Stress and Coping Conceptual Models for Understanding Dementia among Latinos

Julian Montoro-Rodriguez, PhD.

(University of North Carolina at Charlotte)*

&

Dolores Gallagher-Thompson, Ph.D.

(Stanford University)

*Corresponding author:

Julian Montoro-Rodriguez, Ph.D.
University of North Carolina at Charlotte
Director, Gerontology Program
9201 University City Blvd. CHHS #481
Charlotte, NC 28223
Phone 704 687-6166
jmontoro@uncc.edu
ABSTRACT

OBJECTIVES: Since the late 1990s, family caregiving theories have contributed significantly to improve our understanding of the dynamic and diverse experiences of caregivers. Some theories have been translated into best practices to deliver a broad range of programs for family caregivers. However, researchers still have not been able to translate most of these theories into interventions for low-income and culturally diverse caregivers.

METHODS: We examine several salient theoretical frameworks and innovative efforts that led to development of evidence–based knowledge and interventions to meet the needs of Latino family dementia caregivers.

RESULTS: This paper highlights current knowledge, research, and practice available for Latino older adults with dementia and their family caregivers.

DISCUSSION: We discuss how existing support services for Latino caregivers are able to address multiple threats associated with their experience of dementia, their cultural family context, and everyday challenges associated with their low-income status and limited available resources.

Keywords: Evidence-based programs, family caregiving, stress and coping, Latino older adults
Stress and Coping Conceptual Models for Understanding Dementia among Latinos

Alzheimer’s Disease (AD) and related dementias are conditions characterized by a decline in memory and other mental skills that impact the person’s ability to perform daily activities (Alzheimer’s Association, 2017). AD is a degenerative brain disease and the most common cause of dementia (Wilson et al., 2012). The 2017 Alzheimer’s Disease Facts and Figures report describes dementia as a syndrome—a group of symptoms, such as difficulties with memory, language, problem-solving, and other cognitive skills, that has a number of possible causes. These difficulties occur because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed. Dementias are responsible for detrimental health and disability, and generate higher levels of health care cost and depletion of resources for caregivers and people with dementia than for adults with no dementia disorders (Alzheimer’s Association, 2017). Furthermore, dementia caregivers report high levels of burden and other negative psychosocial outcomes (depression, anxiety, etc.) while caring for a person with dementia (Mausbach, 2014).

The Alzheimer’s Association reports (2017) that an estimated 5.5 million Americans of all ages are living with Alzheimer’s dementia in 2017, and that by 2025, the number of people age 65 and older with Alzheimer’s dementia is estimated to reach 7.1 million—almost a 35 percent increase from the 5.3 million age 65 and older affected in 2017 (Hebert, Weuve, Scherr & Evans, 2013). However, among minorities, older African-Americans are about twice as likely to have Alzheimer’s or other dementias as older Whites, and Latinos are about 1.5 times as likely to have Alzheimer’s or other dementias as non-Hispanic Whites (Samper-Ternent, Kuo, Ray, Ottenbacher, Markides & Al Snih, 2012). The lower socioeconomic status of many older
Latinos and the high cost of dementia care, along with the extra financial burdens associated with physical health problems common in older Latinos (e.g., diabetes, heart disease) are associated with an increased demand and need for frequent health services (Alzheimer’s Association, 2017). Given that the number of Latinos is also expected to grow in the coming years and reach 20% of older adults needing care by 2050 (Alzheimer’s Association, 2017) it becomes a priority to examine the unmet needs of dementia family caregivers among Latinos in the United States (U.S.). Furthermore, Latinos’ own cultural values and beliefs about normative family care can place these caregivers at a disadvantage compared to Non-Hispanic White caregivers (Angel & Angel, 2015). In particular, rapidly occurring demographic changes (e.g., increased mobility, smaller family size, less dependence on the extended family, etc.) and changes in patterns of acculturation (greater adaptation to Anglo American culture) may erode traditional family values (Angel & Angel, 2015; Coon, Rubert, Solano, et al., 2004; Montoro-Rodríguez, Kosloski, Kercher & Montgomery, 2009). Reviews of the qualitative literature also indicate that Latino caregivers frequently report “feeling caught” in the tension between cultural expectation of family piety and their ability to fulfill caregiving demands (Apesoa-Varano, Gomez & Hinton, 2015). Latinos often assume multiple family caregiving roles, providing care to older parents and relatives with dementia and at the same time caring for their own children and grandchildren. Recent content analysis of qualitative ethnographic interviews of Latino caregivers indicate that regardless of who the care-recipient is, caregivers’ narratives support similar themes – both positive and negative. These include: duty to family first, sense of satisfaction from caregiving, and willingly sacrificing to be in this role which provides a sense of purpose. At the same time, however, caregiving is described as: physically
exhausting, emotionally draining, and financially straining, leading to role challenges, role captivity, legal stressors, fear, and major stress (Arevalo-Flechas, Martinez & Flores, 2017). Earlier quantitative studies comparing Latino to non-Latino caregivers similarly found higher rates of depression and other indices of psychological distress (Hinton et al., 2006; Pinquart & Sorensen, 2005). This paper highlights current knowledge, research and practices available for Latino adults with dementia and their family caregivers. We outline how existing support services and programs for Latino caregivers are able to address threats associated with the experience of dementia, the cultural family context, and everyday challenges associated with low-income status and limited available resources. Examined in the discussion are the most salient theoretical frameworks and innovative efforts to develop evidence-based knowledge and interventions that contribute to meet the needs of Latino family dementia caregivers.

