



Many parents look forward to the time when their children are old enough to take care of themselves. They crave the freedom of going out without hiring a sitter; they yearn for an end to the tedium of diaper changes and spoon feeding. That end may never come for some Americans. Children do grow up. But grandparents also grow old. As human life expectancy continues to increase, many people find themselves spending more years caring for their elderly parents than they do raising their kids. BY DIANE BOUDREAU

who cares?

People have always cared for aging family members. Modern life, however, makes it a more complicated task today than in the past. For one thing, families tend to have fewer children now, meaning that the burden of elder-care cannot be spread out among many siblings. People are more mobile, and often live far away from their parents. Dual-income families leave neither spouse available to provide full-time care. And of course, people are living longer, lengthening the time during which care may be required.

All of these factors have a huge impact on caregivers. Family, or “informal” caregivers must juggle a myriad of financial, emotional, legal, and medical responsibilities. Paid, or “formal” caregivers have to prepare for an increased demand for their services as working families look to outside help.

Gerontologists Bill Arnold and Katie Schmidt want to make life easier for all of these caregivers. While plenty of resources offer tips for caregivers, no one has really studied what is important to them or identified their biggest needs. Arnold and Schmidt are trying to find out.

Arnold is a professor of communication at Arizona State University. His research and teaching both focus on aging. Schmidt recently received her doctoral degree in educational psychology. “There is a lot out there on training—tips for caregivers and how to take care of yourself. What is missing is the formal research on what is important to the caregiver,” says Schmidt, who addressed this question in her dissertation.

“We want to take this research and begin to use it as a model for training. It’s based on data from surveying formal and informal caregivers. We are using that data to determine what people need when they are searching for help. What should be on, say, a Web site for caregivers?” she asks.

The ASU researchers sent surveys to 29 senior care facilities in the Phoenix area serving a broad range of income levels. Most of their responses have come from the Salvation Army, Beatitudes, and Classic Residence.

The responses may help address the high turnover problem in the field. Some facilities have a 100 percent turnover rate. Arnold and Schmidt want to know why. They also want to learn how best to reduce this problem.

The surveys cover four basic topic areas. One area is “caregiver burden,” defined as the perceived strain or load caused by the physical, psychological, emotional, social, and financial stresses of caregiving. The work of direct caregivers—usually certified nursing assistants (CNAs)—can be physically and emotionally challenging.

ON THE JOB Melissa Brown is a CNA at Beatitudes Campus in Phoenix. On a typical day, she arrives for work at 6:30 a.m.

“Days are chaotic. We come in, get people up, brush teeth, wash faces, comb hair, do breakfast, shower them, and then do activities,” she says. Being out on the floor means not only dealing with the immediate needs of residents, but also any needs or complaints from their families. “If laundry or dietary or anyone makes a mistake, we’re the ones who deal with it,” explains Brown. “We’re the ones who have to face the family.”

The second topic area is the work environment, which can play a major

role in employee turnover. Brown says that she has worked in several facilities, but she stays at Beatitudes because of the pleasant work conditions. “This place makes you feel special,” she says. “You come to work and you feel wanted, and the people above you do everything to make you feel more comfortable.”

Work environment might cause caregivers to hop from one facility to another. However, turnover also occurs when employees leave the field entirely. Becky Coomes, another CNA at Beatitudes, says that some people simply are not cut out for caregiving. “You really have to want to do this. Some people just want the paycheck. If you do it just for the paycheck you’re going to be really disappointed,” she says.

Coomes believes that many caregivers don’t give themselves time to get used to the work or to build relationships with the patients. Coomes has been a caregiver for 22 years, and has spent the past 12 years working at Beatitudes. She says that training programs have become shorter over the years and do not adequately prepare caregivers for the reality of the work.

“My CNA program took a year to complete. Programs now are two weeks to a month. They miss things. When [caregivers] get on the floor they find, ‘This isn’t what I thought it would be.’ Some only stay for one day. A lot will say, ‘I can’t do this, it’s too much.’”

Giang Ho is also a CNA at Beatitudes. She agrees with Coomes. “It’s overwhelming at first. It’s always hard at first, in any job. A lot of people don’t stick it out,” she says.

The CNAs who do stick it out say the patients are what keep them coming back. “The only reason I stay in this work at all is for the residents. My best days are when I come to work and my people are so happy to see me. It makes your whole day go by faster. You don’t care about anything else if your residents are happy,” says Brown.

The last two topic areas in the survey deal with these direct relationships. The survey asks about caregiver satisfaction with patient relationships, and anxiety about communicating with patients.

