Pronoun Use Among Caregivers of People Living with Dementia: Associations with Dementia Severity Using Text Analysis of a Natural Language Sample

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Abstract

**Introduction:** Family caregivers of persons living with dementia (PLWDs) have extensive social, physical, emotional, and financial responsibilities. However, less is known about the relationship and interpersonal connection between caregivers and PLWDs. We examined caregiver pronoun use, as an index of the connection between the caregiver and PLWD, and its associations with caregiver and PLWD health and well-being. **Methods:** Caregivers of PLWDs (N=320) were asked to describe a recent time they felt connected to the PLWD in their care. Responses were transcribed and coded to quantify pronoun use by category (we-pronouns, I-pronouns, they-pronouns). Caregivers also reported on their depression, burden, and the PLWD’s dementia severity and marital satisfaction. Sixty-eight caregivers repeated the same survey 24 months after the initial survey. **Results:** Caregivers used less we-pronouns when the PLWD’s dementia was more severe, at both timepoints. Spousal caregivers used more we-pronouns and less I- and they-pronouns than non-spousal caregivers. There was an interaction between spousal relationship and dementia severity, such that spousal caregivers exhibited a stronger negative association between dementia severity and we-pronoun use. There were no associations between pronoun category and caregiver burden nor depression. **Discussion:** Caregivers may feel increasingly disconnected from the PLWD as their dementia becomes more severe, as reflected by less we-pronoun usage. This study highlights the opportunity to explore relationship connection through text analysis.
**Introduction**

More than 15 million people provide informal care for persons living with dementia (PLWDs) in the United States, which involves immense emotional, physical, and practical support [1-4]. Growing evidence suggests dementia can alter the nature of the PLWD-caregiver relationship, which is closely tied to physical health and psychological well-being [5]. Experiences of connection in the caregiving relationship are important for maintaining hope and demonstrating support [6, 7], yet the caregiver-PLWD connection has not been studied extensively.

Text analysis is a powerful tool for studying relational dynamics, as language often reflects underlying social and psychological meaning [8]. Studies of personal pronoun usage (“we,” “you,” “I,” “he/she/they”) in naturalistic conversation have revealed associations of we-pronoun use with marital satisfaction, marital quality, health, and well-being [9-12]. To our knowledge, no prior studies have investigated pronoun use of individual caregivers in a narrative or interview format, which may offer insights into caregivers’ experience outside of the conversational context.

In the present study, caregivers described a recent time they felt connected to the PLWD, and we measured their pronoun use to assess the quality of that connection. As in prior work [9, 13], we conceptualized we-pronoun use as reflecting greater connection between the caregiver and PLWD, and greater I- and they-pronoun use as reflecting greater perceived separateness. Given documented associations of relationship factors (e.g., satisfaction, closeness, etc.) with caregiver and PLWD health and well-being [14-16], we sought to examine whether a language-based measure of connection (i.e., pronoun use) would reveal similar associations with caregiver health and well-being.

We tested two primary hypotheses. We hypothesized that greater use of we-pronouns would be associated with (1) better PLWD health outcomes (e.g., lower dementia severity); and (2) less caregiver depression and burden. We also explored whether caregiving relationship type (i.e., spouse vs. non-spouse) moderated associations between pronoun use and PLWD outcomes, and whether associations with we-pronoun use were independent of caregiver-reported PLWD marital satisfaction. Hypotheses were preregistered: [https://aspredicted.org/TUD_ACM](https://aspredicted.org/TUD_ACM).
Materials and Methods

Site

The Care Ecosystem is a program in which Care Team Navigators manage caseloads of PLWDs and caregivers by providing emotional support and other resources. The program was administered from two hubs, the University of California, San Francisco (UCSF) and the University of Nebraska Medical Center (UNMC), Omaha; and was studied in a randomized controlled trial. Those in the usual care (control) group completed surveys but did not receive care navigation. The Care Ecosystem intervention improved the quality of life of PLWDs, reduced emergency department visits, and decreased caregiver depression and burden [17].

