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## Men as Caregivers at the End of Life

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### ABSTRACT

**Background:** Few studies have focused on men as caregivers at the end-of-life. The objective of this secondary data analysis was to examine the experiences of men involved in end-of-life caregiving, focusing on caregiver strain.

**Methods:** We used a random sample of Oregon death certificates to telephone survey family caregivers of Oregonians who had died 2 to 5 months earlier in private homes, nursing homes, and other community-based settings. Measurements included single-item indicators and embedded scales to measure caregiver strain and perceived decedent symptom distress. For the 25 husbands, sons, wives, and daughters who reported the highest levels of strain, we also analyzed caregivers' description of the decedent's last few days of life.

**Results:** The sample included 1384 caregiver interviews from a pool of 3048 death certificates. Men constituted 29% of the caregivers, including 15% sons, 9% husbands, and 5% others. In a linear regression model, male gender was a significant predictor of lower caregiver strain ( $p < 0.001$ ). The strongest predictor of high end-of-life caregiver strain was the severity of the decedents' symptom distress. The qualitative analysis revealed that men used fewer words than women did to describe their experiences, and, despite subsequently reporting the highest levels of caregiving strain, only 15% of men spontaneously mentioned their own struggles.

**Conclusions:** As caregivers at the end of life, men are less common and less likely to report caregiver strain and decedent symptom distress. Health care professionals should actively ask men about these issues and listen carefully, as their responses may be brief and understated.

### INTRODUCTION

**I**NCREASINGLY, patients are dying in nonhospital settings where families bear greater responsibility for end-of-life caregiving.<sup>1</sup> To provide effective end-of-life care outside the hospital, clin-

icians must work effectively with family caregivers.<sup>2</sup> For most patients, family members play critical roles, such as assisting with activities of daily living, administering medications, providing emotional support, participating in decision-making, dealing with finances, and communicat-

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ing with health care professionals.<sup>3</sup> Caring for a family member at the end of his or her life can be a very meaningful experience, but it can also be extraordinarily burdensome and result in severe physical and emotional health consequences for the caregiver.<sup>4-6</sup>

Because more women than men have traditionally taken on caregiving roles for ill family members,<sup>7,8</sup> much of the caregiving literature has focused on women. In three decades of family caregiving research, only a few studies have provided insight into the roles men play. Studies comparing relative contributions of each gender invariably find that men provide less personal care to family members and engage in less caregiving overall than women.<sup>9-12</sup> These studies tend to use men as a contrast group to show the additional challenges women face—most notably the consistent finding that women report higher levels of caregiving strain and distress than men.<sup>13-16</sup> While these comparisons are important, they may unintentionally marginalize the unique contributions of male caregivers and minimize the needs of men who play a lead role in caregiving.<sup>17</sup>

Another reason to focus on male caregivers is that they are at high risk of adverse health outcomes. Despite reporting lower levels of strain and distress, four decades of epidemiologic evidence show that bereaved males are at higher risk for death and other adverse health outcomes.<sup>18-27</sup> Male caregivers may also have higher risk for death prior to bereavement. A prospective cohort study of 819 male and female caregivers and matched noncaregiver controls found that caregivers were 63% more likely to die than controls. Prior to bereavement, male caregivers were still 88% more likely to die than female caregivers over 4.5 years of follow-up.<sup>28</sup>

Male caregivers are important in their own right. This paper focuses on a large sample of male caregivers from a statewide study of Oregon caregivers who cared for a family member in the last month of life.<sup>29</sup> We were particularly interested in whether or not men reported lower levels of caregiving strain in the context of end-of-life care and how their experiences compared to those of women.

