

Meeting the Needs of Diverse Family Caregivers

Susan C. Reinhard and Rita Choula
AARP Public Policy Institute

Addressing the needs of racially and ethnically diverse family caregivers can play an important role in reducing unnecessary hospitalizations and nursing home care, and improving transitions between care settings. Qualitative research conducted by the AARP Public Policy Institute shows that many of those needs are not being met. It also suggests that health care professionals can help address the needs of family caregivers as they assume ever-increasing responsibilities in health care management. This research is based on a series of focus groups with Hispanic and African American family caregivers, as well as nurses and social workers, held in cities across the nation in 2011.

Family caregivers are assuming ever-increasing responsibilities for managing health care at a time when the older adult population in the United States is becoming more racially and ethnically diverse. This *Insight on the Issues* highlights themes that emerged from discussions with family caregivers, and with nurses and social workers about their attitudes toward family caregivers and the health care and social service systems in which they work. The research identifies barriers that hinder effective collaboration between diverse family caregivers and health care professionals. It also identifies potential solutions offered by caregivers and health care professionals that can benefit both parties.

Why Explore the Needs of Diverse Caregivers?

Family caregivers are the chief supporters of people with chronic conditions and ongoing needs for personal care. In the past few decades, they have also become lay nurses and social workers. Many perform complex tasks such as injections, wound care, tube feedings, and other kinds of skilled

care that would “make nursing students tremble.”¹ They also serve as care managers, helping their family members navigate the rocky pathways between multiple health care and social service professionals and settings.²

These significant responsibilities are part of the “new normal” for family caregivers, whose unpaid contributions are estimated to be worth \$450 billion annually.³ Despite deep personal and economic investments in the care of their family members, family caregivers report that they seem largely invisible to those who might be able to help them feel more respected and confident in providing care. And, they say, rarely does anyone ask them how they are doing, what their needs are, and how those needs might be addressed.

It is crucial to better assess and address these needs for two reasons. First, supporting the *caregiver as a provider* can bolster confidence and skill in giving care to people who are at risk of worsening health and well-being. Supporting caregivers fundamentally aligns with the public policy imperative

to reduce expensive and unnecessary hospitalizations and nursing home care. Second, supporting the *caregiver as a client* can prevent that caregiver from becoming the person at risk of worsening health and well-being. Without a focus on the caregiver's needs from both of these perspectives, there will likely be two "patients" who need substantial intervention.

But what are these needs? While all caregivers face difficult challenges to maintain their health and emotional well-being, through qualitative research, this report highlights themes specific to the experiences of African American and Hispanic family caregivers and the nurses and social workers who interact with them in hospital and community settings.

One Out of Five Caregivers Is Hispanic or African American

In 2009, some 42.1 million family caregivers in the United States provided care to an adult in need of help with daily activities. Three-fourths (76 percent) of family caregivers are white. One in ten (10 percent) is Hispanic and one in nine (11 percent) is African American.⁴ As the country becomes more diverse over time, these proportions will change. We will see an even greater population of diverse caregivers.

Other important statistics:

- Both Hispanic and African American caregivers earn on average less than \$50,000 annually (56 percent and 59 percent, respectively, vs. 34 percent of white caregivers).
- Hispanic family caregivers are an average of 43 years old and tend to be younger than white (51 years old) and African American (48 years old) caregivers.
 - Marital status also varies according to ethnicity. Hispanic caregivers are less likely to be married than white caregivers (48 percent vs. 63 percent) but more likely to be married than African American caregivers (44 percent).

Focus Groups Offer Insight into Needs

To explore the needs of diverse family caregivers, the AARP Public Policy Institute collaborated with Lake Research Partners to conduct qualitative research with Hispanic and African American caregivers and with nurses and social workers who interact with family caregivers. The research involved seven focus groups completed in January 2011 in California, Illinois, Maryland, and Virginia.

Four groups (one in Spanish) involved diverse family caregivers. Each group had a mix of gender, age, income, and education. All caregivers were required to have had an in-hospital experience with their family member in the past 18 months to qualify for the focus groups.

Three focus groups involved nurses and social workers. These health care professionals were evenly mixed in all three groups, since both interact with family caregivers when it comes to hospital discharge and addressing home care needs.

Nurses represented a variety of specialties, including intensive care, emergency room care, wound care, cardiology, orthopedics, and oncology. Social workers included those based in hospitals as well as private care organizations. The nurses and social workers were screened to ensure that they work with ethnically and racially diverse populations.

What Concerns African American Family Caregivers?

“There was no training in the hospital. The nurses gave you written instructions. They said this is how you do it. This is what you need to do. And this is *your* job.”