Participants

Caregivers enrolled in the Care Ecosystem completed a telephone survey 6 months after enrollment that included the question, “Tell me about a time you felt most connected to [PLWD name] in the last few months.” Of the 439 responses to this question, 119 were not recorded verbatim and were excluded, resulting in a sample of 320 caregiver-PLWD dyads. The same survey was given 30 months after enrollment, and the sample was smaller (n=68) due to study completion, death, and non-verbatim transcription. Demographic characteristics of caregivers and PLWDs are presented in Table 1.

Procedures

Informed consent was obtained from both caregivers and PLWDs upon enrollment. In telephone surveys given 6 and 30 months after enrollment, caregivers responded to questions about PLWD and caregiver demographics, health, and well-being, including an open-ended question about their connection to the PLWD [17]. The UCSF and UNMC Institutional Review Boards approved this study.

Measures

Pronoun Use

Caregivers’ responses to the “connection” question were transcribed and processed using software written by one of the authors [18]. Oedipus Text utilizes a dictionary of personal
pronouns [9, 13] with four categories: (a) we-pronouns (we, we’d, we’ll, we’re, we’ve, our, ours, ourselves, us), (b) I-pronouns (I, I’d, I’ll, I’m, I’ve, me, mine, my, myself), (c) they-pronouns (he, his, him, himself, she, her, hers, herself, they, theirs, them, themself), and (d) you-pronouns (you, you’d, you’ll, you’re, you’ve, your, yours, yourself). Oedipus Text reviewed the transcribed responses and assigned each pronoun used to its dictionary-based category.

Next, a team of five trained coders reviewed each instance of pronoun use to confirm the dictionary-based categorization. Given the interview format, you-pronouns were rare and usually referred to the interviewer; therefore, they were excluded. Pronouns from quotations were retained when the caregiver referred to themselves (e.g., “I said, ‘I’m very happy...’”), but excluded when the caregiver quoted someone else (e.g., “A man came over...and said, ‘You must love your wife very much.’”). We- and they-pronouns were excluded when they did not refer to the caregiver-PLWD dyad (e.g., “we” referring to the caregiver and a friend). To establish the reliability, approximately 22% of responses were reviewed by all coders. Interrater reliability was high (ICC=.99). See Table 2 for example responses.

**Caregiver and PLWD Well-Being Survey**

**PLWD dementia severity** was assessed using the Quick Dementia Rating Scale (QDRS), a 10-item questionnaire asking caregivers to rate PLWDs’ cognition, function, behavior, and mood. Items are summed, ranging from 0-30. Higher scores reflect greater impairment [19].

**PLWD marital satisfaction** was assessed using a single item from the Quality of Life in Alzheimer’s Disease Scale (QoL-AD). Caregivers rated PLWDs’ marital satisfaction on a four-point scale ranging from “poor” to “excellent” [20].

**Caregiver burden** was assessed using the 12-item version of the Zarit Burden Interview (ZBI-12), which measures the perceived impact of providing care on caregivers’ health, personal life, and emotional well-being. Ratings are on a five-point scale ranging from “never” to “almost always.” Higher scores reflect greater burden [21].
Caregiver depression was assessed using the Patient Health Questionnaire (PHQ-9), a 9-item questionnaire asking about mood (e.g., feeling down, depressed, or hopeless) on a four-point scale ranging from “not at all” to “nearly every day” [22].

Results

Data Reduction

We calculated a proportion score for each of the three pronoun categories by dividing the number of pronouns in each category by the total number of pronouns in the entire response. To avoid problems with multicollinearity, we analyzed associations with each pronoun category separately.

Data Analysis

All analyses were conducted in R Studio Version 1.2.1335. First, we evaluated bivariate correlations between pronoun category (we, I, they) and caregiver and PLWD health and well-being (PLWD dementia severity, PLWD marital satisfaction, caregiver burden, caregiver depression). Second, we probed the robustness of significant associations by controlling for a set of covariates chosen a priori based on their expected associations with these constructs: caregiver age, gender, education (in years), relationship type (spouse vs non-spouse), and intervention group assignment. To be conservative, we ran analyses with all covariates in the same model. We re-evaluated significant associations at the month-30 timepoint.

Next, we explored whether being a spousal caregiver moderates significant associations between we-pronoun use and well-being outcomes; and whether significant associations between we-pronoun use and well-being outcomes are independent of caregiver-reported PLWD marital satisfaction (analyses limited to spousal caregivers only). Table 3 presents descriptive statistics of caregivers’ responses.

