THE SOCIAL PRESERVATION OF MIND: THE ALZHEIMER'S DISEASE EXPERIENCE

Jaber F. Gubrium
Marquette University

Data from the Alzheimer's disease (senile dementia) experience are interpreted to extend and refine George Mead's theory of mind. While Mead conceived of mind as an internal conversation, the disease experience shows that the reality-status of mind is more practical and radically dialogical in organization. Taken as collectively preserved, mind is circumscribed through agents by means of rule-guided articulations and closures. Suggestions are offered for a more fully dialogical appreciation of Mead's view.

In his critique of Watson and behaviorism, George Herbert Mead (1934) presented an alternative view of mind. It was Mead's contention that mind, self, or intelligence—he often used these interchangeably (see Mead, 1934:50, 134, 186, 191, 192)—was a discursive process. Thinking was likened to internal conversation (p. 47). Mead took care to point out that, while individuals came to have selves or minds, the latter were not emergent products of nascent structures present at birth, but, rather, were outcomes of the "social side of human experience" (p. 1). Quoting from Mead:

Mind arises in the social process only when that process as a whole enters into, or is present in, the experience of any one of the given individuals involved in the process. When this occurs the individual becomes self-conscious and has a mind . . . (p. 134)

Although Mead's theory of mind has not been without explanatory controversy (see Blumer, 1973, 1977, 1980; Huber, 1973a,b; Lewis, 1976, 1977, 1979; McPhail and Rexroat, 1979, 1980), mind's "logical geography" (cf. Ryle, 1949:chaps. 1-2) remains individualistic both in symbolic interactionism and in the most recent social behaviorism. While it is generally agreed that self or mind is not an inherent individual possession, it is
nonetheless thought to be a state of being located in and about the individual person whose physical presence, with experience, comes to embody it. As Mead (1934:50) argued against Wundt: "The body is not a self, as such; it becomes a self only when it has developed a mind within the context of social experience." Being self-conscious and socially formed, the individual mind is, in turn, transformed through social interaction.

A variety of commonplace experiences suggest a need to refine Mead’s view. In his many dogfight illustrations, Mead asserts that we take it for granted that, while dogs may engage in vivid “conversations of gestures,” the gestures are not “significant.” The gestures are not products of, nor do they concretize, canine selves. As Mead (1934:43) says: “We do not assume that the dog says to himself, 'If the animal comes from this direction he is going to spring at my throat and I will turn in such a way.'” The conduct of dogs is understood to be mindless, the outcome of their mutual conditioning. Yet what are we to make of the common experiences where the assumption is relaxed or even reversed? At times, people do take it for granted that dogs, let alone any quick or inanimate object, significantly reference themselves, have minds, and behave accordingly (cf. Casteneda, 1968, 1971, 1972; Wieder, 1980). In light of such definitions and experiences, is not an a priori assumption to the contrary unduly restrictive? More inclusive would be a radically social version of Thomas’ (1923) notion of “the definition of the situation” (cf. McHugh, 1968).

While some might judge the interpretation of canine conduct and the consideration of what fuels dogfights as marginal to the symbolic depth of human experience, or the ordinary attribution of mindedness to animals as incidental to the ultimate realities and individual location of selves, there is striking evidence of such conduct in the realm of human affairs. As a case in point, the Alzheimer’s disease (senile dementia) experiences of patients, caregivers, and concerned others show that it is not routinely assumed that the demented are mindless but, rather, the assumption, in its own right, is a recurring issue of treatment and caregiving. The patient-oriented actions of the concerned cannot be adequately understood in terms of an internal conversational view of self-location, notwithstanding its social sensitivity. Only the treatment of mind as a social preserve, as an “internal” entity assigned and sustained both by, and for, whomever assumes it to exist, can account for what is taken to be the minded conduct of the mindless, the belief and attitude that the demented have minds when it may be less evident than in the conduct of dogs.

This article presents data toward a more fully social appreciation of Mead’s seminal understanding of mind. Following a medical description of the disease and the study from which the data are drawn, four features of the social preservation of mind are examined: (1) the idea of the hidden mind and the problem of its realization, (2) the question of who is mind’s agent, (3) discernment and articulation rules, and (4) the organization of mental demise. In conclusion, suggestions are offered for a dialogical view.

