Abstract
The course of illness is examined as a location for the assignment of developmental structure. Textual analysis and field data indicate that the stock of developmental codes for structuring the course of illness in the Alzheimer’s disease experience is as varied as the manifold interests of those concerned. Structuring is practical and occasioned, realised in its variety in an ‘ameliorative’ mode of communicative usage. In the ‘tribulation’ mode, in contrast, the course of illness is destructured. A discussion of communicative usage, as a critique of developmentalism, follows.

Introduction
The temporal structure of experience is regularly described in linear and incremental terms. From chronicles of healthy living to courses of illness, the familiar developmental language includes onsets, stages, phases, plateaus, critical periods, turning points, developmental tasks, maturation, and regression. Whether the logic governing lifelines is viewed as socially organised (cf. Becker and Strauss 1956; Goffman 1961; Glaser and Strauss 1968), psychogenetically patterned (cf. Langer 1969; Gergen 1980), or culturally conditioned (cf. LeVine 1973), it is lifelines in principle that are represented, not their articulation. Yet, where would courses of living be were it not for the assignment of chronology to experience?

Based on earlier research (Gubrium and Buckholdt 1977; Gubrium and Lynott 1985; Gubrium 1985; Gubrium 1986), the Alzheimer’s disease (senile dementia) experience is considered for the biographical work – the life-describing activity – that serves to produce linear and incremental depictions of the course of illness. Developmental language is a pervasive code, or means of representation, for the chronology of the disease experience, both the patient’s and concerned others’ versions. All use variations of the
code, in line with their respective interests, providing resources for facing up to the timing of experiential particulars (Bury 1982:179). Yet, the descriptive activity that enters into the disease experience both structures and destructures it, now perceiving developmental order and now total disarray, according to the communicative purposes of those concerned. As such, the temporal component of the experience is not as much structured and embedded in the disease, as it emerges out of communicative conditions and needs.

Following a medical description of the disease, the study in which the data were gathered, and a presentation of the variety of developmental codes, communicative usage is analysed as an interplay of two components – code and application

The disease

Alzheimer’s disease is the most prevalent form of old age ‘senility,’ causing confusion and memory loss in approximately 7 per cent of the ageing population, some 2 millions in the United States. While comparable estimates for the same population in the UK go as high as 10 to 14 per cent in some studies (Kay, Beamish, Roth 1964; Wang 1977) and as low as approximately 4 per cent in others (Bergmann 1975; Roth 1978), international comparisons are plagued by diverse diagnostic and statistical conventions. Nonetheless, the disease is said to be the major contributor to the institutionalisation of elders in long-term care (US Dept. of Health & Human Service 1984). Once little-known and called a ‘silent epidemic’, it is now being recognised as the most debilitating affliction of old age.

The disease affects the cerebral cortex with characteristic senile plaques and neurofibrillary tangles. It was first described in a 55-year-old woman in 1906 by Alois Alzheimer, a German neurologist (Alzheimer 1907). Previously called pre-senile dementia, Alzheimer’s disease is now considered to be continuous with the organic markers and cognitive symptoms of primary degenerative, senile dementia (Terry 1978a).

There are many causal theories – genetic, virological, toxicological, neurometabolic (cf. Katzman 1983). Curiously, ageing itself is said to be a possible cause (Reisberg 1981), even while it is asserted by others (cf. Katzman, Terry, Bick 1978; ADRDA 1982) that, as a ubiquitous slogan asserts, ‘Alzheimer’s disease is not normal ageing!’ Indeed, a continuing controversy in the neuropathological literature is whether there is a quantitative or qualitative distinction to be

...
made between processes of ageing and Alzheimer's disease (Terry 1978b; Tomlinson 1977; Tomlinson, Blessed, Roth 1968, 1970). At present, there is no prevention or cure.

Symptoms are diverse. Some list them simply as confusion, disorientation, and forgetfulness. Other symptomatologies present signs as broad as all conceivable troubles of old age, as wide-ranging as being irritable, restless, and agitated, to not being able to keep a checking account, forgetting to turn off a gas stove, and sleepwalking. The nosological and symptomological status of Alzheimer's disease is such that its categorisation as an illness is constantly challenged by a substantive coincidence with what are said to be normal ageing processes. As such, considerable reality-sustaining work enters into their separation – the descriptive activity of isolating the normal from the pathological (Gubrium 1986). Part of the activity entails bringing temporal order to the disease experience, the topic of this paper.

The study

The chronology of the disease experience was considered as part of a larger study of the descriptive organisation of senility (Gubrium 1986). Data were gathered in a number of settings and from varied texts. The Alzheimer's Disease and Related Disorders Association (ADRDA) is a self-help organisation whose purpose is public education, research support, advocacy, and grass-roots aid to caregivers (Stone 1982; ADRDA 1982). Founded in 1979, the ADRDA is now, in the United States, a national network of over 100 local chapters, each sponsoring or facilitating support groups for caregivers and family members. Participant observation was conducted in the meetings and support groups of ADRDA chapters in two cities in the US, with active membership in one of them. More than any other organisation, the ADRDA has become the constant force behind the Alzheimer's disease movement. The varied activities and campaigns it sponsors, supports, and encourages have made Alzheimer's disease highly visible, virtually underwriting what is now a distinct public culture. Thus, the Alzheimer's disease experience is increasingly indistinguishable from the ideology and organisation of the ADRDA, formal membership in the ADRDA not being so much a source of exposure to the disease's public culture as a certification of it.

