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THE GRAMMARS OF THE OLD AGE PROBLEM: FROM ACTIVITY THEORY TO ALZHEIMER'S DISEASE

by

Robert Joseph Lynott

A Dissertation Submitted to the Faculty of the Graduate School
of Loyola University of Chicago in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

November

1986

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for all you've done and put up with during this long ordeal. To you, I dedicate the following piece of work.

VITA

The author, Robert Joseph Lynott, is the son of the late Edward Alexander Lynott and Ellen (Kennedy) Lynott. He was born on December 11, 1956, in Cedar Rapids, Iowa.

Mr. Lynott attended Loras College from August, 1975 to May, 1979. He received the degree of Bachelor of Arts in Sociology and Bachelor of Science in Psychology, graduating "maxima cum laude." In August, 1979, he entered Marquette University and in May, 1981, was awarded the Master of Arts in Sociology. He began his doctoral studies in Sociology at Loyola University of Chicago in August, 1981. During his tenure, he was awarded a predoctoral fellowship with the Midwest Council for Social Research on Aging and was the recipient of the Arthur J. Schmitt Fellowship. He was also selected as a Junior Scholar for the XIIIth International Congress of Gerontology.

Mr. Lynott has presented papers at a number of professional conferences, including the annual meetings of the Midwest Sociological Society and the Society for the Study of Social Problems. In addition, he has authored several articles dealing with a variety of aging and family issues. They include the following:

- "Family Rhetoric as Social Order" (with J. Gubrium). <u>Journal of Family Issues</u> 5:129-52.

 "Alzheimer's Disease as Biographical Work"
- "Alzheimer's Disease as Biographical Work"
 (with J. Gubrium). In Warren A. Peterson and
 Jill S. Quadagno (eds.), Social Bonds in Later
 Life: Aging and Interdependence. Beverly
 Hills: Sage.
- "Alzheimer's Disease and Institutionalization:
 The Ongoing Construction of a Decision."
 Journal of Family Issues 4:559-74.
- "Rethinking Life Satisfaction" (with J. Gubrium). <u>Human Organization</u> 42:30-38.

reprinted in:

- Beth B. Hess and Elizabeth W. Markson (eds.), Growing Old in America, 3rd edition. New Brunswick, NJ: Transaction Books, 1984.
- "Considerations on a Theory of Descriptive Activity" (with J. Gubrium and D. Buckholdt).

 Mid-American Review of Sociology 7:17-35.

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INTRODUCTION

This is a study of the place of image or vision in the interpretation of experience (cf. Goffman, 1974). The experience considered is aging, in particular, the It is argued that to understand the old age problem. meaning of old age and the problem of aging, one must look beyond the fact of growing old, to the ways growing old and its facts are envisioned. The various approaches that cast the aging experience in one form or another can be thought of as "perception rules," or ways of actually seeing aging. As virtual cognitive languages, the approaches serve as grammars for articulating and perceiving the facts of old age and its problems. Following the argument, I shall use grammar to signify and denote the reality-constructive feature of the approaches. Each approach is, then, a grammar generating a language of experience. Each grammar constructs the observables believed to be the problem of old age.

In examining each of the approaches, or grammars, I shall consider three questions. One, the question of agency, refers to the source of the old age problem as defined in an approach. A second, the question of timing, refers to the pattern by which an approach lays

out the emergence of the old age problem. The third, the question of responsibility, addresses the issue of who or what is held accountable for the problem, given a particular view of agency and timing.

The following approaches are considered: activity theory, disengagement theory, the modernization approach, age stratification, socio-environmentalism, the social-career view, subcultural theory, exchange theory, developmentalism, the continuity approach. Since the late seventies, a new grammar has emerged in medical form, defining the old age problem as disease, Alzheimer's disease. What was heretofore an old age problem secured in the normal troubles of aging has now become one expressed in pathology. Old age is not just a range of troubled experiences fueled by such agents as unequal exchange, discontinuity, and falling status, but is also articulated by illness.

Intervention, scholarship, and research are substantively tied to negative construals of aging. As such, if old age were redefined in positive terms distinct to itself, those who are responsible for servicing elders and their problems, from geriatricians to social workers would, in effect, lose the objects of their labors. It is the negative definition, implied in the various approaches to old age, which makes it

reasonable to search for solutions to what each sees as the old age problem.

GRAMMAR/METHOD

I have chosen the term "grammar" as a way of referencing the variety of approaches to the aging experience. The concept is akin to what Kuhn (1962) calls "paradigms." A paradigm, he asserts, is not just a theory but an all-encompassing way of looking at, and doing, things. Kuhn argues that paradigm changes do not come about through the gradual accumulation of bits of information which eventually form a more accurate picture of the part of nature under discussion. Instead, he sees paradigm as both theory and method and, in the final analysis, as a world of data and experience.

The term grammar accords partially with Kuhn's analysis in that it emphasizes rules and realities (paradigms and communities), less historical emergence. It stresses the discrete, experientially "generative" basis of knowledge, in this case, how theoretical languages in use construe experience in line with their assumptions about it. Webster's New World Dictionary of the American Language (1978), for example, defines grammar as "a body of rules for speaking and writing a given language." The Random House Dictionary of the English Language (1973) defines generative grammar as "a device, as a body of rules, whose output is all of the

sentences that are permissable in a given language, while excluding all those that are not permissable." The concept of grammar, then, suggests separate languages, rules for actually seeing and organizing experiences a particular way.

The theories of aging considered are not only explanatory, but present those concerned with complete worlds of data to which they individually belong. Each theory is as rhetorical as it is descriptive of the aging experience. Each persuades us of its own interpretation, pressing adherents to convey the "facts" of aging taken for granted to be relevant ones, others being extraneous. So it is with the Alzheimer's disease experience, where the ostensible facts of the disease can just as easily, with a shift in grammar (perception rules), present us with the inevitable facts of aging. The issue under consideration is not whether the facts can be accounted for, but rather how facts are literally read into experience in accordance with a working vision (grammar) of them.

As such, each of the varied approaches to the aging experience produces a body of data that are by-products of its own documentation (Garfinkel, 1967). The different sets of data are not as mutually critical of one another as they are about different visions of aging. In this regard, the famous activity/disengagement

controversy is virtually a kind of "talking past each other," their respective grammars referencing entirely different realities—social systemic and individualistic objects of concern. Strictly speaking, then, it is not so much that the various grammars, in their broad range, additively reveal separate parts of the aging experience but, rather, that each grammar displays the entire experience in accordance with its own system of relevancies.

In Relation to Fieldwork

The concept of grammar serves to firmly link the domains of theory and data. The distinction mirrors some rather recent commentary by Schwartz and Jacobs (1979) and Emerson (1981; 1983) concerning the epistemological status of qualitative analysis. The authors distinguish between two completely separate forms of inquiry in terms of the conception of the nature of knowledge being produced: a positivistic one and an interpretive conception. The two conceptions represent different theoretical interests, the first informed by symbolic interactionism and human ecological arguments, the second by ethnomethodological ones. I highlight the difference in the two in terms of what each considers to be the researcher's sense of the reality at stake.

From the positivistic point of view, social objects and events are treated as existing "out there," as it

were, separate from one's attention to them. In this regard, it takes for granted that there is something locatable, called "the field," and that its contents can be accurately described and fully accounted for. This conceptualization represents what could be called a geographic metaphor (Schwartz and Jacobs, 1979). The metaphor is implicit in the fieldwork literature linked with the Chicago School, both in the way ethnographic data are described in monographs and in methodological discussions and/or advocacy on behalf of fieldwork (e.g., Becker, 1958; Becker and Geer, 1960; Bogdan and Taylor, 1975; Habenstein, 1970; Gold, 1958; Thomas, 1923; Whyte, 1943; Zorbaugh, 1929).

When fieldworkers describe themselves or are described as entering a field site and observing it firsthand, the sense of what is being observed is not seriously challenged as problematic in its own right.

Instead, fieldworkers are implored to go to the field, to the place wherein they discover the facts of interest to them. The idea is that the data of interest are located in some delimited arena of human interaction, that once having entered it, the data would become available. One simply has to gain entry (something perhaps not so simple in its own right) and, having accomplished that, to observe the facts located there. The major methodological problem centers on gaining entry and role-

making. When, in effect, one enters and presumably takes his or her place, the data that "anyone can plainly see before his very own eyes" is gatherable.

The formal methodology of this conception of the field is presented in Glaser and Strauss' (1967) book, The Discovery of Grounded Theory. As their analysis shows, it is not the field itself that is of interest but rather its contents, a fairly clear separation being made between them. Thinking geographically, social facts and formations are more or less established and available for observation and discovery.

It is evident, from this approach, that the field is a research-related concept. That is, the concept of the field is the researcher's way of delimiting what he considers to be the relevant facts of interest to him.

The facts obtained, after all, are located in the various scenes observed. The primary task of the researcher is to make those scenes available to him--as might be urged, to "get out there and get the facts."

The interpretive point of view coincides with ethnomethodological interests (Buckholdt and Gubrium, 1979; Cicourel, 1968; Cicourel et al., 1974; Douglas, 1970; Garfinkel, 1967; Leiter, 1980; McHugh, 1968; Mehan and Wood, 1975; Phohl, 1978; Wieder, 1974), and to some degree, with Goffman's (1959; 1974) dramaturgical concerns with conduct. The metaphor here ceases to be

geographic, becoming more linguistic and cognitive. Indeed, field itself becomes more a topic of interest than a resource for gathering information about the "real" objects of concern. (Ethnomethodologists have used the topic/resource distinction to describe their serious concern over their treatment of conventionally trivial procedural matters as important research topics in their own right.) In contrast, the positivistic approach sees the field as a resource used to contain and offer up to fieldworkers its contents, interest being centered not on the idea of field, but on what the field makes available. To treat field as a topic, in line with the interpretive conception, focuses attention on how contents, in effect, become contained (cognitively structured) so that they can be offered up for one's interpretation.

The field, as such, becomes a range of visions—someone's vision(s) or re-vision(s). Being cognitive, they do not exist so much in physical space as they do in orientation. Thus, the researcher's concern with entering the field is primarily limited to administrative details and is not as methodologically relevant in relation to the criteria of objectivity, as it is in the positivistic approach. Indeed, any geographic field can become an unknown number of potential cognitive fields (for researchers and subjects alike). As such, the field

does not make as much sense as which field is being taken up in some time and place. The field, then, <u>is</u> the research project, one question being what field is this to be that is being observed, how is it accomplished?

From the positivistic approach, there is little or no sense that fields are the social projects of their members and as such that there might be variation in the researcher's conception of the nature of social reality such that the idea of the field itself might be open to question. With the ethnomethodological challenge, the field emerges as a theoretical problem. From this point of view, /whatever "the facts" are, are articulated by the researcher's sense of reality at stake. Theory, then, not only serves to describe events, it produces their very existence as well (Filmer et al., 1972). recognition that the theoretical objects of one's attention are, in their essential qualities, always, in certain respects, constitutionally theoretical (Giddens, 1979) makes it reasonable to ask what kinds of "theory" interpret the field. This I have tried to capture with the use of the term grammar. Each of the grammars considered, in effect, constitutes the experience of aging in accord with its particular sense of the facts. The analysis sets aside the question of what is to be the standard of an adequate description and takes up the practice of adequacy in its own right (as the

topic/resource distinction suggests). Thus, the issue is not the relative truth value of facts, but rather how facts are experientially generated as discrete grounds for evaluating the observables in question.

Significance for Grammars of Old Age

The substance and style of the varied grammars of the old age problem are analyzed around three root questions: (1) the question of agency, "Who or what is the source of the problem?"; (2) the question of timing, "When or how does the source of the problem operate?"; and (3) the question of responsibility, "Who or what is to blame for the problem and what can be done about it?" Each of the experiential grammars, from activity theory to Alzheimer's disease, are virtual rules for seeing particular sources of, timings in, and responsible entities for the latter part of life. Each constructs the problem of old age in terms of its particular rules for locating problematic experiences. This is concretely demonstrated in the analysis of the Alzheimer's disease experience, where the ostensible facts of the disease can just as easily, with a shift in grammar, be interpreted as the inevitable facts of aging.

Alzheimer's disease has come to be called the "disease of the century." The phrase signals the monumental importance of the disease for physicians, their patients, helping professionals, and caregivers

(usually a member of the patient's family). Alzheimer's is now recognized as the single most disabling illness of old age, producing intellectual impairment in an estimated 2.5 million American adults. It is an organic illness that results in progressive mental deterioration, characterized by such symptoms as forgetfulness, confusion, irritability, wandering and incontinence. There is, at present, no known cause, prevention, nor cure, yet the disease presents an illness and burden of enormous proportions and significance to those concerned.

As part of a research project aimed at examining the descriptive organization of senility (see Gubrium, 1986), the focus of analysis is not so much to discover the social components and complexities of the medicalization of old age as it is to examine the social organization of two types of discourse (grammar) by which to reference, describe, and explain the "symptoms" of aging. working question for the study is, What social processes enter into discourse framed in terms of aging as opposed/ to framed in terms of disease, and what sustains the latter as a new grammar of the old age problem? transformation is not linear but, rather, oscillates on various levels of the experiences of those concerned in accordance with the descriptive needs at hand. medicalization, in this study, is an ongoing member project, not a linear and progressive process of

redefinition from old age to disease. The study, then, is not a history of medicalization as much as it is a sociology of knowledge approach to it.

ANALYSIS OF THE ALZHEIMER'S DATA

The vocabulary of Alzheimer's disease, the most recent grammar of aging, is analyzed from a number of different sources. The substance and style of the professional, promotional, and popular literature are analyzed for aging versus disease conceptions about senile/Alzheimer's patients. The professional literature includes medically-oriented texts as well as social work and nursing literature. The medical texts consist to a large degree of conference proceedings or edited collections of papers examining the biological and/or behavioral status of the disease. The nursing and social work literature deal primarily with problems of care management and adjustment.

Data are also analyzed from the extant literature of the Alzheimer's Disease and Related Disorders Association (ADRDA). Founded in 1979, the ADRDA is a national network which has grown to over 120 local chapters, one in every major city in the country. Its purpose is to provide support to patients and families in the management and treatment of Alzheimer's and related disorders as well as to disseminate research information, educate the public, and advocate on behalf of the victims

of the disease. The ADRDA's national headquarters, located in Chicago, publishes a quarterly newsletter that is distributed locally to each of the chapter outlets. It informs members and interested outsiders of the latest research findings, legislative successes, and publicity Many local chapters publish their own newsletters too, combining news from "National" with matters of more immediate concern to caregivers such as coping tips and profiles of caregiving experiences. The ADRDA also distributes a variety of promotional and informational material in the form of pamphlets and brochures. Similar kinds of literature are, likewise, offered from cooperating agencies like the National Institute on Aging and the National Institute of Neurological and Communicative Disorders and Stroke. In addition, the news media features a growing number of popular magazine articles, newspaper features, public service announcements, and broadcast programming. information presented, for the most part, focuses on portraits of particular Alzheimer patients and the coping experiences of their caregivers, as well as news on possible "breakthroughs."

I also gathered data by means of participant observation, including conducting fieldwork for a period of four months in a geriatric day hospital affiliated

with a general acute care hospital. The day hospital provided a structured, therapeutic environment for two days a week for nine to twelve Alzheimer's disease patients. The hospital's day care program was conceived as an experiment to assess whether the degeneration associated with Alzheimer's disease could be stabilized. As a participant observer, I often assisted staff in their work, such as taking patients for walks, going bowling, or swimming with them. During the various activities, I was able to appreciate the frustration and the despair of the victim as well as the caregiver. Yet, at the same time, I managed to "stand back" and observe the cognitive tension between the two forms of discourse (aging versus disease) used to make sense of the variety of problems encountered.

As part of the day hospital's research program, the primary caregivers of the patients were tested for their individual definitions of care burdens. Here, too, I recorded their perceptions of impairment and responses to the burden of care, which were regularly evaluated by the day hospital's social worker.

Participant observation was also conducted in a variety of support groups. Connected to the day hospital's program was a weekly support group, in which each patient's primary caregiver participated. The

¹All proper names and places are fictionalized.

session was routinely facilitated by a geriatric nurse, social worker, and geropsychiatrist. Nine to eleven caregivers attended. The ADRDA also sponsors support groups for caregivers in over 120 cities across the country, some being part of state-wide networks of chapters and satellites. Upon obtaining permission, I collected data in ADRDA-sponsored support groups in two cities. Support groups in one of the cities were regularly facilitated by service providers, commonly social workers; support groups in the other city were distinguished by their member facilitation.

Finally, I conducted a series of unstructured but focused interviews with several staff members at the day hospital as well as sixteen caregivers in the households of Alzheimer's patients. The interviews dealt with matters concerning conceptions of the disease, its manifestations in particular patients, the burdens of care, and institutionalization, among a host of factors related to the disease experience (see Appendix A for the complete list of topics covered). Not all topics were discussed with every caregiver and staff member. The interview guide, itself, expanded as additional interviews were conducted, raising new issues for subsequent discussion.

DISSERTATION OUTLINE

The dissertation is divided into the analysis of two bodies of grammar for old age, distinguished according to common usage in the field of aging. gerontologists regularly have contrasted their own studies of the problems of old age with particularly dire ones they have categorized as abnormal (e.g., Kuypers and Bengtson, 1973; Rosow, 1963). In this regard, for example, several volumes of the Duke University studies of old age are entitled: Normal Aging (Palmore, 1970), Normal Aging II (Palmore, 1974), Normal Aging III (Palmore et al., 1985). Standing in contrast to this are old age problems categorized as abnormal, increasingly relegated to the medical domain. Accordingly, part one of the dissertation (chapters 1 through 3) considers the so-called "normal" problems of old age. Part two (chapters 4 through 6) details abnormality--now pathology--as an old age problem in its own right, considering how select problems of aging are medically distinguished from nonmedical problems.

Chapter 1 examines the grammar of the old age problem from the perspective of activity theory. The chapter addresses the activity grammar as an "individualizing" construal of the problem of aging, in terms of maladjustment or life dissatisfaction. The problem lies in an individual state of living that no

longer conforms to the ideal of adjustment reflected in an activity-oriented, work-related standard.

The activity point of view, as the original theory of aging, set the stage for challenge by a range of distinct frameworks, each concertedly posing its own interpretation of the problem of old age. Chapter 2 discusses alternate grammars of life satisfaction and individual adjustment, introducing a variety of social and historical factors into the understanding of personal well-being. Chapter 3 presents the grammars of the political economists and the social phenomenologists, shifting the focus away from attempting to explain individual aging to addressing more thoroughly social conditions—respectively, ideological and epistemological concerns.

Chapters 4 through 6 examine the most recent grammar of the old age problem, Alzheimer's disease. The analysis presents, in detail, a medical understanding of age-related troubles, now separating pathological as opposed to normal old age. Chapter 4 addresses the question of agency regarding the distinction between normal aging and disease. Chapter 5 looks at the timing of the disease experience, considering the onset and course of progress. Chapter 6 examines the issue of responsibility in Alzheimer's, as informed by public and private interpretations.

PART I "NORMAL" AGING

CHAPTER 1

ACTIVITY THEORY AND LIFE SATISFACTION

This chapter examines activity theory, the oldest, but still current (see, for example, Chambre, 1984), and probably most widely applied grammar of aging. Activity theory represents the first analytic statement of the social process of growing old and its impact on the well-being of the elderly, setting the stage for the systematic articulation of the old age experience, its troubles, and problems. Best represented by two key works—Cavan, Burgess, Havighurst, and Goldhamer's Personal Adjustment in Old Age (1949) and Havighurst and Albrecht's Older People (1953)—the theory argues that the life satisfaction of old people is related to the amount of activity in their daily lives. The more active the elder, presumably the more satisfied he or she is with life, the higher his or her morale.

The post World War II concern of sociologists of aging was organized around the concepts of "adjustment," "activity," and "life satisfaction." While the concepts represented features of the aging process, they were not part of a formal theoretical system, but rather centered on the practical problems of elderly well-being. It was

only later that the concern of sociologists in this period came to be called activity theory, with the emergence and direct challenge of disengagement theory (Cumming and Henry, 1961). As a grammar of the old age problem, activity theory is analyzed around the questions of agency, timing, and responsibility.

AGENCY

Activity theorists see growing old as a process of encountering problems of adjustment due to role changes in late life. The authors conceive of the source of the process as focally individual. Growing old is a process whereby individuals—not social systems, not structures of domination, not ideologies—hope to alter themselves in some way to deal satisfactorily with their experiences. The problem is not retirement per se, poverty, widowhood, and/or social isolation; these are the conditions, seemingly "natural" ones. While they referred to them as "the special problems of older people" (Havighurst and Albrecht, 1953:10), the conditions were accepted by the researchers as the way things were, the facts of elderly life.

The route to individual adjustment is located in self-assessment, how the individual defines his or her Own problem as well as what he or she is going to do about it. The problems old people face are understood to be social only as far as their interpersonal experiences.

Indeed, adjustment is defined as "the <u>individual's</u> restructuring of his attitudes and behavior in response to a new situation in such a way as to integrate the expression of his aspirations with the expectations and demands of society" (Cavan et al., 1949:11 [emphasis added]). As such, the scope of concern with the social is delineated by the degree that role loss is handled by individual elders, not how systems of roles in later life define personal adjustment, the latter being a qualitatively different grammar of the old age problem (cf. Chapter 2 of the dissertation).

It is unclear, however, just how the theory views the organization of societal expectations or the mechanics by which individuals respond to them. Societal expectations seem to be that the elderly certainly should continue to engage in many activities. As Havighurst and Albrecht (1953:55) state, "The American formula for happiness in old age might be summed up in the phrase 'keep active.'" Yet, at the same time, society poses restrictions on an elderly individual's activities. The restrictions tend to be "self-protective" for society, dominated by middle-aged adults, and, in Cavan and associates' (1949:22) words, "a way of 'easing' the old person out of activities in order to give the adult group an opportunity to function." An elderly person is expected to stay active but not be too active. He should

"taper-off" or slow down to a noticeable degree, but not slow down too much. As a newspaper headline quoted in Havighurst and Albrecht (1953:36) states, "Grow Old Gracefully--Totter A Little."

Likewise, just how elderly individuals are affected by, or what their response to these demands is, is also unclear. While, on the one hand, Cavan and associates state that an individual should conform to societal demands in order to be well adjusted as well as the fact that "personal adjustment . . . always takes place in the context of a social situation" (1949:14), on the other hand, the authors write:

Personal adjustment is not necessarily secured by achieving the standards set by society, although social standards may have entered into the individual's formation of his level of aspiration. A person tends to be adjusted if his performance reaches his own level of aspiration and unadjusted if he fails to attain it (1949:12).

The implication here is that continuity within ones own life-span may take precedence over societal standards. Notwithstanding the ambiguity of certain aspects of the theory, however, what is clear is that whatever adjusting needs to be done, it is the individual who will be doing it. In this respect, whether or not individual or societal standards of comparison for assessing oneself are used, "the individual is called on to act" (Cottrell, 1942:618). The focus, as such, is not on individuals engaged in role-playing (cf. Becker, 1970) but, rather,

in "role-making," so to speak. While social in nature, it is individuals who make roles what they will be and individuals who make do in relation to the roles they occupy.

Later activity literature (Cavan, 1962; Phillips, 1957; Lemon, Bengtson, and Peterson, 1972), shifts the focus from individual choice of roles to the constellation of role relationships. The analysis gives greater credence to the social features of the adjustment process, with individual well-being more directly tied to role perceptions. For successful adjustment in old age to occur, what is now needed is an approved set of values and roles respected by both society and the specific groups with which an elderly person associates. As such, the informing grammar becomes societal, akin to a qualitatively different way of seeing old age (see Chapter 2). Yet, while there is a social or cultural factor, its independent impact on individuals is tempered by individual action. As Cavan (1962:535), for example, further states in regard to successful adjustment to old "the person must be a member of one of these groups and must value the group's evaluation of himself. will then incorporate within himself the self image approved by the group."

Like Cavan, Phillips (1957) and Lemon and associates (1972) describe individual adjustment in terms of role

definitions, examining various individual role-related self-conceptions. For example, in Phillips' (1957) role theory approach, self-conception means age-group identification, again something over which the individual has control. Phillips argues that age-identification has a significant impact on the relation between role changes and adjustment. He hypothesizes, for example, that role loss leads to maladjustment, but a positive age-identification (defining oneself as young or middle age as opposed to old) reduces the strength of the relationship. Thus, while role loss—a social factor—has an impact on adjustment, its effects can be conditioned by an individual's virtual redefinition of the role effect through varied identification.

TIMING

I now turn to the patterns of adjustment envisioned by activity theorists. Here, the question is, How long can one be successful or well-adjusted while aging before engaging the possibilities of maladjustment? Activity theorists do not specify a definite time point when an individual seriously experiences the problem of old age. As such, an elderly person conceivably can go from adjustment to unadjustment and even back to adjustment again. The different theoretical possibilities range from becoming unadjusted immediately after role losses, to intermittent successful aging, to continual adjustment

or maladjustment. For example, in assuming that elderly persons lose the roles they once occupied in American society, activity theorists predict unadjustment as soon as one retires, upon becoming widowed, or where other major role losses occur. Yet, the actual number, type, and sequence of losses, as well as the individual "doing something about it," can make for various courses of adjustment. Nonetheless, because role loss is considered inevitable, all elderly people are expected to confront, if not to experience, the problem of maladjustment.

Amount and Sequence of Role Loss

Activity theorists maintain that, though everyone experiences some sort of role loss in late life, not all experience them at the same rate. Factors such as physical or mental decline, death of a spouse, poverty, and loss of leadership of various kinds occur at a higher rate for some elderly individuals than for others.

Indeed, while "old age is what the individual makes it, in the majority of cases" (Havighurst and Albrecht, 1953:47), role loss can become so extreme as to virtually eliminate the effect of individual volition in the adjustment process. Yet, as Havighurst and Albrecht (1953:47) point out: "There appear to be few cases of individuals who are so ill, or so dependent financially, that they cannot find some reasonably satisfying roles to live." As a general rule, then, adjustment becomes a

matter of individual incentive, taking as many forms or having as many degrees as effort allows.

The sequence of role loss further complicates the adjustment process. On the one hand, for example, the role loss experienced in the transition from adulthood to old age may be gradual, what Cavan and associates (1949:25) call "one step at a time." Yet, on the other hand, the process may also involve several sudden changes, or "crises," in previously held roles (1949:28). The latter may even make an elderly person seriously maladjusted for a period of time. Depending upon the individual's response to his particular situation, again, many patterns may take shape. a form of intermittent or circular adjustment may result, whereby one could conceivably become maladjusted at one time and be adjusted at some later period, only to subsequently experience maladjustment, should the conditions allow.

Type of Role Gain

Successful aging depends not only on being active in a variety of activities in everyday life, the activities must be socially approved forms of conduct. The portraits of successful aging describe small town middle American life, where acceptable daily life is centered on hobbies, volunteerism, church, family life, and so on. The image is guite evident in the various items of the

Chicago Attitudes and Activities Inventory (Cavan et al., 1949:149-159). The standard of adjustment reflects a stereotypic, small-town, white, Protestant, American lifestyle. To successfully grow old is to be community-involved, church-centered, club-oriented, all reflecting an activity-oriented, work-related lifestyle which serves as the standard of well-being or adjustment.

While the general variable is activity, not all forms of activity appear in the vision of these Few of the following, for example, stand as researchers. portraits of successful aging: muggings, poverty, divorce, telephone talking (cf. Hochschild, 1973), small-time operators and other so-called underworld elderly hustlers (cf. Stephens, 1976), drunkedness, and The vision of age also does not encompass an so on. earlier age in America (pre-20th century), where the affairs of everyday life were affected by the challenges of the frontier. Small town rural America is settled in activity theory, its way of life not continuously a source of dire challenges. Nor is the image in activity a contemporary one, encompassing the central city experiences of many elders, along with the portent of institutionalization (cf. Frankfather, 1977; Siegal, 1978).

Thus, in substance, it isn't roles gained per se that substantiates readjustment, but the substance of

particular roles: gardening, not bootlegging; church attendance, not pandering. The adjusted person is one who takes on a large number and variety of "respectable" roles. Without mentioning this normative definition of role, the theorists predict that the more active the person, the greater his or her life satisfaction or adjustment in late life.

The case of Mrs. Brodie (see Havighurst and Albrecht, 1953:39-43) is exemplary. She occupies several different roles, including mother, grandmother, wife, church leader, club woman, and citizen. Consider her typical day:

The day starts early for Mrs. Brodie. By a little after six each morning, she said she is up and busy about the house. She works "like the dickens" until noon, doing all of her own washing and cleaning. Most of the afternoon she reserves for club work and social activities. The main meal of the household is at noon, and Mr. Brodie walks home from his office for this. Afterwards, while her husband stretches on the davenport, she often reads the paper or magazines to him for a half hour (1953:41).

In their analysis of Mrs. Brodie, Havighurst and Albrecht (1953:41) flatly state that "It is unnecessary to report that nobody in Prairie City has a negative attitude toward Mrs. Brodie; or to say that she is a happy, well-adjusted woman. She fills a variety of generally approved social roles."

Considering the image underlying activity theory as being the implicit standard for successful aging, what

then becomes of the nonrural, nonsmall town, nonWASP, elder in American society? Clearly nothing other than unsuccessful aging, or maladjustment, regardless of amount of individual effort realized. The parochial vision of what it means to be active sets the agenda for what counts as volitional activity in the first place. It is quite clear, for example, that such elders as Stephens (1976) describes as being adjusted to SRO (single room occupancy hotel) living would not be qualified as adjusted in these activity theorists' judgments. As the scoring system of the Chicago Attitudes and Activities Inventory (Cavan et al., 1949:183) illustrates, even the act of sitting and thinking is not considered an activity, a score of zero being given for this "nonactivity." Ironically, the researchers themselves would wind up losers on this item.

Continuity of Life Span

The Calvinistic aura in the work-related features making for successful aging also suggests that elderly individuals should be engaged in activities similar to their adult years. This implies that the type of roles one should engage in should have continuity with earlier roles. The assumption is that work-like activity in old age substitutes for roles typical of middle age as, for example, the farmer in late life turning to gardening illustrates (Cavan et al., 1949:16). Activity theory's

emphasis on the "proper" and unidimensional (work-like) aspect of continuity contrasts with other continuity research which takes continuity within one's life span, in whatever form it takes, as its focus instead of a particular kind and quality of activity as such (see "continuity theory" in Chapter 2 of the dissertation).

Continuity also carries over into an individual's personal attributes. It is assumed that one's ability to adjust to role changes and crises in old age is reflected in an ability to do so at an earlier time in life. As Cavan and associates (1949:76) state:

It is to be presumed that the person who is accustomed to adjusting to life's changes will adjust better in old age than the person who has led a static life; that the person accustomed to making rational decisions will continue to make them; that the person who has evaded issues will continue to evade them.

The same principle is expressed in Havighurst and Albrecht's (1953:50) prognosis for successful aging, declaring that, "The best prescription for happiness in old age seems to be happiness in middle age."

The continuity factor is further interpreted against differences in gender expectations. Consider, for example, Cavan and associates' (1949:23-24) remarks concerning society's ineptness at providing clearly-defined roles for the elderly:

This failure is especially marked in the case of the old man, whose role was previously closely related to his employment and his position as chief wage earner in the family. For the old married woman,

the shift in role is less marked. In fact, such a shift may never be necessary if she is able to maintain her position as manager of her house.

The situation of not having to experience role loss implies that, for some women, adjustment in old age is virtually automatic, something which seems to go against the theorists' assumption that the challenge of adjustment is inevitable in old age. The contradiction of sorts stems from the historical division of conceptions of acceptable male and female work roles. Nonetheless, for women as well as men, once role loss does occur, readjustment is inexorably tied to acquiring roles typical of middle age (see, for example, the case of Mrs. Herman in Cavan et al., 1949:84-86).

The later activity literature, in giving greater credance to social sources as being part of the aging process, see the timing of adjustment as dependent on societal input as well as individual incentive in compensating for differential role loss. In contrast to the earlier activity formulations, the individual cannot as simply overcome the effects of social conditions by reorienting his or her investment in them, such as altering his or her reference group or age-identification.

