

Original Article

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Communicating visit information to family caregivers: How does method matter? A national survey

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Abstract

Objectives. The clinic visit is a critical point of contact for family caregivers. However, only 37% of family caregivers are able to accompany patients to visits. When they cannot attend, caregivers receive visit information to assist with their caregiving. However, little is known about how method of receiving information from clinic visits is associated with important caregiver outcomes. This study sought to determine whether mode of receiving clinic visit information (speaking with the patient, attending the visit, or using an after-visit summary [AVS]) was associated with changes in caregiver burden, caregiver preparedness, and the positive aspects of caregiving.

Methods. Cross-sectional web-based survey of a national sample of adult family caregivers. Multiple linear regression models determined associations between communication modes and caregivers' burden, preparedness, and positive aspects of caregiving, adjusting for sociodemographic covariates.

Results. Respondents ($N = 340$) were mostly male (58%), White (59%), ranged from 18 to 85 years old, and supported patients with conditions including diabetes, dementia, and cancer. Speaking with patients was associated with increases in positive aspects of caregiving (95% CI = 2.01, 5.42) and an AVS was associated with increases in positive aspects of caregiving (95% CI = 0.4, 3.56) and preparedness for caregiving (95% CI = 0.61, 3.15). Using any method of receiving information from visits was associated with the greatest increase in preparedness, compared to not receiving visit information. We did not observe an association between method of communication and caregiver burden.

Significance of results. Method of communicating visit information is associated with improvements in caregiver preparedness and the positive aspects of caregiving, though caregiver burden may be unaffected by information exchange. Given the limitations of current communication methods, future work should explore directionality of the associations we found and identify visit communication strategies with caregivers that optimize caregiver and patient outcomes.

Introduction

In the United States, 53 million adults rely on unpaid family caregivers to provide in-home assistance with tasks related to disease management and day-to-day living (Deng 2017; The National Alliance for Caregiving 2020). Caregiving exists on a continuum which includes positive aspects of caregiving and challenging aspects of caregiving (Yu et al. 2018). Positive aspects of caregiving include personal and social role fulfillment, effective cognitive emotional regulation, and contexts which favor finding meaning in the caregiving experience (Yu et al. 2018).

Yet caregiving is considered to be a major stress factor for caregivers, and family caregivers often report high levels of caregiver burden (Carretero et al. 2009; Li and Loke 2013; DeGregory 2014; Ho et al. n.d.; Miyawaki 2015). Caregiver burden's effect on health outcomes has been shown to be mediated by the caregiver's level of preparedness, which can be understood as the perceived level of readiness for the tasks of the caregiving role, including physical care, emotional support, and dealing with stress of caregiving (da Rocha et al. 2022). As caregiver preparedness grows, caregiver burden's effect on outcomes decreases (Andrén and Elmståhl 2008; Archbold et al. 1990; Magasi et al. 2019). Lack of preparedness has also been connected to caregiver physical and mental health outcomes including increased fatigue, feelings of failure, and role strain (Magasi et al. 2019; Petruzzo et al. 2019). Other studies have reported that caregivers who have a better understanding

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of their care recipient's diagnosis and treatment plan are more prepared, better able to cope, and have reduced psychological stress (Bratches *et al.* 2021; Toye *et al.* 2016).

The clinic visit is a critical point of engagement for the patient, caregiver, and clinician triad (Makoul 2001; Wolff and Roter 2011). Clinic visits are the main setting for triadic communication, or the communication between clinicians, patients, and caregivers. Patients and caregivers both prefer the caregiver to be informed about their tasks (Beisecker *et al.* 1996), and caregivers often provide informational support to patients during clinic visits, like asking questions regarding patient care and explaining clinician instructions (Wolff and Roter 2008). Clinicians find caregivers helpful to facilitate decision-making in clinic visits (Shepherd *et al.* 2008), and caregivers prefer to get information for their caregiving from clinicians: a study of 200 family caregivers found that clinicians were the preferred information source for 98% of those surveyed (James *et al.* 2007).

When caregivers cannot attend visits in-person, a systematic review of studies that communicate information from clinic visits to family caregivers found 2 main methods of communication: speaking with the patient and reading after-visit materials like doctor's notes or the after-visit summary (AVS) (Bratches *et al.* 2021). Speaking with the patient was defined as asking the patient what information they remember from the clinic visit and was associated with improvements to caregiver happiness. Receiving information from after-visit materials was associated with higher engagement in clinic visits, defined by the number of questions that were asked by the caregiver at visits before and after receiving the information.

