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Narrative Practice and the Inner Worlds of the Alzheimer Disease Experience

Jaber F. Gubrium

Alzheimer disease has been formally recognized as a diagnostic category for nearly a century, dating back to the case history of a 51-year-old female patient, Auguste D., presented by physician Alois Alzheimer at a meeting of German psychiatrists in 1906. The case was “peculiar” because signs of dementia were being exhibited at an unusually young age. This so-called presenile dementia took the name of its discoverer and became known as “Alzheimer disease,” or AD. Decades later nosologic developments established AD as a dementia of “the Alzheimer type,” which virtually eliminated the age distinction and further designated AD as one of several other forms of dementia (Wells 1977).

As a matter of routine diagnostic practice, however, AD is of more recent vintage. Until the 1970s, AD was not much of a working diagnosis. My own ethnographic fieldwork in U.S. nursing homes at the time indicated that organic brain syndrome (OBS) and cerebral vascular accident (CVA) were the recorded diagnoses for elderly patients with debilitating dementia symptoms. Rarely if ever was AD listed on patient records (Gubrium 1997 [1975]). As an illness category used by family members, dementia sufferers, and the public at large, AD was effectively born in the late 1970s along with the founding of what was then called the Alzheimer’s Disease and Related Disorders Association, or ADRDA.
(now the Alzheimer's Association). The rapid growth in public awareness of the disease was accompanied by huge increases in funding for research and service provision. As Philip Stafford put it, "Clearly, something has happened to carve out cultural space for a disease which, prior to 1970, was practically unheard of" (1992, 168).

This chapter deals with this cultural space as it was ordinarily articulated in the narratives of service providers, family members, and significant others of those afflicted with AD in the 1980s. It was the period in which the future of AD was being formed at the level of everyday life. In accordance with the "two victims" theme of the disease movement, the chapter considers how folk understandings were used to construct two inner worlds—the disintegrating mind of the disease sufferer, and the developing thoughts and feelings of the caregiver.

**The Narrative Material**

For over three years in the early 1980s, I conducted fieldwork in local chapters of the ADRDA in two North American cities. At the same time I participated in, and systematically observed, the proceedings of various support groups for caregivers. Some of the support groups were formally sponsored by the ADRDA; others were either hospital-based or had other institutional affiliations. In one of the cities, fieldwork was also conducted in a day-care center for dementia sufferers (Gubrium 1986a). The analysis in this chapter centers on some of the social processes at work in the support groups based on the theme that cultural understandings resonate with experience through storytelling.

The illustrations presented are drawn from narrative material collected in four support groups; they represent a small part of the larger study from which the findings are derived—which, in turn, is a fraction of what has become a network of over 2,000 support groups nationwide. Participants in the groups were usually the spouses, adult children, or other close relatives of dementia sufferers. Most were elderly themselves. Spouses tended to be in their 70s and 80s; adult children were typically in their 50s or 60s. A few significant others, such as long-time friends and neighbors, participated, and they too were up in age. On rare occasions a grandchild who had taken on the responsibility for caring for a demented grandparent would attend. While most participants cared for their demented relative at home, a few continued to attend after the relative was placed in a nursing home. This continued attendance was attributed to a desire to help others in their former circumstances, a continued need for support from the group, or the assumption of the role of group facilitator. Although most participants were women, some husbands and adult sons did attend, and many exhibited great enthusiasm for the understanding they received.

All groups were moderated by a facilitator, either a veteran caregiver or a volunteer service professional, usually a nurse or a social worker. The facilitator's function was to facilitate ongoing talk and interaction in the groups. Some felt it important to simply "keep things going" but otherwise remained in the background. Others were didactic, conveying the latest information about progress in treatment or care and occasionally inviting speakers to address the group on topics of interest. Some assertively but sympathetically cajoled participants to think seriously about their circumstances and the future.

Support group meetings articulated the disease's cultural space in a variety of ways. They served as a readily available source of information about national and regional developments. Talk of recent and possible "breakthroughs" in research and treatment was commonplace; facilitators and savvy participants made it a point to convey new information. Oddly enough, such new information might be combined with, or followed by, self-help discussions aimed at encouraging people to "go it alone"—that is, without the well-mean but useless interference of researchers and professionals. It was occasionally said that professionals knew little about the ordinary character of an affliction that had no cure. Pessimism was expressed about the possibility of a cure for what otherwise sounded much like the condition of the aging mind, which was once simply called "senility." Items from the disease's broader public culture were also discussed, such as media and video portrayals of the disease experience. Both ordinary and celebrity portraits were often presented. Rita Hayworth's and Ronald Reagan's stories are notable in this regard. Support group narratives combined these resources with the biographical particulars of their storytellers' personal lives, thereby presenting local cultural renderings that were both general and particular to folk understandings of the disease experience.

Narrative material was collected in two ways. Some groups agreed to have the proceedings tape-recorded; after transcription, the recordings provided detailed narrative material for analysis. Other groups preferred that I participate and unobtrusively take notes if I wished. In these instances, process notes were taken—that is, the general flow of conversations and the sequence of speakers were briefly documented and soon afterward reconstructed in greater detail. As rapport developed, some of the groups that had initially consented only to participant observation invited me to record the proceedings. For example, one
participant asked, "Wouldn't it be much easier on you to just tape the
meeting?" Needless to say, I agreed. The names of all persons and places
were subsequently coded and appear here as pseudonyms.

