

Variability in spousal perceptions of caregiving and its relationship to older caregiver health outcomes

Wesley B. Godfrey, MD¹, Jeremy B. Yorgason, PhD², Yue Zhang, PhD³, Bret L. Hicken, PhD⁴, Wei Chen, MS³, and Randall W. Rupper, MD, MPH^{3,5}

¹Department of Internal Medicine, The Ohio State University, Columbus, OH, USA; ²School of Family Life, Brigham Young University, Provo, UT, USA; ³Department of Internal Medicine, University of Utah, Salt Lake City, UT, USA; ⁴Salt Lake VA Office of Rural Health, Salt Lake City, UT, USA; ⁵Salt Lake VA GRECC, Salt Lake City, UT, USA.

BACKGROUND: The transition to later-life caregiving roles, especially for couples caring for each other, can be rife with ambiguity. The incident discordance in spousal perceptions of one another's role and its relationship to mental health outcomes have not been well-described.

OBJECTIVES: (1) To describe the range of daily agreement between older adult spouses' perceptions of care given and care received; (2) to explore associations between caregiving agreement and daily caregiver depression, anxiety, and marital satisfaction; and (3) to evaluate differential effects for male and female caregivers.

DESIGN: Cross-sectional, ecological assessment (daily diary).

PARTICIPANTS: Sample of 191 couples aged 60–64 (total 5196 daily surveys) drawn from the longitudinal Life and Family Legacies study.

MAIN MEASURES: During 2011–2012, spouses independently completed 14 consecutive daily surveys about their mood, marital interactions, and support exchanges. Caregiving agreement was defined as the daily ratio of spouse-reported care received to self-reported care given. Using generalized linear mixed effect modeling, we examined associations between spousal care agreement and outcomes of depression, anxiety, and marital satisfaction.

KEY RESULTS: Sample data demonstrated broad variability in spousal agreement, with couples exhibiting substantial disagreement on nearly one-third of couple days (780/2598 days). On days where care was exchanged, higher caregiving agreement was associated with lower caregiver depression ($p < 0.01$) and anxiety ($p < 0.01$) in male caregivers, and higher marital satisfaction ($p = 0.03$) in female caregivers. When care recipients reported receiving more support than their spouse reported giving, these associations did not persist.

CONCLUSIONS: Findings suggest that spousal agreement about the amount of care given and received varies broadly and is an important consideration for primary care providers who counsel these patients day-to-day. Furthermore, agreement appears to predict mental health and relationship outcomes and should be further evaluated in this growing population of mid-to-late life adults emerging into caregiving.

KEY WORDS: depression; caregiving; primary care.

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BACKGROUND

An estimated one in six US adults (16.6%) provides informal caregiving for another adult,¹ the equivalent of \$306 billion in US economic value.² More than 85% of caregivers care for someone age 50 or older, with an average care recipient age of 69.³ Furthermore, as caregiver age increases, the likelihood of caring for a spouse also rises (29%, age 65+ vs. 4%, age 15–64),⁴ yet neither qualitative nor quantitative data about spousal perceptions in assuming these roles is currently available.

Many individuals performing caregiving activities do not self-identify as caregivers.⁵ This discrepancy is important, because self-identifying as a caregiver is a key step toward seeking assistance.⁶ Indeed, because functional decline is usually progressive and compounding—especially in patients with specific neurocognitive disorders (e.g., Alzheimer's dementia)—caregivers often assume their responsibilities incrementally, blurring the transition from non-caregiving to caregiving.⁷ Moreover, the dynamic nature of functional impairment in early chronic illness can vary day-to-day,⁸ creating challenges for informal caregivers to recognize their role.⁹ Particularly among spousal caregivers, self-identification may be delayed due to this role ambiguity, with even high levels of daily assistance interpreted as an extension of spousal responsibilities rather than a caregiving role.^{10–12} While caregiving has long been established as a significant risk factor for emotional and relationship distress,^{13–15} the impact of caregiving without self-identification remains poorly understood.

