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**The Person We Knew:
Perceptions of the Identity of Loved Ones With Dementia by Family Caregivers**

Amber Jannusch & Dena Huisman

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ABSTRACT

While several studies have looked at the identity of dementia patients, most focus on the point of the view of the patient. However, caretakers' and family members' view of the identity of the dementia patient is unstudied. This study attempts to see how family caregivers' view of their family member's dementia manifests in communication about the loved one. This study is a preliminary examination of family caregivers' constructions of the identity of their loved one, revealing that caretakers have one of three views: the patient without an identity, the patient as a different person, or the patient as "not lost" or gone. Caregivers' interpretation of the loved one's identity was seen in how the patient was discussed and treated.

Keywords: Dementia, family communication, health communication, caretaker communication, identity and communication

Introduction

Alzheimer's Disease and related dementia illnesses affect approximately 6.8 million Americans (National Institute of Neurological Disorders and Stroke (NINDS), 2009). People with dementia suffer from a decreasing ability to speak, understand, and retain information, including long-established relationships (Alzheimer's Association, 2010). While most studies of dementia focus on the perspective of the patient, this study argues for a more systems-oriented approach to understanding how partners and caretakers understand their partner's changed identity as a dementia sufferer. According to family systems theory, a change in one member is a change for all, which means that these changes in a person suffering from dementia must affect that person's family member as well (Galvin, Dickson, & Marrow, 2006). To examine how the family understands his study examines the ways in which family understanding of the identity of the dementia sufferer factors into their family relationship.

Literature Review

Dementia is not a specific disease, but rather an umbrella term for the symptoms caused by a number of disorders, diseases and conditions that damage brain cells. In addition to a decline in memory, to be classified as dementia, there must also be decline in at least one of the following categories: 1) the ability to generate coherent speech or understand language; 2) the ability to recognize or identify objects; 3) the ability to execute motor activities despite sufficient ability; or 4) the ability to think abstractly or plan and carry out complex tasks (Alzheimer's Association, 2010). The United States Office of Technology Assessment estimates that approximately 6.8 million Americans have dementia, and at least 1.8 million are severely affected (NINDS, 2009). The most common type of dementia, affecting 5.3 million Americans and accounting for an estimated 60-80 percent of cases, is Alzheimer's disease. While different types of dementia have a variety of typical characteristics, most (including vascular dementia and Parkinson's induced dementia) share characteristics with and following a similar pattern of decline to Alzheimer's Disease (Alzheimer's Association, 2010).

Unlike many other illnesses, communication impairment is inherent in dementia (Bayles et al., 1987; Byrne & Orange, 2005a, 2005b), and caregivers notice communication difficulties at early stages in the disease (Byrne & Orange, 2005b). Patients with dementia have difficulty both in communicating needs and in understanding what is being communicated to them. They have some difficulty understanding factual material, and even more significant problems understanding inferential material (Biassou, Onishi, Grossman & D'Esposito, 1995). Alzheimer's Disease researchers have found that patients with AD may understand main ideas but not details, and so encourage caregivers to refer back often to a main idea of a conversation, rather than providing more detailed information (Welland, Lubinski & Higginbotham, 2002). However, Orange (1995) found in his interviews with family caregivers of Alzheimer's patients that communication impairment had a significant effect not just on the dementia patient, but also on the caregiver, who reported common feelings of frustration, loneliness, guilt, embarrassment and isolation, which in turn may affect the caregiver's self-image.

Dementia Patient Identity in Relationships

Patients with dementia exhibit significant behavioral problems, caused by internal and external confusion, excess noise or situational unfamiliarity. These behavioral problems manifest through acting out, depressive episodes, or paranoia. The reduction in basic abilities as well as the change in typical behavior make it seem to the family caregiver as if the patient is no longer the person he or she once was (Baxter, Braithwaite, Golish & Olson, 2002; Gillies and Johnston, 2004). In fact, "those involved in the care of individuals who have [dementia] routinely describe a change in the person's very 'identity'" (Gillies & Johnson, 2004, p. 439). This identity change is twofold: first, there is a daily inability to perform as one did previously, and second, there is an inability to understand what is going on, to know who one is or where one is. The former of these reflects directly on a personal sense of self, and the other as a direct expression of the sense of self.

