Published in final edited form as:
J Psychosoc Nurs Ment Health Serv. 1999 March ; 37(3): 28–35.

Can We Create a Therapeutic Relationship With Nursing Home Residents in the Later Stages of Alzheimer's Disease?

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Inquiry into the problem of dementia has only recently begun to focus on the emotional impact of this disorder on the individual in the later stages. Psychiatrists have focused primarily on the biological processes in the brain and clinical psychologists have limited their analyses primarily to cognition, while nurses have focused on behavior and activities of daily living, leaving other aspects of the experience neglected. Current institutional care of the person in the middle and later stages of Alzheimer's disease (AD) is frequently task focused and relationship impoverished. Several writers have lamented the widespread indifference found among professional and non-professional nursing staff in long-term care settings where few attempts are made to establish relationships with the individuals they care for (Beck & Shue; 1994;Burnside, 1994).

Given this context, it is not surprising that the question of whether it is possible to develop a therapeutic relationship with individuals in the later stages of AD is seldom raised. The purpose of this analysis was to explore the possibility of developing therapeutic relationships with individuals in the middle and late stages of AD. To do this, we examined audiotaped conversations between advanced practice nurses (APNs) and individuals in the middle and late stages of AD for evidence of therapeutic interactions.

Background Literature

To remain in a state of well-being, individuals with dementia depend on others to nurture and reaffirm them. This reaffirming process involves recognizing that persons with dementia are reaching out for social contact, honoring the attempts with a response, providing empathy for their "shattered state," collaborating with them to describe their experience, appreciating the needs expressed, sustaining dementia sufferers' actions, responding to their frame of reference, and "holding" or supporting them through their emotional experiences (Feil, 1993;Kitwood, 1993;Stokes & Goudie, 1990;Wright, Hickey, Buckwalter, & Clipp; 1995).

The caregiver must play this important role if the individual with dementia is to be sustained as a person. Institutional care environments are frequently deprived of such caring and Kitwood challenges us to imagine how the quality of life of the dementia sufferer would improve if this were not so (Kitwood, 1993).

Theoretical Bases for the Therapeutic Relationship

In his book *I and Thou*, philosopher Martin Buber (1958) wrote that every human has an inborn instinct to make contact and develop "lived relations" with others. Moreover, an individual

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becomes "I" through a longing for "Thou." In time, "I" becomes conscious of itself and continues to relate to others from this self conscious perspective. It is this consciousness of self and the ability to live in relation to our whole being that makes us human.

The interpersonal theorists first recognized the crucial role of relationships in mental health. For example, Sullivan (1953) described the development of the self as emerging from reflected appraisals by significant others over time. Positive relationships with significant others result in a strong self system able to withstand the anxieties of everyday life (Sullivan).

The therapeutic relationship in nursing was first described by Peplau in her book *Interpersonal Relations in Nursing* (1952). Built on Sullivan's interpersonal theory, her writings described the nature of a helping relationship and the process by which the nurse can facilitate personal growth in another by helping the person to identify felt difficulties, experience emotions, and understand his or her own behavior. She wrote that a relationship develops in predictable stages and that the patient's behavior changes as the relationship progresses.

Although Peplau did not envision that her work might be applied to individuals with AD, she did design her therapeutic approach with patients with chronic, regressed schizophrenia in mind. She saw the potential for personal growth in that patient population when others in nursing and in other disciplines had a more pessimistic view.

Therapeutic approaches to the person with dementia

Several therapeutic approaches have been suggested for use with individuals with dementia, including reality orientation, validation therapy, progressively lowered stress threshold (PLST), and resolution therapy.

Reality orientation is designed to improve memory through the repetition of information both verbally (such as "Today is Wednesday") and visually (such as displaying clocks, calendars, and directional signs) (Holden & Woods, 1988). Both process and outcomes are cognition based. Emphasis is not placed on recognizing and responding to feelings or interpreting the meaning of what is said.

> Within the resolution therapy framework, disorientation indicates organic illness rather than unresolved conflicts—confused messages are viewed as attempts to express needs in the present.

Validation therapy is designed to validate the person when messages are obscured by confusing speech and behavior. Communicating understanding helps the individual to come to terms with prior conflicts and decrease disturbed behavior (Feil, 1993). Validation therapy is used to help individuals who have been unable to resolve conflicts and issues developed over a lifetime. Feil believes that these unresolved issues are expressed in language and behavior that may be interpreted as dementia.

PLST has been proposed as a conceptual framework for understanding problematic behavior in individuals with AD. Within this model, individuals with dementia are thought to be progressively less able to cope with stressful stimuli in the environment. The recommended approach is environmental modification to reduce noxious stimuli and prevent fatigue thereby facilitating effective coping (Hall, 1994).