**Dementia Caregiving Research: Theories**

During the past thirty years researchers have developed a myriad of social and psychological theories aimed at understanding the experience of family care and its impact on caregivers’ well-being. The early theoretical models were developed to examine sources of caregiver stress, as well as how stress and burden affects psychological outcomes, depression, anxiety, physical health, service utilization, and/or institutionalization of care recipient. Development of this first generation of theories began in the 1960s with the work of Thomas Holmes and Richard Rahe. Holmes and Rahe theorized a direct link between stress and physical and psychological illness (Figure 1). The result was their Social Readjustment Rating Scale, which gave weights to a variety of common stressful life events and used a person’s total score as a measure of their risk for illness (Holmes & Rahe, 1967).
This theory was the foundation for the *stress-process model* developed by Leonard Pearlin and colleagues (Pearlin, Mullan, Sample & Skaff, 1990) and the revised stress model (Folkman, 2008), which examined care demands on the caregiver as stressors, and investigated their cumulative effects, as well as exploring the role of coping mechanisms to reduce their negative impact. Folkman argued that the coping abilities of the stressed individual were also a predictor of whether the person would be ill/distressed or not (Figure 2). For example someone with excellent coping abilities, would not be as severely negatively affected by personal illness as someone with poor coping abilities. Pearlin’s pioneering contribution was to apply this stress-process model to a caregiver’s situation.

Other early models paid particular attention to the *caregiving social content and dyadic interaction* of the caregiver-care-recipient relationship (Kahana, Kahana, Johnson, Hammond & Kercher, 1994), highlighting the importance of both the person and the environment. Later models, including *caregiver identity theory* articulated by Montgomery and Kosloski (2009, 2013) conceptualize caregiving as a series of identity transitions that result from changes in the caregiving context and in personal norms. Caregiver identity is a set of meanings applied to the self in the care context and is used as a reference point to guide behavior, wherein the discrepancy or incongruence between a caregiver’s behavior and his or her identity standards is suggested as the major source of caregiver stress (Montgomery, Kwak & Kosloski, 2016).
Theory-Derived Programs for Caregivers

With the exception of Holmes and Rahe’s work, the theories described in the previous section led to the development of several caregiver intervention programs. The Holmes-Rahe stress inventory did not directly lead to any such programs; in our opinion, its relevance to the field is in how it provided the foundation for Folkman and Lazarus’ cognitive appraisal theory, which informed the development of several evidence-based caregiver interventions we will discuss here.

The first *Coping with Caregiving* psychoeducational program developed by Gallagher-Thompson and her associates, is derived from both cognitive appraisal theory (Pearlin’s stress-process model) and Bandura’s self-efficacy theory (Bandura, 1977). It aims to teach caregivers more adaptive coping skills through education, role playing, and home practice using a small group workshop format. The proposed increase in self-efficacy (resulting from this behaviorally-based learning) mediates positive outcomes. In the multiple randomized controlled trials conducted with this program (or its derivatives), significant reduction in symptoms of depression was common, along with use of more effective cognitive and behavioral coping strategies (compared to emotion-focused coping; see Coon et al., 2012 and Gallagher-Thompson et al., 2012 for comprehensive reviews of this body of work). It is noteworthy that this program has been effectively tailored and translated into Spanish, Chinese, Japanese, and Farsi and then evaluated in several additional studies (Tzuang & Gallagher-Thompson, 2014).

From cognitive appraisal theory also came the *Resources for Enhancing Alzheimer’s Caregiver Health* collaborative research initiatives (REACH I and REACH II; described in Schulz, Burgio, Burns, Eisdorfer, Gallagher-Thompson, Gitlin & Mahoney, 2003). This body of work
began with REACH I, a multisite research program (six sites) sponsored by the National Institute on Aging and the National Institute on Nursing Research. Its main purpose was to test the effectiveness of a variety of interventions (unique to each site) ranging for example, from family therapy at the Miami site (with and without technology enhancement) to small group workshops at Palo Alto, CA. Each site enrolled its own sample and collected its own data. REACH II was an outgrowth of these studies: the most effective features from each successful randomized controlled trial were incorporated into a new, multi-component intervention that was administered, using standard protocol, across five remaining sites, with the same outcome measures collected at each site. Another unique feature of REACH II was that it enrolled a large diverse sample of dementia family caregivers – the largest to date in the US (Belle et al., 2006). The active intervention consisted of components addressing safety, self-care, social support, emotional well-being, and management of problem behaviors. Home visits were conducted (up to 9 total) to develop individualized “action plans” for each caregiver. Participation in a telephone-based support group was also offered. The control condition consisted of education about dementia but with no home visits or support group included as part of the program. Results indicated that caregivers in the active intervention (regardless of ethnicity or race) reported greater significant positive improvement from pre to post participation, compared to those in the control condition, on an omnibus measure of well-being. There was also a trend for greater delay in institutional placement over time – although this was not statistically significant due to the small sample size involved. The success of REACH II was followed by many “variations on the theme” to make the program more affordable to deliver in community-based settings. One example is the
REACHing OUT program (Burgio et al) which tailored REACH II for caregivers in the state of Alabama by shortening it and adding local features considered appropriate for that region. Most recent iterations involve briefer adaptations more appropriate to be implemented and tested in community settings. REACH II is listed and described in detail on the National Registry of Evidence-based Programs and Practices website. REACHing OUT is listed as an evidence-based treatment on the National Alliance for Caregiving (http://www.caregiving.org) and Roselyn Carter Institute for Caregiving websites.

