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Communicating With Individuals With Alzheimer's Disease: Examination of Recommended Strategies

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Abstract

Meaningful conversation with individuals in the later stages of Alzheimer's disease (AD) has been considered difficult if not impossible. Limiting communication to simple concrete subjects and closed-ended questions is frequently recommended. Thirty-five 30 minute conversations with individuals with advanced AD (mean Mini-Mental State Examination [MMSE] = 10) were transcribed and the interactions examined. No significant differences in length or relevance of response by type of question was found indicating that subjects were able to respond to open-ended questions. Use of broad opening statements or questions, establishing commonalities, speaking as equals, and sharing of self-facilitated expression of feeling; recognizing themes with salience for the individual helped to maintain the discussion.

The experience of losing cognitive and expressive abilities is both frightening and frustrating for the person with Alzheimer's disease (AD). No group of patients is more in need of supportive relationships with skilled, caring, healthcare providers and yet caregivers generally avoid communicating with them. Two reasons for this avoidance may be that the verbalizations are confusing and that caregivers receive little feedback, producing both frustration and anxiety in the caregiver (Hallberg & Norberg, 1990;Norberg & Asplund, 1990;Sheldon, 1994;Shulman & Mandel, 1993).Ekman, Norberg, Viitanen, & Winblad (1991)found that the inability to communicate with impaired residents led to feelings of hopelessness and meaningless in caregivers but suggested that more effective communication with severely demented patients could reduce or prevent the meaninglessness experienced when caring for individuals with dementia.

The literature addressing communication techniques for individuals with AD has focused primarily on accommodations to the patient's limitations. Suggestions for the caregiver include simplifying vocabulary and sentence form, avoiding the use of pronouns or abstract content, slowing the rate of speech, maintaining a pleasant tone of voice, and using closed-ended questions (Bayles & Kaszniak, 1987;Frank, 1994;Tappen, 1991). Several authors recommend avoiding open-ended questions and limiting questions to those that can be answered in one or two words such as yes or no (Farran & Keane-Haggerty, 1989;Lee, 1991;Shulman & Mandel, 1993). Farran and Keane-Haggerty (1989) suggest using distraction to avoid discussing negative feelings.

Little has been written about developing a therapeutic relationship with individuals in the later stages of AD. Because most experts have considered meaningful conversation difficult if not impossible, therapeutic communication is generally not attempted. Farran and Keane-Haggerty (1989) write that the demented patient is unable to participate in the therapeutic process.

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Hughes (1987) contends that verbal communication is ineffective for helping Alzheimer's patients. She recommends focusing on building trust by accepting the person, accepting their emotions, remaining patient, and avoiding correcting their mistakes or taking over tasks when they are slow. Adaptations to traditional therapeutic communication techniques have been recommended in the literature but provide little direction regarding what can be done to influence the resident's ability to communicate or to develop a therapeutic bond.

One exception is Bohling's (1991) study of brief (5 minute) interactions between the person with AD and caregivers in which he uses Goffman's (1974) frame analysis to examine how caregivers either establish effective communication by joining the patient's frame of reference or fail to achieve understanding by missing patients' cues regarding their frame of reference, including the time frame to which they are referring. He concludes that sensitive listening may prevent patient anxiety and disruptive behavior. Shulman & Mandel (1993) also recommend listening to the person with Alzheimer's disease to understand the emotions underlying the words. They indicate that responding to emotions will help to decrease isolation.

The purpose of this study was to determine whether or not several of the generally recommended strategies for facilitating communication with individuals with Alzheimer's disease were supported by empirical data. Specifically, we posed the following questions:

What type of question elicits greater and more relevant response from individuals with AD, open, closed, or combination of the two?

What strategies facilitate the expression of feelings and concerns by individuals with AD?

What strategies facilitate the maintenance of a conversation with individuals with AD?

METHOD

To explore the questions posed, we analyzed 35 transcribed interviews with 23 subjects in the middle and later stages of AD. These interviews were conducted by advanced practice nurses as part of a treatment approach being tested in a larger study of communication in AD. Subjects met with the interviewers three times a week for 30 minutes for 16 weeks. Interviews were tape-recorded in the first, eighth, and sixteenth weeks.

