

Voices of Couples Affected by Alzheimer's Disease

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Abstract. The purpose of this research was to identify themes in communication between persons with Alzheimer's disease and their spouse caregivers. Theme identification provides insight so that interventions can be designed to improve communication. The long term goal of this research is to improve quality of life for couples experiencing dementia and increase their satisfaction with their relationship. Thirty transcribed videotaped ten-minute interviews between fifteen couples who consented to participate in a previous study (Principal Investigator: Williams) were analyzed to identify common themes. Themes included *Harmony in Spite of a Memory Disorder*, *Healthy Acceptance*, and *Discord and Contempt*. These themes were further divided into individual subthemes, which included "Loving Affection," "Bringing up the Past," "Orienting Spouse to the Situation," "Giving Assurance," "Fighting Acceptance of Illness," and "Bitterness and Frustration." Understanding the themes generated within the conversations help to further analyze the effects that Alzheimer's disease has on communication in a relationship.

Introduction

Globally, about 44 million people have Alzheimer's disease (AD) and the numbers continue to grow (Alzheimer's Association, 2013). AD is the most common form of dementia, has no cure, and involves loss of thinking skills which decrease the individual's daily functioning (NIH, 2011). Persons with AD need assistance with activities of daily living and family members, most often spouses, gradually take on this responsibility (Zarit & Edwards, 2008). Caregiving is difficult and stressful (Alzheimer's Association, 2013). Often, both physical and mental health suffer as a result of the demands of caregiving (Irwin et al., 2013; Perkins et al., 2013). Communication is the key to establishing and maintaining marital relationships, but when a spouse is diagnosed with a memory disorder such as Alzheimer's disease (AD), the couple is at risk for marital dissatisfaction (Kolanowski, 2004). Along with the loss of memory are the unmet relational needs such as missed opportunities to grow closer to a partner due to frustration, misunderstandings, and unmet expectations (Williams, 2011, p. 28). As a result, spouses are less able to fulfill one another's needs

and caregiving partners may suffer from loneliness and depression, while the one being cared for may be emotionally neglected (Purves and Phinney, 2012). Communication difficulties are a major source of caregiver burden (Watson et al., 2012). Nurses care for families affected by Alzheimer's disease in a variety of settings both inside the hospital and in the community and therefore have the opportunity to support caregivers and to provide anticipatory guidance about changes in couples' relationships. The research question that guided this study was, "What are the patterns in communication between persons with AD and their spouse caregivers?"

The long term goal of this program of research is to improve quality of life for couples experiencing dementia-related illnesses and increase satisfaction in their relationships with significant others. The focus was on understanding the human experience in the relationship between the caregiver and the spouse with AD and identifying common themes, so that education can be designed to improve the quality of communication and satisfaction within relationships.

Literature Review

The theory of person-centered care of Thomas Kitwood

(Kitwood & Bredin, 1992) grounded the study. Respect for personhood was a fundamental tenet of his theory. Tresolini et al. (1994) describes the evolution of this individualistic view to that of relationship-centered care. To provide the best care for persons with dementia he contended that they must be viewed as inseparable from their relationships with significant others. This theory was designed to capture the social experience between caregivers and their spouses.

There have been several studies that have explored relationships between caregivers and their spouses with AD. Purves and Phinney (2012) reported results from a qualitative study of two families with a member diagnosed with Alzheimer's disease. Findings indicated family members' frustration and sadness at the changes in conversation manifested in themes *There's No Point* and *We Don't have Conversations Anymore* (Purves & Phinney, 2012, p. 289). Some hope was revealed in themes titled *You Find Ways* (Purves & Phinney, 2012, p. 290) and *Keeping Conversations Going* (Purves & Phinney, 2012, p. 293). Limitations of the study included the small sample and that they did not analyze conversations between caregivers and spouses but rather asked family members about their perceptions of the relationships.

Davies (2011) used a mixed methods approach to study the meaning of commitment in the context of AD in six couples experiencing early-stage AD using in-depth semi-structured interviews. The researchers interviewed couples about their understanding of their relationship. For example, participants were asked to tell a story about how they met. This approach focused on the participants' perceptions about their relationship rather than analyzing their way of relating as it occurs during the interview. Transcript analysis resulted in themes that spanned pre-diagnosis, diagnosis, and post-diagnosis impact. Couples described themes titles *Partnership for Life* (Davies, 2011, p. 225), *Reciprocity* (Davies, 2011, p. 227), *Resilience* (Davies, 2011, p. 228) and *Forgiveness* (Davies, 2011, p.229). Couples maintained an "us identity" (Davies, 2011, p. 230), focused on the present, and worked on their marriages.