Fieldwork also was conducted for four months in an Alzheimer's
disease day hospital affiliated with an acute care facility. Serving nine to twelve patients, the day hospital provided a structured, therapeutic environment and a support group for their caregivers, all family members. Unlike the ADRDA support groups observed, which were facilitated by experienced caregivers themselves, members of the day hospital’s staff participated in its related support group activities. While not ADRDA-sponsored, the day hospital’s support group included facilitators and members who were active in the ADRDA; those who were not active members were, nonetheless, familiar with, and regularly exposed to, ADRDA activities, literature, and media.

Data also were drawn from disease literature. From its national headquarters in Chicago, the ADRDA distributes a variety of pamphlets and brochures to local chapter members and to the concerned public at large. It also publishes a quarterly newsletter with the latest research findings, legislative progress, legal advice, publicity campaigns, and highlights of the activities of local chapters. Many chapters publish their own newsletters, combining news from ‘national’ with items of community interest, such as personal profiles of the course of illness and burden of care, and anecdotal descriptions of the disease’s typical progress. Local chapters borrow heavily from each other for newsletter copy, so much that, for example, a so-called typical chronology of a caregiver’s or patient’s disease experience appearing in one chapter’s newsletter is soon likely to appear in other chapters’, thereby enhancing their common culture. There is a growing media sector dealing with the disease, appearing in popular magazine articles, public service announcements, broadcast programming, and newspaper features. Besides the lay literature are the varied professional texts dealing with research and therapeutic applications. They, too, offer disease chronologies, which variously enter into the descriptive activities of those concerned.

Developmental codes

As the disease’s public culture grows, so do component descriptions of the disease experience, one of which is its timing. From support group proceedings to chapter newsletters and professional literature, timing is developmentally coded, this despite the repeated assertion that the disease’s varied experiences are broadly diverse on several fronts.
The variety There are many codes, of differential renown. Some are products of experienced professional attention to onset and course of progress; others are offered as merely useful ways to 'get a handle on what's happening to a loved one.'

With repeated emphasis that there is 'tremendous variation in the syndrome picture' (Burnside 1979:16; original emphasis), a good share of the related nursing literature seems to settle on depictions of 'the' three stages of the disease. As Burnside (p. 16) notes: 'Grunthal, in 1926, first described the three stages of Alzheimer's disease and they were described earlier in this paper when the Hayter and Pinel articles were reviewed'.

The Hayter (1974) paper, quoted extensively in the nursing literature and repeatedly referenced in other professional journals as well as in the disease's popular texts, is based on a nurse's experience working with demented patients and her reading of related professional literature. Hayter describes three stages that pertain to the patient's cognitive and motor activities. Each stage is assigned a time period and its 'characteristic symptoms' listed. The first stage of the disease is said to last two to four years. As Hayter (p. 1460) points out, 'Characteristic symptoms are memory loss, time disorientation, and lack of spontaneity. Memory loss is usually the first and most outstanding symptom.' The second stage, 'generally extending over many years,' features uncontrolled motor activity, 'progressive memory loss, aphasia, agnosia, apraxia, a tendency to wander off, and such repetitive movements as tapping, lip-licking, chewing, folding' (p. 1462), their severity and particular manifestation depending on where in the second stage the patient happens to be. The third stage, called 'terminal,' is relatively short, usually lasting not more than one year. It manifests general physical decline and eventual demise. Hayter presents the disease's course of progress as a series of nursing management problems and accordingly applies temporal meaning to the disease's impact on self-control. As I shall continue to note, the specific developmental code assigned to the disease experience is as intimately tied to the particular descriptive interests of those concerned with the disease as it is a characteristic of the disease itself.

Other developmental codes are offered on behalf of caregiver self-help, typically framing 'tips' for sorting out what to do as things get worse. ADRDA chapter newsletters regularly feature reports of how particular caregivers cope with the home management of an increasingly debilitated patient. For example, it might be pointed out that 'at first' or 'in the early stages of the disease,' the caregiver
was in a quandary, say, because her husband was doing 'all sorts of strange things.' In the beginning, she tried to sort out what was happening and how to deal with it. But when she learned the diagnosis and prognosis, and things got progressively worse, the later stages of the disease required, as one feature put it, 'getting my act and feelings together to deal with this thing.' Eventually, it is typically pointed out, one has to confront the inevitabilities, the decision to institutionalise the patient or the acknowledgement of impending death, the presumed last stage. Some suggest that one never completes a final stage as a caregiver, for as a familiar disease slogan describes it, the experience is 'like a funeral that never ends.' While the number of stages and their particular durations are tied to their individual describer's experiential particulars, as developmental codes, they constitute recognisable, collective representations in the service of everyone's self-help (cf. Gubrium and Lynott 1985).

