When a Family Member has Alzheimer's Disease: A Phenomenological Description of Caregiving

By Judith Lynch-Sauer, PhD, RN

It is estimated that 4.8 million Americans will suffer from Alzheimer's disease by the year 2030.1 One of three young persons who have parents surviving over the age of 65 will be involved in their care because of dementia.2 It has been well-documented that the bulk of informal care given to elders is provided by family.3 Studies of informal caregiving have resulted in profiles of the caregivers,3-5 as well as of the elderly care receivers.6-8

There is adequate documentation that the caregiving relationship puts the caretaker at risk both physically and emotionally.9-11 It is also a consistent finding that in the case of dementia, it is not the characteristics of the illness but rather the caregiving context that predicts caregiving function.11A These findings suggest that a clear understanding of the caregiver's subjective perceptions is necessary to caregiver well-being. The purpose of this study was to explicate the subjective experience of caring for a family member with Alzheimer's disease.

METHOD
Sample
The researcher read seven published works of the experience of caring for a family member with Alzheimer's disease.12-18 Of the seven authors, four were women. There were two spouses (one woman, one man), four children (two daughters and two sons), and one daughter-in-law. All accounts included descriptions of the relationship of the author to the patient prior to the dementing illness and all covered descriptions of the progressive nature of the dementing disease. The two spouses and the daughter-in-law were the primary caregivers of the demented patient. Three of the children were intimately involved in the care of their mother, but were not the sole caregivers. One son only sporadically intervened with his father. Of the seven demented individuals, four were women.

Procedure
The researcher read the seven published accounts. Parts of the narratives not describing aspects of the author's caregiving relationship to the demented family member were omitted from the analysis. The steps for carrying out a phenomenological analysis suggested by Barritt et al.19 were used, supplemented by those presented by Giorgi.20 Attention was paid to the five steps of transformation of private experiences into consensually validated knowledge as outlined by Reinharz.21

The researcher read each description and selected from it those moments that seemed to be at the center of the event for the person (theme statements). The theme statements were listed for each author and then compiled into similar categories. Core themes were then derived from the theme statements. The core themes were used to describe the authors' experiences of the caregiving relationships.

Core Themes
The unending attempt to put patients in touch with their surroundings was the caregiving theme that described an observed interruption in the patients' connectedness to their environment, and an attempt on the part of the caregiver to remedy this situation. This disconnection in the patient led to a disruption in the flow of everyday activities for the caregiver. One daughter described how she and her sister made signs that they hung throughout the house to help orient their mother. She said about the signs:

Soon they spread. The hall... was a freeway of billboards... "Do not go into Margaret's room..." (said one) "Put butter in pan before egg..." over the stove. Up they went as we found the need, but we were always one sign behind and would realize that only when the shoes were in the shower.18

There was a sense of trying to stay
ahead of the patient, trying to predict when, where, and in what situation the next disconnection would occur and to prevent it before it could occur. This constant reconnecting was tiring to caregivers, particularly when they realized that the disconnections were occurring more frequently as the dementia progressed.

The progressive experience of asynchronous with the patient extended into many domains of functioning and varied with each individual. The experience of sleep disturbance was the most universal. The patients did not sleep when the caregiver slept. One woman described how her nights were spent:

“I had to creep downstairs every few minutes to see what this ungodly hulk was doing rambling around in the dark.”16 The strain of sleeplessness eventually caused exhaustion in the caregiver. The patients’ rhythms of eating were also disturbed. Some of them ate at entirely different hours than the caregiver and in unusual amounts—either too much or not enough. These disturbances in eating patterns resulted in the gradual dissolution of the social relationship with the patient during mealtime.

The experience of loss of mutuality in the relationship with the patient was conveyed by expressions such as,

“I’m stunned by the realization that I’m still playing the role of the criticized child, but she’s not playing ‘mommym’ anymore.”12 Another author described his mother’s experience during a planned birthday celebration.

