Stress and Coping Conceptual Models for Understanding Dementia among Latinos

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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).
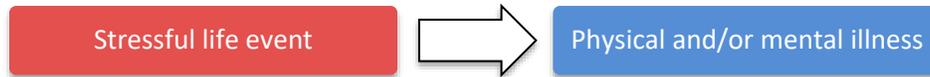
Figure 1: Holmes and Rahe link between stress and illness

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.
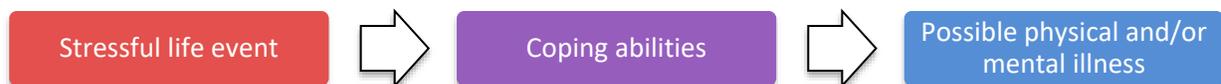

Figure 2: Stress-process model

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
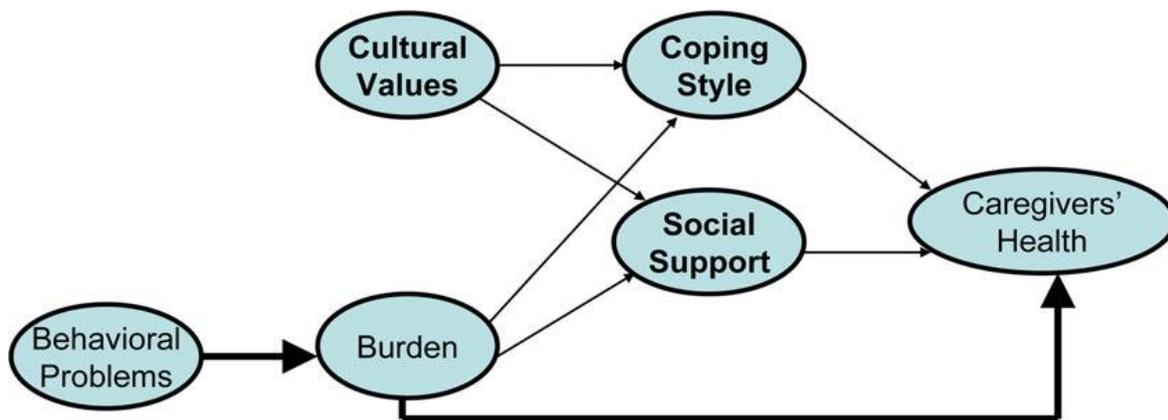
caregiving experience.

Figure 3: Knight's revised stress-process model. Used
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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.

<center><INSERT TABLE 1 ABOUT HERE ></center>

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* 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 believes 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 are 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

Alzheimer's Disease International. (2009). *Caring for people with dementia around the world: Factsheet 5*. Retrieved from http://www. Alz.co.uk/adi/pdf/5caring.pdf.

Alzheimer's Association. (2017). Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 13: 325–373.

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). American Psychiatric Association*. Washington DC. 1994.

Angel, R. J. & Angel, J. L. (2015*). Latinos in an aging world*. NY: Routledge/ Taylor & Francis group.

Apesoa-Varano, E.C., Gomez, Y. & Hinton, L. (2015). Dementia Informal Caregiving in Latinos: What Does the Qualitative Literature Tell US? In. W.A. Vega, K. S. Markides, J. L. Angel & Torres-Gil, F. M. (Eds). *Challenges of Latino Aging in the Americas.* (pp. 141-169). Springer Publishing*.

Arevalo-Flechas, L. C., Martinez, M. & Flores, B. (2017). Caregiving for grandchildren and dementia caregivers: Not that different among Hispanics. *Innovation and Aging*, 1 (Supl 1): 465.

Aranda, M. P. & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A socio-cultural review and analysis. *The Gerontologist*, 37(3), 342-354.

Aranda, M. P., Villa, V. M., Trejo, L., Ramirez, R., & Ranney, M. (2003). El Portal Latino Alzheimer's Project: Model program for Latino caregivers of Alzheimer's disease-affected people. *Social Work*, 48(2), 259-271.

Astell, A. J., Ellis, M. P., Bernardi, L., Alm, N., Dye, R., Gowans, G., & Campbell, J. (2010). Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting With Computers*, 22(4), 267-275.

Bandura A. 1986. The explanatory and predictive scope of self-efficacy theory. *Journal Of Social and Clinical Psychology*, 4(3): 359–373.

Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J. , Gallagher-Thompson, D., Gitlin, L. N., Klinger, J., Koepe, K. M., Chin Lee, Ch., Martindale-Adam, J., Nichols, L., Schultz, R., Stahl, S., Stevens, A., Winter, L. & Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals Of Internal Medicine*, 145(10), 727–738.

Boise, L., Congleton, L. & Shannon, K. (2005). Empowering family caregivers: The powerful tools for caregiving program. *Educational Gerontology*, 31: 573–586.

Brando, E., Olmedo, R. & Solares, C. (2017). The application of technologies in dementia diagnosis and intervention: A literature review. *Gerontechnology,* 16 (1):1-11.

Brown, A., López, G. & Lopez, M. (2016) Hispanics and mobile access to the internet. http://www.pewhispanic.org/2016/07/20/3-hispanics-and-mobile-access-to-the-internet/

Burgio, L. G., Gaugler, J. E. & Hilgeman, M. M. (eds). *The Spectrum of Family Caregiving for Adults and Elders With Chronic Illness*. Oxford University Press. 2016.

Chen, Y.-R. R., & Schulz, P. J. (2016). The Effect of Information Communication Technology Interventions on Reducing Social Isolation in the Elderly: A Systematic Review. *Journal Of Medical Internet Research*, 18, 1.

Cleland, M., Schmall, V. L., Studervant, M., Congleton, L., Kirkbride, K., McFalls, J. & Turner, H. (2006). *The caregiver helpbook: Powerful tools for caregivers*. Portland, OR: Legacy Caregiver Services.

Coon D. W., Rubert M., Solano N., Mausbach, B., Kraemer, H., Arguëlles, T., Haley, W. E., Thompson, L. W. & Gallagher-Thompson, D (2004). Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: findings from the REACH study. *Aging and Mental Health*, (8):330–345.

Coon, D. W., Keaveny, M., Valverde, I., Dadvar, S., & Gallagher-Thompson, D. (2012). Providing evidence-based psychological treatments for distress in family caregivers of older adults. In F. Scogin (Ed.), Making evidence-based psychological treatments work with older adults, (pp.). Washington, D.C.: American Psychological Assn Press.

Coon, D.W., Besst, D.A., Doucet, J.S., Chavez, A., Fenzi, M., Raach, K., … Hirsch, S. (2016). CarePRO: Embedding an Evidence-Based Intervention for Caregiver Empowerment. *Arizona Geriatrics Society, 22*(2), 9-13.

Davis, B., Nies, M., Shehab, M. & Shenk, D. (2014). Developing a pilot e-mobile app for dementia caregiver support: Lessons learned. *Online Journal Of Nursing Informatics* (OJNI), vol. 18(1),

Davis, B. H., Shehab, M., Shenk, D., & Nies, M. (2015). E-mobile pilot for community-based dementia caregivers identifies desire for security. *Gerontechnology*, 13(3), 332-336.

Depp, C., Krisztal, E., Cardenas, V., Oportot, M., Mausbach, B., Ambler, C., Leung, L., & Gallagher-Thompson, D. (2003). Treatment options for improving well-being in dementia family caregivers: The case for psychoeducational interventions. The Clinical Psychologist, 7(1), 21–31.

Elliott, A. F., Burgio, L. D., & DeCoster, J. (2010). Enhancing caregiver health: Findings from the Resources for Enhancing Alzheimer's Caregiver Health II Intervention. *Journal Of the American Geriatrics Society*, 58(1), 30–37.

Folkman, S. (2008). The case for positive emotions in the stress process. *Anxiety, Stress & Coping: An International Journal*, 21(1), 3-14.

Gallagher-Thompson, D., Talamantes, M., Ramirez, R., & Valverde, I. (1996). Service delivery issues and recommendations for working with Mexican American family caregivers. In G. Yeo & D. Gallagher-Thompson (Eds.), *Ethnicity and the dementias* (pp. 137–152). Washington, DC: Taylor & Francis.

Gallagher-Thompson, D., Solano, N., & Coon, D. W. (2003). Recruitment and retention of Latino dementia family caregivers in intervention research: Issues to face, lessons to learn. *The Gerontologist*, 43, 45–51.

Gallagher-Thompson, D., Coon, D.W., Solano, N., Ambler, C., Rabinowitz, Y., & Thompson, L.W. (2003). Change in indices of distress among Latina and Anglo female caregivers of elderly relatives with dementia: Site specific results from the REACH national collaborative study. The Gerontologist, 43(4), 580–591.

Gallagher-Thompson D. & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging*, 22(1): 37–51.

