



ResearchLink

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How Caregiving Impacts the Caregiver: Influences in the Caregiving of Elderly Family Members



Two studies highlight how person-, family-, and context-level characteristics matter in the experience of caregivers who care for elderly family members. The first study examined responses of caregivers when faced with care-related stressors. This study showed that caregivers with low levels of support and high numbers of non-care related stressors experience daily care-related stressors more intensely. The second study examined how familism beliefs influence Hispanic caregivers' responses to family conflict/disagreements about the care situation. This study found that stronger familism beliefs increase negative responses to daily care-related family disagreements as seen in greater depressive and physical symptoms. Because of these findings, a new study is currently under way to further understand family dynamics for Hispanic caregiving families.

Why We Need to be Concerned About Caregivers

Caregiving for older adults by family members represents an increasingly critical focus for research and policy. Indeed, with average life expectancy on the rise due to advances in preventative health services and medical interventions, the size of the older population is growing rapidly in the U.S.¹ Further, with the baby boom generation now reaching their later years, this aging trend will become even more prominent in the next two decades. Although the majority of older adults remain relatively healthy and independent as they age, substantial numbers (more than 14 million) of adults age 65+ have limitations in functioning (due to chronic illness or disability) and require regular assistance with activities of daily living.² Although we may think that these older adults

are cared for in nursing homes or assisted living facilities, the fact is that family members (e.g., spouses, adult children) are the people who most often meet the needs of frail, ill, or disabled older adults.

Previous research has shown that when adults take on the role of caregiver for an elderly family member (and face the stressors that come with that role), their health and well-being may decline.³ They may experience increased levels of depression and anxiety and suffer from more physical health problems compared to non-caregiving adults.

Understanding what factors can intensify or buffer against this risk for declining mental and physical health among caregivers is essential and is the focus of Dr. Susan Silverberg Koerner's research.



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About the Studies

Much of the research on caregiver well-being has used a “snapshot” or cross sectional approach. Using this approach, survey or interview questions are asked of caregivers at *only one point in time*. In longitudinal studies where caregivers are surveyed or interviewed multiple times, usually the gap between surveys or interviews is quite lengthy (e.g., one

social support the caregivers received from family/friends and on how many *non-caregiving stressors* they faced.

In their second study, Dr. Koerner and colleagues focused on Hispanic (Mexican-American) caregivers only. Using daily diaries once again, this time the researchers examined



Text Box 1: Daily Diary Approach versus Other Approaches

Cross Sectional Design (“snapshot”)



Longitudinal Design



Daily Diary



▬ = point of data collection

year). As a result, both of these approaches miss the “day-to-day” ebb and flow in care-related stressors as well as the likely ups and downs of distress or mental health that caregivers may experience.⁴ Dr. Koerner and her colleagues addressed this issue by using a unique alternative for their research — a *daily diary design*.

Specifically, in their first study Dr. Koerner and colleagues used daily diaries (a survey filled out for 8 days in a row) to examine how caregivers respond (emotionally and physically) to the day-to-day occurrence of care-related stressors; they also examined whether caregiver responses to caregiving stressors varied depending on how much

whether caregiver responses to caregiving stressors varied depending on how strongly the caregiver embraced “familism.” *Familism* refers to a set of traditional values that entail high family solidarity. Individuals high in familism are said to place family goals above their own and believe that one should trust and rely on family members more than nonrelatives.^{5,6} Dr. Koerner was interested in finding out whether caregivers high in familism experienced caregiving stressors differently from those lower in familism.

Based on the results of these two studies, Dr. Koerner is now in the process of conducting a new study to further explore the lived experience of Hispanic caregiving families.

Study 1: The Influence of Support and Non-Caregiving Stressors

Sixty-three study participants were recruited through family practice clinics, geriatric clinics, medical supply and equipment stores, and caregiving support groups. Each of these participants was the primary caregiver of a family member who was at least 60 years of age; in fact, the average age of the relatives they cared for was 81 years. A variety of health conditions put these elders in need of care (e.g., cognitive

impairment, mobility problems, cardiovascular conditions, diabetes, and vision and hearing impairment).

After an introductory phone call, survey packets that included an initial survey and eight daily surveys were sent to the participants. Questions asked about *caregiver well-being* (e.g., depressive symptoms, feelings of burden, physical health symptoms), *care-related stressors* (e.g., care recipient problem behaviors, family disagreements regarding care), *social support*, and *extrinsic or non-caregiving stressors*.

