorate the suffering of demented persons. Therefore the expansion of medical turf is a more likely explanation.

According to Conrad and Schneider (1980) prospecting is characteristic of the second stage of medicalization. Here claims, for example, of a new diagnosis or a newly discovered syndrome are published in a professional journal or presented at a conference. While we can point to no one publication that appears to be crucial to the initiative, we can suggest that Katzman's publication in the Archives of Neurology in 1976 in which he equated senile dementia and Alzheimer's disease was an important claim. As already described, this was the first time that this claim was made. The following year the same claim was made not in a single journal article but in face to face discussion between a specialized group of physicians and researchers during a conference. However, publication of a single article or a conference does not assure that the new designation will be accepted. As Conrad and Schneider (1980) have pointed out the new claim requires "champions and moral entrepreneurs to carry the banner and bring the
new problem or definition to public attention. When this happens, the claims making stage begins" (p. 267).

Our data reflect Conrad and Schneider's articulation of this stage. The co-optation of the non-medical claims makers in the form of family members was vital to the process of the medicalization of senile dementia. Conrad and Schneider particularly note that non-medical claims makers usually support the already made professional claims. In short they use the already made medical claims as "ammunition" to promote their needs. This, as we have shown, was characteristic of the family members in the Alzheimer initiative. Their non-medical status allowed more freedom to promote their position. They testified to the very experience of living with an individual suffering from Alzheimer's disease. These sad tales could only be made by the non-medical claims makers. For the medical moral entrepreneurs to make such claims might well undermine their scientific credibility. By supporting the claim that Alzheimer's disease was a major public health problem, non-medical claims makers could then promote their own needs. The testimony of Bobbie Glaze is characteristic (See Chapter VII). She advocated for proper care during the progress of the disease, financial and legal assistance and an informed public to support public policy in these directions.
The coalition of both interests was essential to the vitality of the initiative. In effect it was a combination of instrumental and expressive action. The former conotes human activity as most effective when the individual is productive, rational, efficient, and self-assertive. On the contrary, expressive action emerges when the individual is affective, supportive, nurturant, collective-oriented and spontaneous in relationships with others (Glennon, 1974). Synthesism suggests that humanity is ideally a synthesis of instrumental and expressive capacities. Individuals or groups are most effective when simultaneously instrumental and expressive (Glennon, 1974, p. 8).

Medical claims makers, according to Conrad and Schneider, also attempt to prevail on their professional organization. "If the champions of a particular position are successful in convincing their professional organization to support their claims, the professional society itself becomes an important force for staking a claim" (Conrad & Schneider, 1980, p. 268). Once again our data reflect this strategy. As a result of the 1977 conference an approach was made to the American Psychiatric Association to promote the claim that senile dementia and Alzheimer's disease were one and the same condition.

Legitimacy and institutionalization are terms used to
describe the next stage. This stage is characterized by "victories." Official recognition by professional bodies, the establishment of an agency to organize strategy, media attention and collaboration with the state. This stage, according to Mauss (1975) is the period of greatest power for the movement. It is the stage where social endorsement must be acquired without which the initiative is doomed (Blumer, 1971).

In 1980 our data indicate that the Alzheimer initiative became institutionalized (following the sequential models.) The American Psychiatric Association published DSM III in which Alzheimer's disease was equated with senile dementia. In the same year the National Association was formed, congressional hearings were started and the private sector initiated financial support. The use of the term Alzheimer's disease was increasing in common parlance as indicated by media usage.

Mauss (1975) suggests that collaboration with the state is involved at this stage. As we have shown, regular congressional hearings were organized starting in 1980. Directors of federal agencies such as Health and Human Services supported the initiative in congress. However, the point must be made that the state was involved from the beginning. Indeed the first official plan to target dementia as a research priority came from the state itself.
in the form of the mission statement of the National Institute on Aging. In a sense, legitimacy did not have to be acquired since the authority of the state and the prestige of medicine both combined to provide legitimacy right from the start of the initiative. However, the initiative had to be institutionalized and this is what we observe as first occuring in 1980.