Within the **resolution therapy** framework, disorientation is interpreted as an indication of organic illness rather than unresolved conflicts (Stokes & Goudie, 1990). Confused messages are viewed as attempts to express needs in the present. Stokes and Goudie recommended using counseling strategies in the Rogerian tradition to help individuals with dementia "… meet their needs and cope with their feelings."

Any well being achieved with resolution therapy is thought to be transitory, however, so the techniques would have to be an integral part of every interaction with the individual. In contrast to Feil's (1993) view that unresolved conflicts create behavior which is interpreted as dementia, Stokes and Goudie (1990) believe that counseling interventions can promote well being in confused persons, but only temporarily as a result of the organic nature of the disease. Further, reality orientation or distraction are advised in later stage dementia, not counseling.

Taft, Fazio, Seman, and Stansell (1997) described a psychosocial model of dementia care that includes providing empathic support, involvement, and validation. Kindness, respect, and the opportunity to enjoy activities with other people are important components of this approach. The interventions are said to validate die person with the disease rather than focus on deficits as in the medical model.

Applying Peplau's Approach to Dementia

According to Peplau (1991), the nurse/client exploration of the client's feelings and concerns leads to personal growth in both parties. Creating a therapeutic relationship for persons with AD would involve encouraging and facilitating the expression of the emotions and concerns that accompany the illness experience to preserve the self and to foster self reflection and personal growth.

Peplau (1997) divided the nurse-client relationship into stages: the orientation phase; the working phase (including subphases of identification and exploitation); and resolution. In the orientation phase, the client shares his or her perception of the problem, such as "There's something wrong with my head." The client needs to feel acceptance by the nurse and to be comfortable asking for help.

During the subphase of identification, the client responds to the nurse and forms a trusting alliance. With this level of trust, the client can often express feelings such as "helplessness, dependency, self-centeredness, the wish to cry, and the like."

In the exploitation subphase, the client feels comfortable with the nurse and makes use of the relationship to obtain gratification of needs, such as when the client reaches out for the nurse's hand for comfort. In the stage of resolution, the client withdraws from identification with the nurse and develops a greater ability to cope with challenges of the illness.

> Each nurse entered the relationship with the participant with a sense of expectation and a willingness to accept the idea that a meaningful relationship was possible.

To examine whether it is possible to develop a therapeutic relationship with persons with moderate- to late-stage AD, the authors analyzed transcriptions of sessions between APNs and nursing home residents with AD. According to Peplau (1991). if a relationship were to develop in predictable ways with behavior changes from stage to stage, then it should be possible to identify these changes and therefore the progress of the relationship. In addition to self-maintenance and growth, additional goals for the therapeutic relationship with this population have been identified as:

- forming and maintaining a supportive relationship;
- being understood;
- expressing concerns;
- reducing social isolation;
- maintaining cognitive and verbal abilities as long as possible;
- reducing stress and frustration;

- maintaining dignity: and
- preserving quality of life (Burnside, 1994;Feil, 1993;Miller, 1989; Stokes & Goudie, 1991).

Method

Transcripts of sessions conducted by four APNs with 42 participants in the later stages of AD were analyzed. These sessions were conducted as part of a larger study of communication in AD. APNs varied in educational and experiential background. Two were graduate students in community health and family nurse practitioner programs, and two were doctorally prepared psychiatric/mental health nurses with extensive geropsychiatric experience including care of individuals with AD. All were trained and supervised by the authors.

Sample and Setting

The purposive sample consisted of 42 residents from two large urban nursing homes. All had a 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 (NINCDS-ADRDA) criteria (McKhann et al., 1984). Consents were obtained from proxy health care surrogates under the guidelines of the University's Committee for the Protection of Human Participants and laws of the State of Florida. The participants themselves assented to participate in the conversations and were informed that they were being tape-recorded.

Intervention

The APNs met with the participants 3 times a week for 16 weeks. Sessions were recorded during the first, eighth and sixteenth weeks, There were two or more transcripts for 42 of the 44 participants totaling 107 transcripts. There were 21 participants with 2 transcripts (weeks 1 and 16) and 21 participants with 3 transcripts (weeks 1, 8, and 16).

Each nurse entered the relationship with the participant with a sense of expectation and a willingness to accept the idea that a meaningful relationship was possible. Information about the residents' interests, former occupation, education, and family relationships was provided to the nurse by a family member in the form of a written questionnaire.

