# Caregiver–Oncologist Prognostic Concordance, Caregiver Mastery, and Caregiver Psychological Health and Quality of Life

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Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Prognostic concordance • Environmental mastery • Depressive symptoms • Caregivers • Older patients

### Abstract \_

**Background.** Caregivers of adults with cancer often report a different understanding of the patient's prognosis than the oncologist. We examine the associations of caregiver–oncologist prognostic concordance with caregiver depressive symptoms, distress, and quality of life (QoL). We also explore whether these relationships differed by caregiver environment mastery, an individual's sense of control, and effectiveness in managing life situations.

**Materials and Methods.** We used data from a national geriatric assessment cluster-randomized trial (URCC 13070) that recruited patients aged 70 years and older with incurable cancer considering any line of cancer treatment at community oncology practices, their caregivers, and their oncologists. At enrollment, caregivers and oncologists estimated the patient's prognosis (0–6 months, 7–12 months, 1–2 years, 2–5 years, and >5 years; identical responses were concordant). Caregivers completed the Ryff's environmental mastery at enrollment. At 4–6 weeks, caregivers completed

the Patient Health Questionnaire-2 (depressive symptoms), distress thermometer, and 12-Item Short-Form Health Survey (quality of life [QoL]). We used generalized estimating equations in models adjusted for covariates. We then assessed the moderation effect of caregiver mastery.

**Results.** Of 411 caregiver–oncologist dyads (mean age = 66.5 years), 369 provided responses and 28% were concordant. Prognostic concordance was associated with greater caregiver depressive symptoms ( $\beta$  = 0.30; p = .04) but not distress or QoL. A significant moderation effect for caregiver depressive symptoms was found between concordance and mastery (p = .01). Specifically, among caregivers with low mastery (below median), concordance was associated with greater depressive symptoms ( $\beta$  = 0.68; p = .003).

**Conclusions.** Caregiver–oncologist prognostic concordance was associated with caregiver depressive symptoms. We found a novel moderating effect of caregiver mastery on the relationship between concordance and caregiver depressive symptoms. **The Oncologist** 2021;26:310–317

**Implications for Practice:** Caregiver–oncologist prognostic concordance is associated with greater caregiver depressive symptoms, particularly in those with low caregiver mastery. When discussing prognosis with caregivers, physicians should be aware that prognostic understanding may affect caregiver psychological health and should assess their depressive symptoms. In

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addition, while promoting accurate prognostic understanding, physicians should also identify strengths and build resilience among caregivers.

#### **INTRODUCTION** \_

Caregivers play a crucial role in the care of older adults with cancer [1]. They assist patients with daily activities and help manage cancer- and treatment-related symptoms [1–3]. Caregivers are often involved in patients' decision-making throughout the cancer continuum from diagnosis to end-of-life, serving as important advocates [4, 5]. Therefore, it is imperative that caregivers have a good understanding of the patient's cancer prognosis.

Prior studies have demonstrated that 30%–55% of caregivers report a different understanding of the patient's treatment goal and prognosis compared with the patient's oncologist; most caregivers are more optimistic about the likelihood of cure than the oncologist [6–8]. Patients and caregivers need to have an accurate understanding of prognosis to help them make informed treatment decisions and prepare for the future [9, 10]. However, initial research in this area has shown that accurate prognostic understanding among patients with cancer correlates with worse patient-reported outcomes, including greater depressive and anxiety symptoms and worse quality of life (QoL) [11–15]. Studies have also demonstrated that accurate caregiver prognostic understanding is associated with greater caregiver depressive and anxiety symptoms [13, 16].

Caregiving for older adults with cancer can be demanding and lead to significant caregiving burden, distress, depression, anxiety, and poor QoL [17]. Caregiver environmental mastery, which is an individual's sense of control and effectiveness in managing life situations, reflects a caregiver's ability to cope, adjust, and adapt to problems [18, 19]. Individuals who report poor mastery, meaning they do not feel their life circumstances are controllable, are likely to feel particularly burdened by caregiving and experience greater depressive symptoms [18, Among caregivers of patients with cancer, greater mastery correlates with better caregiver health and less depressive symptoms [21, 22]. Among patients with advanced cancer, prior work has demonstrated that the use of certain coping strategies (i.e., greater use of positive reframing and active coping) moderated the relationship between accurate prognostic understanding and greater depressive symptoms [12]. However, the moderating effects of caregiver mastery on the association between caregiver prognostic understanding and psychological health is currently unknown.