**Narrative Practice**

My approach to the everyday activity of storytelling or narrative
practice as it relates to personal experience, especially the identities of
those concerned, has broad sociological significance. Ordinary talk and
social interaction is of great importance to the examination of the struc-
ture and organization of inner worlds.

The "everyday" and the "ordinary" are no longer considered to be
the poor and ignorant country cousins of what is otherwise profession-
ally or scientifically known about personal experience (see Coulter
1989; Pollner 1987). Rather, such ordinary activities as storytelling are
now, in many respects, considered to be the first and foundational ele-
ments of that knowledge (cf. Lyotard 1984). The personal story, in
particular, is presently commanding considerable research attention.
Early texts are being reread for their heuristic value (Alport 1942; Doul-
ard 1935; Murray 1938; Shaw 1930, 1931; Thomas and Znaniecki 1927
[1918–20]), while narrative analysis has emerged as a significant method
of procedure (see Cortazzi 1993; Dégh 1995; Denzin 1989; Hinchman
and Hinchman 1997; Linde 1993; Richardson 1990; Riessman 1990,
1993).

Increasingly, we are learning to recognize that experience comes to
us in the form of stories and that narrative practice is a key feature of
knowledge about our various worlds—including, in this case, the inner
worlds of the AD experience (Gubrium and Holstein 1998).

Personal stories range from brief accounts of daily events to blow-
by-blow renderings of a lifetime of experience. Personal stories never
stand on their own, however; they are always stories told, heard, and
responded to in the context of the countless occasions for storytelling. In
other words, stories are part and parcel of everyday life. They are
reflexively linked with the actions and aspasures of storytelling, which in
the contemporary world are more multi-sited than ever (Gubrium and
Holstein 1994, 1997). As Ludwig Wittgenstein (1953) reminded us time
and again in conceptualizing language games, stories not only tell of
experience, but they are a "form of life" in their own right.

Schools, clinics, counseling centers, correctional facilities, hospi-
tals, support groups, and self-help organizations provide narrative op-
portunities for conveying personal experiences, including stories about
private spaces we regularly claim to be our very own, such as our minds
and selves. The local cultures of these institutions are an important part
of the resources used by participants to convey to themselves and to
others who they are, what they were, and what they will become in the
future.

But this does not happen automatically. Storytellers are not com-
municative puppets in these circumstances. Personal accounts are built
up from experience and actively cast in preferred terms of reference and
narrative frameworks (Garfinkel 1967; Sacks 1974, 1992). Michel Fou-
cault (see Dreyfus and Rabinow 1982) has shown that discourses of
experience in diverse institutional settings set conceptual limits to the
shaping of subjectivity; nonetheless, the local and the particular con-
tinually insinuate themselves to construct differences. At the same time,
the analysis of narrative practice does not devolve into the molecular
documentation of storied utterances at the expense of story lines, nor
should it reduce them to romanticized individual accounts (see Atkinson
1997). As a communicative genre, stories have both received and de-
veloped plots, characters, themes, and flow that harbor a significant narra-
tive momentum of their own.

**Constructing the Inner World of the Dementia Sufferer**

The inner world of the dementia sufferer was a matter of continuing
concern in the support groups as participants told stories about the mind
or mental status of a cognitively impaired family member or loved one.
Familiar slogans drawn from the public culture of the AD movement
regularly signaled the urgency of coming to terms with "what's going on
in that head of his," as one caregiving spouse put it. Slogans such as "AD
dims bright minds," "brain failure," and "the shell of a former self"
conveyed the seemingly evident fact that an afflicted husband, wife, or
parent just wasn't the same any more—that something "in that head"
had gone seriously wrong. If support group participants hadn't already
learned this from other sources, they were soon informed that the de-
mented mind allegedly changes dramatically and, in time, is lost.

But what does it mean to lose a mind (as opposed to the brain)? How
can one tell when the mind is gone? How is one to conceptualize its
subjectivity? These are urgent questions because their answers organize
thoughts, sentiments, and courses of action in relation to the individual
in question. As a blunt group facilitator once put it to an overly zealou
caregiver, "A person without a mind is just a piece of meat; only your memories keep you thinking of him as all there." As a warning to the caregiver, the facilitator added, "And you can't live forever on memories." The comments conveyed the ongoing need to have a sense of the other, as a precursor to forming attachments and organizing social interaction. Can the thoughts of a "piece of meat" actually be conceptualized? Does it make sense to have feelings for a mindless object, other than what might relate to memories? How does one behave toward someone who is no longer "there"?

Support group participants varied in how they dealt with such questions. There were caregivers who anxiously sought answers and seemingly grasped at any understanding that became available. Other caregivers came to the support groups with ready-made answers of their own, contributing to the local culture of knowledge about the inner world of the demented. Some support groups touted rather definite views of the demented mind, and participants were continuously held accountable to these views. Newcomers quickly learned that the personal stories that made the most sense and that were believed to be realistic were those that conformed to local understandings. Other support groups were relatively fluid in this regard—their shared understandings of the demented mind varied with the flow of storytelling and the comparison of relevant experiences. Discussions of the demented mind wended their way through these differences. The stories were composed as much in response to personal needs and biographical particulars as to locally shared understandings.