The nurses initiated the conversations, but followed participants' lead if they raised a topic of interest or concern. Interviewers were instructed not to use life review, reality orientation, or validation approaches during the conversations, but to make the discussions as meaningful as possible for the participant. The purpose of the conversations was to improve communication skills.

Data Analysis

Narrative analysis was used to explore the question of whether there was evidence of the development of therapeutic relationships between the APNs and individuals with AD over the 16-week period (Manning & Cullum-Swan, 1994).

Using a top-down approach in which we began with a set of criteria based on Peplau's work for evidence of the existence of a therapeutic relationship (Table 1), the analysis focused on the interaction between interviewer and participant reflective of the content of that interaction (Gubrium & Holstein, 1994). The conversations could be characterized as "institutionalized" rather than ordinary, everyday conversation in the sense that they were systematically scheduled and occurred between a health care professional and resident in an institutional setting (Heritage, 1987).

Transcripts were read several times by the authors to become familiar with the interactions that occurred and the topics discussed. This was done for the purpose of developing *Verstehen*, an understanding of the "reality" behind the interview data (Gerhardt 1990)—in this case, if a relationship developed between nurse and resident and whether that relationship could be characterized as therapeutic. For those participants on whom more than one transcript was available, transcripts from week 1 were compared with week 8 and week 16 for evidence of the development of a therapeutic relationship.

Findings

Participants ranged in age from 76 to 103 with a mean age of 87. The sample was primarily female (83%) in the middle and late stages of AD with Mini Mental State Exam (MMSE) scores ranging from 0 to 18 out of a possible range of 0 to 30 (mean=9.76) (Folstein, Folstein, & McHugh, 1975).

A MMSE score between 10 and 19 is considered middle stage AD; a score of 9 or less is considered late stage (Folstein, 1997).

There were evident patterns in the way participants behaved at different stages of the relationship. Typically, residents expressed disinterest, distrust, or irritability with the nurse initially, but in time, this gave way to affection and an expressed desire to continue the relationship in most cases (Table 2).

Resistance to relationships

In the following example, a participant (MMSE=13) responded irritably to the nurse's attempts to establish a relationship during the initial meeting:

Nurse: Remember I told you …I was going to bring my tape recorder so we could have a conversation today?

Participant: Where is the conversation?

Nurse: Right here. You and I are having a conversation.

Participant: This is not a conversation. What we're having.

Nurse: Well, tell me what is that we're having.

Participant: Nothing.

Nurse: Nothing? What is a conversation, then?

Participant: Something worthwhile.

In this excerpt, the resident used sarcasm to express resistance to the development of a relationship. Although her responses were brief and lacked elaboration, the message behind her statements was clear: You and this interaction are not important!

There were more frequent examples of expressing feelings at weeks 8 and 16 as compared to week 1. In week 16. for example, the nurse asked one participant (MMSE=8) about her comfort level and she replied with strong emotion.

Nurse: Are you comfortable?

Participant: I am not comfortable … I am crazy, everything is crazy.

After a lengthy discussion about her perceptions of the symptoms of her illness, she confides her concerns about the relationship.

Participant: I talk to you and I am afraid that you will say that she is crazy. She is crazy, me, me.

Nurse: I would never say that … How can I help you feel better today?

Participant: I believe you.

Anxiety

A common theme among participants was anxiety. For male residents, anxiety about not having money when they reached into their pocket seemed to symbolize a.lack of power or independence and was a genuine source of concern. In the next example, the nurse has been meeting with a man (MMSE=10) for 8 weeks. Shortly after greeting him, she makes a casual comment to which he responds with concern.

Nurse: You have nothing in your pocket.

Participant: That's right, absolutely nothing. So I got scared, I don't know. I'm glad you're here.

In week 16, the same man expresses affection to the nurse.

Nurse: (Pointing to his name on a greeting card) Who is this?

Participant: Someone who likes you.

Although the individual might not remember the nurse's name, a bond developed between nurse and participant and in many cases, participants expressed warmth and appreciation for the visits.

Low self-esteem

Another common theme was low self-esteem related to relinquishing former roles. In week 8, a woman (MMSE=14) shared her negative opinion of herself.

Nurse: Did you work with organizations?

Participant: No. I used to, but not anymore. I am nothing, I have become myself. That's all. I am restricted to myself and that's it. I don't want to be bothered with people bothering me.

Examples of mutuality that existed at week 8 and 16, but was not present earlier in the relationship included expressions of pleasure at seeing the nurse, verbalizing emotions, and initiating physical expressions of affection, such as a hug, stating "I love you," singing to the nurse, and asking the nurse to "come back again" or "don't leave."