## METHODS

This is a secondary analysis of data from a larger 69-question survey that addressed a spectrum of end-of-life care issues.<sup>29</sup> The methods for

the larger survey have been described in detail elsewhere.<sup>29,30</sup> In brief, we selected a systematic random sample of Oregon death certificates for deaths on a monthly basis from June 2000 to March 2002. Eligible decedents were Oregon residents 18 years or older who died from natural causes in community settings such as private homes, nursing homes or adult foster care. We selected 100% of eligible minority deaths occurring statewide during the study time frame ( $n = 779$ ) in order to have a large enough sample to make comparisons by race and ethnicity. For white decedents, we randomly selected 8% ( $n = 2,269$ ) of death certificates from 29,130 that met the inclusion criteria. Using previously reported case-finding methods,<sup>30</sup> we located family caregivers defined as individuals having a significant relationship to the patient, whether by blood, marriage, or other close affiliation. Eligible respondents were 18 years or older and self-identified as having primary or shared responsibility for patient care and/or decision making in the last 6 months of life. Telephone interviews were conducted 2 to 5 months (median = 130 days, range = 76-160) after a family member's death.

Study data consisted of information from death certificates and from family informants. Data from death certificates included decedent age, gender, race (classified as one of four mutually exclusive categories: White, Black, Asian-Pacific Islander, or Native American), ethnicity (Hispanic origin, regardless of race), death information (date, location, and cause of death), and next-of-kin name.

To characterize the relationship between the male caregivers and care recipients better, we initially analyzed the entire sample of caregivers. This larger sample ( $n = 1384$ ) included men and women, adult children, spouses, and smaller numbers of other self-identified "main" caregivers such as friends, siblings, and nonfamily members. Previous studies examining caregiver strain have illustrated the potential importance of distinguishing between the effects of gender and that of the caregiver's relationship to the care recipient (most commonly contrasting spouses and adult children).<sup>14</sup> For example, compared to spouses who care for one another, adult children who care for their parents would be expected to be (on average) younger, to have correspondingly fewer health problems, to be employed, to have childcare responsibilities, and to be more likely to live apart from care recipients. In order to dif-

ferentiate between the effects of gender versus relationship, we focused subsequent analyses on those caregivers ( $n = 1086$ ) who fell into one of four categories:

1. Husbands, including male partners.
2. Wives, including female partners.
3. Sons, including stepsons and sons-in-law.
4. Daughters, including stepdaughters and daughters-in-law.

In this smaller sample, caregiver strain was measured using five items excerpted from Robinson's Caregiver Strain Index assessing the presence (yes/no) of "physical drain," "emotional drain," "financial strain," "sleep disturbance," and "confinement."<sup>31</sup> Because distressing symptoms experienced by the dying relative are a major contributor to caregiver strain in end-of-life care, we also measured caregivers' perceptions of decedents' symptom burden using the Family Memorial Symptom Assessment Scale Generalized Distress Index (FMSAS-GDI). This is a validated adaptation of Portenoy's inventory of 10 common end-of-life symptoms and the degree of distress those symptoms cause the patient.<sup>32,33</sup>

We assessed univariate relationships using  $t$  tests and  $\chi^2$ , and linear regression to examine the effect of gender and relationship on caregiver strain. For the model, we initially included an interaction term to account for any interaction between gender and relationship, but excluded it after finding it nonsignificant. As covariates, we included variables that had been associated with caregiver strain in the parent study: cancer diagnosis, hospice enrollment, sharing caregiving duties, death at home (versus other community site such as a nursing home), and perceived decedent distress (the FMSAS-GDI).<sup>29</sup>

To look for differences between male and female caregivers that might help explain our results, we undertook a qualitative analysis of narrative data. Because we were primarily interested in the most distressed male caregivers, we selected the narratives for the 25 husbands and 25 sons who reported the greatest caregiver strain. We compared these to the narratives of the 25 wives and 25 daughters who reported the greatest caregiver strain. The narrative data consisted of caregivers' responses to an open-ended question asking them to describe "the decedent's last few days of life and what happened leading up to his/her death." Two investigators (E.F. and