Mauss (1975) suggests that fragmentation and demise are potentially the fate of some social movements. In the former strategists start to argue amongst themselves, tensions arise and the original goals may be modified or completely changed. Demise, according to Mauss is seldom recognized within the movement. Goals may have been realized and inertia sets in. The initiative loses impetus. We do not have data to demonstrate any tensions within the Alzheimer initiative with the exception of one document. In May 1985 the *New York Times* published an article entitled "Alzheimer's disease: Families are Bitter" (*New York Times*, 7 May 1985). This was a report of a conference on Alzheimer's disease held at the National Institute on Aging. During the conference family members complained that despite increased monies for research and despite increased research efforts their situation had not changed. They still had problems with the medical profession and still found regular assistance difficult to
get. We also note the concern expressed by social scientists during the second conference (Miller & Cohen, 1981). This concern involved maintaining an equitable balance in public policy between biomedical interests and the particular needs of families. We draw the reader's attention to our data in Figure 8. Here it is shown that topics that generally reflect the expressed family needs were not addressed until 1977. However, the numbers of documents on these topics remained considerably lower than the other three categories which broadly reflect medical interests. The data do not include any other indicators of fragmentation. Nor can we address the issue of demise. Although no new events occurred between 1980 and 1985 our data indicate a burgeoning interest by biomedical researchers and the public as indicated by media interest.

Limitations of the Study

This study is limited in several ways. We have moved freely between micro and macro levels of analysis. That is we have examined what people do in face to face interaction and we have also analysed macro trends as in the analysis of documents. However, by combining both levels we have lost detail in both levels. This is of course a function of the method employed. Documents limit the researcher by their very lack of reactivity. By confining
the base to secondary rather than primary data, much in-
formation concerning individual actors, for example, can-
not be elicited.

The study is limited by a lack of knowledge concerning
the overlap in content between the Index Medicus and the
Social Sciences Citation Index. That is, it was not
possible to ascertain which journals were indexed in
common between the two. Although our findings show similar
trends in the numbers of documents recorded in both these
Indices, documents recorded in the Social Sciences Cita-
tion Index did not decrease in numbers during 1982 as did
those in Index Medicus.

Triangulation as a method is used very loosely in this
study. That is, the linkages between the quantitative and
qualitative data are not clearly articulated. Content
analysis as a method is non-reactive. By confining
ourselves to this methodology linkages between micro and
macro processes are hard to make. In depth interviews with
key informants would have greatly enriched our data.

Suggestions for Further Research

This study has examined the re-construction of a
disease. A concurrent study might examine the experience
of the disease (for example, Schneider and Conrad's (1983)
study on the experience of having epilepsy). A study in
this mode of Alzheimer's disease would have some methodological problems since ultimately a victim of Alzheimer's disease can no longer cooperate in a rational manner. However, it would provide a perspective on the condition which has not been forthcoming. How valuable it would be to provide insight for others into the day to day world of the confused older person and that of his or her caregiver.

It has been shown that the Alzheimer initiative became institutionalized as defined by Mauss (1975) and Conrad and Schneider (1980). A continuing study beyond the time frame of this dissertation could examine the potential for fragmentation and potential demise of the Alzheimer initiative. It is worth speculating what the political impact might be if many years pass without any significant medical "breakthrough." How one might ask could public and indeed medical professional support be maintained for the medical model given a lack of notable research progress. Our hunch is that since the Alzheimer initiative has broadened its base to challenge other social systems such as long term care it may become diluted. This may potentially deflect attention from biomedical efforts and in effect de-medicalization may occur. We can ponder on what new classification might be developed or what old terminology might restored in this event.
A more in-depth analysis of the documents included in this study in order to investigate contrary claims in selected areas would be of interest. Specifically we have in mind an analysis of the various epidemiological claims concerning dementia.

