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# Mental Health and Exposure to Patient Distress Among Families of Nursing Home Residents with Advanced Dementia

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#### **Abstract**

**Context**—The effect of suffering among patients with advanced dementia on their family members' mental health has not been investigated.

**Objectives**—To describe family members' exposure to distressing symptoms among nursing home (NH) residents with advanced dementia and associations between such exposure and family member mental health.

**Methods**—Data were obtained from an 18-month prospective cohort study of NH residents with advanced dementia and their family member health care proxies (HCPs). Exposure to resident symptoms and associated fear and helplessness was measured quarterly using the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale (range 0–120). HCP mental health was assessed quarterly using the Composite International Diagnostic Interview Short Form (CIDI-SF) (depression), K6 (psychological distress, range, 0–24), and SF-12® mental health subscale.

**Results**—Seven hundred seventy-nine SCARED scale assessments were completed by 225 HCPs. The most frequent distressing symptoms were: feeling the resident had had enough (33.2%), choking (21.1%) and pain (18.9%). The symptoms eliciting the greatest fear were thinking the resident was dead and seeing them choke. A sense of helplessness was highest when the resident was observed to be in pain or choking. Family members with SCARED scores > 0 were more likely to meet criteria for depression on the CIDI-SF (adjusted odds ratio [AOR] 2.59, 95% confidence interval [CI] 1.14, 5.85), have a K6 score > 0 (AOR 2.31, 95% CI 1.55, 3.43) and have lower SF-12 scores (adjusted parameter estimate -1.51, 95% CI -2.56, -0.47).

**Conclusion**—Family member exposure to distressing symptoms experienced by their loved ones with advanced dementia is not uncommon and is associated with worse mental health.

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Disclosures The authors declare no conflicts of interest. AU: PLS CONFIRM THIS LAST SENTENCE IS ACCURATE.

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# Keywords

Dementia; caregivers; mental health; nursing home

#### Introduction

An emerging body of literature suggests that suffering among dying patients contributes to worse mental health among their family members, although the majority of this research has been conducted among families of patients with terminal cancer (1–5). Dementia is a leading cause of death in the U.S. (6) and close to 70% of dementia patients die in nursing homes (NHs) (7). However, little is known about how the suffering of NH residents with advanced dementia affects their family members.

Patients dying with dementia experience many of the same distressing symptoms as those with terminal cancer (e.g., pain, dyspnea) (8). However, there are distinctions in the course of advanced dementia that warrant specific examination of how patient suffering impacts family members. First, end-stage dementia patients are severely cognitively and physically impaired. Thus, the manifestation and ability to communicate the presence of symptoms may differ from cancer patients. Second, the time course of end-stage dementia is often protracted. Thus, families endure chronic exposure to their loved one's suffering and may have had prolonged roles as informal caregivers and surrogate decision makers, which may affect their reaction to patient symptoms. Finally, while the majority of cancer patients die at home or in hospitals, terminal care for dementia patients is most often provided in NHs (7), and prior reports suggests this care is often suboptimal (9–10).

No study known to us has rigorously examined the exposure of family members to the distressing symptoms experienced by their loved one with advanced dementia. Therefore, using data from a prospective study of NH residents with advanced dementia, the objectives of this report were to describe the type and frequency of distressing symptoms to which their family members are exposed, and to examine the associations between this exposure and the family members' mental health.

#### Methods

## **Study Population**

Participants were from the Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study, a prospective cohort study of NH residents with advanced dementia and their health care proxies (HCPs) (8,11). Residents were from 22 NHs within 60 miles of Boston having at least 60 beds. Eligibility criteria were: 1) age > 60; 2) dementia (any type); and 3) Global Deterioration Scale (GDS) (12) score of 7 (cannot recognize family, minimal verbal communication, total functional dependence, incontinence of urine and stool, inability to ambulate independently). Residents had to have a HCP who could provide informed consent and communicate in English. For these analyses, HCPs who were not family members were excluded (n=15). The institutional review board of Hebrew SeniorLife approved this study.

#### **Data Collection**

Resident assessments were conducted at baseline and quarterly using medical record reviews, nurse interviews and clinical examinations. HCP data were obtained at baseline and quarterly by telephone interviews. Resident and HCPs were followed for 18 months or until resident death.

