Florida Association of Aging Services Providers e-Newsletter

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Guest Editor: Stephen Ferrante, MSW, Florida Atlantic University

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THIS ISSUE SPONSORED BY:

Message from the President

by Karen Deigl, Senior Resource Association, Inc.

Dear FASP Members:

Thank you, thank you, thank you! As a busy executive myself, I know the demands, planned and unplanned that consume every minute of every day – and many nights too!

But, FASP members, WE did it! We invested our valuable dollars to support our advocacy work on behalf of frail elders with the Florida Council on Aging, the CCE Coalition and Florida Association of Area Agencies on Aging. WE visited Legislators local offices and dropped off the Business Case materials.

WE made calls to Legislators. WE gathered and shared data on the costly impacts of the Background Screening program. WE organized and attended local Advocacy Summits.

WE sent emails to Legislators and Governor Scott. And, WE succeeded in getting all aging programs either at continuation or, many with increases!

And, there is much more:

> *The 2010-2011 budget had been sustained with federal stimulus funds. The Legislature replaced all $27,962,884 of the stimulus funds with state general revenue, averting huge cuts to those programs. And, those funds had been in the non-recurring category; the Legislature made them recurring. This doesn't mean we won't have to fight for them in the future, but it makes them somewhat less vulnerable to consideration in budget cutting exercises.*

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When Driving is No Longer a Safe Option

John Smith, 84, has been demonstrating increasing memory impairment, and his vision has worsened in recent years. He drives daily, whether it is to attend doctor's appointments or run errands, or socialize with friends. His adult children have noticed scrapes and dents on the car that Mr. Smith dismisses. When they ask their mother about their' father's driving, she says that he's "not as good as he used to be." She said she often tells him to stay in his lane, and she said that he has had several "near-misses" in recent months. Mrs. Smith rarely drives due to advanced osteoarthritis, and she relies on her husband for transportation. Mr. Smith's oldest daughter contacted Mr. Smith's physician "to make dad stop driving." The physician was sympathetic, but said that he did not yet consider the situation a medical issue.

For any provider in Florida who works with older adult client drivers, the scenario of John Smith is all too familiar. Some clients can barely see and walk, and yet, drive themselves – and spouses and friends – to doctor's office, pharmacies, shopping malls, grocery stores, restaurants, community centers, churches/ synagogues or other religious sites, hair salons, mechanics, post offices … in short, they go everywhere they've always gone, but now they are questionably safe on Florida's roads. Providers and family members grapple with the risks taken by these impaired drivers, yet often feel "stuck" in part, because of the lack of viable public transportation alternatives.

Florida is experiencing growing numbers and percentages of older adult drivers. Almost one in five drivers in Florida is over the age of 65, and that number may grow to one in four drivers in the next 20 years (Classen, Schechtman, Awadzi, Joo, & Lanford, 2010). Furthermore, national data indicates that older drivers are spending more time on the road, i.e., increasing their annual mileage by at least 25 percent in the last decade (Cheung & McCartt, 2010). This data, combined with the oft-cited fact of the rapidly growing 85+ population, underscores providers' concerns about what is likely to be a growing problem for the foreseeable future.

This article attempts to provide some useful information to providers, beginning with addressing myths about older drivers, then offering some interventions, and finishing with a list of highly recommended resources.

Myth #1: Older drivers, in general, are worse drivers than younger drivers.
No evidence exists to support that older drivers, as a group, have worse driving behaviors than younger drivers. Older drivers have fewer police-involved accidents than younger drivers. Furthermore, the fatality rate of older drivers involved in serious accidents (relative to middle-aged adults) has *decreased* in the last decade from a threefold risk to a twofold risk for those over 80, and to about one and half times risk for those over 70 (Cheung & McCartt, 2010). Researchers concluded that safer cars, wearing seat belts, self-limited driving, improved medical emergency responses, and perhaps, improved health status, may be factors in the increased survival rate amongst older adults involved in crashes (Cheung & McCartt, 2010).

For providers, these findings suggest that encouraging older clients to drive cars with maximum safety features (when financially feasible), providing regular vehicle maintenance, and wearing seatbelts are proactive measures likely to improve road safety. *In regard to the Smith family scenario (above), a provider may want to double-check or have the adult children double check that Mr. Smith's car is being regularly maintained, and that his tires are in good shape and inflated properly. Providers, such as outpatient clinics, may require that clients/patients must be wearing seatbelts in vehicles when leaving the premises.*

Myth #2: The biggest risk factor for unsafe driving is worsening vision or memory impairment.
Driving safety experts emphasize the multiple complex activities and decision-making involved in driving that includes the integration of functional domains such as a variety of vision/perception-related factors; balance, body strength, grip, reaction time, and judgment. An adult child may be concerned about a parent with mild cognitive impairment, but, in terms of driving risk, he/she should be far more concerned about the degree to which the impairment affects *function*, e.g., perception, judgment, and risks for getting lost on the road.

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If providers/individuals/family members want to better assess someone's driving safety, they can use one or more of the many assessment tools easily available. For instance, self assessments such as AAA's online "Roadwise Review" and /or a workbook on driving decisions may help provide more specific information in the safety of one's own home. Professional assessments, usually by trained occupational therapists, may also be available, and may include comprehensive testing in a lab and on a road test. Links to these resources are provided at the end of this article. *In the case of Mr. Smith, providers/family members might convince him to participate in one of these assessments to provide more "objective" data regarding their concerns about his driving safety.*

Myth #3: Risky driving behaviors will only get worse and nothing can be done about them.