A similar program is Care Partners Reaching Out (CarePRO). It was created as a derivative of REACH II by Coon and colleagues who modified REACH II for use in the states of Arizona and Nevada. Coon described the program, “CarePRO aims to enhance the quality of life for both caregivers and their care recipients by teaching caregivers stress management and behavior management skills” (ASU Now, 2013). Over five in-person skills workshops and five telephone calls with an assigned coach, caregivers are taught how to identify sources of frustration, practice mindful breathing, change unhelpful thinking, engage in pleasant activities for themselves, plan for the future, and manage difficult behaviors by their care recipients. Of the over 600 caregivers from Arizona and Nevada that enrolled in this program, over 95% reported having increased understanding of dementia and confidence in providing care after completing their ten sessions. During the launch of this program, over 40 staff members of local Alzheimer’s Association chapters in both states were trained and delivered CarePRO in both Spanish and English (Coon et al., 2016).

The stress process model (Pearlin et al., 1990) has also inspired a wide range of psychosocial programs and support interventions for dementia caregivers. Typically they
include a focus on development of adaptive coping skills to reduce distress. For example, perceived stress may be associated with unhelpful negative thinking about caregiving and the future. In that case, helping caregivers learn how to see their situation from a different perspective can increase their positive coping and reduce stress. Furthermore, the stress-process model later led to development of multicomponent interventions that address several factors likely to cause stress – such as low engagement in positive activities and increasing social isolation. These are represented in best practice programs such as Powerful Tools for Caregivers (PTC) developed by Dr. Vicky Schmall and her colleagues (1999); the Savvy Caregiver program developed by Hepburn and colleagues (2003); and the NYU multicomponent counseling program developed by Mittelman and her colleagues (2004).

Originally developed to address caregivers of adults with chronic health conditions (Schmall et al., 2000), Powerful Tools for Caregivers (PTC) is grounded in self-efficacy theory (Bandura, 1986). The premise of PTC is that increased self-efficacy will promote the use of coping behaviors that will, in turn, enhance self-care and well-being among caregivers (Zeiss, Gallagher-Thompson, Lovett, Rose & McKibbin, 1999). PTC was originally targeted to caregivers of persons with Alzheimer’s Disease, stroke, and Parkinson’s Disease (Boise, Congleton & Shannon, 2005; Kuhn, Fulton & Edelman, 2003). Research evidence indicates that PCT improves caregivers’ self-efficacy, enhances positive views about the caregiver role, and increases self-care behaviors and decreases depression, anger, and guilt (Boise et al., 2005; Kuhn et al., 2003). Recent findings also indicate that this program can be an effective resource for reducing psychological distress and objective burden among spouses caring for disabled partners (Savundranayagam, Montgomery, Kosloski & Little, 2010).
The Savvy Caregiver Program was designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to handle the challenges of caring for a family member with Alzheimer’s Disease and to be an effective caregiver (Hepburn, Lewis, Sherman, & Tornatore, 2003). This intervention has been designated as one of the approved dementia training programs of the Alzheimer’s Disease Demonstration Grants to States (ADDGS) funded through the U.S. Administration on Aging (Wiener & Mitchell, 2007). Research evidence demonstrate the program’s effectiveness in increasing caregiver skill, knowledge, and confidence as well as reducing caregiver distress (Hepburn, Lewis, Tornatore, Sherman & Bremer, 2007; Hepburn, et al., 2003). Findings also suggest significant positive outcomes for caregivers who participated in the program versus those in the control group with respect to the caregivers’ beliefs about caregiving, their reactions to the behavioral symptoms of their care recipient, and their feelings of stress and burden (Hepburn, Tornatore, Center & Ostwald, 2001; Ostwald, Hepburn, Caron, Burns & Mantell, 1999).

The Caregiver Counseling Intervention developed by Mittelman and her associates (2004) at the New York University School of Medicine was originally developed for spousal caregivers of persons with Alzheimer’s Disease or related dementias. This psychosocial intervention provides individual and family counseling along with a support group referral and additional support as-needed. Research findings indicate that the NYU intervention reduces negative appraisals of care recipients’ behavioral problems; increases positive effects on multiple outcomes for spousal caregivers and persons with dementia; and postpones nursing home placement (Mittelman, Roth, Haley, & Zarit, 2004). The impact of this intervention on depression, caregiver appraisals of behavior problems, and delay in nursing home placement
are long-lasting and both clinically and statistically significant. The NYU program has also been found to exert consistent effects in reducing adult child caregivers’ negative reactions to disruptive problems (Gaugler, Reese & Mittelman, 2016). This program has been recognized by the Administration on Aging as an evidence-based protocol.