Further, physical, behavioral, and cognitive changes all play in to the potential perceived identity change by caregivers about the person with dementia (Cohen-Mansfield, Parpura-Gill, & Golander, 2006). One major area where dementia complications have been found is in autobiographical memory. Autobiographical memory is composed of memories, particularly from childhood or early adulthood, which people rely on to give strength and quality to their identity, enabling integration of past and present selves and continuity of identity (Addis & Tippett, 2004). Addis and Tippett examined autobiographical memory of patients with Alzheimer's by administering a test of autobiographical memory and two tests of identity. They found that people with AD have impaired autobiographical memory and accompanying changes in their own perception of their sense of self.

Despite this, some aspects of self-identity can survive even in cases of severe dementia (Dworkin, 1986). Differentiating between personal identity and social identity, Sabat and Harre (1992) theorized that while social identity, which requires interaction with others, is often lost because of the communicative and cognitive implications of dementia, the personal identity can persist. In testing personal identity indicators in dementia patients, Tappen, Williams, Fishman, and Touhy (1999) found clear indices of personal identity in mid to late stage Alzheimer's patients; these patients responded to their names, referred to themselves in the first person, and observed and discussed their own cognitive changes, all signaling some understanding of their personal concept.

However, personal identity is developed in and through relationships, linking with social identity. Dementia necessarily changes the cognitive and communicative patterns within a family unit. Cohen-Mansfield, Golander, and Amheim (2000) found that the patient's place in the family is a domain of identity most likely to be recalled, but loss of memory prevents sharing of memories with loved ones. Given that joint memory constructs social frameworks and leads to shared attitudes, helping to form a self, the declining ability to develop joint memories or hold on to other social memories impacts the ability to develop a social sense of self.

Sabat (2002) addressed the issue of identity in dementia patients with a social constructionist approach, explaining the interaction of three types of self: the self of personal identity, the self of mental and physical abilities and attributes, and the socially presented self (or selves). Dementia affects all three types to varying degrees and in varying sequential order, implicating the ability of a dementia patient to maintain a sense of identity, and the ability of a caregiver to address a dementia patient in terms of a sense of identity (Shenk, 2005). The personal self is affected through the impairment of autobiographical memory; the mental and physical self is affected by cognitive and accompanying physical limitations; and the socially presented self-suffers from the patient's inability to communicate or share memories and experiences with those around them.

As memory, cognition, and communication decline, family caregivers often observe that their loved one is "not the person s/he used to be." This affects how the family member interacts with the dementia patient. Caregivers may separate from and exclude the patient more, imposing an identity of "sick person" or patient, challenging personhood (Kitwood, 1997) and potentially

leading to “social death” (Sweeting & Gilhooly, 1997). On the other hand, some caregivers try to compensate for dementia impairment by hanging on to their relatives’ previous identity (Gillies & Johnston, 2004), often by calling up everyday memories and rituals (Orona, 1990). In so doing, however, the caregiver may be just as guilty of imposing an identity on the dementia patient in failing to recognize that identity is dynamic and changing.

Ambiguous Loss and Dementia

Dementia is a progressive illness without a cure. As the disease progresses, patients continue to decline mentally, and sometimes physically (Bayles et al., 1987). This results in a “living death” where the person is physically present, but not mentally or emotionally present, something referred to in family communication research as ambiguous loss.

Ambiguous loss refers to the relational disorder that occurs with psychological absence of a loved one in a family who is “there, but not there” (Boss, 2007, p. 105). Ambiguous Loss theory has been applied to caregivers of family members with dementia (Boss, 2010; Boss, Greenburg, & Pearce-McCall, 1990; Garwick, Detzner, & Boss, 1994; Kaplan & Boss, 1999; Thomas, Clement, Hazif-Thomas, & Leger, 2001), though typically with a family systems theory approach (Carroll et al., 2007). Boss (2010) summarized her research on ambiguous loss for caregivers of family members with dementia, explaining the anxiety and depression that coincides with the trauma and inability to have closure:

Unlike death, with ambiguous loss (e.g., dementia or brain injury), the process of bereavement is blocked by an external situation beyond the control of the sufferers. Even the strongest people are immobilized in such situations. Grief therapies are understandably resisted (p. 140).

