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# Barriers to the construction of a valued social identity: A case study of Alzheimer's disease

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## Abstract

*This case study describes a person with mild-to-moderate stage Alzheimer's disease (AD) and examines the relationship between malignant positioning and the ability of a person with AD to gain the cooperation of healthy persons to construct a valued social identity. Findings reveal that malignant positioning limited the person with AD to the embarrassing social identity of dysfunctional patient; whereas, the absence of such positioning allowed the subject to gain the cooperation from others necessary to construct a valued social identity, as well as reduce embarrassment and experience greater sense of self-worth. Preliminary recommendations on reducing malignant positioning are provided. Further research is required to elucidate the degree to which the present findings may be generalized.*

*Key words: Alzheimer's disease, dementia, social identity, malignant positioning, psychosocial*

## Introduction

Alzheimer's disease (AD) affects a variety of cognitive abilities such as recall of words and recent events, organizing sequences of voluntary movement, and forming syntactically correct sentences, to name but a few. The behavior of people with AD can be influenced by more than the direct effects of neuropathology. Specifically, the following psychosocial factors significantly affect what the person with AD says and does:

- the reaction of the person with AD to the effects of neuropathology;

- the reaction of healthy persons; and
- the reaction of the person with AD to the ways in which others treat him or her.

Among the factors that can exert a negative influence on the experience and behavior of people with AD are malignant positioning<sup>1</sup> and malignant social psychology.<sup>2,3</sup>

## Malignant positioning

In the conversational interactions occurring in the everyday world, people take for themselves, impose on others, and accept or reject positions that make their actions intelligible as social acts.<sup>4</sup> It is through such positions that a person's moral and personal attributes are defined, strengthened, or diluted, and the means by which story lines or narratives about a person are developed and acted upon by others. Likewise, positioning can be understood as a way in which people explain their own behavior as well as that of others. So, to explain a person's behavior in terms that emphasize the person's negative qualities would be to position the person in a malignant way.

Two types of positioning are especially germane to this article: interactive positioning, wherein one person positions another person; and reflexive positioning, wherein a person positions him or herself.<sup>5</sup> In various social interactions, one person might attempt interactive positioning of another, but the second person, for a variety of reasons, does not desire to be positioned as such. The person not only rejects the position but attempts to position him or herself in a more desirable way (reflexive positioning). It is quite common for individuals to accept as well as to reject positions vis á vis others.

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However, the social situations confronted by people with AD are quite different. They become extremely vulnerable with regard to aspects of their personhood, especially their social identities, because social identity is constructed only with the cooperation of others. For example, a person cannot construct the social identity of a devoted spouse if one's husband or wife does not recognize the person as being his or her spouse. So, if a person with AD who has word-finding problems cannot reject the way he or she is being positioned negatively, that person will be seen in a negative light by others and will not be able to construct a valued social identity; he or she will be limited to the social identity of the dysfunctional patient.

## Malignant social psychology

Malignant social psychology is a term coined by Kitwood<sup>2</sup> and Kitwood and Bredin<sup>3</sup> to describe the ways in which healthy others innocently treat people with AD in depersonalizing ways that diminish their feelings of self-worth. For example, talking about the person with AD as if that person were not present is a form of malignant social psychology called ignoring; speaking to the person with AD in a sing-song way, as if the person were a child, is a form of malignant social psychology called infantilization. If the person with AD reacts with anger in response to being treated in the above ways, and the healthy person views that anger as irrational hostility, the healthy person exhibits another form of malignant social psychology called labeling.

This case study shows how malignant positioning can negatively affect the ways in which persons with AD are seen by others, how they are treated (malignant social psychology), and how they evaluate their own self-worth. Furthermore, as the person with AD is positioned in malignant ways, the ability to reposition him or herself in positive ways can, to some extent, be compromised by 1) deficit-based views held about him or her by healthy persons, and 2) the inability of the person with AD to reject the initial positioning as a result of word-finding and other linguistic problems and the ever-growing sense of a loss of control in social situations. Taking this line of thinking a step further, when a person with AD is positioned malignantly by others, that person's ability to construct valued, worthy, social identities is likewise compromised because the person with AD will receive cooperation from others only in the construction of a social identity such as the "Alzheimer's patient" or the "burdensome, dysfunctional patient." A social identity such as this can be, and often is, anathema to that person, serves to compound his or her feelings of loss, and can cause embarrassment and humiliation.