Communicating the information from clinic visits is recognized by the Caregiver Advise, Record, and Enable (CARE) Act (Reinhard *et al.* 2019). This requires health systems to ask patients whether they have a caregiver, record the name of the caregiver, and enable the caregiver with the information they need to provide care. However, a scan of health systems in the 42 participating states found that our understanding of the means of sharing information with caregivers is lacking (Reinhard *et al.* 2019).

Understanding how family caregivers receive clinic visit information and whether this is connected to caregiver outcomes would help to improve the delivery of information and improve the health-care experience for both patients and caregivers (Glanz *et al.* 2008; Schubart *et al.* 2008). To date, little is known about whether the method or format of visit information is associated with key caregiver outcomes like caregiver preparedness, caregiver burden, or the positive aspects of caregiving: while improvements to caregiver preparedness and caregiver happiness have been identified, the systematic review of interventions that communicate information to family caregivers found only 4 eligible studies for inclusion (Bratches *et al.* 2021).

The aims of this study were to (1) describe the prevalence of receiving different modes of communicating visit information and (2) explore associations between different modes of communication and caregiver preparedness, caregiver burden, and the positive aspects of caregiving. We conducted a national survey of family caregivers of patients with chronic and acute medical conditions. This study advances the understanding of the current knowledge gap in how providing information to family caregivers may be associated with 3 important caregiver outcomes, helping health systems optimize the ways they communicate with family members. Ultimately, this may improve the effectiveness of family caregivers, minimize the burden of family caregiving, and improve how caregivers feel about their caregiving. We hypothesized that receiving with visit information through attending the visit, speaking with

patients, and using an AVS would be associated with decreases in caregiver burden, increased caregiver preparedness, and increased positive aspects of caregiving.

Methods

Overview

Following the Checklist for Reporting the Results of Internet E-Surveys (Supplemental File A) (Eysenbach 2004), we conducted a cross-sectional online survey of family caregivers in the United States. "Family caregiver" was defined as an English-speaking adult (18 years or older) living in the United States who self-identified as being the person most responsible for caring for the health of another adult (18 years or older). This study was deemed exempt from Institutional Review Board review by Dartmouth College's Committee for the Protection of Human Subjects.

Survey design

The survey was developed in consultation with the Open Recordings group, a group of researchers, physicians, patients, and caregivers at Dartmouth College, and the National Alliance for Caregiving (NAC), a national leader in conducting policy analysis and tracking legislation dealing with family caregiving issues. The survey was pilot-tested and refined based on feedback from a 6-member NAC panel including patients, caregivers, and advocacy leaders.

Survey procedures

The survey was distributed through the NAC's newsletter and social media accounts on June 1, 2020. On July 27, 2020, we analyzed the demographics of this initial sample and supplemented this sample with an additional sample through Qualtrics Panels, an online survey platform which draws broad participant demographics (Ibarra *et al.* 2018). Quotas were applied to create a demographic profile by race and ethnicity in our sample similar to the national caregiver demographics described in the 2020 Caregiving in the U.S. Report, a 5-year report that seeks to understand the demographics and experiences of caregivers nationally (The National Alliance for Caregiving 2020). To ensure completeness, all questions were forced response, though respondents were reminded they could opt-out of the survey at any time by closing their webpage. Participants viewed 31–36 questions, depending on their answer selections. There was no "back" button on the survey and all questions were delivered in English only. We excluded "speeders," respondents who completed the survey under half the piloted median time to completion (Greszki *et al.* 2014). Surveys were analyzed if they were more than 97% complete, which indicated they reached the final page of the survey. Finally, we used the "Ballot Box Stuffing" feature in Qualtrics to ensure a participant only took the survey once, though we allowed respondents to resume responses up to 1 week after starting the survey.

Participants

The NAC newsletter was sent to 5,986 people and the survey section was viewed by 449. The social media post received 676 unique views. Of the 1,125 potential participants who saw the survey link from the NAC sample, 268 visited the survey introduction page, and 113 fully completed the survey. Through Qualtrics, we received

an additional 227 respondents to fill quotas based on race and ethnicity. This resulted in a total of 340 respondents.

Measures

Caregiver demographics collected included age, gender, race, ethnicity, time spent caregiving, relationship to the care recipient (spouse or partner, parent or grandparent, or adult child), household income, experience as a caregiver (less than 1 year or 1 year+), and number of patient comorbidities.