The third theory discussed in the previous section, caregiver identity theory, has also recently been translated into a best practice intervention to manage care planning for caregivers. The *Tailored Caregiver Assessment and Referral (TCARE)* best practice program aims to develop a care plan based on assessment of caregiver’s needs, burden, identity discrepancy, availability and preference for services, and change over time. Early evidence (Montgomery, Kwak, Kosloski, & Valuch, 2011) indicates that program promotes the well-being and mental health of caregivers.

In summary, the past two decades have witnessed the development of several theoretical frameworks to understand the conditions under which family caregivers manage stress and maintain their health and positive outlook while caring for their loved ones. As a result, researchers have developed effective interventions to support family dementia caregivers. Nevertheless, the translation from theory to programs and best practices to support family caregivers has been limited by practical considerations such as cost, access, and availability of appropriately trained bilingual/ bicultural staff. There is also some debate in the field as to the efficacy of these non-pharmacological interventions. The reviews by Gallagher-Thompson et al. (2012) and Olazaran et al. (2010) clearly indicate that psychosocial programs with strong education and skill-building components are successful in improving mental health of distressed caregivers. However, other recent systematic reviews and meta-analyses of
psychosocial interventions (see, for example, Gaugler and Burgio, 2016) conclude that this body of literature is limited by a lack of high-quality evidence to derive conclusions of efficacy, an absence of clarity about the type of intervention delivered, and variation in study design, outcome measures and/or screening criteria.

**Interventions for Latino Caregivers**

Intervention research for Latino family caregivers generally follows the models and practices developed in the caregiving literature over the previous decades and described above. However, the quantity of research studies and evidence-based programs aimed at Latinos and other ethnic and cultural minorities is increasing slowly, compared to their growing needs. In this section we review the theoretical models that have influenced past work, as well as the translation efforts to adapt existing programs to the Latino community. We also describe several established support services for Latino caregivers and identify new and innovative initiatives aimed to increase support for Latino caregivers.

The Alzheimer’s Disease Demonstration Grants to the States, which was initiated in the early nineties (Montgomery, Kosloski, Karner & Schaefer, 2002), helped to establish programs which support family dementia caregivers who were not able to access services because of their geographical and cultural isolation. One of the programs directed at Latino caregivers was **“El Portal Latino Alzheimer’s Project”** - a dementia specific outreach and services program targeting Latino caregivers in the Los Angeles County area in California. The project exemplifies an inter-organizational community-based collaborative established to provide dementia-care services to a large, urban Latino community in Los Angeles County. Case management was included among the services offered, along with an array of coordinated services from
counseling, referrals, transportation to support groups, and respite services, both at home and at the adult care center. The key point of the project is that the Portal Latino Alzheimer’s Project provided ethnic-sensitive services to Latinos using culturally-specific outreach and service delivery strategies. Results from the evaluation of service utilization conducted by Aranda, Villa, Trejo, Ramirez and Ranney (2003) indicated that Latinos reported a reduction in barriers to care and an increase in service utilization. The Portal Project was a great model to increase the awareness of Alzheimer’s Disease as a public health problem. The project was also a way to enhance the dementia care capacity among Latino caregivers, as well as a way of alleviating the negative outcomes of the dementia experience.

Along with El Portal, another attempt to understand how cultural values affect Latino caregivers and other ethnic groups was the “Sociocultural Stress and Coping” model (Aranda & Knight, 1997). The model addressed normative expectations about family care and their impact on caregiving outcomes. The model pointed to “a shared common core to stress and coping in family caregivers of persons with dementia that moves from the stressor of the care recipient’s behavior problems to caregivers’ appraisals of caregiving as burdensome to poor physical and emotional health outcomes for caregivers” (Knight & Sayegh, 2009). In the revised version of this stress-process model, the role of cultural values appeared to be group specific, and those values (such as filial piety or familism) had a mediating influence on caregiver outcomes, mostly through coping resources such as social support and coping styles rather than through the caregivers’ appraisal of burden (Figure 3).

Researchers have proposed an expanded socio-cultural model of stress and coping to examine the role of culturally situated factors, such as coping abilities and the caregiver’s self-
efficacy beliefs, as mediators of negative psychosocial outcomes among Latina non-Hispanic white caregivers (Montoro-Rodriguez & Gallagher-Thompson, 2009). Their research findings indicate that the effects of ethnicity and other primary stressors (such as the care-recipient behavioral troubles and the caregiver’s perceived health), are mediated by coping resources and appraisal of self-efficacy in managing the care, specifically on the level of burden of female caregivers. These findings indicate that both structural and cultural factors appear to affect the caregiving experience.