Whether self-identified or not, caregivers and care recipients often have strikingly different perceptions of their own, and each other's caregiving roles. Caregiver-recipient agreement has been evaluated in multiple contexts—including symptom intensity, end-of-life care preferences, and pain management^{16–18}; however, absent data from both caregivers and care recipients, the degree to which agreement about caregiving roles predicts caregiver health outcomes cannot be determined. Biehle and Nielson

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in 2012 suggested that at least among young, married couples, one spouse's acknowledgment of receiving *emotional* support from the other is related to lower depression and anxiety in the supporting spouse (relative to couples where support is not acknowledged); yet, that study did not consider exchanges of practical support that are a characteristic of caregiving relationships.¹⁹ The current study focuses on spousal agreement about *practical* support given and received among older adult couples, and the potential impact of this agreement on health and marital outcomes.

Study aims include (1) to describe the range of daily agreement between older adult spouses' perceptions of care given and care received; (2) explore associations between caregiving agreement and daily caregiver depression, anxiety, and marital satisfaction; and (3) to evaluate differential effects for male and female caregivers.

METHODS

Regulatory approval

The Institutional Review Boards at Brigham Young University and the University of Utah approved this study.

Sample

Data were drawn from the Life and Family Legacies Daily Experiences Study (LFLDES), a branch of the Life and Family Legacies Study (LFLS), which followed 6729 high school graduates from Washington State, longitudinally, beginning in 1966.^{20, 21} Begun in 2011, the LFLDES component evaluated day-to-day interactions among a subset of couples from the LFLS sample, aiming to understand daily health behaviors, emotional health variability, and relationship outcomes for older adult couples. Married LFLDES participants were selected from the LFLS sample, using a random stratification procedure based on health (good vs. poor), rural vs. urban status, and veteran status (veteran vs. not). For a full description of sampling methods and selection protocol, see Yorgason et al. 2016.²²

Data Collection

Couples completed daily surveys, independent of one another, for 14 days (14 surveys each, 28 surveys per couple). Each survey was identical and included measures of caregiving, emotional health, and marital satisfaction. The sample response rate was 34.7%, with 191 couples providing analyzable data (surveys from three couples and from nine individuals could not be used due to missing information) and most couples reporting on all 14 survey days (5196 total surveys; 2.8% of daily surveys missing). Participants were 62.4 years old, on average (range = 60–64 years), and 9% ($n = 17$) self-identified as caregivers of another adult. Socioeconomic, education, and marriage data are described in Table 1.

Measures of Caregiving

Three caregiving variables were assessed for each survey day: (1) self-reported care *given* (i.e., practical support) to one's spouse; (2) self-reported care *received* from one's spouse; and (3) spousal *agreement* about the care exchanged on that day. Each study participant rated the intensity of practical support *given* and *received* during each day of the survey period using a 4-point Likert scale (0 = "Not at all"; 4 = "A lot").²³ As 91% of participants did not self-identify as caregivers, we did not designate a single "caregiver" or "care recipient" in each couple. Thus, a spouse could be a caregiver and/or care recipient on any given day based on their ratings of practical support given and received.

To quantify spousal agreement, we created a "Caregiving Agreement Ratio" (CAR) using paired spousal responses for each day. Mathematically, this ratio is care received by one spouse divided by care provided by the other spouse (Eq. 1).

$$\text{Caregiver Agreement Ratio (CAR)} = \frac{\text{care received (by one spouse)}}{\text{care provided (by the other spouse)}} \quad (1)$$

CAR values ranged from 0.0 to 4.0. A CAR of 0.0 represents a day where no care was given or received; 0.0 to 1.0 represents less care received than provided; 1.0 represents perfect agreement between care received and care provided; and greater than 1.0 represents more care received than provided. CAR was categorized into four quadrants representing states of agreement (Fig. 1). Quadrant A represents a day when a spouse reports receiving care while their partner did not report giving any care. The second and third predictors represent, respectively, situations where reported care given exceeded the care received (quadrant B), and where care received exceeded the care given (quadrant C). On days in quadrant D, no care was exchanged.

For example, if a wife rated her care for her husband as a 3, and her husband rated the care he received as a 1 on the same day, the CAR would be 1 divided by 3 ("received" divided by "provided") or 0.3, which would fall in quadrant C. Alternatively, if a husband reported giving 1 out of 4 points of care and his wife rated her care received at 2 out of 4, the CAR would be 2 divided by 1 (or 2.0) and would fall in quadrant B.

