



## The Hidden Patient

### Polarity Therapy for Dementia Caregivers

By Shirley Vanderbilt

#### Symptoms of Caregiver Stress

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Health problems

– [www.alz.org/Care/Coping/caregiverstress.asp](http://www.alz.org/Care/Coping/caregiverstress.asp)

Porter Shimer, in his book *New Hope for People with Alzheimer's and Their Caregivers*, gives a tongue-in-cheek view of the dementia caregiver's role with this proposed ad — "Wanted: Someone to spend an average of 100 hours a week to oversee the physical and emotional well-being of another human being. Expect frustration, depression, rejection, occasional abuse, and chronic fatigue. No benefits, no vacation, no room for advancement, and no salary. (An annual fee, in fact, of approximately \$12,500 may be required to cover the cost of goods and services not provided by the applicant.)"<sup>1</sup>

For many family caregivers in the trenches with Alzheimer's disease, there are few rewards in this irreversible journey through languishing memories and fading personalities. Sometimes the caregiver receives a smile or a brief recognition, but more likely they encounter confusion, resistance, and a plethora of uncharacteristic, difficult behaviors. My own step-grandmother, a captive of the disease these past 10 years, was transformed from a sweet, loving person to a cursing and combative nursing home patient, unable to recall the faces of those most precious to her in earlier life. The disease finally won when she recently passed on — a blessing and a curse, as those who deal with Alzheimer's disease know all too well. There is no escape, save death.

Unlike some chronic diseases that ravage the body yet leave the mind intact, Alzheimer's steals the "person" while extending, albeit poorly, the life of the body. It's called the "living loss." And the toll it takes on caregivers has led to another coined phrase — the "hidden patient."<sup>2</sup>

#### Caregiver Stress

Rebecca Logsdon, Ph.D., a research associate professor at University of Washington (UW) School of Nursing and clinical



psychologist specializing in gerontology and geriatrics says, "Our research here at the UW Northwest Research Group on Aging has found that the most difficult aspects of caregiving for many family members are dealing with depressive and anxious behaviors and associated problems in their care recipients."

Early signs of forgetfulness and repetitive questioning may test the caregiver's patience, but it's the later symptoms that most test their resilience and strength. As dementia progresses, the increasing cognitive impairment of recall, reasoning ability, and communication skills can lead to severe mood swings, combativeness, and verbal or physical aggression on the part of patients as they become more confused, frightened, and insecure. (See "Dementia Care: Reducing Behavioral Symptoms with Therapeutic Touch, p. 140)

Dealing with and diffusing potentially escalating situations and accompanying anger and depression is an ongoing task for the caregiver, although not all dementia patients will develop these symptoms to such an extreme. For some, the childlike state of regression brings with it a sweet simplicity and less problematic aberrations. But Logsdon says, "Even in the best circumstances, caring for a family member with dementia is time and labor intensive. Caregivers rarely get breaks from their responsibilities, can be isolated and frightened, may be repeatedly awakened by the care recipient in the middle of the night, and often feel guilty about not being able to "fix" their relative's problems. Because of all this, they are at increased risk for depression and anxiety themselves and may suffer from a variety of stress-related medical problems."



Parks and Novielli (2003), reporting on research studies of caregiver burden, also note that stress is more influenced by the emotional state and behaviors of the patient than other factors involved in care. "Interest-ingly, the amount of time spent as a caregiver does not correlate with burden," they say. "Similarly, the worsening of the care recipient's dementia does not increase burden, nor does the degree of functional impairment of the care recipient. Worsening behavioral issues in the care recipient, however, have been shown to increase caregiver burden, as has the presence of depression in the care recipient."<sup>3</sup>

Each stage of dementia comes with its own set of challenges. Alzheimer's is a difficult diagnosis to accept, and denial in the initial stage is common. Families often enter this strange new world totally unprepared. Lack of education about the disease confounds the situation and inappropriate responses on the part of the caregiver, whether well-meaning or emotionally reactive, create frustration for both them and their loved one.