Sample and Setting

All of the subjects in this purposive sample were residents of two large urban nursing homes. Each one had a clinical diagnosis of AD based on psychiatric review using the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association (NTNCDS-ADRDA) criteria (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984). Consents were obtained from proxy health care surrogates in accordance with the guidelines of the University's Committee for the Protection of Human Subjects and laws of the State of Florida. The subjects themselves assented to participate in the interviews and were informed that they were being tape-recorded.

Data Analysis

A deductive ("top-down") narrative analysis, similar to that of content analysis, was used to examine the data (Manning & Cullum-Swan, 1994). Preformulated categories based on recommendations for communicating with individuals with AD and principles of therapeutic communication (Peplau, 1952) were used for purposes of analysis (Psathas, 1995).

The focus of this analysis was on the interaction between interviewer and subject (Holstein & Gubruim, 1994), particularly on the subject's response to strategies used by the interviewer. Interviewers were instructed to avoid frequent correction of the individual but had not been

instructed to use any particular set of strategies, only to encourage the individual to engage in conversation, to attempt to make the conversation as meaningful as possible and to assume that any attempt to communicate had some meaning in it, however difficult it was to ascertain that meaning (Tappen, 1991).

Transcribed interviews were read several times by the investigators to gain familiarity with the range and scope of therapeutic techniques used by the interviewers. Peplau (1952) suggests that the use of open-ended questions is preferred in developing a therapeutic relationship because they elicit descriptive material which can be used to better understand the patient's experiences. Nurse interviewer verbalizations were therefore coded as to whether or not they were open-ended questions, closed-ended questions, or mixed (a combination of the two). Open-ended questions were operationally defined as questions that asked for description, explanation, or opinion and required an answer of more than one word. Closed-ended questions were defined as questions that can be answered by "yes" or "no" or with one word. Mixed questions consisted of an open-ended question followed by a closed-ended question without opportunity for the subject to respond until both were asked.

The purpose of a therapeutic relationship is to help the patient to explore feelings and concerns (Peplau, 1952). For this study, expression of feelings was defined as any statement by the subject that contained a direct expression of emotion, either positive or negative, such as "I am upset" or I love you." Concerns were defined as topics that subjects introduced into the conversation that were personally relevant and that were troubling to them in some way. This included subjects' concerns about their illness, their relationships with family members, and their day-to-day life in the nursing home. For example, one subject's response to a simple question "How are you today?" illustrates the first two kinds of concerns: "Honest, I don't know what I'm doing," (his illness) and "My son and others are too far away" (his family).

Maintaining a conversation is also important to the therapeutic process because it allows the nurse to better understand the subject's experiences and to explore the subject's feelings and concerns. Evidence that a conversational theme was maintained was defined as two or more exchanges (statement and response) between subject and nurse on the same topic or theme.

After categorization of the interviewers' questions as open, closed, or mixed, the mean number of words in response to each type of question was calculated (Tomoeda & Bayles, 1993). Any repetition of subjects' words, including perseverations, were omitted from these calculations. Subject statements were coded as relevant or irrelevant. The meaning of an entire statement in the context of preceding statements was used to judge relevance. The proportion of relevant to nonrelevant responses to each type of question was then calculated.

Original and relevant subject responses were also compared with irrelevant responses to determine what the nurse had said which may have influenced the subject to provide a response with shared meaning. When subjects expressed feelings or emotions, the nurse interviewer's preceding communication strategies were analyzed to determine which were helpful in (1) eliciting expression of concerns, or (2) eliciting further exploration of an idea, and (3) maintaining a conversational theme.

Transcribed interviews were coded by the authors separately. A representative sample of transcriptions (5) were coded by two of the investigators to examine reliability of the coding. Correlations between coder 1 and coder 2 reached an acceptable level of agreement (85%). When differences of opinion were discussed, intercoder agreement reached 100%.

RESULTS

Subjects ranged in age from 77 to 99 years with a mean age of 86. The majority were women (66%). Length of stay ranged from 5 months to 8 years. Subjects were in the middle and later stages of AD with Mini-Mental State Examination [MMSE] (Folstein, Folstein & McHugh, 1975) scores ranging from 2 to 18 with a mean score of 10.

Effect of the Type of Questions Used

Several aspects of the effect of the type of questions used were evaluated: the frequency of use of each type of question, length of subjects' responses to each type, the relevance of these responses, and relationship to cognitive ability as measured by MMSE scores.

To determine the types of questions that elicited longer responses from subjects, questions used by the nurse interviewers were coded as open-ended, closed-ended, or mixed and the mean number of words in response to each type of question was calculated. The nurse interviewers used twice as many closed-ended as open-ended questions (see Table 1). This may reflect their knowledge of the literature recommending closed-ended questions with this client population.