Despite the participants' severe memory impairment, there was evidence that most (84%) were able to form a relationship with a nurse by weeks 8 and 16. The proportion of participants who displayed evidence of a developing relationship at either weeks 8 or 16 is displayed in Table 2.

Even residents with limited verbal skills and MMSE scores of 10 or less were frequently able to express their concerns. One woman who was 91 and had a MMSE score of 9 clearly expressed her anxiety to the nurse in the final week (16) of the relationship.

Participant: Everything goes for me different. Different.

Nurse: Does it make you frightened?

Participant: Frightened, yes, me I rather think.

Another 87-year-old woman with an MMSE of 10 often expressed her despair. At week 8, she expressed suicidal ideation.

Nurse: How do you feel?

Participant: Terrible.

Nurse: What's bothering you?

Participant: I don't know.

Nurse: Can you tell me something?

Participant: I want to die.

Despite treatment with antidepressants, during week 16 of meeting with the nurse, she continued to express low self-esteem and depressed affect.

Participant: I want to die.

Nurse: I know, but why would that make you feel better?

Participant: I'd be happy.

Nurse: What would make you happy about that?

Participant: I don't know.

Nurse: You started to tell me.

Participant: I don't know. Something's wrong with my head.

Seven of the 42 (17%) participants displayed no evidence of a developing therapeutic relationship with the nurse (Table 3). All of these participants had MMSE scores of 10 or less and most had severely limited speech, perseverative speech, or no speech at all. One participant's responses were lengthy, but perseveration and word substitution prevented understanding of her interactions.

The exception to this pattern was an 86-year-old woman with a MMSE score of 6, but considerable communicative ability who actively rejected the nurse at weeks 1, 8, and 16. In week 16, she continued to express negativity and distrust. On the last day, she greeted the nurse with "What the hell do you want?" When the nurse invited her for a walk, she replied "You wouldn't hurt me would you?" Later she told the nurse "Leave me alone." This woman's responses represented the only example of continued avoidance and rejection without evidence of change over the 16 weeks. Table 3 depicts the characteristics of these seven individuals and the primary problem encountered in trying to develop a relationship.

Discussion

The literature provides ample evidence that health care professionals, including most nurses, assume that persons with AD are not good candidates for therapeutic relationships. Indifference, frustration, and apathy among caregivers is widespread (Burnside, 1994;Norberg & Asplund, 1990). Feelings of hopelessness and meaning-lessness in both caregivers and care recipients might be decreased if meaningful relationships were possible.

> Negative responses to living with AD should not be surprising or unexpected at any stage of the disease—nurses must be aware that depression and anxiety are common even in the later stages of illness.

The findings of this investigation suggest that it is time to challenge the assumption that therapeutic work with moderate to severely impaired clients is impossible or futile. The intervention in this study was originally designed to improve conversational skills, not to deal with the emotions and concerns of persons with AD.

However, the APNs found that most participants spontaneously shared their feelings and concerns and that many remembered their nurse, looked forward to her visits, and were saddened by termination.

The effect of the degree of cognitive impairment and severity of language deficits on establishment of a relationship was not consistent, although perseveration and speech limited to a few or no words did interfere with establishment of a therapeutic relationship. All of the participants who did not show verbal evidence of developing a relationship with their nurse had lower MMSE scores (10 or less).

Although it is often assumed by caregivers that there is Jess distress in individuals in later stages of AD (Tappen & Williams, 1998), we found many examples of verbal expressions of anxiety and despair in individuals who would be classified as late stage dementia according to Folstein (1997).

Implications For Practice

Negative responses to living with AD should not be surprising or unexpected at any stage of the disease. Nurses must be aware that depression and anxiety are common even in the later stages of illness. Observation-based rating scales, such as the Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian; 1988), and the Dementia Mood Assessment Scale (Sunderland et al., 1988) are available for assessment of mood in this population. A simple assessment approach that elicits the individual’s input is also available (Tappen & Barry, 1995).

Once recognized, anxiety and depression can be treated with a variety of interventions including pharmacologic, behavioral, and environmental approaches (Tappen, 1997). A consistent, supportive relationship with a professional nurse will provide the individual with AD the opportunity to express concerns and avoid isolation.

In terms of the PLST model (Hall & Buckwalter, 1987), individuals in later stages of AD who are anxious or agitated would be viewed as unable to cope with sensory stimuli that overwhelm them. An alternative interpretation would be that these emotional reactions are very human responses to a devastating illness.