A number of programs and resources may be available to help older drivers improve their driving behaviors, and therefore, reduce their driving risks. This may include addressing remediable medical/health conditions, and training provided by local programs. See the resource list at the end for more information. *In Mr. Smith's situation, providers should first investigate if any of Mr. Smith's driving risks can be reduced through training/remedial programs and/or a review of relevant medical/health factors (e.g., has Mr. Smith been delaying a cataract surgery?).*

Myth #4: All risky driving behaviors are equally predictive of accidents.

Professionals/family members can use lists of risky driving behaviors to informally asses an older driver's road safety. Many resources (available below) provide comprehensive lists of 20 or more risky driving behaviors, including those mentioned in the Smith family scenario (e.g., scrapes and dents on the vehicle, lane drifting, and near misses). However, a recent study conducted in Florida identified three categories of driving errors that "predicted crash-related injuries with almost 50% probability" and should be recognized as "critical driving errors" (Classen, 2010, p. 212). The categories are the following: lane maintenance; yielding; gap acceptance.

Per these researchers, "lane maintenance" includes drifting out of one's driving lane, and difficulties with turns; "yielding" includes poor judgment in determining which car has the right of way at two- and four-way stops; and "gap acceptance" includes misjudging when one can safely turn in front of an oncoming car (Classen, et. al., 2010). Predictors of less-serious accidents included driving too fast or too slow and/or inadequate control of accelerating and braking (Classen, et. al., 2010). The researchers also found in their sample that older female drivers were more likely than older males to be involved in such serious accidents.

These findings underscore the importance for providers and family members to identify the types of problematic driving behaviors exhibited by impaired older drivers, and to act with particular immediacy when drivers have demonstrated difficulties with lane maintenance, yielding, and gap acceptance. *In the case of the Smith family scenario, Mr. Smith's driving behaviors of lane drifting and near misses may indicate an elevated risk for a serious accident, and the need for more proactive intervention.*

Suggestions for working with clients with risky driving behaviors:

Numerous resources are available to help guide providers and family members around initiating discussions with older adults who are demonstrating unsafe driving behaviors. A few suggestions from these resources include the following: Don't wait for the crisis. Begin having conversations before the unsafe driving becomes too serious. *In the case of Mr. John Smith, his family should begin formulating a plan immediately.*

Choose a family member to initiate the conversation who has a trusting, respectful relationship with the older adult. This is typically – but not always – one's spouse or partner. In some cases, an adult child may be most appropriate. In rarer instances, an older adult may prefer a physician or a close friend. Per the Hartford corporation's study on "family conversations" (see the listing below under "Resources"), older adults were least receptive to conversations initiated by the police. The key is that the person who initiates the conversation must have a respectful relationship with the older adult. *In the case of Mr. Smith, he might trust his wife the most, but she has a vested interest in his continuing to drive. In this case, an adult child who is trusted and respected by the parents may be the best choice for initiating conversations about "driving retirement."*

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When talking with an at-risk driver, stress concerns about the person's safety and perhaps relevant functional impairments (not age or disease). Use terms like "driving retirement" rather than "taking the keys away." *John Smith's son might discuss with him how his vision is affecting his ability to drive safely; he might also discuss how local roads have become more congested and dangerous than in earlier times.*

Provide alternatives to the person's driving. For instance, perhaps an adult child or other church member can provide rides to church. Also, consider clustering tasks when providing rides; this reduces the frequency of need for driving. *A family member might suggest that it's more convenient "this week" to drive to church with an adult child – especially if they are congregating afterward. Discussing alternative might emphasize convenience and cost savings (e.g., less money on gas), rather than aggressive tactics that, to Mr. Smith, feel like attacks on his competence and identity.*

The individual may insist that he or she can continue to drive safely to nearby and well-known locations. So, in the short-term, work out a plan for alternative driving arrangements for riskier driving situations, including unfamiliar places, or to places that are further away. *Mr. Smith may insist on driving to church, but he may be willing to allow a provider or an adult child drive him to an unfamiliar medical complex, or a grandchild's graduation ceremonies. Helping him ease into "driving retirement" may not be the safest plan, but probably is the most realistic plan.*

Acknowledge and support the sadness and frustration the person might feel about reducing driving. Also be attuned to the possibilities and consequences of increased social isolation. People with limited access to a car may feel they can still get to where they need to go, but not to where they want to go (Kerschner & Aizenberg, 1999). *If Mr. Smith has limited his driving, what have been the consequences for him? Is he becoming more socially isolated and/or depressed? What can providers do to increase desired socialization opportunities?*

If the person is willing to engage in discussions about driving safety, but denies that he or she is unsafe, help the person engage in more "objective" assessments that might help convince them to reduce or stop driving (see above "Myth #2 and the resource list at the bottom of this article). *If Mr. Smith is ambivalent about acknowledging his lack of safety, he might be willing to allow a family member or provider to use an assessment tool – in the safety and privacy of his own home - to underscore the validity of their concerns. Or, Mr. Smith's family might insist upon a professional assessment if Mr. Smith remains intransigent about not reducing or "retiring" from driving, and his driving, per the family, poses a growing risk for himself and his wife. The results of the assessment can be used either to allay the family's fears, or to clarify to them and to Mr. Smith the degree of risk in his driving behavior.*

What if the individual is unwilling to limit or stop driving despite consistent and worsening risky driving behaviors?