“Each person is different,” explains Coomes. “I had one patient who’d had a stroke, and was in the beginning stages of Alzheimer’s. No one could understand her. But she and I clicked. People thought I was crazy, but she knew I could understand her. You work with somebody so long, you get to know their sounds, expressions, body language. It’s hard when you first get a patient.”

The survey results also show a positive correlation between satisfaction with work environment and satisfaction with patient relationships. Caregivers who are satisfied with the work environment also feel less burdened by their work. Caregivers who were satisfied with their communication also had low anxiety about communicating and liked their work environment.

“Perhaps the facilities could provide training. Not just job training, but other skills that enhance quality of life,” muses Schmidt.

Coomes suggests, “If we helped out on the floors and did more mentoring and hands-on helping, that might make [new caregivers] feel at ease, more willing to come to us with questions.”

“What is missing is the formal research on what is important to the caregiver. What do caregivers need for information?”

EVERY SEVEN SECONDS, A PERSON TURNS 50 IN THE UNITED STATES... ONE IN EVERY FOUR HOUSEHOLDS IS INVOLVED IN CARING FOR A PERSON OVER AGE 50...



“Days are chaotic. We come in, get people up, brush teeth, wash faces, comb hair, do breakfast,

PARENTS, OTHER RELATIVES, OR FRIENDS... IF THE WORK OF THESE CAREGIVERS WAS

REPLACED BY PAID HOME CARE,

It makes your whole day go by faster. You don't care about anything else if your



residents are happy...

COSTS AMERICAN EMPLOYERS \$11.4 BILLION TO \$29 BILLION PER YEAR... AMERICANS SPEND \$83 BILLION ANNUALLY ON NURSING HOME CARE...

to take care of your own mom or dad. At a care center we may have more patience.” GIANG HO

THE NUMBER OF AMERICANS WITH ALZHEIMER'S DISEASE IS ALSO PROJECTED TO NEARLY TRIPLE, TO 13.2 MILLION PEOPLE BY 2050...

I'm so used to having to interpret...you get to know their sounds, faces, body language.” BECKY COOMES



WHEN QUITTING IS NOT AN OPTION Ultimately, the formal caregiver who feels too burdened by the work can quit. However, the person whose mother had a stroke or whose father has dementia doesn't get to opt out.

Schmidt also wants to know how to help these caregivers, perhaps because she has been one. “When my mother was 80, she moved into a retirement setting, one without services. After she moved we felt she was getting lonelier and thinner. After a few years my mom developed physical problems. One night she fell out of bed and hit her head. My mother started living with us for a while, but she kept getting worse. I had to hire a caregiver to come to our home.”

For her dissertation, Schmidt surveyed 309 caregivers who help a parent or grandparent. The average age of these caregivers was 51, and 78 percent were female.

Schmidt asked respondents about the caregiving tasks they performed, their information and training needs, the information sources they used, and the value of those sources. “What do caregivers need for information? Where do they go? What format do they want to see it presented in? There's a lot of information available but is it based on empirical research about what people want to see?”

Schmidt found that caregivers did not necessarily need information about direct care tasks such as feeding, dressing and toileting, but they did need help with indirect care activities such as meal preparation, managing finances, or overseeing medications. For example, managing multiple health conditions can be confusing and scary for a caregiver. “If something goes out of balance it knocks everything else out of balance. Often treating one problem is detrimental to another. It's a very delicate situation,” says Schmidt.

Many older people have multiple health problems that require several medications. Certain medications, however, can interact and cause harm. For example, people who take anticoagulants to prevent harmful blood clots should avoid aspirin, or they can risk excessive bleeding.

When seeking information, caregivers were mostly likely to turn to other people, such as health professionals, friends, or relatives. Non-health-related media sources and public and non-profit sources were less likely to be used, possibly due to lack of knowledge about their existence.

When caregiving begins can make a difference in the information needs and sources of caregivers. When people are suddenly thrust into caregiving—for example, due to a medical crisis—they tend to have greater information needs. They are also more likely to turn to traditional health and crisis intervention professionals than people who enter caregiving gradually. They rely more on religious organizations and support groups, as well.

Although the most commonly used resource was the patient's physician, caregivers did not rank it as the most valuable source of information. They rated friends and relatives higher. Media sources were deemed the least valuable resources by caregivers.

Finally, Schmidt found that older, working caregivers had the greatest information needs of all. This is important given that 74 percent of the respondents said they work, and more than half work full-time. Also, older caregivers reported higher levels of responsibility toward the patient than did younger caregivers.

Balancing work and caregiving can be a struggle. Schmidt notes that even when a caregiver can afford to hire help, it is not always feasible to do so. “We can't just have a caregiver take Mom to the doctor, even though we have a wonderful caregiver. We need to know what the doctor says,” she says.

