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

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

Introduction

19 More than 15 million people provide informal care for persons living with dementia (PLWDs) in
20 the United States, which involves immense emotional, physical, and practical support [1-4].
21 Growing evidence suggests dementia can alter the nature of the PLWD-caregiver relationship,
22 which is closely tied to physical health and psychological well-being [5]. Experiences of
23 connection in the caregiving relationship are important for maintaining hope and demonstrating
24 support [6, 7], yet the caregiver-PLWD connection has not been studied extensively.
25
26 Text analysis is a powerful tool for studying relational dynamics, as language often reflects
27 underlying social and psychological meaning [8]. Studies of personal pronoun usage ("we,"
28 "you," "I," "he/she/they") in naturalistic conversation have revealed associations of we-pronoun
29 use with marital satisfaction, marital quality, health, and well-being [9-12]. To our knowledge,
30 no prior studies have investigated pronoun use of individual caregivers in a narrative or interview
31 format, which may offer insights into caregivers' experience outside of the conversational
32 context.
33
34 In the present study, caregivers described a recent time they felt connected to the PLWD, and we
35 measured their pronoun use to assess the quality of that connection. As in prior work [9, 13], we
36 conceptualized we-pronoun use as reflecting greater connection between the caregiver and
37 PLWD, and greater I- and they-pronoun use as reflecting greater perceived separateness. Given
38 documented associations of relationship factors (e.g., satisfaction, closeness, etc.) with caregiver
39 and PLWD health and well-being [14-16], we sought to examine whether a language-based
40 measure of connection (i.e., pronoun use) would reveal similar associations with caregiver health
41 and well-being.
42
43 We tested two primary hypotheses. We hypothesized that greater use of we-pronouns would be
44 associated with (1) better PLWD health outcomes (e.g., lower dementia severity); and (2) less
45 caregiver depression and burden. We also explored whether caregiving relationship type (i.e.,
46 spouse vs. non-spouse) moderated associations between pronoun use and PLWD outcomes, and
47 whether associations with we-pronoun use were independent of caregiver-reported PLWD
48 marital satisfaction. Hypotheses were preregistered: https://aspredicted.org/TUD_ACM.

49

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

80   pronouns [9, 13] with four categories: (a) we-pronouns (we, we'd, we'll, we're, we've, our, ours,

81   ourselves, us), (b) I-pronouns (I, I'd, I'll, I'm, I've, me, mine, my, myself), (c) they-pronouns

82   (he, his, him, himself, she, her, hers, herself, they, theirs, them, themself), and (d) you-pronouns

83   (you, you'd, you'll, you're, you've, your, yours, yourself). Oedipus Text reviewed the

84   transcribed responses and assigned each pronoun used to its dictionary-based category.

85

86   Next, a team of five trained coders reviewed each instance of pronoun use to confirm the

87   dictionary-based categorization. Given the interview format, you-pronouns were rare and usually

88   referred to the interviewer; therefore, they were excluded. Pronouns from quotations were

89   retained when the caregiver referred to themselves (e.g., *"**I** said, '**I'm** very happy…'"),* but

90   excluded when the caregiver quoted someone else (e.g., *"A man came over…and said, '**You**

91   *must love **your** wife very much.'").* We- and they-pronouns were excluded when they did not

92   refer to the caregiver-PLWD dyad (e.g., "we" referring to the caregiver and a friend). To

93   establish the reliability, approximately 22% of responses were reviewed by all coders. Interrater

94   reliability was high (ICC=.99). See **Table 2** for example responses.

95

96   ***Caregiver and PLWD Well-Being Survey***

97   *PLWD dementia severity* was assessed using the Quick Dementia Rating Scale (QDRS), a 10-

98   item questionnaire asking caregivers to rate PLWDs' cognition, function, behavior, and mood.