Let us compare related storytelling in two contrasting venues: a group that shared quite definite views of how the inner world of the demented operates versus a group that was relatively fluid in this regard, having little or no set understanding of the structure and workings of such a mind. A similar comparison later illustrates how the inner world of the caregiver is also locally produced. In both instances, the point is that the subjectivities of the caregiving experience are constructed within, not separate from, narrative practice, thereby forming considerably different inner worlds.

George’s Inner World

Consider the way Marian, a relative newcomer, reflected on her husband George’s “dimming” mind in a support group with a distinct view of how the inner world of the demented operates. At one point in a humorous discussion of the “stunts” the care receiver sometimes “pulls” in public, Marian tells about a recent restaurant outing with her husband and complains about his behavior. She is soon interrupted and told to “give the guy a break.” Others communicate how they’ve “been there” too, and begin to elaborate on their views of how the minds of the demented work. As the exchange unfolds, note how Marian’s story incorporates aspects of the group’s understanding but still includes her own biographical twist. In the process, participants narratively co-construct George’s mind, building the story of George’s inner world out of the interplay of what is locally given and what is individually contributed. In a brief extract from a later meeting, we find Marian talking about George’s mind in even more elaborate, yet locally understandable, terms. Helen, Rita, and Wilma are regular participants in the group; Evelyn is the facilitator.

Marian: It’s difficult taking him [George] out. He pulls all kinds of stunts. Like he forgets where he’s at and, uh, if he has to go to the john, well what d’ya do? [Chuckle] You can’t go in there with him!

Helen: Cynthia [another participant] would! [Laughter]

Marian: [Sarcastically] Sure. You know what I mean. So you direct him to the door and hang around till he comes out. [Pause] If he comes out! [Laughter] Kind of embarrassing hanging around the men’s room, too, if you know what I mean. [Chuckles] Anyway, Friday, we went to Big Boy’s. He likes going there and it’s cheap. [Elaborates] A glass of Coke and, bang, wouldn’t you know it? He’s got to go to the bathroom. It sounds funny, but when you’re in that situation, it can make you mad as hell. He can be so embarrassing. One time, he came out of the john and walked right into the kitchen with his pants halfway down. They started yelling at him and he got confused and yelled right back. You could hear him from way over on the other side of the restaurant. What could I say? The guy just lost it. [Faura] To me, he’s just gone, or getting there fast. It makes me really mad, even if it’s funny when ya look back at it. It may be a good story, but it’s hell living through it, I’ll tell ya. He can hardly remember my name, and who knows who he thinks I am, if he’s thinking at all. Those tangles [neurological markers of AD] up there have tangled the guy up bad. [Elaborates]

Wilma: Now, Marian, give the guy a break. We’ve all had experiences like that. He’s still got it up there, believe me, it’s just that, well, he’s getting things more and more confused. I know how it is with these guys. Ron [her demented husband] is still there, alright, and from what I can tell, believe me, he’s worse off than George. [Elaborates] They begin to respond more
and more to touch. Maybe the old noodle can't process it used to but, believe me, they still have feelings.

**Marian:** Well, he [George] does respond to touch. Sometimes too much, if you know what I mean. [Chuckles]

**Wilma:** They all do, dear. Believe me. [Laughter]

**Rita:** I haven't been out with Mother in years. She just stays in her room or wanders around the house pretending that she's busy. She gets real agitated, but [pause] you know how when you give 'em a little peck on the cheek, their eyes light up? In her own way, it's working upstairs. You can sometimes actually read her thoughts in her eyes.

**Evelyn:** Marian. Try it. Try looking him right in the eyes and speak to him. Hold his hands. He'll come around. They all respond to touch. It's like the mind is connected to that somehow. Really! The mind works like that. If...

**Wilma:** If you can't communicate the usual way, I say try another way. Words aren't everything, you know. That old noodle doesn't just disappear. We all have the gift of touch and that doesn't leave us till we're dead and buried. [Elaborates on the "phases" of dementia through which the sufferer ostensibly passes, which she claims to have read about somewhere (cf. Cohen, Kennedy, and Eis dorfer 1985, and Keady and Nolan 1994)] Empty shell? Don't believe it. What do the doctors know? They're [the demented] right in there somewhere. Maybe they're lost because the brain ain't sparkin' or something, but they're there. You can't give up on them that easily, believe me.

**Rita:** That's what I was saying. I don't know what it is, but it works. [Pause]

Well, most of the time. Remember a few weeks ago when Mother got lost and we finally found her a couple blocks away? When I caught up with her, oh was she obstinate. I just couldn't persuade her to come along with me. The colobaws had really set in there. But I gave her a big hug all the same, because I was so glad to see her. And bingo, she relaxes, and like she's lucid. Like wakes up.

**Marian:** Could be. The mind's a funny thing. It's that way too, too. I could be mad as hell, just a little affection and I'll melt. I guess George and I are a lot alike that way. When you think about it, maybe we're all like that. I think George is more of a back man; he loves his back rubbed. [Elaborates]

**Wilma:** You know, girls, we oughta teach them shrinks a thing or two about the mind. If you ask me, Henry's [mind] was always pretty closely connected with [pause], uh, down there. [Winks and refers to Marian's comment about George] He's a different kind of back man. [Laughter] And Rita, her Mother secretly got hugs in her noodle. The old noodle like that.