Her whole aura was gloomy and joyless. . . it may be that she had picked up data from the somewhat excited atmosphere of the past few days in preparation for her birthday celebration, and from that created a drama in which she was playing quite a different role from what we intended for her.19

Mutuality is characterized by shared visions, goals, or sentiments. Mutuality occurs when individuals feel or believe that others share their visions and perceptions. This results in a sense of acceptance and the ability to develop rapport with others. The gradual loss of mutuality in the caretaking relationship is experienced by the caregiver as the awareness of no longer being accepted in the everyday role and no longer able to share in a common history with the patient.

A gradual decline of a reciprocal relationship often went unnoticed until “asking impossible things” of the patient painfully brought this loss into awareness. One of the authors described how he had asked his wife to pick him up at work, as she had often done in the past. Instead of arriving at the pre-established meeting place, she had driven miles out of her way and left him stranded and frightened for her well-being. The balanced give-and-take experienced in a relationship is hypothesized to be a crucial aspect of well-being.22

A progressive diminishment of diversity in the relationship to the patient, others, and the environment, was experienced by caregivers. Diversity refers to the distinct qualities or elements experienced in the various connections people develop. There has been documentation that reinforcing and enlarging social supports tend to promote more improved functioning for individuals.23,24 The caregivers were gradually beginning to function within a more narrow constricted environment, both socially and physically. One woman expressed this theme very vividly:

I also had to give up some of my outside involvements . . . noncredit classes for my own enrichment. Finally, I came to accept the fact that my place was at home. I gave up all outside activities during the day.16

The experienced narrowing of the horizons of the caregivers was felt as resentment, anger, and depression. They felt isolated and at times preferred this state rather than the constant feeling of “tension” when taking the patient outside of the home setting.

The attempt to attribute meaning to the patient’s illness was a theme that was present throughout the descriptions. After the caregiver relinquished the caregiving role due to institutionalization or death of the patient, this theme became paramount. All of these authors felt moved enough by the experience to publish descriptions of what it was like to care for someone with dementia. One husband published his book even after he found out that his wife had died from Pick’s disease rather than Alzheimer’s because, “Everything in it still was relevant for anyone who had Alzheimer’s disease and for any family of caregivers.”14 Putting his experience in writing could provide help to others in similar situations. Others found meaning in the lived experience itself: “I did not choose some of the things that happened along the way, but I am grateful for every day and every growth experience.”13

An ever-present search for personal connectedness was a poignant theme. Touch seemed to be the mode most frequently mentioned by the caregiver as a way to maintain a fleeting experience of connectedness with the patient. One son conveyed this search:

Dad is sleeping on my old bed. He looks small and I cannot put all my memories of him into his present shape. I trust to touch, rubbing his back. I put my love into fingertips. Through my fingers I send him all my journeys, all my strengths.15

Another son experienced a sense of
connectedness with his mother by means of a mental image after a family member told him of finding his mother in a regressed state out in a road looking for him.

In a sense, if mother was out looking for me, then I, too, must find mother. In my mind’s eye I conjured up a picture of myself as an infant with my 23-year-old mother walking along a road bathed in moonlight, searching for me. And, there was another image—of myself past my 60th year, searching for my 85-year-old mother on the same road.17

Meta-Themes
Change is a theme about the caretaking relationship that describes its dy-

namic character. The change was slow and insidious, progressing toward eventual dissolution of many of the core themes. The descriptions were rich with comparisons of past experiences with the patients, casting the present relationships in bold relief. Relationships were disrupted and permanently altered.

Individual personal history was a backdrop against which the caregiving relationship was acted out and is an essential theme to understanding the quality of this relationship. The thread of personal history was woven throughout each of the core themes, affecting the modes chosen to cope with the slowly progressive disintegration of each aspect of the relationship. Personal history influenced the creativity of each of the authors as they labored to keep their beloved family member grounded in the world of everyday reality, and personal history permeated the

attribution of meaning to the patients’ illness.