## Health Care Proxy Experience of Distressing Resident Symptoms—HCP

exposure to resident symptoms was measured using the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale. (5) This 10-item scale measures the frequency and associated fear and helplessness experienced when observing the following symptoms: 1) feeling the resident has had enough; 2) inability to eat or swallow, or choking; 3) severe pain or discomfort; 4) confusion or delirium; 5) dehydration; 6) sleeplessness; 7) vomiting; 8) mistakenly thinking the resident was dead; 9) falling, collapsing or passing out; and 10) other distressing events. The SCARED scale had good internal consistency (Cronbach's alpha = 0.77) (5).

The SCARED scale was administered at quarterly assessments to HCPs who had seen the resident in the prior month. HCPs were asked how often over the past month they witnessed any of the symptoms, and frequency was rated on a 0–3 scale as follows: never (0); once or twice a month (1); every week (2); or every day (3). The degree to which each symptom evoked a sense of fear was recorded on a scale from 0–2 as follows: not frightened (0); somewhat frightened (1); very frightened (2). The degree of evoked helplessness was recorded on a scale from 0–2 as follows: not helpless (0); somewhat helpless (1); very helpless (2). To calculate an item score, frequency ratings were multiplied by the fear and helplessness scores and then summed (range 0–12). For these analyses, the total SCARED score (range 0–120) was dichotomized as 0 vs. greater than 0, as 59.7% of SCARED scores were equal to 0, indicating that the HCP either did not observe any resident symptoms or had no associated fear or helplessness.

**Mental Health Outcomes**—Mental health measures were collected at baseline and quarterly. The presence of depression was assessed using the Composite International Diagnostic Interview Short Form (CIDI-SF) (13), based on the Diagnostic and Statistical Manual of Mental Disorders, 3<sup>rd</sup> ed., diagnostic criteria for depression. The K6 (14) was used to measure psychological distress (Cronbach's alpha coefficient =0.89). This six-item instrument assesses depression, worthlessness, fatigue, nervousness, hopelessness, and psychomotor agitation (range 0–24, higher scores indicate greater distress). For these analyses, the K6 score was dichotomized as 0 vs. > 0 because of a skewed distribution. General mental health was measured using the SF-12® mental health subscale (15). The U.S. population normative mean for this scale is 50, with a standard deviation (SD) of 10 points; higher scores indicate better mental health.

**Other Variables**—Resident variables ascertained at baseline included age, gender and residence on a special care dementia unit. Resident variables obtained at quarterly assessments included: cognitive status, determined using the Test for Severe Impairment (TSI) (16) (range 0–24, lower scores indicate greater impairment, dichotomized as > 0 vs. 0); functional status as measured by the Bedford Alzheimer's Nursing Severity Subscale (BANS-S) (17) (range 7–28, higher scores indicate greater disability); resident comfort as quantified by the Symptom Management at End-Of-Life in Dementia scale (SM-EOLD) (18) (range 0–45, higher scores indicate greater comfort); hospice referral; and any acute illness in the prior 90 days (pneumonia, febrile episode, hip fracture, myocardial infarction, stroke, gastrointestinal bleed).

Baseline HCP variables included age, gender, race (white vs. other), education (college or greater vs. less), relationship to resident, antidepressant use and whether the HCP felt they understood the complications expected in advanced dementia. The HCP's relationship to the resident was dichotomized as spouse vs. other due to spouses being at greater risk of poorer mental health (19,20). Quarterly HCP variables included hours spent visiting the resident per week (four or greater vs. fewer), antidepressant use and whether the HCP believed the resident had at least six months to live.

#### **Analysis**

All analyses were conducted at the assessment level. To identify HCP and resident characteristics associated with SCARED scores over 0, bivariable analyses were conducted using *t*-tests for continuous variables and Chi-square tests for categorical variables. Multivariable logistic regression examined the adjusted association between HCP and resident characteristics with SCARED scores over 0. Independent variables associated at the level of *P*<0.1 with SCARED scores over 0 in unadjusted analyses were included in a multivariable model, which was adjusted for the NH using fixed effects and for repeated measures at the individual level using robust standard error estimates (21,22).

