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The Cost of Caring: Economic Vulnerability, Serious Emotional Distress, and Poor Health Behaviors Among Paid and Unpaid Family and Friend Caregivers

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## The Cost of Caring – Economic Vulnerability, Serious Emotional Distress, and Poor Health Behaviors among Paid and Unpaid Family and Friend Caregivers

Journal:	<i>Research on Aging</i>
Manuscript ID	ROA-17-114.R2
Manuscript Type:	Empirical Article
Keywords:	caregiving, Medicaid, health behavior, consumer-driven programs, distress
Abstract:	<p>This study examined differences between paid and unpaid family/friend caregivers to better understand the consumer-driven caregiving workforce. We compared economic vulnerability, unhealthy behavior, and serious emotional distress for 475 paid and 10,500 unpaid family/friend informal caregivers from the 2009 California Health Interview Survey. We then estimated whether caregiver status moderated the relationship between economic vulnerability and health outcomes. Compared to unpaid family/friend caregivers, paid family/friend caregivers had a 27% greater risk (<math>p=0.002</math>) of economic vulnerability. Among all family/friend caregivers, the probabilities of serious emotional distress and unhealthy behaviors increased by &gt;100% and 28% for those with the greatest compared to the least economic vulnerability, and caregiver type did not moderate these relationships. To address economic and health vulnerabilities of paid informal caregivers, policymakers might increase wages in consumer-driven programs. These changes could prove beneficial to both paid informal caregivers and their care recipients, while reducing long-term inefficiencies in consumer-driven programs.</p>

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The Cost of Caring – Economic Vulnerability, Serious Emotional Distress, and Unhealthy Behaviors among Paid and Unpaid Family and Friend Caregivers

For Peer Review

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3 ABSTRACT  
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8 This study examined differences between paid and unpaid family/friend caregivers to better  
9 understand the consumer-driven caregiving workforce. We compared economic vulnerability,  
10 unhealthy behavior, and serious emotional distress for 475 paid and 10,500 unpaid family/friend  
11 informal caregivers from the 2009 California Health Interview Survey. We then estimated  
12 whether caregiver status moderated the relationship between economic vulnerability and health  
13 outcomes. Compared to unpaid family/friend caregivers, paid family/friend caregivers had a 27%  
14 greater risk ( $p=0.002$ ) of economic vulnerability. Among all family/friend caregivers, the  
15 probabilities of serious emotional distress and unhealthy behaviors increased by >100% and 28%  
16 for those with the greatest compared to the least economic vulnerability, and caregiver type did  
17 not moderate these relationships. To address economic and health vulnerabilities of paid  
18 informal caregivers, policymakers might increase wages in consumer-driven programs. These  
19 changes could prove beneficial to both paid informal caregivers and their care recipients, while  
20 reducing long-term inefficiencies in consumer-driven programs.  
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41 Keywords: caregiving-formal, Medicaid, health behavior, distress, consumer-driven programs  
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## INTRODUCTION

Consumer-driven caregiving programs are designed to benefit both caregivers and care recipients. To address the growing support needs of the U.S. older adult population, states have increasingly adopted caregiving programs that pay untrained informal caregivers to provide care (Foster, Dale, & Brown, 2007). The programs are “consumer-driven” because they allow for substantial beneficiary direction—Medicaid beneficiaries can hire, train, and fire their care provider, who can be a family member or friend (Kaye, 2014). A number of states have recently adopted these programs through Medicaid waivers; California’s In-Home Supportive Services (IHSS) program is the nation’s largest consumer-driven program.

However, the implications of increased use of consumer-driven programs are uncertain. There are reasons to believe the programs may benefit both caregiver and care recipient—because a care recipient can retain the services of an informal caregiver they know and trust, while the Medicaid reimbursement may allow a caregiver to avoid the economic losses associated with caregiving (Butrica & Karamcheva, 2014). Caregivers may also financially and emotionally benefit, due to the Medicaid reimbursement, and because they are able to help a loved one (Benjamin & Matthias, 2004; Foster et al., 2007; Simon-Rusinowitz et al., 2014). Further, reimbursement could increase resources for self-care, such as physical exercise or other health behaviors.

On the other hand, there may be drawbacks to the expansion of such programs. The Medicaid programs may not help caregivers financially, because reimbursement rates are low (Hoffman & Wallace, 2012; LAO, 2009). Wages in consumer-directed programs are similar to those of home health agency caregivers, many of whom live in poverty and rely on public benefits (DCA, 2012). Also, caregivers may give up other paid employment when they sign up,

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3 resulting in reduced overall income. More than half of informal caregivers work full-time, while  
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5 10% work part-time (Hoffman & Mendez-Luck, 2011). However, individuals who become  
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8 consumer-directed caregivers may have limited earning potential, as the number of weekly care  
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10 hours for the majority of care recipients in IHSS is 20 hours or less (LAO, 2009).  
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13 The implications of consumer-driven care are important for the future of the program.  
14  
15 First, the economic and health circumstances of paid informal caregivers affects the attraction  
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17 and retention of workers, as unpaid informal caregivers represent the largest source of potential  
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19 labor for consumer-driven care (Benjamin, Matthias, Kietzman, & Furman, 2008). If wages or  
20  
21 benefits are too low, or if providers are dissatisfied with these programs, they are unlikely to  
22  
23 continue as caregivers. A depleted workforce could tamp continuing efforts to expand consumer-  
24  
25 driven programs. Second, financial issues or poorer health of paid caregivers could negatively  
26  
27 impact quality of care, dampening the efficiency and effectiveness of the Medicaid programs.  
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31  
32 Despite the importance for policymakers of empirical information about paid informal  
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34 caregivers, such information is limited. Existing literature has compared paid informal caregivers  
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36 to other paid caregivers, i.e., professional home care agency workers (Benjamin & Matthias,  
37  
38 2004; Foster et al., 2007; Simon-Rusinowitz et al., 2010). But, unpaid informal caregivers are  
39  
40 more like paid informal caregivers—similar socioeconomic backgrounds, often untrained and  
41  
42 caring for family members—and thus provide a more natural comparison group for examining  
43  
44 the well-being of consumer-driven caregivers. However, to our knowledge, no existing research  
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46 directly compares the characteristics of these two groups.  
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51 To address this gap in the literature regarding, we examined the relative economic and  
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53 health characteristics of paid versus unpaid informal caregivers in California, which has the  
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55 nation's largest consumer-driven caregiving program. In this observational study, we had three  
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3 aims: (1) to compare the economic characteristics, emotional distress, and health behaviors of  
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5 paid compared to unpaid informal caregivers, (2) to assess whether informal caregiver health  
6  
7 worsens with increased economic vulnerability, and (3) to determine whether worsening of  
8  
9 health with increased vulnerability varies by paid versus unpaid caregiver status.  
10  
11