Cooperate with patient's need for growth

Peplau (1991) wrote that every person is capable of growth when challenged with the illness experience. She viewed the nurse's role as cooperation with the client's innate need to grow and develop. The role of the nurse in relation to the individual with AD within Peplau's framework would be quite different from that of the nurse in PLST where the nurse protects the client from stimuli as the client's stress threshold decreases.

Future Research

These findings are limited by the fact that they are based on the perspective of only two coders. They are also limited by the dependence on the verbal aspect of the interaction. Anecdotally, the involved nurses described some nonverbal evidence of a relationship with the participants who had severely limited speech or no speech. In this analysis, we were unable to substantiate these claims.

Further study of carefully designed interventions with direct observation of sessions, analysis of videotape recordings, and the addition of additional independent coders is needed to provide professional caregivers with more information on the strategies that could improve the quality of life and promote a sense of well being and continued growth in persons with AD. The question of whether verbal approaches are helpful in improving quality of life for those in late-stage dementia remains to be answered. Further study of this issue appears to be warranted.

KEYPOINTS

Creating a Therapeutic Relationship

Can We Create a Therapeutic Relationship With Nursing Home Residents in the Later Stages of Alzheimer's Disease? Williams, C.L., & Tappen, R.M. Journal of Psychosocial Nursing and Mental Health Services 1999;37(3):28-35.

1. Despite their entrance into advanced illness, the majority (83%) of participants in the study displayed evidence of having begun a therapeutic relationship with their assigned advanced practice nurse.
2. With one exception, those participants who did not evidence development of the relationship had severely limited speech, perseverative speech, or did not speak at all.
3. It is time to challenge the assumption that individuals in the middle and later stages of Alzheimer's disease are not good candidates for developing a therapeutic relationship.

Web notes

This month, excerpts from a review of the book "Elegy for Iris," appear on the Alliance for Psychosocial Nursing's Web site. The book, written by John Bayley, Iris Murdoch's husband of 42 years, is his personal account of their last years together as she slipped into dementia.

For additional information related to patients with AD—and their caregivers, subscribers may visit www.psychnurse.org.

Acknowledgements

This study was supported by Grant R01-NR03322 from the National Institute for Nursing Research. NIH, Ruth M. Tappen, EdD, RN, FAAN. Principal Investigator.

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TABLE 1

Examples of Narrative Analysis

[[Stage of Relationship|]]	[[Criteria|]]	[[Evidence/Behavior|]]
[[Orientation|]]	Verbalizes trust and distrust	Subject: “This is not a conversation. What we’re having.” Week 1
[[Working—identification|]]	Verbalizes emotion and feeling	Subject: “I want to die.” Weeks 8 and 16
[[|]]	Verbalizes satisfaction and enjoyment of interaction	Subject: “I’m glad you’re here.” Week 8
[[|]]	Expresses affection for nurse	Subject: “I love you.” Week 8
[[Working—exploitation|]]	Confides specific emotional event	Subject: “I talk to you and I’m afraid you will say ‘she is crazy. She is crazy, me, me.’” Week 8.
[[|]]	Expresses desire for relationship to continue	Subject: “Thank you for letting me talk to you.” Week 8
[[Resolution|]]	Expresses sadness and loss regarding end of relationship	Subject: “Where are you going off to?” Week 16.
[[|]]	[[|]]	Subject: “You want to sleep here? Are you going now? Going to leave me?” Week 16.

TABLE 2

Participant Behavior During Sessions Weeks 8 and 16

[[Behavior|]]	[[Participants No. (%)|]]
[[Verbalizes emotion/ feeling|]]	[[19 (43)|]]
Verbalizes satisfaction or enjoyment of interaction	[[15 (34)|]]
Confides specific emotional event	[[13 (30)|]]
[[Verbalizes trust|]]	[[5 (11)|]]
Expresses affection for nurse	[[20 (46)|]]
Expresses desire for relationship to continue	[[8 (18)|]]

TABLE 3

Characteristics of Participants Who Did Not Evidence a Relationship With Nurse Interviewer

[[Age|]]	[[Gender|]]	[[MMSE|]]	[[Problem|]]
[[82|]]	[[Male|]]	[[10|]]	[[Severely limited speech|]]
[[84|]]	[[Male|]]	[[2|]]	[[No speech|]]
[[82|]]	[[Female|]]	[[5|]]	[[Severe perseveration|]]
[[90|]]	[[Female|]]	[[5|]]	[[Severely limited speech|]]
[[86|]]	[[Female|]]	[[6|]]	[[Active rejection|]]
[[97|]]	[[Female|]]	[[6|]]	[[Severely limited speech|]]
[[73|]]	[[Female|]]	[[0|]]	[[No speech|]]