Because a loved one with dementia is both present *and* absent at the same time, a caregiver is faced with confusion, depression, and loss of hope and meaning from the inability to have closure or finalization (Boss, 2010).

Boss (2010) explained that ambiguous loss further complicates the caregivers’ attempts to find meaning or make sense of what is happening in their lives. Caregivers often become resistant to loss and change and become rigid, rather than becoming more comfortable with ambiguity (Boss, 1999). The behavioral reactions caregivers have to dealing with this ambiguous loss can reflect how the caregiver views the loved one’s identity, seen in the different ways caregivers respond to social identity changes.

Reaction of caregivers

A significant number of patients, particularly those with early- to mid-stage dementia, are cared for primarily by family and friends in the community. In 2009, an estimated 10.9 million Americans, primarily untrained family members, provide unpaid care for a person with dementia, providing in total 12.5 billion hours of care (Alzheimer’s Association, 2010). Thus, a

number of caregivers of patients with dementia are in a position to notice behavioral and personality changes, and are able to compare a patient's current behavior to the patient's previous behavior.

The viewpoint on identity and the actions a caregiver takes has significant impact on the dementia patient. "Identity loss derives from both internal recognition (subjective or experienced) and external reaction, when, for example, family carers change their attitudes and behaviors towards the affected individual (objective and observed)" (Gillies & Johnston, 2004, p. 436). If a caregiver views a loved one with dementia as a different person, he or she may begin to treat that person as an "other," which can lead to what Sweeting and Gilhooly (1997) termed "social death." This happens when an ill person loses his or her social identity through lack of social recognition (Kitwood, 1997). Caregivers in this situation may impose a generic identity of "sick patient" to the loved one, as is often done by caregiving professionals dealing with dementia patients as well as non-cognitively impaired patients (Wilkinson, 1991).

On the other hand, some caregivers refuse to acknowledge identity changes, trying to compensate for the loved one's impairment by clinging to memories and the relative's previous identity (Gillies & Johnston, 2004). Orona (1990) studied identity loss in people with Alzheimer's Disease, as well as the strategies caregivers use to "hang on" to the loved ones. She found that family caregivers use memories to recall and recreate former identities through rituals and re-enactment of special experiences, as well as experiences of everyday living, because "memory keeping appears to have significance for the relative as an acknowledgment of the person 'as before'" (p. 1254). In so doing, however, caregivers focus on the previous identity, rather than understanding and accepting that identity is a fluid concept (Kelly, 1970). The implication of this is that, like the case of the caregiver imposing an identity of "sick person" on the loved one, these caregivers are also imposing an identity, this time of the person they previously knew.

Most of these studies on identity and dementia tended to focus on the identity of the individual with dementia from that individual's point of view, looking at caregivers' behavior only as it is interpreted by the dementia patient. While this is an important area of identity to explore, it neglects to present the perspective of the caregiver. Because identity is socially constructed and because people behave toward another congruent to how they view that person, the caregiver's emic interpretation of their loved ones' identity is important to add to the study of dementia, caregiving and identity.

The exploration of the family caregivers' point of view of their loved one should be multi-faceted. As a preliminary attempt to set the groundwork for further nuanced identity and caregiving studies, this study looks generally at family caregivers' anonymous reports of whether they think their loved one is "the same" or "different" and what that means, as well as what the caregivers generally conceptualize as the patient's "new" identity. Thus:

RQ: How do family members of individuals with dementia view their loved one's current identity as a dementia patient?

Method

Because the goal of this study is to explore identity considerations by caregivers, we used an interpretive framework in search of the caregiver's unprompted perspective. To explore caregivers' perspectives, we accessed the public message boards of the Alzheimer's Association Online to find mention of identity concerns. This website provides a forum for anonymous comments to and from caregivers for people with Alzheimer's Disease and other forms of dementia, giving an opportunity for caregivers to share their frustrations and techniques without the threat of social desirability biasing their answers (Fisher, 1993). For the purposes of this study, we examined the Caregivers Forum, with over 250,000 posts on a wide variety of issues, and a forum specifically for spouses or partners who are caregivers, which contained over 2000 posts. We started with a list of potentially relevant words and themes from prior research (as stated in the literature review), including "identity," "loss," "changed," and "personality" in various combinations. Including the original topic post and all responses to that post, we collected 44 posts, totaling 20 pages, from 31 caregivers, that contained these words.