DISCUSSION
"The audience of the researcher transforms this written document into an understanding which can function to clarify all the preceding steps and which can also clarify new experiences that the audience has."21

The nine core themes and two meta-themes that emerged from the analysis may serve as guidelines for nurses who provide services to caregivers of demented family members. The themes may also help family members clarify their experience of caring. Caregivers can be taught ways to keep patients in touch with their surroundings for as much as possible. Nurses can facilitate the use of outside resources, eg, respite centers or home health aides, by caregivers to help maintain physical health while dealing with asynchronies in their relationship with the patient.

Nurses can educate caregivers regarding the eventual loss of reciprocity in the relationship, with the goal of giving enough lead time to allow the caregiver to begin finding other support systems in the community. Referring caregivers to a support group would allow them to experience mutual relationships outside of the caregiving dyad and to increase the diversity of their relationships. Ongoing exploration with caregivers of their attempt to find meaning in the illness of their family member could help to uncover hidden strengths in coping with caregiving. Role playing methods, eg, use of touch, building a bridge between themselves and the patient, may give both caregiver and patient special moments of rarely shared joy.

The theme of ongoing negative change helps the nurse to focus on what can be done to address the emerging problems of everyday life. The theme of individual personal history guides nurses as they listen to the descriptions of the lost relationship and provide a context in which to formulate an understanding of the caregivers’ well-being.

REFERENCES
About the author
Judith Lynch-Sauer, PhD, RN, is Assistant Professor, Psychiatric-Mental Health Nursing, University of Michigan, School of Nursing, Ann Arbor.
Address reprint requests to Judith Lynch-Sauer, PhD, RN, University of Michigan, School of Nursing, Ann Arbor, MI 48109.

Alzheimer’s Disease

KEY POINTS

Lynch-Sauer J. When a Family Member has Alzheimer’s Disease: A Phenomenological Description of Caregiving. Journal of Gerontological Nursing. 1990; 16(9):8-11.

1. Caretakers are at risk both physically and emotionally, and in the case of dementia, it is not the characteristics of the illness but rather the caregiving context that predicts caregiving function. An understanding of the caregiver’s subjective perceptions are necessary for caregiver well-being.

2. The core themes expressed include the unending attempt to put the patient in touch with the surroundings; trying to stay ahead of the patient; a decline in the reciprocal relationship; narrowing of the caregiver’s horizons; and a search for personal connectedness.

3. The personal history of the caregivers is essential to understanding the quality of the relationship because it influences the creativity of the caregivers in coping with the illness.

Journal of Gerontological Nursing

your copies are valuable

KEEP THEM FOR READY REFERENCE

Custom-made for Journal of Gerontological Nursing, these magazine cases and binders will keep a year’s copies clean, orderly, and readily accessible for reference. Rich in appearance with a leatherette cover and embossed lettering, these coverings are distinctive companions for your finest bindings. One magazine case is priced at $7.95; 3 cases, $21.95; and 6 cases $39.95. The magazine binders are priced at $9.95 each; 3 for $27.95; and 6 for $52.95.

Journal of Gerontological Nursing
Jesse Jones Industries, Dept JGN, 499 East Erie Ave.,
Phila., PA 19134
I am enclosed $______ for (check or money order only)
______ Magazine cases priced at $7.95 each, 3 for $21.95,
and 6 for $39.95.
______ Magazine binders priced at $9.95 each, 3 for
$27.95, and 6 for $52.95.
For credit card orders ($15 min) call Toll Free
1(800)972-5858 7 days 24 hrs.
Please make check payable to Jesse Jones Industries. Add
$1 per unit Postage and Handling. Outside USA, $2.50 per
unit (US funds only).
Name ________________________________
Address ________________________________________
City __________________ State ______ Zip Code ______
(No P.O. Box Please)
PA residents add 6% sales tax. Satisfaction Guaranteed.