—African American male caregiver
Bethesda, MD

African Americans in the focus groups had assumed their roles voluntarily, and many were juggling a full-time job and young children with caregiving responsibilities. The caregivers were managing a range of health conditions for their family members, including diabetes, high blood pressure, high cholesterol, obesity, amputations, Parkinson’s, and Alzheimer’s or other related dementias. They were also providing an array of services such as bathing, diapering, help with walking, preparing meals, giving injections, and administering medications.

The two focus groups with African American family caregivers revealed a range of common concerns. African American caregivers felt *invisible* in the hospital. Many felt ignored by the hospital staff. Some said doctors, nurses, and social workers often left them out of discussions about their family members, and it was sometimes difficult to get their questions answered. Family caregivers said it is important to include them in these discussions because often patients do not understand what the doctors and nurses are explaining and they fail to retain vital medical information. Other common concerns:

- Lack of training by nurses caused frustration when the family caregiver returned home and had to take charge of care. For example, family caregivers

said they often did not receive sufficient training in administering injections. They also reported that they were not formally trained in other areas, such as how to move their family member from the bed to the bathroom, how to change an adult diaper, or how to get the care recipient to walk.

- Racial stereotyping occurred in some instances. An African American male family caregiver said he was not taken seriously in the hospital because he was dressed in jeans and a baseball cap—“like he was from the ‘hood.’” He felt he had to prove himself and his knowledge of the situation in order for health providers to treat him seriously.
- Most were confused by the hospital discharge process. They felt the information they received was not helpful and often given by a person who had no knowledge of their family member. Most said they were not prepared emotionally or physically to provide so much care; some said they quit their jobs or retired early in order to provide the care.
- Medication management was one of the biggest challenges. Family caregivers reported being confused about dosage amounts and when medication should be administered. They said the instructions on the medications were often not clear and felt the hospital should have given them a few days of medication to use so they did not have to rush off to the pharmacy as soon as they got home. Additionally, they were often confused by the addition of medications to the existing medication regime. They were unsure of what should still be taken versus which medications might no longer be needed.
- Many family caregivers felt isolated and misunderstood. Some felt they were unable to leave the house for fear something would happen to their family member. There was a sense of

loss of the life they used to have before they became family caregivers.

- Mental health needs were difficult for family caregivers to handle. Some caregivers said their family members experienced depression, mood swings, and erratic behavior once home. They did not know where to turn to for resources and help. This added to the family caregivers' stress and worry, affecting their own mental health.

What Were the Concerns of Hispanic Family Caregivers?

“Overall, I am fearful of being able to handle all of her needs. I am fearful that she could fall again. I am fearful that she could get hurt again and that I won't be able to help her. More than anything it's the constant fear.”

—Spanish-speaking Hispanic caregiver
Los Angeles

Hispanic family caregivers said they always knew they would be a caregiver in some capacity and that providing care for someone as they get older is a cultural tradition.

A number of Hispanic family caregivers said they started caregiving when they were very young. Many, particularly female caregivers, have had years of experience caring for their grandparents, parents, aunts, and uncles. However, many said caregiving is still stressful and challenging, especially for those who work at a paying job and have young children at home.

Like African American family caregivers, they were trying to manage complex health problems, such as diabetes, arthritis, stroke, heart attack, cancer, Parkinson's, Alzheimer's and

other related dementias, alcoholism, high blood pressure, and high cholesterol.

- The caregivers said they would never put their family members in a nursing home. They were determined to provide care in their own homes no matter how complex the health needs became. Caregiving responsibilities are shared throughout the family.
- Like African Americans, Hispanics said they often felt invisible in hospitals. These family caregivers believed that they needed to be included in conversations about their family member's care and wanted doctors, nurses, and social workers to address them as well as the patient. “There is a lack of empathy (from nurses and social workers). They don't seem to realize that you (the family caregiver) are the one that is there for them 24/7, and you are the primary caregiver...” said a family caregiver from Chicago.
- Language is a major barrier for Spanish-speaking Hispanic family caregivers in hospitals. They felt that their family members received inferior care as a result of the language barrier and that caregivers did not understand important information. They also said translation services were not always offered and that they had to request them. In many instances the health care professional delegated responsibility for translating to the family caregiver, who might not have a good understanding of the information being translated in the first place.
- Not enough formal training was available in hospitals for Hispanic family caregivers. English-speaking Hispanic family caregivers were more likely to be offered formal training by health care professionals than non-English-proficient Hispanic family caregivers. However, often the training was hurried and informal.

