



23

Intervening with aging families and Alzheimer's disease

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OVERVIEW

This chapter presents a systemic-strategic approach to intervening with aging families managing Alzheimer's disease (AD). An AD patient's problems (physical, cognitive, and/or emotional) both affect and are affected by the family. This relationship is demonstrated through a case study. Interventions to interrupt maladaptive interaction patterns, such as devising strategies to modify difficult behavior, using questions as interventions, reframing the situation, offering positive connotations and split opinions, devising rituals, recommending support groups, and facilitating discussion of institutionalization, are described. Iatrogenic double binds are discussed as well as the analogue that exists between the patient-family system and the family-health care professional system.

CASE STUDY

The Simpson family was referred to the Family Nursing Unit, Faculty of Nursing, University of Calgary (Wright, et al., 1985) by the family physician, who recognized their need for assistance in caring for Mrs. Simpson's elderly sister. At the time of referral the household consisted of John, age 75, a retired postal employee; Mary, age 66, a homemaker; and Mary's sister, Margaret, age 74. Margaret had been diagnosed 3 years before as having Alzheimer's disease (AD) and had lived with the family for the past 2 years, since her husband's death. After enjoying "the freedom of retirement" for 8 years, John and Mary now felt trapped and burdened with their caregiving responsibilities. They had even postponed a holiday for the past 2 years. However, the Simpsons insisted that they "knew" that having Margaret with them was the "right and only thing to do."

The family physician reported that Margaret's most recent neuropsychological evaluation suggested that her AD was not as advanced as her problematic and careseeking behaviors would indicate.

Following a thorough family assessment using the Calgary Family Assessment Model (Wright and Leahey, 1984) one major problem was identified: a helping/helplessness cycle in the family system, which appeared to be perpetuating both Margaret's ongoing, debilitating dependence and the couple's perceived entrapment.

Assessment revealed that the couple's main source of information about AD had been the television. Given Margaret's pre-AD history of dependent behavior (i.e., "she's always needed someone to take care of her"), John and Mary assumed that she needed even more help following her diagnosis.

The couple requested that Margaret not be involved in the sessions, and the request itself was seen as providing insight into family functioning. The sister's absence in the sessions was made present through triadic questioning (Tomm, 1984b) and in the delivery of each intervention.

During five family systems nursing sessions over 6 months, the nurse slowly but consistently challenged the family belief that Margaret was incapable of doing anything for herself and had to be "babied" lest she become upset. Also challenged was John and Mary's strong belief that "caring equals 'doing for' and 'helping more.'" Interventions were designed to increase Margaret's performance abilities, reduce the burden on John and Mary, and increase positive feelings in the triadic relationship and between the various dyads.

In the first session, it was determined that much of the talk in the Simpson household centered around Margaret's health. A vicious circle had developed in which the couple inquired about Margaret's health and Margaret complained; the more she complained, the more the couple pursued the topic, and vice versa. In order to interrupt this negative pattern, John and Mary were instructed not to talk of Margaret's health for 2 weeks; they were told, in addition, not to respond to her complaining and to note her reaction. The task was expected to be difficult, and the couple was encouraged to support each other in its completion. In addition, they were asked to stop performing a single task (of their own choosing) that they usually performed for Margaret.

John and Mary arrived for the next session elated. They had decided to stop providing Margaret with a glass of water at breakfast and found that she took the initiative to get it herself. They also noted a marked reduction in her health complaints when they did not discuss her problems with her. During this second session, it was hypothesized that Margaret used her helpless, "out of control" behavior to maintain control within the family. It was also noted that Mary was more reluctant than her husband to believe that Margaret could be more independent. The nurse hypothesized that perhaps Mary's helpfulness represented her *own* attempt to maintain control. To gently challenge family beliefs and interrupt the helping/helplessness cycle a second time, the couple was instructed to perform an "experiment." Twice during each of the next 2 weeks, they were to "pretend helplessness": Mary would declare that she was too tired to finish preparing supper, and John would "pretend confusion and incapability" when trying to make the toaster work for breakfast.

The intervention rippled dramatically through the family system, and by session three the couple began to instigate changes on their own. John had suggested that Margaret, who was incontinent nightly, begin getting her own clean bedsheets and "get more exercise" by going to the bathroom more frequently. Margaret was now getting bedsheets from the closet, making her bed, making toast, dusting the living room furniture, and "apologizing" when she

didn't pour her own glass of water at breakfast. In order to maintain these rapid changes, the couple was advised to proceed slowly and to consider what to do with the time that was formerly devoted to worrying about and waiting on Margaret. Three weeks later, the couple reported that Margaret had not been incontinent for 4 consecutive days and was continuing to do more for herself. They stated that her appearance was 100% improved. The couple had gone out 3 afternoons "just to enjoy themselves!" Mary reported that she was finding it "easier to sit back more than I used to."

The nurse attempted to solidify the established changes and further challenge the family through a split-opinion intervention. John and Mary were told that half the team felt there had been just the right amount of change and that the couple should not request any more of Margaret, while the other half were convinced that Margaret could do 10% more and that the couple should continue to seek creative ways of increasing her independence.

The overall effectiveness of family intervention with this AD family became apparent 3 months later when the nurse found it almost impossible to arrange the follow-up session—because the couple was busy making last-minute arrangements for a vacation to Ireland!