Daniels, Lamson and Hodgson (2007) conducted an in-depth qualitative analysis of three interviews with a couple experiencing AD. The couple answered questions

such as "Tell us a little about your marital relationship." (Daniels, Lamson, & Hodgson, 2007, p. 164). Themes included *Preparations for Future Changes* (Daniels, Lamson, & Hodgson, 2007, p. 169), *Family Influences and Social Support* (Daniels, Lamson, & Hodgson, 2007, p. 170), *Life Evaluation and Experiences with AD* (Daniels, Lamson, & Hodgson, 2007, p. 173). Much of what was found concerned reflections on the immediate and distant past and future in contrast to the current study that focuses mostly on the present.

Hellstrom, Nolan, and Lundh (2007) reported results of a grounded theory qualitative study which included 20 participants (husbands and wives where a spouse had some form of dementia) and 152 interviews. Interviews were conducted every six months over a period of two years, either in-person or by telephone, in separate or joint interviews. At the beginning of the two year period, themes centered around togetherness, but by the end of the study themes evolved to *Moving On* (Hellstrom, Nolan, & Lundh, 2007, p. 403). The lengthy time span of the study allowed the researchers to describe participants' perceptions of struggling to maintain a close relationship until finally accepting spouses' increasing dependence and subsequent loss of mutuality. As in previous studies, the researchers relied on participants' accounts of their evolving relationships rather than analyzing the relationship as manifested in the encounters.

In another grounded theory study, Corcoran (2011) identified four care-giving styles (facilitating, balancing, advocating, and directing) that caregivers used when relating to a family member with AD. Participants were 42 spouses or other family members who were interviewed multiple times at home. Caregivers were asked about "a typical day," "strategies for meeting his or her needs," caregiving priorities, and how they would advise a fictitious caregiver presented in a vignette (Corcoran, 2011, p. 466). Thirty participants were also videotaped with their family member with dementia. Typologies were based on the caregivers' answers to the interview questions.

In summary, although a number of studies have been conducted to examine the relationship between the caregiver and spouse with AD, none have focused spe-

cifically on analysis of recorded interactions and therefore there is a need for further study. The direct analysis of conversations provides another lens through which to view this relationship. Perceptions are limited by their subjective nature and may differ from spouses' behavior during conversations. The purpose of this study was to analyze communication between persons with Alzheimer's disease and their spouse caregivers (CG) in order to identify themes in communication.

Design and Methods

This qualitative study, which used a method discourse analysis (Potter, 2004), was a secondary analysis of transcribed audio-recorded data designed to characterize communication between 15 persons with Alzheimer's disease and their caregiver spouses. The purpose of the parent study was to evaluate a 10 week educational program about communicating with persons diagnosed with AD. Participants in the IRB approved parent study were recruited from enrollees in a day program for individuals with memory disorders in south Florida and their spouses. Program staff asked spouses if they were interested in hearing more about a research study. Those interested met with the researcher who explained the study, answered any questions and asked spouses for consent. Caregiver spouses signed a consent form for both themselves and their partners while partners were asked for assent at each contact. Data collection took place at their homes. Couples were asked to converse on a topic of their choice for 10 minutes while the researcher turned on the recorder and left the room.

Qualitative Analysis

Although most scientific research is based on objective approaches, Immanuel Kant proposed that perception was based on more than an act of observation and believed it also entailed a subjective reality that supports the notion that "nature was not independent of thought or reason" (Streubert & Carpenter, p. 3). A vital yet most often forgotten side of science is the human subjectivity and interpretation of the world as seen through each individual lens. This study was designed to capture what is happening in marital relationships through the analysis of everyday conversations between spouses.

Transcripts were analyzed with an inductive approach using methods developed by Potter (2004) facilitated by NVivo qualitative software. The first step was to read through all the transcripts looking for the phenomenon of interest: interactions that illuminated the relationship between partners. For example, statements reflecting caregivers' and spouses feelings about their relationship and their strategies to maintain their relationship through conversation were identified. As many examples of the phenomenon as possible were gathered. Narrative data before and after the statements of interest were examined to provide sufficient context to illustrate meaning.

Data reduction. Words, phrases and statements were grouped by commonalities and categorized into codes. The two authors jointly coded a subset of the narrative data by categorizing data together. Differences in coding were discussed until agreement was reached. Next, the first author (AB) independently coded all transcribed interviews.

Data display. Narrative data were re-examined by both authors within each of the categories. Categories were grouped together to form themes. Direct quotations were selected to illustrate each of the themes. Pseudonyms were used to protect confidentiality.

Results

Participant Characteristics

Caregiver participants consisted of five men and 10 women age 55 and older with normal cognitive ability. Their partners' mean score on the Mini Mental Status Exam (MMSE) was 16.81 (SD=7.94), indicating moderate dementia. All couples were living independently in the community, English speaking and all but one was non-Hispanic White. As shown in Table 1, participants were well educated with middle income.