Involve the physician. Ask the physician to write a "do not drive" order. If the at-risk individual ignores this, then a physician in Florida has the option (but not the legal obligation) to contact the motor vehicle department to report an older person who presents as an unsafe driver. Providers can support family members in urging a primary physician to contact the Florida Department of Motor Vehicles. Providing evidence to a reluctant physician (e.g., tracking the numbers/types of driving errors committed in the past month) might convince the physician to request an assessment by the state's department of motor vehicles.

Disable the car so it won't start, or sell the car (if this is legally feasible).

Threaten to call the police - and do so - if an at-risk client insists on driving when he/she is demonstrating impairment that is strongly indicative of an inability to drive safely (e.g., intoxication). Social workers, psychologists, and other helping professionals are required by law to break confidentiality and notify the police when any adult provides a "serious, foreseeable and imminent risk to self or others" (Association for Advanced Training in the Behavioral Sciences, 2007). While this typically refers to overt threats made in clinical settings, helping professionals need to consider if a client's behavior can be reasonably construed to be a "serious, foreseeable and imminent risk."

Article References and Resources

Author: Debra B. Lacey, PhD, Associate Professor, Barry University School of Social Work. Dr. Lacey received her PhD and MSW from the State University of New York at Albany. She also received a Med from the University of Vermont. Prior to receiving her PhD, Dr. Lacey worked as a case manager in an area agency on aging, a long term care ombudsman, a hospice social worker and a research social worker. Dr. Lacey's areas of specialization include gerontological social work, medical social work and narrative practice orientations.

Unique Program Designed by Researchers at FAU Helps Keep Nursing Home Residents Out of Hospital

Hospitalizations of frail nursing home residents can result in higher costs, complications and death. According to the "Revolving Door of Rehospitalization from Skilled Nursing Facilities" a paper published in the January 2010 issue of *Health Affairs*, 23.5% of Medicare beneficiaries discharged from the hospital to a skilled nursing facility (SNF) were readmitted to the hospital within 30 days at a cost to Medicare of $4.34 billion in 2006. These rehospitalizations are frequent and costly. Research suggests that a substantial proportion of these hospitalizations may be preventable.

A low-cost, yet high-impact quality improvement program designed by researchers in the Charles E. Schmidt College of Medicine and the Christine E. Lynn College of Nursing at Florida Atlantic University can play a critical role in assisting nursing home staff to improve quality of care and reduce morbidity and expense of unnecessary hospitalizations. **Interventions to Reduce Acute Care Transfers** ("INTERACT") is a quality improvement program that includes tools that assist nursing home staff in three strategies that can reduce preventable hospitalizations: 1) identifying, assessing, and managing conditions to prevent them from becoming severe enough to require hospitalization; 2) managing selected conditions, such as respiratory and urinary tract infections in the nursing home without hospital transfer when safe and feasible; and 3) improving advance care planning and developing palliative care plans as an alternative to acute hospitalization for residents at the end of life when the risks of hospitalization may outweigh the benefits.

The INTERACT quality improvement projects are directed by Joseph Ouslander, M.D., Senior Associate Dean for Geriatric Programs in the Charles E. Schmidt College of Medicine. The most recent evaluation, supported by a grant from The Commonwealth Fund, was implemented at 25 community-based nursing homes in Florida, Massachusetts and New York over a six-month period. The results of the evaluation in these 25 nursing homes were recently published in the April 2011 *Journal of the American Geriatrics Society*

"The effects of the intervention were substantial." said Ouslander. "The most significant finding from this collaborative quality improvement project was a 17 percent reduction in hospital admissions among the residents. The reduction was even greater in homes that were more engaged in implementing the INTERACT intervention."

The key findings of the study include: The 25 nursing homes that completed the program experienced a 17 percent reduction in hospitalization rates compared with the same six-month period in the previous year. Of the 25 nursing homes, 17 were characterized as "moderately or highly engaged" in the initiative. This group had a 24 percent reduction in hospitalizations, compared with a six percent reduction in the group of eight facilities rated as "minimally or not engaged" and a three percent reduction in a comparison group of 11 nursing homes. The average cost of the six-month intervention was $7,700 per nursing home. The projected Medicare savings in a 100-bed nursing home were about $125,000 per year, enough to support a full-time advance practice nurse or physician assistant in the nursing home or other care improvements in the nursing home, as well as the costs of implementing the intervention.

"If implemented widely, the program could result in fewer complications, lower morbidity from hospitalizations, and reductions in Medicare costs. Some of the savings could be used to support improved care in US nursing homes", said Ouslander. INTERACT is now recommended by the Center for Medicare and Medicaid Services (CMS) as an intervention to improve patient safety and transitions between care settings (http://www.cfmc.org/caretransitions/provider_resources.htm). Programs such as INTERACT are highly relevant to health care reform and the sustainability of Medicare by helping to achieve the CMS "triple aim" of improved care, improved health, and reduced cost.

INTERACT, (developed by Joseph Ouslander MD, Mary Perloe, GNP, Gerri Lamb, PhD, RN, Alice Bonner, PhD, GNP, Laurie Herndon, GNP, and Ruth Tappen, EdD, RN), is a quality improvement intervention, including evidence-based and expert guideline recommended clinical practice tools, designed to improve the early identification, assessment, documentation, and communication about changes in the status of residents in nursing facilities.