Codes vary in detail. There are the ubiquitous simple references to earlier and later stages of select aspects of the disease experience; others are elaborate stage and critical point constructions. One of the most detailed was developed by Berger (1980), a physician. Rather than zeroing in on the cognitive decline of the Alzheimer's patient as such, Berger found it more useful to organise his 'severity rating system' around the progressive care needs of the patient. He explains (p. 235):

Since the aim was toward something simple that nurses, social workers, therapists, and physicians alike could easily remember, and toward a severity rating based on what the patient needed in the way of care, it became a matter of reducing the number of words in the description of each class to a bare minimum, yet retaining a clear distinction between classes.

Berger presents a '6-stage classification,' which, according to him, was developed over a number of years. Severity Class I is described as [the patient] 'can function in any surroundings, but forgetfulness is often disruptive of daily activities,' and Severity Class II as 'can function without direction only in familiar surroundings.' With each severity class, the patient is less able to help himself, making it increasingly necessary to organise cares for him. In Severity Class VI, the final stage, the patient is 'bedridden or confined to a chair and responds only to tactile stimuli.'

Berger notes (p. 235) that the crux of the 6-stage classification is the distinction between Severity Classes III and IV, where a crucial transition or 'core midpoint' occurs:
The key to this 6-stage classification is the distinction between 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). The other classes fall to either side of this core midpoint, from Severity Class I, in which the principal problem is forgetfulness, to Severity Class VI, which concerns vegetative patients.

The transition is critical for it changes patient management from professional concern and guidance to hands-on attention. The other severity classes are simply temporal variations of the distinction between direction and assistance.

With the key or core midpoint, Berger not only is using a relatively elaborate stage model to describe the disease’s timing, but also distinguishes what is often called a ‘critical’ period. A critical period is a time unit like other periods, but reverses the figure and ground of event and chronology. For example, other periods – Severity Classes I, II, V, and VI – frame what is happening, so that time dominates need events. Contrastingly, in bridging Severity Classes III and IV, need events govern timing, the transition depending not as much on the mere passage of time as on how the concrete interactive details of patient response, care, and management are interwoven. While, as timings, critical periods, like developmental stages, are tied to descriptive needs, they assign developmental order to new, not simply emerging challenges.

Complexity is not the exclusive property of professional codes. Field data show that informal personal accounts of coping histories, mutually presented by caregivers gathered in support groups, can ramify complexity well beyond any codes available in lay or professional texts. On occasion, support group proceedings realise empirically embellished codes with infinite stages and substages, developmental terminology used to conversationally indicate both existing and yet unforeseen phases in what is otherwise both a personally and collectively emerging experience. A participant who agreed that everything she’d heard in the lively exchange of stage particulars informed her of ‘all the many phases and stages of this thing,’ added, ‘and I can see down the road all the innumerable other stages there’ll be.’ When another participant responded, ‘And wait until that critical period when he [the patient] doesn’t even recognise your face and thinks there’s a strange woman in the house,’ timing bends as well as glides. In many sessions, such descriptions and language served to frame all forthcoming appreciations and apprehensions of the past and future course of the disease.
Still, from session to session, support group participants were not as much cognitively governed by the complexity of received and emergent codes as they now complicated and now simplified the course of illness in accordance with their ongoing attempt to make temporal sense of the disease experience. Moreover, as I address it in greater detail later, while it is evident that earlier and later serve to organise what is otherwise a highly diverse ensemble of experiences, the experiences are also said by some, on occasion, to be without any rational organisation, neither in time nor substance.

However complex or simple time references are, they nonetheless provide, as ordering devices, a minimal seriality to objects of concern, thereby offering objective reference points for lines of concrete activity (Williams 1984). In this respect, the difference between complex and simple temporal codes lies not as much in their relative capacity to frame and pattern experience, which all codes do; but in their comparative experiential challenges. Those concerned with the concrete products of complex developmental codes simply have 'more' to deal with, whether concertedly or apprehensively. In a manner of speaking, a complex code does more with words to either aid one's hold onto its respective reality or to inform one of its manifold hurdles.

Codes also vary in focus of application. Certain codes present the typical course of the patient's disease experience, some centered on particular aspects such as the stages of the patient's emotional life or cognitive decline; other codes address the timing of the caregiver's response to the disease, what he or she ordinarily 'goes through' as the disease progresses. There are even codes for the stages of decision-making about institutionalisation (cf. Lynott 1983).

Consider, for example, developmental codes pertaining to the caregiver's adjustment to the disease, usually a spouse or an adult child, often said to be the disease's second victim. In part or whole, the stages of adjustment typically resemble Kübler-Ross' (1969) five-stage model of dying, comprised of denial, anger, bargaining, depression, and acceptance. Adapting the model, the caregiver's emotional adjustment is said to progress in the familiar pattern, from a denial that anything is 'really' inexorably wrong with a loved one, to final acceptance of progressive decline and terminality.

Some abbreviate the model, as one support group participant did, who spoke of

... just going from denial to depression. I think I'm in that depressed stage right now. I've seen what's been happening and I'm slowly
realising, as we all try to do and help each other see each other through it. . . . But I just, darn it, I just can’t accept it yet. You try to hang on, like maybe there’s some hope, like that brain pump therapy.