99   Items are summed, ranging from 0-30. Higher scores reflect greater impairment [19].

100

101   *PLWD marital satisfaction* was assessed using a single item from the Quality of Life in

102   Alzheimer's Disease Scale (QoL-AD). Caregivers rated PLWDs' marital satisfaction on a four-

103   point scale ranging from "poor" to "excellent" [20].

104

105   *Caregiver burden* was assessed using the 12-item version of the Zarit Burden Interview (ZBI-

106   12), which measures the perceived impact of providing care on caregivers' health, personal life,

107   and emotional well-being. Ratings are on a five-point scale ranging from "never" to "almost

108   always." Higher scores reflect greater burden [21].

109

110   *Caregiver depression* was assessed using the Patient Health Questionnaire (PHQ-9), a 9-item

111   questionnaire asking about mood (e.g., feeling down, depressed, or hopeless) on a four-point

112   scale ranging from "not at all" to "nearly every day" [22].

113

114   Results

115   Data Reduction

116   We calculated a proportion score for each of the three pronoun categories by dividing the

117   number of pronouns in each category by the total number of pronouns in the entire response. To

118   avoid problems with multicollinearity, we analyzed associations with each pronoun category

119   separately.

120

121   Data Analysis

122   All analyses were conducted in R Studio Version 1.2.1335. First, we evaluated bivariate

123   correlations between pronoun category (we, I, they) and caregiver and PLWD health and well-

124   being (PLWD dementia severity, PLWD marital satisfaction, caregiver burden, caregiver

125   depression). Second, we probed the robustness of significant associations by controlling for a set

126   of covariates chosen *a priori* based on their expected associations with these constructs:

127   caregiver age, gender, education (in years), relationship type (spouse vs non-spouse), and

128   intervention group assignment. To be conservative, we ran analyses with all covariates in the

129   same model. We re-evaluated significant associations at the month-30 timepoint.

130

131   Next, we explored whether being a spousal caregiver moderates significant associations between

132   we-pronoun use and well-being outcomes; and whether significant associations between we-

133   pronoun use and well-being outcomes are independent of caregiver-reported PLWD marital

134   satisfaction (analyses limited to spousal caregivers only). **Table 3** presents descriptive statistics

135   of caregivers' responses.

136

137   Pronoun Use and Dementia Severity

138   *Six-Month Timepoint*

139   PLWD dementia severity was significantly negatively correlated with we-pronouns and

140   positively correlated with I- and they-pronouns. In other words, less use of we-pronouns and

141   more use of I- and they-pronouns by caregivers was associated with greater dementia severity in

142   PLWDs, supporting our first hypothesis (see **Table 4**).

143

144   Next, we conducted multiple regression analyses with pronoun use predicting PLWD dementia

145   severity, controlling for caregiver age, gender, education, relationship to PLWD, and

146   intervention group. All three pronoun categories remained significantly associated with dementia

147   severity when accounting for covariates (see **Table 5**).

148

149   *Thirty-Month Timepoint*

150   Bivariate correlations revealed that dementia severity at the 30-month timepoint remained

151   significantly negatively associated with we-pronouns and positively associated with they-

152   pronouns; but was no longer associated with I-pronouns (see **Table 4**). Given the limited sample

153   size, we did not explore the robustness of these associations using covariates.

154

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

156   We explored group differences in we-pronoun use, comparing spousal caregivers to non-spousal

157   caregivers. Levene's test revealed heteroskedasticity ($p<.001$), therefore we used a Welch two-

158   sample t-test. Spouses used more we-pronouns ($M=.37$, $SD=.35$) than did non-spouses ($M=.19$,

159    $SD=.31$; $t(274.3)=-4.51$, $p<.001$).

160

161   Next, we conducted a regression with spousal relationship (0=non-spouse, 1=spouse), PLWD

162   dementia severity, and an interaction term between spousal relationship and dementia severity as

163   independent variables, and we-pronouns as the dependent variable. In addition to significant

164   main effects for spousal relationship and dementia severity, we found a significant interaction

165   effect, such that being a spouse amplified the negative association between dementia severity and

166   we-pronoun use (see **Table 6** and **Fig. 1**).