### 12 *Background*

#### 13 *California's In-Home Supportive Services (IHSS) Program*

14  
15 IHSS provides paid caregiving to over 450,000 aged, blind, and persons with disabilities  
16  
17 (Taylor, 2015). While the majority of IHSS recipients are adults ages 65 and older, children and  
18  
19 younger adult Medicaid (called Medi-Cal in California) beneficiaries are eligible for the program  
20  
21 as long as they live in their own home (HHS, 2008). Parents of low-income children with  
22  
23 disabilities may be paid IHSS providers under certain circumstances (such as when a parent quits  
24  
25 a full-time job to care for the child) and spouses may also provide paid help under IHSS as long  
26  
27 as the couple meets income requirements and has resources (aside from their home and one  
28  
29 vehicle) valued at \$3,000 or less (HHS, 2008). IHSS and similar state programs may offer  
30  
31 benefits that address longstanding concerns about the well-being of the informal caregiving  
32  
33 workforce (IOM, 2016; National Alliance for Caregiving, 2015).  
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#### 40 *Informal Caregiving in the U.S.*

41  
42 More than 44 million Americans receive help from informal caregivers—family and  
43  
44 friends who offer help to those with long-term physical conditions; of those, an estimated 5.2  
45  
46 million caregivers assisted an ill or disabled spouse (National Alliance for Caregiving, 2015).  
47  
48 Over half of informal caregivers are aged 50 and older while one in five are aged 75 and older;  
49  
50 the average informal caregiver is female (~60%), non-Hispanic white (~70%), has less than a  
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52 bachelor' degree level of education (~75%), and cares for a relative (85%) (Institute of Medicine,  
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3 2016; National Alliance for Caregiving, 2015). Caregiving needs may vary by race, due to  
4 greater functional limitations for older minority racial/ethnic groups (Institute of Medicine,  
5 2016). Although two in three caregivers report part-time or full-time employment status, nearly  
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7  
8 one in three report incomes at less than two times the Federal Poverty Level (Hoffman &  
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13 Mendez-Luck, 2011).

#### 14 *Health and Economic Effects of Informal Caregiving*

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16  
17 Prior research has observed negative associations between caregiving and various health  
18  
19  
20 measures. Informal caregiving can result in negative emotional health effects for caregivers  
21  
22 (Benjamin, Matthias, & Franke, 2000; Garand, Dew, Eazor, DeKosky, & Reynolds, 2005),  
23  
24 unhealthy behaviors (Hoffman, Lee, & Mendez-Luck, 2012; Carolyn A. Mendez-Luck, Walker,  
25  
26 & Luck, 2016), and negative longer-term physical health outcomes (Capistrant, Berkman, &  
27  
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29 Glymour, 2014).

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31  
32 Beyond health, caring for others has negative financial implications. Many informal  
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34 caregivers experience financial pressures when balancing work and unpaid caregiving  
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36 responsibilities (IOM, 2016; National Alliance for Caregiving, 2015). Providing care is time-  
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38 consuming, reducing opportunities for full-time employment; it also may increase spending, if  
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40 care recipients need help to pay for medical equipment, medicine, or medical care. Because of  
41  
42 this, informal care responsibilities can result in lost wages and benefits, as well as out-of-pocket  
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44 costs involving care recipients' care needs (Hoffman & Mendez-Luck, 2011; Reinhard, Feinberg,  
45  
46  
47 Choula, & Houseer, 2015).

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50 Consumer-driven paid caregiving may be beneficial for caregivers as well as care  
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52 recipients. Studies suggest that consumer-driven caregivers are as satisfied, if not more satisfied  
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54 in their caregiving role (and generally had lower emotional strain and limitations to their  
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3 personal social lives), than agency-based workers (Benjamin & Matthias, 2004; Simon-  
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5 Rusinowitz et al., 2014). Also, payment for informal caregiving may translate to reduced  
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7 emotional distress associated with lost wages and employment opportunity (Benjamin &  
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9 Matthias, 2004; Foster et al., 2007; Simon-Rusinowitz et al., 2014). Care recipients also tend to  
10  
11 more highly rate their safety and overall satisfaction with care quality when they receive care  
12  
13 from consumer-driven rather than agency-based caregivers (Benjamin et al., 2000).  
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16  
17 However, as opposed to agency-based caregivers, other non-professional informal  
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19 caregivers provide a more apt comparison group for this analysis. Professional, agency-based  
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21 caregivers differ considerably from unpaid informal caregivers in terms of pay and training  
22  
23 (DCA, 2012). Agency-based caregivers, professionally trained and often low-income and poorly  
24  
25 educated, may not be an ideal comparison group for understanding consumer-driven paid  
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27 caregivers. Therefore, a better understanding of the characteristics of both groups of informal  
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29 caregivers may inform policymakers as to the benefits and areas for improvement with paid  
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31 informal care.  
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## 39 METHODS

### 40 *Data*

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42 We used the 2009 California Health Interview Survey (CHIS), the nation's largest  
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44 statewide health survey. The CHIS employs telephone interviews, employing a multi-stage  
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46 sampling design using a random-digit dial sample of landline and cellular telephone numbers to  
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48 randomly select households. In order to generalize results to the state's non-institutionalized  
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50 population, we employed survey weights. We examined 2009 survey data because caregiving  
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52 was only examined in the 2009 CHIS.  
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### *Study Population*

We examined two groups of informal caregivers caring for family members or friends. We first identified all caregivers ages 18 and over in our sample ( $n=11,321$ ), individuals who responded yes to the question, “Some people provide help to a family member or friend who has a long-term illness or disability. This may include help with things they can no longer do for themselves. During the past 12 months, did you provide any such help to a family member or friend?” Next, we distinguished paid ( $n=821$ ) from unpaid ( $n=10,500$ ) caregivers, with paid caregivers identified as those who responded affirmatively to the question, “Did you get paid for any of the time you spent helping your [family member/friend]?” Subsequently, we identified, among the group of 821 paid caregivers, those who reported having provided care to a Medi-Cal beneficiary ( $n=502$ ) and excluded 77 individuals who provided care to individuals in nursing homes (as IHSS does not allow care for individuals in nursing homes) (DRC, 2008), resulting in a sample of 475 Paid Medi-Cal Caregivers (hereafter abbreviated as *PMCs*). Our comparison group included individuals who reported being caregivers and who said they were not paid for the care they provided. This resulted in a sample of 10,500 Unpaid Caregivers (hereafter abbreviated as *UCs*). See Figure S1 (Supplemental Online Appendix) for sample derivation.

### *Measures*

#### *Outcome Measures*

We assessed measures of economic status and health. First, we measured a set of factors associated with a caregiver’s economic status. Income does not fully capture economic status (ESI, 2012). Therefore, we created an index that reflects both income and additional economic status indicators: (1) poverty (i.e., <100% of the Federal Poverty Level, or FPL), (2) food insecurity (only measured for those with incomes <200% FPL), (3) lack of home ownership (i.e.,