There’s no mention of anger or bargaining in this participant’s comment.

Others present their emotional adjustment in full accordance with Kübler-Ross’ five stages. Some even embellish them, speaking, as one did, of ‘that early phase of the depression stage when you’re just starting to feel blue.’ This she contrasted with a later phase of depression that ‘numbs you, like you feel all alone and unable to do a thing.’ There are critical points, too, where time more nearly serves practice, as when the adult daughter of a patient mentioned to all those gathered in a support group that ‘everyone’s been at that point when things can go to acceptance or bargaining back and forth . . . and that’s the hump you’ve got to get over and it all depends on what you make of your life with him [the patient].’

The Kübler-Ross model also informs the many coping strategies offered in caregiver handbooks and facilitator training manuals. Those who are to professionally intervene in the burden of care or otherwise to help caregivers cope are reminded that there are distinct stages of adjustment and that successful intervention depends on accurately assessing where the caregiver ‘is at’ with his or her feelings. For example, one so-called ‘leader’s guide’ (Bonjean n.d.), prepared to aid those facilitating family support groups in nursing homes, suggests that ‘tearful sessions’ actually be planned for, where ‘at some point in this session, the following emotions should be talked about and clearly identified as “normal” and to be expected’ (p. 13). The emotions listed are those surrounding nursing home placement – guilt, depression, role conflict, loss.

Not all developmental codes pertain to individuals. A substantial literature deals with the natural history of the support group, presenting changes in its concerns in developmental terms. For example, an issue of Generations magazine entirely devoted to Alzheimer’s disease and related disorders contained an article by Gwyther (1982) on caregiver self-help groups. Writing about related roles for professionals, Gwyther describes intervention in terms of the group’s developmental stages. In the early stages, where there is a need for curative and service information, the facilitator can act as a knowledgeable resource. In the later stages, when members of a group need autonomy to examine self-feelings, the professional should disengage. The group’s natural course of progress, from a
curative/patient orientation to a concern with self-adjustment, is repeated in an article by Barnes and others (1981:81) that describes the stages undergone by an eight-week support group established for 15 family members of Alzheimer's patients living at home.

The focus of group discussion seemed to move through three relatively separate stages. At first, discussion consisted primarily of stories about patients, and this allowed ventilation of long pent-up feelings. During the middle phases, members focused on trying to help each other solve their practical problems in the day-to-day task of caring for the patient. In the later sessions, discussions shifted away from the patients and centered more on the personal needs of the caretakers.

All in all, whatever aspect of the Alzheimer's disease experience is focal — the patient's encounter with cognitive decline; the caregiver's adjustment process; the natural history of the support group; the course of intervention — there is a need for order. Nothing (nothing) can be addressed, dealt with, denied, or become adjusted to, until its substance and temporal outline are evident and clear. The press for clarity and order is made quite evident in this comment by Dubler (1982:12), who writes of the legal priorities of the Alzheimer's disease experience and the need for 'teachings' akin to those of Kubler-Ross:

But is that patient not entitled to share the same process of mourning with his or her family as the dying cancer patient? If Alzheimer's Disease is described as a 'living death,' shouldn't patients know about, ponder and face it to the best of their ability? Patients can then be assured of the same continued loving and supportive care promised to dying patients. We may have to await a seminal work, akin to that of Kubler-Ross (1969) to teach us how to talk about 'living death,' how to prepare for it, and what the stages of emotional divestment of a demented person from him — or herself may be.

The tension Despite the developmental texture of the codes and their focal variety, they stand in notable tension with what is regularly perceived as the disease's disarray. The content analysis of disease literature and the field data indicate that, while Alzheimer's is developmentally represented, at the same time, it is admittedly idiosyncratic and without 'rhyme or reason.' As far as timing is concerned, although there is, say, progressive decline in the patient's cognition that can be described as stage-like and finally terminal, it is also said that there is remarkable variation. Indeed, the variation is sometimes so great as to defy developmental logic. The tension hangs on whether disarray is taken to be a more or less
rampant variation on what is otherwise an ordered experience, on
the one hand, or is perceived to eclipse the plausibility of an
overriding order, on the other – the question of how disarray signals
structure.

A popular government publication, _Q & A: Alzheimer's Disease_ (US Dept. of Health & Human Services 1981), distributed by the
ADRDA, describes the disease experience in question-and-answer
format. Following a short answer to the question ‘What is
Alzheimer’s disease?’ its symptoms are presented. The first and
second paragraphs of the answer concerning symptoms are telling,
the first paragraph ordering the disease, the second one presenting
the disease’s individual disarray. Part of the first paragraph reads:

> 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. . . . 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. . . . In the most severe cases, the disease may eventually
render its victims totally incapable of caring for themselves.

The familiar developmental code is evident. As often stated, the
onset of the disease is insidious, frequently mistaken for other
behaviours. But as its inexorable course of progress unfolds, the
symptomatic markers emerge. Finally, total incapacity sets in. The
natural course of the disease is realised – inevitable, progressive
decline.