**Evelyn:** I think you really have to pay close attention to that. Words. Touch. Different ways of reaching into people.

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**Narrative Practice and Inner Worlds of the Experience**

**Marian:** Funny. Mother used to say something like that too. Something about the gift of touch. Didn't think much of it at the time.

These women, many of whom have met regularly for months to discuss their common situations, have formulated a working theory of the inner world of dementia, constituting its subjectivity in decidedly romantic terms (see Downs 1997 for other, professional, constructions). Although it is not a formal rendering of structure and operation supported by clinical or scientific evidence, their construction provides understanding and direction. Their version of the inner world of dementia is, like any conceptual formulation, a basis for talk and action, a point of departure for telling stories about experience and for rendering those stories intelligible. The stories, in turn, articulate the formulation that informs themes and plot lines, reflexively constituting the minds in question in narrative terms.

Let's pick this apart a bit. As Marian recounts a difficult episode, she notes with exasperation that George "just lost it," implicating both neurological and psychological understandings that she has come across. Wilma coaxes her to consider another way of thinking about what happened. Wilma reminds Marian that the group has had a great deal of experience in such matters and goes on to assure Marian that George is indeed "still there," but that he doesn't respond in the same way as before. She casually makes an important distinction—that the mind can be thought of as an entity expressed either in words or in feelings, or possibly both. Noting that "the old noodle doesn't process it like it used to," Wilma informs Marian that, like other "guys," George now experiences more with feelings than with words. George's inner world is confused, but it isn't meaningless. As the disease progresses, the confusion may worsen, but "they respond more and more to touch." The disease, according to Wilma, doesn't destroy everything; the inner calculus of feelings, which ostensibly has an operating logic of its own, remains intact.

The construction of the inner world of the dementia sufferer in terms of "the gift of touch," which short-circuits the need to think of mind and communication as only readable in words and sentences, has broader cultural significance. It borrows from a romanticized version of experience, which has traditionally been a cultural code juxtaposed to language and reason, to words and "mere" thoughts. While the mind that Wilma and others construct for George establishes a local rendition of this aspect of the disease experience, it reproduces a sense
of mind that we can all recognize. As Wilma urges Marian to "give the guy a break," she in effect previews what George's inner world could be, as opposed to what it allegedly no longer is.

The women's discussion is not idle speculation. This particular extract is part of an ongoing conversation, sometimes humorous, often heartbreaking, that has led to a shared view of who their demented relatives are becoming. It would be unfair to their folk understandings to cast aspersions on their reasoning, for it is precisely those understandings that, like all understandings, serve to facilitate talk and interaction. It would be unjust to doubt that an inner world could be designed in terms other than the discourse of words and reason; after all, inner worlds are hardly subject to the immediate witness of independent observation. Instead, the inner world these women have constructed for the dementia sufferer has an ordinary validity. It renders their relatives' actions and their own responses meaningful and sensible.

As the discussion unfolds, the women playfully elaborate on the experiential linkages of the inner world they have constructed. Far from being limited to the head and the spoken word, the inner world of the dementia sufferer is articulated in stories of touch and affectation. Excess touch can, of course, signal sexuality, and this humorous ramification explains the mind under consideration. As anecdotal as it is, evidence is marshaled in support of the unfolding story lines. The fact that Rita's mother's mind works is evidenced from hugs and "pecks on the cheek," which cause the eyes to "light up" and allow Rita to "read her [mother's] thoughts." Evelyn then conveys the conceptual implications of Rita's story, placing it in the broad context of an inchoate folk theory of mental linkages. The mind is connected to touch, just as it later links up with even bigger hugs and backrubs. Wilma elaborates further by dissociating the familiar slogan of "the empty shell" from the language of touch. "The old noodle doesn't just disappear" just because words do, Wilma explains. This launches Rita into a personal story warranting how the inner world can't possibly be mere "cobwebs" because a big hug seemed to communicate what persuasion couldn't.

This prompts Marian to begin telling her own story in the same terms. She communicates her personal experience in the discourse of sentiments. By noting that like George, she responds to affection, she implies that the inner logic of dementia, if viewed in terms of the language of touch and feelings, is less a language for the diseased than a common frame of reference available for detailing any of our lives. Perhaps the "mind is a funny thing" because it is a way of thinking and talking about the inner regions of experience, which, in the course of its

rethinking and rearticulation, forms new and different stories about the regions in question (cf. Ryle 1949). Marian, Wilma, and the others are using words and stories to draw on what we know and share, assembling who we and others are in the best way they can.

Ivy's Inner World

Ivy Lewin's inner world generated a different kind of story in her daughter Karen's support group. Karen cared for her 81-year-old mother at home. It was a large home, and Karen had set aside a spacious bedroom for her mother, who had lived there for about five years at the time I began to participate in her support group. As in Marrian's support group, Karen was one of a core of regulars who attended the group. She had become a regular participant ever since her mother was diagnosed with AD about three years after Ivy moved in with her.