Previous case studies<sup>6-10</sup> have revealed that people with AD in the moderate-to-severe stages of the disease are vulnerable to losing the ability to construct worthy social identities for precisely these reasons, but that they can, with the cooperation of healthy persons, still construct valued, positive social identities despite their losses in cognitive function as measured by standard neuropsychological tests. This case study differs from previous ones in that it concerns a person in the mild-to-moderate stage of AD. The purpose of the case study is to show: 1) that malignant positioning can, and does, occur, even in the case of a person far less seriously afflicted than those reported in previous studies; 2) the effects of an AD diagnosis and relatively mild signs and symptoms on the ability of a person with AD to gain the cooperation required to construct a valued social identity; 3) attempts of person with mild-to-moderate AD to overcome malignant positioning and, subsequently, gain some cooperation needed to construct a positive social identity; and 4) formal as well as informal caregivers can be more beneficial, positive, and supportive of people with AD in the mild-to-moderate stages.

When healthy persons refrain from engaging in malignant positioning of the person with AD in the early stages of the disease, the degree to which the person with AD experiences a loss of control, humiliation, embarrassment, and other losses can be ameliorated. As a result, the person's remaining intact cognitive abilities may be sustained for a longer period of time than might otherwise be the case. Enhanced sensitivity to and understanding of the aforementioned issues can simultaneously ease the anxiety and stress experienced by all concerned and thereby facilitate functional behavior and enhance communication. It must be understood at the outset that malignant positioning is something that is done quite innocently by healthy persons and is often rooted in incorrect assumptions about the remaining abilities of the person with AD. Eliminating those incorrect assumptions may help to reduce malignant positioning.

For example, caregivers could incorrectly (malignantly) position the person with AD as having no memory of recent events and innocently treat that person such that he or she feels embarrassed or humiliated. Subsequently, the person with AD reacts with anger. If the caregivers interpret the anger as irrational hostility rather than righteous indignation, they compound the original problem of malignant positioning. Instances such as this and others have been reported among people with AD in the moderate-to-severe stages,<sup>1</sup> but the origins of these dynamics may be found to exist in earlier stages of the disease as indicated in the present study.

On the basis of a single case study, we do not generalize to other people with AD. However, the present case may

be representative of others. Only further research will illuminate the degree to which this case can be generalized.

## The case of Mrs. E.

### *Her condition*

At the time of our association, Mrs. E. was 81 years-old diagnosed with probable AD according to NINCDS-ADRDA criteria<sup>11</sup> one year earlier but had been experiencing memory problems from the time before her husband's death 1-1/2 years before that. After her husband's death, her adult children found her to be very confused, suffering from memory problems, and in need of supervision. They moved her from her New England home of many years to the mid-Atlantic area to live with her daughter and son-in-law. Mrs. E. became a participant at an adult day center five days per week because, according to the records, she suffered from social isolation, lack of family support, and had a potential for wandering. A CT scan of her brain revealed mild cerebral atrophy. Medical evaluation indicated that she was capable of dressing, bathing, mobility, eating, and using the bathroom without assistance, while requiring general supervision and assistance. She was reported to have misplaced objects of value, to retain little of the material in books she read, and to have difficulty in recalling the names of her children. She was found to be disoriented in regards to the date and day of the week but not to season and place and was assessed as being in the mild-to-moderate stage.<sup>12</sup> At the time of our association, Mrs. E. was taking Aricept<sup>®</sup> to enhance her cognitive functions and Imipramine<sup>®</sup> for depression and anxiety but was not considered capable of managing her own medications. Mrs. E. spoke fluently with infrequent word-finding problems and was aware that she had a memory problem as evidenced by her saying, "My mind's messed up" when she wasn't able to recall the answers to questions. When asked what her daughter did for a living, she replied, "I don't know. Something important. She works for a big company, I guess." Similarly, she was unable to state specifically where she lived (saying, "nearby"), and often repeated statements or retold the same story within a short period of time without apparent awareness that she was repeating herself, suggesting further that her explicit recall of recent events was somewhat compromised. During World War II, she was a pilot in the Women's Air Force Service and flew bomber-type aircraft. In her hometown, before her husband died, she had been a high-ranking law enforcement officer and instituted programs in safety awareness for children in kindergarten through third grade in the local school system. She also drove a locomotive, managed the affairs of

her husband, a corporate executive who traveled internationally, raised three children, and was a homemaker. Mrs. E. and the children often accompanied Mr. E. on his business travels.