RESPONSIBILITY

The standard for successful aging, as described, portrays an elderly person as active in many roles,

typified by the socially "appropriate" round of life in proverbial small town middle America. Maladjustment, low morale, and life dissatisfaction are defined in opposition to the standard; whatever "misfits" is undesirable aging. What or who is to blame when adjustment goes awry?

It is quite obvious in activity theory that it is the individual himself that is responsible for his fate in old age. As Cavan and associates (1949:27) state, for example, in regard to retirement, "It is not sufficient that the elderly person realizes intellectually that at age 65 many people are retired in the trade or profession that he follows. He must accept that fact as related to himself." As such, the first step to be taken was for the individual to accept the role losses that occur in his transition from adulthood to old age. The problem was not retirement per se (or any other role losses for that matter); this was considered to be a "natural" condition of life. Rather, the problem of aging was one of the individual accepting this "fact" and, in turn, adjusting to it. Consider, for example, how the authors (1949:27) describe the situation in which several unrelated changes occur simultaneously: "He [elderly person] undergoes a definite period of unadjustment and may become seriously maladjusted. Usually, however, he

is able to readjust by changed attitudes and activities" (emphasis added).

Cavan and associates (1949) describe continued maladjustment in terms of individual resistance. For these practically oriented researchers, rather than resisting the "facts" of old age, an individual should ideally prepare for them in advance and even manipulate the transition to avoid the crises which often occur, as their description of retirement illustrates:

If he has a conviction or even a lingering hope that he will be one of the rare exceptions, then he has not faced the fact of retirement as it applies to himself. In all probability, he has not prepared himself for the change (Cavan et al., 1949:27-28).

Responsibility is not only tied to the acceptance and preparation of role changes, but to certain ones at that. Indeed, when the "proper" roles are not chosen, it is still the individual's own fault. Consider, for example, the placement of blame in regard to the plight of Mrs. Egan, as opposed to Mrs. Bond. In comparing these two women to Mrs. Brodie's exemplary adjustment, Havighurst and Albrecht (1953:43) conclude: "Mrs. Egan and Mrs. Bond have the unfavored role of widow, but Mrs. Bond adds to this several acceptable and enjoyable roles, while Mrs. Egan makes her case worse by adding a number of inactive, unfavored roles." And, in an earlier passage, again comparing Mrs. Egan and Mrs. Bond to Mrs. Brodie, who has the good fortune of being able to



"grow old gracefully," the authors (1953:41) remark,

"What about the people whom the aging process treats less
pleasantly? Even for such people there are pleasant and
favorable social roles if they will work for them"

(emphasis added). As such, it is the individual elderly
person's responsibility to choose and work toward
accepting and living "active" roles in old age, in
effect, seeking, building, and realizing social approval.

Being responsible for his or her own plight in later life, the aged individual is the agent for what is to be done to treat or prevent maladjustment. Thus, in effect, intervention virtually becomes self-help. The essence of this is captured by that maxim of Protestant behavioral persuasion: "God helps those who help themselves." The resolution to maladjustment, then, is a matter of elderly persons virtually picking themselves up by their bootstraps and putting their lives in order.

Provision was made, of course, for the possibility that elders might need help to solve their maladjustment (Cavan et al., 1949). This was to be located in the aid of what was then a relatively underdeveloped but soon to be a virtual "army" of service providers, whose ideas about social pathology fit the scheme of things very well (Mills, 1943). And, still, it was the individual who was responsible for making good on the services, taking advantage of the opportunities they provided.

The later activity literature (Cavan, 1962; Lemon, Bengtson, and Peterson, 1972; Phillips, 1957), in making greater overtures to the social nature of adjustment, shifts responsibility from the aging individual choosing roles to role-playing together with role-making. As Cavan (1962:532-33) writes: "She [elderly individual] will receive a favorable reflection from her groups if she is courageous, if she attacks practical problems realistically, if she increases her civic or church work, and so forth." With greater emphasis on roles and role constraints, for successful adjustment in old age to occur, social forces must take over some of the responsibility for providing the "proper" roles and values for the elderly person to subsequently define himself.

As the social sources of self-worth are emphasized, a leap into the social is not far away. But, it is important to note, what is at stake in the grammars considered in the next chapter is not a gradual turning to social agents of "maladjustment" but entirely new visions of it, lodged in social systems and structures. As such, the "individual" now becomes a social entity.

CHAPTER 2

ALTERNATE GRAMMARS OF LIFE SATISFACTION

The analytic challenge of life satisfaction as the key to the problem of old age took three forms. One form was to maintain the focus on the aging individual, and life satisfaction in particular, introducing a variety of social and historical factors into the understanding of personal well-being. A second form was that of the political economists, who dismissed individual life satisfaction as a major concern and turned to power and privilege. A third form was social phenomenology, where the entire question of life satisfaction, aging, and individuality were themselves put to analytic scrutiny. In its own fashion, each form is a grammar for agency, timing, and social policy in regard to the problem of old This chapter focuses on the first form; the next chapter considers the grammars of the political economists and social phenomenologists.

Included among the alternate grammars of life satisfaction are nine approaches, each represented here by particular exemplars: disengagement theory (Cumming and Henry, 1961); modernization theory (Cowgill and Holmes, 1972); age stratification (Riley, Johnson, and

Foner, 1972); socio-environmentalism (Gubrium, 1973); the social-career view (see Becker, 1970a, chapters 17 through 20); the subcultural approach (Rose, 1965); exchange theory (Dowd, 1975); developmentalism (see Neugarten, 1968, chapters 6, 14, 17, 49; Erikson, 1950); the continuity approach (Atchley, 1972). I will first examine the range of the grammars. Then, with respect to the range, I discuss each grammar's agency, timing, and policy implications.

THE RANGE OF LIFE SATISFACTION GRAMMARS

Alternative grammars can be understood as occurring across a continuum of micro- to macro-social arguments. They range from macrosociological concerns, with causal emphasis placed on large-scale social structures, at one end, to microsociological sources, emphasizing intrapsychological and face-to-face encounters, at the other. Accordingly, as the following scheme shows, disengagement, modernization, and age stratification theories turned to large-scale social conditions to account for the life satisfaction of the individual. On the other hand, exchange, developmental, and continuity approaches turned to personal and interpersonal sources. And, mid-range, socio-environmental, social-career, and subcultural approaches combined the extremes in different ways.

A Continuum of Life Satisfaction Grammars

Macro-Grammars

Disengagement Modernization Age stratification

Combinations

Socio-environmental Social-career Subcultural

Micro-Grammars

Exchange Developmentalism Continuity

Like any classification, the attempt to achieve a sense of order out of a variety of perspectives necessarily reduces its complications. Likewise, while the scheme does serve as a convenient means for comparing the theories at a general level, each configuration of theory, whether to the left, middle, or right end of the continuum, has its own internal considerations as well. In addition, each theory, in and of itself, is necessarily reduced in complexity to fit my general consideration of the alternate grammars of life satisfaction. It is the major focus of each theory, as well as the similarities within each configuration, that justifies the scheme. Moreover, by serving as a device for classifying theoretical variation, the scheme, itself, serves my primary purpose of distinguishing each major shift in the understanding of the problem of old

age. In this regard, for example, what separates this chapter from the previous one is the emphasis these grammars place on extra-individual sources of individual adjustment. Each, in its own way, stresses an ostensible "outside force" that affects what the individual can do, something in addition to the image of one simply picking himself up by his bootstraps.

AGENCY

While all the alternate grammars are concerned with explaining the process of individual adjustment, their means of explanation differ. Another way of putting it would be that they have a common dependent variable—individual well-being—but diverse independent variables. Thus, as far as the question of agency is concerned, one can distinguish between them by asking how each conceives of the source (the agent) of individual well-being.

Macro-Sources

Disengagement theory set the stage for the analytic challenge of life satisfaction, shifting the focus of attention away from the individual as a source of explanation. With the publication of a tentative statement in 1960 (Cumming et al.), along with Cumming and Henry's (1961) book, Growing Old, disengagement theory marks the first statement where a distinct theory

of aging in scientific form emerges, separate from practical applications, information gathering, and policymaking. Informed by Parsons' (1951) social systemic theorizing, Cumming and Henry (1961:14-15) argue that aging cannot be understood separate from the needs and characteristics of the social system in which it is experienced:

In our theory, aging is an inevitable mutual withdrawal or disengagement, resulting in decreased interaction between the aging person and others in the social systems he belongs to. The process may be initiated by the individual or by others in the The aging person may withdraw more situation. markedly from some classes of people while remaining relatively close to others. His withdrawal may be accompanied from the outset by an increased preoccupation with himself; certain institutions in society may make this withdrawal easy for him. When the aging process is complete, the equilibrium which existed in middle life between the individual and his society has given way to a new equilibrium characterized by a greater distance and an altered type of relationship.

While their study is composed of white, healthy, and economically-secure Kansas City residents, the authors nonetheless maintain the theory's universal status, that the "theory is intended to apply to the aging process in all societies" (Cumming and Henry, 1961:15). The aging process for disengagement theory involves a mutual withdrawal, with society virtually giving permission to the individual to disengage. Whether it be, for example, retirement for men (1961:146) or widowhood for women (1961:154), each is treated as the central task of the later adult years; the individual shows an inherent

"readiness for disengagement" by means of these processes.

Drawing on functionalist reasoning, in which all behavioral patterns are construed in terms of the equilibrium needs of the system, the analysis of social interaction sees persons as being fused with society, wherein they become parts of, and not individuals in, In turning to the system and its needs social systems. for clues to the aging process, disengagement theory explains persons' actions in terms of the ongoing operations of the system of which they are a part. example, in modern societies, with the emphasis placed on standards of achievement and efficiency, the social system, in order to be a viable one, requires its work to be done expeditiously and efficiently. Elderly persons, it is argued, do not contribute to the social system with the comparative efficiency of younger adults and thus present a burden to it. The functional maintenance of social systems, therefore, requires some mechanism for systematically disengaging the elderly from major life roles, roles critical to social systemic maintenance. While people make decisions concerning the life course, the choices they are assumed to make are normatively-defined. The individuals that exist are, thereby, "perfected," a quintessential individualism. Cumming (1963:384) states:

The disengagement theory postulates that society withdraws from the ageing person to the same extent as that person withdraws from society. This is, of course, just another way of saying that the process is normatively governed and in a sense agreed upon by all concerned.

In contrast to the "good citizen" in activity theory, which might be represented in the adage that "God helps those who help themselves," disengagement theory's "good citizen" is a complete member of his or her society, a dutiful sentry for system equilibrium. Bv internalizing the norms and values (becoming fully socialized) of society, the individual becomes the perfect individual, so perfect that he disappears into the normative fabric of the social order. He does not confront his society, participate in it as a member of some self-interested segment, nor does he dramaturgically manage his affairs in it. Rather, what exists in social life are systems of role-players, albeit individual ones, that articulate the functional needs of the wider system of which they are a part.

While, on the one hand, disengagement theorists were decidedly not talking about individuals, they were still, on the other hand, concerned with individual adjustment and life satisfaction. System adjustment spawns satisfied individuals. Based on data generated from the Kansas City Study of Adult Life, wherein age-comparisons in levels of various kinds of social involvement and ego investment as well as attitudinal changes provided

evidence of the disengagement process, adjustment in old age hinged on proper system functioning. The individual in disengagement theory, in effect, takes it as his or her obligation to disengage for the benefit of the social order of which he or she is a part, something which ultimately depicts persons as being completely normatively governed. Indeed, to the extent one actualizes disengagement or becomes what Gouldner (1970) calls an "eager tool" of the system, he is adjusted or happy in old age. Cited by Cumming and Henry (1961:164), the case of Mr. Allen's retirement typifies the process:

One important characteristic of Mr. Allen since we have known him has been his readiness to give up his strong bonds to work. His earlier history was one of competence, devotion, and pride in accomplishment. Yet on retiring he was able to alter his pattern with comparative ease, and with only minor twinges of guilt and feelings of loss. In common with many of our more successful male 'disengagers,' Mr. Allen can point with pride to a past history of instrumental success, but he does not feel still bound to these goals.

(See the cases of Mrs. Brown, pp. 171-179, Mrs. Clark and Mrs. Duncan, pp. 181-189, for similar descriptions of "successful" adjustment.)

Responding to the considerable controversy generated by their original statement, Cumming and Henry offered separate revisions of their theory. This development is similar to the "later activity theorists'" revisions, except that for disengagement theorists, revision was more concertedly related to criticism.

In her article entitled, "Further Thoughts on the Theory of Disengagement," Cumming (1963) responded to the problem of differential adjustment or individual variations in the disengagement process. In her response, rather than merely acknowledging that variations do occur at the individual level, she offered a psycho-biological explanation for it, in a theory of temperament. Those who are temperamentally "impingers" are most likely to remain engaged, while "selectors" are most likely to disengage in later life. Aside from this amendment, the theory remains essentially the same. Henry's (1965) more extreme revision of disengagement theory practically abandons it in favor of a more expressly developmental perspective, an approach discussed later in this chapter.

Cowgill (1974; Cowgill and Holmes, 1972) is the foremost exemplar of modernization theory. The theory argues that the elderly's high status held in past societies has declined (at least until the recent past), due to changes associated with industrialization. Like disengagement theory, the modernization approach is influenced by functionalism. However, whereas the former emphasized the normative features of social order, the latter focuses on structural/comparative factors, concern centering on the analysis of various societies at different stages of development. Cowgill's is not a

political economy of age, since he does not emphasize class dynamics as the force behind the changing status of the aged; rather, Cowgill's emphasis is on evolving systems of age statuses rooted in technological advances.

Cowgill (1972) locates several variables associated with age, across societies, and attempts to develop a basis for a universal theory of aging. For example, he states that "the aged always constitute a minority of the total population" (1972:3). Additionally, he lists a number of age-relevant factors that vary across societies, such as level of technology, or degree of urbanization. Cross-cultural variations in income, urbanization, social mobility, education, and aging of the population, in varied combinations, ostensibly affect the status of the elderly. Together, these constitute Cowgill's (1972:2) independent variable, referred to as the degree of modernization, whereby "various societies can be arrayed on a continuum from least modernized to most modernized."

Cowgill argues that in every society, the status of the aged is inversely related to the degree of modernization. As he (1972:12) writes, "The theory adduced here purports to be general and applicable to all societies." The author uses cross-cultural data that simulate history and thus over-determines the cause of change, in which all societies are assumed to follow our

paths. Persons are, in effect, determined by social structure, and one that is following a certain course at that.

In his later work, Cowgill (1974) sets out to more explicitly define modernization by focusing on how its "four most salient aspects"—health technology, economic technology, urbanization, mass education—contribute to the diminishing status of the aged. (Cowgill also incorporates two other factors—what he calls "extraneous" variables—namely, Work Ethic and Cult of Youth, but they are not as integral to the modernization process.) The four components of modernization represent the source of status, with individual adjustment tied to elders' relations to changing modes of production.

Age stratification theory stems from the work of Riley and her associates (Riley, Johnson, and Foner, 1972). It considers the historical and structural experiences of elders as a means of understanding individual adjustment. The theorists argue that age operates as a basis of stratification in a vein similar to other stratification systems, notably class. They conceive of social stratification in a more general manner than traditionally thought of, referring to it as any kind of hierarchy. In comparing and contrasting age stratification with that of class, the authors attempt to

show the viable features of using a stratification perspective as it applies to age.

Riley and associates describe age stratification in terms of differential age cohorts, suggesting that one attempt to understand the individual experiences of growing old in terms of one's placement in the age Treating social structure in a Mertonian structure. fashion, the authors argue that an individual's location within a given age cohort--defined as "an aggregate of individuals who were born (or who entered a particular system) in the same time interval and who age together" (Riley et al., 1972:9) -- determines his or her social allocation of roles, forming his beliefs and actions. As Foner (1976:17) remarks, in regard to the question of differential placement of individuals in strata, "a concise answer is that stratum membership governs the individual's access to the desiderata of the society and shapes his behavior and attitudes in myriad ways."

The theory presents a cohort stratified society, where there is a configuration of events for various time slots or strata, experienced by select individuals—what Riley and associates (1972) call "cohort centric." The analysis paints a determinant and mechanistic picture of human life: stratum membership governs and shapes the individual, leaving unattended the question of the subjectively—practical interpretation of cohort.

Cohorts are not described in terms of group-like Rather, they are taken to be statistical qualities. categories and categorical uniqueness stressed. approach does not question how, and with what consequences, cohorts become groups for themselves, in the service of their own interests. (This, though is of central concern to Rose (1965), for one, whose subcultural theory is a theory of age-consciousness.) With the group-interested feature of age cohorts overlooked, the potential for intergenerational relations and conflicts is glossed over. The age stratification theorists, in contrast, tend to treat cohorts independently of each other, for analytic and research Their interest is in statistically contrasting the social and psychological characteristics of various cohorts historically in order to display cohort-related variations in them, not in how, for example, their concrete social relations might generate the differences. The source of individual age-status, as such, is the cohorts themselves which, in turn, make for personal well-being.

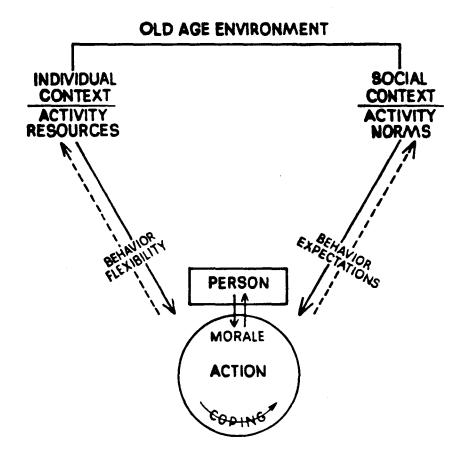
Mid-Continuum Sources

The <u>socio-environmental approach</u>, exemplified by Gubrium (1973), came as a direct challenge to both activity and disengagement theory. Gubrium suggested that the theories were too narrow in not taking into

account what the meaning of activity or disengagement (nonactivity) was for those concerned. Activity theorists assumed that activity was an individually valued conduct; disengagement theorists took the opposite point of view, interpreting value in terms of system needs. The author (1973:33), in stating that "No particular kind or degree of activity is an indicator of a specific attitude," attempted to combine the two approaches by directing attention to the interplay of individual and social contexts of the immediate environment of the aged as it affects a person's morale (see Figure 1).

Figure 1 shows that the socio-environmental perspective has three separate components. The first two--the individual and social components--make up a given old age environment, entailing both activity resources and activity norms. Activity resources include one's level of health, financial solvency, and social support. Activity norms are shared expectations of what is appropriate behavior for different social contexts. Each of the first two features is independent of the other and each can pose various constraints on the person, who makes up the third element of the theory. As Gubrium (1973:36) points out, "Environments for the aged are external constraints on persons' actions. The constraints may be social and/or individual

Figure 1. The Socio-Environmental Approach



restrictions." Persons, on the other hand, take into account the meaning their own activity resources (e.g., good versus ill-health) have in light of surrounding norms.

In considering both the individual and social dimensions of his environment, and the relationship between the two, an elderly individual's adjustment is determined. As the author (1973:59) states:

The aged take both the conditions of their individual resources and the conditions of their social world as contingencies of their environments. Life satisfaction or morale, as a state of mind, is significantly influenced by this two-sided environment.

As such, the object of concern, or independent variable, for this theory is the combined effect of contextual interaction. Depending on the degree of congruence between them, one is either adjusted or not.

Others have advocated a similar kind of approach to old age adjustment (e.g., Kahana, 1974; Kuypers and Bengtson, 1973), whereby the impact of different environments on the well-being of the aged has been examined. Kahana (1974), for example, has argued that individual adjustment in old age is contingent on congruency in person-environment fit, wherein the characteristics of the aging individual are aligned with environmental conditions. As she states (1974:203), "it is hypothesized here that a close fit between environmental characteristics and individual preference

and needs should result in a sense of well-being and adequate functioning of the elderly individual."

what might be called the social-career view of aging (see Becker, 1970a, chapters 17 through 20) is a brand of symbolic interactionism in that it looks at the roles people engage in and how they are socially organized. Life change or stability is a matter of others' definitions of the self. The relationship between self and role is interactional, whereby one comes to know and realize himself by means of various roles (habitual forms of action) played (cf. Karp and Yoels, 1982). situations people encounter in life provide structured settings that socially define the self. The self, on the other hand, is also an active entity that changes with situated interactions. The process involves taking the role of the other, with the self seeking others' definitions of its behavior and subsequent course of Accordingly, shared understandings of life action. experiences develop, making social order possible.

The approach, like many forms of symbolic interactionism, stands between the micro and macro points of view. Becker (1970c) sees both—the analysis of personality components of the self as well as the proper instillation of societal values—as being too simplistic in suggesting that a single course of life change can

explain the many variations in the life cycle. Instead, he (1970c:287) argues,

social structure creates the conditions for both change and stability in adult life. The structural characteristics of institutions and organizations provide the framework of the situations in which experience dictates the expediency of change. Similarly, they provide the counters with which side-bets can be made and the links between lines of activity out of which commitment grows. Together, they enable us to arrive at general explanations of personal development in adult life without requiring us to posit unvarying characteristics of the person, either elements of personality or of 'value structure.'

Becker's analysis is organized around the concepts of situational adjustment and commitment. Situational adjustment is used to account for variations in adult life (as well as life in general), whereas commitment explains constancy. Becker (1970c:279) states that people exhibit marked changes as they move through youth and adulthood (e.g., attitudes, beliefs, styles of interaction) and that concomitant situational factors require one "to act in a certain way or to hold certain beliefs." The author also asserts that situational adjustment is often a collective process involving a "batch" of people. He cites his famous study concerning medical students' shift in belief from a naive idealistic approach to one oriented towards "getting through the system" (see Becker et al., 1961). The self, as such, does not act at will, but rather is constrained by the actions of others or co-participants, a process "in which individuals take on the characteristics required by the situations they participate in (Becker, 1970c:276).

During this process, wittingly or not, persons make side-bets, a process involving "a variety of commitments which constrain one to follow a consistent pattern of behavior in many areas of life" (Becker, 1970c:285). The concept of commitment provides for personal stability in light of changing situations over the life span. As Becker (1970b:301) explains:

A person is committed whenever he realizes that it will cost him more to change his line of behavior than it will to continue to act in a way that is consistent with his past actions, and that this state of affairs has come about through some prior action of his own. So committed, he will resist pressures to adjust to new situations that push him in a contrary direction, perhaps moving out of those situations where that is possible or else attempting to change the situation so that he can continue in the direction of his commitment.

Here lies the dualism of self and social structure. The interplay between the processual self, on the one hand, and the chains of roles organized over time that serve to define it, on the other, make for social-career lines. The object of concern, or independent variable, focuses on the social definition of careers, out of which emerges individual adjustment.

Rose's (1965) <u>subcultural theory</u> of aging also incorporates macro and micro elements in its analysis. The perspective considers the nature and extent of contacts among the elderly as well as the affinity they

have for each other. For Rose, a subculture occurs, when a certain category of people interact with each other to a much greater extent than with other categories of people. The net result, in this case, is the development of an aged subculture with distinctive norms and values, providing a new set of roles for the elderly to define themselves.

It is clear that Rose is referring to one predominant subculture for the elderly. This is seen in frequent references to a subculture or the subculture of the aged in his descriptions of the theory. The title of Rose's (1965) article "The Subculture of the Aging" suggests the same, depicting the notion that "the aging subculture is a general one that cuts across other subcultures—those based on occupation, religion, sex, and possibly even ethnic identification" (1965:7).

Rose argues that the aging subculture has both positive and negative aspects to it. He (1965:78) describes them as follows:

The positive things are those which older people enjoy doing together, or which the whole society encourages them to do together, or which they interpret as being a special opportunity for those with their status. The negative things are those which the elderly do together because they find themselves rejected or otherwise in opposition to the rest of society.

The author compares the negative aspect of the subculture to a counterculture in American society, much like other minority groups. In this respect, minority group theory (Streib, 1965) can be thought of as a theory of subcultures, in this case, a minority aged subculture.

Rose also claims that the status systems of older persons only partially reflect that of the rest of society. As such, the behavior of the elderly is not so much evaluated in terms of some overall social standard or norm but, rather, is tied to the meanings generated out of an endemic subculture, as is the case with other kinds of subgroups. In this regard, such factors as physical and mental health as well as active leadership in old age associations take on special importance.

Being relatively harder to achieve, or maintain, they are more highly regarded and thus have higher status among the elderly.

In general, the theory holds that, as soon as one begins to define himself or herself as old in American society, there comes a corresponding negative change in self-conception, which ultimately leads, for most elderly people, to disengagement and depression. However, a phenomenon known as "aging group consciousness" is, likewise, occurring. The process involves the elderly seeing themselves not merely as a group of people but as a group conscious of itself, having its own common interests and associated courses of action. This enables a new set of meanings and evaluations of old age, such as group pride, to emerge. Here, then, lies the object of

concern, or independent variable: subcultural variations that provide diverse contexts, and standards, by which to evaluate the aging process. A subculture of age provides a collectively representative source of personal understanding and self-evaluation, specific to its members' unique characteristics.

Micro-Sources

Dowd's exchange theory (1975) argues that the relationship between the conduct of elderly persons and individual adjustment, or life satisfaction, can be understood against a contribution/return logic operating in elders' experience. In contrast to activity and disengagement theories, in which the author states (1975:585) that "neither theory . . . attempts to offer anything but the most perfunctory of explanations for the decreased social interaction itself, "exchange theory's main concern is with the question of why elders, for the most part, withdraw from social life. Informed by Homans (1961) and Blau (1964), Dowd's analysis "views social interaction as basically an exchange of rewards between two social actors, be they individuals or groups of individuals" (1975:592). The language of economics is used to describe the contingencies of exchange. However, what is exchanged is not necessarily dollars or goods; it may include such nonmaterial returns as

recognition, compliments, avoidance, or other valued rewards and aversions.

In presenting evidence for elderly dependence "representing the structural realities of twentieth-century industrial society," (1975:109) as well as cohort effects, Dowd does make overtures to macro elements in his theory. Yet, his exchange approach ultimately leads to an analysis of face-to-face encounters, as the following remarks show:

Exchange theory . . . posits that the degree of engagement in old age is an empirical question, an outcome of a specific exchange relationship between an individual or group of individuals and the society in which the more powerful exchange partner dictates the terms of the relationship (Dowd, 1975:593).

Dowd presents an image of age and social integration built on a cost-benefit model of social participation.

In contrast to disengagement theory, he maintains that the withdrawal and/or social isolation of elderly people are not the result of system needs or norms of mutual consent, but rather of an unequal exchange process in which older people are not "getting a fair shake."

Adjustment is contingent on the immediate economy of costs and benefits that exist between persons. A principle of distributive justice—the balance of contributions and rewards—comes into play in aging such that, as elders find they can make fewer contributions because of decrepitude, they experience a decline in

power at not being able to justify social returns. As such, they begin to disengage to balance the exchange equation. Accordingly, Down explains life satisfactions and dissatisfactions.

Developmentalists, in general, are interested in patterned ego changes across the life course. In regard to old age, the work of Neugarten, Gutmann, and others (Neugarten, 1964; 1968; Neugarten, Havighurst, and Tobin, 1968; Havighurst, Neugarten, and Tobin, 1968; Neugarten and Gutmann, 1968; Gutmann, 1968; 1976), as well as part of Erikson's theory of ego/cognitive development (1950), are exemplary. The primary concern is with the person's internal or intrapsychic responses to the aging process. A personality type is treated, at least in principle, as something analytically distinct from self-regard. Because of this, developmentalists are able to raise questions about the relationship between self, on the one hand, and developmental type, on the other.

The theories differ in regard to how they define particular elements of the developmental process.

Concern may center on "developmental tasks," thereby allowing for alternative modes of personality development (Erikson, 1950), or on developmental styles that grow out of different personality types (Neugarten, 1968; Neugarten, Havighurst, and Tobin, 1968), as well as universal, intrinsic properties of growing old (Neugarten

and Gutmann, 1968; Gutmann, 1968; 1976). Thus, while some emphasize the environment in shaping growth, others focus in on the coping styles of types of persons across environments. All, nonetheless, focus on a developmental logic as the source of self-adjustment.

The internal processes or personality are measured by either asking elderly individuals questions or having them interpret visual protocals (among other projective techniques), the answers to which provide a clue to adjustment. The clues also represent the particular stage one is at. The stages are understood to have some sort of impact on the personality, an impact that is universal in nature, regardless of roles inhabited. In effect, the particular stage one is located in determines the personality's adjustment in old age, as when, for example, one manifests an active versus passive mode of mastery in relating to the environment (Neugarten and Gutmann, 1968; Gutmann, 1968; 1976).

Erikson's model, however, does provide for a modicum of freedom for the individual by allowing for developmental alternatives. Likewise, Neugarten and associates' (1968:176-77) analysis of personality types, called "personality continuity," sees the individual as one who "continues to exercise choice and to select from the environment in accordance with his own long-established needs." Yet, while addressing human

freedom, both schemes merely pay lip service to it, the focus instead being on the personality or developmental type arising over time. Consider, for example, how Neugarten and associates (1968:177) summarize their analysis:

we regard personality as the pivotal dimension in describing patterns of aging and in predicting relationships between level of social role activity and life satisfaction. . . . in normal men and women, there is no sharp discontinuity of personality with age, but instead an increasing consistency. Those characteristics that have been central to the personality seem to become even more clearly delineated, and those values the individual has been cherishing become even more salient. In the personality that remains integrated—and in an environment that permits—patterns of overt behavior are likely to become increasingly consonant with the individual's underlying personality needs and his desires.

The object of concern, or independent variable, for developmental theorists is located in one's personality or inner ego processes, the normal (successful) resolution or particular developmental type making for individual adjustment in old age.

The <u>continuity approach</u> (see Atchley, 1972), while not presented as a formal theory of aging, has also been taken into account by a variety of researchers. The view holds that:

in the process of becoming an adult, the individual develops habits, commitments, preferences, and a host of other dispositions that become a part of his personality. As the individual grows older, he is predisposed toward maintaining continuity in his habits, associations, preferences, and so on (Atchley, 1972:36).

As Atchley argues, individuals are inclined to maintain a consistent line of behavior in old age. In contrast to the developmental perspective, where the focus is on emerging inner-psychological life, the concern here is with continued patterns of behavior based on lifelong experiences that are repeated as one ages. The continuity perspective differs from activity theory as well, in that, rather than advocating a "normal" process of continuity (i.e., work-like activity) in late life for successful aging to occur, the focus is instead on continuity per se, regardless of what form it takes. Thus, the source of individual adjustment is the regularity of life conditions over the life course.

Empirically, Townsend (1968) exemplifies the continuity perspective as it relates to adjustment in later life. The approach is a useful foil to the unidimensional and global views of both activity and disengagement theories. Specifically, Townsend had social regularity in mind as a critique of activity theory. Rather than take for granted a modal (normal) level of activity throughout the life cycle, the author focused on the regularity of any level of activity over the span of one's life. He found desolation (e.g., an irregular isolation due to the recent death of a spouse), and not lifelong (socially regular) isolation, to be the major factor affecting one's life satisfaction

in old age. Social regularity or continuity in lifestyle was the critical variable, not any particular level of activity. The source of adjustment, then, is continuity in one's lifelong style of life, what one has become accustomed to as <u>personally</u> normal.

TIMING

I now turn to the timing factor in the alternate grammars. As in the previous section, I look at the macro theories first, then the mid-continuum sources and, finally, the micro end of the continuum.

Macro-Timings

Disengagement theory is described as being not only a mutual and universal process, but also inevitable in later life (Cumming and Henry, 1961). The theory presents the adjustment process as an inexorable feature of old age, eventually occurring in everyones' lives, in all societies. While certain to happen to all, how is its timing explained? In other words, what is the social chronology of the system's adjustment process?

Cumming and Henry (1961:221) use a rainbow metaphor to describe social ties across the life course, with childhood and old age being categorically, but not necessarily totally, individualistically disengaged relative to middle age. There is a continual and systematic confluence of ties with the normative

structure of society as one proceeds from early to middle age (i.e., internalizing society's norms and values); the opposite phenomenon occurs from middle to old age, whereby persons, in their readiness to disengage, become less and less bound to the fabric of society. Once begun, it "becomes a circular, or self-perpetuating, process" (Cumming and Henry, 1961:211).