During nearly a year of fieldwork in Karen's group, I found little or no evidence of any distinctly shared view of how the inner world of the demented operates. Susan, the facilitator, whose husband Raymond had been placed in a nursing home, simply encouraged participants to "share" their thoughts and feelings, drawing on her own home-care experience to make her points, offer advice, and invite comparisons. Occasionally, another participant, a veteran caregiver whose demented husband lived at home, would substitute for Susan in the role of facilitator, following the same script of encouragement and advice. There were many views expressed about "what it's like" for dementia sufferers as they grow forgetful and gradually lose control of their actions.

At times, participants entertained views much like those shared in Marrian's group. The inner world of the demented, bereft of proper thought, was perceived to be filled with feelings, and the body was referenced as a surface of affective mental signs (see Gubrium and Holstein forthcoming). Karen once portrayed her mother's incessant "fidgeting" in these terms:

Mother, bless her heart, has never been your typical rocking-chair type. She's always been that little old Jewish lady on the go. To me, she's just more of the same now. Damned plaques and tangles [neurological markers of AD] are robbing her of her mind, and she simply can't control all that energy. Always fidgeting, fidgeting. It kinda wells up in her and she's on the go again, like she's going to the market. [Laughter] Unfortunately, she doesn't have any sense of direction, or, anyway, she forgets where she's heading. [Elaborate] But she's never that far from me; the old vibes are still
there. They respond very well to touch and your tone of voice. The rare one doesn’t. I guess that’s what they say anyway.

The portrayal was accepted for what it was, and in response, other participants shared similar experiences. None insisted that there was a particular way of thinking about the sufferer’s inner experience, how the mind of the demented is structured, or how it operates over time. Karen’s portrayal was taken to be as much a commentary about how “they” respond, meaning the AD sufferer in general, as on how her mother Ivy reacts to others, given her state of mind. For the purposes of discussion at this point in the proceedings, the inner world of the dementia sufferer was a momentarily useful construct, forming a loose narrative linkage with Karen’s description of Ivy’s fidgeting.

At other times, participants told contrasting stories, articulating a different inner world. The “empty shell” metaphor could be so foregrounded that related stories conveyed a complete lack of subjectivity. Stories detailed a person who was no longer there, only “someone [they] once knew,” a phrase that resonates with the title of a popular Alzheimer’s Association videotape that portrays five disease sufferers and their caregiving circumstances. In the following extract from such a discussion, note the painful admissions surrounding what is spoken of as “the inevitable,” meaning both the inevitable cognitive decline of the disease sufferer and the inevitable “empty shell” that will result. Richard and Ethel are elderly caregiving spouses.

Richard: [Quietly weeping] I don’t know what I’m gonna do. I’m losing more of her [his demented wife] every day. She’s just drifting away from me. I can see it and can’t do anything about it. We’ve never been what you’d call real affectionate. But she’s all I have right now, except for her children [from another marriage] and I’m not real close to them. Never have been. [Pause] I try to reach out to her, but nothing seems to work. I mean nothing. I can’t seem to do anything right to pull her out of it.

Ethel: [Reaches over and sops Richard’s hand] Come on, Richard, don’t be so hard on yourself. They’re not all alike. No one is. I know lots of people like that. They’re not the huggy and kissy type, so you gotta take her for what she is, that’s all. It’s inevitable.

Karen: I agree one hundred percent. Some of ’em just drift away from us. No matter how hard you try to reach them, it just isn’t gonna work. Mind’s just gone. I’m afraid Mother’s getting there and it isn’t a pretty sight. Nothing is going to tell me that she’s the lady I used to know. It’s all very sad, and you have to ask yourself if you can go on like you have been, caring for [pause] what amounts to fading memories, right?

While Karen’s group constructs and entertains varied subjectivities for the dementia sufferer, none of them is as locally privileged as those in Marian’s support group. In Karen’s group, the inner world of the dementia sufferer is occasionally conceived of as including both cognitive and affective areas, the latter’s borders being undefined. On these occasions, storytelling conveys plots and themes centered as much on what the sufferer “is trying to say” as on what he or she “conveys with the eyes” or “the face.” For such a subject, there are alternate communicative routes to the inner world. When “whatever you say” doesn’t seem to work, a back rub, a kiss, or a hug might do the trick. Lucid moments might prompt a more cognitive than affective strategy, while a vegetative status may make it necessary to stay an affective course. On other occasions, neither the thinking nor feeling subject behind the mask of the disease is taken to experimentally anchor what is “no longer you.” On these occasions, participants communicatively tread the margins of the actual and the remembered, as the preceding extract illustrated. Indeed, as Karen suggests at the end of the extract, perhaps the inner world of the demented is ultimately a world composed entirely from others’ memories, sustained as much by their inserting recollections into everyday caregiving as by the ostensible mind of the demented in its own right (see Gubrium 1986b).