## Malignant positioning and malignant social psychology

In the following sections, instances of malignant positioning and malignant social psychology are recounted and interspersed with information gleaned from interviews with Mrs. E.'s primary caregiver, her daughter, as well as observations of Mrs. E.'s behavior and verbal reports to illustrate: 1) the basis of malignant positioning, 2) its relationship to malignant social psychology, and 3) how Mrs. E. reacted. Each instance of malignant positioning is followed by a brief commentary, which shows that the behavior used to position Mrs. E. in malignant ways could be viewed as appropriate for the situation in question and therefore not dysfunctional. The purpose of the commentaries should not be construed as prosecutorial but rather as illustrative of the possibility that nonmalignant positioning may be logical given the circumstances.

### *Example 1*

Malignant positioning, in this case, seems to have originated with Mrs. E.'s diagnosis and her related problems with retrieving information from memory via recall but was exacerbated by her daughter's innocent misunderstandings and misinterpretations of some of Mrs. E.'s behavior. In an interview, the daughter positioned her mother by saying that Mrs. E. "has no attention span" because she "probably could not carry out" the following hypothetical sequence of events: "If she looked in her refrigerator and saw that she needed food, she might not be able to go to the supermarket and remember which items to purchase."

### *Commentary*

If Mrs. E. were unable to remember which items to purchase in this situation, the problem might have nothing to do with her ability to pay sustained attention, but rather with her ability to recall which items to purchase, although she might have been able to recognize which items to buy upon seeing them. To return to the issue of Mrs. E.'s attention span, over a period of four months of our association with Mrs. E., she demonstrated a well-developed ability to carry on coherent conversations that required sustained attention and intact working memory.<sup>13</sup> In addition, Mrs. E.'s daughter recounted how

her mother would talk during the dinner meal about the day's events at the day center if "something memorable happened." For example, Mrs. E. recounted that, on a particular day, a man came to the day center and played music. He said hello to Mrs. E. when she entered the room, asked for her name, and then played an old song that had Mrs. E.'s first name in the title. The dinner conversation occurred more than three hours after Mrs. E. returned home from the day center. Recounting the episode required not only intact memory functions (including encoding, storage, and retrieval) but also the ability to focus and hold her attention on the event in question when it first occurred. Finally, in regards to the daughter's comment about going to the supermarket, there is another important issue to consider: most people make lists of things they need before going food shopping precisely because they know that they will fail to recall some items in the absence of the reminder. Thus, one could plausibly argue that the example used incorrectly to illustrate her mother's "lack of attention span" was, itself, something that could be said about people who don't have an AD diagnosis.

### *Example 2*

In the same interview, Mrs. E.'s daughter commented that her mother "had a problem with the concept of time" and illustrated this by recounting that two months in advance of an upcoming wedding, Mrs. E. was worrying about buying a dress for the occasion.

### *Commentary*

In the absence of the initial malignant positioning, one could offer a very different interpretation of this scenario. That is, one could say, quite reasonably, that Mrs. E. engaged in higher order executive (frontal-lobe-based) functioning by displaying the appropriate ability to plan ahead. Given past experience in finding attire for a special occasion, Mrs. E. was not content to wait until, what was for her, "the last minute." After all, one must first find a dress and then the dress might require alterations, both of which could take substantial time. As a result of malignant positioning, this example of what might be viewed as being appropriate and healthy behavior was explained in dysfunctional terms—that Mrs. E. "had a problem with the concept of time."

### *Example 3*

Mrs. E. expressed a desire to learn Spanish from a teacher rather than by listening to tape-recorded lessons. In discussing her mother's preference, Mrs. E.'s daughter

explained that Mrs. E. "has a lot of trouble learning," thereby positioning her mother in a negative way.

### *Commentary*

Even if one were to grant that Mrs. E. had a lot of trouble learning, an examination of the larger context of Mrs. E.'s life reveals evidence that supports positive, rather than malignant, positioning. According to her file at the day center, Mrs. E. was experiencing "social isolation" and "lack of family support." Given her history of being highly involved with people and socially relevant causes and given that she now suffered "social isolation," it would seem logical that Mrs. E. would prefer learning Spanish from a person as opposed to using tapes, for the person (teacher) would provide her with social interaction that she clearly lacked but strongly desired. This latter form of positioning emphasizes a healthy and appropriate form of goal-directed behavior that is geared to alleviate a real and troublesome lack. Given the initial malignant way in which she had positioned her mother, Mrs. E.'s daughter developed a story line that emphasized dysfunction to explain her mother's preference. That Mrs. E. enjoyed and sought out social interaction with others was made clear in her interactions with many people at the day center.