Besides being inevitable and systematic in its patterning, disengagement theory also has a structured, incremental decline in societal involvement to it. The authors (1961:134) refer to this process as involving at least four stages, as follows:

Those at the beginning or first stage have none of the three characteristics of disengagement; namely, over sixty-five years of age, withdrawn object cathexis, or lack of a central task. The respondents in this category are considered fully engaged. Those at the second and third stages are considered partially disengaged and have one and two characteristics, respectively. Those at the fourth level have all three characteristics and are considered fully disengaged.

Cumming and Henry (1961:211) also state that

"Because people differ in physiology, temperament,

personality, and life situation, disengagement occurs

earlier for some people than for others." They point

out, for example, that such occupations as university

professors and preachers, by having styles "more

compatible with the disengaged condition" (1961:146), or

those "especially endowed biologically" (see the case of

Mrs. Elton, pp. 196-98), are exceptions to the gradual

and systematic decline process. Moreover, in addressing disengagement as a whole, the researchers remark, on a number of occasions, that the precise form the process takes will differ for each person. Thus, at the individual level, the theory allows for considerable variation in the disengagement process, as any unidimensional and global theory must do. On the other hand, drawing on functionalist reasoning, disengagement theorists were not dealing with individuals per se.

Indeed, the individual articulation of what they consider to be a feature of aging roles within a social system is another matter altogether.

In line with their social structural argument, and with functionalism in general, Cumming and Henry point out differences in gender roles and how they affect the timing of disengagement. The differences are due to a division of labor within the system, where men are said to prefer instrumental paths and women socio-emotional ones. As a result, the transition is seen to be easier for women who, granted they are dutiful, may never experience problems of adjustment in the disengagement process; men, on the other hand, categorically experience a more abrupt transition and, as such, may be temporarily unadjusted. Both men and women, however, will experience a crisis after being removed from their central roles in life (work and marriage, respectively) if they are not

provided the proper "disengaged" roles in their gradual process of decline in activity in old age. The structural differences between men and women, within a given system, are similar to those between various systems. As the authors (1961:218) state, "Disengagement is a culture-free concept, but the form it takes will always be culture-bound."

Cumming and Henry interpret the gender differences as simply involving men and women coming upon various stages of the disengagement process at different times, wherein for women, as opposed to men, "There is time to absorb each stage in the well-spaced transition" (1961:159). Indeed, in the final analysis, the two patterns merge into one, as both men and women "display in their eighties and nineties the same pattern of dependency, self-satisfaction, self-centeredness, and placidity" (1961:158). (Those who don't display these patterns are, likewise, said not to be adjusted or satisfied). And, as the authors go on to compare those in their eighties and up, categorically referred to as "the very old," to those in their seventies, assumed to be at an earlier stage of disengagement/adjustment, the continual and systematic pattern of withdrawal is further illustrated:

These very old people seem inwardly directed; all their energy is spent in one form or another on self-concern, without interference from the social norms that once forced them to consider others. On the other hand, our seventy-year-olds still seem to be in the process of being freed from these norms (1961:204).

The ultimate or total form of disengagement, however, is death. Here lies the final end point of timing for disengagement theory; in time, all will disengage. By the same token, it follows that, in time, all will be adjusted.

Death also provides further evidence for the theory as being both an inevitable and universal process of life. The process leading up to death initially involves a psychological shift, where individuals ready themselves for the actual relinquishment of roles central to societal functioning. Functional prerequisites require some means to facilitate one's removal from its infrastructure. As the individual withdraws from more and more social roles, it leads to a final preparation of his or her separation from the social order: "By the end of his life, his bonds have been all but severed—disengagement is complete, he is free to die, and death is the last logical step in the process of living" (Cumming and Henry, 1961:227).

By gradually removing oneself from society and making room for others, one is "free to die," as such, without disrupting the equilibrium of the social system. Dying, therefore, is the final contribution one makes to

societal functioning. Death, in time, sustains the ultimate efficiency of the social system.

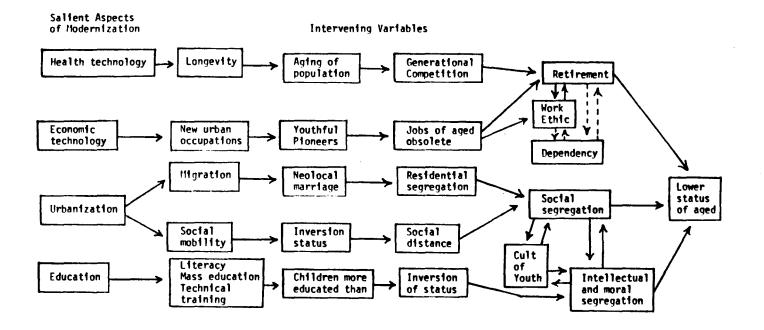
In Cumming's (1963) later psychobiological analysis, the sense of timing remains the same. Henry's (1965) revision, on the other hand, takes on a developmental mode of timing, which is discussed later in this chapter.

Modernization theory, like disengagement, is a functionalist theory of aging. The pattern individual adjustment takes is not the same, however. While both are presented as universal theories by their respective proponents, individual adjustment for the modernization perspective, in contrast to that of disengagement, is connected to history, to the timing of modernization. While disengagement theory acknowledges variations in forms of withdrawal that differ culturally, all, in time, eventually do disengage. Modernization theory, on the other hand, sees a direct link between the rapidity of social change and elderly adjustment. As Cowgill (1972:13) states, "the role and status of the aged varies systematically with the degree of modernization of society"

Each of Cowgill's salient variables--health technology, economic technology, urbanization, education--begins a set of changes adversely affecting elderly adjustment. As he (1974:140) explains, "Selecting the four most salient aspects of

modernization, we have sought to delineate the causal chain linking each with the ultimate outcome--diminished status for the aged." Consider, for example, the health technology factor, as it sets in motion a linear, straightforward sequence of events leading to lower status for the elderly. The process begins with the increased longevity of older people. This, combined with the lowering of the birth rate, results in the aging of the population. The greater proportion of older people causes intergenerational competition in the work place which leads to the elderly being forced out, thus decreasing their status. The other three variables (economic technology, urbanization, and education) similarly trigger their own sequences of events, all ultimately resulting in the elderly's falling status, Cowgill's term for maladjustment (see Figure 2).

Figure 2 depicts individual adjustment as a long-term phenomenon, tied to the timing of modernizing influences within all societies. Modernization theory's global and linear pattern leaves unattended the <u>differing</u> effects industrialization has had on elderly people (cf. Quadagno, 1982). The approach's linearity is not inevitable, however, but rather represents an ideology of developed countries. Modernization is but a glorified expression of the Western model toward which all societies ostensibly move "in time."



palmore and Manton's (1973) additional evidence shows that educational and occupational differences between the elderly and other aged groups tends to level off in more advanced stages of modernization. As such, the pattern of adjustment is curvilinear or, more specifically, J-shaped, where early industrialization depresses the status of the aged, later industrialization increasing it somewhat. This accords with Cowgill's (1974:142) version of change where he states that,

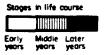
while modernization is detrimental to the status and interests of the aged in is (sic) early stages this trend may "bottom out" in later stages of modernization and from then on there is some comparative improvement in the status and condition of older people.

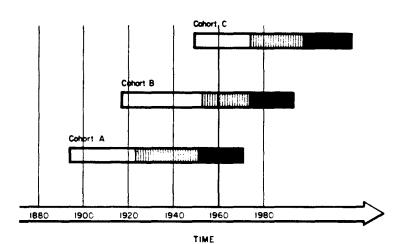
Age stratification's sense of timing also focuses on long-term adjustment patterns, the particular forms taken being linked to cohort/historical components (see Figure 3).

Figure 3 shows that the aging process takes place in a chronological fashion: one grows older, not younger. Simultaneously, groups of cohorts, taken together (age strata), "age" at the same time, a pattern that is both continuous and unchanging. As Riley and others (1972:9) state, "The succession of cohorts . . . is an inevitable and irreversible process."

The critical time element making up individual adjustment in old age is the historical dimension, expressed through cohort analysis. Each cohort enters

Figure 3. Aging and Cohorts Over Time





and proceeds through the age strata with a particular set of historical experiences. The various experiences one may encounter, in turn, make for differential patterns of adjustment. As Riley and associates (1972:11) explain:

patterns of aging can differ, not only from one society to another and from one century to another . . . but also among successive cohorts in a single society. For any given cohort, the pattern of aging will reflect the unique historical background of the cohort, and the special patterns of its compositional segments."

Various demographic characteristics such as race and sex composition as well as differential patterns of longevity, both within and between cohorts, along with one's historical situation, make for a given pattern of adjustment in old age. Thus, the timing of adjustment is cohort-specific. In this regard, Riley and her associates' work, like Cowgill's, features a structured time component.

The authors (1972:524) use an escalator metaphor in analyzing the structured flow of cohorts over time:

imagine an escalator rising through the several floors (which bound the age strata) of a building. All entrants to the building move directly onto the bottom of this escalator (are born), ride steadily upward (grow older), and exit from the building once they reach the top (die). One the way up, the riders can view the scenes on each of the several floors.

They go on to describe what they call a "stable situation," which entails homogeneous successive cohorts on the escalator, versus a "flexible situation," where the size and composition of cohorts both entering the

escalator and riding upward varies, and how such variations make for differences in the age structure. The authors then bring in the historical dimension to display how successive cohorts may differ in the aging process. As they (1972:525) state:

Perhaps the scene on some of the floors is undergoing continual alteration. Then different riders, even though arriving at the same floor, are exposed to widely varied experiences on that floor depending on the time of their arrival. This is the temporal feature of cohort succession that links the population processes to history.

Thus, it is argued that elderly people's evaluation of life--whether life satisfaction, morale, depression, hopefulness, optimism, conservatism--can only be understood by looking at historical and cohort experiences as a way to understand individual adjustment (Riley, 1973). Various examples such as living through the Great Depression, increased longevity, and changing women's roles are cited as evidence of differential cohort effects. For example, it has been argued that, as elderly people age, they become more parochial in their thinking, preferring more conservative lifestyles and taking a reserved view of political and economic change. While much data has supported the proposition, Riley and associates would maintain that this may indeed be a cohort effect. If age experiences were stratified into age cohorts, the foregoing support might only apply to a

particular one. And, at some other historical times, for some other cohorts, the relationship could be reversed.

The timing of individual adjustment, then, rather than being universal, inevitable, and irreversible, is bound (cohort centric) by a particular time and place. While the aging process (chronological aging) is presented as universal, inevitable, and irreversible, being bound to cohorts and, as such, history, makes for variability in patterns of individual adjustment. To the degree time and place are diverse (i.e., flexible situation) so, too, are patterns of individual adjustment. Similarly, more similar conditions produce the opposite effect (i.e., stable situation).

Still, the pattern of adjustment in old age, while infinite to the extent different historical periods are unique, is nonetheless limited in its duration. The finitude of cohorts was shown in the earlier quote about the escalator, where all "passengers" leave the building after their ride through life, regardless of the form adjustment takes. Thus, in time, all eventually do become maladjusted, but in different ways. As such, while particular cohort experiences are historically specific, history has a general course of increment.

Mid-Continuum Timings

Gubrium's (1973) socio-environmental approach sees

the timing of individual adjustment as situationally problematic. As he puts it:

From the socio-environmental point of view, persons and their self-dispositions or attitudes shall be taken as situationally and actively variable. The action of persons is contingent on the significant expectations of others within particular contexts of social interaction. Attitudes toward self vary with changes in the contexts of social interaction and emerge out of the individual and social contingencies of these contexts (1973:34).

Activity resources and activity norms are the two socially contingent factors most prominent in old age. Depending on one's health and economic state, as well as degree of social support, an elderly person will either have the activity resources for being very active or, its opposite, very inactive. As the author (1973:39) states, "Depending on their potential, activity resources determine the flexibility to decide upon a course of action that persons have at their disposal." resources are also influenced by the activity norms of a person's environment. In the same manner that people are constrained by the extent of their activity resources so, too, are they confronted by certain expectations in a given environment. As such, depending on one's activity resources as well as the norms for interpreting them, there are either positive or negative consequences for adjustment in old age.

The constraining features of old age environments make for relatively stable self attitudes, or life

satisfaction, over time. Nonetheless, it is conceivable for there to be many patterns of adjustment in old age, each stable over time. As Gubrium (1973:43) writes, "there are at least as many potential states of high morale as there are legitimized degrees and kinds of activity which are fulfilled by the elderly." The same, of course, holds true for unadjustment in old age. As such, maladjustment is not as much a process in time but one that, depending on the stability of its social and individual contexts, has some or no timing at all.

The social-career view also entails problematic adjustment patterns. The interplay between the emerging self and the variety of social roles that serve to define it make for a number of different possible timings.

Becker's concepts of situational adjustment and commitment not only make up social career lines but, at the same time, provide for diversity in its structure over time. On the one hand, career lines can be very unstable and erratic, which "result from situations which do not permit people to become committed because they deny to them the means, the chips, with which to make side-bets of any importance" (Becker, 1970c:285).

(Becker cites, as examples, students' medical training and their increasing divorce rate.) Other conditions, on the other hand, foster consistent lines of behavior:

Commitment can only occur when there are things present in the environment which are valuable enough that their loss constitutes a real loss. But objects acquire that kind of value only through the operation of a social organization, which both embodies the consensus that ascribes major value to them and creates the structural conditions under which they achieve the necessary attribute of scarcity (Becker, 1970b:301).

The degree to which social structure provides these mechanisms varies not only at the individual level, but also in more institutionalized settings, where side-bets tend to be formalized. Becker and Strauss (1970) describe such patterns in their analysis of career lines in work organizations. Organizational career lines can range from the ideal (which is never fully realized), whereby "recruits enter at the bottom in positions of least prestige and move up through the ranks as they gain in age, skill, and experience" (1970:246), to any number of social configurations. The authors (1970:246) use the metaphor of escalators to describe the patterns:

The flow of personnel through an organization . . . [involves] . . . a number of streams; that is, there may be several routes to the posts of high prestige and responsibility. These may be thought of as escalators.

In applying the metaphor, Becker and Strauss maintain that, while some career lines may be fairly well laid out, in which "higher positions are routinely filled from aspirants at the next lower level" (1970:247), others involve a pattern much more complicated in time and space. The movement of a career line, for example,

need not be upward, but may also be downward, as well as lateral, where one switches to another escalator (switching careers). The speed or pace at which one advances might also vary; for example, sudden vacancies or "being at the right place at the right time" make for rapid movement, while opposite situations such as lack of skills may lead to being "frozen" at a certain level.

Indeed, "some people never set foot on a work escalator but move from low job to low job" (1970:255).

While any number of situational possibilities can make for differential career line patterns, such as recruitment and replacement, training, group allegiance, career interdependence, as well as the changing work world, the focus remains on a developing career over time. This involves various organizational as well as personal side-bets. For example, organizations may provide a set sequence of positions and skills related to a person's age, along with monetary and other rewards, to provide incentives for a certain type of career movement. Individuals, too, may have invested time and money, as well as personal loyalties, along a career route. The particular side-bets involved, which vary by organization, help make for stability. As such, the timing of the particular path a career line takes is related in large measure to the type of structural side-bets. Progress in the course and value of

self-references making up individual adjustment develops accordingly, for better or worse, as selves become committed to certain situated definitions to the exclusion of others. Applied to later life, aging is confronted in terms of the investments and divestments experienced in varied careers of the life course. This makes it possible to relate varied careers to success in the later years.

For subcultural theory, the timing of individual adjustment is linked with an emerging collective consciousness, although exhibited by different degrees of involvement among the elderly. As Rose (1965:3) states, "the aging subculture is developing." While acknowledging the process has a ways to go in that there are certain influences (e.g., mass media, elderly employment) which have kept the aged "in touch" with the rest of society, Rose (1965:74) nonetheless maintains that, "There are certain trends occurring in our society which are tending to create some of the conditions necessary for the development of a subculture." These trends include demographic, ecological, and social organizational processes. The aging of the population, the increase in age-segregated housing, the creation of social welfare programs targeted for the elderly, and the growth of old age organizations, among other factors, combine to produce distinct "aged" conditions (e.g.,

mandatory retirement) as well as isolate them, as a group, from other age groups.

In so doing, the cultural trends serve both to promote interaction among older persons and maximize their exclusion from the population in general—increasing their chances of forming, in Rose's phrase, "aging group consciousness." Various factors related to elderly involvement, however, such as those who continue to accept middle-age values, those who become isolated from all of society except for family, and those who were never "engaged" in the first place, make forecasting the future uncertain.

Micro-Timings

In exchange theory, the timing of individual adjustment is linked with continued social involvement which, in turn, is inextricably tied to the rewards one receives in interaction with others. As Dowd (1975:586) states, "Certain patterns of interaction among social actors (either groups or individuals) are sustained over time . . . because men find such interaction rewarding--for whatever reasons." Depending on the structure of social rewards, interaction is either pursued or avoided.

In regard to the elderly, Dowd argues that, as persons age, their conduct presents a burden to ongoing interaction with others. It takes greater and greater

effort to supplement an individual's shortcomings in a style taken for granted by one's co-participants. With each attempt to maintain a prior lifestyle, an individual's contribution to it, with decreasing competence, shortchanges what others get in return. The benefits to the others outweigh the costs to his continual participation; for example, an older worker's outmoded skills force him to accept a demotion in his job, because he can no longer contribute according to expectations. On the one hand, the elderly person confronts the cost of growing dependence and compliance; on the other hand, others experience the cost of a growing burden of support. The dissatisfaction associated with this leaves the elderly person no other choice but to withdraw or disengage from others.

While Dowd's major concern is with the conditions of disengagement between the elderly and the rest of society (including other elderly persons), by the same token, using the logic of exchange theory, he would also describe the conditions of continued engagement. Dowd would argue that when exchange costs and benefits in the interaction between elderly individuals and others are at least equal, or better, profitable, such elderly persons do not disengage. Likewise, in analyzing the aged as a whole, the author (1975:116) asserts that the unbalanced exchange relationship between them and society "reflects"

current realities and need not, therefore, be characteristic of aging in the future" when more favorable educational and economic factors could change power resources. Maladjustment in old age, therefore, is not inevitable but, rather, is linked to the net return of ongoing exchange transactions. As Dowd (1975:118) states,

an exchange theory of aging predicts outcomes of variable interaction and level of engagement in old age depending upon the relative power of the individual older person or group of older persons vis-a-vis the source of the rewarding interaction, society.

Accordingly, for exchange theory, an infinite number of adjustment timings are possible, depending on the structure of costs and rewards in one's everyday experiences. Individual adjustment among the aged becomes, in effect, a matter of the relative costs versus benefits received in social interaction.

Developmental theorists share a linear concern for the organization of life experiences, typically, a life course with distinct stages or patterns of development. While acknowledging that every individual is different or unique, the perspective assumes that all follow a certain developmental course. The explanations for how and at what pace the self proceeds is one way to represent the variety of theorists (see, for example, Gergen, 1980). Depending on whether, for example, stages are conceived of as transitional (Neugarten and Gutmann, 1968; Gutmann,

1968; 1976) or problematic (Erikson, 1950) the self experiences, respectively, what he inherently goes through, or encounters options related to developmental tasks in what he can go through and become.

The concept of development, conceived of in an orderly and progressive manner, is the dimension that ties age-related experiences together. Consider, for example, the way in which Neugarten and Gutmann (1968) conceive of an ego psychology of adjustment in old age. The process involves three major stages, called mastery styles, which characterize the inner workings of the ego in relation to its outer world. Stage 1 entails active mastery or control of the ego over his world. Stage 2, passive mastery, involves an accommodation process of the ego with his world. And, stage 3, magical mastery, occurs with ego regressing to non-instrumental actions with his world. According to the authors, these are age-related, although there are significant gender-dependent timings affecting their progress.

The personality, in its own right, is also conceived of as having distinct patterns as it develops over time. As suggested in the title of their article, "Personality and Patterns of Aging," Neugarten and associates (1968) analyze distinct patterns, or developmental styles, of personality in old age that grow out of different

personality types. To take from an earlier quote, the authors conclude that, in the normal aging process,

there is no sharp discontinuity of personality with age, but instead an increasing consistency. Those characteristics that have been central to the personality seem to become even more clearly delineated, and those values the individual has been cherishing become even more salient (1968:177).

The key to adjustment, then, is tied to the particular personality type formed (e.g., "integrated" versus "passive-dependent"). Whatever the element of concern--particular personality type (Neugarten, Havighurst, and Tobin, 1968), intrinsic property of aging (Neugarten and Gutmann, 1968), features of societal structure (Neugarten, 1964), developmental tasks (Erikson, 1950) -- the timing of individual adjustment for developmentalists has a fixed set of possible patterns. They relate to an orderly sequence of growth, of "becoming," as it were. While differences in the pace of development occur from theory to theory, all "in time" are either adjusted or not. For some (e.g., Neugarten and Gutmann, 1968), this process is completely determined--all (men before women, however) are destined to be maladjusted -- "out of our hands," so to speak; for others (e.g., Erikson, 1950), it hinges on following what is considered to be a "normal" course of development, a universally set pattern allowing for successful adjustment in old age.

The continuity approach is based on only one particular pattern in the timing process of individual adjustment in old age, regardless of what social category he fits into or what conditions he faces. This pattern involves continuity in behavior over time. As such, what continuity theorists seem to be telling us is that changeless time itself--duration--is the key to adjustment. While adjustment patterns may differ from person to person, for each given individual, it can take only one form. To the extent one continues his lifelong personal pattern in mode of behavior or, after disruption (i.e., desolation), develops a new one, he remains adjusted in old age.

RESPONSIBILITY

Each of the alternative grammars has an implicit moral bent, wherein something is held accountable for adjustment in late life. Accordingly, points of intervention can be located and social policy enacted.

<u> Macro-Policy</u>

The macro approaches, all sharing a common focus on large-scale societal sources--whether structural or normative--as providing for individual adjustment in old age, see responsibility and its implied policy as a long-term proposition. Disengagement theory analyzes individual adjustment in old age by focusing on the needs

and requirements of the social system. Lacking the freedom to act "on their own," persons exist within this system only by virtue of carrying out behavior which is normatively prescribed. The process of disengagement is a gradual one, with continued withdrawal in later life the hallmark of success. Cumming and Henry (1961) show this in their comparison of persons eighty and over (very old) with those in their seventies, the former being described as more adjusted because of their greater degree of disengagement. Individuals, in effect, must aim toward becoming more and more "settled" in old age. The system, in turn, is responsible for moving them To the extent one realizes his obligation and withdraws from life's major roles/activities, the happier he is. As the authors (1961:209) state, "The factor with the greatest bearing on morale seems to be the ability to disengage."

In order to operate smoothly and efficiently, the system must systematically disengage elderly persons from life. To the extent this is achieved, society remains in a state of equilibrium. However, when the process fails—when persons remain engaged in later life—it represents a dysfunctional infringement on system maintenance. It is, therefore, the system's, or society's, responsibility to correct the problem, entailing nonpurposive, evolutionary system adjustment.

Those unwilling to accept society's dictates make continued unsuccessful attempts to stay engaged and become unadjusted. Indeed, when one confronts his society or has some self investment in it, such as enjoyment in continuing to work in later life (see, for example, the case of Mr. Everett, pp. 190-96), he is considered to be maladjusted, a form of deviance from this point of view.

These "late life engagers" represent the problem of old age for disengagement theory. By disrupting "social necessity," they present a burden to system efficiency. As such, the system is responsible for either providing room for their quirks or forcing them to disengage along with others, who, by and large, typify disengagement.

At the system level, no voluntaristic type of social policy follows from disengagement theory. It is eventually system adjustments and readjustments, in a general disengagement process, that sustains the norm. Strictly speaking, individual variation is not what disengagement theory is about. Policy at this level, say, retirement consulting, would constitute patchwork solutions to what is essentially a nonindividual problem. In effect, the system's long-term equilibrating needs stand as its own system of adjustment.

Modernization theory argues that social status in old age is tied to elder's relations to changing modes of

production. The harmful effects of technology, urbanization, and mass education towards the elderly have served to diminish their status, making for unadjustment in later life. As Cowgill (1972:13) states, "[maladjustment] is chiefly a by-product of urban, industrial, mass society." In particular, each of his four salient variables—health technology, economic technology, urbanization, and mass education—instigate a process wherein the elderly, as a whole, become increasingly dissatisfied. Yet, this is most apparent in the early stages of modernization, the later stages providing some improvement in their status.

Responsibility thus lies in the transformation of society, individual adjustment contingent on the degree.

In a manner similar to the "nonpolicy" implications of the disengagement view, one has little or no control over the modernization process as a whole. While varied institutional sectors may be concertedly modernized or persons "motivated to achieve" (cf. McClelland, 1961), the overall process is evolutionary. Thus one can only let things work out for themselves, wherein the elderly should eventually gain back at least part of their previously held status.

Age stratification locates age experience within the context of age-graded cohorts. Treating individuals as being bound to them, the approach portrays an elderly

person who, in all the concrete times and places of his everyday life, acts solely as a member of his own particular cohort. One is, in effect, a product of his times, "marked by the imprint of history" (Riley, Johnson, and Foner, 1972:4). Likewise, location in one or another cohort determines individual adjustment. problems in old age do occur, they are presented as "cohort effects," the particular cohort one belongs to being seen in relation to the other cohorts concurrently making up the age strata. Responsibility for individual adjustment, as such, becomes a historical/structural question, bound to cohort experiences. Tied to cohorts, one must, again, let society (cohorts) run its course. It is changes in the system of age stratification that will influence successive cohorts in the future. example, higher standards of education, while lowering the status of elderly cohorts at one point in history, may make future age cohorts more compatible, or even reverse the relationship between education and aging.

All in all, being a social system concern and, thereby, no one's particular responsibility, maladjustment at the macro end of the continuum is, in effect, something about which no effective social policy can be made. The result is not so much a social fatalism as an evolutionary optimism where, in a manner of speaking, nature knows best.

Mid-Continuum Policy

The mid-continuum approaches locate adjustment problems in the joint effects of structural and face-to-face factors. The socio-environmental approach focuses on the interplay of individual and social contexts of the immediate environment of the aged. Analysis centers on the impact of both individual resources and societal norms on an elderly person's well-In a situation where his activity resources are being. not compatible with surrounding expectations, he is unadjusted. As Gubrium (1973:35) states, "[adjustment] becomes a salient problem among the aged because their activity resources so often lead to a degree of activeness that is at variance with social expectations. This variance leads to negative self-judgments." Responsibility for maladjustment stems from incongruency between persons and their environments.

The kind of social policy suggested by the state of incongruency is to establish programs that meet particular needs and characteristics of the elderly. For example, the provision of certain kinds of housing for the elderly (e.g., age-integrated versus age-segregated), in which they are able to interact with others of similar background (e.g., health, money, family support), would lead to a congruent situation for them. What Kahana (1974) calls "person-environment fit" is an apt way to

describe the prevailing strategy. The consideration of the person is in terms of individual well-being; the environment at stake is face-to-face and immediate.

The <u>social-career view</u>, in emphasizing the importance of others' definitions, focuses attention on social configurations of roles and their consequences for individual adjustment. While the effect that social arrangements have on the self varies with situations, individual behavior can be sustained over time through the process of commitment. As such, depending on how one defines himself in relation to a given configuration of "career" roles, one is either adjusted or not. Those who define their career lines negatively, as interpreted through other's definitions, become unadjusted, encountering a problematic old age. Responsibility for unadjustment lies in the intermingling of given structural arrangements and an active, meaning-seeking self.

The type of policy envisioned by this perspective is one where social settings are organized so as to provide positive meanings for individuals to define themselves. Programs would be developed, as Becker (1970c:287) puts it, "[to] create situations which will coerce people into behaving as we want them to and then to create the conditions under which other rewards will become linked to continuing this behavior." For example, in the case

of occupational career lines, plans would be instituted incorporating upward movement in an orderly and regulated fashion with each next position having appropriate rewards. This would provide both a sense of continuity in one's life and an anticipation of future benefits, enabling persons to continue on a path of adjustment. As far as old age is concerned, this would serve to fill, in an orderly fashion, what Burgess (1960) once called a "roleless role." For example, by tying retirement to company activities, rather than separating its roles from work organizations, career lines would carry into old age.

Subcultural theory centers on developing old age consciousness among the elderly. A subculture effectively isolates the aged from other age groups in society, providing a structure of age-appropriate meanings for self-definition. As such, rather than being interpreted according to societal norms, elderly behavior is appreciated or devalued against the background of expectations tuned to member characteristics.

Ostensibly, to the extent an elder is part of an aging subculture, an opportunity to adjust is available to him. However, his behavior still must be interpreted according to a new set of norms and values and, in that regard, adjustment is personally problematic.

Nonetheless, not being a part and as such subject to

society's often negative judgments, one risks structured unadjustment. This includes, according to Rose (1965:12), a shift in self attitude "as progressively physically and mentally handicapped, from independent to dependent, and from aspiring to declining."

Responsibility is attributed to the developing age subculture which, while it is said to be developing, still has a way to go.

Old age policy centers on the development of self-help or self-pride organizations. In this respect, old age power sentiment is notable. The organizations would include various senior centers and recreational facilities as well as political organizations fostering self-recognition and common interests.

Micro-Policy

Micro approaches see individual adjustment as the outcome of problems in personal or face-to-face experiences. Dowd's exchange theory takes the balance of interactions existing between the elderly and others as the key to personal satisfaction. Individual adjustment in old age hinges on contributing one's share in return for common values. Dowd (1975:587) describes the negative side of this as being a matter of "a series of exchange relationships in which the relative power of the aged vis-a-vis their social environment is gradually diminished until all that remains of their power

resources is the humble capacity to comply."

Responsibility rests on the unequal exchange

relationship, where the elderly are either forced to or

willingly withdraw from social life.

The social policy imperatives envisioned by this approach involve providing the kinds of resources necessary for the elderly to "hold their own." Programs would include plans for studying possible employment opportunities for the aged as well as lobbying groups. The Gray Panthers, for one, have been and continue to be instrumental in this regard. Whatever the details, programs would aim at providing for more equality in the exchanges made between the elders and others, thereby enriching their quality of life.

Developmentalists look to the relation between personality and the developmental environment in analyzing individual adjustment in old age. The source of adjustment centers on a developmental life course and its impact on the individual. Specifically, it hinges on, for example, the successful completion of respective tasks at each stage along a particular course or on the development of a particular personality type.

Responsibility for maladjustment, in these cases, is the particular unsuccessful path followed—from abnormal resolutions of, say, ego-cognition stages along the way. For others, the developmental path is fixed and

determinate, stages being intrinsic properties of aging. Here, problems of adjustment are inevitable in old age.

To the extent that developmentalists "fix" course and stages, voluntaristic policy in unavailable. One is left with the inner-psychological mirror image of functional necessity. Those developmentalists who stress emergence over developmental patterning allow for intervention, for example, training or counseling for the skills or insight necessary to successfully address developmental tasks.

The continuity approach, in arguing that it is not the absolute level of activity per se that determines adjustment in old age but, rather, how continuous current activities (lifestyles) are with earlier ones (lifestyles), locates the source of responsibility for unadjustment in discontinuity. As such, policy necessarily centers on the social maintenance of lifestyle. Researchers of institutional relocation (Tobin and Lieberman, 1976), for example, have advocated smooth as opposed to abrupt relocations, facilitated by individual preparation.

The grammars in this chapter emphasize extraindividual sources of life satisfaction as the key to the
problem of old age, "rounding out," in a matter of
speaking, the activity theory approach. None, however,
rethink the individual problematic of aging, something

which is focally addressed in the following chapter, where one begins to see the possibilities for reflexive grammars. As such, the objects of old age themselves—roles, the person, life satisfaction—become topics in their own right. For some, they are ideological; for others they are social constructs.

CHAPTER 3

BEYOND LIFE SATISFACTION: POLITICAL ECONOMY AND SOCIAL PHENOMENOLOGY

In this chapter, I explore the two forms of grammars of the old age problem--of power and privilege and of social construction--which go beyond life satisfaction. They are radical grammars in the sense that they deny the central reality of the individual as the focus of the aging experience. Rather, individuality is conceived as a by-product of other social forms or processes. It is ideological for the political economists; it is a social construction for the phenomenologists.