In Karen’s group, Ivy’s mind has a more variable narrative organization than it would have in Marian’s. In Karen’s group, Ivy’s mind is sometimes basically what it is taken to be for all dementia sufferers—that is, a mind whose “vibes” respond to tactile stimulation, facilitating communication through feelings. These are occasions for narratively framing stories about how and why touch works, how the mind is communicatively linked with what the eyes say and with what the body in general conveys to others. The occasions thematize the affective lessons of “what they don’t say,” including the very exceptional disease sufferer who ostensibly responds neither to touch nor to the tone of one’s voice. There are other occasions, as the previous extract illustrates, when stories convey mere memories, in which the onus of the sufferer’s inner world ultimately rests on storytelling about what the sufferer once was. Sadly, the moral of such stories can be that when the “mind” goes, so does the person. In its greater narrative constancy, Marian’s group is perhaps also narratively more hopeful. Through stories centered on the
CONSTRUCTING THE INNER WORLD OF THE CAREGIVER

Caregivers are commonly referred to as the disease's "second victims," affirming that, in relation to the everyday subjectivities of the caregiving experience, there are always two inner worlds in question. Both the sufferer and the caregiver are disease victims. Storytelling in the support groups revealed varied structures for the inner world of the caregiver, which also was mediated by the local defining apparatus for the thoughts, feelings, and actions involved.

Of course, there was an important difference as well. Unlike the dementia sufferer, the caregiver's basic cognitive abilities were not in question. He or she continued to be able to speak about what was happening to the care receiver, even while the care receiver's inner world was communicated indirectly and was itself constructively linked to local senses of the disease sufferer's subjectivity. Unlike the disease sufferer, caregivers were also considered capable of intelligibly monitoring their own thoughts and feelings and communicating them both to themselves and to others. While caregivers were viewed as subject to errors in judgment in this regard, they were rarely seen as being unable to put things in the right perspective with proper counseling.

If there was no doubt that the caregiver had access to his or her inner world, there still remained the issue of whether that world was being correctly or authentically represented by those in question. When talk and interaction in the support groups turned to what the caregiver "is going through," which was never completely distinct from talk about what the disease sufferer was ostensibly experiencing, the inner world of the caregiver was deployed in relation to concerns about "how honest [the caregiver is] being with herself," whether the caregiver was "facing up to [his or her] feelings," or whether the caregiver was "denying" what everyone knew to be true. The absorbing immediacies of the AD experience were believed to be continuing interpretive challenges to the most perceptive and reflective persons. Because caregivers were daily in the "thick of things," it was said that they could misconstrue matters of distinct importance to them, such as their very own inner thoughts and feelings.

Especially poignant stories centered on how caregivers responded when the disease sufferer initially failed to recognize who they were.

For some caregivers, it was the first time they were seriously confronted by the very real possibility that both their own and the care receivers' interpersonal identities were in question and could be forever altered. Such stories could represent a narrative watershed: telling them readily led to the question of who the participants in the disease experience were, and whether former responsibilities continued to apply. If a disease sufferer neither recognized the caregiver—as, for example, a spouse of half a century—not to appear to know who they themselves were, the moral underpinnings of the relationship were dramatically put into question. Could they continue to apply on the basis of the mere memory of historical rights and obligations? Were the mere shells of former selves owed the same attention and consideration as a cognizant wife, husband, or parent? In turn, could mere shells of former selves be viewed as holding significant others morally accountable for longstanding commitments? Such questions turned support group participants to the inner realm of their personal relationships with the care receiver.

Dee's Inner World

In this regard, consider extracts from the proceedings of two contrasting support groups, which I will refer to, respectively, as Dee's and Sally's groups. Dee's group was facilitated by Ann and Ruth, veteran caregivers who could be rather forthright in describing what the caregiver goes through in the continuing home care of the demented. While participants in Dee's group rarely minced words in conveying their thoughts and feelings, they were also warmly solicitous and helpful in responding to the various questions raised and dilemmas presented in group discussion. In many ways, these were meetings of critically sincere friends, and newcomers quickly came to realize they had everyone's best interests at heart.

Participant observation indicated that Dee's group had a well-developed sense of the normal course of the disease experience for the caregiver. It was conveyed in terms of the burdens of the so-called 36-hour day that caregiving proverbially entailed and a multiphase chronology reminiscent of Elisabeth Kübler-Ross's (1969) stage model of dying. In the AD experience, the caregiver initially orient to the victim's care and recovery, ignoring his or her own needs, with the result that caregivers devote what can seem like 36-hour days to the disease sufferer. While caregivers eventually acknowledge the inevitability of the sufferer's decline, they initially refuse to believe this applies to their afflicted family member and thus enter a stage of denial. Caregivers may feel that they
are not doing enough for the afflicted and become guilt-ridden when they inadvertently place their own welfare ahead of that of the afflicted person. As domestic life goes from bad to worse, with no hope for recovery for the afflicted and no relief in sight from the burdens of care for the disease’s second victim, caregivers are said to enter into a stage of depression. Soon, it is hoped, they move beyond that and enter into yet another stage, when it is realized that there is more at stake in the disease experience than the sufferer. At this stage, the inevitability of full-blown dementia is accepted; caregivers take stock of the impact of the disease on their own and other family members’ lives. At this point, the possibility of institutionalization or nursing home placement is discussed for the “sake of all concerned.”

Participants in Dee’s support group regularly sorted and discerned their thoughts and feelings in relation to this model, deploying their subjectivity in relatedly structured narratives. This was not, however, the result of a wholesale enculturation in which what was related reflected the internalized by-product of a developmental code. Rather, talk and interaction showed that participants’ practical reasoning could assemble the inner world of the caregiver in biographically different ways. Nonetheless, all the stories either played on, or responded to, what the typical caregiver was believed to go through in dealing with the individual and domestic effects of the “disease of the century.”