Pronoun Use and Dementia Severity

Six-Month Timepoint

PLWD dementia severity was significantly negatively correlated with we-pronouns and positively correlated with I- and they-pronouns. In other words, less use of we-pronouns and
more use of I- and they-pronouns by caregivers was associated with greater dementia severity in PLWDs, supporting our first hypothesis (see Table 4).

Next, we conducted multiple regression analyses with pronoun use predicting PLWD dementia severity, controlling for caregiver age, gender, education, relationship to PLWD, and intervention group. All three pronoun categories remained significantly associated with dementia severity when accounting for covariates (see Table 5).

**Thirty-Month Timepoint**

Bivariate correlations revealed that dementia severity at the 30-month timepoint remained significantly negatively associated with we-pronouns and positively associated with they-pronouns; but was no longer associated with I-pronouns (see Table 4). Given the limited sample size, we did not explore the robustness of these associations using covariates.

**We-Pronouns, Dementia Severity, and Caregiver-PLWD Relationship**

We explored group differences in we-pronoun use, comparing spousal caregivers to non-spousal caregivers. Levene’s test revealed heteroskedasticity ($p<.001$), therefore we used a Welch two-sample t-test. Spouses used more we-pronouns ($M=.37, SD=.35$) than did non-spouses ($M=.19, SD=.31$; $t(274.3)=-4.51, p<.001$).

Next, we conducted a regression with spousal relationship (0=non-spouse, 1=spouse), PLWD dementia severity, and an interaction term between spousal relationship and dementia severity as independent variables, and we-pronouns as the dependent variable. In addition to significant main effects for spousal relationship and dementia severity, we found a significant interaction effect, such that being a spouse amplified the negative association between dementia severity and we-pronoun use (see Table 6 and Fig. 1).

**Observational Versus Caregiver-Reported Relationship Measures and Dementia Severity**

We-pronoun use was not correlated with caregiver-reported PLWD marital satisfaction ($r=.13, p=.126$) in our sample of spousal caregivers ($n=172$). In a regression with we-pronoun use and caregiver-reported PLWD marital satisfaction predicting PLWD dementia severity, we found
that greater proportion of we-pronouns and greater marital satisfaction were each independently associated with lower dementia severity (see Table 7).

Pronoun Use and Caregiver Well-Being

We examined bivariate correlations between pronoun category and caregiver depression and burden, respectively. Contrary to our second hypothesis, neither proportion of we-pronouns, I-pronouns, nor they-pronouns were significantly associated with caregiver depression nor burden ($p > .55$).

Discussion

We examined associations between pronoun used by caregivers in response to a question about their connection with the PLWD with caregivers’ and PLWDs’ health and well-being. Lower use of we-pronouns and greater use of I- and they-pronouns was associated with greater dementia severity. These associations were robust when controlling for covariates and stable across time.

Spousal caregivers used more we-pronouns than non-spousal caregivers. There was also an interaction between relationship type and dementia severity such that the negative association between dementia severity and we-pronoun use was stronger for spousal caregivers than for non-spousal caregivers. Finally, we found that lesser use of we-pronouns by spousal caregivers was predictive of dementia severity, independent of caregiver-reported PLWD marital satisfaction.

We did not find any associations between caregiver pronoun use and caregiver burden and depression.

The association between caregiver we-language and PLWD dementia severity could reflect a loss of connection as the disease progresses. As the PLWD’s dementia becomes more severe, shared activities and conversations may become less frequent and less fulfilling for the caregiver. Additionally, as dementia severity increases, interpersonal problems between the caregiver and PLWD, such as abuse, may also increase [23], impacting their connection.

In contrast, I- and they-pronoun use were positively associated with dementia severity, albeit less robustly (e.g., I-pronouns were not correlated with dementia severity at 30-months). Given prior evidence linking I- and they-pronouns to experiences of separateness [13], these pronouns may
reflect caregivers’ psychological disconnection from the PLWD. As the disease progresses, caregivers and PLWDs may become disconnected because they no longer have as many shared activities, the PLWD may be more self-focused, or the caregiver takes on a more service-oriented role [24].