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3 renting, as opposed to home ownership), (4) lack of health insurance coverage, (5) lack of a  
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5 usual source of medical care, (6) delays in getting medical care and (7) delays in getting  
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7 prescription medications. We obtained a summary index score by adding the total number of  
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9 points across the seven indicators, with one point assigned for an affirmative status for each of  
10  
11 the seven indicator variables. Because some score categories contained small cell sizes, we then  
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13 created a dichotomous indicator for whether individuals were economically vulnerable, based  
14  
15 upon an extreme score in the  $\geq 90^{\text{th}}$  percentile (which averaged to a score of  $\geq 3$  out of a possible  
16  
17 total score of 7). We tested our results with a lower vulnerability score threshold (e.g.,  $\geq 75^{\text{th}}$   
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19 percentile, which averaged a score of  $\geq 2$ ), and obtained similar results (not reported). In  
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21 sensitivity analyses, we also reran all analyses using a continuous score of economic  
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23 vulnerability, although some estimates are unstable or missing due to limited sample size; results  
24  
25 are reported below. Finally, we created a categorical variable indicating economic vulnerability  
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27 levels: score of 0 to 1, 2 to 3, and 4 to 7, with 0 to 1 as the reference category that is used in some  
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29 analyses as a predictor variable.  
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37 Next, we created two measures representing caregiver health. First, we assessed  
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39 emotional health (Schulz & Sherwood, 2008) using the Kessler K6 (range of 0-24), a short  
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41 screening scale used to monitor the prevalence of psychological distress in a general population  
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43 (Kessler et al., 2002). We created a dichotomous indicator for whether individuals were seriously  
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45 emotionally distressed (score  $> 12$  on the K6) (Hoffman & Mendez-Luck, 2011). Second, we  
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47 used a previously developed dichotomous indicator of overall unhealthy behavior (Hoffman et  
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49 al., 2012), which comprised four health behaviors: (1) current smoker, (2) ate fast food more  
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51 than once per week, (3) drank soda more than 3.5 times per week, and (4) demonstrated  
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3 sedentary physical behavior. We identified individuals as having overall unhealthy behavior if  
4 they had  $\geq 2$  of these four unhealthy behaviors.  
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### 7 8 *Predictor Variables* 9

10 We compared economic and health characteristics of two groups of informal caregivers.  
11 To account for factors that could confound the observed relationships between the two outcomes  
12 and the informal caregiver groups, we adjusted for socioeconomic and health characteristics. The  
13 socioeconomic factors we controlled for were age ( $\geq 18$ , continuous), gender, race/ethnicity (non-  
14 Hispanic White, African-American, Hispanic, Asian/Pacific Islander, and Other) and educational  
15 level (less than high school, high school, some college, college, and MA/MS/PhD). Functional  
16 limitations and therefore caregiving demand among older adults vary considerably by age as well  
17 as racial/ethnic status (Institute of Medicine, 2016). We also considered race/ethnicity and  
18 educational level as proxies for cultural caregiving-related preferences, which impact decisions  
19 regarding family caregiving support (Dilworth-Anderson, Williams, & Gibson, 2002) and  
20 because demand for caregiving varies by socioeconomic status (Institute of Medicine, 2016).  
21 Because the presence of a spouse as well as an individual's geographic location and  
22 neighborhood environment affect the availability of informal care and demand for services  
23 (Institute of Medicine, 2016; Pinquart & Sorenson, 2011), we also controlled for marital status  
24 and geographic location, which we measured as residency in an (1) urban, (2) smaller  
25 city/suburban area, and (3) town/rural area (UCLA CHPR, 2008). Given that the decision to  
26 provide care may be affected by health status (Do, Norton, Stearns, & Van Houtven, 2015), we  
27 additionally controlled for a set of caregiver health characteristic indicators: self-rated health  
28 status, history of heart disease, high blood pressure, asthma, and diabetes, whether a health  
29 condition limits basic physical activities, and body mass index.  
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### *Analysis*

We first provided survey-weighted unadjusted descriptive statistics and used T-tests and chi-square tests to identify statistically significant differences (at  $p < 0.05$ ) between informal caregiver populations. Next, we specified logistic regression models to assess the relationship between our three dichotomous outcome variables (economic vulnerability, serious emotional distress, and unhealthy behavior) on our indicator of informal caregiver status (Aim 1). For ease of interpretation, we computed predicted and marginal probabilities. Predicted probabilities are the sample average of the prediction of the outcome of interest when the regressor of interest is reset to a particular value while all other model covariates are kept at their observed values (Stata, 2013). The marginal risk is the difference in the predicted risk across the categories of the regressor of interest (e.g., across the PMC and UC caregiver categories). Next, we tested whether economic vulnerability was associated with the two health outcomes for all informal caregivers (both PMCs and UCs) and the two health outcomes, serious emotional distress and unhealthy behavior (Aim 2). To do so, we separately regressed each of the two health outcomes on the economic vulnerability score. Finally, we tested whether caregiver status (PMC/UC) moderated the relationship between economic vulnerability and the two health outcomes (Aim 3). To do so, we estimated two models which each included an interaction term between the vulnerability score and the informal caregiver category (PMC/UC). All models were specified with survey weights using the Jackknife method with 80 replications to account for the survey's complex sampling design.

### RESULTS

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3 *Unadjusted Results: Paid Medi-Cal Family/Friend Caregivers (PMCs) and Unpaid*  
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6 *Family/Friend Caregivers (UCs) (Table 1)*  
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8 Compared to nearly three-quarters of paid Medi-Cal caregivers (PMCs), just over half of  
9  
10 unpaid caregivers (UCs) were women. Only one-third of PMCs were non-Hispanic white  
11  
12 compared to over half of UCs. PMCs also had lower levels of education, were more often single  
13  
14 or divorced, and were in poorer health compared to UCs. Compared to UCs, PMCs also more  
15  
16 often reported living in poverty, being food insecure (28% vs. 15%), renting rather than owning a  
17  
18 home (46% vs. 32%), and having overall economic vulnerability (56% vs. 37%).  
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22 PMCs provided nearly twice the number of weekly care hours as UCs—44 hours (SD: 4)  
23  
24 vs. 20 (SD: 1) as well as total months of care that was provided to the care recipient—72 (SD: 6)  
25  
26 vs. 36 (SD: 1) (see Online Supplemental Appendix's Table S1). Compared to UCs, more PMCs  
27  
28 reported spending their own money on (59% vs. 46%) and living with their care recipient (62%  
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30 vs. 33%).  
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34 *Adjusted Results*  
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36 *Economic Outcomes, Serious Emotional Distress, Health Behaviors*  
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38 After adjustment for caregivers' sociodemographic and health characteristics, PMCs had  
39  
40 a 45% probability of economic vulnerability compared to a 36% probability for UCs (Table 2).  
41  
42 This amounted to a 27% higher ( $p=0.002$ ) adjusted probability of vulnerability among PMC  
43  
44 versus UCs. When measuring as a continuous score, the predicted economic vulnerability score  
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46 was 1.3 for UCs and 1.5 for PMCs but not statistically significant ( $p=0.08$ ) (Figure S2).  
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50 PMCs and UCs each had an adjusted 9% probability of serious distress—no relative  
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52 difference ( $p=0.91$ ) (Table 2). There were no significant differences in unhealthy behaviors  
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54 across the two family/friend caregiver groups (25% for PMCs and 20% for UCs,  $p=0.21$ ).  
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### *Economic Vulnerability and Health Outcomes Across All Family/Friend Caregivers*

Across all caregivers (PMCs and UCs), the probability of serious emotional distress increased at higher economic vulnerability levels. The predicted probability of distress for those with 4-7 vulnerability scores (15.2%) was more than double that of those with 0-1 vulnerability score (7.1%). Similarly, the predicted probability of unhealthy behaviors was nearly 50% greater for those with a 4-7 score (27.8%) compared to those with a 0-1 (18.4%) score (see Figure 2). Results were similar when economic vulnerability was measured as a continuous rather than dichotomous variable. For each increased unit of vulnerability, the marginal percentage-point increases in distress and unhealthy behavior were 2.0 ( $p<0.001$ ) and 2.2 ( $p=0.001$ ), respectively (Figure S3).