THE GRAMMARS IN THE SCHEME OF THINGS

How can political-economic and phenomenological grammars be understood in terms of the macro/micro continuum presented in the previous chapter? The political economists (Estes, 1979; Olson, 1982; Myles, 1984) would judge it as representing bourgeois society, based on a reification of individualism, in "the spirit of capitalism." As current gerontological theory would have it, the aged, as such, are a social problem (rather than having problems created by society) and have

innumerable troubles. Given this assumption, common theoretical practice has been to investigate the immediate conditions that might serve to maximize or minimize the troubles, conditions like level of activity, role loss, social isolation, and social support. Depending on the state of these conditions, their impact on adjustment and life satisfaction varies. When the conditions that affect the life satisfaction or adjustment of elders are located, solutions to dissatisfaction and unadjustment are thought to be evident. The solutions lie in the alteration of immediate conditions, for example, reactivating withdrawn elders.

The political economists have been critical of the "individualistic" thinking in gerontological theory.

Olson (1982:15), for example, writes that all preceding formal theories of aging—from activity to disengagement, developmental, socio—environmental and age stratification—are individualistic and, in her words, "represent attempts to explain existing conditions in terms of individual adjustment." They are what she calls either "free—market conservative" or "liberal accommodationist" views of the relationship of the state to its constituency. The argument is reflexive in recognizing that the theories are more than alternative formal explanations for the so-called "facts" of aging;

their political undertones serve to marshall <u>select</u> facts. Through research practice, they virtually work to establish certain facts which, upon inspection, confirm an implicit but alienating production process.

The social phenomenologists (Gubrium and Buckholdt, 1977; Hochschild, 1975; Starr, 1982-1983) would see the entire continuum as a construction. They would "bracket" it in order to investigate the reality of its components. The concern here is with the social production of individuality and individual adjustment. While focused on the question of age and aging as a lifespan concern, Gubrium and Buckholdt (1977) have been concerned with the nature of age as such and how it can be described. examining what is conventionally understood as the life course and its varied stages, they describe the practical discourse by which interested members produce a sense of age and/or aging, in the data available to them, about select persons in and about service institutions. Age is treated as a product of experience, rather than as a resource by which to examine it. Likewise, age-related concepts are considered, not in terms of how they represent their objects, but in terms of how they assign meaning to them.

The social phenomenologists have criticized theories of the aging process for taking the existential status of age for granted. While all the theories in the continuum

look at variations in the meaning of age and age behavior along, for example, historical, cohort, and exchange lines, the variations are accepted as background factors or forces operating upon the aged (what I have referred to as the independent variable). As such, the interpretation of the so-called forces and their transformation, in the ongoing practice of everyday life, is ignored. The metatheoretical feature of the argument is that the language of age has an intentional quality (Schutz, 1980), such that its use serves to construct a reality for subsequent observation. Being set, background factors and/or the conduct of elderly persons themselves, as studied by gerontologists, tends to reproduce the existing relationships envisioned. Glossed over is a concern for how age, agedness, and age-related "facts" are produced and reproduced in the first place--a concern for facticity over "facts" as such (Raffel, 1979).

Making use of a similar argument, Hochschild (1975) takes up the issue of reality-production by focusing specifically on disengagement theory. She presents both a theoretical and empirical critique of Cumming and Henry's (1961) argument. Hochschild's epistemological concern, however, centers on proposing a clarification of vaguely-defined concepts for disengagement theory, rather

than developing it into a full-fledged critique of the intentional quality of the theory.

AGENCY

Political Economy

The political economists focus on the role of the state in shaping the social and economic conditions of American society and, in particular, of the elderly as a group. This turns them away from the problems of old people as largely lying, according to gerontological theorists, in "their private troubles" and toward the political economy of growing older. To apply Mills' (1959) language further, attention is largely centered on (1) the public issue of age and, less importantly, on (2) the relationship between public issues and private troubles. Political economists tend to treat private troubles as direct distillations of public issues, as if individuals automatically realize in their personal experiences what is defined at large.

The sources of private troubles such as social isolation and role loss in old age, for political economists, is found in the relations between the state and the economy. Marxists give signal governance to the economy; Weberians provide for relatively independent state influence in social relations. Estes (1979) and, in a more analytic fashion, Olson (1982), reflect an economic emphasis. They argue that the "facts" of aging,

in a capitalist society, are part and parcel of the work requirements of a labor market controlled by the needs of industrial development, the state being but a handmaiden of capitalist interests. Myles (1984), on the other hand, has recently argued for greater state autonomy. In effect, the former analysis centers primarily on the social relations of production or economic sphere, while the latter gives greater credence to the interplay of both the economic and political realm. Both analyses, however, while differing in emphasis placed on state "protection" versus the dictates of the marketplace, agree that the primary source of concern is the social, political, and economic conditions of American society and its effect on the elderly. I will consider the Marxian argument first and then discuss Myles' Weberian "amendments."

In her book aptly entitled, <u>The Aging Enterprise</u>, Estes (1979:2) argues that aging, in American society, must be understood as a business:

In using the term aging enterprise, I hope to call particular attention to how the aged are often processed and treated as a commodity in our society and to the fact that the age-segregated policies that fuel the aging enterprise are socially divisive 'solutions' that single out, stigmatize, and isolate the aged from the rest of society.

Olson (1982) carries the message further, focally arguing that the aging experience cannot be understood separate

from its relation to the mode of production. What she calls "a radical theory of the state" sees:

the origins and persistence of age-related problems as inherent in the normal functioning of American Capitalist imperatives for unfettered capitalism. capital accumulation and maximization of profits are inextricably linked with a ceaseless drive for growth; increasing concentration of private market activities; increasing socialization of production costs with profits appropriated privately; rising structural unemployment; cyclical economic crises; significant and growing inequalities in income, wealth, and power; and production for profit at the expense of satisfying human needs. . . . the government is committed not only to the values of private ownership and private profits but also to the necessity of economic and social inequality. These factors profoundly affect the distribution of benefits and deprivations among the population, including older people (1982:21).

The government, then, rather than serving the needs of the masses, caters to the capitalist class, wherein "the primary role of the state has been to buttress capital accumulation and private profits" (Olson, 1982:21-22).

Both Estes (1979) and Olson (1982) present various examples of "the aging enterprise" in operation.

Consider, for example, the Older American's Act of 1965 (OAA), which was informed by a logic of aging not far removed from that of contemporary gerontological theory.

While OAA had the ideal of establishing the independence and well-being of the elderly, its welfare-oriented articulation further transformed the elderly into a state-dependent class, a welfare class. As Estes (1979:30) states:

The symbolic aspects of the goals of the Older Americans Act reassure the public that somehow the aged are being cared for, while policy is simultaneously constructed so that its material impact will not disrupt the ongoing functioning or power arrangements within society.

The program saw the solution of the problems of aging, in application, largely in local planning for the coordination of fragmented recreation-like programs. For example, rather than make the elderly economically solvent, the strategy was to keep them happy in the confines of places like senior centers. Rather than make them independent, individual managers of their affairs, their very sustenance became bound to a system of dependence, perhaps best symbolized by nutrition programs (hot meals and meals-on-wheels programs). Such programs, Estes (1979:22) asserts, "ignore the widespread poverty of the aged and provide no direct economic relief.

Instead the aged become consumers of services that simply feed the expanding service economy."

What Estes and Olson are arguing is that, upon close inspection, such policies, rather than presenting a burden to a capitalist society in the form of a drain of surplus values, generate considerable economic expansion, all presumably in the "service" of elders. The army of experts, professionals, and service providers that have arisen to dole out benefits of various kinds to the elder population have expanded the service sector of the American economy. A tremendously complex welfare

bureaucracy that both controls and presumably benefits elders also provides an ever-expanding job market for the young. The control comes with the credentialing of job holders (Collins, 1979). The process results in a large discrepancy, on income grounds alone, when comparing the income of bureaucrats servicing the elders with the income of the elders serviced. In effect, the political economy of aging serves those who serve the state more than it serves those who are troubled by its conditions.

Another example of the state support of those who benefit in the political economy of aging is the health care system. The medical welfare bureaucracy, in payment for services to largely self-controlled providers of health care like physicians, hospitals, and nursing homes, is a state-supported means of perpetuating the private troulbes of the elderly (Estes, 1979; Olson, The economic support that the elderly receive is just enough to keep them alive and not enough to alleviate their extreme dependence and poverty, as a result of the minimal benefits. Instead, the health care system produces and expands the panorama of health problems said to be in need of care, which futher expands the market for the services of health care providers. effect, the politics of health care feed on the very target of its presumed concern (Alford, 1975). And all of this is periodically publicized as a problem of

critical proportions said to be a current "crisis" in the care-needs of the elderly (Edelman, 1977). The process both stimatizes the elderly and serves the interests of those who control the state, namely, capitalists.

The issue of state control is seen differently by Myles' (1984) more recent argument on public pensions (see also Quadagno, 1984). Rather than simply representing the whims of the marketplace, he views the current status of the state as incorporating a democratic notion as well--what he (1984:4) calls, "the two main pillars upon which . . . [modern Western] . . . societies are built: a capitalist economy and a democratic polity." The dialectic makes up what Myles calls "the liberal democratic state," consisting of the two contradictory principles, one basing rights on the ownership of property and the other on persons as citizens. liberal state professes the principle of "to each according to his or her contributions" (1984:32), depicted in policies that adhere to the standards of the marketplace (that commodity labor). The democratic state professes the opposite principle, "to each according to his or her needs" (1984:32), in which a person's needs are advocated (decommodifying labor). Both principles, embedded in the current structure of the state, are involved in the determination and implimentation of social policies for the aged. As such, rather than

having programs that simply feed on capitalist expansionist interests, as Estes and Olson would have it, such programs also entail requirements providing for certain basic needs.

Social Phenomenology

The social phenomenologists center their attention on membership in various communities of discourse as the agent accomplishing life in general and, in this case, old age. Borrowing primarily from the works of Schutz (1962; 1964; 1967) and Garfinkel (1967), Gubrium and Buckholdt (1977) treat age, agedness, and other age categories as rhetorical/negotiated features of the occasions for the interpretation of such experiences. Members are treated as articulating the realities and categories considered to be immediately at stake. As the authors (1977:viii) explain:

Age-related expectations are created by members of society as they interact with one another on varied They share ideas about what is real and what is false, practical theories about age and behavior in relation to themselves and others. As a collection of people who deal with each other in the affairs of everyday life, they talk about growth, age, maturity, regression, and the like. meaning of age is presented and negotiated from moment to moment as people participate in sometimes elusive but serious conversation. Through statements like "act your age," "look how grown-up he is," and "you're too old for that kind of work," people invoke life course expectations and thus make When they are convincing, a life may seem to When they are not, a life seems problematic until a proper definition of age is secured.

From this approach, the positivistic concern with objectivity is eclipsed by a theoretical interest in facticity, the latter being the process by which objects gain objective quality. Gubrium and Buckholdt (1977:35) argue that the objects of human life are without inherent meaning; yet, they have experiential reality: "Whatever is real about the social world is located in the talk and work that members do to constitute it." By setting aside belief in the reality of objects as things separate from the language used to describe them, facts of aging are assigned and located in the use of age-related language. In this respect, such age-related expectations and facts as "growing old," "maturity," "human development," "stages," and "life crises" come to life in their assertion, invocation, realization, and utility.

The analysis focuses on the organization of discourse, the reality of age lying in talk itself. As the authors (1977:34) state:

Using this frame of reference, when members refer to such things as a 'stage' of life that they have or have not reached, we treat the stages as features of their talk--not some place or entity at which they have arrived or may arrive. What members consider to be their talk <u>about</u> life and living, we treat as talk <u>of</u> them.

As such, rather than asking how developmental stages organize one's experiences, Gubrium and Buckholdt turn this around and ask how persons make use of developmental explanations and justifications for how they treat each

other. It is not as if talk has no concrete objects but, rather, the concreteness of things reveal objects to speakers only by, and through, their meaningful relationship to them--something which is an outcome of the reality-defining labor of practicioners of everyday life. The key here is that discourse is to be understood as discourse-in-use, a matter of practice. Theirs is a social phenomenological understanding of the language of age.

Discursive organizations and transformations are linked with a spectrum of possibilities associated with stocks of knowledge and limitations in horizons of meaning, what Schutz (1970:237) calls one's "world within common reach." Worlds are, in effect, typifications of human conduct, providing meaning to objects in everyday life as well as organizing experiences. They are not understood as concretely isolatable and aggregatable, but as diffusely linked and socially emergent constructed types. Indeed, a given world of discursive understanding is not a place, a container of facts, but rather is productive of facts as such, any location conceivably organizing myriad worlds.

Being an artifact of its accomplishment, worlds of everyday life are treated as process. As such, the world one belongs to does not make as much sense as which world is being accomplished for all practical purposes, each

accordingly organizing different experiences of conduct. The analytic concern becomes one of how certain times and places come to be treated as the locations for the application of certain interpretive rules in the accomplishment of conduct—the production of a given world of understanding being described in its time and place, the same place being productive of other worlds on other occasions. Consider how Gubrium and Buckholdt (1977:46-47) describe membership in this regard:

Our use of the term <u>member</u> . . . connotes a sense of the world as comprising those who, in the course of their action, belong together at times and at other times not. . . Being members of some meaningful occasion, people speak a common ordinary language that references the same taken-for-granted realities; they take the same natural attitude toward things. To be a member of a collection of people gathered somewhere for some purpose is to proceed, together with other members, to use the same tacit rules and understandings (for example, glossing practices) to "put on" that place.

The authors' sense of the world as an occasioned, member-relevant condition of interpretation, is akin to Garfinkel's (1967) "background expectancies." The approach to the issue of agency is discursive and practical. The agent is not a person or some structure; rather, it is both a sense of the source of conditions as well as the rules and typifications used to produce the sense.

TIMING

Political Economy

The political economists link their concern with timing to widespread social and historical change, in effect, the history of the state. The precise pattern the process takes varies somewhat, however, among the proponents of the approach. While Estes (1979) does not deal directly with history per se and, as such, does not significantly develop an analysis of social change, her approach, in general, is comparable to Olson's (1982). This being the case, I discuss Olson's (1982) and, in turn, Myles' (1984) implicit patterns of change concerning the social, political, and economic relationship of the state and the elderly.

Following Marx, Olson (1982) places the relationship between the state and its constituency within the context of the history and structure of the social relations of production. The history of capitalist relations of production (owners/capitalists versus workers/proletariat), within the framework of Marx's writings (see Bottomore, 1956), is such that they are represented by at least two stages of development. Marx traces the roots of mid-nineteenth century capitalism to the emergence of market opportunities in combination with the availability of freed labor in the seventeenth and eighteenth centuries. Early competitive capitalists took

advantage of new markets, inventions, and technical developments (not necessarily in that order) in establishing new means of production, more or less free of ongoing traditions of obligation--all aimed at maximizing profit and the further expansion of capital (Edwards et al., 1973). Combined with a growing pool of labor expropriated from agrarian relations by such events as land enclosure movements and declining agricultural markets, this sets the relational scene for further development of the capitalist system. Thus, a variety of forces bring together two potential classes, one in need of labor and one in need of wages. With the expansion of the capitalist system, the relations of production are crystalized and universalized. Consider how Olson (1982:27) describes the plight of the elderly in this regard:

deep transformations in the American economy and civil society, fostered by industrial leaders to meet their own needs and supported by growing national state activities on behalf of capital, have had pernicious effects on the elderly. The rise of monopoly capitalism was accompanied by a steady proletarianization and de-skilling of the work force. These changes, along with other corporate and governmental practices intended to enhance private accumulation and profits as well as to control and motivate workers, generated increasing unemployment, forced retirement, economic dependency, and poverty among older people.

Olson's (1982) sense of timing regarding the ongoing class relationship is abrupt and disconnected, though not transformational. The process is one of continual

conflict, involving periodic "crises" between opposed interest-related groups. As she (1982:3) states, "'Crisis' situations affecting the aged and the institutions serving them have erupted intermittently since the 1930s. During the last several decades these have occurred with increased frequency and intensity." The author's analysis depicts tension not only between the state and old age problems, but concrete kinds of confrontations where things "come to a head," so to speak. (Marx would see this as a struggle between the "relations" and "forces" of production.) While clashes between classes do occur, they are resolved, for the most part, in a manner favoring capitalist development.

Consider, for example, the Social Security Act of 1935. Presumably, the benefits of this program were directed toward the interests of old people. As a worker ages and becomes less and less efficient, his capacity to contribute to industrial production decreases, or so it is argued. There must be, then, a systematic means for retiring unproductive workers from the labor force (ala disengagement theory). Yet, it would be undesirable to produce a whole class of disenfranchised members of society. Thus, the social order presumably should provide some means of security for this problem.

Olson (1982), in contrast, argues that the history of social security is the history of the ideological

usages of the alleged incapacities of the aged to feed the expansionist production needs of industrial capitalism. It is a means of reserving a pool of labor that efficiently services capitalist production. It is also a means of placating an increasingly restive labor pool that comes with downturns in economic cycles. The author (Olson, 1982:44) explains:

The underlying concern of the Social Security Act was to control the turbulent masses who, in response to widespread unemployment, mortgage foreclosures, depletion of savings, and destitution, were raiding local relief agencies, mobilizing rent riots, participating in Communist-led marches, and organizing violent protests. . . As growing numbers of people began to question the legitimacy of existing institutional structures, a clear threat to monopoly capitalism and the political system materialized. . . . To promote stability and restore confidence in the system, the Social Security Act aimed at mitigating economic insecurity among selected factors of the working class.

As Olson describes, the years prior to the passing of the act were years of depression in this country, with high unemployment. One way to alleviate unemployment was to reduce the demand on available jobs, to systematically but "fairly" ease a portion of the labor force out of it. The origin of social security, as such, was not so much a compassionate interest in the security of the aged, as it was a means of dealing with unemployment, by making the jobs that existed available to the young while placating the poverty of the retirees. Social security was a big enough crumb to reap the gratitude of an economically and

systematically disenfranchised segment of the labor market.

While Olson (1982) sees time in terms of "crises" encounters, Myles (1984) presents an evolutionary pattern, in a more Weberian analysis. Consider Myles! treatment of history. Although he writes of a similar process that took place as Olson (1982), his analysis takes on a more subdued tone. Rather than continued conflict, the author sees a system of compromises, a sort of "give and take," at work. His dialectical view of the relation between the state and economy, what he calls a "marriage between a protective state and a capitalist economy" (Myles, 1984:30), entails an accomodation process between owners (capitalists) and citizens (workers). This was due to an historical process "fraught with conflict and struggle," whereby citizenship achieved certain concessions, which resulted in the "two opposing doctrines [being] subsumed within a single structure, thereby producing the internal tension which provided the source of its own evolution and transformation" (Myles, 1984:30).

It is important to note that Myles' (1984)
evolutionary sense of time is not "evolution in time"
(compare Cowgill, 1972) but, rather, an "achieved" time,
as it were. The process involves institutional kinds of
accomodations, over time, where things gradually "get

worked out." The evolution of social security, thus, was a continual struggle of compromises between the two principles of distribution—a protective state and a capitalist economy. As the author (1984:37-38) describes:

Since the state was not subject to the discipline of the market, state pensions for the elderly could potentially be organized along guidelines other than those derived from the market. The state, however, was and is, subject to the discipline of the political process. Hence market criteria were frequently abandoned as politics required. What politics required in a formally democratic polity was that from time to time the claims of citizenship and the principle of need be acknowledged.

Social Phenomenology

The social phenomenologists treat time, itself, as a social construction. It is an assignment, a means of describing the time-related features of personal human conduct. Gubrium and Buckholdt (1977:vii) "do not assume that life inherently cycles in some ordered or progressive fashion." Rather, they argue that aging, growth, maturity and other developmental "facts" of life are products of the application of a linear, mechanical and temporal mode of interpretation to the diverse, concrete and practical experiences of the everyday laborers of human affairs. Following this, the authors argue that the use of developmentally-informed theorizing or related forms of gerontological thinking, in their concrete application, produce the facts of aging that,

ironically, upon their inspection, reveal them to the observer (a process of "objectification"). As they (1977:8-9) state:

The important questions are not how people <u>respond</u> to life change or <u>proceed through</u> stages, but how they negotiate and generate the reality and meaning of change, stages, and development; how they come to have a sense of them as things separate from themselves . . . and how they subsequently respond to them as real things.

In this regard, consider, for example, Gubrium and Buckholdt's (1977:187-91) analysis of Kimmel's developmental mode of description, in his book Adulthood and Aging (1974). Kimmel asked his respondents a series of questions about life in terms of a clock-time metaphor (see Hendricks and Hendricks, 1976), which he illustrates in several vignettes. Respondents were asked about life changes, particular stages, and what Kimmel refers to as "milestones." It was not uncommon for respondents to raise a number of questions and make a variety of comments that suggest they were answering developmentally-framed questions in terms of particular interpretations. Questions posed to respondents tacitly become, for the respondent, a "question-for-me." This is evident when the respondent asked how he should answer the question in relation to specific conditions in his life, how he felt in this or that situation, and with what period of time or time frame he should organize his response. When Kimmel's intended sense of some aspect of

life was accepted by a respondent, the respondent formulated a response. A few declared that they had not, or did not think of their lives in a certain way, yet went on trying to do so at Kimmel's behest.

For Gubrium and Buckholdt, Kimmel's respondents were not simply reporting the developmental facts of their lives, but were doing so within the substantive purview of what they took to be the author's requests. Being tied into a clock-time chronology, once produced--being on the respondent's mind as it were--the metaphor "reasonably" organized experiences accordingly. Kimmel's questions, in effect, seemed to be as much a part of his data as was the content of his respondents' lives. From the social phenomenological approach, then, developmental discourse is not just a vehicle for symbolically representing realities; its usage in the practical activities of everyday life--whether inside or outside of the interview situation--is concretely productive of the realities.

In a similar fashion, Gubrium and Buckholdt's (1977) analysis of the discourse of service providers, in formally organized settings, reveals that the language of aging, in its application, concretely produces and, with institutionalization, reproduces a widespread mode of description. Being formally organized in application, the discourse, while "artful" (Garfinkel, 1967) to a

degree in its interpretive flux in respect to the interpretation of particular events, nonetheless homogenizes conduct into conventional images of experience--typically being longitudinal, linear, progressive and mechanical.

The authors present evidence of another vision of experiential interpretation, one that is at the center of practice but, for that reason, perhaps too obvious to notice. Their data reveal worlds upon worlds of time construction, time reversibility, time multiplicity and their complications. In line with this argument, Gubrium and Lynott (1983) have challenged one of the central "facts" of concern to gerontologists, the life satisfaction of elders. Investigating the language of a variety of life satisfaction measures, analyzed thematically, it is suggested that to ask elders to represent their lives in a chronologically linear fashion is to ask respondents to interpret their life experiences accordingly. To the extent they do so, they produce a developmental understanding of their experiences.

Taking from Garfinkel (1967), the authors ask what the facts are of life satisfaction on the occasion of its measurement. Life satisfaction researchers have taken the interview situation to be neutral, virtually nonsocial. But, do respondents consider it likewise? For them, it is a situation that, by request and

acquiescence, calls out an interview-appropriate set of interpretations of their experiences. Thus, that world produces a display of respondents' total life in its own fashion. But, other occasions, too, serve to display members' total lives, but in their own ways. The authors' use of ethnographic data reveals the occasioned and constructed features of life satisfactions, presenting us with a multifaceted view of the aging experience.

In this regard, consider, for example, Frankfather's (1977) study of "looping" by down-and-out elders in urban environments, where agedness, descrepitude, and competency change their meanings as the elders enter into encounters with members or representatives of various types of organizations (worlds of understanding). The author shows that as an elder loops from, say, a community residence, to encounters with the police, medical hospitalization, mental hospitalization, nursing home residence, and deinstitutionalization, his life fluctuates among many senses of what it is and has been. Life comes to be a set of "multiple and contradicting interpretations of the same 'facts'" (Frankfather, 1977:15). Being satisfied with life may, as well, be a feature of which world is at stake in a given encounter.

What Gubrium and Lynott (1983) are arguing is that, one feels old or not, behaves elderly or not, feels

satisfied with life or not, depending upon the background expectancies or relevant worlds serving to interpret the aging experience. Though not described by the authors, consider an episode cited by Matthews, drawn from her study, The Social World of Old Women (1979), where shifts in encounters typify worlds of experience. Matthews describes how many of her respondents stated that they felt old, or older than they otherwise would, whenever they were in new situations. The elderly women reported that, in their initial encounters with other persons, much of their interaction centered on the clues given off by their appearances to such things as their typical feelings, their typical attitudes toward things, their typical lifestyle, and their typical capacities and incapacities. As Schutz (1944) might have it, strangers have recourse to nothing but appearances as a means for initially organizing their responses to the older women (or anyone else, for that matter). Reasonably, the personal typification, culturally signified by gray hair and an elderly stature, made the elderly women feel old. This continued until other relevancies besides appearance entered into the interaction. As Gubrium and Buckholdt (1977:65) state, "Once an occurrence has been redefined as typically something other than previously believed, again, in a flash, another whole world is generated." Unfortunately, many episodes or encounters of everyday

urban life are not lengthy enough to permit much beyond the typifications signaled by appearances to enter into interaction (Karp, Stone, and Yoels, 1977). Thus older women, in the context of encounters with strangers who typify appearances accordingly, felt old among strangers. In time, such a world for defining age may or may not shift as a condition for interpreting and organizing behavior.

What the phenomenological approach suggests is that, to the extent a form of discourse becomes institutionalized (becomes the organizing principle of a variety of formal activities), objects become systematic productions and reproductions of their application to human affairs. Yet, at the same time, worlds upon worlds can also be generated whereby all kinds of seemingly contradictory and inconsistent opinions could be entertained which, all in their proper perspectives (worlds), may seem perfectly reasonable. The analysis reveals the contextual and productive quality of worlds of discourse that serves to make the object described reasonable in any number of ways. As such, time is as stable and fixed or as fluid and changing as are ongoing concerns with it.

RESPONSIBILITY

In this section, I examine the sense of responsibility following the respective grammars' positions on agency and timing.

Political Economy

The political economists argue that to understand the problems of the elderly, one should attend to the political and economic conditions surrounding them. stands in stark contrast to the notion that the aged have problems which they are virtually blamed for--blaming the The solution, for the latter, is for the elderly to "do something about it" or, as actually happened, for an army of experts to help them with the task. To coin a sixties-like phrase, the army "makes war on aging." But, the political economists maintain that "Older persons individually are powerless to alter their social status and condition" (Estes, 1979:15), positing that it is the structure of society itself that has created the problem of old age. Just as its proponents differ in their assessment of the source of the problem, so, too, they differ in where responsibility is to be placed. Estes (1979) and Olson (1982), it is the class structure per se; for Myles (1984), it is the class structure and the political arena. I consider each in turn.

Estes (1979) and, more forcefully, Olson (1982), argue that, as an ongoing condition of daily life, the

class structure and its social relationships prevent the majority of its members from enjoying a variety of opportunities or advantages. The rewards of a capitalist society, aligned with the relations, do not represent the relative contributions to the system of production. is, on the other hand, in someone's interest to see economic equality and inequality as as structure of rewards, and thereby legitimize the ongoing relations of production. As such, the authors contend that, given the current political economic system, the solution to the problem of aging can only be a matter of patchwork. The system, after all, serves the interests of those who control it. Therefore, when problems arise, the issue of control is glossed over by the concern for the management of the problem. The structural source of the problem is ignored and replaced by less threatening causal arguments (cf. Chapter 2). It is in this sense that much current gerontological theory serves the state, is an apology for the status quo, and justifies the social organization of "help." As Estes (1979:225) remarks:

Underlying many such approaches has been an implicit value bias toward social policies and programs that would enhance the social activity and life satisfaction of the aged, with far less attention being given to the economic, political, and social conditions that largely determine the quality of their lives.

Estes (1979) and Olson (1982) offer a more radical policy, one that involves "progressive changes that move

society in the direction of democratic socialism" (Olson, 1982:228). To accomplish this end, to "dismantle the aging experience," necessitates a change in economic structure, to a political economy not centered on the maximization of individual interests but on the maximal benefit of all.

Myles (1984) places responsibility for the current situation of the elderly on both the economy and the polity. In this respect, policy is not a matter of radical state and structural change but, rather, is an evolving empirical problematic. As the author (1984:119) states, "whether it is possible to achieve a full-fledged social democracy and the total realization of citizenship that it entails is a question that can only be answered by the future." What Myles (1984) is arguing is that, in the ongoing evolutionary relationship between the economy and politics, many solutions are possible. however, conceivable (while for now, unlikely) for the elderly to achieve a much desired effect. Indeed, Myles (1984:120) ascertains that "If the citizenship principle continues to evolve, the 'elderly' are likely to slowly disappear as a distinctive status group in a larger society." Whatever the future holds, for better or worse, it is the class <u>and</u> the political system that enter into the particular evolutionary path of age relations.

Social Phenomenology

The social phenomenologists do not deal with the issue of responsibility, other than its social The reason is that, while the approach attribution. generates important data about the process of social production, at the same time, it tends to ignore its structure. That is, it tends to leave off its analysis when the human products of the process have been produced, considering the product not as a configuration of social conditions independent and perhaps confronting members but, rather, in terms of its resources and production and reproduction -- a concern for structuration rather than structure as such (Giddens, 1976). To treat the human contingencies of confrontation--where practitioners of everyday life come face to face with the products of their labors--would necessitate a more concrete vision of objects or social forms than the social phenomenological treatment.

One sees, then, that while the political economists and social phenomenologists are at rather opposite poles in their form of analysis, they both nonetheless change the focus of attention away from attempting to explain individual aging, to addressing social conditions. The political economists address them in terms of the impact on, say, an impoverished collectivity of elders, of their relative relations to the mode of production and how

class dynamics produce poverty. (Note that the modernization approach links mode of production [not class dynamics] on the one hand, to age status, on the other.) The social phenomenologists entertain both the social and individual conditions of aging as constructs organized by prevailing stocks of knowledge. In both cases, the central focus of the alternate approaches presented in Chapter 2—the individual's success at aging—disappears and is replaced by age as a social form, either as a social class or category.

PART II PATHOLOGICAL AGING

CHAPTER 4

NORMAL AGING VERSUS DISEASE: THE OUESTION OF AGENCY

Turning to the Alzheimer's disease experience, one finds an entirely new grammar for defining the old age problem, one founded in a medical construal of growing Rather than, as in the first part of the older. dissertation, viewing the old age problem as a by-product of normal individual or social sources in later life, the old age problem here is treated as an abnormality. normal aging, the old age problem, in principle, can be Furthermore, as "pathology", the old age problem cured. has medical sources, degenerative timing, and nonvolitional accountability -- medical specifications of the questions of agency, timing, and responsibility. this chapter, I focus on the question of agency regarding the distinction between normal aging and disease. Chapters 5 and 6 consider the questions of timing and responsibility, respectively.

Alzheimer's disease was first described in 1907 by a German physician named Alois Alzheimer. It did not emerge as an old age grammar, however, until the 1960s and 1970s. Before then, the disease was believed to chiefly affect those under the age of sixty-five and, as

such, was referred to as "presentile dementia." As for old age ("sentile dementia"), itself, the common understanding was that it resulted from arteriosclerosis or "hardening of the arteries," a view which, as Reisberg (1981:12) notes, is still prevalent today:

The popular image is of blood vessels which become progressively narrowed from fatty deposits. As the vessels of the brain become strangulated and sclerosed, less and less blood is able to reach the brain and provide the nourishment necessary for optimal functioning. Behavioral deterioration is thought to result from these circulatory changes. First, a person may begin to forget things. Later, the lack of blood and oxygen may cause the person to become entirely demented. Often the narrowing of the blood vessels is thought to result in strokes and, ultimately, in death.

Dramatic evidence to the contrary came in the 1960s from a group of pathologists and psychiatrists in Newcastle-upon-Tyne, England (Blessed, Tomlinson, and Roth, 1968; Tomlinson, Blessed, and Roth, 1968; 1970). Having compared the autopsies of fifty demented aged persons with twenty-eight nondemented elderly used as controls, the researchers reported that arteriosclerotic changes accounted for much less dementia than was thought, a much greater percentage (over 50 percent) attributed to certain histopathological changes indicative of Alzheimer's.

The findings, along with results from pathological studies conducted at the Einstein College of Medicine in New York (Terry and Wisniewski, 1975; Terry, 1978), suggested that Alzheimer's was not limited to its

presentile form (as interpreted by Alois Alzheimer in research on a fifty-one-year-old patient), but was a dementia of old age as well. As Reisberg (1981:15) puts it:

Hence, 'Alzheimer's disease' is now thought to be the same condition whether it occurs in a fortyfive-year-old person or a ninety-five-year-old person. The underlying pathology and the disease process, so far as is known, is the same, regardless of the age of onset.