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- Family caregivers looked primarily to doctors and other clinicians as the best source of information about caring for their loved ones. This caused frustration, since many of these clinicians were unable to spend enough time with them.
- Some Hispanic family caregivers misunderstand the role of social workers. Most caregivers believed that social workers only determine the kind of insurance that will pay for the family caregiver's loved one. They did not understand that social workers can link them with community services and information sources that can help them.
- Family caregivers believed they were treated poorly because they are Hispanics. A number of Hispanic family caregivers said they were not treated as well as other ethnicities in the Chicago area, such as Polish or Filipino. They referred to the personal treatment they received from hospital admissions staff and the quality of care their loved ones received. The caregivers believed this stems from stereotypes of Hispanics as being uninsured or undocumented immigrants.
- Most family caregivers felt unprepared to bring their family members home from the hospital. Most felt their loved ones were sicker when they returned home, and as a result the caregivers felt inadequate to provide care. Some family caregivers called it “nerve-wrecking.” Family caregivers also felt isolated when they returned home with their loved ones and often separated themselves from their friends and social life.
- Financial concerns were a barrier to seeking services. If family caregivers perceived services to be expensive, they never investigated them. This was particularly true among Spanish-speaking family caregivers who were afraid that they could not afford extra services that might be available to them.
- Managing multiple health conditions and care needs is difficult. Most Hispanic family caregivers are caring for loved ones with multiple conditions and seeing two or more specialists. These family caregivers seemed to be receiving little or no help from the health system in managing these conditions.
- Lack of knowledge is a barrier to resources. Most Hispanic family caregivers who were not receiving services did not know where to go to find them. That is why they rely on their community for support and advice on caring for their loved ones. Often, family caregivers are routed to resources in their community that do not have translation services. This poses an additional problem for caregivers and their families who need that assistance. Family caregivers agreed that they would welcome more information on resources and services that might be available to them.

What Were the Concerns of Nurses and Social Workers?

“We do see a lot of differences with the (family) caregivers. Sometimes we have to treat the caregivers more than we do the individual patient. There are a lot of differences, culturally.”

—Social worker, Bethesda

Three focus groups brought together nurses and social workers to discuss their attitudes toward diverse family caregivers, their concerns, and their practices. Most of the participants were hospital-based, but some of the social

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workers worked in community settings. The experience levels of both the nurses and social workers ranged from those who had more than 20 years' experience to a few in the beginning of their career.

These health care and social service professionals shared a strong commitment to their work and to helping people. While many entered their profession with certain expectations, their professions have changed in recent years, making their work more difficult and challenging. Their top priority is working with older adults, but they find themselves increasingly spending more time with paperwork.

Demands on nurses and social workers today are different and more intense than when they joined the professions. Many said their patient/client loads are significantly higher and that they are dealing with sicker individuals. Social workers felt they are working more and more with insurance companies to get care for their clients. This left them with less one-on-one time to interact with the clients and their families.

Both nurses and social workers said they remain in their professions because they find it rewarding to comfort and care for those who may be scared to be in the hospital and who need additional help when they return home.

The following themes emerged from the focus groups:

- Nurses and social workers said it is a major challenge to handle cultural differences among their clients on a daily basis, especially because cultures often differ in terms of care preferences. End-of-life issues, which tend to highlight these cultural differences, offer some of the most difficult challenges.
- Social workers said that an effective way to identify cultural needs is to perform an assessment when doing a home visit with the client, first meeting family caregivers and patients in their home. Social workers are increasingly creating and giving families an assessment report when a family member comes home from the hospital. The report provides a comprehensive summary of what care the recently hospitalized person needs, what that person may be able to do on their own as well as what assistance the family caregiver is able to provide, current medications, and the status of insurance (i.e., Medicaid, Medicare, private insurance).
- Translation services can help overcome language barriers. Both nurses and social workers said they frequently interact with families who do not speak English as a first language. While translation services do exist, often they are not immediately available, and delays often conflict with the already hectic schedules of staff and family caregivers. Hospitals use a family member as a translator only as a last resort, because family caregivers may filter information out of fear that it will cause anxiety and scare the patient, and family members themselves may not understand the medical terminology and therefore not interpret it correctly.
- Formal training processes are in place before discharge from a hospital, but families that professionals consider “noncompliant” pose problems. Often standard training procedures are in place for equipment or medical needs such as catheterizing and colostomy bags. The family member is invited to observe the procedure being performed by the nurse at a specific time, which is not scheduled in collaboration with the family caregiver. Due to employment and other responsibilities, caregivers may have no choice but to avoid or skip

these training appointments. These appointments are rarely rescheduled, leaving the family caregiver no training on how to perform the task.