L.D.) read each narrative independently and coded them using a low level of inference intended to simply catalog the issues that each respondent mentioned. Next, they combined their coding schemes and reorganized them into a unified, theme-based coding scheme. Two investigators (L.D. and S.T.) used this scheme to re-code the narratives with a third (E.F.) serving as "tie-breaker" for instances where the primary coders disagreed. At each stage, coders were blinded to any information about the gender and relationship of the respondent. Concurrence between the two primary coders was assessed through calculation of percent agreement and Cohen's  $\kappa$ .<sup>34</sup>

## RESULTS

The entire sample of all caregivers included 1384 caregiver interviews from a pool of 3048 death certificates for an absolute response rate of 45%. Of the remaining 1664 nonparticipants, 852 (51%) could not be located (Oregon death certificates include the name of the next of kin, but no other identifying information), 487 declined to participate or broke appointments (29%), and 325 (20%) were ineligible because of sudden death or absence of a family caregiver in end-of-life care.

Based on demographic information from death certificates, study decedents whose families participated and those who did not were similar in terms of gender and place of death, but not with respect to race, age, or level of education. Fewer families of Black, Hispanic, or Asian-Pacific Islander origin participated than did families of White decedents ( $\chi^2$ ,  $p < 0.001$  for each pair-wise comparison). Participation rates were the same for Whites and American Indians. Family members of decedents under age 65 were less likely to participate than families of older decedents ( $\chi^2$ , 45% versus 51%,  $p = 0.03$ ), as were families of decedents with less than a high school education versus families of persons with postbaccalaureate degrees ( $\chi^2$ , 41% versus 52%,  $p = 0.005$ ).

Consistent with prior studies, men were in the minority, constituting 29% of the caregivers, with 15% sons or sons-in-law, 9% husbands or unmarried partners, and 5% others (including brothers, brothers-in-law, friends, fathers, and other relatives). These results closely resemble the findings of caregiver studies not focused on end-of-life care<sup>35</sup> and the findings of a multistate end-of-life caregiving survey.<sup>7</sup>

TABLE 1. CHARACTERISTICS OF CAREGIVERS AND CARE RECEIVERS ( $n = 1086$ )

Characteristics	Husbands ( $n = 122$ )	Sons ( $n = 203$ )	Wives ( $n = 274$ )	Daughters ( $n = 487$ )
Respondent's mean age	70 years	55 years	69 years	55 years
Respondent was "main" caregiver (vs. sharing duties)	66.4%	43.8%	63.1%	48.3%
Respondent was nonwhite	6.6%	15.3%	11.7%	21.6%
Decedent's mean age at death	70 years	84 years	74 years	82 years
Decedent was nonwhite	15.6%	15.3%	14.2%	19.7%
Decedent died of cancer	57.4%	32.0%	52.2%	29.8%
Decedent enrolled in hospice	71.3%	63.1%	74.1%	64.1%
Decedent died of complications of dementia	9.8%	10.8%	4.4%	10.9%
Decedent died in a nursing home	21.3%	39.4%	23.4%	37.0%
Decedent died at home	68.9%	35.0%	71.5%	43.5%

### Focus on caregiver strain

As described in the methods section, we focused our final analysis on caregiving spouses and adult children in order to examine the effects of gender and relationship on end-of-life caregiving strain. Our final subset included 1086 respondents:

1. 122 husbands (11%).
2. 274 wives (25%).
3. 203 sons (17%).
4. 487 daughters (45%).

Table 1 shows demographic information for respondents and decedents divided according to their relationship. Male and female caregivers were compared for each characteristic, but the only statistically significant demographic difference between male and female caregivers was that the sample contained a higher percentage of female minority caregivers. These were evenly distributed among African American, Hispanic, Native American, Asian and multiracial subgroups. In contrast and as expected, demographic differences between adult child and spouse caregivers were more striking, with spouse caregivers being older (an average of 69 years versus 55 years for adult children,  $p < 0.001$ ), more likely to be the "main" caregiver versus sharing duties (64.1% versus 47%,  $p < 0.001$ ), and less likely to be an under-represented minority (7.3% versus 13.6%,  $p = 0.001$ ). The decedents cared for by spouses were younger (73 versus 83 years,  $p < 0.001$ ) and correspondingly less likely to die of dementia (6.1% versus 10.9%,  $p = 0.008$ ) and more likely to die of can-

cer (30.5% versus 53.8%,  $p < 0.001$ ). Decedents cared for by spouse caregivers were also much more likely to die at home (70.7% versus 41%,  $p < 0.001$ ).