Development of Themes

Several themes emerged from the data that characterized the couples' patterns of relating. In some couples, it was obvious that they remained engaged and that they valued their relationship. Theme 1, *Harmony in Spite of a Memory Disorder* was evident in their

Table 1

Sample Characteristics

	Caregivers		Spouses	
	N	%	N	%
Males	5.0	16.0	10.0	36.7
Females	10.0	36.7	5.0	16.7
	M (SD)		M (SD)	
Mean Age	77.38 (9.64)		80.31 (7.03)	
Years of Education	15.3 (1.84)		14.06 (2.3)	
Years in Caregiver Role	3.99 (1.84)			
Years Married	46.49 Range 17-60			

conversations. This theme was further broken down into two subthemes: "Loving Affection" and "Bringing up the Past." Theme two, *Healthy Acceptance* was another example of a theme that emerged from conversations in which it was evident that couples were aware of and realistic about the memory problem. Within this theme, two subthemes included "Orienting Spouse to the Situation" and "Giving Assurance." For some couples, the third theme *Discord and Contempt* was evident, and its two subthemes "Fighting Acceptance of Illness" and "Bitterness and Frustration" provided evidence of marital problems. Themes and subthemes are explained and supporting data are provided.

Theme 1. Harmony in Spite of a Memory Disorder

Conversations that made up this theme validated a strong positive relationship characterized by intimacy and optimism. Caregivers chose to foster a loving relationship and maintain a healthy outlook on the situation.

Subtheme 1. Bringing up the past

This sub-theme focused on positive reflections about the couples shared experiences in the past. In this example, the caregiver offers encouragement to the spouse by bringing up the care receiver's past life. This is a gesture that seemed to come from the caregiver's intention to lift up the spouse's spirits.

Caregiver: I just told them you're happy all the time. I never met anyone who is as happy as you! You were born happy. You had a good life, had a marvelous childhood, marvelous education, and you had a family that was delightful!

Subtheme 2. Loving affection

Conversations that exemplified this sub-theme were present-focused and contained evidence of the affection they had for one another. In the following interaction, the care receiver is concerned about being a burden, and the caregiver assures that no matter what happens, the spouse will always be loved and cherished.

Caregiver: I don't care if you answer the question or not.

Care receiver: Well, sometimes I do and sometimes I don't.

Caregiver: If you don't answer, it does not affect me. It doesn't make me unhappy that you don't. As far as I'm concerned, you always get 100.

Care receiver: (Laugh)

Caregiver: More than 100, you'll stay that way.

Care receiver: I guess the main thing for me is that I want you to be happy with me.

Caregiver: I'm always happy with you. That's why I say I'm happy with you whether you answer a question or you don't answer a question. (Laughter from both.)

Theme 2. Healthy Acceptance

This theme could be described as being aware of the memory problem yet having a determination to pursue the best quality of life possible despite the problems. This awareness could be in the caregiver, the spouse or both. Awareness allowed them to engage in honest discussions about their situation.

Subtheme 1. Giving assurance

In this subtheme, caregiver demonstrates optimism

and acceptance of the spouse. The interaction included caregivers reaching out to comfort spouses with soothing statements. The statements seem to minimize what is wrong. Caregivers assure the spouse that they still have a loving relationship and many things to be grateful for.

Care receiver: I just think I'm making too much of a big thing about my problem.

Caregiver: No you're not, no you're not.

Care receiver: No?

Caregiver: No you're not. Just relax with it. Everybody's got some problem.

Caregiver: Yeah, and we still have quality of life, we do things, we love each other, we have many friends... We believe that our children and grandchildren care about us. It's a beautiful day. You can see that the sky is clear...And there are so many blessings in spite of the frustrations we go through.

Subtheme 2. Orienting spouse to the situation

In this sub-theme, caregiving spouses made efforts to supply missing information about everyday life so that the spouse with the memory problem could be engaged in the situation as much as possible.

In this conversation, the caregiver not only gives the spouse assurance, but also orients the care receiver to the present situation, offering honesty and support.

Care receiver: There must be something that I'm missing and I don't know what it is.

Caregiver: You're missing hearing some of the things, and you lost some memory, that's all. There's no question your short term memory is not what it was. And part of it is getting older. That's what I learn when I go to these support groups. They're trying to find the answer, and if they do, fine.

Theme 3. Discord and Contempt

Unfortunately, there was evidence of marital discord in some couples. Conversations pointed to problems within the marriage that could be current or long-standing.

Subtheme 1. Fighting acceptance of illness

In this sub-theme either the caregiver or the spouse with a memory problem evidenced lack of understanding of the memory problem. It was not possible to judge

whether this was due to lack of information about memory disorders, negative attitudes or both.