The goal of INTERACT is to improve care and reduce the frequency of potentially avoidable transfers to the acute hospital. Such transfers can result in numerous complications of hospitalization, and billions of dollars in unnecessary health care expenditures. There are four basic types of INTERACT tools: 1) Communication tools; 2) Care Path tools; 3) Advance Care Planning tools; and 4) Quality Improvement tools. The program is implemented by an on-site champion and supported by regular collaborative teleconferences facilitated by an experienced gerontological nurse practitioner. The INTERACT program and INTERACT II tools and resources are available at http://interact2.net. Dr. Ouslander and his colleagues have developed a curriculum that can help nursing homes implement the INTERACT program.

Author: Dr. Joseph Ouslander, M.D., Senior Associate Dean for Geriatric Programs in the
Charles E. Schmidt College of Medicine.

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Alzheimer's disease programs and most Local Services Programs were eliminated in the Governor's budget proposal. The Legislature restored them, and funded them with continuation dollars. This is a huge victory!

The Governor's proposed budget reduced nursing home diversion, Medicaid waivers and CARES. The Legislature restored them and even increased ADA waivers by $5.7 million.

Governor Scott proposed continuation funding for Community Care for the Elderly and Home Care for the Elderly Programs. Following a brief scare of reductions from the Senate, Senator Nan Rich from Broward and Senator Joe Negron from Martin restored both programs with continuation funding.

Then WE flooded the Governor's office with faxes and emails to gain his support for the outstanding Legislative Budget, and Governor Scott let all of the Legislature's actions stand!! Pause and celebrate!! Before we start our important work again for 2012.

As your President, I say thank you. **We are *all* going to need to contribute funding to this important advocacy work.** My agency has done so and we'll soon be asking all of you to do so as well. But, for now, let's thank our Legislators, Governor Scott and each of our colleagues, for we all worked very hard as a team to accomplish this.

Finally, we have many challenges ahead. The 2012-13 Budget will be major. But, the Medicaid Reform Legislation that was passed by the 2011 Legislature will impact us all and the elders we serve. The new Legislators know little about our programs, services, and the needs of our seniors and must be educated if we hope to gain their support. These and other pressing issues will remain critical challenges for the Aging Network. The 2012 Legislative Session will begin early, in January 2012, due to legislative redistricting, with legislative committee meetings beginning in September, 2011. So, with only a brief respite, we will all be called back to work for Florida's elders. We must be prepared!

This issue of our newsletter includes articles that discuss the great work by researchers at Florida Atlantic University in the design of the program called ***Intervention to Reduce Acute Care Transfers*** (INTERACT), support strategies for struggles faced by the "sandwich" generation, and the growing concern regarding the safety of older drivers.

We hope you find this issue informative and an invaluable resource and we welcome and encourage you to participate in the 2011 Florida Conference on Aging (***Aging: Through a New Lens***) in St. Pete Beach, FL in August. Please join us for our Tuesday morning plenary session on the 'Future of Aging' with John Migliaccio of MetLife Mature Markets and Michael Marcus of the Weinberg Foundation. Yolanda Rodriguez and Larry Polivka will be responders for this session and, FASP will present the prestigious Minotty Eye Foundation Best Direct Service Employee of the Year award to Debbie Slade of NU-HOPE Elder Care Services, Inc.

Hope to see you all then!

Sincerely,

Karen Deigl

The Struggles of the Sandwich Generation: Strategies for Support

It was the fifth phone call she had taken and it was only 10 am. She was crouched in the girls' room at the public high school where she was the head librarian. It was her sister calling to say she was becoming increasingly worried about the well being of both their mother and grandmother. The sisters lived 1500 miles apart and each had young children under the age of 6. Their mother had a severe case of shingles in her eye and was unable to see while at the same time their 86-year-old grandmother was in the hospital with congestive heart failure. Elle was the closest in geography but was still a 4-hour drive away. Mia lived 1500 miles away from her family and would have to fly home in order to help out.

Their mother was recently divorced and lived alone. She was unable to drive and was in terrible pain. Their grandmother lived with an aunt who was mentally ill and unable to make medical or legal decisions. Elle decided it was necessary to take time off work and drive down to help stabilize the situation. She had two remaining days of family sick leave that she could access in order to take time off of work. She had to arrange childcare with her ex-husband to make sure someone was taking care of her 4-year-old son.

She drove the 200 miles and spent the next two days at the hospital with her grandmother and taking her mother to doctor's appointments. On the day that she had to return home she was on the phone with her sister again. Was it necessary for Mia to fly home to take Elle's place for a few days? The answer was a resounding yes. Just hours later Mia was on a plane. She left without seeing her children who were at school when the decision was made. Within an hour of landing she was at the bedside of her grandmother. She left her two children, ages 2 and 6 at home with her husband and their father, all of them wondering whether she would be home to spend Mother's Day with them. She was able to take time off of work at the University where she was a professor, missing graduation ceremonies, and faculty meetings.

She spent the next three days arranging hospice care, getting her grandmother home, and setting up 24- hour home health care. There was no one in the family able to provide the around the clock care that her grandmother required until her mother recovered from shingles. So the two of them worked out a schedule. They would each take a week at a time caring for their mother and grandmother. The following week they would return home to care for their children and families. They would continue until the medical situations stabilized enough allowing them to return to the normal duties of full-time working mothers.