In this study, we examined the association of caregiveroncologist concordance in their estimates of patient length of life with caregiver depressive symptoms, distress, and QoL. We also explored the moderating effects of caregiver mastery on these associations. We hypothesized that caregiver-oncologist concordance would be associated with greater caregiver depressive symptoms and distress, as well as lower QoL.

# **MATERIALS AND METHODS**

# Study Design, Participants, and Setting

This was secondary analysis of a nationwide geriatric assessment cluster-randomized controlled trial (URCC 13070,

NCT02107443; Principal Investigator: Mohile). We have previously reported the details of the study [7, 23-25]. The primary study evaluated whether providing geriatric assessment (GA) and GA-driven recommendations to patients, their caregivers, and their oncologists increased discussions about age-related concerns and improved patient and caregiver satisfaction. Inclusion criteria for patients were (a) aged 70 or older with incurable cancer (per the determination of the treating oncologist at the time of enrollment); (b) considering and/or receiving any line of cancer treatment; (c) had one or more impaired domain on geriatric assessment (other than polypharmacy; geriatric assessment domains and definitions of impairment have been reported previously [7, 23-25]); and (d) able to provide informed consent. One caregiver could enroll with each patient if the patient wished. Patients were asked: "Is there a family member, partner, friend, or caregiver (age 21 or older) with whom you discuss or who can be helpful in health-related matters."

A total of 31 community oncology practices in the United States and within the University of Rochester National Cancer Institute Community Oncology Research Program (NCORP) participated in this study and enrolled patients and caregivers between October 2014 and April 2017. The institutional review boards at the University of Rochester and at all the individual NCORP affiliate sites approved the study prior to enrollment of participants.

#### Measures

# Independent Variable: Caregiver–Oncologist Concordance in Estimates of Patient Length of Life

At enrollment, caregivers completed a paper questionnaire and were asked: "Considering the patient's health and underlying medical conditions, what would you estimate the patient's overall life expectancy to be?" Response options were 0–6 months, 7–12 months, 1–2 years, 2–5 years, and more than 5 years. We adapted this question from a previous study of seriously ill older patients (including those with cancer) and their caregivers [26]. Oncologists also completed a same assessment at enrollment. Caregivers and oncologists were considered concordant if they selected the same response option.

# Dependent Variables: Caregiver Depressive Symptoms, Distress, and QoL

Four to six weeks following enrollment, caregivers completed the Patient Health Questionnaire (PHQ)-2 depression screening tool [27] and distress thermometer [28], as well as the 12-Item Short-Form Health Survey (SF-12), which assesses QoL [29]. For the PHQ-2, caregivers were asked how often they have been bothered by the following problems: (a) little interest or pleasure in doing things and (b) feeling down, depressed, or hopeless. Each question was scored from 0 (not at all) to 3 (nearly every day), with a range of 0–6 and a higher score indicating greater depressive symptoms [27]. PHQ-2  $\geq$  2 was considered positive screening [27]. Caregiver



Figure 1. Flow diagram depicting the number of caregivers included in the secondary analysis.

distress was rated from 0 to 10, with a higher score indicating greater distress [28]. Distress  $\geq$ 4 was considered moderate in severity [28]. QoL was measured with the SF-12, which consists of physical and mental health subscales, with each subscale ranging from 0 to 100 and higher scores indicating better physical and mental health [29].

# Moderation Variable: Caregiver Environmental Mastery

Caregivers completed the Ryff's environmental mastery at enrollment [19]. Environmental mastery measures the capacity to cope, adjust, and adapt to problems. The subscale consists of seven statements: (a) In general, I feel I am in charge of the situation in which I live; (b) the demands of everyday life often get me down; (c) I do not fit very well with the people and the community around me; (d) I am guite good at managing many responsibilities of my daily life; (e) I often feel overwhelmed by my responsibilities; (f) I have difficulty arranging my life in a way that is satisfying to me; and (g) I have been able to build a home and a lifestyle for myself that is much to my liking. Options were strongly disagree, disagree, undecided, agree, and strongly agree. The total score ranges from 7 to 35 (question 2, 3, 5, and 6 were reverse scored), with a higher score indicating greater mastery [19]. The Cronbach's  $\alpha$  of Ryff's mastery was 0.76 in our study.