### Caregiving strain

One of the main questions we were interested in was whether or not male caregivers would report lower levels of strain than female caregivers when providing end-of-life care. This was true: male caregivers reported significantly lower levels of caregiver strain (mean = 1.12 versus 1.53,  $t = -6.6$ ,  $p < 0.001$ ) than did female caregivers. We also asked caregivers to comment on the presence and severity of 10 common end-of-life symptoms using the FMSAS-GDI. The symptoms included sadness, worry, irritability, nervousness, lack of appetite, lack of energy, drowsiness, constipation, dry mouth, difficulty breathing, and pain. Similar to caregiver strain, men (as a group) also reported statistically significantly lower levels of decedent symptom distress, although wife caregivers actually reported lower distress scores than sons overall. The raw scores are reported in Table 2.

With other variables controlled in the linear regression model, male gender remained a significant predictor of lower caregiver strain ( $p < 0.001$ ). The complete model is shown in Table 3. The final model was significant ( $F_{8,847} = 20.8$ ,  $p < 0.001$ ) and accounted for 16.5% of the variance in caregiver strain (adjusted  $R^2 = 0.157$ ). The strongest predictor of high end-of-life caregiver strain was the severity of the decedents symptom distress followed by being female, not sharing caregiving duties, and not dying at home (e.g., in a nursing home or other nonhospital facility).

TABLE 2. COMPARING LEVELS OF CAREGIVER STRAIN AND PERCEIVED DECEDENT DISTRESS

Measure	Husbands (n = 122)	Sons (n = 203)	Wives (n = 274)	Daughters (n = 487)	p value for respondents' gender
Caregiver strain mean <sup>a</sup> [standard deviation]	1.17 [0.92]	1.10 [0.83]	1.42 [1.00]	1.60 [0.94]	
Male vs. female		1.12 [0.86]		1.53 [0.97]	p < .001
Decedent distress (GDI) <sup>b</sup> [standard deviation]	0.77 [0.63]	1.02 [0.80]	0.91 [0.71]	1.16 [0.82]	
Male vs. female		0.86 [0.68]		1.11 [0.78]	p < .001

<sup>a</sup>Caregiver's self-reported strain. Scores could range from 0 (lowest strain) to 4 (highest strain)

<sup>b</sup>Caregiver's perception of decedent symptom-related distress. Scores could range from 0 (lowest distress) to 4 (highest distress).

*Qualitative analysis*

In the qualitative analysis, the narratives of these 100 most "strained" caregivers (25 each of sons, husbands, daughters, and wives) yielded three major themes:

1. Men and women were similarly likely to mention patient symptoms and discomfort in their narrative descriptions of the last few days of the decedents' lives (e.g., pain, shortness of breath, vomiting) (38% of men versus 48% of women,  $p = 0.224$ , Fisher's exact test, 1-sided).
2. Men and women were similarly likely to mention hands-on care that they personally provided (e.g., lifting and bathing, managing medications, accompanying patient to doctor appointments). (32% of men versus 48% of women,  $p = 0.079$ ).
3. Men were significantly less likely than women to mention their personal strain or distress (e.g. being overwhelmed, upset, feeling helpless) (15% of men versus 36% of women,  $p =$

0.015, significant with Bonferroni correction for three comparisons).

Concurrence between the two coders was good, with 87% agreement and a Cohen's  $\kappa$  score of 0.723. We also noticed a difference in the length of responses with men's descriptions being typically shorter (an average of 85 words for husbands and 90 words for sons) than women's (an average of 119 words for wives and 127 words for daughters). On average, men used 28.7% fewer words than women.