### The problem of constructing a valued social identity

Malignant positioning can lead to a series of social interactions that can prevent a person with AD from constructing a valued, worthy social identity or persona. Constructing a social identity requires the cooperation of at least one other person.<sup>4,5</sup> The problem is compounded when a person diagnosed with AD is radically misunderstood by caregivers, who describe instances of healthy behavior as dysfunctional. As a result, the person with AD is confined to the social identity of "dysfunctional AD patient" or "dysfunctional day center participant," both of which may be anathema to him or her and a source of embarrassment. Such were the circumstances in the case of Mrs. E.

Mrs. E.'s social identity during the decades prior to her being widowed and diagnosed with probable AD could be said to include the following: she was the "take-charge organizer" and "energetic, devoted helper" in relation to her husband's work; "spouse-mother-homemaker" in relation to her husband, her children, and the family household; and "independent, individualistic career woman" in terms of work history. She made vocational choices that were exceptional for women of her time. She was, in many ways, a trailblazer which

required nothing less than a strong will, highly developed cognitive abilities, and courage. She reveled in being recognized for her accomplishments and wanted very much to maintain her social identity to the greatest extent possible. After her diagnosis, she was no longer a pilot, a high-ranking law enforcement officer, a locomotive engine driver, the organizer of her husband's life, or homemaker for a family. Still, all of these social personae were part of the life she lived for decades and reflected long-held qualities and beliefs she still possessed. As a result, Mrs. E. wanted to be treated with the respect and deference rightfully due to a woman of considerable substance and achievement, in spite of her diagnosis. Thus, it could be said that she possessed proper pride and self-respect, which have been categorized as "indicators of relative well-being."<sup>3</sup>

### The construction of a social identity at home

The social dynamics at home did not provide her with the cooperation necessary to construct and maintain her identity. For example, a hired aide picked out her clothes for her each day even though she was capable of making those decisions herself. This is an example of "malignant social psychology" in the form of disempowerment,<sup>2,3</sup> which resulted in a restricted sense of self-expression. Mrs. E. was always well dressed when she was at the day center, usually wearing wool-blend casual trousers, a colorful top, and often a scarf around her neck. One day, however, she was wearing khaki trousers and said, "It's a good thing that (her daughter) didn't see me go out with these on. She'd say, 'Mother, you go upstairs and put something presentable on'." It should be noted that the khaki trousers that Mrs. E. was wearing were quite presentable and that this sort of response, if made by her daughter, would convey a message that Mrs. E. was akin to a child rather than an autonomous adult and would constitute another form of malignant social psychology called infantilization.<sup>2,3</sup>

Perhaps the greatest challenge to Mrs. E.'s ability to construct a valued social identity at home was the behavior of the professional aides hired by her daughter. The aides' purpose, as explained by the daughter, was to do things with Mrs. E. As a result, the daughter referred to the aides as companions, reflecting a sincere sensitivity. The people hired to be companions were usually nurse's aides who were accustomed to tending to someone who was not nearly as independent or as cognitively able as Mrs. E. Consequently, they were used to being in charge of, as opposed to being a companion to, someone. From the daughter's point of view, though, if Mrs. E. wanted to go for a walk or clean the house, the companion should

walk or clean with her. Mrs. E., however, referred to the aide as a "baby sitter," suggesting that she found the aide's presence demeaning. Mrs. E. had at least one emotionally charged confrontation with a previous aide and reported another with the present aide, as well. Both confrontations occurred when the aide refused to do something that Mrs. E. directed her to do, such as light cleaning or taking a walk with her. The aide remarked, "I'm in charge, not you."

Mrs. E. did not mistake the aides for domestic help: she referred to the aides as "baby sitters" and, in fact, "baby sitters" are "in charge." Mrs. E. asked the aide to take a walk with her and the aide refused. Mrs. E.'s exasperated reaction toward the aide (she threw her purse on the floor according to the aide) can be interpreted as appropriate frustration as well as an attempt to reposition herself vis-à-vis the aide, who acted as if she were there to watch over Mrs. E., thus demeaning and disempowering her. By trying to reposition herself as the lady of the house, Mrs. E. tried to assume a senior position (being in charge) relative to the aide and regain what she saw as her rightful social identity and place. The aide, however, was not cooperating with Mrs. E. in this dynamic and Mrs. E. could not, therefore, construct the social identity that she desired. Insofar as the aides were concerned, they were dealing with a person whose social identity was restricted to "AD patient" of whom they were "in charge." Their explanation of Mrs. E.'s frustrated reaction as being "irrational hostility" reflected their malignant positioning of her.