Conclusion

It is in the course of interaction with one another and with professionals that the problems of people are given definition. If the definition is general and supported by political power, professionals then have strong sanctions in their hands. Professionals do not only serve, they define the very needs which they serve. (Hughes, 1971). Each society defines its own diseases and every culture creates its own responses to illness and disease. Confused older people have become medicalized precisely at the historical moment when, for demographic reasons, it is a common occurrence to be old. Once when senile dementia was not a disease families had no choice but to bear it within the family system of care. Now it is a disease and what the family does for their grandfather or grandmother will be different. There are physicians, clinics, treatment programs and experimental drugs. New problems will arise. When, for example, does forgetfulness become pathological? How can we safeguard
confused older persons against experimentation? As the reframing progresses a host of findings are appearing as we scrutinize the sufferers and their caregivers.

We must recognize that the interaction of cultural patterns and societal trends will continue to change the nature of the world in which we live and thus continuously change perceptions of old age. If we wish to ameliorate the situation of the elderly we must keep our minds open and sensitive to our own preconceptions.
FOOTNOTES

1. In order to define a pathological condition or disease, Koch's Law or Postulate states there are three conditions that must be met. First, the microorganism in question must appear in lesions at all times. Second, pure cultures must be obtained from it. Third, cultures must reproduce disease in animals and pure culture be again obtained from these lesions. The causative agent of Alzheimer's disease has not been identified and attempts to graft brain tissue obtained upon autopsy into animals have not yielded systematic results.

2. Dementia is symptomatic of these diseases. They are however, considered to be pathologically different from Alzheimer's disease. Korsakoff's has been shown to be related to heavy consumption of alcohol. Creutzfeld-Jacob has been demonstrated to be caused by a transmissible virus. In the case of Parkinson's disease, two opposing claims are made. The first suggests that dementia is symptomatic of Parkinson's while the second posits that persons suffering from Parkinson's who display demented behaviors are probably suffering from Alzheimer's disease and Parkinson's simultaneously. It
is posited that studies of families of autopsied patients with Alzheimer's disease have displayed an increased frequency of Down's syndrome.

3. Twenty-three articles on epidemiology were identified. They all broadly addressed the epidemiology of dementia in the context of etiology. That is, issues of distribution by age, sex, occupation and geographic location were characteristic. The major claims of absolute numbers were generally made in passim within the context of other topics and were not contained in documents coded as epidemiology in the analysis.

4. Data on life expectancy at birth and at age 65 in 1900 are based on information obtained from ten states and the District of Columbia. In addition the data also include deaths of non-residents of the United States. The latter stricture also applies to the data cited for life expectancy in 1985.

5. In 1983 $570,000 in a single grant from Dow Chemical was given to the University of Michigan. This grant was omitted from the analysis since it was multi-purpose namely continued support of the Dow
Engineering Building, the construction of a lecture hall at the University's Biological station, and for Alzheimer's disease research at the Medical School. Information regarding the breakdown of the award could not be obtained.
APPENDICES
Appendix A

Listing of Categories

*Index Medicus*
LISTING OF CATEGORIES

INDEX MEDICUS

Anesthesia
Aluminum
Audition
Behavioral Therapy
Community Care
Counseling
Creutzfeld Jacob
Dentistry
Depression
Description of Behaviors
Diagnosis
Dialysis
Downs
Drugs
Education
EEG
Environmental Manipulation
Epidemiology
Ethics
Family
Finger Prints
Genetics
Historical
Huntington's
Insurance
Korsakoffs
Legal Issues

Left Handedness
Medical Practice
Minorities
Nomenclature
Nursing Care
Overview
Oxygen Chamber
Pathology
Parkinsons
Policy Development
Psychological Assessment
Research Needs
Sexuality
Shock Treatment
Shunts
Skin Temperature
Sleep
Special Clinic
Speech
Support Groups
Use of Scans
Virus
Vision
Vitamins/Nutrition
Appendix B

Tabulation of Categories

Index Medicus
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<th>Causation</th>
<th>Assessment</th>
<th>Treatment</th>
<th>Social</th>
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<td>Aluminum</td>
<td>Audition</td>
<td>Anesthesia</td>
<td>Community</td>
</tr>
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<td>Depression</td>
<td>Behavior Therapy</td>
<td>Care</td>
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<td>Description of Behaviors</td>
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<td>Downs</td>
<td>Diagnosis</td>
<td>Drugs</td>
<td>Education</td>
</tr>
<tr>
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<td>Finger Prints</td>
<td>Environmental Manipulation</td>
<td>Family</td>
</tr>
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<td>Left Handed</td>
<td>Medical Practice</td>
<td>Insurance</td>
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<td>Nomenclature</td>
<td>Nursing Care</td>
<td>Legal</td>
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<td>Psychological Assessment</td>
<td>Nutrition</td>
<td>Policy</td>
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Appendix C