**THE DISEASE**

Called “the disease of the century” (Alzheimer’s Disease and Related Disorders Association, 1982), Alzheimer’s or senile dementia is now considered to be the single most devastating illness of old age (Reisberg, 1983:xvii). Long after its discovery in 1906 (Alzheimer, 1907, 1911), it was believed to affect those aged thirty to fifty and thus also
referred to as a presenile dementia. Recent neuropathological research (Terry, 1978a) indicates that the distinction between presenile or Alzheimer's dementia and its senile form is probably arbitrary, implying that the behavioral and organic markers of both forms of debility are actually one disease.

Alzheimer's is a devastating disease. There is a progressive decline in mental functioning in which victims experience confusion, forgetfulness, depression, disorientation, and agitation. The inability to plan and organize actions leaves one unable to complete the simplest tasks of daily living. While in the early stages, a patient can lead a moderately independent life, severe dementia virtually disables its victim such that one, for example, no longer recognizes the once-familiar faces of a spouse or child and is rendered incapable of managing routine activities like eating, voiding, and grooming (see Reisberg, 1981).

However severe the cognitive decline, the victim may be remarkably physically fit. It is said that the only physical markers of Alzheimer's disease may be the senile plaques, neurofibrillary tangles, and ancillary bodies found in the victim's brain, observable upon autopsy. While biopsic examination of the living brain is possible, it is not without considerable risk and rarely done. As such, the diagnosis of Alzheimer's disease remains clinical, based on cognitive evaluation by means of mental status inquiries, family histories, and physical examinations to rule out confounding or concurrent illnesses (Katzman, 1981, 1982; Katzman and Karasu, 1975).

At present, there is no prevention or cure for Alzheimer's disease. While a variety of experimental drugs holds some promise for the treatment of milder symptoms, there is still no effective medical means of reducing severe senile dementia. Medical treatment remains managerial, commonly psychopharmacological intervention. Primarily a custodial problem, the Alzheimer's disease patient becomes the virtual ward of those upon whom he/she is dependent—frequently family members.

The cognitive and pathological status of the disease is even more ominous when its connection with the aging process is taken into account. Although there are repeated reminders, both in the medical and popular literature, that Alzheimer's disease is not normal aging (e.g., Alzheimer's Disease and Related Disorders Association, 1982), there is good evidence that the distinction between the disease and the aging process may be quantitative, not a difference in kind (Tomlinson, Blessed, and Roth, 1968, 1970; Terry, 1978b; Johnson, 1985). As a result, it is not clear whether the inexorably progressive symptoms of the disease are endemic to it or are the characteristics of becoming very aged, prematurely or in due course.

The combination of conditions has meant that Alzheimer's disease virtually has "two victims"—the person afflicted and the caregiver. Its so-called living death devolves into a caregiving problem, not a medical one. Founded in 1979, the Alzheimer's Disease and Related Association (ADRDA), a nationwide network of local chapters and support groups, aims to encourage medical research to eventually find a prevention or cure but, more immediately, to aid, educate, and counsel family members, concerned others, and the public-at-large in dealing with and caring for victims. At the same time, the ADRDA serves as a forum for the mutual support and enlightenment of caregivers.

Both in theory and practice, from medical opinion to custodial concern, the Alzheimer's disease experience is considered to be an interpersonal one, as the "two victims" theme suggests, never the sole problem or burden of the victim proper. The experience virtually exists in the nexus of the "disease that dims bright minds," a now-familiar
phrase, and the burden of care. In and about the daily disease affairs of those who coexist there is the abiding everyday problem of mind, the enduring concern over what is left of the patient's self and, if anything, how to decipher it.

THE STUDY

Consideration of the social organization of mind emerged in conjunction with general reflections on field data and the analysis of disease literature from a larger study of the descriptive structure of senility (Gubrium, 1986). Participant observation was conducted in a variety of sites. A small day hospital for the care of Alzheimer's disease patients was studied over a four-month period. Informal activities were observed, as were scheduled events such as therapeutic recreation, reality orientation, activities of daily living, field trips, utilization reviews, staff conferences, and a support group for the patients' primary caregivers. Fieldwork also was conducted in the ADRDA chapters of two cities, focusing on their caregiver support groups. Few of the support groups permitted patient participation. Some specialized exclusively in the concerns of adult children; others were limited to victims' spouses. Local chapter meetings also were attended; their function tended to be more administrative and educational than expressly supportive.