### *Economic Vulnerability and Health Outcomes by Family/Friend Caregiver Status*

Findings suggest that informal caregiver payment did not moderate the relationship between economic vulnerability and either of emotional distress or overall unhealthy behavior (Figure 3 and Table S2 in Supplemental Online Appendix). As shown in Table S2 and Figure S4, when measured continuously, economically vulnerability was significantly associated with emotional distress for UCs but not PMCs. However, interaction terms (interactions between economic vulnerability category and caregiver type) were not statistically significant in models assessing likelihoods of emotional distress or unhealthy behavior. Generally, we interpret these findings with caution given the large confidence intervals around the point estimates for the PMCs.

## DISCUSSION

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3 Our study showed that, while providing support to a group of physically vulnerable  
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6 Medi-Cal beneficiaries, paid informal caregivers experienced economic vulnerability. Over half  
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8 of paid informal caregivers of Medi-Cal beneficiaries had economic vulnerability and the  
9  
10 likelihood of economic vulnerability was 27% greater among paid informal caregivers compared  
11  
12 to unpaid informal caregivers. Such vulnerability reflected insecurity on a broad set of economic  
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14 measures including food insecurity, home ownership, health insurance coverage, and difficulties  
15  
16 accessing medical care and filling prescriptions. Nearly one in four paid informal caregivers had  
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18 two or more unhealthy behaviors, while at greater levels of economic vulnerability, paid  
19  
20 informal caregivers experienced increased risk of unhealthy behaviors.  
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24  
25 The observed economic vulnerability and unhealthy behaviors have implications for paid  
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27 informal caregivers' future health. Economically vulnerable individuals may experience a  
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29 cascade of unhealthy due to a confluence of economic and caregiving stressors. Limited  
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31 resources for self-care (Catalano et al., 2011) may put economically vulnerable caregivers at  
32  
33 heightened risk for chronic stress (Pearlin, 2010), which can result in future detriment to  
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35 emotional and physical health (Aina & Susman, 2006). Moreover, vulnerable paid informal  
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37 caregivers will experience the burdens of informal caregiving (Schulz & Sherwood, 2008).  
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41  
42 Paid informal caregivers' potential negative health outcomes may also compromise  
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44 consumer-driven programs. The Medicaid program's reliance on financially strapped and low-  
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46 income caregivers may result in quality of care issues—if caregivers' economic and health issues  
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48 affect the care that they provide (Hoffman & Wallace, 2012). At the same time, a reliance on  
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50 low-income providers could have downstream consequences for consumer-driven care. Current  
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52 paid informal caregivers not only represent a primary source of labor for consumer-driven  
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54 programs (Benjamin et al., 2008), but may become Medi-Cal beneficiaries who themselves will  
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3 require consumer-driven care in the future. In our sample, we observed that 10% of both  
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5 informal caregiver groups reported having serious emotional distress while 20% of paid informal  
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7 caregivers indicated that they were themselves Medi-Cal beneficiaries. Therefore, today's  
8  
9 consumer-driven caregivers represent both current and potential future users of Medi-Cal dollars.  
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12  
13 Policymakers have several options to address the economic vulnerability of Medi-Cal's  
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15 paid informal caregivers. First, wage increases for paid informal caregivers may prove  
16  
17 beneficial. Presently, California's consumer-driven caregivers do not receive pay for all of the  
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19 hours of care they provide (Benjamin & Matthias, 2004) given limitations on the total allowable  
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21 monthly service hours for paid informal caregivers (LAO, 2009). Because of this, nominal  
22  
23 hourly wages may not reflect wages received across total actual hours worked. In response to  
24  
25 wage pressures, several county-based IHSS programs have increased their contributions to IHSS  
26  
27 wages. Recently, California passed legislation that will gradually raise wages over time for its  
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29 IHSS workers (Barzar & Gorn, 2016). Other states might follow suit. Beyond wage increases,  
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31 policymakers might also expand monthly service hour thresholds for paid caregivers working  
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33 with beneficiaries who have the most time-consuming care needs.  
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39 Together, these wage-related changes may reduce economic insecurity and, further,  
40  
41 reduce turnover in the consumer-driven caregiver workforce. A prior study observed a 57%  
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43 decline in the job turnover rate among home care workers after implementation of a living wage  
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45 in San Francisco and, for each \$1 increase in the hourly wage rate, there was a 12-percentage  
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47 point increase in the probability of staying in the workforce for more than one year (Howes,  
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49 2004). Thus, a wage increase could reduce the high program turnover among consumer-driven  
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51 caregivers that has been previously observed (Benjamin et al., 2008; Hoffman & Wallace, 2012).  
52  
53 Moreover, a reduction in job turnover may positively impact emotional health among consumer-  
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3 driven caregivers (Catalano et al., 2011). Also, given that newer caregivers have less training and  
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5 familiarity with their care recipients, reduced turnover among caregivers might improve the  
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7 efficiency and quality of care provided in consumer-driven programs.  
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11 Finally, our findings suggest that policymakers might leverage consumer-driven  
12  
13 programs to further bolster the health of care recipients and paid informal caregivers. Innovative  
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15 consumer-driven programs address the economic vulnerability of informal caregivers (CAPA,  
16  
17 2012), but policy changes might improve downstream health outcomes for both members of the  
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19 program's caregiving-care recipient dyads. Medicaid might invest in paid informal caregivers  
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21 both directly—through higher wages and more paid service hours—and indirectly—through  
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23 improved case management, links to community social supports and services, and preventive  
24  
25 care for care recipients with long-term care needs. These care recipient supports might relieve  
26  
27 some of the caregiving burden for consumer-directed providers. Such an approach would also  
28  
29 align with the growing emphasis on family-centered care, in which care delivery takes into  
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31 account family relationships, joint decision-making, and care preferences of both patients and  
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33 their family members (IOM, 2016; C. A. Mendez-Luck, Amorim, & Anthony, 2016).  
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### 38 *Limitations*

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41 The study had several limitations. First, our consideration of paid Medi-Cal caregivers as  
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43 representative of California's IHSS caregivers may have involved some misclassification. Unlike  
44  
45 our paid Medi-Cal caregivers sample which includes just family member and friend caregivers,  
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47 IHSS caregivers additionally include individuals who are not family members or friends.  
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49 However, data on IHSS caregivers indicate a high degree of similarity between the total number  
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51 of family and friend caregivers in IHSS and paid Medi-Cal caregivers in our sample. When  
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53 extrapolated to the total California population in 2009, our sample's 475 paid Medi-Cal  
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3 caregivers represent statewide an estimated ~260,000 paid Medi-Cal caregivers—a nearly  
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5 identical amount when compared to the estimated number of family and friend IHSS caregivers.  
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8 Approximately 70% of 450,000, or 317,000, IHSS care recipients received care from a family  
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10 member or friend in 2014, and on average each of those family or friend caregivers provided  
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12 care to ~1.2 care recipients—totaling ~260,000 unique family or friend consumer-driven  
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14 caregivers (LAO, 2014). Second, given that opportunity costs of time can influence individuals'  
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16 decisions regarding caregiving and that socioeconomic and health factors may correlate with  
17  
18 opportunity costs (Do et al., 2015), our study may have selection bias. Although our  
19  
20 multivariable models controlled for socioeconomic and health characteristics, we cannot  
21  
22 conclude from our study that paid informal caregiving causes financial harm. Even accounting  
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24 for clear differences in socioeconomic and health factors, however, paid informal Medi-Cal  
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26 caregivers have greater risk of economic vulnerability than unpaid informal caregivers. Finally,  
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28 our economic vulnerability measure may overweight healthcare problems given items #4-7 (see  
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30 Methods above), which will most acutely affect individuals with the poorest health.  
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### 36 *Conclusion*