Subjects' responses to the three types of questions were compared in terms of the mean number of words used. Results revealed a trend toward a higher number of words in response to open-ended questions followed by mixed questions, with the lowest number of words in response to the nurses' closed-ended questions. Differences were not statistically significant when subjected to analysis of variance procedure (see Table 2).

Longer responses are important clinically only if the response is also relevant. Surprisingly, most of the subjects' responses were relevant. This differs from testing situations in which the proportion of relevant responses may be considerably lower (Tomoeda & Bayles, 1993). To determine the type of question that elicited more relevant responses from subjects, the proportion of relevant to irrelevant responses was examined for each type of question, open, closed, or mixed. Comparison of responses to open, closed, and mixed questions revealed no significant differences in the proportion that was relevant. The slightly higher proportion of relevant responses to closed-ended questions may reflect the fact that these were usually simple questions requesting a one-word answer (see Table 3).

The use of each type of question was also compared with subjects' MMSE scores. Mixed questions were used infrequently overall but more often with subjects who had lower MMSE scores ($r = -.35$, $p = .03$) than higher scores. Correlations between MMSE scores and the use of open-ended or closed-ended questions were − .22 and − .20 respectively but neither were statistically significant (see Table 4). As the MMSE score decreased, the total number of questions used by the interviewer also increased, probably as a result of greater effort to maintain the conversation on the part of the interviewer. In the following excerpt from a conversation with a subject whose MMSE was 2, the interviewer asks a series of questions without giving the subject a chance to answer. "Can you tell me how long you've lived here? In this place? Have you lived here a long time?" The interviewer doesn't seem to expect the subject to respond to the first questions without clarification.

The relationship between MMSE scores and the length of the subjects's response to open and closed-ended questions was positive but surprisingly weak and not significant. There was an even smaller nonsignificant relationship ($r = -.05$) between length of subject response to mixed questions and MMSE score (see Table 5).

Finally, the proportion of relevant responses elicited by type of question was compared with MMSE scores. There were weak, nonsignificant positive relationships between relevant

responses and the use of open-ended and mixed questions and no correlation between relevance and closed-ended questions (see Table 6).

Facilitating Expression of Feelings and Concerns

The transcribed interviews were also examined to determine the types of interactions that elicited expression of feelings by the individual with AD. Several communication strategies appeared to facilitate the expression of feelings and concerns. These were (1) the use of broad openings, (2) speaking as equals, (3) establishing commonalities, and (4) sharing of self.

Broad openings—Using a broad opening such as “Tell me how you are feeling today” appeared to allow the subject to answer with as much information as he or she was able to provide. Having an opportunity to answer to the extent of one’s ability may encourage response. A simple opening often revealed a great deal about the subject’s mood. One nurse asked “How’s everything going?” The subject replied “Everything is over. The best is backed over.” This statement provided a powerful message that could be explored during that meeting. In another situation, the nurse asked “How are you?” and the subject’s response was “I’m good. Yeah, good for what?” This general approach seemed to establish a permissive atmosphere in which the subject did not feel pressured to think of a specific response.

In contrast, requests for specific information were sometimes met with anger. When a nurse asked a female subject what kind of work her son did, she replied “He is OK, whatever he does.” In another session with a different subject, a nurse asked “When did you get married?” The subject responded irritably “Who the hell knows, who cares?” The reminder that the individual cannot remember a specific fact about his or her past leaves the person feeling diminished rather than enhanced by the encounter.

Speaking as equals—Speaking as equals involved assumption of an attitude of humility on the part of the interviewer. The interviewer was open to learning from the individual with AD and attempted to develop a partnership in which both participants were equally valued. There was an absence of hierarchy in the relationship. Although the interviewer placed the needs of the subject in the forefront, there was a recognition of mutual benefit as well. For example, in a termination visit the nurse explained to the subject “You’ve always given something, E.” The subject’s response indicated her need to give “Oh, yes. That’s very nice to hear, that I’m giving.” Later in the same meeting the nurse tells the subject “You gave me your friendship …” and E replied “All right. You have my friendship. I’ll miss you very much."