In addition, diverse documents and texts were analyzed for related themes. The mind of the Alzheimer's patient, in theory and in practice, is the frequent topic of both prose and poetry in the disease literature. The presentations and transcribed discussions of medical conferences (e.g., Eisdorfer and Friedel, 1977; Katzman, Terry, and Bick, 1978; Katzman, 1983) show evidence for formal concern for issues raised casually by caregivers: "How does the victim lose a mind?" "How can the mental status of the Alzheimer's patient be assessed when the patient is characteristically incommunicable?" An exploding body of professional and semiprofessional literature addresses the questions, too, presenting the results of controlled studies as well as advice for practical application. With the growth of public concern over the disease and the emergence of an Alzheimer's disease movement centered in the ADRDA, a number of how-to books for caregivers has appeared (see Heston and White, 1983; Mace and Rabin, 1981; Powell and Couritce, 1983). In their own fashion, the books offer a range of practical solutions—rules—for the discernment and preservation of mind. Mind also is thematised in the prose and frequently appearing poems of the disease's folk literature, especially the newsletters of the many local chapters of the ADRDA. It is the poetry, more than any form of written text, that, even in its simplicity and sentimentality, brings the reader or listener to the very heart of mind.

A HIDDEN MIND

A persistent question for all concerned is "What significance is assigned the patient's gestures and expressions?" For most caregivers, it is evident that the patient, to paraphrase a widely used slogan, at one time had a bright mind now dimmed by the disease. The victim was once intelligible, fully in command of wit and wisdom. As another slogan puts it, the disease seems to steal that mind away. Yet, while the victim's outward gestures and expressions may hardly provide a clue to an underlying humanity, the question remains whether the disease has stolen it all or only the capacity to express it, leaving an unmanifested, hidden mind.
A focal theme of newsletters and support groups, the issue of the hidden mind bridges two native senses of mind, one individualistic but more structured than Mead’s, the other structured but more fully social. Newsletters and support group proceedings show that there is a clear sense that it is individual persons who possess minds. While the social origin of mind is rarely discussed, its social sustenance frequently is. Caregivers and concerned others commonly deliberate over, share information, and offer each other practical advice about how to maintain whatever remains of the Alzheimer’s victim’s mental life.

In one sense, mind is more structured than Mead’s conception in that it is taken to be less an internal communicative process than an objective “thing,” an entity owned by the person that, once secured, can be expressed. This is evident in varied common references to “the state of mind,” whether a patient has fully “lost his/her mind,” when he/she will be completely “out of his/her mind,” “what his/her mind is really like,” “how to get into a victim’s mind,” among many similar expressions. In the Alzheimer’s experience, such statements are more than casual metaphors; they are taken to be concrete references.

In contrast to this usage is a sense of mind more fully social than Mead’s. While mind as entity is, in a manner of speaking, what all concerned are up against, it is at the same time a thing that is existentially tied to all. Because it is hidden—if not completely stolen—by the disease, others are charged with its realization. A common sentiment, it is said to be “up to us” to look and listen carefully for what the Alzheimer’s victim is really trying to communicate. A familiar claim, only those who truly love the person, who may hate the disease, can make the difference between the continued realization of the victim’s person as opposed to his/her loss to the “mere shell” of a former self. The contrast with Mead is a mind that persists in and through social assignment, the external (public) preservation of self.

The following exchange, drawn from the proceedings of one of the support groups observed, illustrates both senses of mind. The group is comprised mainly of the elderly spouses of Alzheimer’s patients. Attention is centered on the mental status of a particular patient. The patient’s spouse (call her Rita), asks what to think about her husband’s very demented condition of late.

“I just don’t know what to think or feel. It’s like he’s not even there anymore, and it distresses me something awful. He doesn’t know me. He thinks I’m a strange woman in the house. He shouts and tries to slap me away from him. It’s not like him at all. Most of the time he makes sounds but they sound more like an animal than a person. Do you think he has a mind left? I wish I could just get in there into his head and see what’s going on. Sometimes I get so upset that I just pound on him and yell at him to come out to me. Am I being stupid? I feel that if I don’t do something quick to get at him that he’ll be taken from me altogether.

Immediately responding to Rita, another participant, Sara, explains:

“We all have gone through it. I know the feeling…, like, you just know in your heart of hearts that he’s in there and that if you let go, that’s it. So you keep on trying and trying and trying. You’ve got to keep the faith, that it’s him and just work at him, ’cause if you don’t…, well, I’m afraid we’ve lost them. That’s Alzheimer’s. It’s up to the ones who care because they [the victims] can’t do for themselves.”
In the exchange, mind is both individual and social. It is an entity possessed by the victim; yet the possession is also a gift allocated faithfully toward its subsequent realization. It is evident that, in practice, Rita, Sara, and their coparticipants, are literally “doing” mind in order to realize it (see Garfinkel, 1961; Mehan and Wood, 1975). Applying Mead’s conversational metaphor, we can interpret their activity as a radically social turn on individual mental life. The status of the victim’s internal conversation is, simultaneously, an articulation and practical realization of whomever enters into it. As Sara’s response implies, it is those concerned who preserve mind, as ably as they can.