![Figure 3: Knight’s revised stress-process model. Used with Permission from Copyright Clearance Center.](image)

Additionally it is important to consider the impact of acculturation on caregiver distress. Acculturation refers to the degree to which someone has adopted the values of the dominant culture of the country they have immigrated to. Acculturation levels vary from community to community, from region to region, and from individual to individual. Programs designed to target specific racial/ethnic minority groups must be mindful of the different levels of acculturation, and must modify their program to make it meet the expectation of that groups’ collective acculturation level. Angel and Angel (2015) comment on ways to measure
acculturation, and stressed its complex role in family caregiving. The interested reader is referred to their book for a much more in-depth discussion of this issue.

Many of the caregiver intervention researchers mentioned in the previous section adapted their programs to better meet the needs of Latino communities (see Table 1). As previously described, from Folkman and Lazarus’ cognitive appraisal theory came Coping With Caregiving. A Spanish translation of this program was created to make it more accessible to Latino caregivers, and the program inspired the creation of a *fotonovela* (bilingual picture book) and a *webnovela* (online telenovela) that each showed a Latino caregiving family facing challenging situations and displaying appropriate skills to care for their loved one (described in next section). CarePRO is also available in Spanish, and has been delivered by trained bilingual/bicultural staff of local Alzheimer’s Association chapters.

The REACH studies, which were based on cognitive appraisal, also made significant efforts to reach Latino communities. REACH I included two samples of Latino dementia caregivers: Cuban Americans in Miami, Florida, and Mexican-Americans (primarily) in Palo Alto, California. Each site offered a different program: a family-therapy based approach in Miami (Schulz, et al., 2003) and a Cognitive-Behavioral Therapy (CBT) and psycho-educational intervention focusing on coping skills in Palo Alto (The Coping with Caregiving CWC program; Gallagher-Thompson et al., 2003). Based on positive results from these studies and the larger REACH II investigation, the Southern Caregiver Resource Center (SCRC) in San Diego, along with several other community-based organizations and the County of San Diego, developed and implemented Spanish adaptations and translations of REACH (Gallagher-Thompson et al., 2015). This *REACHing Out* program, a new and abbreviated version of REACH I, was titled
CALMA (Cuidadores Acompañándose y Luchando para Mejorar y Seguir Adelante), and the adapted version of REACH II was named CUIDAR (Cuidadores Unidos Inspirados en Dar Amor y Buscar Respuestas). These were tailored to the needs of lower-literacy individuals and families living in that region (Southern San Diego County, CA). These programs included lay Latino community peer educators/counselors or health advocates, known as promotores/as, who were considered essential to successful outreach and involvement of the target community. Careful study of the impact of both interventions -- CALMA for caregivers experiencing high levels of burden but whose depression was low, and CUIDAR for caregivers with high levels of depression -- found that both programs reduced caregivers’ levels of burden and depression (Gallagher-Thompson, et al, 2015). However, since one is much less labor-intensive than the other (CALMA is done in a small group format whereas CUIDAR is done in home visits) this group recommends careful assessment at the outset so that caregivers can be referred to the most appropriate program to meet their needs.

These and similar programs have also made efforts to better reach Latino caregivers through targeted outreach, employment of bilingual/bicultural staff, and concentrated training so that fidelity to the “parent” program(s) is maintained. Powerful Tools for Caregivers is known to be effective among caregivers from multiple cultural backgrounds, and has served Spanish, Korean, Chinese, and Vietnamese caregivers with translated materials. The Northern Manhattan Hispanic Caregiver Intervention Effectiveness Study, underway in 2017 (Luchsinger, Burgio, Mittelman, Dunner, Levine, Knog, Silver, Ramirez & Teresi, 2017), examines the effectiveness of the Caregiver Counseling Intervention program among Latino caregivers in New York City.
To help the Savvy Caregiver program better serve Latino caregivers, researchers translated it into a Spanish-language program culturally appropriate to address the needs of the Latino caregivers (Oakes et. al., 2006). Kally and colleagues (2014) examined the impact of Savvy Caregiver among Latino, African American and Asian/Pacific Islander descent and found that caregivers of all three ethnic groups showed better competence, reduced depression, greater tolerance for care recipients’ memory problems, better management of their situation, and improved perception of their situation 6 months after enrollment, with the achieved improvements maintained at 12 months after enrollment in most cases. These encouraging results indicate that the Savvy Caregiver program has been successful at meeting the needs of the minority groups it serves.

Finally, TCARE, which is based on caregiver identity theory, has been translated into Spanish, and adapted for use with Latinos in LA and Washington State (Montgomery, 2014). TCARE has not been tested to examine whether outcomes for those using the Spanish version are different. However, feedback from care managers suggests that it works well with Latino caregivers. The measure has been translated into many other languages and is used by researchers in many countries.