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39 Even as federal policies increasingly incentivize community-based as opposed to  
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41 institutional care, California's sociodemographically diverse caregivers for Medi-Cal  
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43 beneficiaries experience greater risk of economic vulnerability compared to other informal  
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45 caregivers. While caring for the most vulnerable Medi-Cal recipients, these paid caregivers  
46  
47 themselves exhibit vulnerability in their finances and health, with the most vulnerable among  
48  
49 them at substantially greater risk of unhealthy behaviors. While consumer-driven programs  
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51 appear to provide an innovative and useful framework for delivery of long-term services and  
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53 supports, policymakers may wish to address the vulnerability of its paid caregiver workforce.  
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3 Changes to provider compensation or service hour thresholds may in the long-term benefit the  
4 program's cost-effectiveness while strengthening the program's focus on both economic and  
5 health needs of caregiver-care recipient units—particularly among family caregiver-care  
6 recipient dyads who have the greatest economic and health risks.  
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For Peer Review

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Table 1. Weighted Sociodemographic, Health, and Economic Characteristics of Paid Medi-Cal and Unpaid California Informal Caregivers, 2009

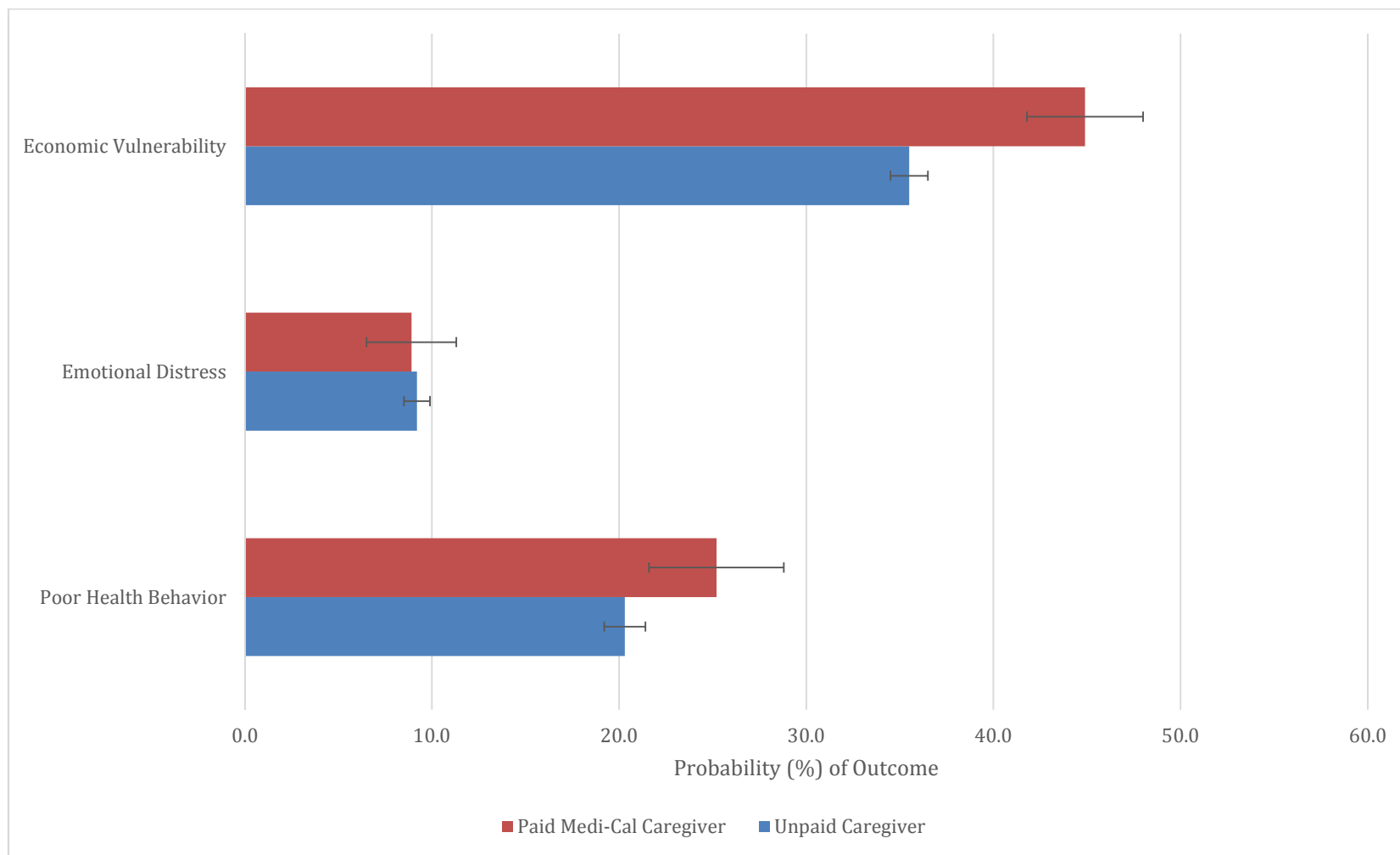
	Paid Medi-Cal Caregiver	Unpaid Caregiver
	Mean, SD / %	Mean, SD / %
Female*	72	56
Age (mean, SD)	46 (1)	46 (0)
Race*		
Hispanic	35	29
Black	15	6
White	32	53
Asian/PI	15	9
Education*		
< High school	22	11
High school	33	25
Some college	26	30
College	13	22
MA/MS/PhD	7	12
Married*	48	61
Health Status*		
Excellent/Very good	36	51
Good	35	31
Fair/poor	29	18
Activity Limitations	22	18
<b>Economic Characteristics</b>		
Income Below 100% FPL*	24	14
Food Insecure <sup>a*</sup>	28	15
Currently Uninsured*	27	18
No Usual Source of Care	18	16
Rents Home*	46	32
Delay Prescription Due to Cost	17	13
Delay Care Due to Cost	25	22

	Paid Medi-Cal Caregiver	Unpaid Caregiver
	Mean, SD / %	Mean, SD / %
Economically Vulnerable Index*	56	37
<b>Health Behaviors and Distress</b>		
Smoking*	26	16
Sedentary Behavior	81	77
Fast Food	69	65
Soda	27	21
Unhealthy Behavior Index*	29	20
Serious Emotional Distress	12	9

\*  $p < 0.05$

<sup>a</sup> Measured for individuals at  $\leq 200\%$  FPL.