## Covariates

Covariates included caregiver demographics, patient cancer type (gastrointestinal, genitourinary, lung, or other), and study arm (geriatric assessment or usual care). Caregiver demographics were age, gender, education (some college or above, high school graduate, or less than high school), race (non-Hispanic white or other), annual household income (>  $$50,000, \leq $50,000$ , or decline to answer), and marital status (married or nonmarried).

## **Other Relevant Measures**

Caregivers were asked the extent they have discussed the patient's prognosis with the oncologist. Patient overall survival was captured by clinical research associates at individual practices.

## **Statistical Analyses**

We used descriptive analyses to summarize our study population and measures. We used a two-sample t test to evaluate caregiver depressive symptoms, distress, and QoL among concordant versus discordant dyads. We then conducted generalized estimating equation models to evaluate the associations of baseline concordance with caregiver depressive symptoms, distress, and QoL at 4-6 weeks, adjusting for caregiver demographic, patient cancer type, study arm, and accounting for practice sites. Subsequently, we assessed the moderation effect of caregiver mastery on these associations. We created an interaction term (concordance [1, concordance; 0: discordance] X mastery [continuous variable]) and included this term, along with both concordance and mastery as independent variables in the model. If the interaction term was significant, we performed analyses within the subgroups (i.e., higher [median or higher] vs. lower [less than median] caregiver mastery).

For sensitivity analyses, we divided baseline discordance into caregivers estimated a longer patient length of life and oncologists estimated a longer patient length of life. We repeated the generalized estimating equation models (concordance vs. caregivers estimated a longer patient length of life and concordance vs. oncologist estimated a longer patient length of life).

A two-sided p < .05 was considered to be statistically significant. We used SAS v.9.4 (SAS Institute Inc., Cary, NC) to perform all analyses.

# RESULTS

The primary study included 414 caregiver–oncologist dyads; 3 dyads were excluded because of missing all caregiver demographics (Fig. 1). Mean age of the 411 caregivers was 66.5 (SD, 12.5; range, 26–92) years. Three-quarters of the caregivers were female, and 90% were White. Approximately 64% of caregivers had some college education or above, and 43% had an annual household income >\$50,000. In terms of patient cancer type, lung cancer was the most common (26%), followed by gastrointestinal (23%), genitourinary (14%), and breast (11%). Other caregiver demographics are shown in Table 1.

# Caregiver–Oncologist Concordance in Estimates of Patient Length of Life

Among the 411 dyads, 371 caregivers and 408 oncologists provided estimates of patient length of life at enrollment (Fig. 2). A total of 369 caregiver–oncologist dyads provided estimates of patient length of life. Approximately 28% (n = 103) of the dyads were concordant in their estimates of patient length of life; 1% dyads estimated the length of life to be 0–6 months, 5% estimated it to be 7–12 months, 8% estimated it to be 1–2 years, 8% estimated it to be 2–5 years, and 7% it to be estimated >5 years. Among the discordant dyads (n = 266), 85% (n = 225) of caregivers estimated a longer patient length of life than the oncologists.

### Other Relevant Measures

Of the 396 caregivers that responded to the question "To what extent have you discussed the patient's prognosis with



 Table 1. Baseline characteristics of caregivers, patient cancer type, and study arm

Variables	Caregivers (n = 411)
Age, mean (SD, range), yr	66.5 (12.5–26–92)
Gender, %	
Male	101 (25.6)
Female	310 (75.4)
Marital status, <sup>a</sup> %	
Married	335 (81.5)
Other	76 (18.5)
Race, %	
Non-Hispanic White	369 (89.8)
Non-White	42 (10.2)
Education, %	
Some college or above	263 (64.0)
High school graduate	118 (28.7)
< High school	30 (7.3)
Annual household income, <sup>a</sup> %	
> \$50,000	178 (43.4)
≤ \$50,000	151 (36.8)
Decline to answer	81 (19.7)
Patient cancer type <sup>a</sup>	
Breast	44 (10.7)
Gastrointestinal	94 (22.9)
Genitourinary	58 (14.2)
Lung	105 (25.6)
Other	109 (26.6)
Study arm	
Intervention	229 (55.7)
Usual care	182 (44.3)

<sup>a</sup>One patient had missing data.

the cancer doctor," 31% (n = 123) reported "completely," 32% (n = 127) reported "mostly," 28% reported (n = 112) reported "a little," and 9% (n = 34) reported "not at all."