- Distractions at the hospital can also be a barrier to effective training for family caregivers. With so much activity in the patient's room—x-rays, clinician visits, nurses taking vital signs—family caregivers can be overwhelmed by the amount of information they are given. Also, nurses and social workers often come into the room to talk about discharge planning, community resources, and equipment training in the final moments before discharge. One suggestion to solve this problem was that if patient care were better scheduled to include the family caregiver as well as the patient, patients and family caregivers might have more time to absorb the information and ask questions.
- Written materials for the caregiver are often complicated, use too much jargon, and are hard to follow. Nurses generally think the materials are overly detailed and use complex, medical language. Social workers say they have trouble understanding the discharge instructions provided by the hospital. Some nurses are using pictures and videos to train family caregivers.
- Questions about medications are common once a patient is home. In fact, medication is the number one topic. Patients are not given refills on their medications before they leave the hospital. Discharge often occurs in the evenings. If a family member has to drop the patient at home and then leave the house again to pick up prescriptions, it can be overwhelming.
- Side effects of medications pose serious concerns for caregivers.

While caregivers are given booklets about medications, there is so much information that caregivers cannot digest all the information in just a few hours. They are particularly confused when new medications are prescribed on top of the medication already at home. Which ones should be given?

How Can Collaboration and Communication Be Improved?

In this qualitative research study, all three groups—African American and Hispanic caregivers and health care professionals—were presented with potential solutions and asked to score each on its effectiveness in addressing the needs of diverse family caregivers. The solutions were aimed at increasing collaboration and communication between the families and the professionals.

Both African American and Hispanic family caregivers favored the following solutions:

- Establish a 24/7 help phone line, where caregivers could call for answers to questions regarding the care of their loved ones at home.
- Health care professional first show caregivers how to do the task, with training sessions called “return demonstrations,” where the professional observes the family caregiver performing the task. An additional way to teach family caregivers the specific tasks they may need to perform would be a follow-up phone call to see if the family caregivers retained the information.
- Prior to discharge, a nurse schedules an appointment with the physician or other clinician so patients know when they need to return for follow-up care.

- A care coordinator is available following discharge from the hospital. If the patient's health care needs are very complex, the health care professional, likely a nurse, would be able to visit the patient at home for several months after discharge, as needed, and also be available by phone.
- Social workers call patients and caregivers after discharge to make sure patients receive the services outlined in the discharge plan. A care coordinator also would be helpful in navigating the health care system.

In addition to the above solutions, African American family caregivers were most interested in online support and a telephone line to call for additional information. Hispanic family caregivers felt that non-English-proficient patients and caregivers should have routine access to translation services, especially during discharge, so they can understand the instructions.

Nurses and social workers often agree with the diverse family caregivers on how to ensure communications and collaboration. They support a 24-hour hotline to have caregivers' and patients' questions answered and to give caregivers confidence that they have an easily accessed resource. The care coordinator—rated high among African American and Hispanic caregivers—was rated the top solution by nurses and social workers.

Conclusion

African American and Hispanic family caregivers seem eager for more outside resources to help manage the needs of their family members. But they feel such assistance is not always present in hospitals or during a rushed discharge process.

These family caregivers say they want resources to help them better care for their family members, not someone else to perform the tasks for them. They want more knowledge and confidence, and backup if they need more training and information. A 24-hour hotline and training sessions would be the most helpful, according to diverse family caregivers.

Social workers and nurses who work with diverse family caregivers express their concerns about interpreting what caregivers need and how to make them feel confident that they can care for their loved ones after they return home. They agree that a care coordinator would be beneficial to help family caregivers navigate the complicated health care system.

Some solutions require changes at the individual level where health care professionals and caregivers interact. Care managers, for example, could help family caregivers navigate the complicated health care system. Nurses can also integrate family caregiver assessment into their daily practice.⁵ In 2010, the National Association of Social Workers (NASW), in partnership with the AARP Public Policy Institute, developed NASW standards for social work practice with family caregivers of older adults. The standards address support for family caregivers across a range of care settings.⁶

But meeting the needs of diverse family caregivers also requires organizational support and changes in public policy. States should incorporate a culturally competent assessment of caregivers' needs in all publically supported programs.⁷ As health care delivery reformers invest resources in reducing unnecessary hospitalizations and improving care transitions for people with multiple chronic conditions from one setting to another, they should address the needs of caregivers in general and provide targeted interventions for diverse caregivers.

Because supporting family caregiving is a key dimension of a high-performing system of long-term services and supports, states need to incorporate a culturally competent assessment of caregivers' needs in all publically supported programs.⁸

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Endnotes

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601 E Street, NW, Washington, DC 20049
www.aarp.org/ppi
202-434-3890, ppi@aarpp.org
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