Survey results provided valuable information. With a better understanding of what caregivers need, the researchers now want to find the best way to help provide for those needs. Arnold has been active in bringing eldercare issues to public attention. He recently participated in an Arizona Town Hall meeting on healthcare and end-of-life issues. A series of similar meetings will take place around the country in the coming year, culminating with a national meeting in Washington D.C. in November 2004.



Where do they go? People don't want to think about having to care for their parents.” KATIE SCHMIDT

MORE THAN 7 MILLION AMERICAN HOUSEHOLDS (ABOUT 54 MILLION AMERICANS) PROVIDE INFORMAL CAREGIVING FOR SPOUSES,

shower them, and then do activities. My best days are when I come to work and my people are so happy to see me...

THE COST WOULD BE \$45 BILLION TO \$94 BILLION PER YEAR... EMPLOYEE ABSENCES AND LOST PRODUCTIVITY DUE TO CAREGIVING

The only reason I stay in this work at all is for the residents.” MELISSA BROWN

“It’s frustrating

BY THE YEAR 2031, EVERY BABY BOOMER WILL BE OVER 65 YEARS OLD... ARIZONA’S ELDERLY POPULATION IS PROJECTED TO TRIPLE BY 2050...

“You really have to want to do this. If you do it just for the paycheck you’re going to be really disappointed...”

FOR A COPY OF THE ARIZONA TOWN HALL REPORT, “HEALTH CARE OPTIONS: HEALTHY AGING—LATER LIFE DECISIONS,” VISIT WWW.AZTOWNHALL.ORG

“One in four households is providing care, and it’s only going to get worse.” WILLIAM ARNOLD



The meetings will highlight the eldercare crisis in America and encourage legislators to address it. For example, Arnold supports passage of the Family Caregiver Act, which would provide funding to people who are forced to quit their jobs to care for elders.

Arnold also serves on the board of directors for “And Thou Shalt Honor,” a documentary that first aired on PBS in October 2002. The show describes the state of eldercare in America and highlights a variety of caregivers. The documentary is accompanied by a companion book (*And Thou Shalt Honor: The Caregiver’s Companion*, edited by Beth Witrogen McLeod) and Web site (<http://www.thoushalthonor.org/>). “Every person should have a copy of the book,” says Arnold. “It’s the Dr. Spock book of elder care.”

Schmidt agrees. “It’s like having a child, in that you have to prepare for it. But childbearing is a happy event. No one wants to prepare for something negative. People don’t want to think about having to care for their parents.”

Schmidt and Arnold urge everyone to think about the issues surrounding eldercare before parents actually need help. Arnold recommends that families develop a plan together, based on the wishes of those who may need care. Many times families assume they know what their loved ones want, but they might not. “When my mother had cancer, she didn’t want chemotherapy or radiation. She was ready to go, but she didn’t want to be in pain. She died in two months, but she died pain-free,” says Arnold.

Becky Coomes echoes Arnold’s advice. “You’ve got to talk to your parents, to your siblings, to your spouse. There are a lot of fights. You have to work it out between you, before it gets to a critical stage.”

For example, Coomes says that even if there are multiple siblings, only one person can be given medical power of attorney. Hospitals and nursing homes will give out patient information only to that person. So siblings have to communicate with one another and share information. Coomes advocates going as far as writing up a pseudo-contract. What would the parents like

each person to do? What is everyone capable of doing? “And everyone should sign it. It might not work, but it can help,” she adds.

Often families fight over whether or not to move a parent into a facility like Beatitudes. Many times parents make their children promise never to put them in “a home.” Other times siblings disagree with each other about what to do. All of the CNAs at Beatitudes recommend that families visit a facility like theirs before making a decision.

“Lots of people think nursing homes are just a place to go to die. It’s not like that anymore. It’s not like it was 30 or even 20 years ago,” says Coomes. “A lot of people have never been in a nursing home. They don’t know what to expect.”

Ho adds that families should think about the nature of a loved one’s needs when deciding on how to care for them. “Caring for an aging parent and caring for a parent with, say, Alzheimer’s is very different,” she explains. “It’s frustrating to deal with a loved one with Alzheimer’s. It’s frustrating to take care of your own mom or dad. At a care center, we may have more patience.”

Ultimately, families have to make choices that work for themselves and their loved ones. Arnold and Schmidt hope to help people see all the choices they have and to make those choices fully informed. “One in four households is providing care, and it’s only going to get worse. We’re putting a lot of money into research on Alzheimer’s, Parkinson’s, etc., but not into caregiving research,” says Arnold.

Schmidt adds, “We’re trying to make it better for the caregiver, who will in turn make it better for the patient.”

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