Figure 1. Probabilities and 95% Confidence Intervals of Economic Vulnerability, Serious Emotional Distress, and Unhealthy Behavior by Status of Caregiver among California Informal Caregivers, 2009



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Figure 2. Probabilities and 95% Confidence Intervals of Serious Emotional Distress and Unhealthy Behavior by Economic Vulnerability Level among California Informal Caregivers, 2009

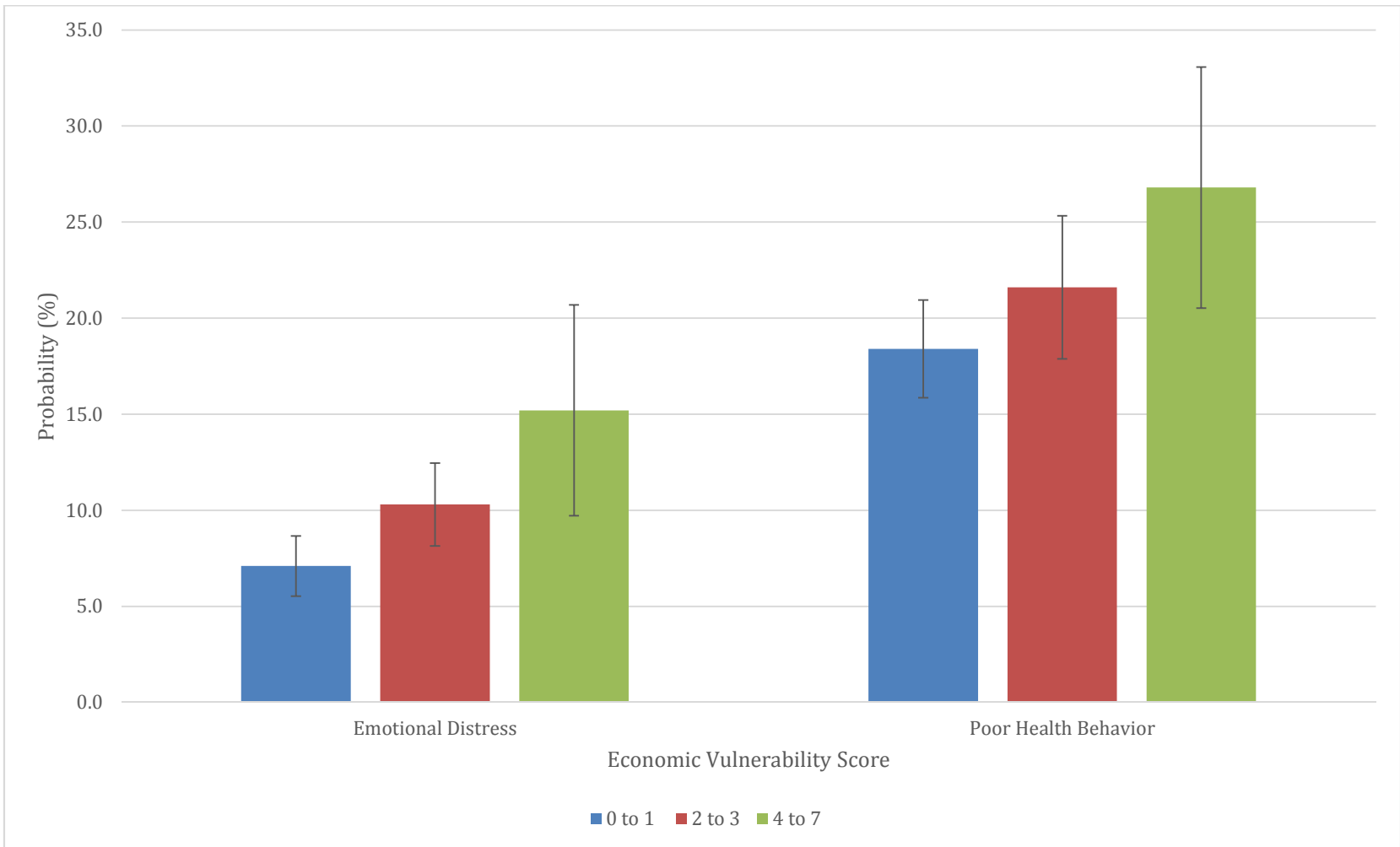
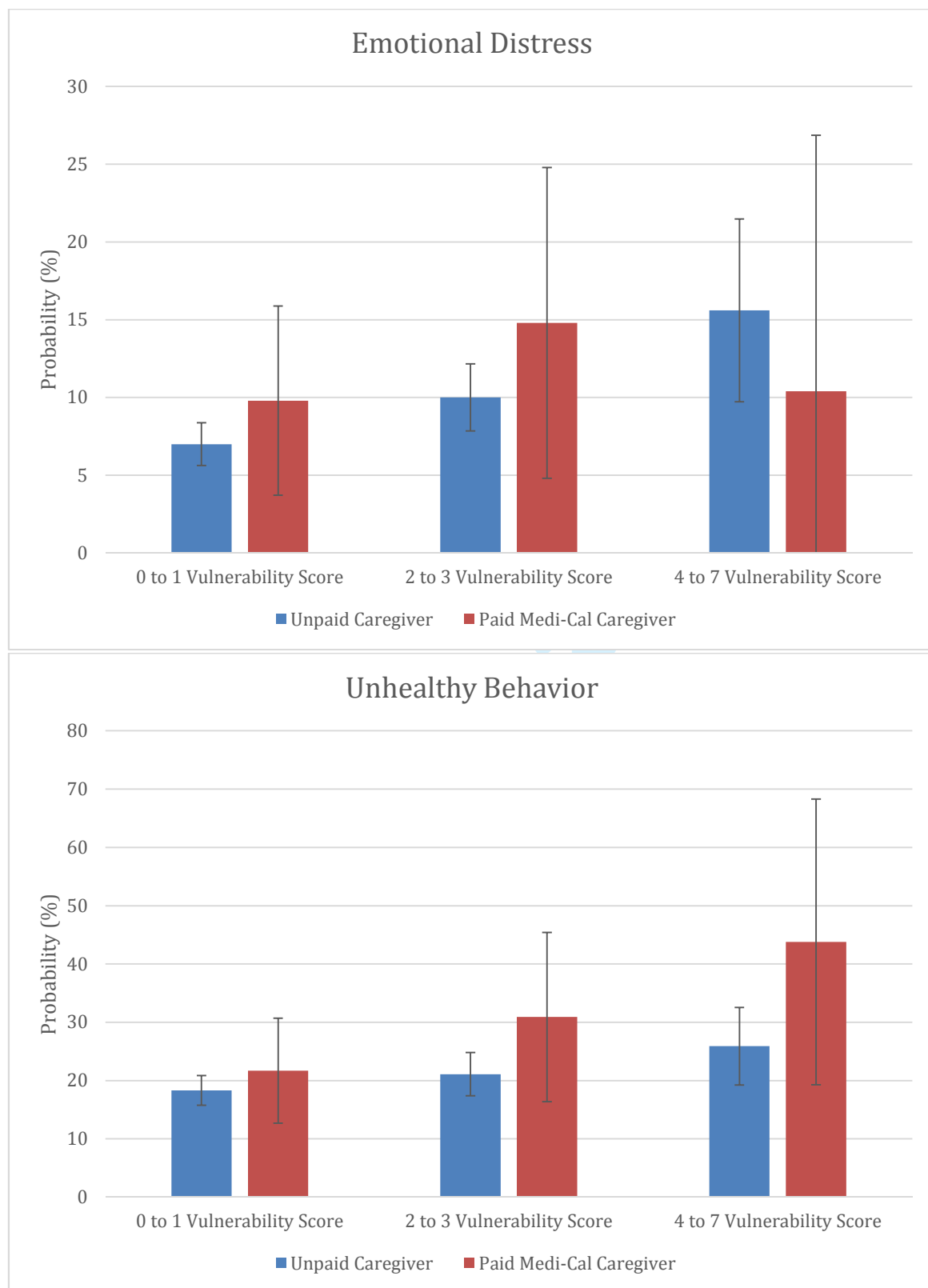