Following Sara’s response, several participants question the wisdom of maintaining faith in the face of decreasing evidence that the victim still has a mind. With this, participants directly confront the understanding so central to Mead’s view: the status of mind’s internal conversation. Participants deliberate over the warrants of their faith. One of them, Jack, asks Sara whether she wouldn’t feel foolish to realize that all her faith in, and effort to communicate with, her husband were for naught because, as he claims of his own spouse, “she’s like the living dead.” He adds:

That’s why I’m looking for a nursing home for her. I loved her dearly but she’s just not Mary anymore. No matter how hard I try, I can’t get myself to believe that she’s there anymore. I know how that can keep you going, but there comes a point where all the evidence points the other way. Even at those times (which is not very often) when she’s momentarily lucid, I just know that’s not her speaking to me but some knee-jerk reaction. You just can’t let that sort of thing get your hopes up because then you won’t be able to make the kind of decision that’s best for everyone all around. You know what I mean?

Sara interjects:

Well, I know what you’ve gone thought, and I admire your courage, Jack. But you can’t be too sure. How do you really know that what Mary says at times is not one of those few times she’s been able to really reach out to you? You don’t really know for sure, do you? You don’t really know if those little plaques and tangles are in there, do you? I hate to make it hard on you, Jack, but I face the same thing day in and day out with Richard [her husband]. Can I ever finally close him out of my life and say, “Well, it’s done. It’s over. He’s gone”? How do I know that the poor man isn’t hidden somewhere, behind all that confusion, trying to reach out and say, “I love you, Sara”? [she weeps]

In this touching scene, we find that even the attempt to empirically confirm or disprove the supposition of mind can’t penetrate its existence or the possibility that it has been altered. Mind’s existence seems to be experientially tied, in the final analysis, to the faith of those concerned and to the social preservation of the assignment, to minding. The working sense of mind found in the Alzheimer’s disease experience is, at once, individual, social, and discursive. It radicalizes Mead’s vision of social individuality. Rather than presenting mind as secured individual property, the Alzheimer’s disease experience repeatedly raises the question of how to define it as such. Although essentially hidden, when mind is faithfully assigned, it is an entity, a structure, articulated as much by those concerned as by those for whom there is concern. All are equally mind’s agents,
in common ownership of those who seek it. Unassigned, mind is no longer in hiding and thereby experientially nonexistent, its apparent expressions meaningless.

**THE QUESTION OF AGENCY**

As a thing located somewhere behind gesture and expression, mind never presents itself directly to those who take it into account. Hidden as it is, mind must be spoken for. As the Alzheimer's disease experience plainly shows, persons may not be able to speak their own minds. It should be noted, though, that the Alzheimer's disease experience is not unique in this regard, only more visible and urgent in the presentation of what is otherwise a universal problematic. Daily life is full of the pursuit of others' insights into individual minds as well as claims to know individual mind's better than those who ostensibly possess them. As the professionalization of mental concern indicates, agency has even been commodified, a purchasable service available to those desiring expert access to their minds.

Speakers for the victim's mind are a motley set. They may be a formal group, as is the health-care team who reviews a patient's conduct to keep it in tow. In the day hospital observed, the team consisted of a physician, psychiatrist, nurses, a recreation therapist, and a social worker. In varied ways and degrees, each team member spoke for the patient as a means of arriving at a shared sense of his/her mental status for diagnostic, prescriptive, and therapeutic purposes. In the Alzheimer's disease experience, of course, the caregiver is a key spokesman, his/her assertions warranted by intimate daily contact. At times, the patient may also serve as agent for this own mind; at other times, his/her very vocal, insistent, or seemingly intelligible testimony on his/her own behalf may be discounted because of his/her disease (see Gubrium, 1980).