Participants completed 3 validated scales (Archbold et al. 1990; Li and Loke 2013; Pendergrass et al. 2018):

- (1) The Preparedness for Caregiving Scale, an 8-item scale measuring perceived preparedness for physical and emotional aspects of caregiving, with scores ranging from 0 to 32 and higher scores indicating higher preparedness and decreased anxiety (Petruzzo et al. 2017);
- (2) The Burden Scale for Family Caregivers-Short Form, a 10-item scale measuring level of perceived caregiver burden, with scores ranging from 0 to 30 and higher scores indicating higher levels of burden and loneliness (Graessel et al. 2014); and
- (3) The Positive Aspects of Caregiving Scale, a 9-item scale measuring how positive a caregiver feels about their caregiving, with scores ranging from 9 to 45 with higher scores indicating higher positivity and improved relationship quality (Yong Ming Siow et al. 2017). Specific positive aspects of caregiving measured in the Positive Aspects of Caregiving Scale include overall positive aspects of caregiving, self-affirmation, and outlook on life.

Mode of communication

Respondents were presented with different methods by which they receive information from their visits (attending the visit, speaking with the patient, and reading the AVS, either printed on paper or accessed through the patient portal) and were asked to indicate the frequency of receiving information from each method on a 4-point Likert scale. Participants were asked about their general visit habits, rather than specific visits they did or did not attend. Possible answers included Never, Sometimes, Often, or Always. In the sensitivity analysis, printed paper summaries and patient portal-based summaries were combined into "Any Method of Receiving Information."

Statistical analysis

Descriptive statistics were used to describe respondent demographic characteristics.

Multiple linear regression

Separate linear regression models were performed, adjusting for covariates, to determine the association of different visit information communication methods on caregiver preparedness, burden, and the positive aspects of caregiving. We also performed a sensitivity analysis by stratifying based on the source of the sample (NAC or Qualtrics) to see if there were differences between our sampling sources.

Statistical analyses were conducted in R v4.0.3 (Boston, MA). All models were tested for collinearity between variables by using

the variance inflation factor, where a factor greater than 5.0 indicates strong collinearity (Fox and Monette 1992). If collinearity occurred, the research team met to discuss the variables in question to determine which should be included in the model. A pre-defined alpha level of 0.05 or less was chosen for statistical significance.

When included as covariates, caregiver burden, caregiver preparedness, and caregiver positivity were dichotomized as high or low based on previously established, clinically significant cutoffs to aid interpretability (Allen 2017): a score greater than or equal to 15 on the Burden Scale for Family Caregivers – Short indicating high burden (Archbold et al. 1990), a score of 20 or higher on the Preparedness for Caregiving Scale indicating high preparedness (Magasi et al. 2019), and a score of 35 or higher on the Positive Aspects of Caregiving Scale indicating high positivity (Affinito and Louie 2018). When used as outcome variables, the continuous scales for caregiver burden, caregiver preparedness, and caregiver positivity were used as continuous variables to allow for more power to detect associations (Ragland 1992). Linear regression models were used to estimate the association of mode of visit communication on caregiver outcomes. Two additional models were run to examine the association between using any method of communication and using both AVSs and speaking with the patient, on caregiver burden, caregiver preparedness, and caregiver positivity.

Results

Descriptive results

Respondents were primarily male (58.1%) and White (59.7%), and most performed between 1 and 3 hours of caregiving-related tasks per day (40.6%) (Table 1). Most caregivers had been providing care to a patient for more than 1 year (60.7%). Most caregivers cared for patients with diabetes (33%), dementia (17%), developmental disabilities (11%), or cancer (10%). The majority of respondents reported receiving visit information (defined by selecting a choice other than "Never") by attending the clinic visit with their care recipient (77.4%), relying on the patient's memory (74.7%), using a written AVS (63.2%), or using the patient portal (61.2%).

The mean Caregiver Burden Scale score was 17.48 (SD 7.65), the mean Preparedness for Caregiving Scale score was 23.34 (SD 6.22), and the mean Positive Aspects of Caregiving score was 35.67 (SD 7.59), indicating the sample had a high level of preparedness, high level of burden, and a high positive aspects of caregiving sample based on our established cutoffs (Affinito and Louie 2018; Archbold et al. 1990; Magasi et al. 2019).

Regression analyses

Burden Scale for Family Caregivers

In the fully adjusted analysis, no methods of visit communication were significantly associated with caregiver burden. Caring for a spouse or partner ($\beta = 5.27$; 95% CI = 2.36, 8.18; $p = <0.01$) and caring for a parent or grandparent ($\beta = 2.96$; 95% CI = 0.33, 5.59; $p = 0.041$) were associated with increased burden scores. A household income of greater than \$50,000 was associated with a decrease in burden ($\beta = -3.11$; 95% CI = $-5.64, -0.58$; $p = 0.02$).