In the next analysis, a SCARED score greater than 0 was the main independent variable and the following mental health measures were examined as outcomes: CIDI-SF, K6, SF-12. The outcome measures were taken from the same quarterly assessment as the SCARED score. Fixed covariates were carried over from the baseline assessment (e.g., gender). Dynamic covariates (e.g., TSI score) were ascertained from the same assessment as the SCARED score. Logistic regression was used to examine the association between SCARED scores over 0 and the dichotomous outcomes of depression (CIDI-SF) and psychological distress (K6 score greater than 0). Linear regression was used to examine the association between SCARED scores over 0 and the continuous outcome of general mental health (SF-12). All independent variables associated with the mental health outcomes in unadjusted analysis at the level of P<0.1 were included in a multivariable model in addition to HCP age and sex. The baseline CIDI-SF score was included as an independent variable in the model examining CIDI-SF as an outcome. For the outcomes of K6 score and SF-12, the values of these scales measured at the assessment prior to that from which the SCARED score were included in the model. Robust standard error estimates were used to adjust for clustering due to repeated measurements among individual HCPs (21,22). Statistical analyses were performed using STATA SE version 10.0 (STATA Corporation, College Station, TX).

#### Results

#### Resident and HCP Characteristics

Of the 323 HCPs of residents with advanced dementia recruited into the CASCADE study, 308 were family members of the resident. Of these, a total of 49 residents survived less than three months from baseline; therefore, there were no quarterly interviews completed among the family members of these residents. Among the remaining 259 family members with at least one quarterly follow-up interview, 34 did not complete any SCARED scores because they had not seen the resident in the month prior to the follow-up interview. Thus, a remaining 225 family-member HCPs completed at least one SCARED score during the quarterly assessments. Overall, 779 SCARED scores were collected from these 225 HCPs. All subsequent analyses are based on these 779 assessments, with individual HCPs contributing multiple SCARED scores.

Residents and HCP characteristics on the 779 assessments are presented in Table 1. The mean resident age was 84.1 years,  $\pm 7.4$  (SD), 87.6% were female, and 44.0% lived on a special care dementia unit. The mean HCP age was 59.0 years,  $\pm 11.5$  (SD), 58.9% were female, 92.0% were white, 75.0% were college educated, and 12.1% were spouses of the resident (76.1% were children, 4.0% were siblings and 5.9% were nieces or nephews and 1.9% were other family). Comparisons between the HCPs in our analytic sample (n=225) and those excluded (n=98) revealed no statistical differences between all baseline characteristics presented in Table 1.

#### **SCARED Scores**

Among the total 779 SCARED scores, 314 (40.3%) were greater than 0. Of the 465 scores equal to 0, 304/465 (65.4%) were cases in which HCPs did not observe any resident symptoms, and 161/465 (34.6%) were cases where at least one symptom was observed but the HCP did not experience any fear or helplessness.

Individual SCARED item responses are displayed in Table 2. The most frequently observed symptoms were: feeling the resident had had enough (33.2%), observing the resident choking (21.1%), and severe pain or discomfort (18.9%). Among the cases where a symptom was observed, those that elicited the most fear were thinking the resident was dead (57.7), seeing the resident vomit (47.4), and seeing the resident unable to swallow (47.0). The symptoms that caused the greatest sense of helplessness were seeing the resident in pain (68.7), unable to swallow (67.1), and thinking the resident was dead (61.5).

**Factors Associated with SCARED Scores**—Table 1 presents the associations between resident and HCP characteristics and having a SCARED score over 0. In adjusted analysis, factors associated with SCARED scores over 0 were: greater HCP visitation (adjusted odds ratio [AOR] 1.95, 95% confidence interval [CI] 1.09, 3.51), and greater resident functional impairment (AOR 1.11, 95% CI 1.01, 1.22). Factors associated with lower odds of a SCARED score over 0 included greater resident comfort (AOR 0.96, 95% CI 0.93, 0.99), and the resident living on a special care dementia unit (AOR 0.39, 95% CI 0.21, 0.76).

In order to determine whether the relationships between these variables and SCARED scores over 0 were caused by more frequent exposure to distressing symptoms or greater evoked fear or helpfulness, we conducted separate logistic regression analyses examining the association between each of these variables and the components of the SCARED score (frequency of exposure, and a sense of fear or helplessness). HCPs who visited > 4 hours/week (P-value < 0.001) and whose loved one had lower comfort (SM-EOLD) (P-value < 0.001), were more likely to have had some exposure to distressing symptoms. Resident functional impairment and residing on a special care dementia unit were not associated with greater symptom exposure. Among those with at least some exposure, HCPs were more likely to experience fear and helplessness (score > 0) if the resident did not reside on a special care dementia unit (71.9% vs. 58.7%) (P=0.003). Frequency of visitation, resident comfort and functional impairment were not associated with greater fear and helplessness among HCPs who had at least some exposure to distressing events.