<INSERT TABLE 1 ABOUT HERE >

**Caregiver Interventions using Information and Communication Technology**

Extending the stress and coping conceptual models to the Digital Age has potential because information and communication technologies are becoming effective supportive tools for caregivers. Information technology stresses the role of unified communications. The convergence of audio-visual and telephone networks with computer networks through a single
cabling or link system makes possible that large number of people around the world access information via the Internet, many of them through smartphones. This rapid growth, especially in developing countries, has changed everyday life and made information technology a vital resource for many. Dementia is a global phenomenon with increasing incidence and prevalence around the world (Alzheimer Disease International, 2009). Therefore it is not surprising that caregivers, educators, and health professionals are turning to technology to help dementia patients and their family caregivers to reduce their burden, stress, and depression and to preserve quality of life. Technology has the added benefit of reaching a large number of people and promising permanent access to those resources.

Recent culturally-tailored non-traditional caregiver interventions using a form of information technology include the development of a fotonovela and a webnovela for Latino dementia caregivers in California. The Fotonovela “Together We Can! Facing memory loss as a family,” is an innovative intervention developed for Latinos at Stanford University (Gallagher-Thompson, Tzuang, Hinton, Alvarez, Rengifo, Valverde, & L.W. Thompson, 2015). It is a 20-page bilingual “picture book” containing a dramatic storyline where Latino actors depict specific challenging scenes designed to illustrate skills for managing stress and difficult behaviors, employing adaptive coping strategies, and asking for help from other family members. This psycho-educational program provides Latino caregivers with accurate information about dementia and illustrates, in a culturally appropriate manner, constructive ways of coping with various stressful situations confronting Latino caregivers. It addresses specific needs by reaching out to Latinos with low-literacy levels and potentially less than accurate knowledge about dementia. Initial results from a study using a sample of Latino caregivers in California
found that those in the **Fotonovela** condition reported less depression at the conclusion of the program, and found it more helpful overall, compared to caregivers in the control condition who received typical Spanish-language educational materials (Gallagher-Thompson, et al., 2015). The **Fotonovela** is a culturally tailored program that not only impacts level of depressive symptoms in Latino caregivers by training them with effective coping strategies to deal with stress, but also delivers benefits to low income families, such as helping them to access needed resources. The **Webnovela MIRELA** is a short online Telenovela in Spanish which is specifically designed for Spanish caregivers to teach Latino caregivers how to cope with dementia caregiving, reduce burden of care, decrease stress and alleviate depression. MIRELA is based on the Coping with Caregiving program (described earlier) as a Cognitive-Behavioral theory-based psycho-educational intervention that is both entertaining and informative. The randomized controlled trial has just finished and preliminary analyses of data indicates that MIRELA is significantly more successful in reducing symptoms of depression and caregiving stress than the education-only control condition to which it was compared (manuscript in preparation).

Other technology-based interventions developed for caregivers include the **iCare program** that can be currently found at the [iCarefamily.com](http://icarefamily.com) website (iCareFamily, 2010). The **iCare Stress Management e-Training** program is entirely an internet-based adaptation of the CWC program. The initial evidence for program indicated that change in perceived stress was significant for the iCare condition in comparison to the education only group condition (Kajiyama, Thompson, Eto-Iwase, Yamashita, Di Mario, Tzuang, & Gallagher-Thompson, 2013). These promising results will need to be replicated and further adapted to increase caregiver’s participation and engagement with the program.
The Pew Internet surveys show steady growth in the use of technology by both bilingual and Spanish-dominant Hispanics; the most recent (Brown, Lopez & Lopez, 2016) notes Latinos’ increased dependence on access to the Internet through mobile devices, such as cellphones and tablets. Highlights of technology-based interventions over the last several years show equal expansion in the kinds of communicative and social interactions being developed for persons with dementia in collaboration with their caregivers. Such interventions join Telenovelas, now being displayed on tablets and phones (Gallagher-Thompson, et al. 2015) and other Telehealth applications (Tirado, 2011).

The research review of interventions targeting Hispanic/Latino caregivers by Llanque and Enrique (2012) noted the negative impact of caregiving on the caregivers’ health although caregivers report less stress and perform greater personal care. The authors caution that Hispanics/Latinos do not represent a cohesive group, instead are a different cultural grouping requiring different and tailored interventions. The flexibility offered by technology can potentially address this diverse cultural group. For example, StoryCall, a tablet-based app (emobile application) was originally developed on cellphones to support caregivers in any cultural grouping by sharing 60-second stories of how they overcome challenges in daily caregiving such as dispensing medications or soothing agitation. In pilot tests of this research, the caregivers of U.S. Veterans with dementia were identified as having a desire for maintaining personal privacy and security while also developing or expanding social and community contacts (Davis, Nies, Shehab, & Shenk, 2014). Touchscreen technologies are also growing in popularity (Astell, Ellis,Bernardi, Alm, Dye, Gowans, & Campbell, 2010; Purves, Phinney, Hulko, Puurveen & Astell, 2015; Kerssens, Kumar, Adams, Knott, Matalenas, Sanford, & Rogers 2015).
Astell and colleagues (2010) reported on the interactive CIRCA utility, a multimedia touch screen system that contains a wide range of stimuli to prompt reminiscing for adults with dementia. The intention is that people with dementia and caregivers will explore CIRCA together, using the recollections sparked by the media as the basis for conversations. The evaluation of the utility of CIRCA confirmed that people with dementia can use the touch screen system and that the contents prompt them to reminisce. The interactive utility also supports caregivers to interact with people with dementia as more equal participants in the conversation. The results suggest that interacting with the touch screen system is engaging and enjoyable for people with dementia and caregivers alike and provides a supportive interaction that positively benefits their relationships. The use of video and multimedia on emobile devices allows caregivers to support as well as to go beyond reminiscence (Davis, Shehab, Shenk & Nies, 2015; García-Betances, Jiménez-Mixco, Arredondo & Cabrera-Umpiérrez, 2015).