We then coded analytically, following Miles and Huberman's (1994) outline of qualitative data analysis. This involved highlighting all specific references in the data, then inductively coding for themes or patterns of similarity in how the poster framed the identity of the patient as a family member and individual. From there we organized our coded data into coherent themes. We continued to revise the codes within each category to determine whether all instances were similar enough to be grouped or to be separated into separate codes or subcategories. We found enough commonality not to require further categorizing, resulting in three categories of responses to our research question. However, the third category did suggest further distinction, leading to three subcategories. Saturation was reached at the 24th post, after which previously identified codes were sufficiently comprehensive and no additional distinct codes were needed for the remaining data.

Results and Discussion

Comments from caregivers reflected one of three major positions on the identity of their loved one who has dementia: the loved one is a different person, the loved one is still there, or the loved one has lost his or her identity. This last position can be further broken into three major reasons for the loss of identity: because of personality changes, because of ability decline, or because of the disease itself.

"He's Losing Himself"

Some caregivers expressly tied identity to personality, arguing that the personality of the person with dementia has either been lost or changed, causing a loss of identity. In these responses, caregivers implied that they had lost their partner because the disease took their identity away from them. For example, one poster wrote about her husband's, her mother's and her own dementia diagnoses:

He is slowly but surely losing (sic) himself to his disease. I can say that because I too have EOAD/FTD [Early Onset Alzheimer's Disease/ Frontal Temporal Dementia] and I know I am slowly dying (losing [sic] my identity, my personality, and my mind). I am, also, a caregiver to my Mom who has Alz (Alzheimer's Disease). She told me the same thing about herself. We are all as terrified as you are.

This caregiver (and eventual patient) seems to view identity and personality as tied together, and, as both are affected by dementia, this loss of identity results in a virtual death; she seems to suggest that if you are not a person with a personality, you are no one.

Another poster argued that one's identity is made from memories and personalities: "I think there's a location in the brain that takes remembered elements of people's personalities and assembles them into identities. When it gets damaged, the elements no longer go together into a coherent whole." This poster suggested that dementia damages the brain, making people forget parts of their personality. Because, in his view, identity is made up of these personality elements, dementia in turn makes people lose their own identity. This view sees identity to be made of a combination of memories and personalities, both of which are affected by Alzheimer's Disease and dementia.

Blurring the line between personality and ability effects on a loved one's identity, one poster suggested that the loss of these two is what creates one's identity:

So much of what we did as professionals and what our loved one's (LO's) did are a large part of our identity. The personality essence of the person and ourselves together are also part of that identity and the world as we know it in our sphere of existence.

This post addressed the web of interaction involved in figuring out the identity of a loved one with dementia. The changing personality of the loved one affects both his or her own identity, as well as the interaction with the caregivers and the world. This interaction, in turn, affects identity.

A number of posters wrote of the decline in a loved one's abilities, then tying that decline into the loss of identity. For these posters, the inability to do something, whether professionally or personally, as one did it before affects one's identity. One poster referred to his father's loss by saying, "I remember when we had to take the keys away from my dad...and it was really hard, especially because my father drove for a living. Driving was a huge part of his identity." When this patient could no longer drive, he lost the professional identity of a driver, as well as losing a large part of his personal liberty, according to his son and caregiver.

These posts identify the connection between abilities (such as the ability to take care of one's self) and identity, suggesting that the loss of independence because of dementia contributes to a loss of identity. Dementia patients, particularly those who need more extensive care in a

home or professional setting, often lose these little elements of independence, perhaps because of how the caretaker or family member views the identity of the patient. The caregivers who tie personality or ability to identity may assume that because the patient does not display himself as before, he is bereft of identity; in turn, they may react with caregiving styles that reinforce this conclusion, such as removing wallets and being overly restrictive on independence.

