Implications of the CARE Act for Latino Caregivers
Billy A. Caceres, PhD, RN, AGPCNP-BC; and Adriana Perez, PhD, CRNP, ANP-BC, FAAN, FGSA

ABSTRACT
The Caregiver Advise, Record, Enable (CARE) Act has the potential to make a positive impact in the lives of Latino older adults and their caregivers. As Latino individuals are the fastest growing older adult population, the number of Latino families and caregivers is also expected to grow, particularly among those providing care for someone with Alzheimer’s disease or other dementias. Caregiving has been considered a culturally embedded value among Latino individuals. Although few studies have focused on caregiving in this population, those that exist suggest that Latino caregivers struggle to find bilingual and bicultural support and information and show higher levels of distress and health disparities. The purpose of the CARE Act is to help and support family caregivers when older adults are admitted to the hospital and during care transitions. The current article examines the potential implications of this state law, specifically on Latino individuals, including recommendations for policy implementation. [Journal of Gerontological Nursing, 44(3), 9-14.]

ABOUT THE AUTHORS
Dr. Caceres is Post-Doctoral Research Fellow, Comparative & Cost-Effectiveness Research, Columbia University School of Nursing, New York, New York; and Dr. Perez is Assistant Professor of Nursing and Senior Fellow, Leonard Davis Institute of Health Economics, University of Pennsylvania School of Nursing, Philadelphia, Pennsylvania.

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Address correspondence to Adriana Perez, PhD, CRNP, ANP-BC, FAAN, FGSA, Assistant Professor of Nursing and Senior Fellow, Leonard Davis Institute of Health Economics, University of Pennsylvania School of Nursing, 418 Curie Boulevard #411, Philadelphia, PA 19104; e-mail: adrianag@nursing.upenn.edu. doi:10.3928/00989134-20180213-04
The Latino population in the United States, currently 56.6 million, constitutes approximately 17.6% of the population, making it the largest ethnic minority group in the country (U.S. Census Bureau, 2016). Although most Latino individuals (75%) are U.S. citizens (Cruz, 2016), approximately 15% of those who immigrated to the United States are 65 and older (Zong & Batalova, 2017). Most older immigrants move to the United States after age 50, and the majority live with their children or extended family, thus developing family or caregiver networks that differ compared to U.S.-born older adults (Miller-Martinez & Wallace, 2017). The growth of the Latino population is expected to continue through the next several decades, with Latino individuals becoming the largest ethnic minority group of older adults by 2028 (U.S. Census Bureau & National Center for Health Statistics, 2015). This level of growth provides an opportunity to examine policies that affect the health and well-being of Latino older adults and their families and caregivers. The purpose of the current article is to describe the current progress and potential impact of the Caregiver Advise, Record, Enable (CARE) Act (Reinhard & Ryan, 2017) among older Latino individuals and their caregivers, including recommendations for policy implementation.

**Latino older adults experience health disparities, with a disproportionate burden of chronic health conditions, including diabetes, cardiovascular disease, and many types of cancers.**

Latino older adults experience health disparities, with a disproportionate burden of chronic health conditions, including diabetes, cardiovascular disease, and many types of cancers. Chronic neurodegenerative diseases and dementias, such as Alzheimer’s disease, are also on the rise among Latino individuals. By 2060, it is projected that the number of Latino individuals living with Alzheimer’s disease will increase more than nine-fold from 379,000 in 2012 to 3.5 million in 2060 (Wu, Vega, Resendez, & Haomiao, 2016). As older adults with Alzheimer’s disease and their caregivers is limited, existing studies show that they receive minimal or no assistance from state and federal sources (Borrayo, Salmon, Polivka, & Dunlop, 2004). However, these families spend 44% of their annual income on caregiving-related expenses and dedicate 52% more time per week giving care compared to the rest of the population (Rainville, Skufca, & Mehegan, 2016).