This is a typical story about the pressures of providing care to multiple generations of family members at the same time. It is a story repeated over and over again across the country. This scenario is a pretty good one given that there were responsible fathers present and economic resources to help pay for care. It can be even more stressful when employers or spouses are not supportive and flexible. Often aging parents are living with families making the responsibilities 24 hours, 7 days a week. *This is a true story though the names have been changed to protect confidentiality.*

Often it is women who find themselves in the sandwich generation, though more sons and fathers are finding themselves as caregivers too. These people have both young children to care for and aging parents or grandparents. The trends in delaying childbirth have meant that people are having children later in life and thus their parents are older too. It is not unusual to have a baby in your forties while at the same time your parents are in their seventies. Children are increasingly being supported to a much older age too especially given the state of the economy now. Parents are often financially contributing to children well into their 20s.

An analysis of the National Longitudinal Surveys found that 9% of women aged 45-56 years old are simultaneously supporting both their parents and children and would be included in the sandwich generation (Pierret, 2006). These women contribute $18 billion and 2.4 billion hours of care each year. They are invaluable in the care of children and parents.

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“Tell Us What We Can Do”

Older African American and Afro-Caribbean Adults Describe Their Difficulties Obtaining Diagnostic Evaluation and Treatment Services For Loved Ones Evidencing a Progressive Memory Loss.

While conducting a series of cognitive screenings and focus groups at southeast Florida senior centers serving African American and Afro-Caribbean individuals, we heard a common refrain: Most of the participants reported that they were at a loss as to how to help their loved one, whether family member, close friend or neighbor, who was experiencing a progressive problem with their memory and other cognitive functions.

In listening to these seniors’ stories, the most predominant themes were difficulty getting health providers to attend to their concerns about their loved ones, trouble getting information about the prevention and treatment of Alzheimer’s disease (AD), knowing how to recognize when diagnostic evaluation and treatment are needed, and obtaining resources to have patients diagnosed and treated.

Almost all had seen the effects of Alzheimer’s disease or a related dementia on a loved one and were eager to tell their stories. Most said they had had trouble getting help for several reasons. First, the individual with the memory problem often is unwilling to admit something is wrong so it was difficult to persuade them to agree to an evaluation. “People do not like to talk about this. They try to keep it a secret,” said one group member. They found no one who could help them or provide some guidance on how to accomplish this first step.

Even more frustrating, if they could be persuaded to see a doctor, their loved one often told the doctor, “Oh, I’m fine” and nothing more was done. This was the next challenge: to persuade their primary care provider (PCP) that indeed there was something “wrong” with their loved one. They told us that they had trouble finding a PCP who would listen. Most of them say, “It will get better” or “It’s just a part of getting older.” Others reported that their PCPs did not ask the patients about memory concerns and the patient will not say anything. Furthermore, when they do visit a PCP, they are often rushed and there is little time to discuss a memory concern. If they do convince the PCP that a problem exists, “they just give you pills.”

Several also talked about how hard it was to find a place to have cognitive testing done. One enterprising participant reported calling her state senator to find out where this could be done and was given useful information. Not one individual reported calling the Alzheimer’s Association chapter or knowing about the several memory disorder clinics in our region (Tappen, Gibson, & Williams, in press).


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Although most of these older adults were retired or semi-retired and receiving Medicare benefits, they still found the cost of obtaining evaluation and treatment prohibitive. The extent to which their health insurance would cover the cost was frequently raised as a barrier to obtaining care.

The literature tells us that mistrust of the medical community, the stigma of mental illness and misconceptions about AD, particularly the notion that it is simply part of growing older, are barriers to early diagnosis and treatment in African American and Afro-Caribbean groups (Alzheimer’s Association, 2010). Our informants provided a different perspective: eagerness to know more about this disease and a strong desire for more guidance on how to help a loved one who is developing AD or a related dementia.

Yes, they did say that the people developing the disorder try to hide it but there was no indication of reluctance on their part to seek help for their loved one, only frustration with the barriers they described so well: difficulty directing the PCP’s attention to the memory concern, cost of evaluation and treatment and difficulty finding out where to turn for help.

We have some excellent resources in our community but clearly they have not yet reached everyone who needs them, particularly older members of the African American and Afro-Caribbean community and the PCPs and others who provide their care.