Establishing commonalities—To establish commonalities, the nurse and resident discussed and shared interests and perceptions. In the following example, the nurse and subject talk about the simple but powerful act of being together. The nurse asks “What are you doing?” and the subject responds “I’m just sitting next to you … I’m thinking with you.” The nurse asks for clarification “You’re thinking with me?” and the subject responds “Yeah.” Rather than probe further, the nurse accepted the response with “OK."

Sharing of self—In sharing of self the nurse acknowledged her own feelings such as “I’ll miss you” or relating what the subject had given to the relationship. The nurse interviewers found a variety of ways to share with subjects. In one interview, they shared stories of grandchildren and reactions to *Fiddler on the Roof* that evoked feelings of sadness in both of them.

Maintaining the Conversation

To maintain the conversation, it appeared to be necessary for the nurse to first recognize a salient theme that connected consecutive thoughts. When this occurred, it was important to

follow the subject's lead and to avoid changing the subject of conversation. This was a challenge because the person with AD may not verbalize a complete thought or may substitute one word for another (Bohling, 1991). Therefore, the interviewer did not always recognize the subject's need to continue discussing a topic. In the following example, the subject is distressed about having her room changed. When the nurse interviewer redirects the conversation, the subject brings the discussion back to her concern about being in an unfamiliar room.

Subject: Oh God, it's too much honey.

Nurse: Uh huh.

Subject: I have good help.

Nurse: That is good and you have a new roommate.

Subject: I don't know who my roommate is.

Nurse: No, you don't know her.

Subject: No.

Nurse: How have you been sleeping lately?

Subject: No good.

Nurse: You wake up a lot?

Subject: Wake up a lot.

Nurse: Why do you think that is?

Subject: This is because I have no steady place to put my head on the pillow.

The theme of relocation was important enough to the resident that she persisted in discussing it even after the conversation had apparently changed to a new topic.

In another instance, the nurse was about to end the conversation but recognizes the subject's need to continue talking.

Nurse: Have a good afternoon, all right?

Subject: I'll try, it's just to me this whole damn thing went to the bottom.

Nurse: What whole thing?

Subject: Today's day.

Once the interviewer recognized a salient theme, the use of such techniques as verbal and nonverbal encouragers, reflection, paraphrasing, and summarizing helped to maintain the conversation.

In summary, although nurse interviewers asked many more closed-ended questions, subjects responded positively to all types of questions. In fact, open-ended questions which are thought to be too difficult for cognitively impaired individuals most often resulted in relatively long, meaningful responses. There was little evidence that all of the communication strategies

recommended for the development of therapeutic relationships need to be abandoned for individuals with AD.

DISCUSSION

In this study, we sought to clarify whether a number of communication techniques used in the development of a therapeutic relationship with nondemented adults might be used successfully with subjects with AD disease and whether the modifications commonly recommended for this population facilitated communication. These recommendations usually include avoidance of open-ended questions. Results suggest that, although nurses used more closed-ended questions than the other types, subjects were able to respond to open-ended questions with equal ability. In fact, there was a trend toward longer responses to open-ended questions. Because they are very specific and focused, closed-ended questions may be more helpful when assisting a resident to complete activities of daily living but may be too restrictive when attempting to develop a relationship or to discuss feelings and concerns.

Because an important goal of communication is to establish shared meaning, eliciting a relevant response is of paramount importance. Regardless of the type of question used by the interviewers in this study, more than 80% of subjects' responses were found to be relevant in the context of the conversation. This is remarkable in light of the sample's mean MMSE score of 10. There was a moderately higher proportion of relevant responses to closed versus open-ended questions (91% compared with 82%). This result could be explained in part by the length of the answers given. The meaning of a one-word answer such as yes or no is more likely to be readily interpreted. Furthermore, because there were no significant differences between relevance of responses to one type of question versus another, the data suggest that there is little reason to continue to recommend avoidance of open-ended questions when working with individuals with AD unless the specific situation indicates a need for this type of question.

Comparisons of question format with subject's MMSE scores indicated that nurses probably responded to the individual with a lower MMSE with more frustration. They asked more of all types of questions but the number of mixed questions increased as MMSE score decreased. This suggests that they tried to clarify the question before allowing the subject to answer. The length of response to mixed questions was negatively related to subjects' MMSE scores suggesting that although more mixed questions were asked of subjects with lower MMSE scores, they had more difficulty answering this type of question.