THE NURSING PROCESS

Assessment

The health problem: Alzheimer's disease. Alzheimer's disease (AD) has been termed "the silent epidemic" and "the disease of the century"; it now affects the lives of 1.5 million older "victims" and 4.5 million of their families and friends. Who is the AD "patient"? From a family systems perspective, of course, the whole family is the "patient"; however, for purposes of this chapter, the older person with AD will be termed "the patient."

The National Institute of Neurological and Communicative Disorders and Stroke estimates that 15% of people over 65 years of age have varying degrees of dementia or deterioration in intellectual capacity (McKinstry, 1982). Sixty percent of these cases are attributed to Alzheimer's disease.

Alzheimer's disease is a progressively degenerative brain condition with no known cause or cure. It is characterized by neurofibrillary tangles, senile plaques, and granulovascular structures; as these anomalies in the brain increase, cognitive functioning deteriorates. Chronic decline in intellect, memory, judgment, concentration, self-care abilities, and personality all reflect physiologic changes in the brain.

Although the AD's "cause" is not presently known, possible etiologies include viruses, biochemical changes, aluminum intoxication, genetic defects, and immune system malfunction (Schneck, et al., 1982).

Consistent with this elusiveness in cause and cure, accurate diagnosis of AD is difficult; positive confirmation is available only through au-

topsy. Diagnosis thus revolves around exclusion of other disorders—i.e., drug use, circulatory problems (strokes, cardiac insufficiency), head trauma, tumors, or metabolic disorders (Cohen, 1980)—that might produce similar cognitive symptoms.

Zarit and Zarit (1984) emphasize the need to distinguish dementia from delirium and depression. Depression is the most frequent psychological cause of cognitive impairment in elderly patients and frequently masquerades as dementia (Wells, 1979). A brief mental status examination can be used to differentially diagnose dementia from either depression or delirium (Kahn and Miller, 1978; Zarit, 1980); the history of problematic symptoms will also help establish the diagnosis. Wells (1979) developed a comparative table for differentiating pseudodementia from irreversible dementia, highlighting both family and individual manifestations:

Pseudodementia. Family is aware of dysfunction. Symptoms progress rapidly following a precise, identifiable onset. Patient complains of cognitive loss and communicates strong distress. Nocturnal accentuation of dysfunction is uncommon. "Don't know" answers are typical. Patient's task performance varies widely, even on tasks of similar difficulty.

Dementia. Family is unaware of dysfunction and its severity. Symptoms develop slowly and progress; patient complains very little about cognitive loss and appears unconcerned. Nocturnal accentuation of dysfunction is common. "Near-miss" answers are frequent, and task performance is consistently poor on tasks of similar difficulty.

Although AD is characterized by an insidious onset of symptoms and marked variability in the course of the illness, some guidelines can be presented (Table 23.1). Over a period of years, the patient becomes bedridden, emaciated, and helpless; dementia and physical incoordination increase. Death occurs from infected pressure sores or bronchopneumonia (Dewis, 1982).

Aging families and adult children. Families do not exclude their elderly; indeed, most continue to provide assistance at great personal cost. Twice as many bedridden and housebound elderly patients are being cared for by families as are in institutions (Shanas, 1979), a statistic that holds true for AD patients. Family members care for 90% of America's older, mentally impaired persons (Zarit et al., 1980).

Stimulation, patience, and security have been noted to be three essential ingredients in effective care of the demented (Arie, 1973). Caregivers may understandably be overwhelmed when attempting to operationalize these parameters of care. As AD patients' awareness of their disability decreases, security needs take precedence, further increasing demands on caregivers.

Table 23.1 Stages of Alzheimer's Disease

Stage	Duration (yrs.)	Characteristics
Forgetfulness	2 to 4	<ul style="list-style-type: none"> • (Possible) First indications: memory loss regarding present events/familiar objects or people (for example, own telephone number, route to office or home) (Dewis, 1982) • Loss of spontaneity, initiative, sense of humor (Hayter, 1974) • Reduced attention span • Withdrawal from activities (first sign of difficulty) (Zarit, 1982)
Confusion	2 to 20	<ul style="list-style-type: none"> • Progressive memory loss • Aphasia • Agnosia • Apraxia • Wandering • Nocturnal restlessness • Repetitive motion(s) • Temporal disorientation • Mirror sign (inability to recognize self in mirror) (Pinel, 1975)
Dementia*	1	<ul style="list-style-type: none"> • Complete disorientation • Seizures • Gait disturbances • Pseudoparkinsonism • Forced laughter • Crying • Klüver-Bucy-like syndrome (hyperorality, flat or decreased affect, bulimia, usual agnosia, hypermetamorphosis or compulsively touching everything)

*All symptoms described by Sjogren (1950); Sjogren et al. (1952).

Impact of Alzheimer's disease on the family. AD caregivers (usually a spouse or adult daughter) face time- and energy-consuming responsibilities that must often be discharged at tremendous personal cost in terms of social isolation; lack of time for self, family, and friends; career interruptions; financial drain; and heavy physical labor (Archbold, 1982; Brody and Lang, 1982). The entire experience can produce a variety of conflicting emotions, including sadness, frustration, anger, guilt, discouragement, empathy, rejection, pity, revulsion, and entrapment (Mace and Rabins, 1981). Life narrows, and caregivers may feel very alone. Caregivers, usually women, are caught "in the middle" in three senses: generation, age, and competing demands on their time. The Philadelphia Geriatric Center identifies these "women in the middle" as those most in need of assistance in cases involving aging families (Brody, 1981).