Prior text analysis studies have linked greater use of we-pronouns with better caregiver health and well-being [9-11]; however, we did not find similar associations in the present study. One reason for this may be that prior studies focused on dyadic conversations that can be influenced by many issues in the caregiver-PLWD relationship. These conversations elicit language (and pronoun use) by both members of the dyad as well as moments of felt emotion that may have stronger ties to caregiver health and well-being. Our study only examined caregivers’ direct comments about a lived experience of connection, which is less likely to occur during dyadic interactions. We expect that studying pronoun use in both contexts, dyadic interactions and open-ended interview questions, will provide a richer understanding of the ways pronoun usage is related to the different aspects of the caregiving experience, the caregiver-PLWD relationship, and the longer-term impact on health and well-being.

We also note that our study did not address the longitudinal changes that occur in caregivers’ experience of connection nor the ways these changes are associated with changes in caregiver health and well-being. For example, ample research suggests that distance and disconnection may be helpful for caregivers. In a recent study from our research group, lower levels of emotional empathy in caregivers (i.e., not feeling the emotions of people in distress) were associated with having fewer mental health problems [25]. Disconnecting from the PLWD as dementia progresses may be a natural part of caregivers’ grieving and loss [26]. Indeed, longitudinal research has found that decreased caregiver-rated closeness can be a protective factor when dealing with cognitive and functional decline in the PLWD [27].

Finally, we found that we-pronoun use was significantly associated with dementia severity when accounting for caregiver-reported PLWD marital satisfaction. This finding points to the advantage of assessing caregiver pronoun use in addition to more commonly used self-report measures. When assessing current relationship quality, caregivers may face difficulty
disentangling feelings from the present and past. Measuring connection in spontaneous speech may capture different aspects of current perceptions and reduce bias. For this reason, clinicians may find it useful to pay closer attention to the words caregivers use to gain a deeper understanding of the impact of the PLWD’s disease on the caregiver and the caregiver-PLWD relationship.

Limitations and Future Directions

Several limitations should be considered. First, despite the large sample size at the 6-month timepoint, the sample at the 30-month timepoint was limited. Additionally, all analyses were based on brief natural language samples (the average length was 28 words) that may not adequately capture the full extent of caregiver’s experiences of connection as compared to longer language samples and language that occurs in conversation between caregivers and PLWD.

Future research should: (a) examine relationships between language, dementia progression, and caregiver health and well-being longitudinally; (b) integrate language samples from multiple sources (interview questions, conversations, etc.); and (c) study the possibility that reduced use of we-pronouns may be protective for the caregiver.
Statement of Ethics
The study was conducted ethically in accordance with the World Medical Association Declaration of Helsinki.

Study Approval Statement
The study protocol was reviewed and approved by the Institutional Review Boards of the University of California, San Francisco (IRB #: 14-14537) and the University of Nebraska Medical Center (IRB #: 483-14-FB).

Consent to Participate Statement
Patients with capacity to provide informed consent were given the opportunity to consent for themselves; otherwise, consent was obtained from a legally authorized representative. Caregivers also provided informed consent. Consent was provided with written or electronic (digital) signature.

Conflict of Interest Statement
Dr. Possin reported receiving grants from the Centers for Medicare & Medicaid Services (CMS), National Institute on Aging (NIA), National Institute of Neurological Disorders and Stroke (NINDS), Global Brain Health Institute, Quest Diagnostics, and the Rainwater Foundation during the conduct of the study and personal fees from ClearView Healthcare Partners and Vanguard outside the submitted work.

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Author Contributions

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Data Availability Statement

Public archiving of the anonymized data is not permitted under the study's IRB approval. Specific requests can be submitted through the UCSF MAC Resource Request form: http://memory.ucsf.edu/resources/data. Following a UCSF-regulated procedure, access will be granted to designated individuals in line with ethical guidelines on the reuse of sensitive data. This would require submission of a Material Transfer Agreement, available at: https://icd.ucsf.edu/material-transfer-and-data-agreements. Commercial use will not be approved.
CAREGIVER PRONOUN USE AND PATIENT DEMENTIA SEVERITY

References


Legend of Figures

Figure 1
Spousal Relationship Moderates the Association Between Dementia Severity and We-Pronoun Use

Spousal caregivers (depicted in black) have a stronger, negative association between we-pronoun use and PLWD dementia severity, as compared to non-spousal caregivers (depicted in gray).