The new disease classification has resulted in considerable confusion over the terminology of Alzheimer's (see Reisburg, 1983:3-5). Because the term "dementia" is primarily a clinical disorder, originating from many types of organic lesions, one of them being the neuropathologic changes associated with Alzheimer's, the phrase "senile dementia of the Alzheimer type" (SDAT) is frequently used to distinguish the disease.

Alzheimer's is considered to be both an organic and a behavioral disease, the former characterized by neurofibrillary tangles and senile plaques in the brain, the latter by memory loss and confusion. While the brain/behavior markers ostensibly make for a disease entity separate and distinct from aging in general, the distinction is by no means straightforward. All existing evidence, from neuropathological to psychological, can be and is garnered on behalf of both. Indeed, as published transcripts of medical conferences on Alzheimer's disease show, the fundamental factual tension of the disease is

its nosological (categorical) status in respect to the "normal" aging process. As will be shown in this chapter, conference proceedings display direct evidence of the interpretive work involved in sorting out what the realities at stake—disease versus normal aging—are to be. It is being argued that it is not the facts per se that serve the distinction, but how the facts are put to use or socially constructed.

Alzheimer's can be devastating for the victim and the caregiver. Yet, what is the devastation to be? The devastation of premature or advanced aging--something which is believed to be normal--or the product of a disease agent? The issue is not whether people suffer, but to what suffering is to be assigned. Biological sources of the suffering is considered first, the behavioral sources second.

THE BIOLOGICAL SOURCE: READING NEUROPATHOLOGY

The neuropathological markers of Alzheimer's are
revealed by light and electron microscopy. They include
neurofibrillary tangles and senile plaques as well as
granulovacuolar and other bodies. Severe cerebral
atrophy (shrinkage) is also present, but does not serve
differential diagnosis. Neurofibrillary tangles are the
organic hallmark of the disease. As Reisberg (1981:1719) describes:

The most important and characteristic change is the appearance of unusual quantities of neurofibrils in certain areas of the brain. These neurofibrils have a characteristic shape and size. In Alzheimer's disease they are found predominantly in the cerebral cortex. They are found in particularly large concentration in the hippocampus, which is the part of the brain thought to be associated with short-term memory, and especially in the pyramidal cells of the hippocampus. . . .

The neurofibrillary tangles . . . consist of pairs of filaments wrapped around each other in a helical fashion. . . [They] are also known as paired helical filaments (PHFs) because of their unique configuration, [and] have been found only in human beings, [and] are encountered in certain human conditions apart from Alzheimer's disease.

Reisberg goes on to describe the two other histopathological changes characteristic of the disease:

Classical senile or neuritic plaques, as they are also called, consist of an amyloid core surrounded by degenerative neuronal processes and reactive nonneuronal cells. The degenerative neuron processes are known to consist almost entirely of axonal terminals or perterminals. In the region of these degenerative neuronal processes, and to a lessor extent in the dendrites and synaptic endings outside the plaque area, one encounters the PHFs (1981:24).

And the author continues:

The third characteristic pathological change in the brains of patients with Alzheimer's disease is "granulovacoular degeneration." This is really a descriptive term for certain changes which appear inside cells. Specifically, the interior of a cell undergoing this form of degeneration becomes crowded with fluid-filled "vacuoles" as well as with granular material. . . . An increased concentration of granulovacoular degeneration [is found] in certain areas of the hippocampus (1981:35).

Yet, there is clear evidence of the <u>same</u> organic bodies in the brains of normal elderly persons, leading some researchers to be cautious about the disease

implication. The researchers point out that the changes commonly associated with Alzheimer's, as opposed to the normal aging process, are the basis for a quantitative, not a qualitative distinction. As Terry (1978:12), expressing his reluctance to make the disease distinction, explains:

It is usually argued that there are clear differences, and that senility is a disease while normality in this sense is the absence of disease. This writer, however, is less than convinced on this point. . . . Plaques and tangles are present in area H2 of the hippocampus of the elderly normal and the SDAT specimens. This is true ofthe great majority of aging normal people. The difference here is clearly a quantitative one, since large numbers of these lesions elsewhere (H1) in the hippocampus and the neocortex correlate quite closely with the presence of dementia. Even the chemical changes do not present qualitative differences between elderly normals and dements.

Given such evidence, Terry and Wisniewski (1977:3) conclude:

One cannot help but wonder, then, whether we should consider that a pattern of continuous changes characterizes the passage from normalcy to that dreadful extreme, senile dementia.

The nosological tension often gets repeated in descriptions of the neuro-organicity of Alzheimer's disease. For example, in Reisberg's account of the characteristic changes associated with Alzheimer's quoted earlier, the author (1981:35-36) also takes note of its age-related features:

Each of these pathological hallmarks [neurofibrillary tangles, senile plaques, and granulovacuolar degeneration], individually, is positively associated with progressive idiopathic

(senile) dementia in man. Each of these pathologic hallmarks is also seen increasingly frequently in many nondemented aged individuals.

Moreover, Tomlinson, Blessed, and Roth (1968:355), in their pioneering work, assert that:

Finally it is clear that great caution is needed in the interpretation of 'senile' changes of the kind described in the pathological investigation of any disease in old age, since, provided they fall within the range described they are likely merely to reflect the age of the patient.

In effect, what is tacitly being said, but at the same time glossed over, is that the neuropathological markers of Alzheimer's can be the organic hallmark both of a disease and of advanced (normal) old age.

Other researchers, however, are inclined to interpret the facts differently. Katzman, for example, in a discussion following a conference paper presented by Terry and Wisniewski (1975), entitled "Pathology and Pathogenesis of Dementia," takes issue with Terry's quantitative interpretation. Quoting from the transcription:

DR. KATZMAN: I did want to emphasize the one major difference in outlook between Dr. Terry and myself in regard to the relationship of normal aging to Alzheimer's disease. I have become convinced that Alzheimer's disease is a disease and not simply an acceleration of normal aging. There are, to be sure, pathological changes which are identical in the two. However, the distribution of these changes differs, that is, they are primarily in the temporal lobe and hippocampus in the nondemented patients. Tomlinson has reported that if you look at the cortex of demented and nondemented patients, there is clearly almost no overlap in the number and incidence of both plaques and tangles in the two population groups (Fields, 1975:147).

Unlike Terry, who is reluctant to distinguish the disease qualitatively from what is called "normal aging," Katzman sees the distribution of neuropathological changes in the brains of demented and nondemented persons as great enough to merit a disease distinction, a category in and of itself, not merely an extreme version of the aging process.

Whether the observables are taken to be a disease entity or advanced old age, their reality-status is not obtainable by a mere detection of the "facts" at hand.

Rather, the question becomes one of how the facts are to be interpreted. As Terry's and Katzman's statements show, facts "do not speak for themselves" but, rather, are spoken for. As such, they become facts-for-us, description being as much a part of the data as representative of it.

While the age-related features of the organicity of Alzheimer's disease underpins a continuing controversy among medical researchers as to what exactly it is they are dealing with, in the final analysis, even among the skeptics, the disease definition prevails. Still, given the problematics concerning the neurological basis for clearly differentiating ostensibly diseased from normal elders, how the conceptualization of an abnormal entity is arrived at is not a simple and straightforward

process, but rather often involves considerable interpretive discretion.

Published transcripts of edited discussions following paper presentations at medical conferences display the social and interpretive work that enters into discourse, a process of framing in terms of a disease grammar or framed in terms of aging. Consider, for example, an excerpt (Katzman, Terry, and Bick, 1978:265-266) taken from part of the proceedings of a 1977 conference on Alzheimer's disease, senile dementia, and related disorders. The conference was co-sponsored by the National Institute of Neurological and Communicative Disorders and Strokes, the National Institute on Aging, and the National Institute of Mental Health:

DR. SOKOLOFF: Are these plaque formations part of the normal aging process or part of the disease?

DR. ROTH: Statistically they are normal.

DR. TERRY: All normal people have a few, but I think that we are working at this from the wrong end. We still have to prove that the plaque and the tangle are more than simply 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 or senile dementia just on the histologic diagnosis?

DR. TERRY: No. If you gave 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.

DR. SOKOLOFF: In what age groups do you see this? Do you see it in infants who died?

DR. TERRY: No.

DR. ROTH: Whether it is pathological or normal aging does not influence the desire to control the phenomenon if it is correlated with intellectual impairment and, at its extreme, with gross intellectual impairment.

DR. SOKOLOFF: It may be correlated with a process about which I can do absolutely nothing.

DR. ROTH: You can't assume that in advance.

DR. SOKOLOFF: We don't know that it isn't.

DR. ROTH: What is the purpose of deciding that in advance of investigating?

DR. SOKOLOFF: That brings us back to the last question. Is it a disease or is it normal aging?

DR. ROTH: Would you accept senile dementia as a disease?

DR. SOKOLOFF: Yes.

DR. ROTH: If you accept senile dementia as a disease, then the existing evidence, such as it is, shows that it is merely an extreme variant of what

you find in the brains of perfectly well-preserved people who go to their graves with plaques in their brains, nobody being any the wiser. If it is an extreme variant of that sort, there may be hope of influencing the factors that potentiate that change, and there are many factors which do: pernicious anemia, hyperthyroidism, head injury, and perhaps serious cardiac failure. If you accept that this is so, then we are justified in investigating the conditions under which the accumulation keeps you this side of the threshold.

In the excerpt, the issue arises of how to define the neuro-organic observables under consideration.

Initially, the researchers engage in what might be called a "philosophical agenda," concern focusing on what the objects seen before their very eyes are to be considered. Here caution is exercised over the evidence pertaining to an underlying disease structure. As Terry notes, "We still have to prove that the plaque and the tangle are more than simply labels, that they are causal" (Katzman, Terry, and Bick, 1978:265). Immediately following this, however, the "philosophical" concern is glossed over and the conversation shifts to a more "procedural agenda," as the issue of diagnosing the <u>disease</u> is raised. This leaves a pathological interpretation intact, with empirical discovery the primary issue.

The shift from caution over the disease's existential status to disease as such is not just accidental but involves getting on with the task at hand, the reality-status of the observables being intricately tied to a desire to intervene in the matter. It is,

after all, as Terry states, "a process that diminishes the well-being of the public." Terry's remarks depict a certain impatience with dwelling on the epistemology of the observables. Rather than debate the issue of what it is, he asserts that the concern should be one of doing something about it, it being a distinct thing about which something can be done.

For these pathologists, doing something about it involves attempting to locate the cause or causes of a disease (a medical agent), treating its symptoms, and eventually finding a way to prevent the problem. The concern is with locating abnormality and disease in patients, not variations of normality in aging persons. Interest in intervention implies a disease entity, disease being something that can be detected and cured, as opposed to aging per se, a natural process of inevitable human variation to be accepted and cared for, not medically eliminated. Sokoloff's later remark that "It may be correlated with a process about which I can do absolutely nothing" shows that for his purposes, as a neuropathologist, to do something about it, it must be a disease, not normal aging--reiterating his earlier comments that they "certainly are not going to cure aging." Here again, the procedural agenda overshadows the philosophical issue, shown in Roth's "scientific" response to Sokoloff that the matter will only be solved

empirically, by further investigation where, eventually, the facts will hopefully speak for themselves.

The philosophical issue over whether the observables depict a disease entity or aging itself is dismissed as the neuropathologists shift concern to investigating and ameliorating its devastating effects. As such, the question of what it is, is revealed in the practical and useful purposes it can serve, such as destroying the menace that "dims bright minds" and which "makes shells of former selves," two familiar slogans.

The sense of urgency to intervene is repeatedly expressed by all those involved with the problem, a problem which, if not concertedly dealt with, will pose an even more serious threat to society in the future. Consider, for example, Hughes' (n.d.:10) alarm in this regard:

By the year 2030 more than a third of the country's population will be over the age of 65 and a huge number will be subject to Alzheimer's disease. It is estimated that at this time approximately 10% of those over age 65 may have the disease, and if this percentage continues, then a large absolute number will need to be cared for in nursing homes and in a very expensive manner by the year 2030. Aside from needs that individual families have now, the country as a whole has a considerable stake in working with this disease process and making it amenable to modern medical treatment.

Aronson (1982:7) presents in more detail the devastating financial costs of the disease:

For society, the dollar cost has not been determined accurately. Sixty percent of all patients in nursing homes carry some diagnosis of dementing

illness. Thus, if one were to take 60% of the current \$25 billion long term care bill, dementing illness would appear to cost \$15 billion per year. However, more dementia victims--even very deteriorated patients -- reside in the community than in nursing homes and other institutions, so this is a vast underestimate. A figure used by Drachman (1982) is \$20,000 per patient, which would yield an estimate of \$60 billion per year. Thus, whatever the actual amount, the cost to society is staggering. And with a demographic projection of a large increase in the elderly population by the year 2000, there will be a proportionate increase in the number of demented individuals. Thus, dementing illness is a major and fast-growing medical and social problem which impinges on all gerontologic practice.

Framed in terms of a disease grammar, the demographic projection warns of the expected increases in diseased persons. At the same time, the relationship to age itself is glossed over. Indeed, the costs to society and the alarm it generates makes those concerned flatly state that, "Alzheimer's disease is not a normal consequence of aging," as the following illustrates:

Alzheimer's disease is a surprisingly common disorder that destroys certain vital cells of the It produces intellectual disability (senile dementia) in more than 50 percent of all persons admitted to nursing homes. Consequently, over 1.5 million American adults are affected at a cost of an estimated 20 billion dollars annually. This incidence and cost are many fold higher than those associated with multiple sclerosis, cystic fibrosis, or most of the better known lethal diseases of man. In fact, Alzheimer's disease is the fourth most common cause of death in the United States. family out of three will see one of their parents succumb to this disease. In some cases a familial predisposition to the disease will occur and whole generations will be affected. <u>Alzheimer's disease</u> is not a normal consequence of aging (Glenner, 1982:59 [emphasis added]).

As a distinct disease entity, it is reasonable to entertain the hope that one day it can be exposed, treated, and even eliminated. This has led to much research being conducted into the possible cause for the neuropathological changes associated with Alzheimer's disease (see Katzman, Terry, and Bick, 1978; Katzman, 1983; Reisberg, 1983). Such factors as environmental toxins and trace metals (especially aluminum), viroids (e.g., a slow virus), and genetics have been suggested as ultimate causes.

Evidence linking aluminum accumulation in the brain come from studies of animals, such as cats and rabbits, who showed progressive dementia and neurofibrillary degeneration after being injected with aluminum salts (Klatzo, Wisniewski, and Streicher, 1965; Crapper, Karlick, and De Boni, 1978). Yet, the evidence is inconclusive (Terry and Pena, 1965; Wisniewski, Sturman, and Shek, 1980). Studies done on humans also have supported the aluminum theory, showing higher levels of aluminum in autopsied Alzheimer's patients than in agematched controls (Crapper, Krishnan, and Dalton, 1973a; 1973b; Crapper, Krishnan, and Quittkat, 1976; Trapp et al., 1978). Other researchers, however, found no significant differences in this regard (McDermott et al., 1977; McDermott et al., 1979; Markesbury et al., 1981).

As the Report of the Secretary's Task Force on Alzheimer's Disease further notes:

The role of aluminum . . . is far from clear, since those with the greatest exposure to aluminum, such as aluminum workers and individuals on renal analysis, do not develop neurofibrillary tangles nor Alzheimer's disease. Scientists are still uncertain as to how aluminum actually gains access to the brain. The etiological role of environmental toxins in the pathogenesis of Alzheimer's disease remains unproven and controversial (U.S. Department of Health and Human Services, 1984:13).

Likewise, the role that viroids and genetics play is inconclusive. While there is data suggesting a connection between slow viruses and Alzheimer's (see Salazar et al., 1983), attention has also been called to the fact that "as yet there is no direct evidence that slow, latent, masked, hidden, incomplete, or defective viruses are involved in any of the progressive degenerative changes usually associated with senescence" (Gibbs and Gajkusek, 1978:559). As for genetics, some findings have been produced linking families of early onset victims to increased susceptability (Heston et al., 1981); the same study, however, found that late onset victims (70 years or over) present no greater threat in this regard. In addition, in their review of the literature, Matsuyama and Jarvik (1982:20-21) report:

There are 11 family studies and one twin study in the world literature concerned with familial incidence of Alzheimer Disease or Senile Dementia of the Alzheimer Type. Increased familial incidence has been found but no clear genetic etiology established (emphasis added).

In the final analysis, the testimony and debate of those concerned suggest that the grammar of Alzheimer's disease is inextricably tied to the way the "facts" are interpreted. The very biological facts of aging regarding dementia can be either normal features of the aging brain or indicative of disease. The line distinguishing them is, as it was shown, a "philosophical" choice. Dismissing the philosophical and turning to facts as disease facts serves to secure the gaze of the concerned, from philosophical confrontation to empirical.

THE BEHAVIORAL SOURCE: READING DEMENTIA

Alzheimer's disease is recognized to be a behavioral entity as well as an organic illness, a brain/behavior condition. The neuro-organicity of the disease--marked by neurofibrillary tangles, senile plaques, and granulovacoular degeneration--has its correlate in dementia, a diffuse cognitive and intellectual impairment (Tomlinson, 1977; Wells, 1978). The characteristic symptoms include memory loss and confusion, as well as conditions such as lack of judgment, disorientation, and agitation. A typical clinical portrait of the disease is as follows:

The behavioral hallmark of Alzheimer's disease seems to be memory loss, especially for recent events. But many other behavioral changes are caused by the illness. In its early stages, Alzheimer's disease can lead to inability to concentrate, anxiety,

irritability, agitation, withdrawal, or petulance. Later, the Alzheimer's patient may lose the ability to calculate, may exhibit lack of judgment, may become disoriented as to time and place, may be unable to understand jokes or cartoons. Some persons with Alzheimer's disease tend to wander about and lose their way; some become prone to temper tantrums; some are depressed; some forget the names of friends and neighbors, or forget words, or forget how to make change. . . . the timing and sequence of lost function varies from patient to patient. . . . Occasionally, though not always, Alzheimer's patients become incontinent in the final months of life (U.S. Department of Health and Human Services, 1980b:2-3).

As the preceding extract shows, there is frequent use of indefinite terms like "can," "may," "some," and "occasionally" in describing the behavior of Alzheimer's disease patients. Such usage is found wherever descriptions of the stages and symptoms of the disease appear. This includes not only the texts and talk of medical researchers, but personal documents and conversations of caregivers, ADRDA newsletters, and the many pamphlets and handbooks that explain the disease and its management. The use of indefinite terms allows for the full range of conditions to be characteristic of the disease. It makes quite a difference, for example, to state that <u>some</u> Alzheimer's patients manifest withdrawal or petulance and others do not, rather than that Alzheimer's patients manifest withdrawal and nonwithdrawal or petulance and nonpetulance. The first is reasonable, the second contradictory.

The use of indefinite terms is also prevalent in descriptions of the problems in activities of daily living (ADLs) that Alzheimer's patients experience. of the impairments in ADLs commonly used to illustrate cognitive deficiency were presented in the preceding clinical portrait of the disease, such as forgetting names or how to make change. Other typical dysfunctions include the inability to use a checkbook, forgetting to turn off the oven, misplacing things, inability to control bodily functions and loss of enthusiasm, among a host of problems which could be considered to be ADLs, such as problems of sleep, exercise, personal hygiene, speech, self-esteem, traveling, and so on. The list of impairments could, conceivably, run the entire gamut of everyday behaviors, elaborating the disease grammar to include whatever problems of daily living that may occur among the elderly. As such, the use of indefinite terms provide remarkable flexibility in the selection of typical disease characteristics, allowing for the variety of experiential behaviors of old age to be underpinned by a single disease entity.

Many of those whose job is to service victims of the disease are well aware of the "umbrella" problem.

Consider, for example, the following remarks made by a geriatric clinical specialist in nursing at the day hospital studied:

There's already a lot of controversy. Like even between the neurologists and the regular doctors. Neurologists kind of like to hedge around. not too sure about Alzheimer's but regular doctors . . . well it's cut and dry for most of them, like a That's the way they approach it. got these symptoms, so it means such-and-such a disease. Never mind the way the symptoms show up against the family background or how they present themselves at home. They're doctors after all! they know what symptoms mean! It's too bad when you see so much evidence that it's not that simple, especially in a real shady area like memory loss, confusion, and all the other behavioral things. It's not all their fault either because the whole system is set up so that it just can't handle all that uncertainty about symptoms. It's like they've got to mean something if they're symptoms. So you have this category called "Alzheimer's" and you find people to fit it, sometimes, I think, too well.

The "shady area" the nurse cautions against reflects the well recognized observation that some sort of memory loss occurs in all aging persons. The question then becomes a matter of where to draw the line between what is considered normal versus pathological decline. Kral (1978) does make a distinction between the two, one that is widely shared in the medical community. With respect to "normal" memory loss in old age, Kral (1978:47-48) has coined the term "benign senescent forgetfulness" which, as the author states:

can be found in aged people who are not suffering from Alzheimer's disease or other types of dementing process. Psychometric tests have demonstrated a lowering of memory scores in all aging individuals compared with young adults. Although the correlation between chronological age and memory loss is, on the whole, paralleled by the results of the memory tests, there is a remarkably wide range in scores achieved by the individual subjects within the unselected quinquennial subgroups. Although this could be explained by the initial individual

variability of the memory function of the subjects, one has also to consider the possibility that qualitatively different types of memory impairment might be hidden behind the quantitative differences in memory scores.

Kral chooses to interpret the "individual variability" of memory loss in old age as qualitatively distinct "types" of decline, not as a process involving "more or less of the <u>same</u> thing," so to speak. The author also describes the two types of memory loss which, as he puts it, "might be <u>hidden</u> behind the quantitative differences." In contrast to the "amnestic syndrome" associated with Alzheimer's, "characterized by shortened retention time, an inability of the subject to recall events of the recent past, and an inability to recall not only relatively unimportant facts of an experience but the experience itself," Kral portrays the second type (benign senescent forgetfulness) as follows:

the second type of senescent memory dysfunction is characterized by the inability of the subject to recall relatively unimportant data and parts of an experience (e.g., a name, a place, or a data), whereas the experience of which the forgotten data form a part can be recalled. However, the same data not recalled on one occasion may be retrieved at another time. The 'forgotten' data seem to belong to the remote rather than the recent past. Also the subjects are aware of their shortcomings and try to compensate by circumlocution and they may apologize . . . it was proposed to term this type of senescent memory dysfunction 'benign' in contrast to the 'malignant' type, the amnestic syndrome (1978:48).

Kral's use of the term "benign" and "malignant" clearly show his preference for a disease distinction to

categorically separate pathology from the aging process in general. They are, in effect, two separate things. One (benign) does not just become the other (malignant), either prematurely or in advanced old age; instead, one contracts, is stricken by, falls victim to, or is struck down with the latter.

As with different interpretations regarding the meaning of the neuro-organic markers of the disease, different clinical realities are separated and assigned meaning. While some, such as Katzman (Katzman, Terry, and Bick, 1978:44; Fisk, 1979:29; Katzman and Karasu, 1975:110-111; Fields, 1975:147), maintain that the two processes (symptom versus benign characteristics of aging) are indeed separate, others, like Terry (Katzman, Terry, and Bick, 1978:12; Terry and Wisniewski, 1975:135), see the process differently, as the following comments illustrate:

I would cautiously disagree in regard to the socalled benign memory loss. I can't help but wonder whether there is only a quantitative rather than a qualitative difference between that change and the dementia [Alzheimer's disease] in which we are interested today (Terry and Wisniewski, 1975:135).

Most medical practitioners, on the other hand, are not as concerned with the debate over the nosological problem of whether or not Alzheimer's is considered a disease entity separate and distinct from aging (either on organic or behavioral grounds), as they are with "successfully" accomplishing what Katzman (1982:8) calls

"the complex problem of diagnosis." For most, the disease status is largely taken for granted. As one physician at the day hospital flatly put it, referring to Alzheimer's, "It's definitely a disease. It's certainly not a part of the normal aging process." Still, a good deal of effort enters into the process of interpreting the diverse and related experiences presented by patients and family members as either Alzheimer's or not. The diagnosis is based primarily on clinical evidence. As Katzman (1982:8) explains:

In many areas of medicine, diagnosis may be accomplished by a single blood test, a special radiological procedure, endoscopy, or other specific investigations. The diagnosis of dementia and of Alzheimer's Disease remain, however, in the domain of the clinician and requires a comprehensive workup.

A "comprehensive workup" involves a number of different procedures, summarized by Kaufman (1982:2) as follows:

WORKUP OF A DEMENTED PATIENT

	ALL PATIENTS	SEL	USE ECTIVELY
1.	History from patient and relative	1.	EEG
2.	Mental status examination	2.	Drug levels
3.	Physical examination with vital signs	3.	Toxic screen
4.	Neurological examination	4.	Brain scan
5.	CAT scan	5.	Lumbar puncture

- Thyroid functions, serum B, and folic acid
- 7. CXR, EKG
- 8. CBC, UA, VDRL & FTA, glucose, BUN, Ca, albumin, electrolytes, alkaline phosphatase, ESR

The workup is performed to rule out diseases other than Alzheimer's. While said to account for fifty to sixty percent of all persons suffering from a progressive dementia (Katzman, 1982), Alzheimer's is diagnostically a disease of exclusion. It differs from fifty or so other pathological conditions that may behaviorally mimic it. Among them are such degenerative diseases as Hallervorden-Spatz and Parkinson's disease, a number of metabolic disorders including the liver and parathyroid glands as well as hypoglycemia, uremia and Cushing's syndrome, vitamin deficiencies, drug reactions, brain tumors, subdural hematoma, infections of various kinds, normal pressure hydrocephalus, depression, and multiinfarct dementia (Haase, 1977). The CAT scan (computer assisted tomography) can be used to identify many of the reversible and/or treatable conditions which present as dementia such as brain tumors, subdural hematomas, and normal pressure hydrocephalus. The instrument cannot, however, detect the neuropathologic lesions

(neurofibrillary tangles and senile plaques)
characteristic of Alzheimer's disease. As such, it is
repeatedly noted that only upon autopsy can a definitive
diagnostic conclusion be drawn. Ostensibly, post-mortem
neuropathological data, as revealed by the quantity and
distribution of plaques and tangles in the brain, will
either confirm or disconfirm a clinical diagnosis.
(This, however, is debated by those medical researchers
who see the Alzheimer's/normal aging distinction in
quantitative rather than qualitative terms—see Katzman,
Terry, and Bick, 1978:267).

The differential diagnosis of Alzheimer's, as such, lies in both further ruling out other causes of dementia and, in so doing, attempting to "get at" the disease.

Two pathological conditions that are especially difficult to distinguish from Alzheimer's are multi-infarct dementia and depression. The cognitive and intellectual impairment found in multi-infarct dementia (hardening of the arteries), the second most frequent cause of dementia in the aged, is similar to that of Alzheimer's.

Moreover, it has been estimated that the two disorders occur together in approximately twelve percent of elders with a progressive dementia (Katzman, 1982). Yet, as Hachinski (1983:188) points out, "Clinical evaluation remains the single most important means of distinguishing AD from multi-infarct dementia." Whereas Alzheimer's

presents as a slow, progressive condition, multi-infarct dementia is frequently abrupt in onset with a stepwise course of progress, and with focal neurological signs. Hachinski (1978) has devised what he calls an "ischemic score," composed of the above criteria, which is commonly cited as a useful means of differentiating between the two conditions.

Depression, or what is often called "pseudodementia" (Kiloh, 1961; Wells, 1979), is also at times very difficult to discriminate from Alzheimer's. Depression has not only been shown to mimic dementia to a considerable degree (McAllister and Price, 1982) but, as with multi-infarct dementia, can also occur along with Alzheimer's disease (Wells, 1983). These complications have reportedly resulted in several mistaken diagnoses (Nott and Fleminger, 1975; Ron, Toone, and Garralda, 1979; Liston, 1977). Wells (1983:194) offers the following solution in this regard:

The clinician who attacks these problems must do so largely with the tools of clinical observation; ancillary diagnostic procedures, though sometimes helpful, cannot establish the correct diagnosis for the clinician, and indeed they depend for their correct interpretation on the clinician. In most instances, careful attention to details of the history and clinical observation will lead the physician to the correct diagnosis.

What Wells is suggesting is that the use of diagnostic aids will not yield the "true" condition of a patient. His is a useful caution against the common

practice of uncritically relying on mental status examinations or questionnaires (see, for example, Pfeiffer, 1975) to diagnose Alzheimer's. Wells points out that while these tests provide measures of cognitive impairment, that alone is inadequate in diagnosing a brain/behavior condition such as Alzheimer's disease (Wells, 1983; Wells and Buchanan, 1977).

In the preceding extract, Wells also speaks of the considerable discretionary powers of the physician. While Wells provides an understanding of the complexities of clinical diagnosis, his concern is with providing the "correct interpretation" in order to get at the "correct diagnosis," not in impairment construction itself. He, like others, does not directly question the vocabulary and grammar of Alzheimer's disease.

The patient's family, too, is a considerable resource in the diagnosis of the disease, especially in regard to the patient's history—what Wells, in the preceding quote, advocates. The information they provide can be quite valuable in determining, for example, whether the problem behaviors' onset and course was sudden and stepwise or gradually progressive, the former signalling multi-infarct dementia, the latter Alzheimer's. A family member or relative might also report that the patient "was always poor at figures" or "never cared a hoot about politics," challenging the

results of mental status questionnaires and other diagnostic procedures. As one social worker put it, "You might come across something that looks like extreme withdrawal but then, if you bothered to ask a family member, you find out that he's been that way all his life and all the family considers that normal."

Yet, while the patient's family and friends provide much needed data, what they report is not necessarily the same interpretation of the patient's presenting condition as the physician's and/or other service providers'. A physician at the day hospital, for example, commented on families' conflicting testimony by stating that he felt "in most cases, the family thinks the patient is worse than he really is, but you also have the opposite situation where the family member unconsciously protects the patient."

The patient's self-presentation also must be interpreted. Often, he or she is characterized as still possessing many social skills (Paulson, 1977) as well as, among other things, denying the impairment. As Wells (1977:3) describes:

[The] lack of awareness and concern for memory loss in most patients with significant dementia attests to the effectiveness of the defense mechanisms of denial.

Early in the process of dementia a variety of other symptoms may present and may capture the attention of the patient, his family, and his physician. Many of these early symptoms of dementia differ little either qualitatively or quantitatively from those that occur in normal, healthy individuals

who are exhausted, anxious, or subject to severe environmental pressures. . . Often the patient's attention centers on various somatic complaints, previously present or arising de novo, for which no adequate organic cause can be found and for which the usual remedies provide no relief. Here only the physician's acumen prompts him to search beneath the facade of somatic symptoms for the nidus of the problem.

At this juncture, the "definition of the situation" is perhaps most readily apparent, with what the author calls "the physician's acumen" taking center stage.

While eliminating other pathological conditions at the same time signals a diagnosis of Alzheimer's, the physician also faces the task of reading the behaviors presented before him as dementia rather than "normal" old age forgetfulness. In this regard, certain experiences such as the inability to manage one's finances are more apt to be cited as a "sign" of the disease. As Katzman (1982:8) writes:

The diagnosis of dementia is usually suggested by a history of forgetfulness, repetitiousness, losing one's way around; there may be loss of ability to perform complex tasks on the job--for example, a radiologist may no longer be able to interpret the x-ray film. In our society, one of the most demanding tasks is control of one's own personal finances and checkbook; deterioration in this function often heralds the development of a progressive dementia.

Consider also the following remarks made by a nurse at the day hospital concerning one of the caregivers who attended their weekly support group, the adult son of a demented mother:

Don't you all think that Sam has some dementia. You visited with him and talked for awhile. He's always late. You know how he forgets and sneaks in here a half hour and sometimes an hour late. He comes in and looks at me and shrugs his shoulders and . . . like he's saying . . . 'what can I do?' He drives around and is always running over curbs. . . . You can't tell me that he couldn't get his income tax done. I mean he just filed for his 1980 taxes. He keeps writing in and getting extensions. And of course, he's late on his '81 taxes too. I really think he's got some dementia, don't you?