Silverstone (1979) clarifies our understanding of the multiple demands, transitions, and tasks that AD caregivers may face by viewing their situation in terms of their developmental tasks: relinquishing youth, adjusting to the "empty nest" (which Silverstone considers a euphemism for the multitude of feelings this life-cycle stage may generate), facing mortality and age, and assuming a filial role in relation to parents. The interdependence of these tasks can complicate even further the potential conflict between the middle-aged woman's filial, marital, and parental responsibilities, thus placing daughters of aging parents at "the fulcrum of familial stress" (Bloom and Munroe, 1972).

Simos' (1973) seminal study of adult children and their view of the problems of their aging parents concluded that most children can handle their parents' physical problems, even those that may require considerable time and attention. What disturbed them were the psychological, interpersonal, and social problems associated with managing their elderly parents' isolation or ineptness. The adult children studied responded to their perception of these problems by "attempting to console or comfort the parent, struggling with negative feelings aroused by the parent, serving as peacemaker with caretaking personnel and others, dealing with family disruptions set off by the parent, or in rare cases attempting to limit the parent's insatiable demands" (p. 80).

Zarit and colleagues (1980) measured the level of burden experienced by the primary caregivers of impaired elderly; such burdens were evoked by "lack of time for oneself, the excessive dependency of the patient on the caregiver, and (the) caregiver's fears about further deterioration in the patient's behavior" (p. 652).

The results of this investigation indicated that caregivers' burdens were unrelated to behavior problems resulting from the elderly person's impairment. Rather, they seemed associated with the caregiver's degree of social support—specifically the number of visits by other family members to the elderly parent. The correlation was negative; the more support received (as indicated by the number of visits), the less burdened the caregiver felt.

Pratt and colleagues (1985) were among several researchers to examine how Alzheimer's caregivers decreased their perceived burdens. Self-confidence in problem-solving and the ability to reframe (redefine stressful experiences to provide new understanding and facilitate management) were effective internal strategies (McCubbin, et al., 1981). Spiritual and extended-family support were identified as effective external coping mechanisms (McCubbin et al., 1981), as was taking turns providing care ("principle of substitution") (Johnson, 1983; Shanas, 1979).

Spiritual support may provide a basis for assigning meaning to an AD problem, allowing the caregiver "to neutralize a potential stressor by seeking positive attributes in the situation or making positive comparisons to others" (Pratt et al, 1985, p. 31). Because of the numerous losses accompanying Alzheimer's and the need for caregivers to continually modify their reactions to the patient in order to maintain a calm environment, many find spiritual support particularly helpful.

Pratt and coworkers (1985) associated an internal strategy of "passivity," employing avoidance responses, with higher levels of caregiver burden. This association may be understood by hypothesizing that high levels of perceived burden evoke passivity. The more passive and nonconfident one is, the more burdened one becomes.

Perceptions of burden were found to be related to the caregiver's health status. Those in excellent or good health felt lower burden levels than those in fair or poor health. Seventy-nine percent of caregivers studied indicated that caregiving had negatively affected their health status; 35% indicated a great negative effect on health, while 44% cited moderate impact.

Family impact on Alzheimer's disease. So far, this chapter has emphasized the impact of AD on the family. But what of the impact of the family on AD? Roth (1977) and Tomlinson and colleagues (1970) found that up to half of all behavioral problems in Alzheimer's and vascular dementia patients arise from factors other than brain cell loss. These additional factors included the patient's personality, personal history, and current life situation.

Interaction patterns in aging families can stimulate, exacerbate, or ameliorate AD deficits. Herr and Weakland (1979b), operating from a brief strategic therapy model, have broadened their perception of age-related problems from "seeing these problems as arising only from individual, age-related and usually irreversible or progressive deficits, to seeing that at least part of the difficulties involved may be related to family communication" (p. 144). They define communication as the "patterns of interactions which have the potential for pathogenesis" (p. 145).

Herr and Weakland also assert that elements of the traditional double bind can be present in the adult child-aging parent relationship and may promote diagnosis of senile dementia. For example:

- An *intense relationship* exists due to the increased dependency needs of the elder and/or the social pressures on the adult child.
- Advancing age prompts emergence of sensitive topics that may involve *contradictory levels of messages* to the elder. For example, the following

contradictory message may be given to a recent widow by her children: "We will help you to remain independent. If you refuse our help (by not following all our advice and directives) this will be a sign to us that you are unable to continue living independently" (p. 147). The message is paradoxical. The only way the mother can remain independent is to be dependent (follow orders).

- The *opportunity* to leave the field is minimal for the elder because of physical, social, and economic restrictions.
- "Elders may have *difficulty commenting on the contradiction* because of minor cognitive impairments which would not be of much significance in other respects" (p. 147).

Therefore, it is useful to look beyond the question of "Why did this problem first appear?" to that of "What is the cycle of interaction in the family system that maintains or escalates the problems of the family coping with Alzheimer's?" (Weakland et al., 1974).