The proportion of relevant responses to open-ended questions was positively correlated with MMSE score whereas there was no relationship between relevance of response to closed-ended and MMSE score. This suggests that the level of difficulty of open-ended questions is slightly higher than closed-ended questions. Mixed questions may also be more difficult to answer and, as expected, the proportion of relevant responses to mixed questions was positively correlated with MMSE score.

Very little is found in the literature regarding techniques for establishing rapport or encouraging discussion for individuals with moderate to late stage AD. In this study, several useful strategies were identified. For the purpose of facilitating expression of feelings and concerns, broad openings, speaking as equals, establishing commonalities, and sharing of self were helpful. The use of broad openings and speaking as equals are consistent with Peplau's recommendations for therapeutic relationships in general (Peplau, 1952). Broad openings allow the subject to determine the direction of conversation and to bring up topics which are important to him/her. This is similar to Ramanathan-Abbott's findings that encouraging the individual with AD to decide which events he or she wishes to discuss facilitates extensive and meaningful talk (Ramanathan-Abbott, 1994). Speaking as equals promotes equal status for

both parties in the relationship although it does not diminish the interviewer's responsibility to focus on the subject's needs in the conversation.

Establishing commalities and sharing of self would be inappropriate from Peplau's psychodynamic perspective (Peplau, 1952). In her view, the role of the nurse is to remain in the background in the relationship to facilitate transference by the patient. Others have recommended therapeutic self-disclosure, however, to let patients know they are understood (Blazer-Riley, 1996;McDonald, 1996). In this analysis, these strategies seemed to stimulate subjects to express their feelings and concerns.

Maintaining a conversation posed special challenges for the interviewers in this study. Recognition of the subject's efforts to bring up and to discuss a salient topic seemed to be a difficult component of maintaining a conversation. Following a theme in conversation required recognition of the connections between thoughts despite the subject's difficulties in expressing thoughts coherently. The techniques which were helpful in facilitating discussion of a theme were the same as those recommended by many experts for this purpose: the use of verbal and nonverbal encouragers, reflection, paraphrasing, and summarizing (Carkhuff, 1993;Kneisl, 1996).

Much of the literature on communicating with individuals with AD has been based on clinical experience rather than empirical evidence. Techniques which can be useful for the development of a therapeutic relationship between caregiver and patient are needed to guide nurses in working with this vulnerable population. This study identified communication strategies which were helpful in creating and maintaining a therapeutic relationship with person in the later stages of AD and compared them with recommendations in the literature for the development of a therapeutic relationship for patients in general and for people with AD. Further testing of the effectiveness of these strategies and their potential therapeutic value is recommended.

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Table 1

Frequency of Questions Used by Interviewers

[[|]]	[[Mean|]]	*SD*
[[Open-ended|]]	[[15.87|]]	[[9.85|]]
[[Closed-ended|]]	[[33.32|]]	[[21.97|]]
[[Mixed|]]	[[3.19|]]	[[2.9|]]

Table 2

Length of Subject Responses: Number of Words Per Response

[[|]]	[[Mean|]]	*SD*
[[Open-ended|]]	[[7.22|]]	[[5.9|]]
[[Closed-ended|]]	[[5.94|]]	[[5.30|]]
[[Mixed|]]	[[6.1|]]	[[11.72|]]

f = .25 NS.

Table 3

Percent of Subject Responses Judged Relevant

[[|]]	[[Mean|]]	*SD*
[[Open-ended|]]	[[82%|]]	[[17.62|]]
[[Closed-ended|]]	[[91%|]]	[[12.04|]]
[[Mixed|]]	[[85%|]]	[[28.74|]]

f = 1.70 NS.

Table 4

Correlation Between Type of Question and MMSE Score

[[Question Type|]]	[[MMSE|]]
[[Open-ended|]]	[[−.22|]]
[[Closed-ended|]]	[[−0.2|]]
[[Mixed|]]	[[−35|]] *

* $p = .03$.

Table 5

Correlation Between Length of Subject Response and MMSE Scores

Subject Response (Mean No. Words)	**[[MMSE Score|]]**
[[Open-ended questions|]]	[[.14|]]
[[Closed-ended questions|]]	[[.21|]]
[[Mixed questions|]]	[[−.05|]]

Table 6

Correlation of Response Relevance and MMSE Score

[[Proportion Relevant (%)|]]	[[MMSE Scores|]]
[[To open-ended questions|]]	[[.19|]]
[[To closed-ended questions|]]	[[.00|]]
[[To mixed questions|]]	[[.16|]]