A brief conversation between Ann and Ruth (the two facilitators), Dee, and two other participants suggested that the link between the local culture of the disease experience and the deployment of the caregiver’s subjectivity was not automatic. Instead, it was formed from the interplay between what was locally shared and the invoked biographical particulars under consideration. In the next extract, we detail the group proceedings after an extended exchange between Ann, Ruth, and Belle about how similar their personal experiences in home care have been. Note how a shared recognition of what one goes through crops up throughout the discussion, referenced in terms of how one can “see what happens,” how “we’re all in this thing together,” how one “knows what is coming,” and how one goes through a stage of “feeling lonely and depressed.” Even Dee, who starts off by presenting a mind of her own, shares in the group’s developmental understanding of the typical caregiver’s inner world.

Dee: I don’t know, Belle. Sure, I can see what happened... why you decided to start looking for a place [nursing home] for Harold [Belle’s demented husband]. I guess if I was in your shoes, I wouldn’t fight it anymore either. You do have to start thinking about how you feel inside and what’s happening to your family. God knows, the kids would have been ignored. [Dee has no children of her own.]

Ruth: [To Dee] Well then, dear, what’s your problem? We’re all in this thing together. You’re no different. You just think you are. I was like you once. [Elaborate] I did everything. I had no time to think. It was get this, do that, and take care of Ben [her husband] 24 hours a day. Well, I learned the hard way and nearly put myself in the hospital. Ben’s on a waiting list [for nursing home placement] at Pine Crest. God help me, it won’t come too soon.

Belle: I don’t think I’m ready for that yet, but I know I’ll have to pretty soon. I know it’s coming. It’s only a matter of time.

Dee: I don’t think it’s that simple, Belle.

Ann: Oh, come on, Dee. That’s what it is in a nutshell. You have to start thinking about yourself. [Elaborate] Look at you. You’re all worn down, and I’ll bet you’re feeling lonely and depressed.

Dee: That’s what I was trying to explain last time. I’m not really lonely, I’m...

Ruth: You’re denying. We all try to deny it.

At this point, there was an extended discussion of denial, its workings, and how that had once applied to several other caregivers. The discussion made it clear that the story Dee was telling was not one that coincided with local understanding. In the context of denial, the story was in virtual need of retelling so that it coincided with what Ann later declared was what “we know all about.” As Dee continued, she constructed a space for a distinct narrative. Notice, however, that she didn’t question what everyone, Dee included, already knew was typical in the matter under consideration.

Dee: I don’t think so. Seriously, if I was in the same situation as most people, maybe I’d be denying, but basically I’m here to learn how to cope with his [her husband]... you know, how to dress him and what’s going to happen to him in the months ahead. [Elaborate]

Ann: Dee, you’re forgetting that we know all about this.

Dee: I know. I know that’s the way it works. I understand that. But you’re forgetting one thing, too: he’s all I have. He’s a friend, a companion, even if he forgets who I am sometimes. It doesn’t matter that much anyway, because I know he knows in his heart that it’s me. [Elaborate] If we had had kids, maybe it’d be different. I’d probably be going through all the phases of this thing. [Describes how she would have progressed through the phases] But I don’t have kids, and his family’s not around, and I don’t know who mine are.
We've been pretty much on our own and with each other all our lives. If I give him up, it'd be, well, giving up on life. It's not like I'm going to get back to my life after he's gone. What life are we talking about? Life with Gordon is all I've ever really had. Gordon's my family.

Acknowledging the stage model's general validity, Dee views herself as an exception to its developmental rule. For her, the issue is one of applicability, not denial. Adherents of the model assume that there is a course of progress in the caregiver's adjustment to the disease experience. In the normal scheme of things, the caregiver eventually breaks the clutches of denial. Indeed, at an unstructured point of the proceedings, the group's two facilitators explained that one of their goals was to help others do just that. Dee, however, thought of herself differently. She linked her subjectivity with her particular domestic circumstances and constructed a contrasting story.

Dee narratively disentangled her experience caring for Gordon from the prevailing model of caregiver adjustment. Instead, she combined caregiving with the story of a life that she and Gordon had built alone. This obviated the typical competing familial obligations that informed the model. The impact of caregiving on others in the family network, especially as it affects one's own well-being and related ability to be responsible to all concerned, was a primary consideration. As Dee stated at the start of the first extract from this discussion, she would have had to start thinking of "what's happening to [her] family" if she had had children—who, she added, "would have been ignored." In contrast, Dee's particular story purportedly fell outside the purview of "the way [Dee acknowledged] it works," which established narrative grounds for particularizing local culture. She, in effect, was an exception to the local constituting rules concerning responsibility, inner experience, and the taken-for-granted borders of the familial. Her exceptional status proved the rules, allowing Dee's difference to stand rationally juxtaposed with the typical organization of the caregiver's inner world.

Sally's Inner World

Contrast this with a support group that had little or no prevailing understanding of caregiver adjustment. By and large, proceedings were made up of shared thoughts and feelings from the previous week's happenings on the home front. Participants made use of a diverse history of shared examples against which they assessed and interpreted individual caregiving experiences. Still, as with the other groups, participants felt the need to understand what was happening to their lives. Answers to questions centered on what they were "going through," were drawn from continuing interpersonal comparisons with little or no overall standard (or model) for evaluation.