Yet, as we read on to the next, the second, paragraph, we learn
otherwise. It states:

> There are many different patterns in the type, severity, and sequence of
changes in mental and neurological functioning that result from
Alzheimer’s disease. The symptoms are progressive, but there is great
variation in the rate of change from person to person. In a few cases,
there may be a rapid decline, but more commonly, there may be many
months with little change. Limitations in physical activity during the
later stages may cause the person to have less resistance to pneumonia
and other physical illnesses that may shorten remaining life expectancy
by as much as one-half.

And so, we learn, too, that while the disease is progressively
debilitating, the sequence of changes is varied. This implies both ups
and downs, so to speak. Indeed, there may be lengthy periods of
time when little or nothing changes in the patient. But as the second
paragraph reports, while there are many different patterns (disarray), they do not upstage the relatively clear description of gradual decline depicted in the first because what is being addressed is developmental theme and variation.

In another widely disseminated government pamphlet, aimed at health care practitioners (US Dept. of Health & Human Services 1980), the simultaneity of developmental logic and disarray appears again, this time nested, not juxtaposed. On pages two and three of the pamphlet, the distinct developmental chronology of the disease is outlined and, intermittently, seemingly upstaged. It is worth quoting at length.

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. Although the timing and sequence of lost function varies from patient to patient, those in the final stages of Alzheimer's disease tend to exhibit the same traits — apathy, disorientation, and lack of concern about others' opinions.

Occasionally, though not always, Alzheimer's patients become incontinent in the final months of life.

We are presented the disease's hallmark stages and, within the very course of the presentation, find buried the statement that timing and sequence — the theoretical badges of developmental logic — vary individually. But because the disease is being highlighted, the interpretation and understanding of variable particulars serve to illustrate the diversity of the developmental theme.

In a similar vein, recall Berger's (1980) six-stage severity rating system. After outlining and illustrating the need characteristics of each stage, Berger cautions (p. 235) that 'it is the composite picture [not 'a single failing'] that helps to decide what the patient needs and where the patient will fit in this classification.' He continues:

Moreover, it is not uncommon, particularly before serious deterioration sets in, for the picture to vacillate 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.

Note that, as in an earlier extract from a government publication, Berger categorically separates the disease, on the one hand, from the individual patient, on the other. The tension in the developmental logic, between the severity classification system's structuring of the disease and the possible eclipse of order by individual patient variations, is resolved in favor ("may well be rewarded") of a reclassification of individuals in an otherwise overriding classification system.

Now consider a series of exchanges where the course of illness is both structured and destructured, where, alternately, disarray serves to thematise ordered variation and to destructure it. The series of exchanges is illustrative of what is a virtually admitted case of structuring and destructuring. As argued and shown in the second part of this paper, the apparent tension in these and other instances is resolved by what is communicatively being accomplished with disease description – usage – not through representational clarification.

In one of the support groups observed, sponsored by the Alzheimer’s disease day hospital, staff members regularly apprised participating caregivers of the latest research findings and experimental treatments. Caregivers were repeatedly cautioned, too, against false leads, unrealistic expectations, and quack cures; in turn, they frequently consulted staff facilitators for disease information.

On one occasion, a research psychologist requested permission to ask caregivers if she might observe them in their homes for two or three hours at a time, to gain the benefit of the real life details of home care for Alzheimer’s patients. Along with the request, caregivers were reminded that the psychologist continued to conduct her study of the patients’ cognitive decline and the burdens of care, and were invited to ‘ask the expert,’ if they wished, about her findings for particular patients.

Accordingly, one of the caregivers, whose husband was a day hospital patient, asked if the psychologist could offer an assessment of the patient’s early, middle, and later stages of disease. The inquiring wife explained that she wasn't able to ask about it earlier when she and the psychologist had reviewed the husband’s test results. The psychologist responded by cautioning the participants as a whole against gullibly accepting stage theories of Alzheimer’s, explaining that
... there's just no consistent evidence for many of them [stages], and that's what's so frustrating about it. You read about one stage model and another and you ask what evidence it's based on, how many cases, but they don't usually say. Each case is unique and different from others. They come up with stages ... [she pulls a brochure out of her briefcase] like this one here. [pauses to find example in the brochure]

As the psychologist flipped through the brochure, the inquiring wife remarked:

Well, I can see and I think we all accept that everyone is different. Each one is a unique individual. But there must be some overall pattern to it. ... otherwise how can anyone say that there's any sense to the whole thing?

But as the psychologist now read the excerpt from the brochure that meant to illustrate her caution against unacceptable models, the wife, listening, heard stages described and readily agreed that, yes, there were stages to the disease such as those read aloud by the psychologist. Indeed, the wife was especially responsive when the psychologist read that, in stage two, it becomes more and more difficult to make sound business decisions. The wife, whose now demented husband had owned and once successfully managed a fairly large business, elaborated the particulars of what she heard as stage two by illustrating it with reference to several 'poor business decisions' her husband had made before the disease was fully realised. The wife pointed out that the decisions were not perceived as a stage of the disease until much later. To this, the psychologist responded:

That's pretty typical, as I'm sure most of you would agree. The beginning stages of this thing ... as we say, the 'onset' ... it's pretty unclear. It's an insidious onset. But as the disease progresses, the picture gets clearer and you start to get the typical symptoms of the disease's later stages - the disorientation, the confusion, the wandering, the poor decisions like you mentioned. And you cope and manage as well as you can. The picture's a very familiar one.