Attention to the cybernetic aspects of family interaction can also provide vital information about the elderly, their problems, and potentials (Watson and Wright, 1984). Circular epistemology looks for recurrent negative patterns—that is, vicious cycles of interactions. It prompts a shift from evaluating family members' intentions to evaluating the effect(s) of their behavior...and the effect of the effect(s) (Tomm, 1984a). Circular causality perspectives can provide new pieces to the Alzheimer's family puzzle.

As AD progresses, family members frequently report that their loved one (the patient) becomes a virtual stranger, doing things that are uncharacteristic of the former self. This "strange" behavior elicits uncharacteristic responses from the family members, which can lead to a house full of "strangers," all of them trying to make sense out of each other's behavior. As a result, the AD caregiver may become preoccupied with the physical aspects of care and begin to "talk over" the patient as if he were not present. "When this happens the patient's world begins to die around him, and his motivation to remain connected to reality diminishes" (Dewis, 1982, p. 34), which verifies to the caregiver that the patient is "not really there." The cycle perpetuates itself, aggravating Alzheimer's symptoms.

AD, particularly in its early stages, has few physical symptoms; that can make it difficult for the family to lower their expectations of the patient. One person said, "If I wore a bandage or used a crutch I would get more understanding" (Dewis, 1982, p. 33). Families may respond instead by exhorting the patient to change, thus increasing his frustration and discouragement. Family members may then conclude that "if only he wouldn't get discouraged and (would) just try harder he could do more."

Even when the disease is finally acknowledged and becomes "visible," either through patient behavioral/personality changes or through family education, the family may render the patient "invisible" by not expecting anything of him because he is "not there." The more they think of the patient as "not there," the less connected he will be to them or to reality, once again perpetuating a counterproductive cycle.

Family assessment model. The Calgary Family Assessment Model (CFAM) (Wright and Leahey, 1984) can be used to assess aging families coping with Alzheimer's disease. The visual impact of the two tools for *structural* assessment—that is, the genogram and the ecomap—make them immediately useful to the nurse. Diagramming three generations of family members, their ages, occupations, and living arrangements facilitates identification of potential family resources.

The ecomap diagrams each family member's contacts with "outside" systems, for example, work, church, community, and friends. A "before" and "after" AD ecomap is especially revealing, since family members typically become isolated from former social contacts as the illness progresses. The nurse may uncover through ecomap questions a pattern of diminishing personal and increasing professional contacts. Sample questions include:

- "How have your friends responded to your husband's AD diagnosis?"
- "With what other health care professionals is your family presently involved?"

Developmental assessment focuses on the three major tasks of aging families:

- Shifting from the work role to leisure and/or retirement.
- Maintaining both systemic and individual functioning while adapting to increased age.
- Preparing for one's own death and dealing with loss of spouse, siblings, and/or parents (Wright and Leahey, 1984).

The developmental impact of AD can be assessed through such questions as:

- "What did [the patient's] forgetfulness affect first: his work or leisure?"
- "What do you and [the spouse/patient] still do together, in spite of the illness, to make you feel like a couple?"
- (To adult child) "Of your mother and father, whom do you think was more satisfied with his or her life's accomplishments before [the patient's] AD was diagnosed?"

Instrumental functioning is a particularly critical area in AD families. The caregiver's burden and the family's abilities to assist the primary caregiver and utilize community resources effectively can be assessed through direct questioning about the routine activities of daily living.

The CFAM's nine *expressive functioning* areas help nurses assess the AD family's underlying dynamics; one area, beliefs, is especially useful. A nurse must understand each family member's beliefs about AD. Such information can be obtained by asking, "What is your understanding of Alzheimer's disease?" or, "What do you think causes Alzheimer's disease?" or, "How do you think your family is coping with Alzheimer's at this time?"

AD myths and misconceptions abound, and nurses can play a vital role in providing and clarifying information. Several points should receive particular emphasis:

- Senility is not a normal part of growing old.
- The patient may be the first to know that something is wrong; one cannot assume that AD patients do not suffer because they do not know that anything is wrong.
- AD is not contagious.
- AD does not result from excessive strain or emotional stress.
- AD-related mental declines are not from laziness.

Assessment of the presenting problem. Since AD's stages may vary from person to person, and therefore from family to family, the caregivers cannot foresee the duration, type, or severity of symptoms. A nurse must therefore obtain or record specific descriptions of the patient's behavior, cognition, and affect at the time of initial assessment. The nurse must find out what behavioral, cognitive, and emotional changes the family has weathered, and how they weathered them.

To intervene effectively and efficiently with AD families, nurses need to obtain a clear picture of the disease problem in the family context. This requires asking each family member, "What is the problem that is concerning your family the most at this time?" This process is vital, since a problem without a definition is a problem without a solution (Herr and Weakland, 1979a).

In defining the problem, it is important to be specific:

- Ask the patient and family about specific instances of forgetfulness and behavioral problems.
- Avoid accepting such vague descriptions as "he had poor judgment."
- Obtain a specific history of the problem, and the situation(s) in which it arises, in order to place complaints in a broader context. For example, a person who has always had a poor memory for names should not be labelled demented if that trait continues into old age.