In terms of actual survival of patients with a caregiver enrolled (n = 399), 24% died between 0–6 months after enrollment, 22% died between 7–12 months, and 54% were alive beyond 1 year.

# **Caregiver Environmental Mastery**

At enrollment, the mean caregiver mastery score was 27.5 (SD, 4.6; range, 7–35; n = 395), higher than prior studies of cancer survivors [30] and caregivers of frail older adults [31]. Table 2 shows the distribution of the mastery subscale items. Approximately one quarter (22.4%) agreed or strongly agreed with the statement "the demands of every-day life often get me down." Similarly, 21.8% agreed or strongly agreed with the statement "I often feel overwhelmed by my responsibilities." Seventeen percent agreed or strongly agreed with the statement "I have difficulty arranging my life in a way that is satisfying to me."

## Caregiver Depressive Symptoms, Distress, and QoL

Four to six weeks after enrollment, mean PHQ-2 and distress scores were 0.65 (SD, 1.3; range, 0–6; n = 350) and 2.7 (SD, 2.6; range, 0–10; n = 347), respectively. Approximately 19% screened positive for depression (PHQ-2  $\geq$  2), and 32% reported moderate distress (distress  $\geq$ 4). For SF-12 (n = 349), mean physical health, mental health, and total scores were 46.7 (SD, 10.3; range, 15.7–64.7), 50.8 (SD, 10.0; range, 11.2–71.9), and 97.5 (SD, 14.1; range, 53.7–119.1), respectively.

# **Multivariate Analyses**

On multivariate analyses, caregiver–oncologist concordance in their estimates of patient length of life was associated with greater depressive symptoms ( $\beta$  = 0.30; p = .04). The



Figure 2. Distribution of caregiver and oncologist estimates of patient length of life.

Table 2. Distribution of the Ryff's environmental maste	ry su	bscale	e items
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ltems	Strongly disagree, %	Disagree, %	Undecided, %	Agree, %	Strongly agree, %
In general, I feel I am in charge of the situation in which I live <sup>a</sup>	3.6	5.6	11.7	47.7	31.5
The demands of everyday life often get me down <sup>a</sup>	24.9	38.8	14.0	21.1	1.3
l do not fit very well with the people and the community around me <sup>b</sup>	50.0	35.5	9.1	2.3	3.1
I am quite good at managing many responsibilities of my daily life <sup>b</sup>	3.0	2.8	3.8	48.6	41.8
l often feel overwhelmed by my responsibilities <sup>b</sup>	26.3	37.5	14.4	18.5	3.3
I have difficulty arranging my life in a way that is satisfying to me <sup>c</sup>	29.4	39.9	14.0	13.2	3.6
I have been able to build a home and a lifestyle for myself that is much to my liking <sup>b</sup>	4.1	5.1	11.9	46.7	32.2

<sup>a</sup>17 caregivers had missing data.

<sup>b</sup>16 caregivers had missing data.

<sup>c</sup>1 patient had missing data.

**Table 3.** Multivariate analyses evaluating associations of caregiver–oncologist concordance in estimates of patient length of life with depressive symptoms, distress, and quality of life