## A Traditional Approach to Chronic Illness

The Center for Traditional Medicine specializes in the prevention and treatment of chronic illness, such as diabetes, post-traumatic stress, and autoimmune disorders. Drawing from worldwide indigenous approaches to healing, the clinic offers massage and energy therapies along with medicinal herbs, nutritional guidance, and mental health counseling. Educational opportunities include certificate through master's level courses in traditional and energy medicine, ethnobotany, ethnonutrition, and indigenous studies. The donation-assisted Nutrients for Natives program provides traditional medicine treatment, self-care education, and culturally-congruent nutrients for Northwest natives with diabetes and other chronic diseases. For more information, go to [www.centerfortraditionalmedicine.org](http://www.centerfortraditionalmedicine.org)

"When the care recipient is newly diagnosed," Logsdon says, "family members may not think of themselves as 'caregivers,' and changes in roles and expectations can be difficult for everyone." Basic issues, such as driving, medication management, and financial concerns have to be addressed and "caregivers struggle with how much to intervene," she says. "As the disease progresses, caregiving becomes more stressful because of increased behavioral changes, functional limitations, and sleep disturbances. Decisions about getting outside help, medical management, and residential care options can be difficult, and resources may be limited."

With the growing recognition of stress as a major health risk for caregivers, the Alzheimer's Association and a number of other supportive organizations now offer an abundance of tips and resources to decrease its effect. But there remains that "living loss," the absence of relationship and touch that defined human connection between caregiver and recipient before the disease settled in.

### Restorative Power of Touch

Leslie Korn, Ph.D., director of the Center for Traditional Medicine (CTM) in Olympia, Wash., is on a mission to ease stress and the loss of reciprocal touch in caregivers' lives. As an agency of the Center for World Indigenous Studies (CWIS), CTM's clinic serves both American Indian and non-Indian populations in the Northwest, providing natural and indigenous medicine, public health and education, and research. In 2004, CTM received funding from the National Institutes of Health, National Center for Complementary and Alternative Medicine, to conduct the American Indian Caregiver Health Study. The research is aimed at determining the effectiveness of polarity therapy for reducing stress and improving the health of American Indians who care for elders with memory loss or Alzheimer's disease.

As a specialist in traditional medicine and cross-cultural psychology, Korn has spent most of her career working with indigenous populations. During the 1970s, in the rural village of Yelapa, Mexico, she established a small, natural medicine public health clinic. Offering her skills in polarity therapy and other energy approaches to her neighbors, she in turn learned about their medicinal plants and indigenous treatments. By the late 1990s, Korn had added an educational component for visiting practitioners and was also deeply involved in the study of native nutrition. The center joined with CWIS, moving to Olympia where Korn has had an opportunity to expand her culturally-congruent approach to the vast American Indian populations of the Northwest.

Korn says it was a confluence of events that led her to develop the caregiver study. "I returned to the United States, after living in



Mexico, in large part because I needed to care for a mother with dementia," she says. With the center relocated to the Northwest, she was in contact with area health professionals and social service providers, "all of whom are very impressive with their dedication and compassion. I began learning a great deal about the issues of dementia but also the problems of being a caregiver which revolve around stress and, in many ways, the inescapable nature of it when providing care for a dementia family member.

"I observed that many programs provide emotional and cognitive support, but of course, as a bodyworker, I felt that the missing piece was touch therapies. This also addressed an ongoing interest I have had throughout my career as a traumatologist in the role of touch and restoring capacity for attachment relationship. And it occurred to me that the role of being a family caregiver involves a slow, inexorable loss of attachment as it is expressed through reciprocal touch."

Now half-way to completion mark, the American Indian Caregiver Health Study has primarily addressed underserved needs of the American Indian population. But the study has garnered such tremendous support in the local community that area agencies are now providing funds for a concurrent study arm with non-Indian participants. This expansion of the subject base will afford researchers the potential for preliminary comparison of caregiver stress and response to the experimental therapy across ethnicities.