The decline of abilities and eventual loss of individuality and independence is, as these caregivers recognize, a generally inevitable part of the progression of dementia. But while some caregivers point to specific abilities that contribute to identity, others suggest that the disease itself results in the loved ones “losing their minds/self/identity” as we stand by and feel helpless.” Interestingly, in this comment, the mind is essentially equated with the self and with identity. Similarly, another poster linked the mind to the self by stating that the disease “is like being given a death sentence for one’s personhood” and yet another said “it is like identity theft only more complete and unrelenting.” These posters, then, view identity of their loved one as something tied to personality or ability, both of which are affected by dementia. This effect, then, causes the dementia patient to lose his or her identity completely.

“This disease has totally changed him”

A similar yet distinct view in the posts suggested that dementia patients are a “different person” rather than a lost person. In this case, the caregivers do not claim that the loved one has no personality or identity, but rather that the identity of the loved one is merely changed from what it was before. One poster wrote a long list of identities her mother-in-law used to be (shortened here):

If my MIL was who she was before this disease reared its ugly head, she would still be in the home she loves (without forgetting how to cook for herself, or turn the burners off when she is done), would still be running her household efficiently (without getting 6+ months behind in her bills and having her utilities turned off)...She would still be socializing...She would not have to be in a state of frustration all of the time, because her life would continue just as it had been. She would not have to pack her belongings each day, believing she is going "home" tomorrow...Yes, she is still my beloved Mother-in-law, Mother of my Hubby, and doting Grandmother to my children...but she is definately (sic) a different person.

This post illustrates how complete the life change can be when a loved one has Alzheimer’s Disease or dementia; the loved one is no longer the “same person” doing the same activities as he or she did before the onset of the disease but still the person they know.

A number of caregivers used the phrase “different person” to describe their loved one. Generally this comes off as a kind of mourning for the person their loved one used to be or frustration with the current personality display, but occasionally this view was identified as a coping mechanism:

When it comes to the car and driving my father says especially hurtful/mean [things] and can get VERY angry. When he asks for the car we tell him it needs new tires to be inspected etc. (even though I sold it a few weeks ago). This seems to settle him until the next day when he asks again... This disease has totally changed my father into a different person and I know he would be horrified if he understood what he said/did. I try to remind myself of this often.

For some of these caregivers, the fact that their loved one is different can be a way of justifying the strange and hurtful outbursts common with dementia. For others, it is a way of explaining that their memories of the loved one do not comport with the patient's current actions.

Viewing the loved one with dementia as a "different person" also helps caregivers explain the effect the disease has on themselves and their relationships. One caregiver explains:

I grieve deeply for the finality of the unalterable changes connected to her life. While making these changes are a drastic and permanent alteration to the universe of our loved ones; it also alters ours in relationship to how it always "was" and "used to be" with them. The most basic belongingness, comfort and identity is of being ourselves at home. Home. We hear the echoes of their lives and how they lived them. We see this in our heart and mind's eye without words but with feelings. Who they were, and who they will never return to be again. This is the tragedy.

The fact that the patient with dementia is completely different, in this view, helps explain the personalities changes and helps the caregiver cope, without completely denying the personhood or identity of the loved one.

Some caregivers work to acknowledge and understand the change in their loved one and the apparent "different person" with whom they now interact, while still holding on to the person their loved one "used to be."

My grandparents live with us for about half the year. I've just started noticing how my Grandma is acting like a kid (playing with toys and coloring books) and it definitely hurts a lot. I hate to see her suffer like this because I've always been close to her. The best thing you can do is remember who she was, the good times you had and hold onto those as long as you can. Even though she is a totally different person now, a little bit of her is still there.

Caregivers in this situation reconcile their view of the loved one's identity as it was and as it currently is, while trying not to remove their personhood. In so doing, they are attempting to deny the dichotomy between "same" and "different" – their loved one is a different person in personality and action, yet the same person in more than just a shell.