### The construction of a social identity at the day center

Upon meeting Mrs. E. at the day center for the first time, the authors were struck immediately by her warm, open, energetic, and welcoming personality; she would initiate social contact (an "indicator of relative well-being") and introduce herself. Part of the first conversations she had with a number of volunteers as well as with student interns included her recounting stories about having flown planes during WW II, having been a high-ranking law enforcement officer in her hometown, and having driven a locomotive. It is in the dynamics of these initial encounters that one may become sensitized to the way in which malignant positioning can come into being simply as a result of the setting in which one meets a person.

Upon hearing Mrs. E. talk about her various jobs, many of the student interns as well as some volunteers at the day center reacted with skepticism. Given that she was elderly, that she evidenced some recall problems and was attending an adult day center where many participants had been diagnosed with dementia, many interns

and volunteers thought that Mrs. E. was delusional or confused. In what might be construed as evidence of her awareness of the skeptical reactions of her interlocutors as well as an initial attempt to reposition herself, she commented to a few of the interns, "You'd be surprised at the knowledge some of these people have despite their incapacities." This was her first attempt at repositioning herself (as well as other participants), but her second attempt was perhaps the most telling.

During the following week and for a few weeks thereafter, Mrs. E. brought in a series of photographs taken of her when she was a pilot during WW II, when she was a uniformed policewoman, and when she was driving a locomotive. Perhaps she had sensed her interlocutors' incredulity and realized that proof was required, perhaps not, but she did nonetheless manage, as a result of showing the photographs: 1) to dispel the skepticism that existed regarding her autobiographical stories, and 2) to garner the cooperation she needed from others to construct a social identity more in keeping with her wishes. Approximately one month later, she no longer brought the photographs with her to the day center, which might be interpreted as reflecting her assessment that she had, indeed, succeeded in receiving the cooperation she needed in order to construct the worthy, valued social persona that she so fervently desired. Her efforts to construct a valued social identity did not end at this point, however, but it was necessary for her first to establish a social identity based upon her significant accomplishments in decades past rather than solely upon her diagnosis and presence at the day center.

Mrs. E. then began to bring and display prominently on the tables before her, books, correspondence, or Spanish language tapes, "because I often get bored here." With these displays, Mrs. E. signaled to others that she was someone who had varied interests, including learning a foreign language, friends with whom she communicated, and that she was a person who enjoyed reading and learning. As she said, "You know, I have to be active; I need to be busy learning. I have been learning all my life." Here she was attempting to reposition herself in the eyes of others by: 1) differentiating herself further from being "the AD-patient-day-center participant," and 2) showing that what she was doing at the present time was consonant with the way she had lived in healthier days. Thus, she was positioning herself as someone who was productive and interested in pursuing healthy, socially valued activities each of which (reading, writing, learning) entailed the use of higher order cognitive functions.

It is not surprising that Mrs. E. would work to reposition herself in the eyes of others and eventually succeed in gaining the cooperation she required to construct a

worthy social identity given that she was in the mild-to-moderate stage of AD. What is noteworthy in her case is that, even though she was only mildly to moderately affected by AD, she still had to work diligently to reposition herself in the first place because she was already being positioned in a negative way by others and limited by the social identity of "dysfunctional AD patient."

Mrs. E. was quite open about her problems with memory, acknowledging them on several occasions, thus displaying prominently that she was aware of her difficulty and was not in denial. For example, when she couldn't recall the name of another participant (although she correctly recognized the person as being someone she knew from the day center), she said, "My brain doesn't work the way it used to. I can't remember her name, but we are here together every morning." At the same time, however, she did not want her social identity to be based solely on this dysfunctional attribute. To create a valued social identity at the day center, she needed the cooperation of others. Having established herself as a person of accomplishment in the past, she wanted to build on that and be seen as someone of estimable qualities in the present. Thus, she brought evidence of her present cognitive abilities and interests.