CAR values on either side of 1.0 (see bolded circles on diagonal, Fig. 1) represent fundamentally different caregiving situations. For CAR values < 1.0, increasing ratios approach 1.0 (perfect agreement). Alternatively, when CAR values are > 1, increasing ratios approach 4.0 (lack of agreement). Thus, perfect agreement itself (CAR = 1.0) was conceptualized to be the natural end point on the continuum of ratios < 1 as they approach agreement. Thus, we dichotomized daily CAR values as CAR ≤ 1.0 (quadrant C) and CAR > 1.0 (quadrant B) to

Table 1 Sample Characteristics and Baseline Caregiving Values

Primary Respondents ^a		Male (n=117, 61.3%)		Female (n=74, 38.7%)	
		Mean	SD	Mean	SD
Age (years)		61.5	0.7	61.4	0.8
Annual Income (in thousands)		87.8	43.6	90.9	43.1
		n	%	n	%
Marriage order	1 st Marriage	65	55.6	41	55.4
	2 nd Marriage	31	26.5	22	29.7
	3 rd Marriage	16	13.7	9	12.2
	Missing	5	4.3	2	2.7
Education	HS or less	18	15.5	10	13.5
	Undergraduate degree ^b	70	60.3	38	51.4
	Graduate Degree	28	23.9	24	32.4
	Missing	1	0.9	2	2.7
Chronic Conditions					
	Heart problems	21	17.9	9	12.2
	Cancer	15	12.8	13	17.6
	Stroke	3	2.6	1	1.4
	Diabetes	24	20.5	14	18.9
	Chronic lung disease	3	2.6	6	8.1
	Arthritis	37	31.6	29	39.2
All Subjects ^c		Male (n=191, 50%)		Female (n=191, 50%)	
		n	Mean (SD)	n	Mean (SD)
Care Received (self-report)		188 ^d	2 (1.3)	184 ^d	1.7 (1.2)
Care Given (self-report)		189	1.7 (1.3)	182	1.7 (1.2)
Caregiving Agreement Ratio (CAR)					
	CAR>1 (see Quad B, Fig 1)	34	2 (0.8)	57	2.1 (0.7)
	CAR≤1 (see Quad C, Fig 1)	103	0.6 (0.4)	87	0.6 (0.4)
	Care Received (spouse-report, see Quad A, Fig 1)	47	1.5 (1.2)	44	1.8 (1.3)
	Total CAR	184	1.1 (1.0)	188	1.3(1.0)

^a Those who participated in the 2010 wave of the Life and Family Legacies Study (LFLS), that is - no spousal information available for these indices

^b Or completion of some college

^c Primary respondents, as well as spousal information included

^d Variables with missing data were handled utilizing a maximum likelihood analysis native to SAS generalized mixed effect modeling. As such, days (rows) with missing data were excluded from the final analytic sample in each model, which explains the differences in final sample N values compared to the total sample of 191 couples from whom analyzable data were collected. SD= Standard deviation