Gallagher-Thompson, D., Gray, H.L., Dupart, T., Jimenez, D., & Thompson, L. W. (2008). Effectiveness of cognitive/ behavioral small group intervention for reduction of depression and stress in Non Hispanic White and Hispanic/Latino women dementia family caregivers: Outcomes and mediators of change. Journal of Rational-Emotive and Cognitive-Behavior Therapy, 26(4), 286-303.

Gallagher-Thompson, D**.**, Tzuang, M., Au, A., Brodaty, H., Charlesworth, G., Gupta, R., Lee, S. E., Losada, A., & Shyu, Y-I. (2012). International perspectives on nonpharmacological best practices for dementia family caregivers: A review. Clinical Gerontologist, 35(4), 316-355.

Gallagher-Thompson, D., Tzuang, M., Hinton, L., Alvarez, P., Rengifo, J., Valverde, I., & Thompson, L. W. (2015). Effectiveness of a fotonovela for reducing depression and stress in Latino dementia family caregivers. *Alzheimer Disease and Associated Disorders*, 29(2), 146-153.

Gallagher-Thompson, D., Alvarez, P., Cardenas, V., Tzuang, M., Velazquez, R. E., Buske, K., & Tilburg, L. V. (2015). From ivory tower to real world: Translating an evidence-based intervention for Latino dementia family caregivers into a community Settings. In Laura Roberts et al., (Eds). *Partnerships For Mental Health* (pp. 105-123). Springer International. 2015.

García-Betances, R. I., Jiménez-Mixco, V., Arredondo, M. T., & Cabrera-Umpiérrez, M. F. (2015). Using virtual reality for cognitive training of the elderly. *American Journal Of Alzheimer's Disease And Other Dementias*, 30(1), 49-54.

Gaugler, J. E., Reese, M. & Mittelman, M. S. (2016). Effects of the Minnesota adaptation of the NYU caregiver intervention on primary subjective stress of adult child caregivers of persons with dementia. *The Gerontologist* 2016; 56 (3): 461-474.

Gitlin, L., Belle, S., Burgio, L., Mahoney, D., Gallagher-Thompson, D., Burns, R., Hauck, W., Zhang, S., Schulz, R., Ory, M., & REACH Investigators (2003). Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at 6-month follow-up. *Psychology and Aging*, 18, 361-374.

Hebert, L. E, Weuve, J., Scherr, P.A & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology* 80:1778–83.

Hepburn, K. W, Tornatore, J., Center, B., & Ostwald, S. W. (2001). Dementia family caregiver training: Affecting beliefs about caregiving and caregiver outcomes. *Journal Of the American Geriatrics Society*, 49(4), 450-457.

Hepburn, K. W., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist*, 43(6), 908-915.

Hepburn, K., Lewis, M., Tornatore, J., Sherman, C. W., & Bremer, K. L. (2007). The Savvy Caregiver Program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal Of Gerontological Nursing*, 30-36.

Hinton L, Chambers D, Velásquez A, Gonzalez H, Haan MN. Dementia Neuropsychiatric Symptom Severity, Help-Seeking, and Unmet Needs in Sacramento Area Latino Study on Aging (SALSA). Clinical Gerontologist, 29(4):1-16, 2006

Holmes, T.H., Rahe, R.H. (1967). The social readjustment rating scale. *J Psychosom Res*. 11:213–8.

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

Kahana, E., Kahana, B., Johnson, J. R., Hammond, R. J. & Kercher, K. (1994). Developmental challenges and family caregiving. In E. Kahana, D. E. Biegel & M. L. Wykle (Eds.) *Family caregiving across the lifespan* (pp, 3-41).

Kajiyama, B., Thompson, L. W., Eto-Iwase, T., Yamashita, M., Di Mario, J., Tzuang, Y. M., & Gallagher-Thompson, D. (2013). Exploring the effectiveness of an Internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Program. *Aging and Mental Health*, 17: 544-554.

Kally, Z., Cote, S. D., Gonzalez, J., Villarruel, M., Cherry, D. L., Howland, S., Higgins, M., Connolly, L & Hepburn, L. (2014). The Savvy Caregiver Program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. *Journal Of Gerontological Social Work*, 57(6-7), 681-693

Kania, J. V., & Kramer, M. R. (2013). Embracing emergence: How collective impact addresses complexity. *Stanford Social Innovation Review*. January.