A recent survey by the National Hispanic Council on Aging (2017) reported the greatest challenges Latino caregivers face are: (a) balancing family and personal responsibilities (64%); (b) difficulty understanding government programs, such as Medicare, Medicaid, Social Security Income, Supplemental Nutrition Assistance Program, and others (56%); and (c) accessing information and educational resources to guide their care (47%). The authors noted that a major concern among Latino caregivers is that many are untrained, and approximately 50% would like to receive guidance and training on caregiving techniques in Spanish. When asked what Spanish language resources caregivers would like to have, in addition to caregiver training, 56% of caregivers indicated stress management. Indeed, 71% of survey respondents reported that caregiving placed a significant emotional toll on them. Other studies also show that Latino caregivers exhibit more depression and report worse physical health compared to White caregivers (Family Caregiver Alliance, 2016).

As older adults with Alzheimer’s disease and other dementias progress through the stages of disease, and experience greater memory...
loss and confusion over time, they will require more care (Alzheimer’s Association, 2016). Thus, it is imperative to guide and support family caregivers in accessing appropriate health care services. A recent report by the University of Southern California Edward R. Roybal Institute on Aging and the UsAgainstAlzheimer’s network highlights the challenges Latino individuals living with Alzheimer’s disease and other dementias experience, including underutilization of formal caregiving, such as long-term care and hospice, compared to non-Latino White individuals (Wu et al., 2016). Policy recommendations include addressing health system barriers to improve delivery of timely, quality care, as well as training and support to connect caregivers to necessary resources, particularly through transitions of care.

THE CARE ACT

The Home Alone: Family Caregivers Providing Complex Chronic Care Study (Reinhard, Levine, & Samis, 2012) found that many family caregivers perform critical and complex medical/nursing tasks without adequate instruction. In 2014, AARP developed model state legislation known as the CARE Act. The overall purpose of this model legislation is to support family caregivers through health care system transitions. To date, the CARE Act has received bipartisan support and has been enacted across 39 states and territories, demonstrating the importance of the issue of caregiving among state leaders and policymakers (Reinhard & Ryan, 2017). It is notable that Arizona and Florida, with some of the largest populations of Latino individuals in the United States, are among the remaining states yet to enact the CARE Act. According to the Long-Term Services & Supports State Scorecard, Arizona ranks 23rd and Florida ranks 46th in terms of support to unpaid family caregivers (access http://www.longtermcarecard.org).

In addition to providing much needed support and guidance to family members, including friends or neighbors, who may be serving as caregivers, the CARE Act may prevent costly readmission of older adults to hospitals or long-term care settings. The three important provisions of the CARE Act include:

- recording the name of the family caregiver into the electronic health record when an older adult is admitted to a hospital or rehabilitation facility;
- providing adequate notification to the family caregiver of discharge plans to another facility or back home; and
- providing instruction of the medical/nursing tasks (e.g., medication management, injections, wound care, transfers) that the family caregiver will perform at home.

The AARP Public Policy Institute, with funding from AARP, The John A. Hartford Foundation, and the Ralph C. Wilson Foundation, continues to conduct a national scan of health systems in states that have passed the CARE Act. The purpose of this scan is to learn how health systems are incorporating the provisions of the legislation into their hospital policies and procedures. While visiting select states, conversations will be held with family caregivers to gain a better understanding of their experiences. The Home Alone Alliance—a collaborative of AARP—includes members from a diverse group of public, private, and non-profit organizations who seek to create a change in how health care professionals and the systems in which they work recognize and support family caregivers. Through the work of the Alliance, resources and tools are being developed for family caregivers and health care professionals who interface with them, including family caregiver instructional videos and resource guides on a variety of medical/nursing tasks and educational articles for nursing professionals through the American Journal of Nursing. Consistent with a family-centered approach to health care, the CARE Act provisions reflect the necessary engagement of family, especially because families perform 50% of complex health care tasks, such as medication management, including administering intravenous fluids and injections, and wound care (Reinhard et al., 2012).

IMPACT OF THE CARE ACT AMONG LATINO INDIVIDUALS

The AARP’s Home Alone Study called for future research, particularly among diverse family caregivers whose primary language is not English, and other groups whose experiences may differ from the national sample (Reinhard et al., 2012). This recommendation is consistent with a review of the past 30 years of caregiving research that revealed a paucity of intervention studies among ethnic minority caregivers (Apesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young, 2016). The importance of greater cultural inclusion was also emphasized in a recent report on family caregiving from the National Academy of Medicine (National Academies of Sciences, Engineering, & Medicine, 2016).