### Differentiating herself from other participants

Instead of participating with the rest of the group in activities she found lacking, such as exercise classes, she preferred to engage student interns including two of the present authors: "I don't want to go to that exercise class. Let's you and me go for a walk. I prefer to forego exercise. I find it silly and belittling." She proceeded to mimic the exercise leader by touching her head and shoulders repeatedly and then explained that by walking she was getting better exercise than she would in the class. In this and in other respects, she continued to work to construct a social identity of "being independent" and differentiate herself from the other participants. In yet another example of her attempts to differentiate herself from other participants, when she was invited to join a group discussion, she refused and commented to one of the authors, "That's where people talk about their problems. I don't have any problems of their kind; we are lucky."

In relation to the student interns, Mrs. E. presented herself as a "source of advice and support," thus continuing to behave in ways consistent with her past behavior toward young people (she served as a mentor to adolescents in her hometown in previous years). She expressed concern about how and when the students would eat lunch while at the day center and gave them advice about

their futures. When a few of the student interns were discussing graduate schools and various difficulties with the admissions process, Mrs. E. quickly added, "My husband had degrees from Harvard, Yale, and Princeton, and my daughter has at least two from Harvard," thus aligning herself with the group of "accomplished academics." When one of the student interns was discussing some of her trepidations about gaining admission to elite graduate programs, Mrs. E. tried to ease the student's mind by saying, "You know, I just went to a state school. You don't need all of those degrees to do the kinds of things that I did." In saying this to the student, Mrs. E. was attempting to convey that people could attain a measure of success in life even if they did not attend one of the most prestigious graduate schools. The students cooperated with her to allow her to construct a social identity that was consonant with her desires and abilities and, in so doing, benefited from her experience and encouragement.

Likewise, Mrs. E. tried to help other participants during particular activities, such as art classes, in which she herself encountered few problems, completing the projects quickly. During these activities, she would glance around the table to make sure that other participants could complete the task at hand and provided assistance if needed. Many of the participants became frustrated at times and simply could not complete the projects, but Mrs. E. noticed this (due in part to her intact ability to focus her attention for a sustained period of time) and attempted to provide support. When it was clear that someone could not complete the project at all, she would diminish the significance of the project by saying, "These things don't matter; they are so silly anyway."

At times, however, her attempts to be helpful to other participants were misunderstood by some staff members who thought that Mrs. E. was trying to take over and "run the show." As she put it, "Perhaps they are angry with me for trying to be anything more than a participant...between you and me, I do so many of the leadership roles around here...you know, I am really just like a volunteer here. Because my son-in-law and daughter work all day, I have decided to come and help out with things. I have been doing these things all my life." She commented that "the worst part about getting old" was that people don't let her do things that she used to do because they no longer believe her to be capable. Despite her stated desire to be helpful to the staff at the day center, she had not been called upon frequently to perform any duties, such as setting the tables before the lunch meal or clearing them afterward, both of which she was more than capable of doing, given that she did these sorts of things at home. In fact, before she began to attend the day center regularly, it was her hope, and that of her daughter, that Mrs. E. could indeed serve as a volunteer

there. In spite of the fact that she was not given that opportunity, Mrs. E. wished to differentiate herself from the rest of the participants. That is, she wanted to construct a social identity that would not be a source of embarrassment to her but, rather, one in which she could take pride. In this quest, however, she achieved only mixed results.

## Summary

One of the major psychosocial problems confronting Mrs. E. was the malignant positioning to which she was subjected. Malignant positioning had its origins in the effects of neuropathology, such as problems with the recall of recent events. Explanations of her behavior that were based on dysfunction were then extended to abilities that were not compromised and many instances of her healthy behavior were explained in dysfunctional terms. In other words, through this sort of malignant interactive positioning, some of Mrs. E.'s worthy remaining cognitive abilities were misinterpreted or not seen at all. As Snyder<sup>14</sup> commented about one of her clients with AD, "Despite her verbal abilities, she became more defined by her impairments and less validated by her capacities." In the present case study, the problem of malignant positioning extends beyond the effects of neuropathology:

1. Neuropathology problems were innocently mislabeled (Mrs. E.'s recall problems were misconstrued as being problems in sustaining attention).
2. Intact, appropriate, valued abilities possessed by Mrs. E. and seen in otherwise healthy people were explained as being species of dysfunction (Mrs. E. had "problems with the concept of time" rather than the ability to plan ahead).
3. Mrs. E. was often treated as if many of her remaining worthy abilities either did not exist or were hopelessly compromised (e.g., she was not called upon by day center staff members to provide assistance when and where she was able).
4. She was, to a significant degree, thereby confined to a social identity that was based upon her diagnosis and emphasized attributes that were sources of shame and humiliation.
5. To the extent that Mrs. E. could not reject the malignant positioning and reposition herself, she did not gain the necessary cooperation from others (who had positioned her in malignant ways) to construct a valued, worthy, social identity.