In the sensitivity analysis, we found no statistically significant association between using any method of visit communication with caregiver burden or using both AVS and speaking with the patient with caregiver burden.

Table 1. Participant characteristics

Total (N = 340)	
Age	
Mean (SD)	40.3 (13.9)
Range	18–85
Gender	
Male	199 (58%)
Female	141 (42%)
Race/ethnicity	
White	203 (59.7%)
Asian	42 (12.4%)
Black or African American	42 (12.4%)
Other	12 (3.5%)
Hispanic	41 (12.1%)
Education	
College degree	129 (37.9%)
Less than college	69 (20.3%)
More than college	142 (41.8%)
Income	
\$100,000 or more	127 (37.4%)
<\$50,000	91 (26.8%)
\$50,000–\$99,999	122 (35.9%)
Rurality	
Rural	54 (15.9%)
Urban	286 (84.1%)
Care for >1 condition	
No	210 (61.7%)
Yes	130 (38.2%)
Preparedness for Caregiving Score (32 High)	
Mean (SD)	23.341 (6.221)
Range	0.000–32.000
Caregiver Burden Score (30 High)	
Mean (SD)	17.482 (7.651)
Range	0.000–30.000
Positive Aspects of Caregiving Score (45 High)	
Mean (SD)	35.671 (7.586)
Range	9.000–45.000

Caregiver Preparedness Scale

In the fully adjusted analysis, a printed paper summary ($\beta = 1.88$; 95% CI = 0.61, 3.15; $p = 0.01$), high Positive Aspects of Caregiving Scale score ($\beta = 5.08$; 95% CI = 3.82, 6.35; $p < 0.01$), caring for a spouse or partner ($\beta = 2.47$; 95% CI = 0.40, 4.53; $p = 0.02$), and caregiver experience of 1 year or more ($\beta = 1.44$; 95% CI = 0.24, 2.65; $p = 0.02$) were associated with increases in preparedness scores. Compared to an income greater than \$100,000, an income between \$50,000 and \$99,999 ($\beta = -2.21$; 95% CI = -3.69, -0.73; $p = 0.01$) was associated with decreases in preparedness scores.

There was a statistically significant association between the interaction term for caregiver preparedness, relationship to the care recipient, and gender ($p = 0.021$). After stratifying by relationship to the care recipient, we found that when caring for a spouse or partner, patient portal use was associated with an increase ($\beta = 3.12$; 95% CI = 0.49, 5.74; $p = 0.02$) in preparedness for caregiving, while female caregiver gender was associated with a decrease ($\beta = -2.6$; 95% CI = -5.11, -0.08; $p = 0.02$). Among those who cared for a parent or grandparent, using a printed paper summary was associated with an increase ($\beta = 2.01$; 95% CI = 0.37, 3.65; $p = 0.02$) in preparedness for caregiving.

In the sensitivity analysis, we found that the effect of using any method of communication was associated with an increase ($\beta = 6.15$; 95% CI = 3.31, 9.00; $p = <0.001$) in preparedness score. We also found that using both an AVS and speaking with the patient was associated with additional improvements ($\beta = 2.97$; 95% CI = 1.63, 4.32; $p = <0.001$) to preparedness scores, compared to using just an AVS or just speaking with the patient.

Positive Aspects of Caregiving Scale

In the fully adjusted analysis, speaking with the patient ($\beta = 3.72$; 95% CI = 2.02, 5.42; $p = <0.01$); receiving information from a printed paper summary ($\beta = 1.98$; 95% CI = 0.40, 3.56; $p = 0.01$); identifying as Asian compared to identifying as White ($\beta = 2.43$; 95% CI = 0.09, 4.77; $p = 0.04$); higher preparedness ($\beta = 6.10$; 95% CI = 4.37, 7.82; $p = 0.04$); and comfort using a computer ($\beta = 2.55$; 95% CI = 0.78, 4.32; $p = 0.01$) were associated with increases in positive aspects of caregiving scores. Caregiving for a patient with more than 1 condition ($\beta = -1.55$; 95% CI = -3.06, -0.04; $p = 0.05$) and high caregiver burden ($\beta = -1.58$; 95% CI = -3.15, 0.02; $p = 0.05$) were associated with decreases in positive aspects of caregiving.