While select behavioral conditions are more frequently described in the attempt to "spot" dementia, there are no simple and "ready-made" solutions which can be used as automatic diagnostic criteria. How, then, is the affair accomplished? What sort of interpretive rules are used in defining a presented behavioral trouble or troubles as pathology as opposed to normal (natural) old age development?

Consider, in this regard, Katzman's (1982:8) definition of dementia:

Alzheimer's Disease presents as a dementia, that is, as a progressive deterioration in intellectual capacity in an otherwise alert individual. The deterioration must be sufficient to interfere with social or occupational performance or both. This definition of dementia paraphrases that in the Third Edition of the <u>Diagnostic and Statistical Manual</u> of the American Psychiatric Association. This definition is welcomed by most physicians since it marks the agreement by the psychiatric community to drop the awkward term 'chronic organic brain syndrome' for the more specific descriptive term of 'dementia.'

The definition, in effect, provides a working ruleof-thumb for revealing an underlying pathology out of the diversity of behaviors and conditions a physician

confronts (see Drachman's comments in Katzman, 1983:9-10 for a similar definition). As Katzman puts it, while the disease presents as a "progressive deterioration in intellectual capacity in an otherwise alert individual, [the] deterioration <u>must be sufficient</u> to interfere with social or occupational performance or both" (emphasis added). By the same token, "insufficient" interference includes those conditions of aging that have their own, not incapacitating, impact on performance, what Kral, in the earlier quoted extract, refers to as "benign" memory loss. As such, Katzman locates the differential diagnosis in the everyday social competence of the suspected patient, its particulars being detailed on the occasions of their consideration. This, ironically, brings the clinical picture of the disease experience back to the tacit disease/normal aging tension. As with the use of indefinite terms, evidence is marshalled to cover a wide-range of old age experiences. "Sufficient" deterioration, for example, may show up one way for this patient, another way for that patient, and take yet another form for the next, conceivably stretching the symptomatic grounds of the disease to include troubles as diverse as advanced old age itself--with all of the diversely-related particulars collectively representing each other as a single entity, Alzheimer's disease.

The nebulous features of the disease are wellrecognized by those who share the experience. It should
be noted, however, that while many may stand to benefit
or have special interests in the disease distinction,
professionally-concerted deception is not the basis of
its existence. In fact, as will be shown in Chapter 6, a
rather strong case can be made that it is the ADRDA,
itself, that is at the center of the disease's public
recognition. Whatever the "hidden" intent, as such, from
medical researchers to service providers and caregivers,
what brings all of them together is their belief and
concrete knowledge that something has gone wrong with
elders of concern to them, that something ostensibly
being Alzheimer's disease.

It is the urgent need and active pursuit to do something, about the "silent epidemic" that "dims bright minds" that breathes life into the disease's reality-defining existence, something which, at the same time, however, also creates the tension between it and old age. Yet, as one nurse at the day hospital, after discussing the shortcomings of the "medical model," exclaimed, "They're real problems out there begging for help. . . . You can't just sit around and do nothing." As such, in getting on with the task at hand, Alzheimer's, as evidenced by it's brain/behavior markers, is revealed by

the grammar that articulates what it is surely said to be: a disease, not a normal part of aging.

CHAPTER 5

ONSET AND COURSE OF ILLNESS: THE QUESTION OF TIMING

In this chapter, I turn to the question of timing as a way of organizing the Alzheimer's disease experience, the second component of its grammar. The problematic that was introduced in the last chapter—the relationship between the experience as a disease structure, on the one hand, and as a configuration of aging, on the other—is considered here in terms of the progress of the experience. Focusing on onset and course of decline, I consider how disease as opposed to normal aging interpretations are applied.

It is argued that a rational vision of timing organizes the experience to define it as illness, something which stands in considerable tension with the variety of symptoms encountered. While not challenging the reality status of the disease itself, caregivers and service providers nonetheless face its highly diverse presentation in their attempts to understand and deal with its "troubles." In this respect, it is further argued that the vision facilitates the use of formal assessment procedures for dealing with the feelings and perceptions of caregivers, the "other victims" of the

disease. Finally, in conjunction with the latter, the decision of whether to continue home care or to seek institutionalization is analyzed.

THE RATIONAL VISION

The first step in the rationalization of the Alzheimer's disease experience is to give the experience a name, the effect of which supplies a containable (categorical) thing to describe. (The interpretive challenge posed in this regard was examined in the last chapter.) The "fleshing out" of the rational vision, as it were, produces a well-defined disease chronology, in principle, one with a relatively clear beginning and a regular course of progress (Lynott, 1983). Underpinning the vision is a sense of a systematic process of decline, where behavioral changes occur in a more or less preestablished manner, with associated levels of care burdens.

The Question of Onset

Consider, first, the course's point of origin. It is repeatedly noted in the related popular, promotional, and professional literature that Alzheimer's disease has an insidious onset, one that, as Wells (1977:3)'states "is often dated in retrospect and with imprecision, the informant being aware that things are seriously amiss at present but unaware just when things began to move in

this direction." The endeavor is further hampered due to the diagnostic ambiguity of the disease. As noted in the preceding chapter, Alzheimer's is a disease of exclusion, having no known detectable cause. As such, the task of isolating dementia presenting as Alzheimer's from the fifty or more "nonAlzheimer's" dementias that mimic it must also be dealt with. The insidious uncertainty of Alzheimer's disease is well illustrated in the following example:

Over the period that we worked together . . . I became gradually aware that the fine edge of his intellect was becoming dulled. He was less clear in discussion and less quick to make the jump from a new piece of evidence to its possible significance. He spent more time over his work and achieved less; and he found it increasingly difficult to get his results ready for publication. He tended also to become portentous and solemn about his subject, as though one small corner of knowledge nearly filled his world, and the wider horizons were narrowing in. The change was so slow as to be barely perceptible, and the signs vanished when I tried to pin them down: they were like those faint stars which are seen more easily when they are not in the direct line of vision. I was left with a feeling of uneasiness which I could not justify. . . . after a period of absence, I looked forward with special pleasure to my homecoming, but when we met I knew with immediate certainty that I had lost the companion of my earlier years. The change was as yet mainly a loss of intellectual clarity and he remained himself, but a self that was subtly devitalised. To me it was as though a light had gone out, but no-one else seemed to notice anything amiss.

By this time he was worried about his general health and attended a doctor from time to time with rather vague symptoms. For several years he had been said to have low blood-pressure, but nothing was found wrong apart from this, and he was reassured (Wells, 1977:3-4).

Though it may be indicated repeatedly that Alzheimer's disease has an insidious onset, it is, nonetheless, considered concrete and factual in people's lives, not being equally descriptive and constitutive. It thus becomes reasonable to search for the onset of a particular patient's problem in order to conclude that it occurred on this or that date. While caregivers and service providers might change their minds or disagree with one another over the age of onset, the differences are understood in terms of error, not as reconstructions. The insidious quality of onset, as such, is the result of the lack of a means of handily detecting its emergence, not of a missing origin per se. The search for onset, thus, is a reasonable, albeit perhaps difficult, pursuit. In discussing the preceding quote, for example, Wells (1977:4) notes how easily the "subtlety of presenting signs and symptoms . . . may be overlooked even by a concerned and qualified observer" (emphasis added). As such, while admittedly sometimes hard to detect, the onset of illness can be located, in principle, in particular aspects of people's lives, existing at some "objective" point in time. The "discovery" of onset as a discrete and self-contained entity provides a beginning for the disease chronology.

The Course of Progress

Consider next the presented course of progress of the disease. The course is commonly delineated into stages, phases, or earlier and later parts, the former being part of more formal models of decline, the latter, less so. The divisions provide rationalized (systematically organized) general descriptions of a disease process with a common, developmental complement of decline. Consider, for example, Cox's widely quoted developmental scheme, taken from the July, 1984 issue of the Cleveland ADRDA Chapter's Newsletter (reprinted from the Tucson ADRDA Newsletter). Cox states that his model is explicitly directed towards "practical considerations which lead to decisions concerning level of care or degree of intervention appropriate to any particular stage." The stages are then presented as follows:

- 1. The first stage of AD is made only in retrospect; in other words, it is all of those little changes in memory, intellect and social function which had been observed in the early phases of the disease but really were overlooked or not thought significant until such time as the patient was disabled enough to require formal medical evaluation. Once the diagnosis is established, then by looking back one can tie in 'all those little things' with the known diagnosis and see how the first stage of AD is subtle indeed in many cases.
- 2. Phase two really begins with the establishment of a clinical diagnosis. The degree of disability at this point depends largely upon the sensitivity of the family in terms of seeking medical help... Stage two goes from the time of diagnosis to the time of significant incontinence of bowels or bladder. (Incontinence is used as the dividing line

between stage two and stage three because it is such an important determinant of levels of care that most families find it really not feasible to care for an individual with significant incontinence in the home-setting.)

- 3. Stage three goes from the time of the onset of incontinence to the development of a rather severely dependent and almost 'vegetative' stage. At this time, the patient may be totally unable to communicate, to recognize family or loved ones, to do any element of self-care and probably will needs to be bodily lifted from bed-to-chair or bed-to-toilet.
- 4. Stage four is basically the end-stage of the disease from the development of extreme dependency and noncommunicativeness until death, this latter usually caused by either pneumonia (from the inability to swallow without getting food or fluids, etc., into the lungs) or urinary tract infection usually subsequent to chronic bladder catheterization.

While Cox, wittingly or not, describes the nebulous and discretionary features of Alzheimer's disease, especially its earlier manifestations which can be recognized "only in retrospect," what is clear is that the concern is with a single entity—Alzheimer's disease—that is being referenced. Cox presents its, the disease's, systematic and progressive course of development, noting the inexorable process of cognitive and, eventually, physical debility that takes place. The process of decline is linear and sequential, like clock time (see Hendricks and Hendricks, 1976). The clock—time understanding informs service providers' and caregivers' ongoing attempts to distinguish the early, middle, and later stages of impairment and its corresponding care

burdens. The disease, as such, is structured as a wellordered entity to permit intervention. Yet, following
his stage descriptions denoting the "typical" path the
disease follows, Cox informs the reader of its unordered
and inconstant features, as follows:

The time course through any phase is completely individual and variable. Whether an individual goes through all four stages is determined in part by the age of onset of the disease, by its rapidity of progression and by the presence or absence of other significant or serious medical problems which may be far more important in determining longevity than is AD.

The homogeneous and straightforward time scheme depicted in Cox's stage descriptions now becomes heterogeneous and uncertain, having no set time pattern. Indeed, the temporal quality of the disease, being "completely individual" and having no clearcut course of progress, becomes as diverse as are the varied experiences characterizing old age. Once again, this time in terms of the progress of the presented disease, the tension between Alzheimer's as a unified and concrete entity in people's lives and normal age-related troubles is manifested.

The descriptive tension is not unique to Cox's presentation but, rather, is depicted across all levels of concern with the disease experience. Consider, for example, Berger's (1980:235) "Severity Rating System," a six-stage classification scheme pertaining to degree of functional capacity. His model is also geared to those

servicing the disease, especially practicing physicians. The class ratings follow:

Severity Class I: can function in any surroundings, but forgetfulness is often disruptive of daily activities; Severity Class II: can function without direction only in familiar surroundings; Severity Class III: needs direction to function even in familiar surroundings but can respond appropriately to instruction; Severity Class IV: needs assistance to function; cannot respond to direction alone; Severity Class V: remains ambulatory, needs assistance to function, but cannot communicate verbally in a meaningful fashion; Severity Class VI: bedridden or confined to a chair and responds only to tactile stimuli.

Berger's time scheme, like Cox's, is unilinear and progressive, both viewing change, either in decline or increasing burden, as developmental and stage-like. The sense of timing in Berger's (1980:235) rating system is further distinguished by what he calls a "core midpoint," separating "Severity Class III, in which the patient must be told to pull up his pants (direction), and Severity Class IV, in which someone has to pull up his pants for him (assistance)." Later, however, the developmental pattern shifts to being nondevelopmental and irregular, as Berger (1980:235) illustrates:

Moreover, it is not uncommon, particularly before serious deterioration sets in, for the picture to vacillate from day to day. Further, while the disease remains, the severity is not permanent nor is it forever progressive. Once the patient feels secure in his environment, or the superimposed congestive heart failure has cleared, or the bronchitis has subsided, the physician, the patient, and the loved ones may well be rewarded with a change from Class IV to Class II.

Here, again, the tension between disease versus normal aging interpretations is apparent. What was earlier described as a well-delineated, progressive time trajectory is now depicted as erratic and regressive. While the latter, idiosyncratic/nonrational view, is suggestive of variations in old age behavior (some perhaps unpleasant) due to factors such as changes in environmental or health conditions, for the author, "the disease remains," as a taken for granted, unified, and concrete thing, separate from its diverse presentation.

There are still other, more elaborated, formal models of decline. One such scheme, presented in the June/July 1984 issue of the Portland ADRDA Chapter's Newsletter, describes the "progressive phases of Alzheimer's disease" along three separate dimensions: cognitive, personality, and functional changes. component, itself, contains a detailed list of activities of daily living to further illustrate a given level of The course of progress even specifies timing along chronological lines. Yet, while it is stated that the course of Alzheimer's disease is progressive and the "symptoms reflect a continuous decline," also noted are its volatile and shapeless features, where "some symptoms will overlap," some will "vary in sequence and the rate at which they progress," and "some may be absent in individual patients." Indeed, depending upon such

factors as age of onset, the condition of one's health, and availability of support systems, it is stated that the disease "may last from a few to twenty years," which comes close to being about as unpredictable and eccentric as the aging process itself.

There are also less formal models of the disease course, emphasizing a beginning, middle, and end or earlier and later aspects. As with the more elaborate stage model presentations, a distinct temporal feature of the disease process is readily apparent--Alzheimer's has a course that is inexorably degenerative, leading to eventual institutionalization and death. Here again, this form of discourse structures Alzheimer's as a welldefined disease entity, one with a relatively clear beginning and systematic course of progress. At the same time, however, the disease is said to have no coherent pattern, its timing being as diverse as the aging experiences it presumably is not. While less formal models of timing are found throughout the disease literature, they share a considerable likeness in wording and format. The following example, presented in a pamphlet published by the U.S. Department of Health and Human Services (1980a), is illustrative. Consider, first, the systematic and progressive time element presented:

At first, the individual experiences only minor and almost imperceptible symptoms that are often

attributed to emotional upsets or other physical illnesses. Gradually, however, the person becomes more forgetful, particularly about recent events. The individual may neglect to turn off the oven, may misplace things, may recheck to see if a task was done, may take longer to complete a chore that was previously routine, or may repeat already answered questions. As the disease progresses, memory loss increases and other changes, such as confusion, irritability, restlessness, and agitation, are likely to appear in personality, mood, and behavior. Judgment, concentration, orientation, and speech may eventually render its victims totally incapable of caring for themselves.

Immediately following, the erratic and highly diverse symptomatology and course of progress are pointed out:

There are many different patterns in the type, severity, and sequence of changes in <u>mental</u> and <u>neurological functioning</u> that result from Alzheimer's disease. The symptoms are progressive, but there is great variation in the rate of change from person to person.

The same cognitive tension concerning the grammatical status of Alzheimer's also exists in spoken form. Service providers and caregivers commonly make references to a rational understanding of the disease's course of progress. For the most part, descriptions of changes in the disease are casual and incomplete, with statements such as, "[the patient] is in the later stages" or "[the patient] is in that early, hard to detect, stage," without any further description.

Rationalized understandings are most apparent when Alzheimer's is described as a general entity, typically referencing stage-like features of the disease. On other occasions, however, the disease is portrayed as not

having a distinct course of progress, because "it all depends so much on the circumstances and the personalities involved," and "no two cases are alike," again abrogating a disease structure.

Measurement

Another component in the rationalization of the disease experience is the formal assessment of caregiver tolerance or "felt burden" (Zarit, Reever, and Bach-Peterson, 1980). With no cure available, the medical and human service care of the patient is largely custodial, limited to symptomatic relief and behavioral management. As one social worker at the day hospital put it, in describing some of the program's scheduled activities patients engage in, such as "getting their daily cup of coffee," "feeding the fish," "playing catch with the ball," "helping to prepare lunch," or "taking an afternoon walk:"

I don't think there's any magic about it in terms of the activities that we do. It could be done at home. I think the big thing is that somebody else is doing it, which also gives the caregiver a break. That's a big thing. Another thing is just in terms of the preprofessional relationships. I find it real difficult to tell my dad to brush his teeth. I think my dad would find it real difficult to accept those kinds of things. I think it makes it easier to accept those kinds of things being here than being with their families.

Thus, the primary focus of attention, in terms of intervention, is the caregiver, who, because of the patient's mental demise combined with a body that is

As part of the day hospital's research program,
assessments of caregivers' felt burden were regularly
measured by asking them a series of questions concerning
their personal experiences with their Alzheimer's
patients. Part of the test format consisted of
completing a "burden interview," comprised of twenty
items drawn from Zarit, Reever, and Bach-Peterson's
(1980) 29-item, self-report inventory. Caregivers were
asked how they felt about select aspects of their
patient's impairment, rating each of the twenty items for
"burden" on a scale from "not at all" to "extremely."
Following is a sample of the items (see Appendix B for
the complete inventory):

- 1. Do you feel that your spouse/parent makes requests which you perceive to be over and above what he/she needs?
- 2. Do you feel embarrassed over your spouse's/parent's behavior?
- 3. Do you feel guilty about your interactions with your spouse/parent?
- 4. Do you feel that your spouse/parent currently affects your relationships with other family members and friends in a negative way?
- 5. Do you feel that the present situation with your spouse/parent doesn't allow you as much privacy as you would like?

In attempting to relate measured burdens to given levels of decline, service providers are again faced with a working tension in the disease experience. The tension

centers around the attempt to rationally assess burden and tolerance when the latter are matters of continued interpretation. On formal measurement occasions, the formality of the questioning, itself, "demands" answers, more or less definitive ones. They are demands in the sense that an answer is desired, a nonanswer being treated as useless for the most part. Comparing this with the flux of answering that caregivers provide and offer up concerning their level of tolerance on other occasions show that the measures seem to tap only crystallized moments of interpretation of the condition under consideration.

The tension is resolved for the practical purposes at hand, in this case, for the purpose of collecting ostensibly precise information about the felt burden of care. The information gathered can be used to counsel family members on how best to cope personally with the heavy demands of patient care as well as facilitate what is believed to be the eventual decision to institutionalize. For example, when an Alzheimer patient is considered to be at a certain state of decline, service providers would then be informed of the related burdens of care and, depending on their express assessment, that a family might now seriously or not yet seriously seek institutionalization.

The tension between the rational, unitary vision of the disease course and its relationship to the diverse experiences of service providers and caregivers with the Alzheimer patient exists across all levels of concern with the disease experience. It was shown, for example, how the disease's popular, promotional, and professional literature, in describing the symptoms and course of progress of the disease, also takes precaution to mention its varied individual manifestations and chronology. Likewise, service providers and caregivers, whether presenting the "typical" progress of the disease or attempting to assess and manage the presumed corresponding burdens of care, face the same problem, namely, recognizing temporal unity (a disease structure) out of the diversely-related experiences. In the remainder of this chapter, I show how the working tension is socially organized, first, by describing the role of exemplars in the disease experience and, then, by displaying its socially constructed temporal features.

EXEMPLARS

Part of the process of making sense of the disease experience involves the use of public exemplars, a means of transforming private troubles into public understandings (Mills, 1959). Celebrities who now have or had the disease, like Rita Hayworth, Norman Rockwell, and Edmond O'Brien, together with their caregivers,

combine with less renowned disease victims and caregivers to provide a slate of comparable exemplars by which to evaluate individual impairments. Rita Hayworth, the Hollywoood actress, is perhaps the most famous exemplar of the disease. Her story, entitled "The Tragedy of Rita Hayworth," is presented in an article written by Rosemary Santini and Katherine Barrett (1983) in the popular magazine Ladies' Home Journal. The article describes the onetime "glamorous movie star" as still physically attractive, a well-dressed older woman with "shoulderlength red hair," and "dark brown eyes." But she now stares ahead fixedly, her eyes "clouded and uncomprehending." As Rita's daughter, Princess Yasmin Aga Khan (Santini and Barrett, 1983:84-85), explains:

It's so hard to know what she's feeling, what's going on inside. . . . I don't know what she can understand, but there are fleeting moments when I'm sure that she's at least somewhat aware.

I do know that she needs the security of my love, that in some way I bring her joy. And I visit her as often as I can because I need to be there for her, to tell her I love her, to tell her everything is all right.

The article goes on to introduce the reader to the "devastating illness that has slowly been robbing Rita of her memory, her ability to function and, finally, her personality":

It is called Alzheimer's Disease, and because it affects the outer layer of the brain--creating a chaotic tangle of nerve filaments--a patient's intellectual ability is eventually destroyed. Other victim's relatives have likened it to 'a slow death,' a 'funeral that never ends.' Often they

speak of their afflicted wives or husbands or parents in the past tense. Like Yasmin, 33, they describe the agony of not being recognized, or their feeling that a stranger has inhabited the body of their loved one (Santini and Barrett, 1983:85).

The course of Rita's disease experience is presented under two sections entitled "The rumors about Rita" and "The growing darkness." Yasmin describes Rita's "stormy" career, her five turbulent marriages, as well as the dogged coverage by the press of her alcohol problems and otherwise "bizarre" behavior. The article explains:

What no one--not Yasmin, nor even Rita's doctors-knew at the time was that the former movie star was
already gravely ill. Only Rita herself may have
suspected that something was wrong. An introverted
person, she may have been worrying silently for
years about her mind's growing darkness. When an
interviewer asked her about a past she couldn't
remember, or when her extreme mood changes began
costing her longtime friends, she must have been
terrified (Santini and Barrett, 1983:139).

Rita is reported to be in the final stages of the "dread disease," her insidious onset and "slow, agonizing changes" having resulted in the "confusion and terror that still seem to remain after all other emotions and thoughts and memories have faded away" (Santini and Barrett, 1983:142).

A portrait of the caregiver as "the other victim" is also presented. Resembling her mother, Yasmin is beautiful, "an extremely attractive woman, a classical singer who temporarily abandoned her own career a year ago to devote herself to her mother's care and to the Alzheimer's Disease and Related Disorders Association"

(1983:139). Like the title of the popular caregiver handbook, The 36-Hour Day, Yasmin's experience informs the reader of the time-consuming and emotional sacrifices caring for an Alzheimer patient entails. As she reports:

This whole thing has been too grueling emotionally for me to devote my energies to singing. . . . I'll continue my music later. I don't resent that. This is a time when my mother's needs come first (Santini and Barrett, 1983:139).

Yet, demanding as it is, Yasmin at least can afford round-the-clock care for her mother. Those less fortunate, who cannot so readily obtain outside help, seemingly face an even more difficult caregiving task.

The Rita Hayworth story is a centerpiece for sharing individual disease experiences, a public mirror for personal reflection (Gubrium and Lynott, 1985). It is relayed in national and ADRDA newsletters and is frequently reported in the print and the broadcast media. Indeed, it is often stated that Alzheimer's disease is "Rita Hayworth's disease," or "what Rita Hayworth has." While Rita's victimization is the most widely recognized, there are many other stories that display "what it's like."

Consider, for example, the portrait of a "typical" disease experience which first appeared in Barry Reisberg's (1981) book, <u>Brain Failure</u>, but has since been reprinted as a caregiver handbook and retitled <u>A Guide to Alzheimer's Disease</u>. Reisberg devotes an entire chapter

to Joe S., a once successful newspaperman who had always possessed "an enviable memory," and his "loving and devoted" wife, Ilia. The author (1983:101) describes when Ilia, Joe's writing assistant, who "knew his abilities and style better than anyone," first began to notice "a change in [his] previously enviable performance." Among other things, Joe's "dictations began to lose their customary flow" and he "seemed to encounter some difficulty finding exactly the proper word for what he wished to say." Reisberg goes on to describe Joe's course of decline through three separate phases of the disease, presented as the "forgetfulness phase," "confused phase," and "dementia phase."

Early on, Reisberg informs the reader of the pace of Joe's initial decline, one that was more rapid than "many" others with the disease; one that had "symptoms nearly identical" to those same "many" as well. As the author (1981:102) states:

Many elderly people who begin to notice 'forgetfulness' symptoms nearly identical to those observed by Joe and his wife seem to live with these symptoms for many years without any further decline. Joe, as we shall see, was not so fortunate.

Reisberg (1981:100-22) chronicles Joe's deterioration from his initial "distress at his loss of cognitive facility and his desire to 'do something about it,'" to "denying the extent of his impairment," to, in the final phase, "being unable to sit still," engaging in

"continuous purposeless activity." And, still later,
Joe's condition is described as getting to a state where
he "would become very angry and shout and verbally attack
people without apparent provocation." The author
provides an extensive description and cites numerous
examples illustrating Joe's transition from stage to
stage, at the same time, portraying the plight of Ilia,
"the other victim" of the disease. For example, in
presenting an instance of Joe's condition in stage three,
the author (1981:105) describes:

the intact energy of these dementia-phase patients is expressed as restlessness and rapidly changing, seemingly random activities. For example, when Ilia actually took Joe out onto the street, he immediately wanted to return home. Dutifully, Ilia would take him home, whereupon Joe would again insist upon leaving. Joe was like a man 'possessed,' wanting to do things but not really knowing what he wanted to do.

Unable to cope with the "36-hour" burden Joe presented,

Ilia eventually had to place him in a nursing home--her

almost daily visits and recurring guilt vividly

displaying a labor of love.

Like Hayworth's, Joe's story presents a model for interpreting individual experiences. There are, of course, other exemplary models of the disease experience. These include the more well-known cases of caregivers Bobbie Glaze, ADRDA's national chairperson for program development, and Jerome Stone, the organization's President. There are also visual portraits that

exemplify the disease experience, including, for example, the five different victims and their caregivers presented in the frequently shown videotape Someone I Once Knew. In their variety, they offer an expanded platform for interpreting experienced particulars. There are many local exemplars, too, whose stories have spread through the routine borrowing of news and coping items among ADRDA chapters, reprinted in their newsletters. Often without formal authors as such, the portraits further expand the disease's horizon. Regardless, though, of how familiar or of what style, exemplary presentations provide a considerable chronological resource, typically describing the disease's onset, diagnosis, course of progress, the decision to institutionalize, and the burdens of care while, at the same time too, communicating a recognizable means of sharing diverselyrelated disease timings.

Finally, there are the ad hoc exemplars that serve as temporary examples for comparing other patients' symptoms and courses of progress. In the day hospital's support group, for example, caregivers not only shared their personal burdens of care, but had also interacted with each other's patients in a weekly social and recreation program. Over time, caregivers witnessed several patients' conditions, enabling them to compare

firsthand what the mental and physical status of their own victims is "really like."

All in all, exemplary details collectively represent the "typical," yet diverse disease chronologies. The question of which specific exemplar provides the semblance of particular cases, however, is not just a simple matter of matching exemplary onsets and courses of progress, and their interrelated "task burdens," with individual experiences with the disease. As the following section shows, in practice, the use of exemplars to display "what it's like" often entails a considerable amount of negotiation in its accomplishment.

APPLICATION

Having seen that the rational vision of the disease experience and its illness interpretation does not square with the highly diverse symptomatology and course of progress as well as the burdens of care, how, then, is the tension socially organized? How is a sense of temporal unity recognized out of the individual chronologies? In application, through the use of exemplars as well as other disease-related concerns that enter into the perception of severity, the pattern becomes as unilinear and systematic or varied and unpredictable as are disease versus aging discourse. In the process, timing becomes an artifact of the work that all concerned do to assign reasonable courses of progress

to the disease experience. I consider first the onset of the disease, then its course of progress and, finally, the caregiving burden.

When did it begin?

The arrival of a given date or period of time when some sort of impairment, typically memory loss, first occurred is something that does get achieved. Caregivers often discuss among themselves the particular years when problems began to emerge. It is not unusual, for example, for a wife to state that her husband's illness began in the summer of 1977 "when he started forgetting things," or some such date. As discussed earlier, the question of onset is important to caregivers and service providers because it provides a starting point or benchmark by which to estimate the changing needs of both patient and caregiver, in effect, to rationally organize care and treatment.

While obtained, information about age of onset is retrospective and is continually sensitive to its current considerations (Lynott, 1983). It was not uncommon for caregivers in the support groups to state that they wish they had kept a record of events of the course of their patient's illness, that such a log would have helped them to better plan how to deal with it. As one caregiver remarked, "If only we had kept a diary or something, at least now we might know where we stand, instead of being

so confused about it all." But, at the same time, they also stated that such a record would have been impossible to keep since they "usually didn't know what was happening until much later." Indeed, caregivers frequently said that they thought the patient was "just getting old" with its accompanying limitations until a diagnosis of Alzheimer's was made. Only then did they interpret the patient's problems as disease.

When asked about the onset of their patients' illness, caregivers indirectly refer to the retrospective nature of their estimates. They typically preface their responses with phrases such as "Now that I think back on it, I really think it began in . . ." or "It's hard to say but we [family members] were just talking about that and. . . ." Others remark that they really don't know for sure, but, upon being urged to provide a given time of onset, proceed to reconsider past events in terms of the request.

Moreover, the times of onset that are provided are sensitive to ongoing exemplary comparisons. The exchange of information and experiences that takes place in interactions with others and by reading available literature about the disease provide a slate of exemplars which serve to inform caregivers' changing accounts about the onset of their patients' disease. For example, a wife who had determined the year 1976 as the age of onset

of her husband's illness might later learn of an event in the life of another patient said to manifest the disease, one that similarly occurred in her husband's life but in 1974, and thus proceeds to reconsider the age of onset of her husband's illness. The work of assigning a given time of onset, as a concrete point in the past, is reconsidered time and again as exemplars enter into its chronology.

Consider an example drawn from one of the support groups studied. One of the regular participants, Harold, had a rather definite sense of the onset of Alzheimer's in his wife Cynthia. Both in and out of the proceedings, he said he was certain that Cynthia's disease began about four years before when she started to forget where she had placed various items. Harold said that his wife began to behave much like a husband who was well-known to most of the local ADRDA chapter membership. Cynthia forgot simple things at first, such as taking off her wedding ring to wash the dishes and not remembering where she had done so. Harold began to suspect that Cynthia's forgetfulness was worsening, again, "just like" the exemplary husband. Later, still resembling the husband, Cynthia began the typical accusations, blaming Harold for misplacing her ring, even accusing him of deliberately hiding things from her.

Harold's daughter, Martha, would sometimes

participate in the support group. While the question of
onset was not considered at each meeting, it became a

topic of conversation at one point when both Harold and
Martha were in attendance. As usual, Harold described
the disease's onset in Cynthia and compared it with the
well-known husband. Listening, Martha respectfully
disagreed. She then turned to her father and asked:

Dad, don't you think that it started much earlier than that? Mike [her brother] and I were talking about this the other day and I think that Mother had symptoms at least ten years ago when she was still working. Remember how she would come home and complain about how everyone at work was down on her because of the way she filed things? Remember how we all blamed it on that woman she worked with, who we didn't much like anyhow? I really think now that it's more like the Rita Hayworth thing, like Mother had it for a long, long time but we just didn't notice it.

Harold considered the possibility that his daughter, and his son, might be right. He stated that he hadn't really given their interpretation much thought. Other caregivers, too, addressed the alternative, continuing to cite various exemplars, more or less popular, in the negotiation of Cynthia's onset. They did this until, as on other occasions, the issue of "when it all began" was settled for the time being.

The process of determining "when it all began" might again later be redetermined, as it were, as caregivers take into account service providers' and other caregivers' ongoing considerations. Yet, while

originally a product of retrospective and practical considerations, the time of onset does, at some point or another, begin to take on a life of its own, toward which caregivers subsequently interpret other aspects of their caregiving experiences. The assigned beginnings provide the concrete basis for disease, not normal aging, a distinction which continues to be problematic in considering the disease's ensuing course of progress.

Where does it go?

The course of progress of the disease, as earlier examined, is encountered in two ways. One way is that impairment is described as increasingly progressive and systematic until death. As informed by the rational vision, this form of description is most apparent when caregivers and service providers engage in a developmental mode of reasoning, referencing stages and their duration. Yet, the disease also is said to be erratic, having no clear course of progress. The variety of symptoms among early onset patients is often depicted to be as great as among all patients. Likewise, those who have had the disease for years are described as "remarkably different."