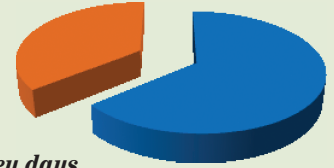
Key Findings

- This study revealed that on days when caregivers face more than their usual number of care-related stressors, they experience higher levels of:
 - depressive symptoms (e.g., lacked enthusiasm, cried easily, or felt like crying)
 - feelings of burden (e.g., lack of time for self, guilt over not doing more for care recipient)
 - physical health symptoms (e.g., headache, dizziness, and tightness in chest)
- Notably, feelings of burden were found to be the most sensitive to care-related stressors: on days when the caregivers faced more care-related stressors, it was feelings of burden that were most likely to increase. This is an especially important finding as feelings of burden have been found to predict both caregivers' decision to institutionalize their care recipient and caregiver harsh or abusive behavior.⁷
- Study 1 also showed that social support and non-caregiving life stressors can influence how caregivers respond to care-related stressors:
 - Caregivers with low levels of social support and high numbers of *non*-caregiving stressors experienced care-related stressors more intensely as reflected in depressive and physical health symptoms.



whether their relative needs care, how care was being provided, and the fact that their other relatives (e.g., siblings) were not helping out and/or were not aware of the elder's needs.

64% of these Hispanic caregivers reported that they experienced at least one family conflict/disagreement about care in the 8 survey days.



- Those caregivers who reported higher levels of family conflict/disagreement regarding care also reported more depressive symptoms.
- Familism played a critical and somewhat surprising role. Those caregivers who held strong familism beliefs were most sensitive to (and more likely to be negatively affected on) days when they faced family disagreements/conflicts about care. Perhaps this was because these caregivers expected greater family solidarity and support; when instead, they hear criticism and receive little or no assistance, frustration is likely.

Implications of Findings from Studies 1 and 2

- Caregivers with low levels of social support and high numbers of *non*-caregiving stressors experience care-related stressors more intensely.
- Family disagreement regarding care results in decreased well-being for caregivers.
- Stronger familism beliefs increase negative responses to daily care-related family disagreements.

Study 3: How Hispanic Families Manage Decisions and Circumstances Regarding Care

Dr. Koerner's current research aims to further explore the experience of Hispanic caregiving families – a population that has often been overlooked in research on caregiving families. This focus seems especially important given her previous research highlighting the role of familism – a set of beliefs often associated with Hispanic culture.

Data collection is currently underway for Hispanic families. Of the 67 participants from Study 2, 32 have been interviewed. These in-person interviews focus on the family dynamics of their caregiving experience. The aim of the current study is to explore the following issues:

Study 2: Family Disagreements and the Role of Familism

Recruitment was similar to the previous study, but participation was for Hispanic caregivers (of Mexican descent) only. A total of 67 caregivers returned completed surveys, including their 8 daily surveys. For this study, questionnaires were offered to participants in English or Spanish, as preferred.

The focus was on measures of *caregiver well-being* (depressive symptoms, feelings of burden, physical health symptoms), *family conflict/disagreements regarding care*, and *familism*. Familism beliefs were measured on three dimensions: familial obligations, support from the family as central, and family as referent.

Key Findings

- A majority of these Hispanic caregivers reported experiencing family conflict/disagreements regarding care. The conflicts/disagreements were about things such as

- Who becomes the primary caregiver and how
- Whether and how caregiving responsibilities are shared among family members
- Whether and what care issues cause disagreement/conflict/differences of opinion among family members (and why)
- How disagreement/conflict/differences of opinion regarding care are managed
- How disagreements/conflicts/differences of opinion regarding caregiving may affect the primary caregiver's well-being, relationships, morale, and caregiving behavior
- How providing care may impact the caregiver's marital relationship



Text Box 2: Caregiver Support Groups

Are you a primary caregiver? Are you looking for support or just someone to talk to about your experiences? There are numerous support groups around Tucson to fit your schedule.

- Pima Council on Aging
<http://www.pcoa.org/>
- Caregiver's Education & Support Group (for caregivers of cancer patients)
<http://www.azcc.arizona.edu/>
- UA Caregiver Support Group (open to the public)
<http://lifework.arizona.edu/ec>
- VA Caregiver Support (for caregivers of veterans)
<http://www.caregiver.va.gov/>

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This ResearchLink summarizes two studies:

- (1) Koerner, S. S., Shirai, Y., & Kenyon, D. B. (2010). Sociocontextual circumstances in daily stress reactivity among caregivers for elder relatives. *Journal of Gerontology: Psychological Sciences*, 65, 561-572.
- (2) Koerner, S. S. & Shirai, Y. (2012). The negative impact of global perceptions of and daily care-related family conflict on Hispanic caregivers: Familism as a potential moderator. *Aging and Mental Health*, 16, 486-499.
- (3) Koerner, S. S. (in press). Caregiving for older adults in Hispanic families: An in-depth qualitative examination of family issues.

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