Memory problems may arise only in specific contexts, "either antecedent to some event or when the problem results in positive consequences or reinforcements for the individual" (Zarit, 1979, p. 242). It is always important to look for a functional basis for the difficulty.

When an individual problem has been specifically outlined and illustrated with examples, a nurse may steer discussions to a more systemic level by asking how the situation concerns family members. She might ask an adult daughter, for instance, "How is your father's forgetfulness and confusion a problem for you?"

Exploring each family's attempts to resolve its problems can also reveal any vicious interactional cycles that might maintain or escalate the AD problem. Questions such as, "When your husband forgets his words, what do you do?" or, "What has worked the best/the worst?" can be helpful.

Finally, assessing the presenting problem involves goal setting. Herr and Weakland (1979a) offer a useful question: "What is the smallest amount of change that would indicate to you that you are making progress in solving the problem?"

Planning

The information derived through assessment allows the nurse to formulate hypotheses about the interaction between family dynamics and the problematic AD symptom(s)—hypotheses that will guide intervention.

Zarit (1979) specifies several intervention goals for families coping with progressive cognitive deterioration of an elderly member (Table 23.2). Working from a systemic (Tomm, 1984a) and a strategic (Fisch, et al., 1982) perspective of family dynamics, the intervention goal(s) is (are) to introduce greater complexity into the family system and to build upon existent but formerly untapped family competencies and resources.

Table 23.2 Intervention Goals for AD Families

- Maintain maximum patient independence/function.
- Strengthen family caregiving capacity through emotional and informational support.
- Correct misconceptions about AD.
- Encourage/permit caregiver(s) to meet personal needs.
- Respond to patient's major behavioral problems.
- Arrange for appropriate outside support/care services.

Intervention

The systemic-strategic approach directs therapeutic efforts toward changing interactional patterns between people rather than toward changing a particular individual.

Provide information. Simply introducing new information about AD into a family system can interrupt vicious cycles of family interaction, because family members characteristically act according to their beliefs/perceptions of "reality." New information may change not only the existing beliefs/perceptions of the illness, but also perceptions of family members' behaviors and motives, resulting in a "new family reality." AD families need information about the causes, cures, and consequences of cognitive decline (Zarit and Zarit, 1984) and about the course of the illness (Gwyther and Matteson, 1983).

Causes of AD. The nurse should explain that the causes of AD are not currently well understood. Genetic inheritance has been considered but not confirmed; the slow-acting virus hypothesis has not been substantiated. Inactivity is considered not a cause but a result of AD (Zarit and Zarit, 1984).

Cures. Zarit and Zarit (p. 240) also point out that "one of the most crucial parts of an intervention is to dissuade (the family) from seeking out quack or ineffective cures while still maintaining hope that something can be done."

Consequences of cognitive decline. The nurse can help the AD family understand memory loss by explaining that the patient cannot remember that he/she forgets and that forgetfulness does not result from lack of effort, and by elucidating its behavioral impact.

Disease course. Gwyther and Matteson (1983) indicate that most families who have received basic AD information want to know how the disease will progress. This is especially true of families who have coped effectively in the past by gathering information and making plans. However, three issues can complicate this process:

- family ambivalence about how much they want to know about the disease (Gwyther and Matteson, 1983)
- highly idiosyncratic disease processes, which make it difficult to predict specific functional changes over time (Berman and Rappaport, 1984)
- variation in family members' knowledge about AD, their misconceptions, and their desire for more information.

The nurse should verbally ascertain each family member's present understanding of AD and perceived knowledge deficit, and then provide specific information *in writing*. Two communication skills are better than one, especially when a family is confused and in crisis.

Zarit (1982) does not consider the concept of AD stages useful since patient deficits and the symptoms that families find distressing vary widely. Gwyther and Matteson (1983, p. 94) however, determined that "the stages of the illness offer some structure for the family caregiving efforts."

Given the debatable usefulness of guidelines for patient decline, it is beneficial to inform family members about *their own* changes relative to the patient. Relatives need to recognize and prepare for the progressive loss of the family member they know. They must acknowledge that the patient's ability to fulfill established family roles (e.g., "Mr. Fix It," "peacemaker," "news agency") will decline or disappear. As the patient deteriorates, family members will be required to "assume the role of 'protective kin,' 'pocket brain,' or 'interpreter' for their disabled relative" (Gwyther and Matteson, 1983, p. 94). They will be forced to make decisions for their relative without his concurrence or approval.

Modify difficult behavior. Specific strategies for managing the emotional and behavioral problems common to Alzheimer's patients should be explained to the aging family. A compilation of suggestions offered is found in Table 23.3.

Use questions as interventions. The interview process—specifically circular questioning—can be used to release new information into a "stuck" family system. By encouraging family members to explore differences and acknowledge connections between their behaviors and their beliefs, implicit information can become explicit and "new" (Tomm, 1984b). Tomm explains that productive interview questions are based on two fundamental assumptions: that information lies in differences and that a behavior's meaning is derived from its context.

Circular questions—for instance, difference, behavioral effect, hypothetical, and triadic—probe the family system and mobilize existing but previously inaccessible internal resources. For example, when instrumental tasks change as a result of the patient's decreasing abilities, it becomes important to ask, "Which of the tasks that your husband used to perform will be most difficult for you to assume? Who can help you the most with this? Who in the family would be most helpful?"