#### **Mental Health Outcomes**

Among the 779 quarterly assessments with SCARED scores, HCPs met the CIDI criteria for depression in 7.4% of assessments. The mean (SD) K6 score was  $2.76 \pm 3.46$ , with 490 (63.6%) having scores greater than 0, and the mean (SD) SF-12 mental health subscale score was  $51.31 \pm 9.31$ . HCPs with SCARED scores greater than 0 had worse mental health as quantified by all three outcome measures (Table 3). Compared to those with SCARED scores of 0, HCPs with scores greater than 0 were more likely to have depression (11.0 vs. 4.8%) (AOR 2.59, 95% CI 1.14-5.85) and K6 scores over 0 (76.2% vs. 55.1%) (AOR 2.31, 95% CI1.55-3.43) as well as lower mean SF-12 mental subscale scores indicating worse mental health (49.0 vs. 52.9), (adjusted parameter estimate -1.51, 95% CI -2.56, -0.47).

#### **Discussion**

This prospective study describes family members' exposure to distressing symptoms among NH residents with advanced dementia and demonstrates an association between these

exposures and worse mental health. Among the distressing symptoms measured, a sense that the resident had had enough, observing pain, and observing choking were most commonly experienced by family members. Fear and helplessness were highest when the family member observed the resident choking, in pain, vomiting and when the resident was thought to be dead. Stressful reactions to residents' distress were more likely among family member who visited more often, whose loved one suffered greater discomfort or worse functional impairment, and when care was not provided in a special care dementia unit. Family members who had stressful reactions to their loved ones' distress had higher levels of depression, psychological distress and worse general mental health compared to those who did not experience these events. These observations offer an opportunity to prepare families for the symptoms they are likely to observe in their loved ones with advanced dementia and identify those at greatest risk for adverse reactions to that exposure.

Family members of NH residents with advanced dementia experienced exposure to and distress from seeing their loved one in pain, although at a lower level than caregivers of terminal cancer patients (5). However, pain is common among patients with advanced dementia and is undertreated in the NH compared to the home care setting (8–10). Our findings underscore that adequate pain relief has important ramifications not only for patients, but also their families. The onset of eating problems often heralds the end of life in advanced dementia (8). Choking was more commonly observed among family members of patients with dementia than previously reported among cancer patients, although associated distress in reaction to this symptom was high in both (5).

Not surprisingly, greater exposure to distressing symptoms was associated with greater family visitation and lower resident comfort. Family members of residents not in special care dementia units did not observe more distressing symptoms, but did have greater fear and helplessness in reaction to their loved one's distress. Quality of care (23) and family satisfaction with care (24) is higher in special care dementia units. Our findings suggest that these units may not only do a better job of caring for residents, but also may help families prepare for and deal with distressing patient symptoms.

High quality end-of-life care, including palliative treatments, hospice and alleviation of pain is related to better mental health among the caregivers of patients with cancer (1–4). Studies from community settings document that patient behavioral disturbances (e.g., wandering), or greater perceived emotional distress are associated with anxiety and depression in dementia caregivers (25,26). Our study extends these finding, for the first time, to family members of NH residents with advanced dementia. Our results suggest that reducing resident discomfort may impact family members' stressful reactions to observing their loved one's distress and possibly also impact on their own mental health. Although treatment of pain in patients with dementia is complicated by difficulties in assessing symptom levels and response to treatment, a prior report from this cohort found that 39.1% of residents had pain at least five days per month, which indicates that the opportunity for treatment is frequent (8). The most common symptom, reported by one-third of family members, was the sense that the resident had had enough. NHs can potentially address this symptom and the sense of helplessness that it evokes through advance care planning to better align family members' perceptions of patient quality of life with the stated goals of care.

This study should be considered in light of certain limitations. First, the CASCADE study was limited to the Boston area and a mostly white and well-educated cohort, which may limit the generalizability of our findings. However, the facility and resident characteristics are comparable to similar cohorts nationwide (11). Secondly, the SCARED scale measures family members' report of their loved ones distress, rather than documented resident symptoms. However, validity of the SCARED scale is suggested by mean scores being

significantly higher during assessments where residents had lower comfort levels. This is the first paper to our knowledge to utilize the SCARED scale in a population of patients with advanced dementia; thus, we are unable to compare our results to other data from similar populations. In addition, as this scale was not developed specifically for patients with dementia, there may be some symptoms relevant to this population that are not included in the scale. We acknowledge that there may be unmeasured confounders, such as family member guilt, which may influence both the reaction to resident symptoms and family member mental health. Finally, although we cannot establish a cause and effect relationship between family members' stressful reactions to resident distress and mental health outcomes, the direction of this association (i.e., greater stressful reaction causes worse mental health) is strengthened by adjustment in the multivariable models for prior levels of mental health.