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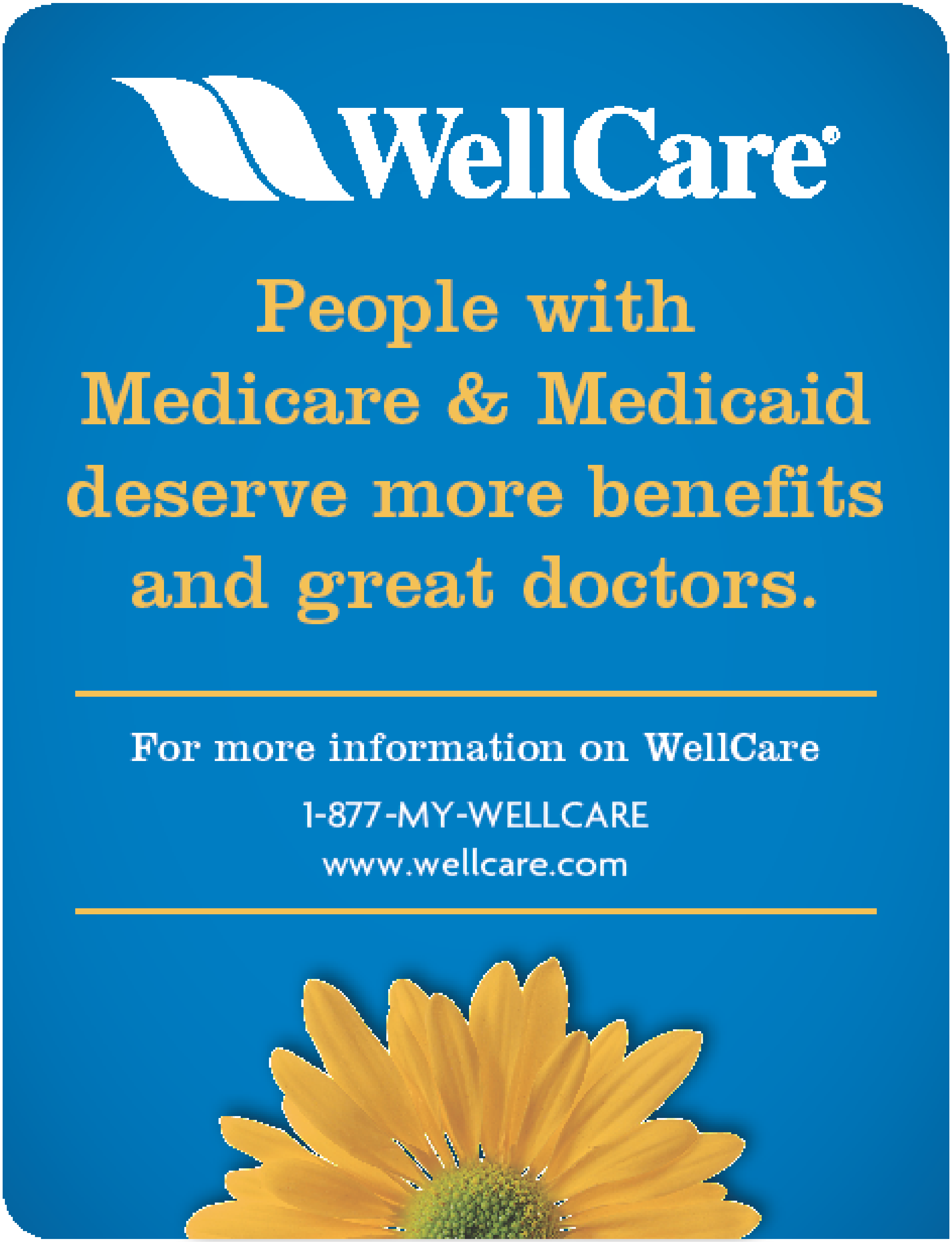

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Thoughts from a Researcher and Son

My 83-year-old father recently passed away after a six-month stay in a rehabilitation center / long-term care facility. Day after day during those long months, I watched my polished black leather feet walk down a long dull corridor to my Dad's room, never knowing what to expect when I walked through the door.

Although I was, overall, satisfied with the care my father received, I held my breath during that three minute walk each day. The human resource and financial difficulties facing long-term care facilities sometimes results in serious challenges for patients and their uninformed family members. If Dad's regular nurse or aides were not on duty, his care often suffered.

Questions like the following consistently concerned me. Would the nurse on duty today know Dad was to take NOTHING by mouth or would she ask me, with liquid in hand, if he could drink? Would the per diem agency nurse know he was not communicative due to stroke, or would he ask Dad several questions in vain before he *really* checked his chart. Would the nurse aide dress, clean, and shave Dad so he would be ready for therapy, or would I find him uncovered, in diapers, and falling out of bed, having been left along because he "looked weak." (In actuality, he was dehydrated and had a blood pressure of 86/46).

Besides staff-related worries, my other questions had nothing to do with staff, but impacted my interactions with staff just the same. Would Dad be able to sing our favorite songs like *You are my Sunshine* and *'Til Then*, or simply inquire about my long-deceased mother. If he could sing, I was happier. If not, I would ask questions about his dementia medications. Another question was "Could Dad endure another day of rehabilitation so the insurance company would keep paying for his care?" If not, he might softly whisper 'I'm tired' and start me asking the therapists if I should continue to "encourage" him to keep struggling with wobbly legs.

Fortunately, my last step into Dad's room often was accompanied by a sigh of relief and an excited "Hi Dad!" His return "Hi Poppy" (we are Hispanic) was like a Rumba to my ears. He still knew who I was – and he was still alive. Dad lived with a feeding tube because due to dysphasia, and a catheter due to an enlarged prostrate. But he rarely complained about his circumstances, although he understood his plight – some of the time. Once, however, when we both struggled for him to use the toilet, he declared "I shouldn't be alive." But he stated it as a fact, not a wish. In fact, Dad was fortunate *to be* alive. His 130-pound frame had survived a stroke, two heart attacks, two bouts with pneumonia and a bout of dehydration that led to a re-hospitalization.

Dad didn't talk much but when asked directly about his condition; he seemed resigned to live as long as God or his family wanted him to. And his three children often second-guessed our allowing heroic medical interventions to keep him going, even after his primary care physician encouraged us to "Let him pass the old-fashioned way."

Other articles in this issue provide research-based insight into the challenges faced by families of the elderly and residents of long-term care facilities. Although I too am a professor of research, I am also the recently orphaned son of my father, and the married father of an eight-year girl. I struggled to balance caring for the dying while providing for the living. I am among those frustrated by the limited guidance that exists to help family members understand the workings of hospitals, nursing home, rehabilitation centers, etc., not to mention how to know the difference between a nurse practitioners, a nurses, a nurse aides, and a physical therapists. Where was my user's guide?!