There is no guarantee, in practice, who will serve or be accepted as mental agent, only that mind emerges by way of agency. Before mind is spoken for, the issue of who speaks credibly must be resolved. For example, in ascertaining the victim's mental status, the victim may be taken to speak competently for himself, even at the end stages of the disease when he might otherwise be considered vegetative. As the earlier extracts showed, the concept of "lucid moments" raised the possibility that there were occasions when the virtually fully demented were to be taken as temporary agents for minds still functioning behind the disease. As such, the disease is a communicative malfunction, the lucid moment serving to convey aspects of a mind otherwise hidden. The issue of agency may become lodged in deliberations over the lucidity of such moments, over the question of whether what was said and heard was, in fact, lucid (a clear and distinct expression of the victim's mind) or the mere appearance of lucidity (perhaps a so-called parroting). The discernment of lucidity may itself turn on the assessment of discernment credentials, as one or another party to a deliberation claims to know best in such matters because of experience, education, or insight, among a host of interpretive warrants. Indeed, the figure and ground of warrants and discernments continually shift in the flow of mental discourse.

Mind experientially persists to the extent that some agent preserves it, be the agent the one whose mind is at stake or some other. While in theory, mind is referenced as a thing, it is articulated and realized by a type of existential labor. Agents are themselves practicing features of mind, even though mind, in its own right, is taken to be a separate and essentially hidden entity. As a support group participant explained:
Look, you and I know that if we don’t make a real, loving effort to listen, to really hear, what they’re [Alzheimer’s patients] trying to say to us, that you might as well call it quits. I know that Dad hasn’t said a word for years, but when I touch his hand or put my arms around him—God bless him—he knows. He really knows! You can’t tell me he’s gone. As far as I’m concerned, Dad’s as much with us as he always was. The damned disease has just made it impossible for him to communicate with us. It’s an effort and someone’s got to believe in them. You just can’t ever forget that it’s a life and you can’t give up on it.

Now, of course, not all of those gathered in this or in other support groups feel as this devoted daughter did. Some cease to be the victim’s agent because they consider it foolish to do so, not because it is foolish to care but, rather, foolish to continue caring for something they no longer believe exists. Those continuing to maintain what is called the illusion of the patient’s lucidity, who try to preserve the semblance of the victim’s former self, are said to be “denying,” the irrational sustenance of mind. In contrast, for others, the ultimate question of mind’s existence experientially overshadows whatever evidence is brought to bear in the matter. For them, denial is mere rhetoric, someone’s way of being diagnostic. When all is said and done, the question remains, as Sara put it earlier, “How do I know that… behind all that confusion, [he’s not] trying to reach out and say: ‘I love you, Sara?’”

Given the liberal tenor of Mead’s philosophy, he understandably tended to limit agency to the individual, embodied articulators of mind, as if to say, when self-consciousness occurs, an individual can speak his/her own mind. Diverse, casual evidence and the Alzheimer’s disease data suggest the need for a broader interpretation, cast as discursive and practical individualization. Accordingly, mind is anyone’s responsibility, everyone being a potential agent, the person conceivably self-conscious despite himself/herself.

**ARTICULATING MIND**

Hidden as it is, mind requires articulation. In Mead’s view, it is the individual person, in possession of self-consciousness and sensitive to others, who expresses himself/herself, to others and to himself/herself. The Alzheimer’s disease experience poignantly confronts those concerned with the everyday issue of articulation. While there are any number of agents for the victim’s mind, how do they go about their work? Consider here the social organization of preservation; in the next section, we turn to closure or mental demise.

A difficult task confronts the caregivers and concerned others who seek the Alzheimer’s victim’s mind: to read outward signs of mind bereft of common meaning. The disease is said to destroy the victim’s capacity to communicate by gesture or expression. Left with little or no memory, muddled speech, erratic movement, or other unintelligible activity, in diverse combinations, the usual route to mind is virtually nonexistent.

In the face of this, rules of thumb are offered to facilitate articulation, some based on professional practice, others being “tips” for hearing what the patient is trying to say drawn from individual caregiving experiences. Articulation rules are regular features of the disease literature, especially nursing and social work writings, the advice books for caregivers, and the many ADRDA chapter newsletters.
The foremost rule is that those concerned must be prepared to articulate what the patient is trying to communicate. Before the actual interpretation process begins, agents must sharpen their perception so that whatever clues there are to the patient's inner intentions can be captured, obscure and fleeting as they may be. Called "active listening" by some (e.g., Philadelphia ADRDA Newsletter, January 1983) and a "special kind of listening" by others (e.g., Bonjean, 1979), preparation is said to require objectivity. An active listener attempts to hear without being judgmental, which would confound what the patient means. As explained in the Philadelphia ADRDA Newsletter (and reprinted in other chapter newsletters):

This method [active listening] conveys nonjudgmental interest and a sincere willingness to understand the other person. The result is a clarification of the situation for both the person speaking and the "active" listener, and—in many cases—the person with the problem is able to come up with more insight about his/her problem through the conversation. (p. 3)

The rule not only prepares the listener to perceive the patient's intentions but, through the active listener's effort, both the listener's and the patient's insight into the latter's mind is achieved. As such, active or special listening is preparatory to the common realization of intention.