Kerssens, C., Kumar, R., Adams, A. E., Knott, C. C., Matalenas, L., Sanford, J. A., & Rogers, W. A. (2015). Personalized technology to support older adults with and without cognitive impairment living at home. American Journal Of Alzheimer's Disease And Other Dementias, 30(1), 85-97.

Knight, B. G. & Sayegh, P. (2010). Cultural values and caregiving: The updated Sociocultural Stress and Coping Model. *The Journals Of Gerontology: Series B: Psychological Sciences And Social Sciences*, 65(1), 5-13.

Kuhn, D., Fulton, B. & Edelman, P. (2003). Powerful tools for caregivers: improving self-care and self-efficacy of family caregivers. *Alzheimer's Care Quarterly,* 7, 4: 189–201

LaPorte, M (2016). Building a Dementia-Friendly Movement. *Disrupting Dementia*. September.

Lee, C. C., Czaja, S. J., & Schulz, R. (2010). The moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of a multicomponent psychosocial caregiver intervention in three racial ethnic groups. *The Journals Of Gerontology*, Series B, 65(2), 185–194.

Llanque, S. M., & Enriquez, M. (2012). Interventions for Hispanic caregivers of patients with dementia: A review of the literature. *American Journal Of Alzheimer's Disease And Other Dementias*, 27(1), 23-32.

Lorig, K., Thompson-Gallagher, D., Traylor, L., Ritter, P. L., Laurent, D. D., Plant, K., Thompson, L. W. & Hahn, T. H. (2012). Building better caregivers: A pilot online support workshop for family caregivers of cognitively impaired adults. *Journal Of Applied Gerontology*, 31(3), 423-437.

Luchsinger J. A., Burgio L., Mittelman, M., Dunner, I., Levine, J. A., Knog, J., Silver, S., Ramirez, M. & Teresi, J. A. (2017). Northern Manhattan Hispanic Caregiver Intervention Effectiveness Study: protocol of a pragmatic randomized trial comparing the effectiveness of two established interventions for informal caregivers of persons with dementia. *BMJ Open* 2016; 6:e014082.

Mahoney, D. F., Coon, D. W., & Lozano, C. (January 01, 2016). Latino/Hispanic Alzheimer's caregivers experiencing dementia-related dressing issues: corroboration of the Preservation of Self model and reactions to a "smart dresser" computer-based dressing aid. *Digital Health*, 2.

Matthews, J. T., Campbell, G. B., Hunsaker, A. E., Klinger, J., Mecca, L. P., Hu, L., Hostein, S. & Lingler, J. H. (2016). Wearable technology to garner the perspective of dementia family caregivers. *Journal Of Gerontological Nursing*, 42, 4, 16-22.

Mausbach, B. T., (2014). Caregiving. *The American Journal Of Geriatric Psychology*, 22: 743-745.

Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a Caregiver Intervention on Negative Caregiver Appraisals of Behavior Problems in Patients with Alzheimer's Disease: Results of a Randomized Trial. *Journals Of Gerontology - Series B Psychological Sciences and Social Sciences*, 59(1).

Montgomery, R. V., Kosloski, K., Karner, T. X., & Schaefer, J. P. (2002). Initial findings from the evaluation of the Alzheimer's disease demonstration grants to states programs. In R. V. Montgomery, R. V. Montgomery (Eds.), *A new look at community-based respite programs: Utilization, satisfaction, and development* (pp. 5-32). New York, NY, US: Haworth Press.

Montgomery, R. V., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Generations*, 33(1), 47–52.

Montgomery, R. V., Kwak, J., Kosloski, K., & O'Connell Valuch, K. (2011). Effects of the TCARE® intervention on caregiver burden and depressive symptoms: Preliminary findings from a randomized controlled study. *The Journals Of Gerontology: Series B: Psychological Sciences And Social Sciences*, 66(5), 640-647.

Montgomery, R. V., & Kosloski, K. (2013). Pathways to a caregiver identity and implications for support services. In R. C. Talley, R. V. Montgomery, R. C. Talley, R. V. Montgomery (Eds.) , *Caregiving across the lifespan: Research, practice, policy* (pp. 131-156). Springer Science + Business Media.

Montgomery, R. V. (2014). *Has the use of Tailored Caregiver Assessment and Referral® System impacted the well-being of caregivers in Washington*? Report to the Washington Aging and Long-Term Support Administration.