The nurse's questions can help the family support its caregivers and recognize caregiving efforts. For instance, in a meeting with family members, the nurse might ask an adult child, "What do you think your father might be most grateful to your mother for these days?"

As AD shatters family members' dreams and life expectations, other family supports are needed and can be stimulated. In a family interview an adult child may be asked, "How different do you think life is for your mother now that your father has AD? What dreams and expectations did she have that she feels cannot be fulfilled? Which dreams can still be realized? Which need modification or letting go?"

Questions useful for prompting the family to examine its beliefs about the patient's abilities are:

- "Was there something that [the patient] did in the last month that surprised you?"

Table 23.3 Caregiving Strategies for Alzheimer's Patients

Patient Problems	Initial Family Reaction	Family Members' Interventions
Sleep disturbance	Sleep disturbance, irritability	<ul style="list-style-type: none"> • Keep patient awake during day. • Adjust time of patient's tranquilizer. • Provide exercise for patient. • Provide soothing stimulation (massage).
Exacerbation of symptoms in the evening (i.e., increased confusion)	Decreased patience	<ul style="list-style-type: none"> • Identify patient's "worst" time period. • Identify events/activities contributing to stimulus overload. • Decrease stimulation in environment around that time. • Get more rest. • Use diverting tasks.
Repetitive questions	"Last straw" effect	<ul style="list-style-type: none"> • Recognize that repetitive questions derive from fear and uncertainty. • State "I will take care of you." • Ignore questions. • Give attention to patient.
Repetitive acts	Annoyance	<ul style="list-style-type: none"> • Give patient a task to do or a soft toy. • Use gentle but firm touch to curtail activity.
Clinging/following	Distress, irritation, lack of privacy	<ul style="list-style-type: none"> • Recognize that the world is a strange place to someone who cannot remember. • Reframe patient behaviors from "irritants" to "compliments." • Remember that a patient is confident that you know the world. • Give patient something to do. • Find someone to be with patient. • Take time for self periodically.
Complaints, insults, accusations	Insulted, angry; fear that patient will insult/alienate outside help, therefore reluctant to ask for assistance	<ul style="list-style-type: none"> • Be empathetic; consider patient's point of view. • Look for underlying meaning and respond sympathetically. • Interpret malevolent remarks in a benevolent way; e.g., "You are cruel" may be a way of saying "life is cruel."
Misinterpretation of sounds and sights	Fear regarding personal safety (i.e., is there <i>really</i> someone in the house?), patient's stability (i.e., is patient <i>really</i> crazy?)	<ul style="list-style-type: none"> • Keep environment well lighted. • Explain what things are, but do not disagree directly. • Address patient directly by name. • Do not talk about patient in third person in patient's presence.
Demanding behavior	Feel manipulated, attributing demands to patient's pre-AD style of relating.	<ul style="list-style-type: none"> • Recognize that manipulation takes planning. • Relabel "demanding" behavior as patient's "need to be connected." • Look for something that is making patient feel lonely, abandoned, frightened.

(continued)

Patient Problems	Initial Family Reaction	Family Members' Interventions
Demanding behavior (continued)		<ul style="list-style-type: none"> • Be specific and direct: "I will see you (when)." • Set limits on what you can do. • Determine extent of patient disabilities.
Apathy/listlessness	Hopelessness, exhaustion	<ul style="list-style-type: none"> • Keep patient active. • Do simple tasks that patient can perform successfully. • Go for a walk. • Play music.
Anger	Defensiveness, anger	<ul style="list-style-type: none"> • Respond calmly. Do not respond with anger. • Remove patient from the stimuli that prompted outburst or remove stimuli.
Difficulty understanding directives/communicating	Impatience	<ul style="list-style-type: none"> • Keep assuming that patient can understand. • Supply word(s) if patient appears to be fumbling. • Look for meaning in patient behaviors. • Recognize that hearing loss often accompanies cognitive decline. • Recognize that patient may be able to read, even if unable to talk. • Keep voice low; remember that a male voice is easier to hear. • Repeat directives using same gestures and words. • Allow patient 2 minutes to respond.
Frustration related to not being able to succeed at former tasks.	Desire to take over and "do for"	<ul style="list-style-type: none"> • Break tasks into sequential steps or pieces.
Losing weight Not eating	Worry, frustration, impatience	<ul style="list-style-type: none"> • Offer one food at a time. • Offer six small daily meals. • Decrease external stimulation at meal time. • Allow patient 40 minutes per meal. • Relax.
Depression about declining cognitive abilities	Helplessness, protectiveness, withdrawal	<ul style="list-style-type: none"> • Ask patient what having AD means to him/her. • Be honest about diagnosis. • Involve patient in pleasant activity.
Aggressive behavior	Anxiety	<ul style="list-style-type: none"> • Recognize patient's sensitivity to nonverbal behavior. • Look for what might have provoked aggression (rushing, etc.). • Keep track of situations triggering adverse reactions. • Remove patient from situation.