As the psychologist now used developmental language to frame her comments on the disease's course of progress, she was joined by others in the group, who didactically elaborated the particulars of each stage referenced by means of individual disease experiences. It was soon admittedly evident to all, including the psychologist, that the group had learned a great deal about the typical course of the disease, what to expect, and how to deal with each stage. At one
point, in fact, the inquiring wife thanked the psychologist for shedding light on where her husband now was and where he soon would be.

References to what the husband under consideration would become immediately generated disagreement. One of the caregivers, the adult son of a demented mother, gently challenged the psychologist’s description of aggression as a hallmark of the third stage of the disease:

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.

Another participant, the wife of a demented patient, claimed that she’d never seen a trace of what she would call aggression in her husband. According to her testimony, it was the wandering and confusion that ‘opened [her] eyes to the fact that he just wasn’t the same man I married.’ Several others deliberated the varied and differential features of each stage, at times agreeing but more often disagreeing about what was typical.

Amidst the deliberations, the psychologist indicated how exasperating the disease was, how it was a different thing for each of them, as she reminded the caregivers what she had pointed out in the first place. Several times, participants shrugged in frustration, concluding that there just wasn’t any sense to it all. In exasperation, the adult daughter of a demented mother asked, ‘How am I supposed to know what to do if no one can figure anything in this thing?’ What had earlier been, and what was later again to be, developmentally structured, had momentarily become undone. But the destructuring of the experience under consideration was soon to be transformed into renewed order, at the repeated behest of the wife who posed the original question that began the day’s exchanges. Addressing a facilitator, the wife pleaded:

Would one of you please help us to sort this out? Teach us how to see what’s happening so that... so’s we can at least see some kind of pattern and the changes and everything.

The wife’s request was not unusual. Such requests are frequently in evidence in the varied personal disease accounts that appear in ADRDA chapter newsletters. While some accounts express frustration that one of the burdens of the disease is its unpredictable course,
where 'no two cases are alike,' other accounts present detailed
depictions of what, despite the broad individual variations, is 'the
classic course of the disease.'

Communicative usage

How can the acceptance of order and disarray in the course of illness
be explained? For that, I turn to communicative usage.

Communicative usage is descriptive activity, to be distinguished
from descriptions as such, or representations. As descriptions,
representations are commonly evaluated in terms of whether they
consistently and accurately depict their subject matter, otherwise
referred to as reliability and validity. Those concerned with the
acceptability of representation, from laypersons to medical scientists,
take it for granted that accurate descriptions stand in one-to-one
correspondence with their subject matter.

Yet, descriptions are also part of describers' everyday lives.
Acceptable or not, we must describe in order to have descriptions.
As an activity, description takes on communicative usage and,
accordingly, can be examined for the purposes toward which it is
being put. Therein lies an interpretation of the representational
tension apparent in the developmental order and disarray of the
Alzheimer's disease experience.

Amelioration versus tribulation Communicative usage in the
disease's oral and written accounts suggests that those concerned
serve two different purposes in assigning to, or withdrawing
developmental order from, the course of illness: ameliorating the
disease experience under consideration or expressing its tribulations.
As it is often put, amelioration refers to attempts to 'do something
about what's happening.' What is happening, of course, is manifold,
ranging from the cognitive and affective responses of both patients
and caregivers, to the changing orientation of supportive concern in
self-help groups. Likewise, doing something about it is as varied as
the responses of those concerned, from professional attention to the
course of illness to caregivers' attempts to plan for, and make
personal adjustments to, the home care of the patient.

I refer to communicative usage in regard to descriptions concerning
doing something about what is happening as its ameliorative mode.
For example, a professional article that sets out to organise the
course of illness in accordance with patient management needs, as
Berger's (1980) does, describes the disease experience in the
ameliorative mode. The articles aim to structure an aspect of the experience for purposes of intervention. Or, for instance, a participant in a support group who wishes to look ahead and plan for the home care of her patient, wants to be taught what to expect. She asks for a description of things to come in the ameliorative mode.

The ameliorative mode is not necessarily wholly charitable or obviously beneficial. It merely refers to the use of developmental logic in the service of ‘doing something about it,’ regardless of the desirability of outcomes. For example, there were times in the support groups studied when some participants took what others considered to be a rather harsh attitude toward institutionalisation, in which those concerned wanted to know precisely when – at what stage – in the course of illness one experienced ‘the last straw’ and began seriously to look for a nursing home. That particular stage was commonly described as the crucial moment, the critical point at which doing something about the illness meant entering upon a different timeline of concern than home care.

The tribulation mode, in contrast, refers to communicative usage in respect to frustration over the lack of perceived order in what is happening, not in the absence of happenings as such. Both written and oral accounts of the disease’s timings suggest that, on occasion, those concerned perceive too many different things as occurring: aggression throughout the course of illness for some, aggression at a particular point in time for others; gradual confusion and disorientation in some cases, periodic lucid moments in others; progressive emotional adjustment by some caregivers, continual denial or recurrent anger among others.