167

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

169   We-pronoun use was not correlated with caregiver-reported PLWD marital satisfaction ($r=.13$,

170    $p=.126$) in our sample of spousal caregivers ($n=172$). In a regression with we-pronoun use and

171   caregiver-reported PLWD marital satisfaction predicting PLWD dementia severity, we found

172   that greater proportion of we-pronouns and greater marital satisfaction were each independently

173   associated with lower dementia severity (see **Table 7**).

174

175   **Pronoun Use and Caregiver Well-Being**

176   We examined bivariate correlations between pronoun category and caregiver depression and

177   burden, respectively. Contrary to our second hypothesis, neither proportion of we-pronouns, I-

178   pronouns, nor they-pronouns were significantly associated with caregiver depression nor burden

179   (ps > .55).

180

181   # Discussion

182   We examined associations between pronoun used by caregivers in response to a question about

183   their connection with the PLWD with caregivers' and PLWDs' health and well-being. Lower use

184   of we-pronouns and greater use of I- and they-pronouns was associated with greater dementia

185   severity. These associations were robust when controlling for covariates and stable across time.

186   Spousal caregivers used more we-pronouns than non-spousal caregivers. There was also an

187   interaction between relationship type and dementia severity such that the negative association

188   between dementia severity and we-pronoun use was stronger for spousal caregivers than for non-

189   spousal caregivers. Finally, we found that lesser use of we-pronouns by spousal caregivers was

190   predictive of dementia severity, independent of caregiver-reported PLWD marital satisfaction.

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

192   depression.

193

194   The association between caregiver we-language and PLWD dementia severity could reflect a

195   loss of connection as the disease progresses. As the PLWD's dementia becomes more severe,

196   shared activities and conversations may become less frequent and less fulfilling for the caregiver.

197   Additionally, as dementia severity increases, interpersonal problems between the caregiver and

198   PLWD, such as abuse, may also increase [23], impacting their connection.

199

200   In contrast, I- and they-pronoun use were positively associated with dementia severity, albeit less

201   robustly (e.g., I-pronouns were not correlated with dementia severity at 30-months). Given prior

202   evidence linking I- and they-pronouns to experiences of separateness [13], these pronouns may

203   reflect caregivers' psychological disconnection from the PLWD. As the disease progresses,

204   caregivers and PLWDs may become disconnected because they no longer have as many shared

205   activities, the PLWD may be more self-focused, or the caregiver takes on a more service-

206   oriented role [24].

207

208   Prior text analysis studies have linked greater use of we-pronouns with better caregiver health

209   and well-being [9-11]; however, we did not find similar associations in the present study. One

210   reason for this may be that prior studies focused on dyadic conversations that can be influenced

211   by many issues in the caregiver-PLWD relationship. These conversations elicit language (and

212   pronoun use) by both members of the dyad as well as moments of felt emotion that may have

213   stronger ties to caregiver health and well-being. Our study only examined caregivers' direct

214   comments about a lived experience of connection, which is less likely to occur during dyadic

215   interactions. We expect that studying pronoun use in both contexts, dyadic interactions and open-

216   ended interview questions, will provide a richer understanding of the ways pronoun usage is

217   related to the different aspects of the caregiving experience, the caregiver-PLWD relationship,

218   and the longer-term impact on health and well-being.

219

220   We also note that our study did not address the longitudinal changes that occur in caregivers'

221   experience of connection nor the ways these changes are associated with changes in caregiver

222   health and well-being. For example, ample research suggests that distance and disconnection

223   may be helpful for caregivers. In a recent study from our research group, lower levels of

224   emotional empathy in caregivers (i.e., not feeling the emotions of people in distress) were

225   associated with having fewer mental health problems [25]. Disconnecting from the PLWD as

226   dementia progresses may be a natural part of caregivers' grieving and loss [26]. Indeed,

227   longitudinal research has found that decreased caregiver-rated closeness can be a protective

228   factor when dealing with cognitive and functional decline in the PLWD [27].