Although I teach statistics and promote the use of numbers to lead us to a better understanding of issues related to health care service, my last months with Dad unraveled emotions no numbers can quantify. Themes related to frustration at yet another trip back to the hospital, or feelings of helplessness regarding a doctor's decision to use morphine in hospice without telling me. I felt ignorant though awash with data. I was angry at siblings who delayed paying bills or who rarely visited, even though they knew these were our last days with the man who never stopped giving to his children and grandchildren. And, of course, I felt guilt.

Dad is gone now. He is in a much better place – where his tears have been wiped away, his body transformed and his mind renewed. And I no longer visit the facility that had become as much a part of my life as it was a part of Dad's. As a son, my duty is over – or is it? As a researcher, I have so many questions on my heart and mind that beg for answers so we can improve the quality of service and care for the frail and elderly. One day perhaps I will have the strength to search for those answers. In the meantime, I will never forget the words of one of Dad's fellow residents, a petite elderly woman whose moist eyes silently pleaded for attention. One day, when I slowed my pace and softened my gaze at her, she asked "Are you the calvary?" As I smiled and slipped away from her piercing question, I stared at my shoes and thought – "I wish I were, Lillian. I wish I were."

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Disparities in Chronic Pain Management Among Racial and Ethnic Minority Elders

Introduction

Racial and ethnic minority elderly (65 years or older) represent one of the fastest-growing populations in the United States (Helme & Gibson, 2001). Minority elders are expected to constitute 25% of all older adults by 2050 (Administration on Aging [AOA], 1994-1995). As the proportion and absolute numbers of minority elders continue to grow, poor health outcomes in this group represent a major public health problem (Bruce, Fries, & Murtagh, 2007).

Racial and ethnical minority elderly are not only more vulnerable than nonminority elderly and suffer increased rates of morbidity due to chronic pain; they are at risk for undertreatment or inadequate pain assessment and treatment associated with disparities (Green, Baker, Smith, & Sato, 2003) in pain prevalence, pain assessment and treatment, access to quality pain care, and pain-related outcomes (Cintron & Morrison, 2006; Edwards, C. L., Fillingim, & Keefe, 2001). Race/ethnicity has been identified as a patient-related factor that is likely to influence pain prevalence and perception as well as assessment and treatment (Cleeland, Gonin, Baez, Loehrer, & Pandya, 1997).

Pain Prevalence and Perception of Pain

Racial or ethnic differences exist in the prevalence and severity of chronic pain (Reyes-Gibby et al., 2007). African Americans and Hispanics report higher prevalence of chronic pain (Odutola & Ward, 2005), higher pain severity (Reyes-Gibby et al., 2007), and more functional limitations/impairment as a result of pain than do non-Hispanic White or Hispanic older adults (Odutola & Ward, 2005; Reyes-Gibby et al., 2007). Andersen et al. (1999) reported that 26.4% of Mexican American women and 32.8% of African American women reported knee pain, compared with 22% of White counterparts. Functional limitations resulting from pain were more prevalent among Hispanic and African American older adults than among non-Hispanic White older adults (Stump, Clark, Johnson, & Wolinsky, 1997).

One study exploring racial/ethnic variation in pain found a greater negative affective effect of pain in African Americans than in non-Hispanic Whites (Edwards, R. R., & Fillingim, 1999), which may contribute to racial/ethnic differences in pain perception and ratings (Shavers, Bakos, & Sheppard, 2010). African Americans reported higher levels of pain severity and depression/disability resulting from pain than Whites and a stronger connection between emotions and pain behaviors than Whites (Edwards, R. R., Doleys, Fillingim, & Lowery, 2001).

Pain Assessment and Treatment

Inaccurate pain assessment by health care providers may lead to undertreatment of pain in racial and ethnic minority patients (Lasch, 2002). Cleeland et al. (1997) reported that African American patients were almost twice as likely as other racial/ethnic groups to have their pain underestimated by their physicians due to inadequate pain assessment. In terms of self-reported pain ratings, Asians reported significantly lower pain scores than other ethnic groups on four pain scales (i.e., pain presence, intensity, location, and duration; Im, Guevara, & Chee, 2007).

Racial and ethnic minority elders may be challenged in effectively communicating their pain to health care providers (Miner, Biros, Trainor, Hubbard, & Beltram, 2006). A language barrier may result in misinterpretation of the patients' pain and inaccurate assessment of the pain. Providers who are not culturally sensitive to the patient's culture may depend on personal beliefs and attitudes that do not accurately characterize the patient or the patient's pain behavior, which may impede effective pain treatments (Shavers et al., 2010). Language barriers also limit access to adequate treatment; Hispanic patients reported that they did not understand how to use pain medications because instructions were unclear or written in English (Juarez, Ferrell, & Borneman, 1998).

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Racial and ethnic minority patients are less likely than non-Hispanic patients to receive pain medications, more likely to receive lower doses of pain medications (Bonham, 2001), and less likely to receive prescriptions for pain medication from a physician (Cintron & Morrison, 2006). Bernabei et al. (1998) reported that minority older nursing home residents with cancer pain were less likely than non-Hispanic Whites to report pain, even after controlling for language differences.