The preparatory rule has a selection provision. While the active listener should be objective, he/she should not listen to everything the patient conveys, for much of what is said and done is meaningless, arbitrary, or unintended. As a result, one listens for what the patient is truly saying, not literal expressions. As Bonjean (1979:8) advises: "Sometimes, listening means attempting to hear what is felt rather than what is reported, what is meant rather than what is actually said." And as pointed out in the Philadelphia Newsletter: "In active listening, one listens not only to the literal meaning of the words spoken but also to the emotional content underlying the words" (p. 3).

The active listener fine-tunes for affective messages. This resolves the challenge of communicating with the incommunicable. As defined by the rule, in the final analysis, the route to mind is by way of feelings. From physicians to caregivers, those concerned repeatedly reminded each other that, while the Alzheimer's victim may be cognitively deficient, it does not mean he/she doesn't have feelings, the very heart of mind. Needless to say, this puts a considerable interpretive burden on listeners.

Other rules link details of the patient's conduct with particular meanings. Some of the most explicit are described in a widely quoted article by Bartol (1979) titled "Nonverbal Communication in Patients with Alzheimer's Disease." Explicit rules are suggested in the following passages.

Pacing the halls, restless behavior, and inability to sleep tell us clearly that the patient is anxious, [the patient asking us] "What is wrong with me? Can't you see I am getting worse? How much worse will I get?"

Withdrawn behavior and signs of nervousness tell us that the patient may be afraid, [the patient saying to us] "I am frightened of what is happening to me! Help me!"

Not all interpretive rules are as straightforward. Many emerge from deliberations over the particular meaning of unintelligible gestures or expressions. From professional staff-
ings to support group proceedings and casual conversation, the concerned inform each other of how to interpret the patient’s conduct, warranting their claims on grounds as varied as training, expertise, and intimacy of contact. Whether formal or casual, the application of interpretive rules is organized in usage. Rules themselves are interpreted, transformed, and applied as the need arises, working guides for making sense of individual expressions, discovered, interpreted, and applied case by case.

Just as words are believed to stem from mind, feelings are taken to have a source. But what thing do feelings express? The answer lies in the affective analog of hidden mind: the referential heart.

Time and again, in speech and text, those concerned distinguish between the feelings and words the patient conveys, as do rules for active listening. Words and feelings are located, respectively, in references to matters of mind and heart. For some, heart is the mind that has all but failed, the spirit of intention, the heart of mind. As frequently noted, “His mind might no longer be active, but he’s still got a heart and feelings.”

The heart of mind has the same discursive properties as mind itself. It is a thing, hidden, inferentially describable. Where there can be mental anguish, so, too, there is heartache. Where there is sincerity, there also are heartfelt intentions. Even mind’s past—membrances—has its counterpart in heart’s memories. Originally appearing in the Kansas City ADRDA Newsletter and reprinted in the August 1984 issue of the Des Moines ADRDA Newsletter, extracts from a poem titled “Heart’s Memories,” said to be written by an Alzheimer’s disease victim, share the heart of mind’s past:

I remember you with my heart
  My mind won’t say your name
I can’t recall where I knew you
  Who you were
Or who I was.
...
But I do know you
  I know I knew you
And I do love you
  I know how you make me feel
I remember the feelings we had together
  My heart remembers
It cries out in loneliness for you
  For the feeling you give me now.
...
Please, please don’t forget me
  and please don’t stay away
Because of the way my mind acts
  I can still love you
I can still feel you
  I can remember you with my heart
And a heart memory is maybe
  The most important memory of all.

While the folk poetry of the disease experience would be judged crude by some, its place in the conduct of the concerned cannot be judged on literary grounds. The folk
The Social Preservation of Mind

Poetry not only reveals how the ultimate structure of mind is envisioned by those concerned, it is also a way of voicing, by means of words, what words cannot convey. Ironic as that may be, it is taken to articulate the heart of mind, a thing indescribable in its own right.