In the following conversation, the caregiver expressed frustration with the spouse's longstanding style of relating. Changes in communication are attributed to "the way you are" rather than symptoms of the memory disorder.

Caregiver: And it's not just the Alzheimer's problem, it's part of your personality I feel because you never put yourself out in the beginning so I don't feel that you can really blame it all on your sickness now...But that's the way you always were. You always withdrew from a lot of stuff because you didn't want to get involved.

Subtheme 2. Bitterness and frustration

Emotional distress in the form of anger, irritation, or frustration was the subject of this sub-theme. The following conversation reveals the bitter feelings that the caregiver holds against the spouse's past actions in a certain situation. The caregiver's attitudes about the relationship are expressed in the midst of the illness, and the care receiver's frustrated reaction toward this bitter approach is observed.

Caregiver: Do we still have to continue this? Two more minutes, okay, my god. I don't know what to say anymore.

Care receiver: You're insisting on one thing and...

Caregiver: You're insisting on another thing. That's the story of my life. It's always been that way.

Care receiver: Poor thing. You really got this whole thing I created.

Caregiver: Excuse me, I really don't even want to hear it.

Care receiver: Of course you don't want to hear that.

Caregiver: Okay, you know, if you want to hear exactly how I feel..

Care receiver: Nothing to do about it.

Caregiver: If you ever asked me how I felt when I had my breast cancer. When I had my...

Care receiver: I was with you.

Caregiver: Oh yeah.

Care receiver: I was with you. I was with you

the first time.

Caregiver: Yeah, yeah. You were with me. You know, being with me physically is one thing.

Care receiver: What am I supposed to do? I'm not the doctor. I can't go and fix it.

Caregiver: I didn't ask you to fix it.

Care receiver: The first time, I was there all the time.

Discussion

The primary objective of this research was to analyze the communication between individuals with AD and their spouses who were also their caregivers. This study adds to the literature because it focuses on analyzing conversations and relationships in action rather than analyzing interviews conducted with caregivers or persons with AD alone. Rather than viewing the relationship as told by the participants, we analyzed the conversations. We found three overall themes: *Harmony in Spite of a Memory Disorder*, *Healthy Acceptance and Discord and Contempt*. Each of the themes contained subthemes. *Discord and Contempt* contained subthemes of "Fighting Acceptance of the Illness" and "Bitterness and Frustration." The theme *Healthy Acceptance* included the two subthemes "Giving Assurance" and "Orienting Spouse to the Situation." The theme *Harmony in Spite of a Memory Disorder* included the subthemes of "Bringing up the Past" and "Loving Affection." We compared our results to other studies of couples affected by a memory disorder, but it was somewhat difficult to compare findings since previous researchers focused on participants' reflections about their relationship rather than analyzing conversations between partners. Davies (2011) found only positive themes in couples' reflections about their relationships, including *Resilience and Reciprocity* (Davies, 2011, p.227-228). These findings may have differed from ours because the couples in Davies' study could have concealed any discord in the interviews. Daniels, Lamson, and Hodgson (2007) reported very general themes such as *Life Evaluation* (Daniels, Lamson, & Hodgson, 2007, p. 173) that did not convey the emotional richness found in our results. In a longitudinal study, Hellstrom, Nolan, and Lundh (2007) reported general themes from interviews as well. They noted a change from a sense of *Togetherness to Moving on* (Hellstrom, Nolan, & Lundh, 2007, p. 403). Their theme of *Moving on* may have some

similarity to our theme *Discord and Contempt* with subthemes such as "Bitterness and Frustration." With the negative emotions we found, it is possible that some participants might begin a process of *Moving on* to create emotional distance.

The results of the study revealed several themes presented in conversations between the couples. The knowledge gained contributes to nursing knowledge and allows nurses to be better equipped to educate patients and their spousal caregivers about the importance of communication in maintaining quality of life. Research still needs to be done to add to the literature, especially regarding the long term outcomes of incorporating therapeutic communication in these relationships. A longitudinal study analyzing the effects of these therapeutic communication strategies may serve to change how we approach communication during interactions with those experiencing AD. The caregivers in this study were mostly women from one ethnic group, non-Hispanic, Caucasian. Future studies could include comparisons by gender and ethnic groups.

Conclusion

By studying conversational themes between spouses experiencing AD nurses can begin to devise strategies to help. With a greater awareness of what is typical, nurses can teach caregivers what to expect. With anticipatory guidance, caregivers are more likely to approach their conversations with more confidence and tact. The primary goal of this line of research is to improve quality of life for couples experiencing AD and increase their satisfaction with their marital relationship. Education and implementing change in communication strategies is a step that leads us closer to this goal.

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