This presented a contrasting narrative organization for communicating personal experience, highlighted in caregiver Sally's extended remarks at an evening's meeting. Responding to participants' comments about how it felt when the care receiver failed to recognize the caregiver as a family member, Sally related the story of her own thoughts and feelings. Toward the end of the following extract, note how she even served as a kind of narrative model for herself, as she told herself ("Sal") the inner meaning of the relationship under consideration.

I can't say that it's been the same for me as Violet [another participant]. Of course, you do think about what all this means sometimes. Like this last week, Al [her husband] turned around...just like that...and asked me, "Who are you? What are you doing in here?" It was like I was a stranger in the house or something. God, did that set me back. They say it wakes you up and makes you realize what it's all about. I got scared. I remember how Sara [a participant] reacted when her mother yelled at her about not wanting a stranger running around in the bedroom. I felt like that. How could Al think I was someone else? It was real hard to take. I remembered what Sara said, and it snapped me back a bit. They [AD sufferers] get confused sometimes. They don't know how to express things and so it comes out all twisted around, like they don't know who they are, even. It's not their fault. I remembered that, and that calmed me down a bit, and I thanked Sara for having shared that. [Pause] I think what a person has to do is keep in mind what we've heard from everyone here tonight. Down the road, well, I know if I stand back and think back to myself and what happened, I'll say to myself, "Hold on there, Sal. Remember what happened last week or last month and how it made you feel, and tell yourself how you should feel right now." You learn from experience, all the experiences, and that helps to answer things that keep coming up in your mind, like what's happening to your marriage or if you even have one to speak of...you know, what you owe to each other after all those years.

Conclusion

Drawn from the larger body of narrative material collected in the study, these illustrations offer considerable food for thought concerning the subjectivities of the AD experience.
First, there is the issue of whether we can continue to think about inner worlds as constitutively separate from their diverse social contexts. It is a rather common practice to conceptualize and formulate approaches to inner worlds as if they were principally self-contained entities, even while much has been made of their social shaping and development. Thus, we model "the" caregiver's adjustment and we metaphorically structure or destructure "the" disease sufferer's mind (Gušbrum 1987). Reasonably, given such understandings, we move ahead if we can to help, change, support, or otherwise ameliorate related personal suffering and address, or come to terms with, the mental status of the afflicted. At the same time, it is evident that what we understand and communicate about these inner worlds is narratively organized; what we believe and say are part of the stories we tell about who we and others are, were, and will become. Indeed, stories are the very empirical grist of this knowledge and communication, which, in turn, are constitutively embedded in the varied circumstances of storytelling. The narrative material presented here suggests that inner worlds are as much a part of these circumstances as they are individual experiential entities in their own right.

A second issue relates to the cultural mediation of experience. AD only became a widely shared framework for assigning personal meaning to the cognitive experiences of later life in the 1970s. Narratively, what became a disease experience—as opposed to one of the natural facts of old age—provided a new framework for formulating stories about the inner worlds in question. Such stories were laced with the language of brain failure, progress in treatment, psychosocial adjustment, and other medicalized themes and terms of reference.

This cultural space helped to make AD newly meaningful to those concerned, filling related experience with new kinds of understanding. The affliction, of course, is one thing; its diverse meanings are, in many ways, something else—formulated, organized, and managed through their own distinct dynamic. The social organization of related storytelling that emerged in the late 1970s not only gave experiential birth to a diagnosable experience but also provided variably urgent diagnostic identities for those concerned. In addition to constructing new subjectivities for late life, AD gave the concerned much more to worry about. As the opportunities for telling related stories flourished in a variety of venues, such as support groups, the inner worlds and personal distresses of the disease experience took shape. It is this diverse cultural space that has given narrative presence to the everyday subjectivity of what is ordinarily thought and felt about becoming demented or caring for afflicted persons.

Third, there is the issue of intervention. Producing an inner world with a developmental logic, which Dee's group shared and perpetuated, suggests a considerably different form of intervention strategy than would be implicated by an inner world constructed through continuing interpersonal comparisons, such as in Sally's group. If a general folk model is a recipe for wholesale intervention, these differences move us in rather different directions, fueled by the practical needs of particulars. The narrative materials suggest that both general models and particularized understandings are constructive and narratively conveyed, neither privileging the general nor the particular in everyday understandings of the inner worlds in question. Narrative practice suggests that intervention is best understood in relation to local variations in the cultural space that has developed around the disease experience. These domains—some highly medicalized, others psychosocial, and still others antiprofessional—make distinct forms of intervention phenomenologically sensible and experientially necessary.

It is clear that the sensibilities of intervention will also be constructed in relation to this relatively new cultural space. As such, those concerned will act to transform their inner worlds, perhaps alleviating their related troubles by way of stories of "the gift of touch," "closing the hooks on the shell of a former self," "taking care of the second victim," and "going through all the phases of this thing." In other words, doing something about these inner worlds is itself a set of stories, part and parcel of the narrative opportunities made available in the new cultural space provided by AD in the late 1970s.

**References**