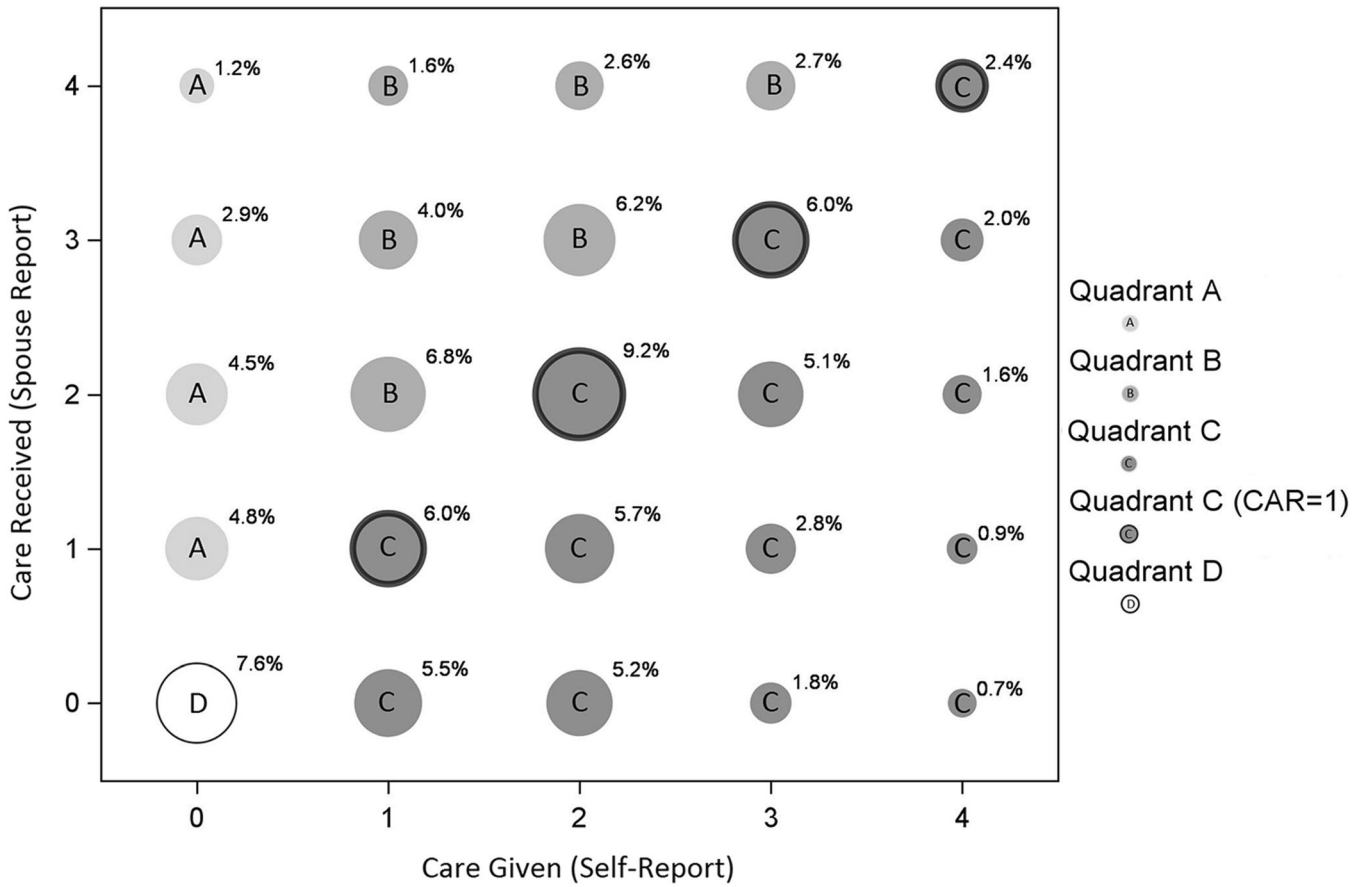


Figure 1 Distribution of spousal responses about care given and received over 14 days (percentages are relative to total couple days over 14-day study period (total of 5196 surveys). Bubble size is proportionate to count(percentage). Caregiver agreement ratio (CAR)=care received (by one spouse) divided by care given (by the other spouse). Quadrants represent CAR values, with encircled letters (A = care received, when no care is reported given by the other spouse; B = more care received than given; C = equal or more care given than received; and D = no care reported by either spouse). Perfect agreement is on diagonal, as represented by bolded outline of circles.

characterize the impact of agreement or disagreement on each couple survey day.

Health and Marital Outcomes

Depression/Anxiety. Measured using nine items from the Profile of Mood States (POMS): five depression items (sad, discouraged, unworthy, lonely, gloomy) and four anxiety items (tense, shaky, uneasy, nervous).²⁴ The anchors were modified from the original 7-point scale to a 5-point scale with responses ranging from 0 (“not at all”) to 4 (“extremely”). Subscale items were summed to create a daily measure of depression and anxiety.

Marital satisfaction. Measured using a modified scale from McNulty and Karney.²⁵ Respondents rated their satisfaction with their spouse/partner in the areas of division of household labor, emotional support, amount of time together, disagreements, conversations, affection, and dependability using a 0

(“very unsatisfied”) to 6 (“very satisfied”) scale. Items were summed to create a daily marital satisfaction score.