229

230   Finally, we found that we-pronoun use was significantly associated with dementia severity when

231   accounting for caregiver-reported PLWD marital satisfaction. This finding points to the

232   advantage of assessing caregiver pronoun use in addition to more commonly used self-report

233   measures. When assessing current relationship quality, caregivers may face difficulty

234   disentangling feelings from the present and past. Measuring connection in spontaneous speech

235   may capture different aspects of current perceptions and reduce bias. For this reason, clinicians

236   may find it useful to pay closer attention to the words caregivers use to gain a deeper

237   understanding of the impact of the PLWD's disease on the caregiver and the caregiver-PLWD

238   relationship.

239

240   **Limitations and Future Directions**

241   Several limitations should be considered. First, despite the large sample size at the 6-month

242   timepoint, the sample at the 30-month timepoint was limited. Additionally, all analyses were

243   based on brief natural language samples (the average length was 28 words) that may not

244   adequately capture the full extent of caregiver's experiences of connection as compared to longer

245   language samples and language that occurs in conversation between caregivers and PLWD.

246

247   Future research should: (a) examine relationships between language, dementia progression, and

248   caregiver health and well-being longitudinally; (b) integrate language samples from multiple

249   sources (interview questions, conversations, etc.); and (c) study the possibility that reduced use

250   of we-pronouns may be protective for the caregiver.

251 **Statement of Ethics**

252 The study was conducted ethically in accordance with the World Medical Association

253 Declaration of Helsinki.

254

255 **Study Approval Statement**

256 The study protocol was reviewed and approved by the Institutional Review Boards of the

257 University of California, San Francisco (IRB #: 14-14537) and the University of Nebraska

258 Medical Center (IRB #: 483-14-FB).

259

260 **Consent to Participate Statement**

261 Patients with capacity to provide informed consent were given the opportunity to consent for

262 themselves; otherwise, consent was obtained from a legally authorized representative. Caregivers

263 also provided informed consent. Consent was provided with written or electronic (digital)

264 signature.

265

281

Author Contributions

283 *Concept and design:* Bernstein Sideman, Wells, Merrilees, Shdo, Yee, Possin, Levenson

284 *Acquisition, analysis, or interpretation of data*: Bernstein Sideman, Wells, Merrilees, Shdo, Yee,

285 Possin, Levenson

286 *Drafting of the manuscript:* Bernstein Sideman

287 *Critical revision of the manuscript for important intellectual content:* Bernstein Sideman, Wells,

288 Merrilees, Shdo, Yee, Possin, Levenson

289 *Statistical analysis:* Wells

290 *Obtained funding:* Possin

291 *Administrative, technical, or material support:* Bernstein Sideman, Wells, Merrilees, Shdo, Yee,

292 Possin, Levenson

293 *Supervision:* Possin, Levenson

294

Data Availability Statement

296 Public archiving of the anonymized data is not permitted under the study's IRB approval.

297 Specific requests can be submitted through the UCSF MAC Resource Request

298 form: http://memory.ucsf.edu/resources/data. Following a UCSF-regulated procedure, access

299 will be granted to designated individuals in line with ethical guidelines on the reuse of sensitive

300 data. This would require submission of a Material Transfer Agreement, available

301 at: https://icd.ucsf.edu/material-transfer-and-data-agreements. Commercial use will not be

302 approved.

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376

377 **Legend of Figures**
378
379 **Figure 1**
380 *Spousal Relationship Moderates the Association Between Dementia Severity and We-Pronoun*
381 *Use*
382 Spousal caregivers (depicted in black) have a stronger, negative association between we-pronoun
383 use and PLWD dementia severity, as compared to non-spousal caregivers (depicted in gray).