Racial and ethnic minority elders often delay seeking medical treatment (Limaye & Katz, 2006; Richards, Funk, & Milner, 2000) due to various reasons, such as cultural background and socioeconomic status (Carey et al., 1996). These reasons may play a significant role in how chronic pain is managed and expressed by patients and family caregivers (Juarez et al., 1998). For instance, Asians rarely complain about pain; they are likely to delay seeking help until the pain becomes severe (Im, Liu, Kim, & Chee, 2008). Older Asian American patients are likely to consider cancer pain to be the body's spontaneous and unavoidable reaction to cancer. Hispanic patients reported telling God when they were in pain, as one way of coping with the pain and cancer. Enduring pain is seen by this group as a reflection of personal strength.

Ethnic minorities are more likely to use complementary and alternative pain treatment (Juarez et al., 1998). Hispanic and African American patients are more likely than non-Hispanic Whites to use traditional methods (Mackenzie, Taylor, Bloom, Hufford, & Johnson, 2003), such as home remedies, herbs/teas, poultices, ointments, creams, and oils (Juarez et al., 1998). American Indians have a traditional healing system based on shamanism and sacred ceremonies (Hsiao et al., 2006). Elderly American Indians were more likely to ignore pain than to allow it to interfere with activities (Kramer, Harker, & Wong, 2002a). The most common strategy for coping with chronic joint pain was to endure the discomfort by various distraction strategies (e.g., meditation, prayer, deep breathing, visualization, and positive mood; Kramer, Harker, & Wong, 2002b).

Implications for Health Care Providers

Health care providers may lack knowledge and training related to health care services for racial and ethnic minority patients, resulting in inadequate pain assessment and treatment, as well as mistaken beliefs and unrealistic expectations regarding patients (Anderson, Green, & Payne, 2009). Providers who do not understand ethnic variations in pain perception and expression are more likely to interpret patients' needs and behaviors in terms of their own ethnic background, which may differ from that of the patient. The results may adversely influence the patient's pain assessment and management. Understanding ethnic variations in patient perception and response to pain is essential to optimal pain management (Shavers et al., 2010). Educating health care providers in communication skills, use of interpreters, and broad understanding of variations in perception and expression of pain may be an effective intervention for providing appropriate care for minority patients (Anderson et al., 2009).

When providing treatment to racial and ethnic minority patients with chronic pain, it is vital to be nonjudgmental, sensitive, and respectful. Health care providers may (a) incorporate the patient's traditional or complementary and alternative pain management, such as relaxation, acupuncture, yoga, massage therapy, and religious and spiritual practice, into the care plan when possible; (b) involve family caregivers in the patient's care; (c) ensure that instructions for medications are available in the native language and understood by the patient and caregiver (Juarez et al., 1998); and (d) consistently assess coping strategies used by diverse older adults, as well as their beliefs about treatment and expectations regarding treatment outcomes. Caregivers should be encouraged to be actively involved and to report symptoms of uncontrolled pain to health care providers (Limaye & Katz, 2006). When older minority patients' beliefs and values are respected and integrated into the treatment plan, compliance with pharmacological and other medical interventions is likely to increase (Juarez et al., 1998).

Article references

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Upcoming Events

July 2011

July 27-29, 2011: Washington, DC. Generations United 16th International Conference. For more information visit http://www.gu.org.

August 2011

August 15-18, 2011: Hilton Orlando Bonnet Creek, Orlando, FL. Florida Health Care Association Conference - *Timeless Elegance. A Celebration of Caregiving.* For more information please visit www.fhca.org

August 22-24, 2011: 2011 Florida Conference on Aging: *Aging: Through a New Lens.* TradeWinds Island Grand Hotel, St. Pete Beach, FL. For more information please visit www.fcoa.org or call 850-222-8877 - Hotel reservations call 1-800-808-9833.

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Resources

"The MetLife Study of Elder Financial Abuse: Crimes of Occasion, Desperation, and Predation Against America's Elders," (June 2011, .pdf format, 25p.).
http://www.metlife.com/assets/cao/mmi/publications/studies/2011/mmi-elder-financial-abuse.pdf

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Continued from Page 7 -The Struggles of the Sandwich Generation: Strategies for Support

For aging and social service providers it becomes a question of how to best assist the sandwich generation? How can agencies help people manage dual responsibilities of caring for children and parents? How can employers and policy makers help people take time off work? Is there enough respite care or any for that matter? Are their economic resources to pay for care? What have researchers found out about the unique service needs and pressures the sandwich generation face?

There are many support strategies that incorporate clinical programs and policy interventions. Some of these include; support groups, respite care, financial and estate planning, legal assistance regarding medical powers of attorney and living wills, and training on how to provide basic home health care. Policy interventions that would support the sandwich generation include expansions of paid family and medical leave policies, flexible work place schedules, expansion of childcare funding, and more generous coverage of home health services through Medicare.

Dr. LeaAnne DeRigne, (MSW, PhD), Assistant Professor of Social Work, Florida Atlantic University, will be presenting at the Florida Conference on the Aging. She will give a presentation on the "Recent Scholarly Evidence on the Sandwich Generation". Come find out what is really known about the sandwich generation and how to better support them.

Pierret, C. (2006). The 'sandwich generation': women caring for parents and children. Monthly Labor Review, September 2006, 3-9.

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The mission of FASP is to support and advocate for public and non-profit organizations engaged in the provision of community-based services to Florida's elders to improve their quality of life.

Mark your calendars now!

The 2011 Florida Conference on Aging
will be held
August 22-24, 2011
at the TradeWinds in St. Pete Beach

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