The CARE Act has the potential to improve transitions for Latino older adults, reflective of decades of research that supports the role of familismo (i.e., family) as a core Latino value, important in promoting health (Marin & Marin, 1991), as well as demonstrating respeto (i.e., respect) and dignidad (i.e., dignity) through caregiving, especially for an older adult in the family (Arévalo-Flechas, Acton, Escamilla, Bonner, & Lewis, 2014). Ultimately, this policy has the potential to improve the lives of Latino older adults and their family caregivers by addressing many of their unmet needs and reflecting cultural values during a vulnerable phase of their health care.
BARRIERS TO IMPLEMENTATION AMONG LATINO CAREGIVERS

Existing demands, fast pace, and complex health care systems present challenges to implementing the CARE Act in general and impact how provisions may be implemented among vulnerable Latino older adults and their caregivers. Documented barriers include lack of sufficient time, lack of staff knowledge and confidence, and limited education tools for patients and families (Coleman, 2016). One of the most significant barriers to achieving the full potential of the CARE Act among Latino families and caregivers may be the lack of a bilingual and bicultural health care workforce charged with implementing this policy. Experts have called for an increase in the capacity and pipeline of diverse health care professionals that reflect communities served and can effectively detect, treat, and assist Latino individuals living with Alzheimer’s disease and their caregivers (Wu et al., 2016).

Equally important is the need to train Latino individual-serving health care providers, who may not be Latino themselves, in cultural awareness, avoiding stereotypes, and care planning for Latino families.

To facilitate the third provision of the CARE Act, Coleman (2016) recommends the use of the Family Caregiver Activation in Transitions (FCAT) tool to guide interaction between family caregivers and the health care team. This self-efficacy measure of transition-specific tasks has not been tested among Spanish-speaking older adults and caregivers. Thus, future research is necessary to validate this tool for Spanish-speaking families. However, recruiting Latino individuals for research participation remains a challenge. Latino individuals remain underrepresented in Alzheimer’s disease and caregiver research (Wu et al., 2016). Studies have found that Latino individuals comprise approximately 1% of clinical trial participants nationwide (Tierney, 2011). Recruitment and clinical trial designs must be culturally tailored to reflect the values and needs of Latino caregivers and older adults. One way to address this barrier includes investing in increasing the pipeline of diverse health care professionals and scientists. Latino individuals are more likely to participate in clinical research if recruitment is conducted by research team members with whom they can identify and speak their language (Oh et al., 2015). Although these efforts may take time to yield desired results, partnerships with Latino organizations and inclusion of health promoters, or lay community health workers, to raise awareness of Alzheimer’s disease and caregiving needs in underserved populations are promising strategies (Wu et al., 2016). In addition, because the CARE Act includes education and instruction, the existing health care team must take into consideration not only language barriers, but also low levels of literacy in the population, as well as issues related to affordability, lack of health insurance coverage, and transportation needs (Wu et al., 2016).

Another barrier to implementation that should be considered by health care providers, policymakers, and consumers is immigration status. In 2014, there were approximately 11.1 million undocumented immigrants in the United States (Passel & Cohn, 2016). Undocumented immigrants report significant barriers to health care access including fear of deportation, shame, language discordant care, and lack of access to resources (Hacker, Anies, Folb, & Zallman, 2015). Therefore, many undocumented Latino older adults and their caregivers may hesitate to provide information to health care providers. Providers who practice in areas with a high number of immigrant populations should be cognizant of how immigration status may impact health care in these communities.

ADVANCING POLICY IMPLEMENTATION

Similar to other ethnic minority groups, Latino older adults often have strong affiliations with faith-based organizations/churches (Gallagher-Thompson, Solano, Coon, & Areán, 2003), offering opportunities to build effective and inclusive alliances that can help raise awareness about health care topics and policy implementation to support family caregivers. Implementation efforts could be enhanced by diverse organizations that represent and advocate for Latino communities (including churches) and whose core mission is to address the economic, education, and health needs of Latino individuals nationwide. For example, the National Association of Hispanic Nurses, National Hispanic Medical Association, Latino Medical Student Association, National Hispanic Council on Aging, LatinosAgainstAlzheimer’s, UnidosUS, and League of United Latin American Citizens are some of the leading national organizations that can assist with implementation and may advocate for the CARE Act in remaining states. These organizations offer thought leadership in policy implementation and can increase awareness of important cultural implications in the population.