Not only can social comparisons suggest overall developmental disarray, but self-comparisons over time can too. It was not uncommon, in the tribulation mode, for individual participants in the support groups observed to engage in near soliloquys over the ongoing perceptual travails of the illness experience, notably over their inability ‘to get a handle on it’ and with the lack of any ‘rhyme and reason’ in all of it. References were made to different experiences that refused to developmentally bear out each other. Later periods didn’t seem to reasonably follow from earlier ones, nor were earlier ones predictors of things to come. In regard to her feelings, one adult daughter stated, ‘It’s like an emotional roller coaster; sometimes you think you’re going up and, bang, you come down.’

The relationship between the tribulation mode and the related
frustration is not unidirectional. There are occasions when deliberations over the typical course of illness leads to disagreements and a final consensus about the lack of order, commonly exasperating participants. There are other occasions when commiseration over erratic burdens of care infer that there is no clear structure to decline, leading those concerned to question the clarity of the disease’s developmental logic. The overall concern with the course of illness, as it enters into the related affairs of those involved, is, in the tribulation mode, a mutual documentation (Garfinkel 1967) of frustration and perceived lack of temporal order. It is a round of practical theory and proof which serves to confirm that, as one caregiver remarked, ‘You just can’t seem to makes heads or tails of where it’s going.’

The uses of disarray In the ameliorative mode, diverse individual temporal experiences are used to document the general – typical developmental codes – which, in turn, provides a concrete sense of order and variation, structuring the disease experience. A regular feature of ADRDA chapter newsletters are items presenting the various stages of select disease facets. For example, the summer, 1985 issue of the Fort Myers, Florida ADRDA chapter’s newsletter offered two different stage models, explaining:

Many different articles have been written about the different stages of Alzheimer’s Disease. Here are two that seem helpful in looking at the progression of AD in very different ways. The first article is from the Portland Area Chapter, and divides the [three stage] changes into cognitive, personality, and functional areas. The second article comes from the St. Louis Chapter and was written by Valerie Watson, 15. In ‘Understanding My Grandmother,’ she documented the age of her grandmother when a symptom occurred. The stages [in a four-phase model] were developed by research scientists but Valerie shows how individual the process of deterioration really is. Keeping a similar record might be beneficial to you.

Thereafter followed the two models.

In the ameliorative mode, the developmental models are highlighted as two proffered means of doing something about the course of illness, formulated in the phrases ‘two [models] that seem helpful’ and ‘similar record might be beneficial to you.’ Both Valerie’s individual account designating the specific years her grandmother changed, and the illustrative individual behaviours listed under each stage or phase of the respective models, serve the descriptive purpose of indicating developmental theme and variations. While
Valerie’s account ‘shows how individual the process of deterioration really is,’ it is nonetheless presented in the service of illustrating variations on an overarching developmental code, not as a fundamental challenge to its ordering function. Indeed, readers are invited to ‘keep a similar record,’ using the stages as a ‘beneficial’ means of documenting individual variations in the process of deterioration. Thus, Valerie’s ‘really’ individual difference does not as much serve to destructure the developmental course of the disease as it is used to display an instance of it. Likewise, the two models presented offer readers a choice of ‘looking at the progression of AD in very different ways,’ while still looking at the progression, as did the great variety of codes discussed earlier offer a diverse, yet commonly developmental stock of resources for structuring (‘staging’) any range of individual differences.

In this regard, returning to Berger’s (1980) model presented earlier, we find that the apparent descriptive tension over developmental order and disarray does not destructure what, according to him, should be a ‘composite picture,’ because individual differences are presented as variations on a general code. The severity rating system, in fact, is presented toward the clarification and organisation of individual disarray. As Berger notes, even while there are individual differences, ‘the disease remains.’

In tribulation mode, in contrast, individual differences, and diverse developmental codes in their own rights, serve a different communicative function, their descriptive tension resolved in favour of disorder, deconstructing the disease experience. For example, at one point in the proceedings of an Alzheimer’s disease conference sponsored by a chapter of the ADRDA, it was evident that the stock of developmental codes itself was considered to be too great to accommodate any credible sense of order in select attendee’s experiences with the disease. In an afternoon discussion period following a presentation of the stages of adjustment to the burdens of care, a social worker in the audience remarked at length:

I’ve heard many things today. This morning we were told by . . . a neurologist I believe it was . . . that there are three stages of progressive decline and that means that we, as service providers, should be prepared to deal with three stages of adjustment. Now I hear about six stages and, if my notes are correct, some of them sound to me like they’re the reverse of what we heard earlier. Several times, a couple of the presenters warned us about there being no discernible stages.

As a social worker with a lot of experience working with Alzheimer’s patients and their families, I run across many, many opinions about how
the disease progresses and many models and, if you ask my opinion, I think it’s gotten out of hand. I can just pick and choose whatever I need to say and say it. It’s that simple. It really doesn’t help matters much when you really want to understand what’s happening to these families.