"As an American Indian organization we have a mandate to serve Indian communities primarily and with traditional medicine," Korn says. "So it also then became important to ascertain whether or not the polarity therapy protocol (and indeed the whole study design) would be culturally congruent with what traditional Salish peoples in this region would be interested in." The center, as an agency of CWIS, utilized tribal connections throughout the area to create an interdisciplinary team of American Indian consultants and advisors, including Korn's husband, Rudolph Ryser, Ph.D., a Cowlitz tribal member, and as executive director of CWIS, an expert in social science research. Korn also pulled together a collaborative team of researchers and dementia experts, including Logsdon, to assist in planning and execution of the study.

"In holistic approaches, we tailor treatment to our clients," Korn says, "yet the foundation of biomedical clinical research is to provide the same protocol to everyone. In order to address both needs, we designed a 21-point protocol that we felt would achieve an effect in everyone — indeed could be foundational. Hence, we chose points and holds that everyone could relate to, could, we feel, benefit from and also would not pose obstacles or be culturally inappropriate."

Polarity therapy is based on balancing the positive and negative energies of the body through gentle manipulation. Although therapists may include stretching, nutrition, and attitudinal counseling in their sessions, the protocol in this study is limited to bodywork techniques in order to ensure standardization of the intervention. Similar to her 21-point protocol for diabetes, Korn says, "It is designed primarily to induce parasympathetic dominance and to cover areas around the whole body: head, neck, diaphragm, belly, knees, feet, spine, hands. We do some release in the diaphragm, as emotional tension and anxiety is often held there. Releasing the diaphragm stimulates vagal response. The knees are often neglected in bodywork protocols. In polarity, they form part of the earth triad and support good fecal elimination."

As a control comparison, half of the participants are randomized to a respite group, receiving a weekly 3-hour "time out" while in-home care for their elder is provided by a qualified substitute caregiver. The respite period can be used however they choose, whether to engage in some outside activity or just have personal time at home.

Both the experimental and control groups undergo a series of assessments during the 8-week treatment period. The design approach is holistic, Korn says, incorporating both quantitative and qualitative data. Salivary cortisol levels and heart rate variability provide biological and physiological markers, and self-report scales are utilized to evaluate factors such as quality of life, depression, sleep quality, perceived stress, and overall health. Throughout the study period, subjects are asked open-ended questions regarding their treatment response and progress, providing the qualitative data.

In addition to community funding of the non-Indian portion of the study, donations and gifts have poured in to cover respite care activities, locations for treatment sessions, and a myriad of other services and support needed to complete the research. Results on a variety of findings will be published, Korn says, as well as shared with the community. The preliminary data will also provide direction for a larger study with increased sample size.

### Cultural Perspectives

More than 70 percent of Alzheimer's patients are cared for in the home by family and friends, according to Alzheimer's Association statistics. That number is likely higher in the American Indian community, although there is no research to confirm this. Typically, indigenous families are more prone to maintain close ties, with an inherited respect for, and responsibility toward, caring for their elders.

Recruitment of American Indian participants for the CTM caregiver project necessarily calls for sensitivity to cultural perspectives of the native community, especially in the use of terminology. Clinical coordinator for the study, Tiffany Waters, has an academic background in anthropology with a special interest in indigenous politics. Relating from her personal perspective as an American Indian and as part of the research team, she says, "We found that there is a disconnect between the word 'caregiver' and the American Indian community. Rather than it being something separate from their own identity, they tend to see it as a part of who they are. It has been a political challenge, to have people say 'I am a caregiver.' That's what the study is oriented around." In an attempt to find common ground without imposing on cultural perspectives, CTM's approach has been to encourage family members to recognize the presence of stress and be open to receiving help from the center. "Through that awareness they have a greater desire to care for themselves, in addition to caring for their elders," Waters says.

Likewise, the term "dementia" was another conundrum. In her own native community, Waters says, "It had bad connotations, and it was not favorable to identify anyone as having dementia. It's not used in everyday conversation and some would almost find it disrespectful." So the CTM flyers invite participation by simply asking, "Are you caring for a family member with memory loss?"

Waters says, "They do not want to identify the person they are taking care of as having Alzheimer's or dementia." In some cases where the elder has been diagnosed, the family may be more open to discussing the disease. But for others, she says, "It is a private matter."

