Signs of Change for Alzheimer's Patients
Four million Americans are afflicted with Alzheimer’s, the most common dementia disease. The dementias affect the neocortex and limbic cortex, areas of the brain which are responsible for higher mental function. Alzheimer’s disease primarily affects elderly people. Victims suffer from memory loss, have difficulty performing familiar tasks, problems finding the right word or completing sentences, and experience disorientation of time and place.

“A dementia disease is the hardest for a family to bear,” says Beverly Barnett, an administrative director at the Scottsdale Village Square Senior Adult Community in Scottsdale, Ariz. “You can’t say good-bye.”

Most research on Alzheimer’s disease focuses on biomedical aspects of the illness. While scientists search for causes, however, Carvalho and her colleagues are working to improve the quality of life for the people who must live with Alzheimer’s disease.

The students work under the direction of William Arnold, professor of communication at ASU. Carvalho and two other graduate students are analyzing the communication behaviors of Alzheimer’s patients and caregivers at Scottsdale Village Square. Currently, they are testing a simplified sign language that may help Alzheimer’s patients convey their basic needs.

Carvalho, Pat Book, and Beth Campbell are now conducting the third phase of the study, which began in 1993. Carvalho is a pre-medical student with a degree in psychology. She visits the Alzheimer’s patients at Scottsdale Village Square about three times a week, playing games designed to teach four manual signs—hunger, thirst, sleep and pain.

The “sign bucks” game was created by Book, a master’s student in communication. Book also visits the facility regularly, toting her sign bucks, and stickers to trade for them, in her grandmother’s antique button box. Book currently works with about 20 patients who are in the beginning stages of the disease. They still have the ability to speak.

Carvalho works with a slightly less functional group of about seven or eight patients. Although they have lost many of the abilities that Book’s group has, they are not yet in the final stages of the disease.

The researchers try to teach the signs to patients who are still quite alert. Their hope is that these patients will have time to repeat the signs and store them in long-term, “iconic” memory, which deteriorates more slowly than short-term memory in Alzheimer’s patients.

The students had few precedents for designing their methodology.

“There’s no other research in this area,” says Campbell, a doctoral student in communication. She currently is tabulating the results of previous phases of the study.

In addition to making the study valid from a scientific standpoint, the students also must make it interesting enough to hold the attention of their participants. As a result, they developed ideas like the sign bucks, which not only reward the patients but also serve as records of their progression.

The bucks come in different denominations depending on how much help the patients need in answering the questions. They also come in different colors to represent the four different signs. When a patient trades in his or her bucks at the end of the game, Book knows exactly how many questions that person answered correctly for each sign.

At least, she usually knows. Sometimes patients hoard the bills and don’t return them. This is just one of the difficulties the researchers face in a study that is far from the cut-and-dried science experiment. Several factors inherent to Alzheimer’s disease make the condition difficult to study.

Carvalho often has difficulty keeping her small group together long enough to play a game. “It gets frustrating at times,” she says.

At the start of a recent session, a resident named Helen remembered that she had left her key by the piano in the recreation room. “I have to get my key first,” she said as the group sat down to begin. Five minutes later she returned without her key. She started to sit down, then stopped and said, “Oh, I have to go get my key first,” wandering off again.

Once the patients start playing the games, there are more difficulties. Some of the patients consider the games “kid stuff,” not realizing their actual purpose.

“There is an attitude much like that of a student who says ‘Why do I need to study a foreign language, or research methods?’” Arnold says.

Another problem for the study is that Alzheimer’s disease does not follow a standard progression. It is hard to tell whether patients’ abilities improve from learning signs or simply from coincidence. This unpredictability is not only troubling for researchers,
but also for caregivers and family members.

“Families want to know how the disease will progress and you can’t tell them,” Book says. “You can’t predict those things.”

But perhaps one of the hardest parts about working with Alzheimer’s patients is the frustration that the disease causes its victims, as well as the people close to them.

Carvalho knows this frustration firsthand. Normally calm and quiet, she becomes outraged when she talks about her experiences with the disease.

“Alzheimer’s makes me so mad!” she exploded while describing Marie, a patient she met in a nursing home where she once worked.

“We could talk normally, like you and I are talking. We used to talk personally with each other–we got kind of close. Then she started to deteriorate,” Carvalho says. “During that time it was so frustrating for her. She was such a bright woman–she was a schoolteacher.”

As her memory faded, Marie began to cry. “It was so frustrating for her. She was such a patient. She would approach me and say it was so frustrating for her. She was such a bright woman–she was a schoolteacher.”

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The study will feature common household scents such as fabric softeners, furniture polish, room fresheners, and baby powder. Beth Campbell is designing the study. She poses a variety of questions she hopes to answer. For example: Can positive scents enhance the quality of life of the residents? Do some scents produce a more favorable reaction than others? Do positive scents increase resident interaction? Do scents increase the recall of residents? What is the relationship of scents and residents’ behavior?

Responses ranged from simple wakefulness to smiles, laughter, talking, and eye contact.

Without fail, interaction increased sharply during the older shows. Perhaps this should be expected, given the fact that people with Alzheimer’s tend to “live in the past,” acting as if they remained in a previous stage of their lives.

According to Arnold, many nursing homes have small staffs and tend to use television to entertain the residents. “If TV is used as a ‘baby-sitter,’ then facilities should use programming the audience enjoys,” he says.