(continued)

Table 23.3 Caregiving Strategies for Alzheimer's Patients
(continued)

Patient Problems	Initial Family Reaction	Family Members' Interventions
Nocturnal wandering	Worry, sleep disturbance	<ul style="list-style-type: none"> ● Recognize that much wandering is goal-directed even if patient cannot express goal. ● Provide rocking chair, music. ● Walk patient during day. ● Keep patient active during day. ● Secure name tag on patient. ● Dead-bolt doors. ● Provide stuffed animal (has been found to decrease wandering and repetitive behaviors).

Sources: Mace and Rabins, 1981; Hirst and Metcalf, 1985.

- "What circumstances surrounded this event?"
- "How did the family members respond?"
- "Who was the most surprised?"
- "What was the last thing [the patient] did that seemed like his old self?"
- "What sense do you make out of this change in behavior?"

The nursing interview can also be used to facilitate resolution of problems associated with such AD behaviors as wandering. Useful questions include:

- "When [the patient] wanders, what does [the caregiver] do?"
- "Is [the patient] wandering more now than last month?"
- "What do you think is most upsetting to the [the caregiver] about (the patient's) wandering behavior?"

Reframing. Reframing provides a new way of looking at a situation or problem (Herr and Weakland, 1979a) for the purpose of generating new solutions. When family caregivers are encouraged to look for underlying, benevolent meanings to the AD patient's malevolent or noxious behavior, they are being encouraged to "reframe" (see Table 23.3 for examples). Families of AD patients must be reminded that the patient has no memory of the moments that went before (Mace and Rabins, 1981); they need to understand that the behavior is not willful or intended to irritate, but is instead beyond the patient's control. This relabeling can break a vicious cycle of argument between patient and family members.

Although all family caregivers require periodic respite, many reject such suggestions for fear of neglecting their perceived responsibility to the patient. They may feel guilty about taking time for themselves or frustrated by the conflicting desire to "take time off" and the desire to "take care of" the loved one. "Do not tell me to take time for myself.

If more than one person tells me to take time for myself, I am going to scream" is a commonly expressed sentiment and a definite indication that the caretaker *needs* some personal time.

By reframing, "taking time off" for oneself as another way of "taking care of" the patient, caretakers can often balance AD care and their own needs more effectively. In a particularly work-oriented family, the nurse might even prescribe relaxation as a family task—so that it seems like work!

Provide an opinion. The nurse might deliberately offer a summary statement, explanation, or opinion that differs from prevailing family beliefs.

Positive connotation. With positive connotation, the symptom is reframed and connected to other behaviors in the family system, and vice versa. "The presenting problem is construed as a solution (albeit a temporary one) to some other hypothetical or implied problem that could or would occur should the symptom not be present" (Tomm, 1984b, p. 264). The nurse must identify connections carefully and select issues relevant to the family's current life situation; in short, the opinion must be plausible, based on information that the family itself provided in response to circular questions (Tomm, 1984). For example, a wife refused to take her cognitively-impaired husband home after hospitalization, which incited her children to anger and action. Her behavior was positively connoted as a demonstration that she needed her family's help with the caretaking responsibilities and allowed a positive opportunity for the children to demonstrate their concern. Because the mother had previously done everything for herself, her behavior was positively connoted as being sensitive to her children's awkwardness in offering unsolicited help. The children's behavior was positively connoted as sensitivity to their mother's "little red hen" approach to life and concern about undermining her independence.

Split-Opinion. Split-opinion can be a useful intervention if intrafamily conflict hinders decision making. For example, family members may argue *ad nauseum* about the AD patient's functional abilities and about the need for institutionalization. During a family interview, the nurse can maintain engagement with the various family factions and stimulate decision making by mirroring their positions and/or by adding another perspective. The important thing is to avoid showing a preference for any particular point of view.

A nurse delivered the following split-opinion to an AD family at the end of a family interview: "Part of me feels that your husband/father can do a little more than what he is presently doing. That part of me would like you to do a little less for him next week. However, another part of me thinks that your husband/father is doing all he can do; in

fact, that part of me is concerned about what might happen to you and your relationship with him and others if he did any more. That part of me would like you to think about and write down the consequences of your husband/father doing more and of you doing less."

Devise rituals. A therapeutic ritual is a specific task to be carried out by family members. This task is not intended to become part of the daily activity pattern; rather, it is to be used as an experimental change in usual family interaction patterns.

A caregiver reluctant to take respite despite persistent recommendations by the family and nurse was advised by the author to "make a list of things you used to enjoy doing that would consume no more than one hour of your time. Write each of these activities on a separate piece of paper. Place the pieces of paper in a bowl. Every Sunday night select one piece of paper from the bowl and see what your task for the week is. Schedule this duty into your week's labors." This ritual employed the client's language of hard work whenever possible. Leaving the choice of activity up to chance reduced the guilt that might be associated with "choosing" to take time off.

Rituals introduce clarity where there is too much confusion within the family. An odd day/even day ritual (Selvini, et al., 1978) can help sort out contradictory double-binding behaviors by prescribing sequence (Tomm, 1984b).

Eliminate double binds. While a planned double bind can sometimes be useful, the intervening nurse must be careful not to unintentionally "double bind" the caregiving family. Instructions given to family members often appear to send conflicting messages (for example, Mace and Rabins, 1981; Gwyther and Matteson, 1983). Gwyther and Matteson (1983) say that the AD patient cannot show appreciation because of cognitive deficits, yet they also assert that the patient may feel robbed of independence and resent caregiver intrusion. In other words, the instructions assert that the AD patient is at once aware and unaware, on different cognitive levels. Caregivers are told that patients do not understand but are also told to speak directly to them.