Consider an example of the tension as it occurred in one of the support groups studied. A psychologist attending the session, in responding to a caregiver's remark that, while each individual was different, "there

must also be some general patterns to the disease,"
cautioned about overgeneralization and then proceeded to
describe different stages of the disease from a care
manual she had on hand. As the psychologist described
the different stages, the others present began to "fill
in" their patient's respective chronologies. Upon
hearing the characteristics of stage two, for example,
the inquiring caregiver exclaimed, "Fantastic, I can see
Max right there." Yet, the tension concerning the
disease's "typical" course would soon become focal.
Another caregiver, the middle-aged son of a demented
mother, took issue with the presented characteristics of
stage three--featuring aggression as one of the primary
symptoms--stating that his mother has always been that
way:

I don't want to be disagreeable but my mother's been aggressive all through this thing. It's the first thing we noticed. You all know how easy-going and considerate she was . . . well, when she started to bully the family, I think that's when I started to notice the Alzheimer's. It's been like that from the very beginning.

Others, too, pointed out related stage difficulties. One caregiver, for example, mentioned that her demented husband had never shown any signs of aggression, that her main problem was his constant wandering.

When asked to explain the discrepancies, the psychologist, reminding the caregivers of her earlier caution about overgeneralization, then explained how

"each patient's a unique individual that's different from the rest" and, as such, "has to be evaluated on its own terms." While the disease's chronology, of course, would again become developmentally depicted, rendering Alzheimer's as a structured entity, the tension was clearly manifested in its diverse presentation. How, then, faced with the dilemma, do those concerned manage to discuss their "common" disease experience?

There are two significant features of the disease experience that enable its social chronology to be accomplished, each discussed in turn. The first is that it is never entirely clear just what a given patient's "actual" course of progress is, impairment being as much a product of ongoing interpretations and exemplary comparisons as it is a feature of the disease itself. What an earlier or later deficit is described to be often shifts as caregivers and service providers hear the details of other patients' conditions and care burdens. Such shifts might even occur several times in the course of a single support group session as participants share their patients' functional impairments.

Consider an example as it occurred during one particular session (Gubrium and Lynott, 1986). One of the caregivers, Fern, the middle-aged daughter of a demented mother, complained about the terrible burden her mother was getting to be. Citing the results of mental

status examinations the patient had recently taken as well as her own personal experiences with the patient, Fern described how her mother had declined considerably in just the last few months. Turning to a caregiver seated next to her, Fern asked, "Rose, haven't you noticed the same thing?" Rose replied that she did indeed notice it, especially the mother's changing disposition, a woman who, most agreed, had always been one to laugh easily. Fern continued:

And the worst of it is, Rosie, that I used to be able to stand all the other things, you know, the folding [of clothing] and you know how stubborn she can be sometimes. It wasn't as bad at least when I could laugh at some of the silly things she did and she'd laugh too. But it's not the same anymore. She still does all those same things but I think she's gotten worse because she's gloomy all the time. She's got that vacant look more and more, kind of staring ahead like they say Rita Hayworth does. It's a really, really heavy situation, and I feel it.

When another participant remarked that a patient's temperament was a major factor in the illness, the discussion turned to the general question of the relationship between functional impairment and patient mood in the caregiving burden. A husband, for example, commented that his wife's lack of humor was especially difficult for him, that he could, in his words, "take twice the wandering if she'd only be happy and laugh again."

Yet, the previous consensus over the relative importance of mood and physical functioning altered when

another caregiver, Milt, offered a different interpretation:

I wouldn't be too sure about that if I were you. That's not the way I see it. I don't know if I can place that much faith in the person's mood. It isn't all it's cracked up to be. I get sick and tired of all that happiness stuff and that 'smile is your umbrella.'

You all know Belle [his wife, the patient] very well and you all can see for yourself that she's the real joker and tease of the group [day hospital patients]. She's a very social person. She's always been. Talking and always laughing, like you wouldn't believe. Well, I hate to say it, but it's just driving me bananas. The constant chattering and laughing at everything. It's gotten so's I wear my Walkman [radio headphones] whenever I'm at home and Belle's around. The only time I get any peace and quiet is when she comes here [the day hospital] twice a week. All that chatter and giddiness have made her a real handful. You should all thank God for small favors. I only wish Belle's mood were like your mother's. It would really lighten the burden. It's not me, I don't think, because any of you would have a time of it in time.

The group then turned their attention to Belle's mood. Each member knew her well, having regularly interacted with her in the day hospital unit. There was no doubt that Belle was a happy patient. Each of the support group members had frequently commented on her mood, to the point where she came to exemplify for them what the happy, yet functionally impaired, patient can be.

As Milt continued his argument for the real burdens of excessive joviality, another caregiver, Charlotte, whose demented husband, Phil, was perceived as happy-go-lucky, began to reappraise Phil's impairment. Her change

in outlook was based on what she also saw as the general implausibility of a simple mood-dysfunction argument, considered against particular experiences with her own husband. Charlotte explained:

I'll tell you. Fern, until I started to really hear what Milt was saying, I thought the same. Who could argue with that? Better a happy wanderer than a miserable one. Right? But you know, when I think of my Phil, now he's a happy enough fellow. You know. I don't have to explain. But it can really get to me, too. Like I know how it gets to Milt. I mean, just face it, things just aren't that funny. Just because Phil treats everything like it's a joke, it makes his restlessness twice as difficult. He just can't get serious about himself and it only makes the wandering worse, just awful sometimes, like he's laughing at you and kicking you in the behind at the same time.

Charlotte's remarks did not convince either Fern or Rose. They responded that they'd much prefer Phil over their own patients. In support of her view of the composition of impairment, Rose incredulously asked all participants, "You mean to say that someone like that wandering, morose mother in that movie we saw [a popular documentary about five Alzheimer's patients, entitled "Someone I Once Knew"] is not as much a burden as Phil or Belle; you've got to be kidding!" Rose maintained that the wanderer depicted in the film was "clearly" a case of what any caregiver would want to avoid because, as she declared, "That's really what I would call a 36-hour burden," repeating the familiar slogan. For Rose, it was "plain as day," as she put it, that the patient in the movie was the worst kind of impairment short of being a

vegetable. Correcting herself, Rose noted that at least totally demented and bedridden victims stay put.

A short while later, however, Fern, like Charlotte before, also reconsidered her own patient's impairment, this time describing it as "not so bad after all," in comparison to another caregiver's tearful story of how her demented husband, "once a kind and loving person," had recently attacked her with one of his old golf clubs. Addressing Rose in a lowered voice, Fern went on to state, "Those combative types are really the worst kind. We're pretty lucky after all."

As this and other support group proceedings show, there was no overall consensus as to the apparent facts of impairment for any given case. Indeed, what for one caregiver was seen as nearly total impairment, for another was likely to be perceived much more benignly. Moreover, each caregiver's judgment of his or her own patient's concrete set of dysfunctions seemed to become objectively different "stages" of decline depending on what, and to whom, it's "task burdens" were compared.

Yet, while a patient's "actual" course of decline could be transformed into greater or lesser degrees of impairment, at the same time, there were regular agreements and routine conclusions about the objective impairment and burden presented by each case. Different types of patients came to exemplify a wide-range of

behaviors and chronologies, from the "very rapid declines," "plateaued victims," and "near vegetables," to the "combative types," "wanderers," and those who periodically displayed "lucid moments." In their variety, exemplars served to inform caregivers' and service providers' changing accounts of their patient's presented symptoms and burdens of care, impairment having at least as many interpretations as exemplars.

Moreover, the use of such terms as those or them (see Fern's comments above) enables caregivers and service providers to "bridge the gap," so to speak, between patients' contrasting conditions. Manifestations of the disease which do not conform to a particular patient's deficits or course of progress are explained as the way those patients' behave or the way they have declined, acknowledging that it is "them," that kind of patient, not mine, or some other type, that is being referenced. Exemplars, then, in their detailed usage, combine to collectively document the experiential particulars the disease is understood to be about.

Those who experience the collective "details" of the disease experience, in their diverse presentation also, at times, come to question the existence of a single underlying disease entity. This is the second way the disease's varied chronology is socially organized,

through the elaboration of the conception of the disease. Consider, for example, one service provider's comments:

Sometimes you wonder because the diagnosis of Alzheimer's is difficult and sometimes you look at other people and wonder if it's just something that they're displaying; is that really Alzheimer's disease or could dementia become something else too? So I don't know. I don't think I could say for sure that everyone in there [the day hospital] is in a different stage of . . . I mean they've all been diagnosed as Alzheimer's disease but I think there are probably some different types of Alzheimer's . . . or there could be . . . hopefully if they learn more about it, there would be different, several different types of dementia.

Exemplars are also used to elaborate the disease's symptoms and course of progress by medical researchers. Consider, for example, how Drachman organizes his understanding in excerpts from a roundtable discussion of a 1978 conference at the Banbury Center of Cold Spring Harbor Laboratory in New York. Following a videotape presenting three exemplary-type patients in different stages of the disease, Drachman remarked on patients' contrasting conditions:

When we have examined all this semiology—all the signs and symptoms—what do we do with the details? We have followed perhaps 150 patients closely in our dementia clinic, and the semiology is enormously variable. This is an important concept to get across: that, while you have seen three stages of dementia, there are many, many more clinical attributes in which demented patients may differ substantially (Katzman, 1983:10).

The researcher goes on to present the diverse clinical features of the disease that he has encountered

in dealing with patients, describing several unnamed exemplary types in the process. For example, he writes:

You may see patients whose dementia is <u>early in</u> onset or <u>late</u>. . .

Some patients progress <u>rapidly</u>, some <u>slowly</u>.

Recently, I saw a woman of 84 who had had AD for 10 years, but had retained all of her gracious mannerisms; at a cocktail party, you would not pick her out of the crowd. At the same time, I saw a much younger woman who had had AD for 4 years and was absolutely anarthric; not the slightest sound emerged from her mouth; and her manifestations included a stooped posture, tremendous paratonic rigidity, and excessive attentiveness to each person who talked, presenting the appearance of someone watching a tennis match (Katzman, 1983:10-11).

After finishing his descriptions and a discussion of the disease's diagnosis, Drachman states that, in his opinion, Alzheimer's is not a single disease but, rather, is composed of a number of other conditions. Drachman is not questioning the existence of disease itself, as he is the existence of a disease's ability to accomodate the varied character as displayed in its exemplification. Rather than abandon the disease grammar as a unifying principle, the researcher instead elaborates its structure to encompass the multitude of experiential particulars to which it applies. As his later remarks illustrate, following other researchers' comments regarding the videotape:

We certainly do make the assumption, though, tacit though it may be, that this is a disease. And I think the crucial point is that we don't know that at all. We don't know that this patient who had, perhaps, a 9-, 10-, 11-, or 12-year course until he was really severely disabled is quite the same as the individual who goes careening downhill in 3

years. I think that until we have made those observations, we need to retain a certain degree of uncertainty as to what the subsets are, whether we're severely overlooking different diseases which masquerade under the general rubic of AD (Katzman, 1983:20).

Drachman's elaboration to include different forms or types of the disease enables him to account for the diversely-related experiences, patients so much alike, and yet, at the same time, so very different. However elaborated and transformed, the characteristics of Alzheimer's, in their variable manifestation, take on as many meanings as is required by those concerned. In practice, through the use of exemplars, the meanings collectively represent a unified disease structure while, at the same time, displaying as many individual timings as there are exemplars to share the experience—as patterned or unpatterned as disease versus old age itself.

What is the Response?

The interpretation of the progress of the experience as a disease structure provides a developmental time frame by which to assess and, thereby, intervene into caregiving affairs. How does the social organization of measurement and the question of institutionalization fit with the disease's temporal quality?

Consider, first, the social timing of assessment procedures. During measurement situations, caregivers'

comments and questions concretely display the ongoing practical constructions and transformations of the meaning of felt burden. This was quite evident when, completing the "burden interview," caregivers prefaced their responses to tolerance items with "well it depends," "I tolerate it sometimes but not other times," and "I tolerate it more now than I used to, I think."

The levels of tolerance that caregivers do provide during measurement might later shift from, say, being overburdened and depressed by a patient's impairment, to feeling rather fortunate and not "so bad after all."

Indeed, in the span of a few moments, the felt burden defined against what is perceived as overwhelming impairment might change, as it did for one caregiver, to "not burden really but just those daily irritations," when compared to the "really frightening picture" presented by another caregiver's patient.

What is clear is that differences in levels of tolerance expressed vary with the context of their consideration—across testing and nontesting occasions—not chiefly with some objective state of impairment. As such, the felt burden evident in any caregiver's experience "depends" on the occasions, situations, and comparisons taken into account in their interpretation, having as many disease—related timings as there are assigned meanings.

The same social configuration is also featured in the decision to institutionalize the patient (Lynott, 1983). The decision commonly focuses on the question of when "it's time." The expression signals the decision in a variety of sources, including ADRDA chapter newsletters, caregiver handbooks, and support group discussions. Consider, for example, a poem, itself entitled "It's Time," written by Dorothy Hessel of the Detroit chapter, which lists the conditions indicating when one should "let go" and seek a nursing home placement. Following the initial question, "When should I give up my loved one to another's care?" among the conditions cited are:

When he [patient] sits in front of me and objects when I talk on the phone.

When he doesn't remember to use the bathroom.

When he gets out of bed and runs into the night.

When he thinks people are "after him."

When he runs away and I am GLAD to have a few minutes to myself.

When I DO fall asleep and I am too tired to respond to his needs.

When I feel I might die first.
Yes! It's time!

While these and other maxims pertaining to institutionalization suggest that timing is a straightforward process of matching patient conditions against caregiving capabilities, determining when to seek a nursing home placement is socially organized. Some link their readiness to the patient's vegetative state, as in the response, "I don't think I'm ready for that [nursing home] because Sara's not a vegetable." Others link it to family pressures. As one caregiver put it, in relation to placing his mother in a nursing home, "I have to think about my wife and how she needs me too." At still other times, however, caregivers say that they don't know when "it's time" to institutionalize the patient.

Being an ongoing issue among support group members, the expression "it's time" is routinely heard in the sharing of caregiving experiences. For example, after an exchange of stories about the "really bad things" that have recently occurred, a common retort might be, as one caregiver put it, "Yes, you know it's time when they start to piddle on the floor!" Yet such statements do not automatically signal a decision to institutionalize, for timing and such unpleasant conditions as piddling are interpreted, compared, and reinterpreted against ongoing considerations, such as the loss of companionship, familial obligation, the shame of giving up, and even the

denial of one's love for the patient. Such comparisons are part of the continuing interpretation of burden.

Consider, for example, a series of discussions in one of the support groups studied (Gubrium and Lynott, 1986), which centered on a wife's frustration over her demented husband's increasingly careless toilet habits. For two weeks, participants had been sharing what one of the facilitators had called "horror stories" about patient conduct, such as tales of midnight wanderings in subzero temperatures and violent outbursts in public places. For example, after a patient's daughter, Carol, told how upset she had been when her mother had mostly missed the toilet when the mother last defecated, another caregiver, Vel, whose husband had Alzheimer's, flatly stated:

Look when I hear those things, I think if it comes to that, that's it! No way will I put up with that kind of thing. I love Ben dearly but I couldn't handle that. I'd really have to find a place for him. I hate to say it but that's when I'd say, "It's time."

Yet Carol's response suggested that patient behavior and the decision to institutionalize were not simply linked. Carol remarked that putting her mother in a nursing home had, indeed, crossed her mind as she cleaned her and the soiled bathroom but went on to say:

But, then, I thought, too, well it really wasn't her [the mother's] fault. She didn't mean it. It was an accident. And we all have accidents, don't we? Even the dog sometimes makes a mistake right there on my carpet and I wouldn't dream of putting him

away. Sure, at the time, I thought this was the worst thing that could happen. But, later, you change your mind. She could have wandered off and gotten hit by a car. But, thank heavens, she didn't [Carol knocks on wood].

Carol continued to discuss the incident, what it had meant to her then and how its meaning had changed over time. The incident represented a different degree of impairment as Carol considered her mother's related intentions and compared what the mother had done with what other impairments her mother and other patients, even family pets, presented. It was evident that the decisive impairment and felt burden were matters of ongoing interpretation.

The decision to institutionalize is complicated even more by family obligations and concerns. Caregivers would frequently comment on their loyalties for the patient and the contrasting burdens of their care. One caregiver, the husband of a demented wife, described his feelings this way:

I know Sophie's not the same person that I married. I have to be realistic about it. All I've got left is someone who's become a stranger to me. And you have to think about your own needs too. Sophie demands a lot of work . . . the girls [daughters] help. But tough as it is at times, I know what she was and that's all that matters.

Other caregivers, however, especially those who had experienced burdens of caregiving for a long time, told how the disease took a toll and affected loved ones.

They spoke of finally coming to terms with the dilemma of

love and hardship, and having to "face the fact" that a nursing home was the only answer. Consider, for example, the following caregiver's strong retort:

[you have to] shake yourself and wake up to the realization that you've got a life of your own to live. You've got to face the fact that the guy doesn't know you, doesn't even know who he is. Dear, when it comes to the point where they're unaware of anything, then what's the difference? It's time to start seriously thinking about a nursing home.

Even after institutionalization, decisions thought to be permanent are entertained, as new situations and sources of comparison emerge. Whatever the burden that was once "objectively" assessed, it is continually reconsidered in relation to ongoing considerations and experiential comparisons.

The timing of the disease experience for all concerned, then, is not simply a matter of the disease working itself out. What is made of onset, course of progress, and their ensuing senses of burden and tolerance is a matter of social comparison, retrospective reconsiderations, and prospective visualizations of things to come. These temporal assessments of the disease serve to articulate its experience.

CHAPTER 6

THE PUBLIC AND THE PERSONAL: THE QUESTION OF RESPONSIBILITY

In this chapter, I turn to the third question of the three that have been brought to bear on each of the grammars—the question of responsibility. Having discussed the nature of agency in the disease experience in Chapter 4, I now consider the moral consequences of locating agency in the disease as opposed to normal aging. Asserting and demonstrating that "Alzheimer's disease is not normal aging," concerned agents of the ADRDA aim to publicize the fact. As a medical, not a normal condition of aging, interpretation of "symptoms" shifts responsibility from personal intention to pathological conditions.

PUBLIC RESPONSIBILITY

Consider, first, the public side of responsibility. The major concern here is in "spreading the word" about Alzheimer's. Since its establishment in 1979 (see Stone, 1982), the ADRDA has been the chief organizational force in this regard. A self-help organization with missions of public education, research support, advocacy, and

caregiving assistance (ADRDA, 1982), the ADRDA has engaged in continuing efforts to increase public awareness about the disease. It is interpersonally connected with other cooperating agencies like the National Institute on Aging, the National Institute of Neurological and Communicative Disorders and Stroke, and the Gerontological Society of America as well as related professional interests in medical schools where Alzheimer's disease research is conducted. The ADRDA itself, however, "orchestrates" the disease's growing public recognition, a concerted attempt to expose the so-called "silent epidemic."

The ADRDA's success in "spreading the word" has proved to be far-reaching. In 1982, the organization persuaded Congress and the President to proclaim National Alzheimer's Awareness Week from November 21-27 (extended to include the entire month of November the next year). The following Spring, 1983 issue of the national ADRDA Newsletter reported a surge in media attention that resulted, noting, too, that the "ADRDA supplied the bulk of their source material." The newsletter goes on to state: "This is a major breakthrough for us; it indicates that our efforts have impressed the urgency of the AD problem upon the media." The newletter cites numerous examples of media exposure since the event. During that November, for example, "literally hundreds of newspaper

articles appeared around the country and nationwide TV coverage began." As part of the coverage, a "very sensitive piece was shown on the CBS Network News with Dan Rather." In January of 1983 the article, "The Tragedy of Rita Hayworth," written by Rosemary Santini and Katherine Barrett, appeared in the Ladies Home Journal. On January 18, Marion Roach, the author of the New York Times Magazine article "Another Name for Madness," appeared on NBC's Today Show and later, on February 11, on CBS Nightwatch. The espisode of CBS' Trapper John, M.D., entitled "Forget Me Not," which aired January 30, featured a surgeon who was "showing all the early symptoms" of the disease. The newsletter story goes on to describe still more examples of media attention, with the following concluding remarks:

While Alzheimer's Disease is still not exactly an everyday household word, our goal of increased public awareness is steadily being realized. We've come a long way in 2 1/2 years, but still have a lot more work ahead. Meanwhile, Alzheimer's is a topic that could appear in your favorite newspaper or magazine or on your television screen at almost any time.

The ADRDA's continued success in its publicity campaign is celebrated in bold headlines on the front page of the Spring, 1985 issue of the national <u>ADRDA</u>

Newsletter, which reads: "ALZHEIMER'S NO LONGER A SILENT EPIDEMIC". The following column credits its success to the "unprecedented" media attention given to Alzheimer's disease during the previous six months. Most notable was

Newsweek's December 3, 1984 cover story, "The Agony of Alzheimer's Disease," where more than "3,000,000 readers were given an in-depth view of AD." Other highly visible sources included nationally syndicated columnists Ann Landers and Bob Greene (Chicago Tribune), who "have brought home the message of Alzheimer's in daily newspaper columns which addressed common questions and issues surrounding AD," as well as the nationally televised Phil Donahue talk show, which featured Dr. Peter Rabins, co-author of The 36-Hour Day, actress Maria O'Brien, daughter of former actor Edmund O'Brien who is now an Alzheimer's patient, and two other family members of Alzheimer's patients. Documentaries and radio programs also are mentioned in the newsletter as contributing to the cause, including Group W Westinghouse's airing of the film "Whispering Hope," hosted by Jason Robards, and the radio show "Prime Time," which has transmitted its broadcasts from Washington, D.C. to more than 450 stations nationwide.

The ADRDA's efforts are supported by a number of other well-known figures as well. The Fall, 1982 issue of National's <u>ADRDA Newsletter</u> reports, for example, that actor Jack Lemmon "helped to tell the Alzheimer's Disease story" in a public service announcement which Michael Landon directed. And the Winter, 1985 issue cites Joanne Woodward, whose mother has been diagnosed as having

Alzheimer's, as another celebrity who "has helped to spread awareness about AD through her moving portrayal of an AD victim in the television special, 'Do You Remember Love.'"

Yet publicity itself is not enough to win the war over Alzheimer's disease. As the old saying goes, "money speaks louder than words." Accordingly, it is the public's dollars that will ultimately support the research needed to someday hopefully find the elusive cure. The ADRDA's publicity campaign, as such, is also intended to elicit a societal obligation to "join the fight against Alzheimer's disease."

In addition to research funds, the ADRDA advocates for Alzheimer's victims and their caregivers, especially with respect to the financial burden. For example, because Medicare (a federal program providing medical insurance for the elderly) only pays for skilled nursing care and Alzheimer's is considered to only require custodial care, victims' families are not eligible for the assistance. Most private insurance policies also do not cover custodial long-term care. This leaves many spouses, whose assets are considered the same as the patient's, in the situation of having to dilute their savings until being able to qualify as indigents and thus receive Medicaid—a joint federal and state welfare program which covers both skilled and custodial care.

The ADRDA's advocay successes regularly are reported in its national newsletter and reprinted in the various chapter newsletters. Growing research dollars, from individual donations and contributions in memory of a recently deceased loved one, to much larger sums from grants awarded by foundations such as the Andrew Mellon, the Wood-Kalb, and Lauder, are welcomed, the latter often making front page headlines in National's ADRDA Newsletter.

Legislative developments are also broadcast. Winter, 1983 issue of the national ADRDA Newsletter, for example, under the heading "Government Responds In The Fight Against Alzheimer's Disease," reports how "government leaders put aside their political and ideological differences to unite behind legislation dealing with AD." The column emphasized the ADRDA's ability to get Congress to unanimously designate National Alzheimer's Disease Awareness Month in November of 1983 and the President's subsequent proclamation. approved legislation includes providing additional funds to support research into possible causes of Alzheimer's disease and its treatment as well as the creation of specialized centers to deal with the "complex nature of the disease." Achievements yet to come include the passage of bills which would relieve some of the financial problems for the families of Alzheimer's

patients, such as reforms in Medicare and tax credits to caregivers.

In addition to efforts focused at the national level, the ADRDA has over 120 local chapters across the country engaged in publicity and advocacy. The grass roots efforts run the entire gamut of activities, from fundraising events and media appearances directed towards greater public awareness, to sponsoring public seminars to educate professionals and community groups, lobbying for key legislative issues nationwide, and providing help to family members in the multitude of support groups. Local contributions are selectively highlighted in the regular "Chapter News" feature of the national newsletter, demonstrating the "persistent team work at both the Chapter and national level" in the ADRDA's mission of public recognition and support (national ADRDA <u>Newsletter</u>, Fall, 1985). A sample taken from the Spring, 1982 issue illustrates the grass roots lobbying and educational efforts:

ADRDA--Northern Virginia launched a telephone campaign to local delegates of the Virginia House of Delegates when a bill was being introduced in the House to appropriate money for Alzheimer's research. The bill passed the House of Delegates and contact is now being made with the Senate Finance Committee. The chapter wants to involve more members in contacting their legislatures concerning pending legislation.

ADRDA--Greater Philadelphia participated in a large Health Fair sponsored by a major TV station at Independence Hall Quadrangle and also at a Health Fair sponsored by a local hospital. Literature has been mailed to all neurologists in the area, and speakers from

the chapters have appeared before professional and community groups.

The Spring, 1984 issue reports on other kinds of local publicity:

ADRDA--Omaha had an "Alzheimer's Disease Night" at an Omaha Royals baseball game to raise money and promote awareness. The Royals' general manager helped by printing 200 posters and 20,000 tickets. He also arranged for Chapter members to see Coke donated by the Coca Cola Company with the cooperation of the local concessionaire. This fundraising event was so successful, they are already planning for a bigger and better AD night at the ball park for next year.

ADRDA--Providence has an active membership of well over 600 families and seven support groups meeting monthly. The Chapter's Speaker's Bureau has been providing inservice education to long-term care facilities as well as community health agencies and to hospitals for two years. They also speak to senior citizen and church groups. Local media coverage has kept the office telephones busy.

And the Spring, 1985 issue presents continuing media attention, publicity events, and legislative incentive:

ADRDA--Chicago Chapter members appeared on ABC-TV's AM Chicago with Oprah Winfrey, Jan. 14 and worked closely with WLS-TV on a 5-part series on Alzheimer's which aired Feb. 4-8. An AD Conference was held in Springfield, IL 12/10 under the auspices of the Illinois House Appropriations II Committee and the Southern Illinois University School of Medicine on Alzheimer's Disease:

Directions for State Policy. ADRDA Chapters in the state of Illinois are now actively involved in formulating legislative initiatives, in both the state House and Senate to benefit AD victims and their families.

ADRDA--Cleveland is planning three major events: A Phonathan--Feb. 25/27 and March 3, with 25 volunteers staffing the phones. Our goals are to increase membership support for program development. A workshop for professionals is planned for March 31st, jointly sponsored by ADRDA and Cleveland State University. The biathlon "Race for Reason" will be May 5th which we hope will attract over 700 participants from Ohio and surrounding states, who will bike and jog in support of AD. Local racing clubs along with ADRDA volunteers are hard at work to make this event a whooping success!

ADRDA--Houston National AD Month activities included efforts which led to state and local proclamations, large scale distribution of posters, provision of PSAs to radio and TV stations. Channel 13 devoted several news program segments to AD and aired both the Phil Donahue show the "Whispering Hope." We also participated in an all-day workshop on AD sponsored by the Texas Department on Aging and Health and by local Councils on Aging.

The ongoing need for more funds to support research efforts as well as alleviate the deep financial crunch many families face require the full effort of the membership. Members are encouraged to write their representatives in Congress requesting additional support. The April, 1984 issue of the <u>Honolulu Chapter</u>, for example, under the heading "News from National," presents the following plea to its members:

November was National Alzheimer's Disease Month last year--the <u>first</u> every!!!! Well, this year we need to support this measure again to assure Congressional approval of AD Month, 1984! According to Jim Novy from the national ADRDA public relations office, it will be a matter of years before the resolution for AD Month becomes automatic.

PLEASE--it is urgent for you to call or write to our Hawaii representatives in Washington and ask them to support National Alzheimer's Disease Month 1984.

The message goes on to ask for letters:

ANOTHER IMPORTANT request from national is to write Congress to urge their support for ADDITIONAL FUNDING for RESEARCH on Alzheimer's Disease and for AD research CENTERS. Last year additional funds were approved, but NOT ENOUGH! With the aging of the population and with costs of AD care and treatment estimated to be 26 billion last year, government must increase funding! (Almost \$40 million was appropriated last year for research, which is an extremely small percentage of the research dollar, especially when you consider the

numbers of people with the disease--an estimated 2.5 million in the United States.)

The column also provides the addresses and phone numbers of legislators as well as advice on how to formulate the letter and what to include in it. It ends with the charge: "DO IT NOW!! TODAY!!" Other chapter newsletters present completely written sample letters as guides for requesting money for research and aid to families of Alzheimer's patients. However detailed, the pursued goal is the same, to marshall as much support as possible for the Alzheimer's disease organization.

To this end, Princess Yasman Aga Khan, on behalf of her mother, has written President Reagan asking for whatever help he might give. The letter was reprinted in a number of places, including the Spring, 1983 issue of the national newsletter. Under the heading "A Plea to the President," the letter reads:

Dear Mr. President:

My mother is the actress Rita Hayworth a woman known and loved throughout the world for her beauty and spectacular screen career. She is one of the 1.5 million victims of Alzheimer's Disease, and because of this, the simple things that we all take for granted have slipped away from her.

More research is needed on this silent epidemic. We ask that you give us your support, and help to persuade the public, the insurance companies and the representatives in our government of the importance of fighting this devastating disease.

Thank you.

Princess Yasmin Aga Khan

The President's response to Princess Yasmin's letter, conveying his commitment to a growing public

concern over the threat of Alzheimer's disease as well as the dearth of funding for research, was printed in the Summer, 1983 issue of National's <u>ADRDA Newsletter</u> as well as the chapter newsletters:

THE WHITE HOUSE

WASHINGTON

May 10, 1983

Dear Princess Yasmin:

Like most Americans, my true understanding of the tragedy called Alzheimer's Disease is relatively recent. For too long this insidious, indiscriminate killer of mind and life has gone undetected, while the families of its victims have gone unaided.

In your letter, you asked for my help in increasing this awareness--among the public, insurance companies and governmental representatives. It is assistance I will provide whenever and wherever possible.

You asked, too, for the commitment of additional research funds. I am pleased to note that Federal funding for this will increase by nearly 50%--from \$17 million to \$25 million--in fiscal 1984. Also, Secretary Margaret Heckler of the Department of Health and Human Services has established a task Force on Alzheimer's Disease to coordinate and promote the Department's many activities in this area.

In closing, I sincerely wish to applaud your efforts and those of the thousands of ADRDA volunteers who tirelessly provide support and hope to Alzheimer's Families nationwide.

Sincerely,

Ronald Reagan

At the other end of the spectrum, ADRDA members have been encouraged to share information about the disease with their friends and neighbors or anyone else who might

benefit or be interested in supporting the cause. The October, 1980 issue of the Cleveland ADRDA Chapter's Newsletter, for example, presents the following directive:

SPREAD THE WORD

The more people you talk with about Alzheimer's disease, the more support we are likely to get. By talking about Alzheimer's disease with your friends and neighbors, more people become aware of the disease and concerned about its cause, cure and the care of those afflicted. You never know when someone you talk with might know of someone with the disease whose family and friends would be grateful to know of our organization or someone else who would like to donate his time or money to our efforts.

The ADRDA also takes it upon itself to inform its members of a variety of disease-related information to enable them to both better understand the disease and cope with its effects. The national ADRDA Newsletter carries regular "Research Update" and "Ask the Doctor" columns, which present news about the latest research developments and general scientific knowledge about Alzheimer's disease and related disorders. Care is taken to be as straightforward as possible, with caution offered against so-called advances in the disease, lest false hope be raised. For example, under the heading "A Word of Caution," the Spring, 1984 issue of the national ADRDA Newsletter states:

Several regimens, treatments, food substances and drugs have been advertised as "cures," "treatments," and "retardants" for Alzheimer's Disease. Some may have questionable value. Says

Dr. Robert Katzman, chairman of ADRDA's Medical and Scientific Advisory Board, "The fact is that at this moment we don't know of any drug or any other treatment that stops the progression of Alzheimer's Disease."