Arnold also encourages facilities to use music and radio shows in addition to television. “One assumption people make is that all older people like the same TV and music,” Barnett says. “But ‘old people music’ has categories too. It will be interesting to see when we all have a dementia what music we like!”

On the horizon, Arnold and his students have planned a study which focuses on the sense of smell. Scientists have discovered that one of the earliest changes of Alzheimer’s disease is a decline in the sense of smell. But past studies on the subject examined only biomedical aspects.

Arnold wants to know how the deterioration of senses affects the ability to learn, as well as overall quality of life. The future study will examine how odors influence things such as mood, appetite, and memories.

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The olfactory study also will take place at the Scottsdale Village Square facility, which has worked with ASU for more than three years. Barnett says she welcomes the research, which helps keep the facility on the cutting edge. Additionally, it helps give the patients’ families hope.

According to Arnold, it is premature to say that sign language will be an effective substitute for speech communication. But the interpersonal contact and attention involved in the study already has improved the patients’ quality of life.

Campbell has shown that test scores which are used to measure cognitive ability remained stable or improved in patients while they were learning signs. Also, the length of utterances and the number of complete thoughts spoken stayed higher than average. One explanation for the finding could be that the patients are getting mental stimulation they might not otherwise receive.

“Although the research, it’s still positive for patients and family,” Barnett says.

The research team is trying to spread the word to other caregivers about positive interactions with Alzheimer’s patients. Book has collected questionnaires from several facilities in the metro Phoenix area in exchange for information about her research. The researchers also speak to support groups for caregivers and family members. Book and Campbell also have scripted a performance about Alzheimer’s disease based on the actual words and stories of patients.

For more information about research to improve the quality of life of people with Alzheimer’s disease by using sign language and other communication techniques, contact William Arnold, Ph.D., Department of Communication, College of Public Programs, 602.965.5559.
Alzheimer’s disease is not the only illness that causes memory loss or disorientation. Disorders such as Parkinson’s disease, stroke, or even severe depression can produce similar symptoms in a patient. Often, elderly people have more than one of these problems at the same time.

Precise diagnosis for Alzheimer’s still eludes the medical profession. Although the presence of the disease can be inferred through medical records, a physical and interview, there is no way to get a completely accurate diagnosis until an autopsy is performed. During the autopsy, doctors can examine brain tissue for the tell-tale characteristics of Alzheimer’s disease: microscopic lesions called “senile plaques,” and an excessive amount of nerve cells filled with neurofibrillary tangles.

“When you’re working with Alzheimer’s patients, you never know for certain that they are in fact Alzheimer’s patients,” says Joseph Rogers, director of the Sun Health Research Institute in Sun City. According to Rogers, scientists continually are searching for a reliable method of diagnosing the disease. Contenders have ranged from a “scratch and sniff” test, based on the fact that Alzheimer’s patients lose the sense of smell early in the disease, to the recently publicized eye drop test, which can only differentiate a person with Alzheimer’s from a normal person.

“I don’t need an eye test to do that. I can just ask you ‘What day is it?’ or ‘Who is the president?’” says Rogers. “What we need is a diagnostic to differentiate Alzheimer’s disease from other forms of dementia.”

In 1995, Rogers may have a chance to find such a test with the help of ASU communication professor William Arnold and his team of research assistants. Arnold refers to the project as a “communications autopsy.” The work will involve the help of 20 local families who have lost a loved one to a dementia disease.

In a reverse process, the researchers will first interview families about the deceased’s communication behaviors. Armed with this information, they will try to determine which disease affected the patient. They then will compare their analyses with actual autopsy data from the Sun City facility, piecing together the communication behaviors that correlate with each disease.

This information will be helpful for caregivers in treating patients with dementia diseases. For example, Arnold’s group has found that while Alzheimer’s patients prefer entertainment such as television and music from the past, a stroke victim does not live in the past and would probably prefer something more current.

The ASU researchers also may use their findings to educate the general public, which is quick to credit Alzheimer’s for memory loss. “As soon as Mom or Grandpa or Uncle Harry begin to forget things, we say ‘It must be Alzheimer’s,’” Arnold says. “But there are several forms of dementia.” — Diane Boudreau

William Arnold demonstrates signs with a Scottsdale Village patient.

Stories We Tell Ourselves

Graduate students in the ASU Master of Fine Arts Program in Creative Writing have worked at the Scottsdale Village Square Vistas Unit since the fall of 1992. Teams of two or three poets and fiction writers conduct semester-long workshops with residents who write or speak their poems and stories. Each semester, MFA candidates devise new curricula and invent creative projects involving the writer-residents of Vistas. In 1993, the students won first place in the Rousseau Awards competition sponsored by the ASU Adult Development and Aging Program. They won for Stories We Tell Ourselves, an anthology of written and oral poetry.

Alice, a woman who no longer spoke aloud, wrote this poem:

CLOVES

A little girl thin year
with some grass amid the house
and dark vegetables getting
further away in the year
for a green thought.

In the spare time,
in the house next
to the spruce and the wheat.
In the urgent house,
the house of cleaning,
the house in the trees
in the time of the heart
amid the fish.

In that place is
a good trip
on this paper.

When the next semester’s project started, Alice was no longer in the writing group. She had died. The students were glad to have her good trip on that paper.

The next team members wrote in the introduction to their anthology, “As we dealt with the effects of Alzheimer’s disease, we came to appreciate the freeing aspects of memory loss on the creative process. Very soon we were able to embrace an insight Butch offered on the very first day we met: ‘Does it really matter if it’s true?’” — Karla Elling