Montgomery, R. V., Kwak, J. & Kosloski, K. (2016). Theories guiding support services for family caregivers. In Vern L. Bengtson & R. A. Settersten, Jr. (Eds.). *Handbook Of Theories Of Aging* (pp. 443-462). Springer.

Montoro-Rodriguez, J., & Gallagher-Thompson, D. (2009). The role of resources and appraisals in predicting burden among Latina and non-Hispanic White female caregivers: A test of an expanded socio-cultural model of stress and coping. Aging & Mental Health, 13(5), 648-658.

Montoro-Rodríguez, J., Kosloski, K., Kercher, K., & Montgomery, R. V. (2009). The impact of social embarrassment on caregiving distress in a multicultural sample of caregivers. Journal Of Applied Gerontology, 28(2), 195-217.

Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T. & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist*, 39(3), 299-309.

Oakes, S. L., Hepburn, K., Ross, J. S., Talamantes, M. A., & Espino, D. V. (2006). Reaching the heart of the caregiver. *Clinical Gerontologist*, 30(2), 37–49.

Olazaran, J., Reisberg, B., Clare, L., Cruz, I P-C; Del Ser, T; Woods, B; Auer, S; Spector, A/ Fazio, S.; Bond, J; Kivipelto, M; Brodaty, H., Rojo, J. M., Collins, H., Teri, L; Mittelman, M; Orrell, M; Feldman, H.H. & Muniz, R. (2010). Nonpharmacological therapies in Alzheimer's disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders,* 30, 161-178.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594.

Pinquart, M. & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45, 90-106.

Purves, B., Phinney A., Hulko W., Puurveen, G., Astell, A. (2015). Developing CIRCA-BC and exploring the role of the computer as a third participant in conversation. *American Journal of Alzheimer's Disease & Other Dementias*, 30 (1): 101-107.

Richardson, G. P. (2013). Concept models in group model building. *System Dynamics Review*, 29, 42-55.

Samper-Ternent, R., Kuo, Y. F., Ray, L. A., Ottenbacher, K. J., Markides, K. S, & Al Snih, S. (2012). Prevalence of health conditions and predictors of mortality in oldest old Mexican Americans and non-Hispanic whites. *Journal Of American Medical Directors Association*, 13:254–9.

Savundranayagam, M. Y., Montgomery, R. V., Kosloski, K., & Little, L. T. (2011). Impact of a pscyhoeducational program on three types of caregiver burden among spouses. *International Journal Of Geriatric Psychiatry*, 26(4), 388-396.

Schmall V. L., Cleland, M. & Sturdevant, M. (2000). *The caregiver help book (use in the Powerful Tools for Caregiving)*. Oregon, Oregon Gerontological Association: Legacy Health System.

Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L. N., & Mahoney D. F. (2003). Resources for enhancing Alzheimer's caregiver health (REACH): Overview, site-specific outcomes, and future directions. *The Gerontologist*, 43(4), 514-520.

Tirado, M (2011). Role of mobile health in the care of culturally and linguistically diverse US populations. *Perspectives in Health Information Management*, 8, 1- 7.

Turner, R. M., Hinton, L., Gallagher-Thompson, D., Tzuang, M., Tran, C., & Valle, R. (2015). Using an emic lens to understand how Latino families cope with dementia behavioral problems. *American Journal of Alzheimer's Disease And Other Dementias*, 30(5), 454-462.

Wilson, R. S., Segawa, E., Boyle, P. A., Anagnos, S. E., Hizel, L. P. & Bennett, D.A. (2012). The natural history of cognitive decline in Alzheimer's disease. *Psychology and Aging* 27:1008–17.

Wiener, J. & Mitchell, N. *Alzheimer's disease demonstration grants to states: Cross-state report on initiatives targeting limited English speaking populations and African American communities.* Research Triangle Institute. 2007.

Zeiss, A., Gallagher-Thompson, D., Lovett, S., Rose, J., & McKibbin, C. (1999). Self-efficacy as a mediator of caregiver coping: Development and testing of an assessment model. Journal Of Clinical Geropsychology, 5(3), 221-230.

	Table 1	
	List of Selected Evidence-Based Intervention Programs Adapted for Latino Caregivers	
Theory	Intervention	Cultural Adaptations/ Translations for Hispanic/ Latino Dementia Family Caregivers
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 perdidade 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 C**UIDAR (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
	Powerful Tools for Caregivers (PTC)	1. Has effectively served Spanish, Korean, Chinese, and Vietnamese caregivers with translated materials.
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.