Malignant positioning can serve as a springboard for malignant social psychology, wherein the person is treated in ways that ultimately result in depersonalization. For example, if healthy persons position the person with AD as having “no attention span,” or as one who “can’t remember anything,” they are more likely to disempower the person with AD, or talk amongst themselves as if the person with AD is not there, even though the person in question is present and can, in fact, understand and be hurt by what is being said and how he or she is being treated. This dynamic deepens his or her feelings of embarrassment, shame, and depression.

The present case reveals the degree to which one or two neuropathology (AD related) dysfunctions (mainly some deficits in recall of recent events and mild cortical atrophy) can lead to powerful malignant positioning. Mrs. E had a plethora of remaining intact cognitive and social abilities: she spoke fluently with infrequent word-finding problems, formulated syntactically correct sentences, was able to dress and feed herself as well as take care of personal hygiene without assistance, could plan ahead for future events, initiated social contact with people, was sensitive to the needs of others, and sought to provide help to other day center participants, even telling staff members, “If you need help with anything, let me know.” At home, she emptied the dishwasher, prepared vegetables to be cooked for dinner, and brought in the newspaper in the morning. Still, she had to work quite diligently to reposition herself as capable to gain the cooperation she needed to construct a worthy social identity instead of the imposed identity of “dysfunctional AD patient and day center participant” that she found insulting and distasteful.

## Recommendations

Although Mrs. E. was successful in constructing a social identity that was consonant with her long-cherished and well-developed inclinations and abilities as well as her present intact abilities, that success occurred to a far greater degree with student interns and the authors than it did with the staff members at the adult day center she attended. The relative absence of malignant positioning was related to the greater degree of cooperation that Mrs. E. was able to gain from the interns and authors than from the staff.

It is clear that many caregivers radically misunderstood Mrs. E. How might such a radical misunderstanding be redressed or even prevented? The following are some initial, but hardly exhaustive, recommendations:

1. It is necessary for practitioners and other formal caregivers to be very clear about the dysfunction caused by neuropathology. It is important,

for example, to differentiate between problems of “recall” and problems of “memory” or “attention.” It is possible for a person to have deficits with recall but not with other forms of retrieval from memory, such as recognition and implicit memory.<sup>15</sup> Implicit memory is a change in a person’s behavior as a result of prior experience that the person may not be consciously aware of having had. If a person had completely defective recall abilities, that fact would not mean that the person had “no memory functions whatsoever” or “can’t learn anything new.” If such a person, after repeatedly being shown where the restroom is at a day center, seems to be able to find the restroom on his or her own, there are clearly (at least implicit) memory functions still working. Such a person can still be emotionally reactive to people even if the person cannot recall exactly why the emotional reaction is occurring. In addition, if the person can, as Mrs. E. did, recount significant events that occurred at the day center hours earlier, she cannot be said to have “no attention span.”

2. Formal and informal caregivers should ask themselves the question: If a person who didn’t have a diagnosis of probable AD behaved in this way, would it be correct to characterize that behavior as being defective or pathological? For example, Mrs. E. wanted to look for a dress for a wedding two months in advance. Do people without AD do this sort of thing? If the answer is yes, then her planning ahead should not be interpreted as a defect, but, rather, as a strength. This is especially true if the person in question has a history of taking action. The same logic applies to a person’s wish not to be defined principally in terms of his or her foibles, faults, or deficits.

3. It is important to invoke the idea of “giving the benefit of the doubt” when reacting to what the person with AD says about his or her experiences. Volunteers and student interns were highly skeptical about Mrs. E.’s stories of her past experiences primarily because of her diagnosis and her presence at the adult day center. If any of those individuals met Mrs. E. at a reception and heard the same stories and were unaware of her diagnosis, none would assume that she was delusional or confused. It is extremely important to verify information before negatively (malignantly) positioning the person with AD and then treating the person on that basis.