Deliberation over the timing of select aspects of the disease experience also shows that conversants oscillate between communicative usages, thereby serially structuring and destructuring the disease’s developmental order, evident in the earlier case of a psychologist’s participation in a support group’s proceedings. In the ameliorative mode, the psychologist was asked to describe the disease’s stages in a husband, to which the psychologist responded, in tribulation mode, that one of the disease’s frustrations is that there are no clearcut stages. Attempting to illustrate her comments, the psychologist inadvertently served to suggest its opposite to the inquiring caregiving wife, who subsequently lent concrete individual support to the general account of stages she heard being offered. Responding to the wife’s comments, the psychologist then began to virtually teach the disease as expressed in the husband, for which a number of others provided personal credence. But then, in a challenge to the developmental code being considered and elaborated, a number of participants began to compare stages and, in a manner of speaking, proceeded to upstage it all. This time, the individual differences in their experiences with the course of illness were seen as too great to accommodate a clearcut, general order, being, in turn, a sign of the disease’s frustrations. The psychologist now reminded the group that she had said as much earlier. Yet, as time passed, it became evident that the need to be able to do something, to rationally organise an approach or adjustment to what was happening, urged another structuring of experience. Disarray, thus, was serially used to structure, destructure, and restructure the course of illness.

Conclusion

In and about worlds of everyday life are innumerable signs of order, more or less articulated through material traces and behavioural regularities. Confusion, disorientation, and agitation, it is said, are among the signs of dementia in old age, definitively being Alzheimer’s disease when accompanied by characteristic organic markers in the cerebral cortex and the appropriate long-term personal and family histories. Yet, interestingly, equivalent signs
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represent what is called 'normal ageing,' grounded in the organic and life historical markers. I have argued elsewhere that we must partially turn away from such apparent contradictions and their subject matter as such, to their practical organisation, in order to reveal the separately perceived entities that disease and normal ageing are taken to be (Gubrium 1986). As Silverman (1985), too, more generally maintains about the relationship of order and assignment, the realities of everyday life are located in their practical dialogue, the realities being equally concrete and artful, sustainable as separate entities only within courses of concern and conduct.

In this paper, I have examined the apparently ordered, and yet likewise disordered, world of a course of illness. It is a world fraught with a wide-ranging stock of ordering structures – developmental codes by which to perceive pattern in particular facets of related experiences. The variety is as broad as the formal and informal interests of those concerned. As such, that which is perceivable in the Alzheimer’s disease experience reflects manifold attentions and intentions.

Still, while there is a weighty and continually expanding stock of developmental codes, those concerned do not repeatedly code and recode – structure and reconstruct – their charges and personal or collective responses. The Alzheimer’s disease experience, for one, shows that a particular form of descriptive activity serves to deconstruct it. Examined in terms of communicative usage, we have seen that experience is not exhausted by codes and codification; a good share of it is concertedely uncodified, admittedly uncodifiable. The tribulation mode of address destructures it. Of course, it thereby serves inaction, the inability to do something about ‘it.’

Therein lies a very important clue to the nature of the varied ‘its’ of everyday life – how inexorably tied things are to the lifeworlds of those concerned. The lesson of the tribulation mode is that it is important, too, not to make ‘every-thing’ out of experience, as it were, for, on occasion, it is frustratingly comprised of nothing at all. (I would venture to guess that the overfilling of experience with concrete meanings – things – is as much a product of social scientists’ aim to reveal its structures as it is an ongoing artifact of native practice.)

I suppose one might argue that the tribulation mode contains a code of its own, the structure of disarray. Yet what is this to comprise as a guide to practice? Doing nothing? The Alzheimer’s disease data suggest that, rather than being a course of action, doing
nothing is a tribulation, something acknowledged on occasion but to be avoided if anything at all is to be done. There is a difference between advisedly doing nothing because, as things stand, nothing should be done, on the one hand, and not being able to do anything because nothing is evident to do anything about, on the other. It is the latter experience that confronts those concerned in the tribulation mode, the lack of order, not what it suggests we don’t do in response to it. In this vein, the tribulation mode contains no temporal code, leaving those concerned bereft of a meaningful object of address, actively or inactively. Unless analytic credence be given to the difference between structures and de-struction, as concrete conditions of experience, all behaviour is reduced to conduct, all attuned to objects of concern, the relation between doing nothing and nothingness indistinguishable.

The developmental code and its disarray, and the mutual documentary applications of individual experiences and the disease, offer those concerned broad descriptive resources for communicative purposes. As Durkheim (1961) might have suggested, like people and their gods, those involved in the Alzheimer’s experience get the disease and course of illness they both deserve and need. The concerned do not as much encounter general developmental regularity in the course of illness, as they use it and its destructured opposite to both express and guide their actions and related frustrations. In practice, we find that developmentalism enters into experience more as culture than as regulating structure, revealing developmentalism’s symbolic and practical functions (cf. Gubrium and Buckholdt 1977; Bury 1982). As such, while I have focused in particular on the developmental structuring and destructuring of a course of illness, the argument is, more generally, a critique of developmentalism as a temporal theory of conduct.
\textit{Disease of the Century: The Case for the Alzheimer's Disease and Related Disorders Association and Its Fight Against Alzheimer's and Related Diseases \mbox{Chicago: ADRDA.}}


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