Social Sciences Citation Index
Primary Categories of Alzheimer's Disease
by Year

265
Alzheimer, Alzheimer Disease, Alzheimer-Like, Alzheimer Type, Alzheimer's, Alzheimer's Disease, Alzheimer's Type, Senility, Presenile Dementia, Demented, Dementia, Dementia Specific, Dementias, Dementing.

1984 Alzheimer, Alzheimer Disease, Alzheimerism, Alzheimer Type, Alzheimer's, Alzheimer's Disease, Senility, Presenile Dementia, Demented, Dementia, Dementias, Dementing.

1983 Alzheimer, Alzheimer Disease, Alzheimer Diseased, Alzheimer's, Alzheimer's Disease, Senility, Presenile Dementia, Demented, Dementia, Demential, Dementias, Dementing.

1982 Alzheimer, Alzheimer Disease, Alzheimer's, Alzheimer's Disease, Senility, Presenile Dementia, Demented, Dementias, Dementing.

1981 Alzheimer, Alzheimer Disease, Alzheimer Type, Alzheimer's, Alzheimer's Disease, Senile Dementia, Senility, Presenile Dementia, Demented, Dementia, Dementias, Dementing.

1980 Alzheimer, Alzheimer Disease, Alzheimer's, Alzheimer's Disease, Senility, Presenile Dementia, Demented, Dementia.

1979 Alzheimer, Alzheimer Disease, Alzheimer's Disease, Senile Plaques, Senility, Presenile Dementia, Demented, Dementia, Dementias.

1978 Alzheimer Disease, Alzheimer's, Alzheimer's Disease, Senility, Presenile Dementia, Demented, Dementia, Dementias, Dement, Dements, Dementia Dialytica

1977 Alzheimer, Alzheimer Disease, Alzheimer's, Senility, Presenile Dementia, Demented, Dementia, Dementias.

1976 Alzheimer, Alzheimer Disease, Alzheimer's, Senility, Demented, Dementia.
1975  Alzheimer's, Senility, Dementia.
1974  Alzheimer's, Senility, Demented, Dementia.
1973  Alzheimer's, Senility, Dementia, Dementias.
1972  Alzheimer's, Senility, Demented, Dementia.
1971  Alzheimer, Alzheimer's, Alzheimer's Disease, Senility.
1970  Alzheimer's, Senility, Dementia.
Appendix D

Magazines Publishing Articles on Alzheimer's Disease By Frequency, Year and Title
MAGAZINES PUBLISHING ARTICLES ON ALZHEIMER'S DISEASE BY FREQUENCY, YEAR AND TITLE

1979
Science News
Newsweek

1981
Boston Magazine

1982
Prevention

1983
New York Times Magazine \( (N = 2) \)
US News and World Report \( (N = 2) \)
Time
50 Plus
Aging \( (N = 4) \)
Science Digest \( (N = 2) \)
Chatelaine
Bioscience
Consumers Digest
Newsweek
Science News
Essence
Ladies Home Journal

1984
Prevention
Psychology Today \( (N = 2) \)
Consultant
American Medical News
Science '84 \( (N = 2) \)
Current Health
Esquire
Modern Maturity
McCall's
CoEvolution Quarterly \( (N = 3) \)
Science News \( (N = 3) \)
Newsweek \( (N = 5) \)
Forbes
USA Today
Aging \( (N = 3) \)
50 Plus
1985

Scientific American (N = 2)
Nation's Business
Prevention
People (N = 3)
Vogue
Washingtonian
TV Guide
Science News (N = 2)
Good Housekeeping
Macleans
US News and World Report
Discover
Library Journal (N = 3)
Publishers Weekly
Science '85
Horn Book
FDA Consumer
School Library Journal
Jet
American Medical News
Nursing Homes (N = 2)
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