	Caregiver–oncologist concordance in estimates of patient length of life			n value for
Measures	Beta Estimate	SE	<i>p</i> value <sup>a</sup>	interaction
PHQ-2 ( <i>n</i> = 328)	0.30	0.14	.04	.02
Environmental mastery <28 (n = 146)	0.68	0.23	.003	
Environmental mastery $\geq$ 28 (n = 181)	-0.07	0.14	.63	
Distress (n = 326)	0.47	0.28	.10	.58
Environmental mastery <28 (n = 146)	0.49	0.35	.16	
Environmental mastery $\geq$ 28 ( <i>n</i> = 179)	0.24	0.31	.44	
SF-12 ( <i>n</i> = 327)	-3.21	0.90	.07	.65
Environmental mastery <28 (n = 146)	-2.43	2.72	.37	
Environmental mastery $\geq$ 28 (n = 180)	-2.89	1.98	.14	
SF-12 Physical Health (n = 327)	-1.43	1.10	.20	.27
Environmental mastery <28 (n = 146)	-0.33	5.96	.84	
Environmental mastery $\geq$ 28 (n = 180)	-2.10	1.49	.16	
SF-12 Mental Health (n = 327)	-1.66	1.31	.21	.70
Environmental mastery <28 (n = 146)	-2.09	1.89	.27	
Environmental mastery $\geq$ 28 (n = 180)	-0.79	1.42	.58	

All models were adjusted for caregiver age, gender, race, income, education, marital status, patient cancer type, and study arm, accounting for clustering at practice sites.

<sup>a</sup>Interaction term was not included in the model.

Abbreviations: PHQ-2, Patient Health Questionnaire-2; SF-12, 12-Item Short-Form Health Survey.

associations of concordance with distress ( $\beta = 0.47$ ; p = .10), physical health ( $\beta = -1.43$ ; p = .20), mental health ( $\beta = -1.66$ ; p = .21), and QoL ( $\beta = -3.21$ ; p = .07) were not statistically significant (Table 3).

# **Moderating Effect**

On sensitivity analyses, caregivers in the concordant dyads reported greater depressive symptoms compared with those who estimated a longer patient length of life than the oncologist ( $\beta = 0.32$ ; p = .05). Depressive symptoms were not different between caregivers in the concordant dyads and those who estimated a shorter patient length of life than the oncologist ( $\beta = 0.26$ ; p = .20).

A significant moderation effect was found between concordance and mastery for caregiver depressive symptoms (p = .02; Fig. 3). Among caregivers with low mastery (less than median), caregiver–oncologist concordance in estimates of patient length of life was associated with greater depressive symptoms ( $\beta = 0.68$ ; p = .003). Among caregivers with high mastery (at or above median), concordance was not associated with depressive symptoms ( $\beta = -0.07$ ; p = .63; Table 3). Mastery did not moderate the associations of concordance with distress and QoL.





Ryff's environmental mastery subscale total score (range 7-35, higher is better)

Figure 3. Moderation effect of mastery on the association between caregiver–oncologist concordance and caregiver depressive symptoms.

#### DISCUSSION

In this secondary analysis of a nationwide geriatric assessment cluster-randomized controlled trial, we found that caregiver–oncologist concordance in estimates of patient length of life was associated with greater caregiver depressive symptoms. We demonstrated that caregiver mastery moderated the association between caregiver–oncologist concordance and caregiver depressive symptoms. Specifically, we found that caregiver–oncologist concordance was associated with greater depressive symptoms among caregivers with low mastery but not among those with high mastery.

Prior studies have shown an association between accurate patient prognostic understanding and worse patientreported outcomes [11-15]. Data on these associations among caregivers, however, are limited. A prior crosssectional study of 167 caregivers of patients with advanced lung cancer in Japan showed that caregivers with an accurate understanding of prognosis had greater levels of anxiety and depression [13]. A separate longitudinal study by Loh et al. in the U.S. demonstrated that caregiver-oncologist concordance in beliefs about curability was associated with greater anxiety symptoms among 97 caregivers of adults with advanced cancers [16]. In this prior study, psychological health and QoL was assessed 7 months after the death of the patient, compared with the current study, which examined anxiety 4-6 weeks following enrollment of caregivers. Taken together, the findings from these studies emphasize the necessity of providing psychological and emotional support to caregivers, especially to those with an accurate understanding of the patient's poor prognosis. Of course, physicians should not be discouraged from disclosing accurate information regarding disease prognosis to patients and their caregivers. Prior studies have shown that most patients want to know about prognostic information [32], prognostic disclosures are not associated with worse patient-physician

relationships [33], and end-of-life discussions are associated with less aggressive care, which in turn is associated with lower depressive symptoms in bereaved caregivers [34]. It is important that oncologists tailor the amount and type of prognostic information and communicate these information to both patients and caregivers at the appropriate timing. When prognosis is disclosed, it is also important that oncologists facilitate referral to mental health or social work services, when appropriate.