“Never write someone off”

Some caregivers, rather than denying their loved one’s identity or considering their new or different identity as a dementia sufferer, insist that their loved one remains who he or she is, despite the dementia. One poster advises, “Never write someone off – there is always a person in there. Even if they don’t know your identity, you know theirs and that affirms their personhood.” By this interpretation, personhood exists in the “other,” not just in the individual. In other words, identity is not personally owned, but is also a product of the memories and actions of those around a person. This construction of identity as socially constructed allows caregivers to hold on to their loved one’s previous identity. Some insist their loved one is “not lost” and retains his or her personhood. For example, one poster wrote:

Be sure to relate with them [dementia patients] as if their own personalities are still present, even when it seems they are just a shell as I’ve heard it put. Each day your LOs live is a part of their identity here on this earth. Who is to say they are empty. Even today, after Pat has been gone for a week, I feel her CARING for me now. Whether it is all in my mind or not, it comforts me to know our LOs have someone there in the moments most needed.

By this interpretation, existence itself is what determines one’s identity. As long as the patient is alive he or she maintains the identity of that loved one in the eyes of family and friends.

Caregivers who insist that their loved one is “not lost” often commented on the need for a more person-centered style of care. One poster lamented the view of patients in some professional settings, asking,

“How is it, if someone is quite elderly or has dementia, they lose their identity? I have often witnessed patient’s (sic) unintentionally treated like an inanimate object, or being without personhood. I often recommend to families to bring photos of their loved one to put about the bed so that staff can see the REAL being inside the body.”

Another poster, concentrating on the importance of preserving a loved one’s identity, observed that “communicating our needs, wishes and feelings is vital” and insisted that “as a carer, it’s important to encourage the person with dementia to communication in whichever way work best for them.” For these caregivers in particular, the view of identity is tied to their actions and caregiving style; because they see the patient as “not gone” and still the loved one they remember, they may be attempting to hold on to the identity or role of the loved one as he or she was before.

In the perspectives in this category, family members care for the patient based on an identity in their own memory in interaction with the body of the patient. These caregivers

manage their family relationships by focusing on what was as a factor in what currently is for the family around the patient.

Conclusion

Family caregivers of loved ones with Alzheimer's Disease or other forms of dementia commonly commented on their interpretation of their loved one's identity on the anonymous Alzheimer's Association forums. These caregivers tended to have one of three major approaches to identity of dementia patients: either 1) they considered the patient to have lost his or her identity, 2) they considered the patient to be a different person, ostensibly with a different identity, or 3) they insisted that the loved one maintained his or her own identity in some manner.

How a caregiver viewed his or her loved one was somewhat reflected in their attitudes toward the patient. Those who insisted that the person was "not lost" emphasized communication and person-centered treatment; those who thought of the loved one as a "different person" used that consideration to cope and to understand the different actions of their loved one.

This preliminary study can allow future researchers to use these general pattern outlines to further explore both how caretakers view the identities of their loved ones with dementia, as well as how, if at all, this view manifests in interaction with the patient. Findings can also be used in professional settings, to raise awareness of the complications of identity in cases of dementia, particularly in light of the social construction of the self.

One limitation of this study is the relatively small sample size. The sample size was only 44 messages, which may mean only a small component of the range of views of caregivers. Future studies should consider using multiple message boards, a local support group, or surveys to broaden the range of responses.

Anonymity of the posters was both a benefit and a drawback. On one hand, having anonymity in posting may make posters feel more comfortable being fully honest without risk to being seen as careless or mean to their family member (Fisher, 1993). On the other hand, we still can't guarantee full honesty as even anonymous people manage their public performances of proper caregivers. Further, because of the nature of our collection, we were unable to ask follow-up questions to clarify posters' views on their loved one's identity. We could only rely on what they wrote at one moment of their lives.

To resolve both potential limitations, we encourage future researchers to conduct interviews or surveys that allow for a more holistic and focused perspective on the range of views about identity of dementia patients by their caregivers. In particular, we encourage interviews to understand the potential dialectical tensions that may occur when caregivers both love their family member while also feeling frustration, anger, or even resentment at their loss of relational identity, tied to ambiguous loss.

We further recommend that future research consider how these issues connect to the caregiver's relationship with other family members in the system. How do family groups

communicate together about the identity and care management of the dementia sufferer? How do family members construct the identity of the caregiver as well as the patient?

Given that millions of Americans are suffering from dementia-related illnesses, leading to countless more family members connected to this body of illnesses, more communication research must be done to better understand the complicated relational dynamics that surround the stress and loving care that go into managing family and individual identity in ambiguous loss.

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