**DISCUSSION**

Consistent with prior studies, we found that males constituted a smaller fraction of caregivers and reported lower levels of caregiving strain. Although daughters reported the highest levels of strain and sons the lowest, the relationship variable (spouse versus adult child) was not statisti-

TABLE 3. LINEAR REGRESSION MODEL FOR CAREGIVER STRAIN

Independent variables	Standardized coefficient Beta	Significance p
Caregiver was male	-0.142 <sup>a</sup>	<0.001
Caregiver was a spouse (vs. an adult child)	0.047	0.167
Caregiver shared caregiving duties	-0.104 <sup>a</sup>	0.001
Decedent's perceived symptom distress (FMSAS-GDI score)	0.336	<0.001
Decedent died at home	-0.087 <sup>a</sup>	0.016
Decedent died of dementia	0.003	0.934
Decedent died of cancer	0.005	0.879
Decedent was enrolled in hospice	0.052	0.144

<sup>a</sup>Variables with negative  $\beta$  coefficients predicted lower caregiver strain, and vice versa.

cally significant after other decedent and caregiver variables were controlled in the regression model. Caregivers who shared their responsibilities with others and who cared for the decedent at home (versus a nursing home or foster care facility) also reported lower levels of caregiving strain. We were surprised that male and female caregivers were equally likely to report sharing caregiving duties. Others who have studied the issue more closely have found that men are more likely to share caregiving duties with informal caregivers.<sup>7</sup> The finding that caregivers who provided care at home reported less strain could seem counterintuitive, but this survey was retrospective and may reflect the relief often reported by at-home caregivers after the person they are caring for dies.<sup>36,37</sup> In addition, caring for family members in nursing homes can present difficulties for family caregivers such as guilt, reduced contact, and loss of control.

It is important to note that the strongest predictor of greater end-of-life caregiving strain was the severity of the decedents' symptom distress, not gender. Although not explicitly measured by Robinson's Caregiving Strain Index, decedent symptom distress can profoundly disturb caregivers and worsen caregiving strain. Ferrell et al.'s studies of cancer pain patients and their caregivers found that caregivers experienced severe distress over feelings of helplessness, fears of addiction to pain medications, and relate issues.<sup>38</sup> These experiences may be more intense in end-of-life care.<sup>3</sup> Similarly, severe concomitant caregiver strain may influence how caregivers experience and remember decedent symptoms causing them to rate symptoms and distress higher.

Why is it that male caregivers also reported lower levels of decedent symptom distress? It is possible that the decedents cared for by men had fewer symptoms and less distress than those cared for by women, but a more likely explanation is that in the same way that men reported lower levels of caregiving strain for themselves, they also reported lower levels of symptom distress for decedents. This is consistent with the observation that men are less likely than women to attend to and express their emotions.<sup>39</sup>

Along the same lines, are male caregivers really less burdened by caring for dying family members or are they simply less likely to report it? In analyzing narrative data from the 100 most "strained" caregiving sons, daughters, husbands,

and wives, we found that men used fewer words than women in responding to our request to describe their loved ones' last few days. Despite this difference, men were similarly likely to spontaneously mention hands-on care that they provided to decedents and to discuss decedents' symptoms. Men rarely made voluntary disclosures about their own strain and distress out of their narratives. This is despite the fact that the sub-sample contained the men who, when specifically asked, had reported experiencing the highest levels of personal strain of the 325 male respondents. Male caregivers also rated the symptom distress of those they cared for lower than female caregivers did. This may have important implications for pain and symptom management in patients who can no longer communicate.

Health care professionals face special challenges in caring for and supporting husbands and sons who are experiencing high levels of caregiving strain. In particular, health care professionals should not assume that "everything is OK" for male caregivers—they should inquire specifically about caregiving burdens and how the caregiver is handling them. Our findings suggest that even when male caregivers are distressed, they may not mention their struggles unless asked.