Another contradiction occurs when family members are cautioned not to respond to an AD patient as they would to a well-functioning person because this might *provoke catastrophic reactions* in the cognitively-impaired person. At the same time, caregivers are told that they are *not responsible for the reactions* and declining abilities of the patient. If there is a catastrophic reaction, the caregivers are told, "Don't worry, the patient will forget" (Mace and Rabins, 1981).

The caregiving family is thus in a paradoxical situation. The AD patient looks well and yet behaves "inappropriately." The relationship is intense; the patient gives conflicting messages, as do helping professionals; the caregiver can neither comment on the situation nor "leave the field." All the elements of a classic double bind (Watzlawick et al., 1967) are present.

Recommend a support group. Faced with the confusion and burdens of caring for an AD-afflicted relative, many families find consolation in talking with others who have "been there." Support groups offer both an emotional outlet and a source of management techniques. Support from family and friends reduces stress and vulnerability to illness (Caplan, 1981) and may reduce the caretaking family's sense of burden (Zarit et al., 1980). Group support may allow family members to delay the AD patient's institutionalization and enhance the family's ability to cope with the dementing illness.

Lazarus and colleagues (1981) studied changes in the psychological well-being of participants in a discussion group for relatives of Alzheimer's patients. Compared to nonparticipating AD relatives, group members felt more in control of their own lives and less at the mercy of fate.

By analyzing the most effective parameters of AD support groups, Kapust and Weintraub (1984) devised a flexible group approach that suits the constantly changing nature of AD management. They recommend that group sessions be scheduled realistically—in light of the special problems of AD caregiving—and that outside help with the patient during meetings be facilitated. The researchers also suggest that groups be heterogeneous and contain only 5 to 10 people, most or all of whom should be family members (spouse or adult children) caring for patients with varying degrees of AD-related impairment and living in diverse locations (i.e., home, institution). "Those with relatives still at home can become prepared for what lies ahead. Those with relatives in a nursing home can recall what it was like to have the patient at home. These comparisons are critical in coping with the gradual loss they are experiencing" (p. 460).

Through education and emotional ventilation/validation, support groups can deal with the following issues: the patient's medical work-ups, management problems, emotional reactions to having family roles changed by AD, utilization of community resources, and thoughts about the future.

Address the issue of institutionalization. Using the interventions just described, nurses can help family members cope more effectively with the problems presented by AD, perhaps delaying or even preventing

institutionalization. However, when the patient's psychological and physical needs outweigh family and community resources, institutionalization becomes necessary.

Geiger and Berman (1983) identified five reasons for institutionalizing patients with a dementing illness:

- physically assaultive behaviors
- major physical/medical care needs
- incontinence
- physical/emotional illness in the caregiver
- financial inability to maintain patient at home.

If institutionalization is not discussed until the decision *must* be made, family members are usually too emotionally, physically, and financially exhausted to think clearly. Advance planning will allow more—and more productive—family involvement. To stimulate family discussion of this difficult decision while energy and time are still available, the nurse might ask family members, “How bad would things have to get for you to think about alternative living arrangements for [the AD patient]?” or “What would you observe in [the primary caregiver] that would indicate that it is time to place [the patient] in a nursing home?”

The family coping with AD will have many opportunities to discuss difficult topics during the course of their loved one's illness; those topics include management of property and financial affairs, mental incompetence, and power of attorney, just to name a few. The nurse can prepare the family for these highly sensitive discussions by involving as many family members as possible in early assessment sessions. Family members who feel that their perceptions of the problem are valued will be more likely to continue their support through difficult decision-making processes.

Evaluation

Evaluation is an ongoing process—not a terminal objective. The nurse working with the AD family must evaluate family responses to interventions continually; nursing interventions are like trial balloons that may either fly or fall but will always provide information helpful in generating other interventions.

Wasson and co-workers (1984) evaluated their outreach treatment to psychiatrically impaired elderly by defining “improvement” as:

- decreased symptoms
- increased sense of well-being (patient); and/or
- significantly reduced tension in relationships between the patient and significant others.

Patients with dementing illnesses demonstrated more improvement than those diagnosed with depressive or paranoid disorders.

From the family systems perspective, it is important for nurses to analyze how the interventions impact not only on the AD patient, but also on family members. It is important to note that family improvement will manifest itself in reduced caregiver symptoms, increased well-being in family members, a decreased sense of burden, and more positive perceptions of family relationships.

CONCLUSIONS

Effective intervention with aging families with AD must consider analogous patient and family experiences. The helplessness, suspicion, and confusion every patient feels are mirrored in family member interactions with the patient and with helping professionals.

This chapter has presented interventions to help AD families overcome their caregiving problems. As the AD patient becomes increasingly dependent on the family, so too may the family become dependent on the nurse's interventions. Unwittingly, the nurse may foster dependence and decreased functioning in the family, just as the family may foster the patient's debilitation. Therefore, the most important interventions are those that expose and interrupt the dependence and helplessness that exists between patients and families, and between families and nurses.

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