Finally, new interest in wearables that send signals to phones or tablets has spurred the development of interventions to help caregivers address persons with dementia (Mahoney, Coon, & Lozano, 2016), and to share caregiver perspectives (Matthews, Campbell, Hunsaker, Klinger, Mecca, Hu, Hostein, & Lingler, 2016). Chen and Shultz (2016) offer analysis on how technology can reduce social isolation. Brando, Olmedo & Solares (2017) review 30 studies that apply technology for diagnosis, for neuropsychological rehab, and for caregiver interventions. The findings include that while multiple efforts at providing better diagnoses are abundant, the same cannot be said for interventions involving caregivers, who are often left out of any analysis of impact on either caregiver or caregiver recipient. In sum, technology is easing its way into the caregiver world, with some promising beginnings, but there remains much to do. The
programs for caregivers using Information Technology are also promising and while they are being tested for caregivers they are still in the process of being translated and tailored to caregivers of diverse cultural backgrounds.

**Summary and Future Research**

The theories of family caregiving reviewed in this chapter have been a source of inspiration to develop support services and programs for caregivers and their families. Evidence-based interventions have been developed based on these theories, and some of them have been adapted and translated into culturally appropriate programs for Latino caregivers of elderly patients in the U.S. and across the world. Although great progress has been made, it is necessary to advance our understanding of the characteristics of caregivers for whom specific programs are/are not effective so that we can do a better job recommending appropriate programs to each individual. For example, caregivers suffering from significant depression or anxiety may benefit most from a counseling-oriented approach, whereas those with less stress may benefit from psychoeducational programs, and those with very mild distress may be helped sufficiently with technology-based programs. Alternatives such as these to pharmacological treatments need to be developed and tested with diverse caregivers.

In considering the progress made during the past years and looking at what needs to be done to increase support programs for dementia caregivers in the Latino community, we are encouraged by the many efforts directed to develop culturally tailored evidence-based programs. However, we believe we still face a real challenge to develop evidence-based interventions more specifically directed to Latino caregivers—not just “derivatives” of programs developed primarily for middle-class Caucasians. Such interventions need to identify the main
barriers that limit access to social and medical health services, and address the main challenges associated with Latinos’ lower socioeconomic status, higher level of health problems and their struggle with their own cultural values in the midst of their process of acculturation. We propose that research be directed to conceptualize the interactive nature of family caregiving for Latino individuals, their families and communities, using not only linear models addressing causal relations between stress and caregiving outcomes but also a system dynamic perspective that builds upon current stress and coping frameworks and the empirical findings in the literature. This approach would illustrate how changes in one factor can have wide-ranging and reciprocal impacts on other factors (Richardson, 2013). The goal in a system dynamics is to examine how relationships between endogenous variables (such as supporting programs for adults and caregivers, the availability of family and caregiver resources, etc.) can explain system behavior over time (e.g., caregiver outcomes, such as physical and mental health). From a systems perspective the development of programs to support Latino caregivers and their families will entail the use of a mixed methodology approach where researchers working with Latino caregivers and their families and community partners in the broader Latino communities participate in a discussion to develop a qualitative system dynamics conceptual model that represents the reciprocal relationships that impact the caregivers main concerns and specific needs. This conceptual model highlights the interplay of the existing resources (human and social capital) and the Latinos aspirations/outcomes, in the context of the larger social and organizational opportunities that contribute to support or neglect such aspirations. From a systemic perspective the expected system outcomes for caregivers (such as well-being) can be subjected to either reinforcing (positive) or balancing (negative) impacts at any specific time.
The core cultural beliefs of Latino family caregivers (such as family orientation) may impact well-being as a reinforcing factor (decreasing stress and depression) and in turn increasing the ability of the family to provide quality of care for their members. On the hand, cultural values (such as the duty to care, or the expected caregiving role for women) may impact negatively the well-being of caregivers and in turn diminish their ability to seek the help they need or to maintain or increase their available network of support. A system dynamics approach that consider the constellation of these reciprocal relationships over time may offer a promising path to better understand the complexity of the caregiving experience among Latino families.