#### *Suggestions for health care professionals*

Unfortunately, a direct question about caregiving strain may not be the most fruitful approach. Male caregivers in particular may resist openly acknowledging strain or difficulty coping, because they feel they must be strong and in command of the situation. Less direct questions that might be posed are:

- How much does helping your parent/loved one interfere with your work?
- Have you had to miss work in order to care for your loved one?
- Do you have financial concerns about the caretaking?
- How are you sleeping?
- What do you find that works really well as you care for your spouse/parent?
- What is the most difficult aspect?
- Where do you get rest or get away for a bit?

Similar to the caregiving literature, which has focused on women, research on use of caregiver

services such as support groups and individual counseling by men has also been limited. Because the majority of caregivers have been women, supportive services have been largely tailored to meet their needs. In addition, male caregivers may prefer the idea of family members providing care and be reluctant to turn to outside services, providers, or professionals.<sup>40,41</sup> A national survey of support group facilitators reported that one of the greatest deterrents to male participation was the generalized belief that men feel they should be able to manage their family responsibilities without assistance.<sup>42</sup> The facilitators also noted that for men, participation in support groups was often viewed as an admission of weakness and failure. Men who take on caregiving responsibilities also report a decreased likelihood of accepting community or government sponsored services.<sup>43</sup>

Kaye and Applegate<sup>44</sup> found that men cited several additional barriers to using professional services or support for their caregiving needs. The barriers include:

- A fear of appearing as though they are unfamiliar with their caregiving role;
- A reluctance to share personal feelings;
- Low participation of other males and a lack of identification with other caregivers;
- Lack of an apparent concrete benefit to participation; and
- A need to remain independent and strong in their caregiver role.

In an effort to increase utilization of caregiver services by men, Barusch<sup>45</sup> and Kaye<sup>46</sup> recommend giving some consideration to the following components when planning services:

- Engage men in the marketing aspects of new or expanded services (e.g., use men in outreach efforts, to provide testimonials, etc.);
- Have men actively participate, serve as leaders and participate in group decision making;
- Hold interventions in environments men would find comfortable;
- Design interventions to be informational rather than therapeutic; and
- Allow building relationship skills to be part of the intervention rather than its focus.

Men need encouragement to seek the opportunities and benefits afforded by supportive

services as they strive to provide care for family members at end-of-life. Practitioners and other family members need to be able to recognize the warning signs that a male caregiver is in need of help. Men should also be able to undertake this role without having to model the traditional female version. Health professionals need to carefully evaluate reports of pain and symptom distress severity, remembering that men may rate symptom distress lower than women do.

#### *Study strengths and limitations*

Strengths of this study were the use of state death certificates to achieve a large sampling frame including large numbers of husband and son caregivers. The random sampling approach avoided the selection bias of convenience sampling and allowed for the inclusion of decedents who had received little or no formal healthcare services. One limitation of this approach was that the retrospective nature of the survey introduces an element of recall bias. With 2–5 months having elapsed since the decedents' deaths, some respondents' objective and subjective recollections may have changed. Another limitation was that it excluded those who could not be located. And another was that the use of telephone interviews meant that caregivers without telephones or with hearing impairment, cognitive dysfunction, or language barriers could not be included. Although the overall participation rate was only 45%, the 72% participation rate of located, eligible caregivers is quite good given the sensitivity of the topic.

For the qualitative analysis, the caregivers were asked to describe the last few days of the decedents' lives—they were not asked directly about caregiver strain. It is very likely that more men would have discussed their personal difficulties had they been asked about them directly.

Despite these limitations, this study adds to the literature on end-of-life caregiving because of its relatively large, representative sample size and its focus on male caregivers. Because male caregivers are less common and less likely to report caregiver strain and decedent symptom distress, we recommend that health care professionals be proactive in inquiring about these issues and listen carefully, as their responses may be brief and understated.

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