In the U.S., there are currently an estimated 5 million individuals suffering with dementia, a number expected to increase to 13 million by 2030 (27). The involvement of family members is critical to the care of these patients, even after institutionalization. This prospective study of NH residents with advanced dementia documents that family members experience fear and helplessness in reaction to exposure to resident symptoms, and that this exposure is associated with worse general mental health, increased psychological distress and depression. Our results suggest that improved palliative treatments and the provision of counseling to family members regarding the complications of advanced dementia may lessen family member distress and potentially decrease their risk for adverse mental health outcomes.

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Table 1

Characteristics of Nursing Home Residents with Advanced Dementia and Their Health Care Proxies, and Associations with Health Care Proxy SCARED Scale Scores Over 0a

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Characteristics	All Assessments ( <i>n</i> =779)	Assessme	Assessments Where		Adjusted Odds Ratio <sup>c</sup> (95% CI)
		<b>SCARED</b> = $0 (n = 465)$	SCARED > 0 $(n=314)$ P-value <sup>b</sup>	$P$ -value $^b$	
Resident					
Age in years, mean ± SD	84.1 (7.4)	84.5 (7.5)	83.6 (7.1)	0.08	0.97 (0.93, 1.01)
Female, n (%)	682 (87.6)	401 (86.2)	281 (89.5)	0.18	
Functional impairment (BANS-S) $^d$ mean $\pm$ SD	21.4 (2.2)	21.2 (2.2)	21.6 (2.1)	0.01	1.11 (1.01, 1.22)
Test for Severe Impairment $>0$ , $^e$ $_n$ (%)	117 (15.1)	72 (15.5)	45 (14.6)	0.73	
Special care dementia unit, $n$ (%)	343 (44.0)	221 (47.5)	122 (38.9)	0.02	0.39 (0.21, 0.76)
Referred to hospice, n (%)	61 (7.9)	31 (6.7)	30 (9.7)	0.13	
Acute illness in prior 90 days, $f_n$ (%)	204 (26.3)	115 (24.7)	89 (28.6)	0.23	
Comfort (SM-EOLD) <sup>g</sup>	37.7 (7.6)	38.4 (7.2)	36.6 (8.0)	<0.001	0.96 (0.93, 0.99)
Health Care Proxy					
Age in years, mean ± SD	59.0 (11.5)	60.5 (11.6)	56.8 (10.9)	<0.001	0.99 (0.96, 1.02)
Female, $n$ (%)	459 (58.9)	258 (55.5)	201 (64.0)	0.02	1.23 (0.72, 2.13)
Race, white vs. other, n (%)	717 (92.0)	423 (91.0)	294 (93.6)	0.18	
College education or greater, $n$ (%)	591 (75.9)	358 (77.0)	233 (74.2)	0.37	
Spouse of resident vs. not, $n$ (%)	94 (12.1)	69 (14.8)	25 (8.0)	<0.01	0.40 (0.13, 1.27)
Visits at least 4 hours per week, $n$ (%)	312 (40.1)	165 (35.5)	147 (46.8)	<0.01	1.95 (1.09, 3.51)
Understands complications of late dementia, n (%)	618 (81.2)	379 (84.0)	239 (77.1)	0.02	0.70 (0.37, 1.33)
Believes resident has at least 6 months to live, $n$ (%)	653 (87.3)	401 (90.1)	252 (83.2)	<0.01	0.67 (0.29, 1.52)

 $<sup>^</sup>a$ Analysis at the assessment level representing 225 health care proxies.

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b-tests for continuous variables, Chi-square test for categorical variables.

 $<sup>^{\</sup>rm c}{\rm Logistic}$  regression predicting SCARED over 0.

 $<sup>\</sup>frac{d}{d}$  Bedford Alzheimer's Nursing Severity Subscale (range 7–28, higher scores indicate greater disability).

 $<sup>^</sup>e$ Test for Severe Impairment (possible scores 0–24; lower scores indicate greater impairment).

 $<sup>^</sup>f$ Pneumonia, febrile episode, hip fracture, myocardial infarction, stroke, gastrointestinal bleed.

<sup>8</sup>Symptom Management at End-Of-Life in Dementia scale (range 0-45, higher scores indicate greater comfort).