Figure 3. Probabilities and 95% Confidence Intervals of Serious Emotional Distress and Unhealthy Behavior among California Unpaid Informal and Paid Medi-Cal Caregivers by Level of Economic Vulnerability, 2009



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Figure S1. Sample Derivation: Paid Medi-Cal Caregivers Ages ≥18 years and Unpaid Caregivers in 2009 California Health Interview

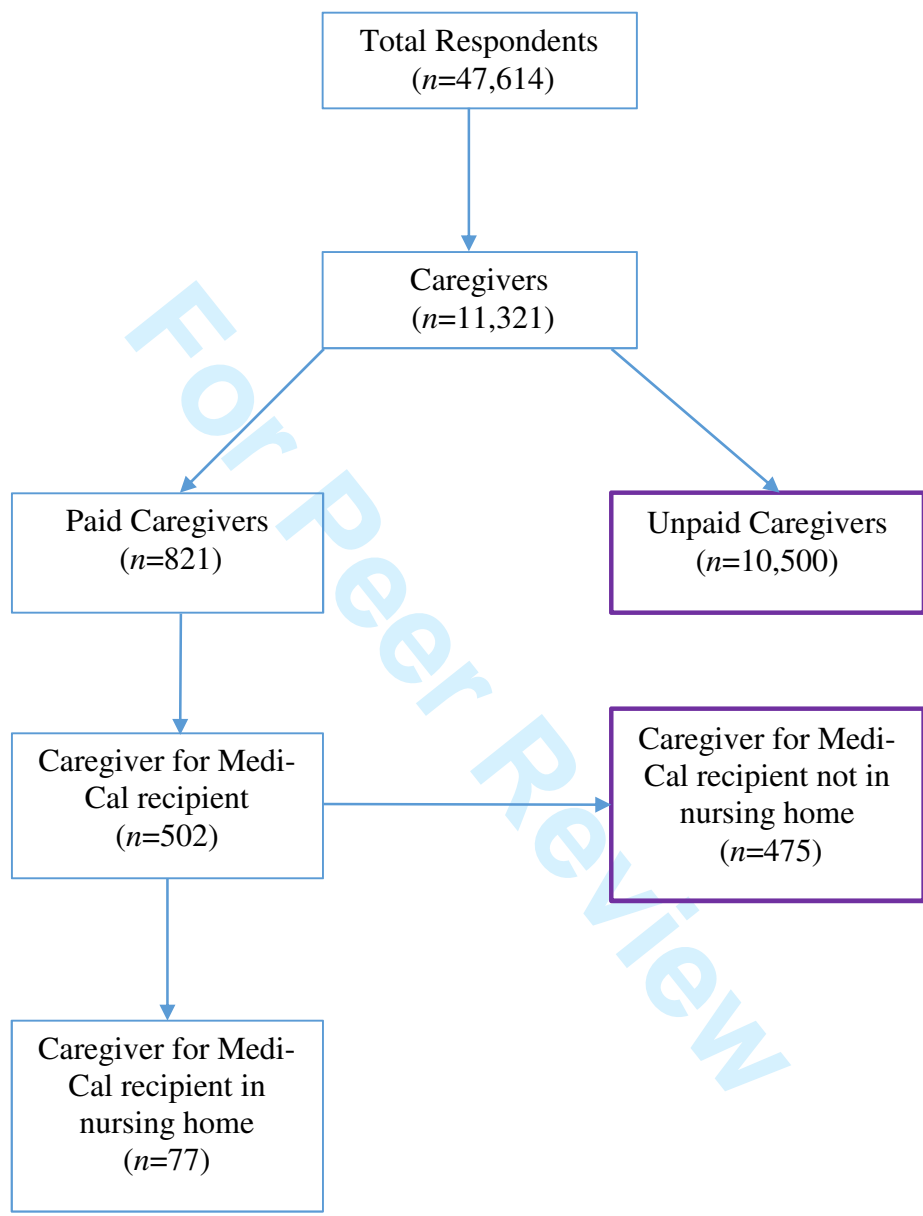


Table S1. Weighted unadjusted Caregiving Characteristics of Paid and Unpaid California Family and Friend Caregivers, Ages  $\geq 18$ , 2009

	Paid Medi-Cal Caregiver <i>n</i> =475 Mean, SD / %	Unpaid Caregiver <i>n</i> =10,500 Mean, SD / %
No. of Care Recipients		
1	66	65
2	23	23
$\geq 3$	11	12
Weekly Care Hours Provided (mean, SD) *	44 (4)	20 (1)
Months of Care Provided (mean, SD) *	72 (6)	36 (1)
Recipient Receives Medicaid*	100	37
Ever Used Respite Care*	24	13
Help if Respite Not Available*	74	83
Own Money Spent on Recipient*		
None	41	54
\$1-1000	55	42
>\$1,000	4	4
Provided Care >3 Months*	95	68
Relationship to Care Recipient		
Partner/Spouse	8	9
Parents/In-Laws	34	41
Other Relatives	35	29
Friends/Neighbors	24	21
Lives With Care Recipient*	62	33
Received Medicaid Training*	17	2

\*  $p < 0.05$



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Figure S2. Probabilities and 95% Confidence Intervals of Economic Vulnerability Score by Status of Caregiver among California Informal Caregivers, 2009