Another promising area of intervention happening in communities across the USA, refers to the social, environmental and contextual readiness to accommodate and support caregivers and their families. New community initiatives directed to develop “Age and Dementia Friendly Communities” are now gaining popularity. These initiatives are still in the piloting implementation phase, but there are increasing efforts to test their effectiveness in a variety of individual, family and community outcomes. These initiatives are long-term commitments by organizations from different sectors to agree to a common agenda for social change and propose solutions to current social challenges. Research indicates that collective impact initiatives (as opposed to isolated social change initiatives) are more effective in bringing social change and serve more effectively in providing a unified voice for policy change (Kania & Kramer, 2013). In the United Kingdom the Alzheimer's Society's Dementia Friends initiative was developed to improve inclusion and quality of life for people with dementia. The goal was to change people’s perceptions of dementia and transform the way the community thinks, acts and talks about the condition. Volunteers become a Dementia Friend as they learn about what
it's like to live with dementia and how to do something about it. Dementia Friends are a group of people who have come together to learn more about dementia and the ways they can help, from telling friends about programs to visiting someone living with dementia. Dementia Friendly Communities encourages communities to sign up and work towards establishing Local Dementia Action Alliances for creating a group of people who have come together to create a dementia friendly community.

The Dementia Friendly America (DFA) initiative is the U.S. licensee of the international Dementia Friends program (see website: http://www.dfamerica.org). The DFA has put in motion a movement to more effectively support and serve those across America who are living with dementia and their family and friend care partners. The lead organizations represent all sectors of community and are collectively leveraging their national reach to activate their local affiliates, members and branches to convene, participate in and support dementia friendly community efforts at a local level. In Minnesota, the movement has led to the development of a variety of meaningful opportunities for community engagement and education that include memory cafés, a play in Spanish to increase awareness of dementia, an intergenerational dance hall, book displays at local libraries, a local leaders forum to stimulate community conversation around Alzheimer’s disease, and a chorus for individuals with dementia and their caregivers, among other programs (LaPorte, 2016). According to the DFA collaborative communities are encouraged to progress through four phases as they journey to become dementia friendly: Convene-Engage-Analyze-Act. An assessment of the community’s needs, community dissemination of priorities and assessment findings are key component. The DFA tools have been successfully deployed by dozens of communities across the USA, and are now present in
more than 80 communities in 25 states to join them by the end of 2016. The group’s goal is to have dementia friendly initiatives in all 50 states by the end of 2017. The DFA initiative was acknowledged with the 2015 Public Trust Award presentation at the LeadingAge Annual Meeting in Boston, Massachusetts for its work in fostering dementia friendliness across the country. Certainly we expect that these initiatives will be culturally tailored interventions.

In summary, certain cultural and psychosocial factors can serve either as buffers against stress, or can greatly augment the stress that dementia family caregivers experience. Culturally tailored interventions are recommended for use with diverse caregivers in different contexts, such as in-home and community settings, to help in the effective management of stress and depression. Developing community partnerships is encouraged as are collaborations to better engage and initiate change among low income and underserved dementia caregivers. Research that builds upon conceptual models that incorporate the caregiver’s cultural context and specific situational factors is also encouraged. Future research that specifies both moderators and mediators of evidence-based interventions among diverse caregivers will be invaluable to the field. Clearly, this is an expanding area of research, and it is expected that there be an increase in the number of empirical studies showing the effectiveness of various interventions for dementia caregivers among Latinos in the U.S.
References


ICareFamily. (2010). ICare: Stress management training for dementia caregivers. Video.


### Table 1
List of Selected Evidence-Based Intervention Programs Adapted for Latino Caregivers

<table>
<thead>
<tr>
<th>Theory</th>
<th>Intervention</th>
<th>Cultural Adaptations/ Translations for Hispanic/ Latino Dementia Family Caregivers</th>
</tr>
</thead>
</table>
| Folkman and Lazarus: Cognitive Appraisal theory | **Coping With Caregiving/ Our Family Journey**                               | 1. Spanish Translations of both available on request; CWC also adapted for Chinese, Farci, and Japanese  
2. *Fotonovela:* Unidos Podemos! Enfrentando la perdida memoria en familia  
3. Webnovela: *Mirela* – How a Latino family copes |
| REACH 1, REACH 2, REACHing Out              |                                                                              | 1. Original REACH materials are in Spanish and English  
2. *REACHing Out,* aka *CALMA (Cuidadores Acompañándose y Luchando para Mejorar y Seguir Adelante)*  
3. Translation of REACH II, aka *CUIDAR (Cuidadores Unidos Inspirados en Dar Amor y Buscar Respuestas)*  
*Both were specifically adapted for San Diego county (lower literacy)* |
| CarePro                                     |                                                                              | 1. Spanish translation  
2. Bilingual staff of the Alzheimer’s Association trained to implement program in AZ & NV |
| Pearlin: Stress / process model             | **Caregiver Counseling Interventions: NYU Program**                           | 1. *Northern Manhattan Hispanic Caregiver Intervention Effectiveness Study,* underway in 2017, to examine effectiveness of program among Latino caregivers. |
|                                             | **The Savvy Caregiver Program (SCP)**                                        | 1. Culturally appropriate Spanish translation  
2. Review of program effect on minority caregivers shows positive results |
| Montgomery: Caregiver Identity Theory       | **The Tailored Caregiver Assessment and Referral® (TCARE®)**                 | 1. TCARE translated into Spanish, and adapted for use with Latinos in LA and Washington State. |