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 $\label{eq:Table 2} \textbf{Exposure and Reaction of Health Care Proxies to Distressing Symptoms Experienced by Nursing Home Residents with Advanced Dementia^a$ 

Item on SCARED <sup>b</sup> Scale	No. (%) Exposed to Symptom <sup>c</sup>	No. (%) Reporting Fear <sup>d</sup>	No. (%) Reporting Helplessness <sup>d</sup>
Feeling resident has had enough	259/779 (33.2)	57/259 (22.0)	151/259 (58.3)
Unable to eat or swallow/choking	164/779 (21.1)	77/164 (47.0)	110/164 (67.1)
Severe pain or discomfort	147/779 (18.9)	58/147 (39.5)	101/147 (68.7)
Confusion, delirium	103/779 (13.2)	36/103 (35.0)	58/103 (56.3)
Dehydration	76/779 (9.8)	29/76 (38.2)	38/76 (50.0)
Other event	63/779 (8.9)	18/63 (28.6)	34/63 (54.0)
Insomnia/sleeplessness	42/779 (5.4)	6/42 (14.3)	20/42 (47.6)
Vomiting	38/779 (4.9)	18/38 (47.4)	19/38 (50.0)
Thought resident was dead	26/779 (3.3)	15/26 (57.7)	16/26 (61.5)
Falling, collapsing, passing-out	21/779 (2.7)	7/21 (33.3)	7/21 (33.3)

 $<sup>^{</sup>a}\mathrm{Based}$  on 779 SCARED scale scores collected quarterly over 18 months

 $<sup>^</sup>b\mathrm{Stressful}$  Caregiving Adult Reactions to Experiences of Dying (SCARED) scale

<sup>&</sup>lt;sup>c</sup>Frequency of symptom exposure over prior month reported as never, once or twice a month, every week, or every day. The data describe the proportion of assessments in which health care proxies reported having had at least some symptom exposure

dThe degree to which the HCP experienced fear or helplessness was reported as: none, somewhat, or very. The data describe the proportion of assessments in which the health care proxies reported being somewhat or very frightened/helpless (vs. none) among those exposed to each symptom

 Table 3

 Associations Between SCARED $^a$  Scale Score Over 0 and Mental Health Outcomes Among Health Care Proxies of Nursing Home Residents with Advanced Dementia

	SCARED = 0 n (%) or Mean (SD) Value	SCARED > 0 n (%) or Mean (SD) Value	Unadjusted <sup>b</sup> Parameter Estimate (95% CI)	Adjusted <sup>b,c</sup> Parameter Estimate (95% CI)
Depression (CIDI-SF) <sup>d</sup>	19/393 (4.8%)	30/273 (11.0%)	2.43 (1.34, 4.41)	2.59 (1.14, 5.85)
Psychological Distress (K6) <sup>e</sup>	253/459 (55.1%)	237/311 (76.2%)	2.61 (1.89, 3.59)	2.31 (1.55, 3.43)
General Mental Health (SF-12/) <sup>f</sup>	52.9 (8.50)	49.0 (9.98)	-3.83 (-5.14, -2.51)	-x1.51 (-2.56, -0.47)

<sup>&</sup>lt;sup>a</sup>Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale, dichotomized as 0 vs. > 0; higher scores indicate greater distress.

<sup>&</sup>lt;sup>b</sup>Depression and psychological distress outcomes modeled with logistic regression, parameter estimate is odds ratio. General Mental Health outcome modeled with linear regression, parameter estimate is beta coefficient.

<sup>&</sup>lt;sup>C</sup>Adjusted for: health care proxy age, sex, education (college or greater vs. less), relationship to resident (spouse vs. other), baseline antidepressant use, hours visiting resident per week ( $\geq 4$  vs. < 4), current antidepressant use, baseline depression (CIDI-SF outcome only), prior assessment K6 score (K6 outcome only), prior assessment SF-12 score (SF-12 outcome only), resident age, resident comfort (Symptom Management at End-Of-Life in Dementia scale) (CIDI-SF outcome only), and adjusted for clustering due to repeated measurements.

 $<sup>^</sup>d$ Short Form Composite International Diagnostic Interview (CIDI-SF), n=610.

 $<sup>^{</sup>e}$ K6, (range 0–24), higher scores indicating greater distress, dichotomized 0 vs. > 0, n=769.

fSF-12 mental health subscale, higher scores indicate better mental health, *n*=772.