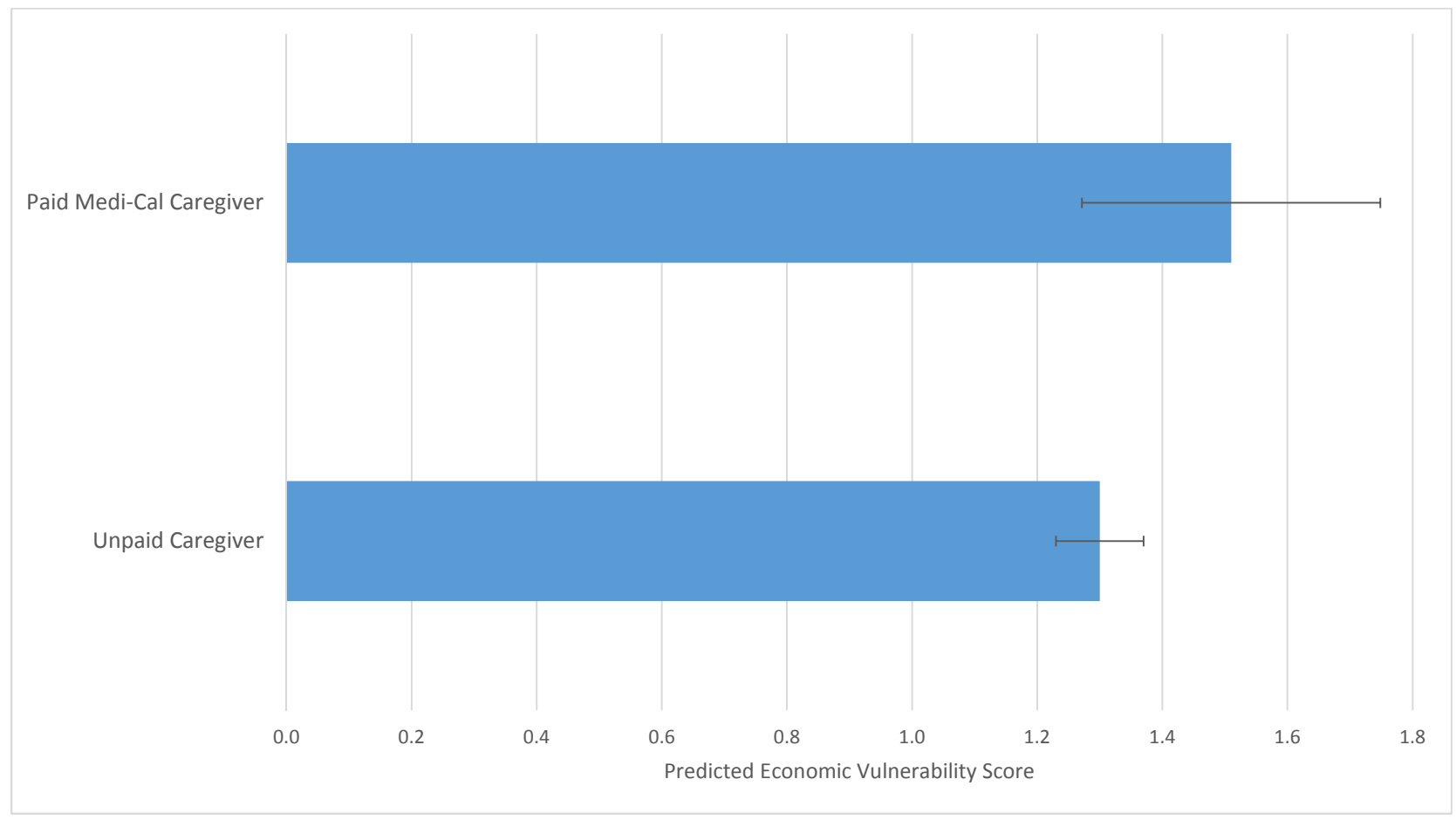
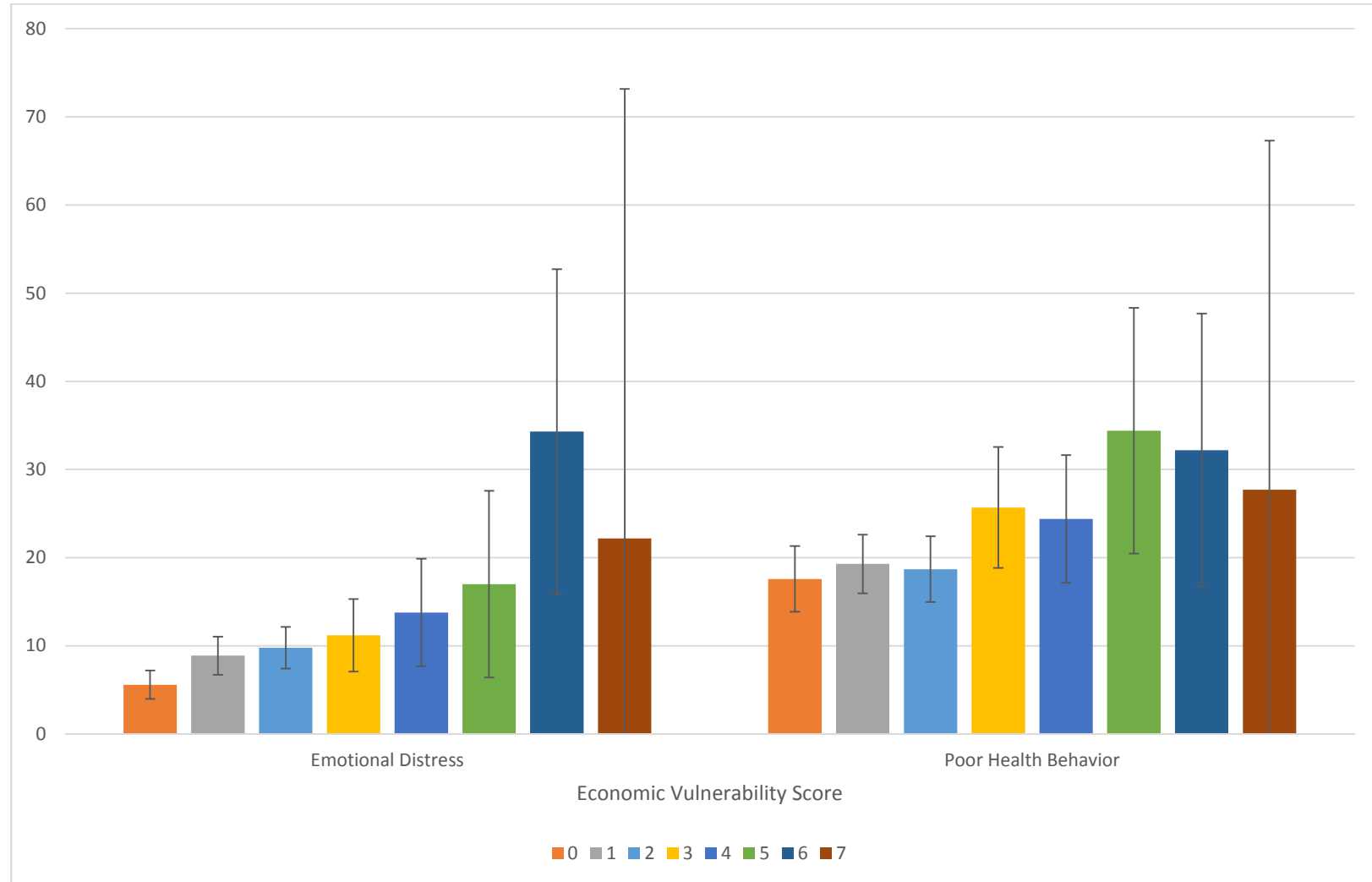


Figure S3. Probabilities and 95% Confidence Intervals of Serious Emotional Distress and Unhealthy Behavior by Economic Vulnerability Score among California Informal Caregivers, 2009



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Table S2. Predicted Risk and Marginal Risk Differences of Poor Health Behavior and Serious Emotional Distress at Each Level of Economic Vulnerability among Paid and Unpaid California Family and Friend Caregivers, Ages ≥18, 2009

		Economic Vulnerability Score								Marginal Risk Difference	
		0	1	2	3	4	5	6	7	Coef.	<i>p</i>
Unhealthy Behavior											
	Unpaid Caregiver	17.6	19.0	17.6	25.8	24.1	31.3	35.9	27.1	2.1	0.003
	Paid Medi-Cal Caregiver	16.2	26.6	34.0	26.4	31.6	65.9	1.5	—	4.2	0.04
Serious Emotional Distress											
	Unpaid Caregiver	5.3	9.0	9.4	11.2	14.1	17.9	36.6	21.8	2.1	<0.001
	Paid Medi-Cal Caregiver	14.5	5.4	17.0	12.0	7.3	13.5	10.7	—	0.1	1.00

Figure S4. Probabilities and 95% Confidence Intervals of Serious Emotional Distress and Unhealthy Behavior among California Unpaid Informal and Paid Medi-Cal Caregivers by Economic Vulnerability Score, 2009