A commonplace dilemma, caregivers and concerned others frequently complain that they "just can't put into words" the feelings they and/or their patients are experiencing or desire to communicate. It is not a problem of "really knowing deep down," but one of articulation. More than any other vehicle, it is the growing poetry of the disease that succinctly serves that purpose. For example, in one support group session, several participants were struggling to describe to each other the inner feelings of their respective patients. For some time, one caregiver in particular tried unsuccessfully to do so. She claimed to know very well what was in her demented husband's heart, what the disease progressively and insidiously had hidden from her, but had difficulty articulating what she knew. Many agreed that it was hard for them, too. At one point, though, as she once again attempted to describe her husband's heart, she fetched a poem from her purse and read it aloud. On the face of it, its words were no different than the words she had earlier used ineffectively to convey the feelings. Yet, when she had read the poem, her message was received with clear understanding, various members of the group acknowledging that "it said it all." What that was, of course, cannot be described. The point of the poetic message was that, despite its words, it was taken to be clear communication: emotive discourse. The poem was what the poem did; thereby, poetry-in-use became a social relationship—common understanding, community.

THE DEMISE OF MIND

For some participants, the function of support groups is to teach one to realize, as a veteran put it, "that there comes a point where to keep thinking that they're still sensible and lucid underneath it all is ridiculous and blind." The attitude is not necessarily uncaring but realistic, for, just as those who claim to find definitive evidence of mind and heart in the conduct of their patients, others become equally convinced of their absence. As a daughter explained:

When all is said and done, for all the finagling they do trying to figure out Mother's strange speech and erratic ways, Mother's just not there anymore. You might just as well be talking to a wall. It's a plain fact as clear as day. All that listening and all the clues in the world are not going to tell you that that brain's still working up there. Everyone should realize that sooner or later. If you ask me, it's more in their [caregivers'] minds than in the patient's.

The comment brings us face to face with the social nature of mind and minding. It informs us that, as entities, heart and mind are objects-for-us. The sentiment is that minding should in due course cease, for it eventually represents no conscious thing, nothing. Continued, unrestrained minding itself becomes an affliction—pathological denial—further victimizing the "other patient" of the disease, the victim's caregiver.

In a study of the social organization of death in two hospitals, Sudnow (1967) described dying as a social state of affairs. He reported on the physical preservation and
closures linked with interpretations of the social worth of the dying. The Alzheimer's disease experience shows that closure is not only social but, for some, programmatic, processed by rules as formal as those serving articulation. The interpersonal relations of the patient and the caregiver are sometimes said to have a natural history. In veteran and professional judgment, it is only natural for, say, the wife of a recently diagnosed spouse to eagerly search for a cure or some other means of sustaining his "once bright mind." Indeed, the search and hope might last for years, well into the most debilitating stages of the disease. For some, the search virtually outlives the victim, as the former caregiver retrospectively attempts to regain the semblance of what the patient "really must have [meant or] felt even though he couldn't even remember his own name, where he'd been, or where he was going." Yet, as those who claim to know from experience or from being expert in such matters, there comes a point when it's only natural to begin closing off one's affairs with the hopelessly demented.

The professional rationalization of intervention is crystallized around a developmental-stage view of the closure process. Discussions and advice columns in ADRDA chapter newsletters and the human service literature of the disease show that Kübler-Ross' (1969) well-known formula of the five stages of dying has been adapted to Alzheimer's disease counterparts. A familiar concern is where the caregiver or a support group "is at." "Is at" refers to some point in the natural history of concern. For example, in regard to a particular caregiver, it may be said that he/she is at the stage of denial or in the acceptance phase, respectively, meaning that he/she refuses to close off his affairs with the person behind the disease or comes to accept the need for closure with what is now only the shell of a former self. Support groups also are said to progress naturally through stages of concern. A group comprised of novice caregivers is likely to dwell on articulation, particularly the cure that will again reveal the minds of those were were once so bright. A group of experienced participants is more likely to have confronted, discussed, and perhaps come to terms with mental demise. Indeed, support groups are described as more or less mature depending on whether they are, as a geriatrician put it, "still preoccupied with cure or are getting their own lives in order."