A word of caution to our readers: skepticism can be very healthy. Before embarking on any program or any course of treatment, it would be wise to check with your family physician, ADRDA Chapter, local medical school, or perhaps, when in doubt, the Food and Drug Administration. You can then make an informed decision.

Tips and advice frequently appear concerning how to deal with the many problems that inevitably crop up in the disease experience. While National's ADRDA

Newsletter has its "Helpful Hints" and "Ask the Lawyer" features, chapter newsletters focus explicitly on the day-to-day management of concrete caregiving. Advice is offered on how to manage a whole range of problems, from the patient's sexual behavior, eating habits, and incontinence to problems of vacationing, bathing, and communication. Assistance in obtaining power of attorney or conservatorship, handling financial affairs, seeking respite care, and institutionalizing the patient, among a host of considerations, are also available.

Caregivers are frequently asked to share their caregiving knowledge and strategies in print, which gets passed on to other chapters. The following care tip, for example, was offered by Shirley Nimitz, a chapter member, in the July, 1984 issue of the Columbus ADRDA Chapter's Newsletter. The information is introduced with the statement, "Caregivers will appreciate the following

suggestions from one of our members who recently lost her husband:

When I cared for my husband at home, it seemed to me that I should explain what I was trying to do, in the hope that he would understand and cooperate. I was so wrong. To explain things to a man who had lost his ability to understand words was useless.

Then, I discovered that if I didn't speak, things went so much better. The anger, the total frustration, the disappointment cannot be conveyed by the tone of voice, if the caregiver remains silent. Sometimes humming a tune would help, sometimes other quiet music of the patient's liking would ease the strain.

I also found that if my husband resisted my efforts to help him, that if I walked away and came back a few minutes later, he would be more cooperative. By saying, 'Are you ready to do this?' I found it was then his choice to do what needed doing and the resistance would cease.

The following "TIPS FOR DRESSING," which originally appeared in the Greater New Orleans ADRDA <u>Newsletter</u>, and reprinted in the Spring, 1985 issue of the Western Pennsylvania ADRDA <u>Newsletter</u>, is an example of how assistance is shared by all:

When men or women are having a hard time getting dressed, e.g., when patients can no longer button, jogging suits provide a warm, goodlooking, easy care and easy to get into and out of clothing. There is the added advantage of not requiring underwear or brassieres, no zippers at the waist or belts. While a patient can still dress himself, difficulty may come in deciding which clothes to wear and in what order to put them on. You may assist by laying out clothes in the correct order or by handing the patient one item at a time.

While caregiving assistance is sought and received at many levels throughout the Alzheimer's disease movement and support groups continue to flourish, the

ultimate goal of the ADRDA is to find a means of prevention and cure. In the meantime, hope is highlighted and public awareness efforts engaged in full force. To this end, the disease itself has truly become the "disease of the century."

PERSONAL RESPONSIBILITY

The ADRDA's diligence in generating widespread exposure of Alzheimer's disease has increasingly brought opportunities for its recognition and subsequent application. As the earlier quoted comments taken from the Spring, 1983 issue of the national ADRDA Newsletter pointed out, "Alzheimer's is a topic that could appear in [one's] favorite newspaper or magazine or on [one's] television screen at almost any time." The chances of coming across the disease, at some point or another, are thus quite high.

Consider, for example, how the ADRDA helped one person learn of Alzheimer's, as revealed in the following anonymous letter taken from the March, 1981 issue of the Chicago ADRDA chapter's Newsletter:

Dear Friend,

Recently my father, 86, died. He was a victim of Alzheimer's Disease, but it was only the last two years of his life that this was known. His symptoms had been attributed to senility.

No one in my family had ever heard of the disease. My mother, caring for my father in their home in Pennsylvania, had become increasingly

perplexed and distraught by his continuing physical and mental deterioration.

Not long after the tentative diagnosis was made (at a gerontology clinic in Pittsburgh), there was an announcement in the Sunday edition of The Chicago Tribune of an Alzheimer's self-help group. I called the number listed, hoping for some sort of information. The response was immediate and personal. Every bit of information that ADRDA had was made available to me and I, in turn, sent it to my mother.

The letter goes on to report how the knowledge acquired "was of great value in giving [the mother] some framework within which to understand" her husband's condition (emphasis added). Having a medical means for interpreting old age troubles not only provides a new way of seeing dementia, but has moral significance as well. Like the mother in the letter, a caregiver is able to locate the source of travail in something other than the person. The focus centers on pathology, not individual characteristics. This provides a pointable and referencial thing toward which to place blame. Thus, dementia becomes something that one, anyone, simply cannot help. As one caregiver described, in reference to the disease, "It's like sayin' someone has a heart attack, and that can happen to a younger person too."

The ability to cast blame onto something other than the Alzheimer's patient is quite beneficial to those concerned. Such troubles as the patient's "constant chattering," midnight wanderings, or even not recognizing a spouse of over 50 years, can be attributed to a

disease, not its victim. Thus the person is absolved from deviance, making it possible to still love and forgive the patient for behaviors he or she cannot control, while at the same time hating the disease.

The blame function, however, is not automatic. the everyday experience of living with the patient, even the "little things" done can weigh on the most valiant caregiver's attempt to be patient and understanding. Caregivers frequently state how, in their frustration and anger, they will fail to recognize that the patient is helpless, at times reporting that they "forget" the patient even has a disease. As the spouse of a demented husband explained, "Charlie does things that I know he can't help but sometimes I forget that and I really get mad at him . . . like I think he deliberately is trying to annoy me by forgetting and repeating everything." caregiver's plight and conflicting feelings are well illustrated in the following poem, entitled "No Longer You, "written by Lois Ellert of the Boulder, Colorado Chapter and reprinted in various chapter newsletters:

You are no longer you;
The body is yours, a shell,
The head and face the same,
But the light has gone from your eyes,
Windows of a vacant house.

You sit for hours, often a little unkempt, Nodding, dozing, or trying to put together The puzzle of your life; But many of the pieces are missing, And you ask me for them.
I give them to you,

But they will not stay in place, And so you ask again, And again---And again---

The daily irritations are small, But like the constant dripping of water on a rock, They eat away at my love and patience.

In sleep there is respite,
In dreams a return to normalcy,
But you jolt me back to the nightmare of reality
By rousing me at three in the morning,
To ask me where we are living,
Or what time it is,
Or if I want to make love.

Weariness and rage overcome me;
Angrily I tell you to go back to sleep.
Then I am filled with remorse,
For I know you cannot help it
And you do not mean to be unkind.
But there is no way I can explain
Or make you understand
That the marriage of our bodies, our minds, our spirits
Has ceased to be.
You are not my husband,
Nor I your wife.

I am only your caretaker. And you? You are no longer you.

As the poem's message conveys, caregivers and other family members face extreme frustration. The pain and suffering of living with "someone once known" is a heavy toll to bear. While a mind has been stolen from them, they must still deal with its bodily reminder, an active, often remarkably fit "shell" of a former loved one. The annoyance of that presence easily leads to an angry response on the part of the caregiver who, when he or she

is reminded that it is a disease, not the person, that is the source of inappropriate conduct, guiltily "realizes" the patient's helplessness and lack of accountability.

Caregivers who have experienced the same situation, as well as service providers and the related disease literature, offer support and comforting advice on how to feel and manage such behaviors and their responses.

Caregivers are informed, for example, that feelings of anger are common reactions and that they should try not to feel guilty, that "it's only human" to respond that way at times and that the patient usually forgets the episode anyway. Caregivers are also told that such reactions on their part do not worsen the disease for the patient, which will run its own course in any case.

Besides the "daily irritations", for many caregivers, the patient's actions and speech are often directed at the caregiver. Having to face such untoward behavior from the patient often evokes personal hurt and resentment. Caregivers are advised not to take such behaviors personally, that it is impossible to know what the patient's "true" feelings and thoughts really are, as the patient is not able to express them accurately in his distortion of the world around him. As the popular care manual The 36-Hour Day (Mace and Rabins, 1981:105-06) cautions, "Even though the person looks well, he actually has an injury to his brain."

Caregivers are advised that it is important to separate the behavior of the patient from the person. While the patient may, say, complain or shout verbal insults at a neighbor or loved one, the acts should not in themselves be seen as a reflection of an underlying intent but, rather, the frustrated expression of the confusion and helplessness experienced by the person hidden behind the ravages of the disease. For example, the expression "'You're cruel to me' may really mean 'life is cruel to me'" (Mace and Rabins, 1981:106). Such distinctions display the patient's inability to express accurately the "deep down" sentiments and meanings of the lived experience. In this regard, those concerned are cautioned to appreciate and sympathize with the human being that still exists under the shroud of disease, one who, while not evident, faces his own torment and burden. The following poem, entitled "Advice on Caring for Alzheimer Patients," written by Joy Glenner of the San Diego Chapter and reprinted in a number of newsletters, illustrates the point:

Dear Family and Friends:

Please try to understand
What I am now, not think of me
As I was.
I am alone, shut in
With my fears
My frustrations,
My forgetfulness.

Forgive me if I strike out at you. Why do I do that?

What has happened to me?
I cannot cope with this alien world.
I feel threatened. I am frightened.

Speak softly, approach slowly. Repeat again and again what you Want of me. Those twisted tangles in my brain Have messed up my world.

Be patient, for I do love you, And I need your help and love So very, very much.

Your Alzheimer Patient

Information such as the poem offers can be of great value and a source of relief to the families of Alzheimer's patients in coming to terms with the patient's combativeness. A patient who "strikes out" at a loved one is often the most difficult challenge to It is here that the disease can be the most understand. devastating and merciless to those who must endure its conditions. As such, caregivers are repeatedly reminded from the varied sources to try and accept such violent outbursts and "odd reactions" as due to the manifestations of the disease, not as any change the patient may feel towards them nor as having anything to do with the care they are providing. Indeed, as one caregiver put it, knowing that "No one is really at fault except for that damn disease," allows one to focus anger and resentment more concertedly on pathology. In that regard, consider the following anonymous letter printed in the Summer, 1984 issue of the Albuquerque ADRDA

Chapter's <u>Newsletter</u> (reprinted from the Duke ADRDA <u>Newsletter</u>). Under the heading, "Coping with Combativeness," the letter reads:

"Last night he hit me. This strong man, eleven inches taller, 80 pounds heavier than I am. He could have beat me to death in his sudden rage. This person, so familiar to me after 40 years of living together, this man always so confident in himself that he could be a gentle father and a tender, loving husband.

Yet, as I leaned over to untie his shoe so he could start undressing for bed, he grabbed my hair, spun me around, on hand fastened onto my wrist, he hit me with his other fist, twice, hard. How lucky, only on my shoulder and arm.

My anger is so deep, I retch. At this moment I know I could rage and scream and claw like an animal myself. But my tears release me.

If he could see himself, he'd despise his actions, he wouldn't believe it could happen. There is no remorse now, he is unaware. This morning, my anger is still there, my body aches, I can't forgive himbut I can't blame him. Alzheimer's disease is the real enemy.

Even though there is something other than the person upon which to attribute blame, as the example shows, that does not simultaneously get rid of the felt hurt and anger. Such actions may be understood to be unintentional on the part of the patient, yet their effects are quite real indeed. While the physical and emotional pain and suffering of having to deal with the patient's aggression, together with the burdens of the day-to-day activities of caring for the patient, is very disturbing, as the woman in the example notes, even in her extreme situation, while she "can't forgive him," she

also "can't blame him," for it is Alzheimer's disease that is "the real enemy."

The Alzheimer's patient's life history might also be morally reconstructed to absolve him or her of past actions, interpreted to fit the biography of a diseased person. Consider, for example, how the lifelong troubles of Rita Hayworth, the Hollywood actress discussed in the previous chapter, were recast. Earlier on, alcohol was believed to be the cause of Rita's troublesome behavior, including her "recurring lapses of memory" and "extreme mood changes," even her five difficult marriages. As the article in the Ladies Home Journal (Santini and Barret, 1983:139) reports:

Everyone seemd to agree that Rita was drinking heavily, and when she entered the Silver Hills alcoholic treatment center in Connecticut in 1977 few people were surprised. "At that point, I also thought alcohol was her problem," says Yasmin [Rita's daughter]. "I thought it was really destroying her brain."

With Rita's later diagnosis of Alzheimer's, however, her actions are then explained as having been all along "really" the manifestations of the disease. As the authors (1983:141) report:

If, as Yasmin suspects, Rita began suffering from Alzheimer's as long ago as twenty-five years, it could explain a great deal about her difficult personal life. . . . In retrospect, it could very well be that because of Alzheimer's she began to lack the judgment to pick her friends wisely.

Looking back, the evidence of Alzheimer's may already have been showing up when Yasmin was a child. At the time, Rita's problems weren't

dramatic enough to affect her career . . . but there were hints of the tragedy that was to come.

Another example of retrospective interpretation occurred on the Phil Donahue Show, which was shown in Chicago on CBS in December of 1984. One of the quests featured on the show was Maria O'Brien, daughter of Edmund O'Brien, another well-known Hollywood figure diagnosed to have Alzheimer's disease. At one point during the telecast, in response to a statement made by Donahue concerning the initial appearance of symptoms in her father, Maria reflected back on how his earlier "fabulous memory," which allowed him to "recite reams of Shakespeare at will," soon failed to remember even the "very basic things" of the famous dramatist's work. In describing her attempts to understand her father's behavior at that time, Maria noted that, "He would sweat buckets just going to work and we thought it was just because he had this incredibly energetic and wild personality." Now, with the benefit of hindsight, Maria describes her father's "real" problem as having been an "early fear of not being able to cope with remembering." She went on to state how "we didn't understand what he had until about two or three years ago," during which time, "over a fifteen year period, he faked coping with reality without really any help at all," noting even further how she "refused to speak to him for periods of time because [she] thought he was so crazy."

A medical interpretation also affects caregiver reactions to the patient's appearance in front of others. Having a culprit, other than the individual in question, caregivers and other family members are able to acknowledge their experiences with others without embarrassment. Many caregivers informally interviewed stated that after they "really began to understand" the patient's problems, they were less troubled by their friends' and neighbors' reactions. Their previous attempts to cover up the patient's disease, and even pretend that it didn't exist, were frequently discarded, breaking the "conspiracy of silence." For example, the following caregiver described these experiences:

Before, I used to try and hide it. When someone would ask him a question, I knew he wasn't going to answer so I used to speak up for him. And one fella one time says, 'Don't you ever let him talk for himself?' Then it hit me, oh my God, do I really do it that much that . . . I was trying to conceal. I suppose I was embarrassed for him. But now I don't. And it's a lot easier too, knowing that it's a disease. People look at it differently. I just tell them it's what Rita Hayworth has. They can identify with her because she was written up in the paper three or four times.

Initially, after learning of Alzheimer's, caregivers may still be somewhat reluctant to share their burdens with others or may feel awkward when the patient is present in social gatherings. Reminders by other caregivers, by service providers, and by the varied literature on Alzheimer's aimed at easing the burden of care that, as one newsletter put it, "illness is no cause

for shame," serve to lessen the tension. Caregivers are also encouraged to find out more about the disease so that they can better explain and share their patient's behavior to "outsiders." Having more knowledge about the disease provides caregivers with an available store of information by which to warrant their testimony.

Caregivers are able to explain, for example, that their patient is in this or that particular stage or manifests this symptom as opposed to some other form of the disease. Those more knowledgeable about the disease and its treatment can also describe the disease's neuro-organicity or the latest drugs now being used. The more detailed the explanation, the more the disease gets objectified as a discrete and concrete entity in its own right, separate from the person described.

Public acknowledgment of the disease provides personal recognition and elaboration. The two go "hand in hand," so to speak, reinforcing the disease experience on a number of levels. In coming to see common cause with others, by means of and through a growing disease culture, those concerned see themselves in the light of the common knowledge and find that they share the same experience. A growing public response affirms a definition, and the limits, of personal responsibility.

CONCLUSION

The conclusion addresses two considerations. First, I summarize the argument and what the approach and study say about the meaning of the aging experience, considering grammars against the so-called "facts" of aging. Second, I place this in a broader context, in terms of a general understanding of human conduct.

SUMMARY AND ASSESSMENT

This dissertation has examined a variety of approaches to the old age problem, from activity, modernization, and exchange theories to Alzheimer's disease. The term grammar was used throughout the study to stress the separateness of the approaches considered regarding the reality construction of the aging experience. I have argued that each approach has a different understanding of what the old age problem is and interprets concrete observables accordingly. Each sees the problem in terms of its "perception rules" for locating particular agents, timings, and responsible entities in later life.

Chapter 1, "Activity Theory and Life Satisfaction," centered on "busyness" as the arena of the good old age.

The source of satisfaction was contingent on the

individual, found in an ability to stay active and adjusted—in effect, to "remain young." Inactivity signaled unsuccessful aging.

The distinguishing characteristics of old age shifted in Chapter 2. Outside conditions were treated as independently affecting individual adjustment, even while the object of explanation remained the individual.

Disengagement, modernization, and age-stratification theories located large-scale social conditions as sources of the life satisfaction of the individual. Exchange, developmental, and continuity approaches emphasized interpsychological and face-to-face encounters as background. And, the socio-environmental, social-career, and subcultural approaches combined the macro and micro sources in different ways.

Chapter 3 saw a further shift in focus to more theoretically self-conscious grammars. The approaches dismissed individual life satisfaction as the central feature of the aging experience, seeing it instead as an outcome of other forms or processes—respectively, ideological and epistemological concerns.

Chapters 4 through 6 saw abnormality in its own right as a new grammar for defining the problem of old age. Centered in medical conditions, the old age problem was pathologically revealed in neurological and

behavioral markers, in degeneration, and disease culpability.

Approaching grammars as reality-defining understandings, not representational of social objects, does not mean that they are fictive. Grammars are not simply labels but, rather, have concrete empirical referents. There are, after all, objects in the world that do exist. Yet, it is the meaning of the objects of experience that is critical. While, for example, it can be pointed out that those in late life experience the withdrawal from roles previously held, what it means to withdraw is entirely different depending on how it is framed.

To a spokesperson of activity theory, withdrawal infers maladjustment. To a spokesperson of disengagement theory, it is precisely the opposite, adjustment on behalf of societal functioning. The grammar of continuity construes either adjustment or unadjustment against the backdrop of earlier life. For the socioenvironmental approach, the degree of congruence between personal needs and environmental conditions determine individual well-being. The grammar of developmentalism sees personality type and "growth" as the keys to success or failure in late life. The political economists turn to the capitalists, the state, and the mode of production

to investigate a <u>class</u> of persons and their life conditions and chances.

The "same" conditions, then, as revealed in the respective grammars of the aging experience, represent discrete, experiential realities. Accordingly, the "factual" status of old age becomes as manifold as the variety of grammars that articulate the experience.

The social construction of fact was concretely shown to be part of the Alzheimer's disease experience, what I have argued is the most recent grammar of aging. disease was not a mere label or vested fiction for the parties concerned. It was clear that those affected by the disease's conditions experienced considerable suffering. The existence of the objects of turmoil-tangles and plagues in the brain and their erratic behavioral correlates -- were equally empirically validated as was the alarm they generated. Their meaning, however, was problematic, the realities pinpointed being tied to the practical usages they served. In this regard, the desire to ameliorate the conditions observed were part and parcel of Alzheimer's assigned factual status. Likewise, the ADRDA's instrumental efforts in spreading the word about what was increasingly presented as a disease's devastating effects served to transform the meaning of the conditions dealt with. The result was that "Alzheimer's disease [was] not normal aging."

telltale signs of aging became a disease, the "disease of the century." By implication, a reality meaningfully came to possess its own concrete facts.

Yet, it was clear that the ongoing assignment and descriptive practices of those concerned were continually productive of what the sense of this thing-aging/disease--was to be for the practical purposes at hand. For example, in the support groups for caregivers of Alzheimer's patients, a condition of a patient could be interpreted as a sign of a late stage of the disease against a background of certain comparisons with others. That "same" condition could shift with a change in framework, to an interpretation of old age, or another stage of the disease. In this respect, there were no straightforward facts concerning any aspect of the disease experience. Rather, the facts entered into ongoing practical experiences as more or less useful ways to understand the condition and related experiences under consideration.

THE BROADER IMPLICATION

At a broader level, what does the analysis say about the epistemological relation between the practical use of facts and their objects of concern, as it relates to the varied grammars described in the dissertation? In his book, <u>Knowledge and Human Interests</u> (1971), Habermas distinguishes three kinds of cognitive interest toward

any world of concern. Cognitive interests are the general intellectual task orientation taken in describing a world of objects. Asking, in effect, "For what purpose is this knowledge?" he offers three answers, three cognitive interests. One he describes as an interest in control. From this viewpoint, in distinguishing between facts and what they represent, one might be interested in how facts, in their use, serve to reveal "natural" objective relations between the objects represented. The state of objects is delineated by variously "manipulating" them in order to discover how they are organized in relation to each other.

Within sociology, Blumer (1969), has referred to a form of this as "variable analysis." (Blumer's term is not as radically metatheoretical as Habermas' sense of cognitive interest.) The aim of "variable analysis" is to control in two senses: (1) to control variables in order to display their objective organization and (2) with the knowledge of the organization, to control the organization itself, such as exists in the variety of ways to intervene in social affairs, as a consequence of policymaking.

With the exception of the phenomenologists, whose cognitive interest will be discussed shortly, interest in control is implicit in all of the grammars described in this dissertation. For spokepersons of these grammars,

from activity theory to Alzheimer's disease, the object of concern is postivistic in that the conception of the relationship between the social phenomena of interest, on the one hand, and the subjects' attention to them, on the other, is considered to be obvious. The grammar of activity theory, for example, takes for granted that aging is an individual social problem. The researcher's business is to investigate its manifestations in the individual, to discover its variety of resolutions, and to offer solutions based on the facts gathered. is suggested, on the basis of what are discovered to be the correlates of life satisfaction, that adjustment is the result of variables such as church attendance and membership in voluntary associations, among other forms of personal involvement. The implicit sentiments of researchers dealing with individual membership in the social order, such as allegiance, loyalty, and the moral obligation of self realization through hard work reveals, in the data, its mirror image. What these researchers discover to be the nature of aging--individual unadjustment and life satisfaction is readjustment--has its source in their implicit grammar of the nature of Their work and data reproduce the vision. growing old.

The remaining normal grammars of the old age problem treat the subjects studied as, more or less, "subject to" the variety of conditions, forces, and other social facts

of their everyday world. Accordingly, they gather data on variables like social systems, cohorts, careers, stages, or the relations of production, on the one hand, and on variables such as self-esteem or life satisfaction, on the other. They then attempt to trace the relationship between the sets of variables. Control here lies in the assumption of the objective status of the variables whose objects they name and their consequent manipulation (control) in order to discover their "natural" variations. Once discovered, knowledge of their variation allows one to effectively intervene in the relationship, or at least to suggest alterations, in order to bring about desirable changes (control) in other aspects of the relationship.

The research concern for these grammars is with the question of explanatory robustness, that is, relative explanatory power in respect to a select set of data. While this was perhaps most pronounced in the famous activity/disengagement debate, the other grammars, likewise, claim to better explain "the data", in one fashion or another. For example, Dowd (1975) has offered his exchange theoretical challenge to disengagement theory. Gubrium (1973) has attempted to bridge the gap between activity and disengagement theory in his socioenvironmental approach. Riley and her associates (1972) have treated social structure in a Mertonian fashion,

defining age stratification in terms of differential cohorts, suggesting that one attempt to understand the individual experiences of growing old by means of membership in the age structure. The political economists, while metatheoretical in their questions raised concerning "individualistic" thinking in gerontological theory--asking, in effect, "Whose interests are served by thinking of age in particular ways?"--nonetheless offer their own causal argument, namely, a class explanation for the helplessness of the position of the aged. The Alzheimer's disease grammar, likewise, takes for granted an obvious body of knowledge, having concrete consequences in its accomplishment in that it serves to organize its assigners' courses of For example, the disease distinction allows medical researchers to search for treatments and possible cures that aging itself does not. Its utility function also serves to locate fault in pathology, not selves. As such, the disease grammar sets new agendas for organizing and altering human affairs.

It is important to note that while spokespersons of these grammars are not aware of their implicit interest in control as such, at the same time, grammars do not completely dominate their users' actions. Those who reference grammars are free enough from them to recognize them as entities separate from themselves (Giddens,

1979). This is so whether they are useful justifications for one reality or another or useful apologies for challenges to ongoing realities. For the most part, however, few directly address grammars as such, for their concerns are with the objects of description, not description or discourse in its own right.

A second cognitive interest described by Habermas is understanding (verstehen). From this metatheoretical point of view, attention turns away from that which is signified and toward the signs themselves, in terms of how objects are produced. The question here is, "How are 'things' to be understood?" It is an interest that is prior to control, whose understandings are taken for granted by control interests. It is an entirely different cognitive interest and organization than the first one, not in any way reducible to it.

This form of interest underlies the social phenomenological grammar as an interest in social forms and objects. The concern lies with the issue of how the objects of and ideas about things are understood by people who experience them and how these experiences serve to produce and reproduce themselves along certain lines. The product of research from this viewpoint—as "understandings"—is radically different from "facts" or "data" as products. The latter terms are only reasonable when cognitive interest is in control; the former is

reasonable when cognitive interest is in understanding. There is a double sense of the term "understanding" here. One, sometimes called "verstehen," refers to the researcher's discovery of his understanding; the other refers to what respondents offer up as their own understandings. Giddens (1979), in his book, Central Problems in Social Theory, refers to this as a "double hermeneutic," the interpretation of interpretation.

A third cognitive interest specified by Habermas is an interest in emancipation. In contrast to the first cognitive interest, this one does not take for granted the separate and objective existence of objects, separate that is from those for whom they are objects. Thus, for example, old age, as a thing, is not treated as an entity ontologically distinct from those who experience it. would make no sense with this interest to ask how persons enter into old age since the entering itself, in some critical sense, produces old age. On the other hand, in contrast to the second cognitive interest, it does not as totally bracket an interest in objects in the service of inspecting their understandings. Rather, it concerns itself with the processes by which socially constructive subjects come to encounter a world of objects. interest here is in the process by which, on the one hand, the objects of the world like systems, individuality, careers, stages, and the like, get

produced by meaningful action and, on the other hand, how these productions are, upon their realization, encountered by actors.

The interest in emancipation arises out of the understanding that all action is, on the one hand, productive of objects and yet, on the other hand, in the course of human affairs, the source of the objects gets lost. To be interested in revealing the manner by which objectivity is "the lost subject" is to free the subjects from objects, to reveal to him or her that the objects of his or her experiences are products of his or her labor.

The research task for this cognitive interest is critique and thus theory becomes critical. What is critiqued is transformations of the relationship between subject and objects from being genuine to being alienated. Thus, a major concern for critical theorists, with respect to the grammars of the old age problem, would be how they represent a language serving to reify experience as something separate from those doing the experiencing.

Critical theorists assail what they call "identity thinking," which they would apply mainly to control interests. For example, critical theorists would resist the identification of experience with the objects experienced. They see the relationship between signs and what is signified as in a state of tension. What is in

tension is intention, that is, the subject is seen as in tension with the object he or she intends, the negative reduction of tension being alienation, its positive form being emancipation.

All description, it is assumed, is generated from some ground(s). Accordingly, for this dissertation, those grounds have been understanding and emancipation. The broader implication of the analysis is to shed light on the factual status of late life. I have argued that the potential realities assigned to the aging experience are constitutionally tied to ameliorative concerns with old age. The critique is the attempt to demonstrate how much the old age problem is a problem of our making, the grammars we use constructing the problems we view.

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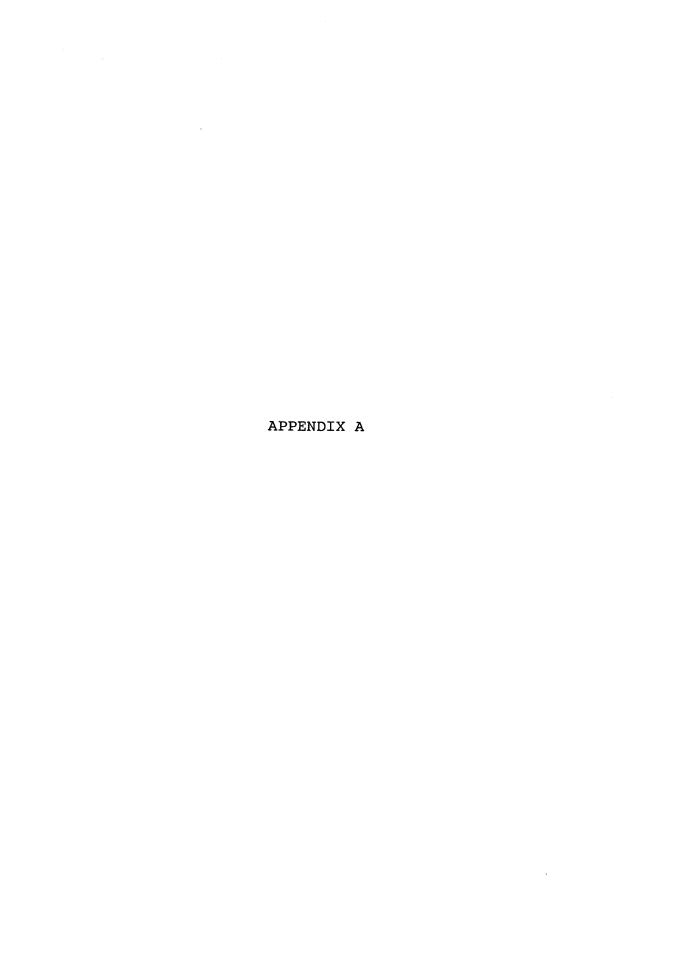
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APPENDIX A

TOPIC GUIDE FOR INFORMAL INTERVIEWS

OF CAREGIVERS

- 1. Patient impairments
- 2. Onset
- 3. Burden of care
- 4. Personal responsibility; others; family
- 5. Personal feelings (history of)
- 6. Coping strategies
- 7. Sources of information; knowledge of disease
- 8. Hospital and professional contacts
- 9. Typical day
- 10. Institutionalization
- 11. Disease labelling
- 12. Burnout
- 13. Caregiver respite; daycare
- 14. Association with ADRDA; resources
- 15. View of future



APPENDIX B

BURDEN INTERVIEW

- 1. Do you feel that your parent makes requests which you perceive to be over and above what he/she needs?
- 2. Do you feel that because of your involvement with your parent you don't have enough time for yourself?
- 3. Do you feel stressed between trying to give to your parent as well as to other family responsibilities, job, etc.?
- 4. Do you feel embarrassed over your parent's behavior?
- 5. Do you feel guilty about your interactions with your parent?
- 6. Do you feel angry about your interactions with your parent?
- 7. Do you feel that your parent currently affects your relationships with other family members and friends in a negative way?
- 8. Are you afraid of what the future holds for your parent?
- 9. Are you pleased about your interactions with your parents?
- 10. Is it painful to watch your parent age?
- 11. Do you feel that your parent is dependent on you?
- 12. Do you feel strained in your interactions with your parent?
- 13. Do you feel that your health has suffered because of your involvement with your parent?
- 14. Do you feel that you are contributing to the well-being of your parent?

- 15. Do you feel that the present situation with your parent doesn't allow you as much privacy as you would like?
- 16. Do you feel that your social life has suffered because of your involvement with your parent?
- 17. Do you feel uncomfortable when you have friends over?
- 18. Do you feel that your parent seems to expect you to take care of him/her as if you were the only one he/she could depend on?
- 19. Do you feel that you don't have enough money to support your parent in addition to the rest of your expenses?
- 20. Do you feel that you would like to be able to provide more money to support your parent than you are able to now?

APPROVAL SHEET

The dissertation submitted by Robert Joseph Lynott has been read and approved by the following committee:

Dr. Helena Z. Lopata, Director Professor, Sociology, Loyola

Dr. Judith G. Wittner
Assistant Professor, Sociology, Loyola

Dr. Philip W. Nyden Associate Professor, Sociology, Loyola

Dr. Jaber F. Gubrium Professor, Sociology, Marquette

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Date | 1986 | Illena Lopake
Director's Signature