Statistical Analysis

Generalized linear mixed effect models estimated effects of daily care given, care received, and CAR on the primary outcomes. We employed sex-specific gamma regression (with log link functionality), and subject-level random effects to capture correlation among the repeated measures inherent to daily diaries. All models were adjusted for number of times married, income, and education among primary respondents (LFLS 2010 survey), as well as gender, as these factors are frequently important in evaluating caregiving experiences (see 1–2, 13). We also adjusted for daily diary date (before or after the first 4 days) when modeling depression and anxiety because of confounding with these two outcomes. Analyses used SAS 9.4 (SAS Institute, Inc., Cary, NC). The effects of care given and received on primary outcomes are described using

Table 2 Caregiving and Caregiving Agreement in Relation to Caregiver Health Outcomes

	Percent change ^a (<i>p</i> value)		
	Depression ^b	Anxiety ^b	Marital satisfaction ^b
Covariates			
Care received (self-report)	-0.99% (0.002)	0.31% (0.377)	3.61% (<0.001)
Care given (self-report)	0.35% (0.391)	0.20% (0.647)	1.48% (<0.001)
CAR > 1 (see Quad B, Fig. 1)	-2.45% (0.012)	-1.25% (0.245)	0.87% (0.248)
CAR ≤ 1 (see Quad C, Fig. 1)	-0.17% (0.796)	-1.21% (0.089)	0.66% (0.187)
Care received (spouse-report, see Quad A, Fig. 1)	-0.07% (0.894)	0.39% (0.517)	1.64% (<0.001)

^aPercent change on a given day relative to an individual's mean value over the 14-day study period

^bCaregiver outcomes relative to the caregiving spouses' self-reported measures of mood and marriage each day

percent change scores. Scores quantify change in caregiver outcomes on each survey day, relative to a one-unit increase in predictor variables beyond an individual caregiver's mean response over the 14-day period.

RESULTS

Variability in Couple Agreement

Sample characteristics from LFLS (2010) and caregiving measures at baseline (i.e., on survey day 1) are reported in Table 1. In reference to study aim 1, couple responses from across the 14-day study period yielded a wide range of agreement ratios (CAR). On 1819 (70%) couple days, couple responses about care given and received were relatively concordant (i.e., within one point on 0–4 scale). On 811 of these days, couple responses were in perfect agreement (see diagonal in quadrant C, Fig. 1). However, on nearly 1/3 of couple days (780 days), couple ratings about care were more discrepant (i.e., ≥ 2-point difference). These agreement data are represented proportionally (by count) relative to the total number of couple days in the study (2598 days) in Fig. 1.

Although agreement proportions did not differ by sex (not shown), some trends emerged in reports of giving and receiving of care. At baseline, husbands reported receiving more

care than they gave, and wives estimated that they gave the same amount of care as they received (Table 1). The mean baseline CAR for both husband and wife caregivers was 0.6 (quadrant C), suggesting that husbands and wives generally reported giving more care than their spouse reported receiving. Gender differences were also seen at the study outset. More wives had CAR > 1 (quadrant B) than their husbands (i.e., relative to men, women more often reported receiving more care than was reported given by their spouse at baseline). In contrast, quadrant A CAR values—discordant ratings where one spouse did not report giving any care while another spouse reported receiving care—did not differ meaningfully by sex.

Agreement on Health and Marital Outcomes

Regarding aims 2 and 3, analyses revealed that giving care to a spouse was related to higher marital satisfaction on that same day relative to persons' mean satisfaction level over the 14-day study period (Table 2). However, there was no difference in depression or anxiety in the same comparison. Caregiver sex did not moderate this association, as giving care to a spouse was linked to higher marital satisfaction for both females and males, though anxiety and depression remained unrelated to giving care for either sex (Table 3). In contrast, persons receiving care experienced lower daily depression and

Table 3 Caregiving and Caregiving Agreement in Relation to Caregiver Health Outcomes—Stratified by Sex