While in theory the natural history view is a linear vision of closure, even veteran caregivers and mature support groups, on occasion, confront that persistent question: "How do I know ... behind all that ... , [he's not] trying to reach out ... ?" Sometimes, the question rushes ahead of its own deliberation, the fact of it having raised it in the first place taken to be callous and uncaring, the assumption made that, "of course," the victim still has feelings, if not the ability to rationally express them. In the circumstance, closure may be transformed into urgent preservation, with former hard evidence of total mental demise, of so-called brain failure, becoming previously unrecognized clues of the living person behind the disease. There are support groups sessions where ongoing shifts in the discourses of articulation and closure serve to construct, deconstruct, and reconstruct the victim's mind. As such, mind experientially dies and is reborn time and again, in and through formal and informal concern, an ongoing achievement.

CONCLUSION

Consider two principles of Mead's theory of mind in light of the Alzheimer's disease experience. One is the principle of minded individuality; the other is the principle of
social formation. As set forth in Mead's eponymous book, *Mind, Self and Society*, the first refers to Mead's treatment of mind as individual property, as an owned, internal conversation. The second principle discerns mind as a social achievement, formed and transformed in and through experience, in relation to others. Mead could be interpreted as seeing the principles as in continual dialog, neither one in that regard being a first principle but, rather, simultaneously operative, as Blumerians would prefer (see Blumer, 1969). In this sense, the Alzheimer's disease experience suggests that mind is pervasively dialogical, an individual product of its own discourse.

At times, though, Mead's statements reveal a distinct inequity in the application of the principles. Certain usages suggest that, once enlivened, the individual mind takes on more than an empirically independent existence. Mead speaks of the occurrence of self-consciousness and, then, the presence of mind. But the treatment is such that, while social in development, mind is occasionally described *theoretically* as referencing a self-conscious entity, embodied in the individual, foreclosing the further analysis of the dialogical status of that now separate and distinct internal conversation.

This sense of mind's logical geography constrains the data of the Alzheimer's disease experience, where mind is a poignantly problematic category, the common responsibility and property of those concerned. The concerned may settle their affairs with the heart of mind, concluding that there is indeed a self-conscious, feeling entity hidden somewhere behind the disease, or they may not. In either case, it is continually subject to their brand of epistemological scrutiny. They have the work of assigning and reassigning internality to portions of the common dialog of mind, whose participants include all conversant, from victims to caregivers and concerned others (cf. Todorov, 1984).

The practical dialog that now constructs, deconstructs, and then reconstruels mind is not an epistemological dilemma for its participants. They work at its components; they are not numbed by its overall challenge. Thus we sometimes find caregivers raising the question “How can we really know?” together with the understanding that knowing is essentially tied to the faith of those concerned. Yet, at other times, they set that aside to deal with the object of their concern, as if to temporarily stop the dialogical whirlwind in order to see through to its major point of reference, to mind.

The Alzheimer's disease experience suggests that Mead's principles be detached from their bourgeois individualism and appreciated as concrete dialogical themes. With that, mind becomes a more fully social entity, one born with attention to self-consciousness, unfettered by a conclusive self-possession. Not far removed from Mead's internal conversation metaphor, minding is open dialog centered on its essentially unarticulated, but phenomenally describable source: mind.

REFERENCES

Alzheimer, Alois  

Alzheimer's Disease and Related Disorders Association (ADRSA)  
1982 A Disease of the Century: The Case for the Alzheimer's Disease and Related Disorders Association and Its Fight Against Alzheimer's and Related Diseases. Chicago: ADRDA.
Bartol, Mari Anne

Blumer, Herbert

Bonjean, Marilyn J.

Casteneda, Carlos

Eisdorfer, Carl and Robert O. Friedel (eds.)

Garfinkel, Harold

Gubrium, Jaber F.

Heston, Leonard L. and June A. White

Huber, Joan
1973b "Reply to Blumer: but who will scrutinize the scrutinizers?" American Sociological Review 39:788-800.

Johnson, Horton A. (ed.)

Katzman, Robert
1981 "Early detection of senile dementia." Hospital Practice 16:61-76.

Katzman, Robert (ed.)

Katzman, Robert and T.B. Karsu

Katzman, Robert, Robert D. Terry, and Katherine L. Beck (eds.)

Kübler-Ross, Elisabeth
Lewis, J. David
Mace, Nancy L. and Peter V. Rabins
McHugh, Peter
McPhail, Clark and Cynthia Rexroat
Mead, George Herbert
Mehan, Hugh and Houston Wood
Philadelphia ADRDA Newsletter
Powell, Lenore S. and Katie Courtice
Reisberg, Barry
Ryle, Gilbert
Sudnow, David
Terry, Robert D.
Thomas, W.I.
Todorov, Tzvetan
Tomlinson, B.E., G. Blessed, and M. Roth
Wieder, D. Lawrence