Language and perceived roles aside, American Indians are especially vulnerable to health risks. According to Korn, this population has a higher mortality rate at an earlier age than the average American, primarily due to a life of cultural and socioeconomic oppression and the ongoing layered stress accompanying it.

### Emerging Trends

At midpoint of the study, some interesting trends have already been noted. "So far we are seeing very depressed levels of awakening cortisol in all of the study participants, which may likely signify chronic stress," Korn says. "Under acute stress, one's cortisol is often high. However, over time, the adrenals just cannot keep coping and become exhausted, hence the lower levels."

Initially, the study targeted caregivers in the 30 to 70 age range, but their enrolled subject group now ranges from age 35 to 55. This is the "sandwich" generation, those caring for elders while

still raising their own children. Particularly in American Indian communities, with the cultural cohesiveness and responsibility for extended family, Korn says, some family members are taking on these multiple roles earlier in life.

"We've found many are not realizing how stressed they were," Waters says. Although scores on perceived stress scales may start out low at initial assessment, Waters has seen scores peak at a higher point later in the treatment period as the participant's awareness of their stress increases. "When there's an outlet to talk about it and scales to measure it, they become more aware."

Therapists in the program have noticed a similar trend. Trish Hinman, a massage and polarity therapist from Exeter, N.H., initially became an intern at CTM after reading about Korn's success in using polarity therapy and other natural treatments with diabetes. "With diabetes becoming almost epidemic in our society, I wanted to be able to offer a natural healing alternative." But she got more than she came for when she was invited to join the study team as a therapist for the experimental protocol.

"The people I have seen with regard to the study are very stressed, mentally, emotionally, and physically," Hinman says. "What I see most happening in my sessions is a self-awareness about stress and how they can change their own responses. The profound relaxation they achieve within the session makes them more attuned to where they want to be. Lots of them have never been in that state. They begin to notice more quickly the things they do, whether it is obsessing over a small matter or hunching their shoulders, and are able to correct that. That behavioral change can make a huge difference to them. There is more realization of the need to take care of themselves."

### Access for All

The American Indian Caregiver Health Study is guided by CTM's fundamental philosophy of promoting the cross-cultural healing arts and sciences and advancing social change. "Ultimately it's my goal to move policy along so massage isn't just available to upper middle class," Korn says. "People know intuitively that touch helps. By demonstrating efficacy scientifically, we shall continue to make progress in moving public policy toward funding these types of services."

There is a mismatch for American Indians under the current healthcare system, says Clara Berridge, research assistant for the study and a social work graduate student specializing in caregiver policy and well-being. "Healing practices are inextricably tied to those ways of describing and interacting with the world that form one's cultural identity, spirituality, and sense of social connection." The way in which tribal-land clinics are designed and services

designated conflicts with the healing methods traditionally accepted and practiced by these communities. "You have a nice, shiny clinic, but it's not being utilized," Berridge says.

The CTM research team looks for validation from this project to pave the way for funding of continued research and implementation of traditional medicine programs. At least for those caregivers involved in this study, there will be available — for a time — a touch therapy that complements their holistic heritage. The "living loss" will be lessened and the "hidden patients" will have the care they need.

### References

- 1 Shimer, Porter. *New Hope for People with Alzheimer's Disease and Their Caregivers*. Roseville, CA: Prima Publishing; 2002. 149.
- 2 Parks, Susan Mockus, M.D., and Novielli, Karen D., M.D. *Alzheimer's Disease Caregivers: Hidden Patients*. *Clinical Geriatrics* 2003 May; 11(5). Available at [www.mmhc.com/cg/displayArticle.cfm?articleID=cgac348](http://www.mmhc.com/cg/displayArticle.cfm?articleID=cgac348). Accessed August 2005.
- 3 Ibid.

### Resources

- Korn, Leslie, Ph.D. *Polarity Therapy: A Brief Review of the Literature*. *Energy* 2004 Spring: 7-10.  
Alzheimer's Association, [www.alz.org](http://www.alz.org).

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