4. If a person with AD refuses to be positioned negatively (as Mrs. E. did not want to be seen as being part of the larger group of day center participants), the refusal itself and the manner in which it is expressed should not be interpreted as dysfunctional; that is, the person should not be characterized as being “uncooperative” or “obstinate” or “aloof.” Rather, that person should be seen as expressing pride and self-respect,<sup>3</sup> both of which might be tapped to the advantage of others. Mrs. E.’s ability to sympathize with and provide support for participants and her ability to do such things as set and clear tables could have been used to great advantage. In addition, it would have helped her construct a valued social identity in which she could have taken pride.

5. The person with AD in the mild-to-moderate stages must not be assumed to be as disabled as might be supposed on the basis of standard clinical evaluation and testing because these assessments do not tap a host of higher cognitive functions that might be intact.<sup>1,6-9,15,16</sup> Mrs. E. suffered social isolation as a result of the loss of her husband and her relocation to her daughter’s home several hundred miles from her home of many decades. She had a history of being deeply involved in her community and was clearly a service-oriented person who had a great deal of experience organizing details and chores. As a consummately social person, a “helper and giver” by nature, she retained those dispositions and motivations, as well as the need to manifest them in her social world. It must be assumed, until proven otherwise, that she is capable of carrying them out some way if given the opportunity. Thus, persons like Mrs. E. must be given cooperation by formal and informal caregivers to construct positive social identities and thereby experience enhanced feelings of self-worth. However, this process requires the relative

absence of malignant positioning in the first place. To do otherwise would be to rub salt into an already existing wound, to the detriment of the person with AD as well as to his or her formal and informal caregivers.

## References

1. Sabat SR: *The Experience of Alzheimer’s Disease: Life Through a Tangled Veil*. Oxford: Blackwell, 2001.
2. Kitwood T: Toward a theory of dementia care: Ethics and interaction. *J Clin Ethics*. 1998; 9(1): 23-34.
3. Kitwood T, Bredin K: Towards a theory of dementia care: Personhood and well-being. *Ageing Soc*. 1992; 12(92): 269-287.
4. van Langenhove L, Harré R: Introducing positioning theory. In Harré R, van Langenhove L (eds.): *Positioning Theory*. Blackwell: Oxford, 1999.
5. Davies B, Harré R: Positioning and personhood. In Harré R, van Langenhove L (eds.): *Positioning Theory*. Blackwell: Oxford, 1999.
6. Sabat SR: Excess disability and malignant social psychology: A case study of Alzheimer’s disease. *J Community Appl Soc Psychol*. 1994; 4(3): 157-166.
7. Sabat SR: Recognizing and working with remaining abilities: Toward improving the care of Alzheimer’s disease sufferers. *Am J Alzheimers Care Rel Disord Res*. 1994; 9(3): 8-16.
8. Sabat SR, Collins M: Intact social, cognitive ability, and selfhood: A case study of Alzheimer’s disease. *Am J Alzheimers Dis Other Demen*. 1999; 14(1): 11-19.
9. Sabat SR: Surviving manifestations of selfhood in Alzheimer’s disease: A case study. *Dementia: Int J Soc Res and Pract*. 2002; 1(1): 25-36.
10. Sabat SR, Harré R: The construction and deconstruction of self in Alzheimer’s disease. *Ageing Soc*. 1992; 12(4): 443-461.
11. McKhann G, Drachman D, Folstein M, et al.: Clinical diagnosis of Alzheimer’s disease: Report of the NINCDS-ADRDA work group under the auspices of the Department of Health and Human Services task force on Alzheimer’s disease. *Neurology*. 1984; 34(7): 939-944.
12. Reisberg B, Borenstein J, Salob S, et al.: Behavioral symptoms in Alzheimer’s disease: Phenomenology and treatment. *J Clin Psychiatry*. 1987; 48S: 9-15.
13. Baddeley AD, Hitch GJ: Developments in the concept of working memory. *Neuropsychology*. 1994; 8(4): 485-493.
14. Snyder L: *Speaking Our Minds: Personal Reflections from Individuals with Alzheimer’s*. New York: Freeman and Co., 1999.
15. Knopman DS, Nissen MJ: Implicit learning in patients with probable Alzheimer’s disease. *Neurology*. 1987; 37(5): 784-788.
16. Temple V, Sabat SR, Kroger R: Intact use of politeness strategies in the discourse of Alzheimer’s disease sufferers. *Lang Commun*. 1999; 19: 163-180.