When providing care for Latino families, the CARE Act provisions can be enacted to ensure meeting the cultural and linguistic needs in several ways:

Name of the Family Caregiver. It is important to get to know Latino families. Although most studies indicate that older children, often daughters, may serve as primary caregivers for Latino older adults (Ruiz & Ransford, 2012), it is vital to identify the primary family member whom the older adult depends.
on the most for care, “el familiar o la persona de la que depende para su cuidado.” It is vital to understand their language preferences and health literacy early during hospitalization to determine how this may impact communication and discharge needs. Caregiving responsibilities might be shared or might include extended family members as well (Ruiz & Ransford, 2012). Therefore, health care providers and facilities should recognize and have systems in place for older adults who might identify more than one primary caregiver to include during caregiving instruction.

**Family Caregiver Notification of Discharge.** Most Latino caregivers maintain a full-time job in addition to balancing their caregiver role. A recent study found that 40% might take a leave of absence, change jobs, decrease work hours, or stop working entirely to fulfill the caregiver role (Evercare and National Alliance for Caregiving, 2008). Latino caregivers, similar to other adult caregivers, may experience job pressure or biases for providing care to older parents/family members. When notifying Latino caregivers of discharge, it is important to demonstrate sensitivity to their multiple roles to plan ahead for discharge needs. For example, some institutions have expected discharge times. Working together with family caregivers so that they do not have to leave work needlessly might offer relief (Evercare and National Alliance for Caregiving, 2008).

**Explanation and Instruction of Medical/Nursing Tasks.** Bilingual materials and instruction are an obvious need in the Latino population. First and foremost, Latino individuals trust and report (81%) turning to health care professionals, including physicians, nurses, social workers, and pharmacists, more than any other sources (Evercare and National Alliance for Caregiving, 2008). Including more than one family caregiver in discharge teaching might also be well received, as 66% of Latino individuals report turning to family and friends for help. This strategy can also offer reinforcement post discharge. Approximately one half of family caregivers turn to government sources for information as well; therefore, multi-level strategies for follow-up explanation and instruction may be necessary and may be addressed through bilingual helplines and consumer referrals (Wu et al., 2016). Alliance partnership support can promote effective health care transitions in the local community. For example, many of the family caregiver instructional videos are available in Spanish. AARP and other Home Alone Alliance members should continue to work and expand collaboration with Latino national organizations that can market and disseminate materials widely.

There are currently no feedback loops to determine the effectiveness of the CARE Act implementation strategies other than readmissions and patient/family satisfaction surveys. Funding for research testing such strategies, including follow-up health, patient, and caregiver outcomes, is necessary and should be part of gerontological nursing advocacy efforts.

**SUMMARY**

This article describes the current progress and potential impact of the CARE Act among older Latino adults and their family caregivers, including recommendations for implementing the CARE Act provisions at the bedside. The three provisions provide guidance to help nurses start this dialogue with families, creating opportunities to get to know their patients in a meaningful way. Getting involved in shared governance within the practice setting can also give nurses a voice in effectively translating this policy to practice. In addition, advocating for the passage and enactment of the CARE Act in the remaining states may include calling state legislators and educating the public about the legislation.

The CARE Act is a step forward in addressing the needs of a population that contributes $470 billion annually of unpaid care across states and generations (Reinhard, Feinberg, Choula, & Houser, 2015). The early bipartisan support among stakeholder groups and policymakers provides a great opportunity to address needs of caregivers and ultimately the health of vulnerable older adults. Considering the needs of diverse communities, such as Latino individuals, immigrants, and other marginalized groups, may help achieve the intended outcomes of public health policy. Gerontological nurses in particular have a key leadership role in providing care to patients and their families, conducting research, educating and supporting the largest health care workforce, and serving in decision-making bodies that can shape and inform policy. Ensuring that policy is evidence-based, as well as inclusive and reflective of the growing, multicultural population in the United States, remains an important public health concern and essential to eliminating health disparities.

**REFERENCES**


Arévalo-Flechas, L.C., Acton, G., Escamilla,