	Percent change ^a (<i>p</i> value)		
	Depression ^b	Anxiety ^b	Marital satisfaction ^b
Male spouses			
Care received (self-report)	-1.00% (0.030)	-0.27% (0.590)	4.36% (<0.001)
Care given (self-report)	0.40% (0.518)	-0.13% (0.841)	1.19% (0.008)
CAR > 1 (see Quad B, Fig. 1)	-0.02% (0.988)	-1.92% (0.100)	0.78% (0.320)
CAR ≤ 1 (see Quad C, Fig. 1)	-2.96% (0.048)	-3.34% (0.042)	-0.41% (0.709)
Care received (spouse-report, see Quad A, Fig. 1)	0.46% (0.589)	0.37% (0.689)	1.51% (0.016)
Female spouses			
Care received (self-report)	-0.99% (0.025)	1.12% (0.020)	2.57% (<0.001)
Care given (self-report)	0.39% (0.470)	0.56% (0.338)	1.86% (<0.001)
CAR > 1 (see Quad B, Fig. 1)	-0.32% (0.674)	-0.64% (0.450)	0.47% (0.461)
CAR ≤ 1 (see Quad C, Fig. 1)	-1.90% (0.1241)	0.97% (0.478)	2.32% (0.027)
Care received (spouse-report, see Quad A, Fig. 1)	-0.59% (0.400)	0.52% (0.494)	1.81% (0.002)

^aPercent change on a given day relative to an individual's mean value over the 14-day study period

^bCaregiver outcomes relative to the caregiving spouses' self-reported measures of mood and marriage each day

higher marital satisfaction, though anxiety remained unrelated. When analyzed by care recipient sex, higher care received was linked to lower depression and higher marital satisfaction. Female recipients also experienced increased anxiety when reporting higher care received (Table 3). Thus, giving and receiving care were positively associated with marital satisfaction in both spouses; only receiving care was related to emotional outcomes, though negatively with anxiety in wives.

Spousal *agreement* about daily caregiving exchanges (i.e., CAR) was predictive of each of the primary outcomes in specific circumstances. On days when CAR was ≤ 1 (quadrant C, Fig. 1), increasing spousal agreement was associated with lower caregiver depression overall compared with that caregiver's mean depression score across 14 days (Table 2). However, CAR was significantly predictive of depression and anxiety only in male caregivers (Table 3). CAR predicted higher marital satisfaction for female caregivers only.

When considering CAR > 1 (quadrant B), increasing spousal agreement about care (i.e., CAR *decreasing* toward 1.0) was not predictive of caregiver depression, anxiety, or marital satisfaction overall or by sex (Tables 2 and 3). However, when one spouse did not report giving any care and at the same time the other spouse reported receiving care (quadrant A), higher care received was associated with higher marital satisfaction in the "caregiver" (Table 2); sex-stratified results for marital satisfaction demonstrating similar results (Table 3).

In summary, on days when care received is less than care provided, better agreement is related to improved caregiver emotional health and marital outcomes. Nevertheless, on days when the care received exceeds care given, improved agreement does not appear to be predictive of outcomes in caregivers.

DISCUSSION

This study suggests that perceptions of daily care given and received—including level of agreement between spouses—range broadly. Indeed, on one-third of study days, couples showed substantive lack of agreement. Furthermore, level of agreement predicted caregiver depression, anxiety, and marital satisfaction. Sex differences manifested as an important modifier. As the population of caregiving couples grows, these findings are relevant for patients and their medical providers.

Range of Agreement About Care Given and Received

These data highlight a novel consideration for clinicians when evaluating stressors in their patients, particularly those experiencing a transition to a caregiving relationship. Only 7.6% of couple days resulted in spouses

endorsing a total absence of care exchanged, so some caregiving appears normative among mid-to-late life couples. These findings highlight the importance of obtaining the perspectives of both spouses regarding functional assistance. Moreover, future studies should consider assessing factors that may predict such discrepancies among partners.

Agreement and Caregiver Outcomes

Congruent with studies of younger couples in which discrepant spousal opinions about shared life situations are associated with distress,^{26, 27} these results suggest that in some circumstances, disagreement in spouses who are older (in this study, spouses were typically 61 years of age) is associated with increased depression/anxiety and worsened marital satisfaction. Recent surveys demonstrate that 70% of caregivers experience depressive symptoms with up to half meeting diagnostic criteria for major depressive disorder,¹⁸ and meta-analysis shows that the largest difference between caregivers and non-caregivers is not in physical health ($g = .18$) but rather in depression ($g = .58$).¹³ Hence, increasing understanding about potential mediators of depression (and related mental health and relationship outcomes) is imperative. The current study highlights one such mediator—discordances in couple agreement.