Several previous studies have demonstrated associations of mastery with caregiver outcomes [21, 22, 35]. For example, Yeh et al. found that mastery was positively correlated with the health of caregivers of patients with cancer [35]. Greater mastery also correlates with lower depressive symptoms among caregivers of patients with cancer, although none of these studies focused exclusively on older adults with cancer [21, 22]. Nijboer et al. showed that mastery moderated associations between caregiver experiences and caregiver depression, such that caregivers who perceived caregiving in a negative way and reported lower mastery were more likely to experience greater depressive symptoms [22]. Among caregivers of older adults, greater mastery has been shown to correlate with lower caregiver burden and less anxiety and depressive symptoms [18]. Caregiver involvement is often more substantial in the care of older adults [24, 36], and caregivers generally receive very little training [37, 38]. Therefore, understanding how mastery is associated with caregiver outcomes among those caring for vulnerable older adults with cancer is important.

To the best of our knowledge, this study is the first to demonstrate the moderation effect of caregiver mastery on the association between caregiver–oncologist concordance and caregiver depressive symptoms. Successful management by caregivers of environmental factors and activities (physically, by being able to provide the needs of their loved ones, and mentally, by regulating their emotional responses to caregiving) may decrease the negative impact of prognostic concordance on their psychological health [39, 40], although this needs to be investigated further. Examples of interventions that have been shown to improve mastery of caregivers of patients with other illnesses included the use of telemonitoring system for heart failure symptoms at home with follow-up calls by an advance practice nurse and group programs focusing on problem-solving techniques simulation for caregivers of patients with dementia [41, 42]. These interventions could potentially be adapted for caregivers of older patients with cancer. In fact, electronic symptom monitoring has been shown to improve patient outcomes [43-45] and could be further studied in caregivers of these patients. Our findings also have implications for the development of interventions targeting both prognostic understanding and mastery among caregivers. One such example is palliative care interventions for caregivers [46]. In one study, palliative care improved prognostic understanding among patients with cancer [39], potentially through improving their coping skills [12, 47]. Future studies should investigate if palliative care interventions could improve prognostic understanding and mastery among caregivers of older patients with cancer and thereby help decrease caregiver depressive symptoms.

The strengths of our study include its large number of caregivers of older adults with advanced cancer recruited from a national sample of community oncology practices. Our study has several limitations. First, our caregivers were mostly non-Hispanic White and well-educated, and therefore, our results may not be generalizable to caregivers of other races and ethnicities and with lower education levels. Second, we excluded approximately one-eighth of the caregiver-oncologist dyads because they did not provide a response to the question on patient length of life estimates. Future studies should explore the characteristics of these individuals and reasons for why they refuse to answer the question on patient length of life estimates. Third, we lack information about the discussions of prognosis among the patients, caregivers, and oncologists in this study. We did not ask caregivers if it was helpful for them to discuss or know the patient's prognosis. Similarly, we did not ask oncologists if they had disclosed the patient's prognostic estimates to the patients or caregivers. Fourth, we cannot establish causality among prognostic understanding, mastery, and depressive symptoms. Finally, we did not adjust for multiple testing, given that this was an exploratory analysis.

#### CONCLUSION

We found that caregiver-oncologist concordance in patient length of life estimates was associated with greater caregiver depressive symptoms. Interestingly, we found that caregivermastery moderated this relationship, such that caregiveroncologist concordance was associated with greater depressive symptoms among those with lower mastery but not

#### **R**EFERENCES \_

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a need for additional research to further investigate how prognostic understanding might lead to depression among caregivers of patients with cancer, particularly those with low caregiver mastery. When discussing prognosis with caregivers, physicians should be aware that prognostic understanding may affect caregiver psychological health and assess their depressive symptoms. In addition, while promoting accurate prognostic understanding, physicians should also identify strengths and build resilience among caregivers.

among those with higher mastery. These findings underscore

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# DISCLOSURES

Kah Poh Loh: Pfizer, Seattle Genetics (C/A); Supriya Mohile: Carevive (RF). The other authors indicated no financial relationships. (C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honoraria received; (OI) Ownership interests; (IP) Intellectual property rights/ inventor/patent holder; (SAB) Scientific advisory board

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