Previous studies demonstrate that the effects of giving and receiving care are complicated by both caregiver and care recipient perceptions of the exchange. Recent work in older married couples specifically highlights that higher perceived spousal support is related to less negative affect; yet, it also suggests that when support occurs, perceptions can be associated with more vulnerability to negative affect between spouses.²⁸ Similarly, studies of care recipients have consistently found that feelings of support *availability* during life stressors, more than the actual receipt of support itself, mitigate negative health consequences (e.g., depression).^{29, 30} In fact, observational studies have demonstrated that receiving a higher amount of support seems to potentiate recipient distress,^{26, 27, 31, 32} which one study characterized as feeling "overly dependent on" and "indebted to" their spouse as a result of receiving care.³³ Consistent with these findings, female spouses in the current study who reported that they received greater care, also endorsed increased anxiety on that same day. Because caregiving is frequently viewed as a traditional role for female spouses,³⁴ they be more likely to experience anxiety when a need for care causes role reversal. This role conflict might relate to the need for care³³ and/or concern for their ability to provide care to others.

In contrast to these data, though not unseen in previous investigations,^{34–36} we found that for both males and females, spouses reporting that they received a higher level of care had lower daily depression and higher marital satisfaction on that day. These seemingly

conflicting findings may be explained by Bolger et al., who suggested that the timing of care provision relative to the course of a patient stressor may produce markedly different, and frequently positive, mental health outcomes in recipients.²⁷ Furthermore, in the present analysis, our focus was on practical support, rather than emotional support—where these associations were originally noted. It is also possible that caregiving exchanges in this study avoided the emotional costs sometimes associated with receiving care (e.g., dependency or ego detriments), because these interactions occurred prior to severe functional impairment and/or clear spousal caregiving roles.^{37,38}

Limitations and Strengths

This study is limited by homogeneity of participant ethnicity, socioeconomic status, and education. The couples involved in the current sample were exclusively Caucasian, reflecting the LFLS cohort, but restricting generalization of these results to more diverse populations. Moreover, participants comprised primarily an upper-middle class cohort. Future research including more diverse couples is needed. Finally, these results cannot be extrapolated to other caregiving situations (children-to-parent, parent-to-children, spouse to non-co-residing spouse)—where differences in pre-morbid kin relationships among caregiving dyads modify outcome measures significantly.³⁹

There are several notable strengths to this study. First, our sample isolates a rapidly growing demographic of married couples in whom caregiving roles and expectations are yet mostly undefined and support transactions between partners may be understood discrepantly. Insight provided by the current study into how caregiving and recipient spouses interpret these introductory caregiving exchanges could prove important for early recognition and prevention in couples at risk for the negative health and relationship impacts born out of disagreement about care. A further strength is the daily diary methodology, which included a large number of older adult couples and generated over 2500 days of paired survey data on caregiving agreement.

Clinical implications

In practice, the Medicare Annual Wellness Visit already includes simple cognitive, mental health, and other screening evaluations.⁴⁰ Future development of a screening tool for caregiving perceptions, including level of agreement among couples, might identify couples at risk of adverse outcomes—particularly in cases with no self-identified caregiver. Early identification could lead to interventions previously shown to improve caregiver health outcomes.⁴¹ Regardless, the current study highlights how simple information about the different experiences of caregiving in couples might lead providers to initiate conversations and assist couples in transitioning to caregiving roles.

CONCLUSION

Given the widespread societal and individual burden of informal caregiving worldwide, understanding unique relational and emotional health impacts of agreeing about care is critical. This study suggests that spousal agreement about the amount of care given and received is widely variable and predicts lower depression/anxiety and higher marital satisfaction among spousal caregivers. Uniquely, these findings relate to a growing population of emerging older adult caregivers in whom little specific research has been conducted. Daily diaries are well-suited to capturing the often rapidly shifting relationship dynamics associated with developing spousal roles. Future research should focus on validating these associations and/or proposing clinical interventions that can reliably reproduce these positive health outcomes, especially for couples emerging into caregiving and receiving roles.

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Corresponding Author: Wesley B. Godfrey, MD; Department of Internal Medicine The Ohio State University, 3rd Floor Faculty Office Tower, 395 West 12th Avenue, Columbus, OH 43210, USA (e-mail: wesley.godfrey@osumc.edu).

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Conflict of Interest: The authors declare that they do not have a conflict of interest.

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