In the sensitivity analysis, we found the effect of using any method of communication was associated with an increase ($\beta = 6.62$; 95% CI = 3.10, 10.14; $p = <0.001$) in positive aspects of caregiving score. We also found that using both an AVS and speaking with the patient was associated with an increase ($\beta = 3.8$; 95% CI = 2.15, 5.45; $p = <0.001$) in positive aspects of caregiving scores, compared to using just an AVS or just speaking with the patient.

Unadjusted models, sensitivity analysis, and subgroup analysis can be found in Supplemental File B. Fully adjusted models can be found in Table 2.

Discussion

Our study aimed to understand whether mode of clinic visit communication to family caregivers was associated with caregiver preparedness, caregiver burden, or the positive aspects of caregiving. In our sample, we found caregivers who receive information from printed paper summaries reported higher levels of preparedness to provide care. When caregivers receive information from patients or from AVS, we found improvements to the positive aspects of caregiving. Mode of communicating information from clinic visits was not associated with caregiver burden.

Comparison with prior work

Our sample displays characteristics that are comparable to published literature for family caregivers regarding their caregiver burden, caregiver preparedness, and caregiver positivity. A study of 386 family caregivers found that the mean score (SD) on the

Table 2. Adjusted linear regression analysis

Predictors	Positive Aspects of Caregiving			Preparedness for Caregiving			Caregiver Burden		
	Estimates	CI	p	Estimates	CI	p	Estimates	CI	p
(Intercept)	26.9	22.32, 31.47	<0.001	13.6	9.92, 17.29	<0.001	17.51	12.51, 22.51	<0.001
Age	-0.02	-0.08, 0.04	0.533	0.03	-0.02, 0.08	0.265	-0.04	-0.11, 0.03	0.266
Gender									
Male (referent)									
Female	0.21	-1.42, 1.84	0.802	0.59	-0.72, 1.90	0.377	-1.11	-2.96, 0.74	0.24
Education									
More than a college degree (referent)									
College degree or less	-1.39	-3.09, 0.32	0.11	-0.85	-2.22, 0.53	0.226	-1.43	-3.37, 0.52	0.15
Race									
White (referent)									
Asian	2.43	0.09, 4.77	0.042	0.65	-1.24, 2.53	0.5	-2.03	-4.71, 0.65	0.137
Black/African American	0.63	-1.68, 2.94	0.591	0.88	-0.98, 2.74	0.354	0.05	-2.60, 2.69	0.971
Ethnicity									
Hispanic	0.28	-2.01, 2.56	0.813	0.08	-1.76, 1.92	0.932	-0.18	-2.79, 2.44	0.894
Income									
\$100,000+ (referent)									
<\$50,000	-0.38	-2.61, 1.85	0.739	-0.42	-2.22, 1.38	0.647	-3.11	-5.64, -0.58	0.016
\$50,000-\$99,999	0.17	-1.68, 2.03	0.855	-2.21	-3.69, -0.73	0.004	-1.86	-3.98, 0.26	0.086
Caregiver experience (1 year or more)	-1.25	-2.74, 0.25	0.102	1.44	0.24, 2.65	0.019	-0.37	-2.09, 1.35	0.673
Relationship to care recipient									
Caring for a child (referent)									
Caring for a parent or grandparent	0.77	-1.55, 3.08	0.515	1.58	-0.28, 3.45	0.095	2.96	0.33, 5.59	0.028
Caring for a spouse or partner	1.18	-1.38, 3.75	0.364	2.47	0.40, 4.53	0.019	5.27	2.36, 8.18	<0.001
Caring for >1 condition	-1.55	-3.06, -0.04	0.045	-0.66	-1.89, 0.56	0.288	1.6	-0.14, 3.34	0.071
High positivity				5.08	3.82, 6.35	<0.001	0.17	-1.72, 2.06	0.86
High preparedness	6.1	4.37, 7.82	<0.001				1.16	-0.92, 3.25	0.272
High burden	-1.58	-3.15, -0.02	0.048	0.26	-1.01, 1.52	0.689			
Comfortable using a computer	2.55	0.78, 4.32	0.005	-0.28	-1.71, 1.15	0.701	1.97	-0.06, 4.00	0.057
Comfortable using a tablet	-0.15	-1.76, 1.47	0.858	1.3	0.01, 2.60	0.048	-1.15	-2.99, 0.68	0.217
Comfortable using a smartphone	1.37	-0.26, 3.01	0.1	0.66	-0.66, 1.98	0.323	-1.27	-3.14, 0.60	0.182
Urbanity	0.21	-1.71, 2.14	0.827	-0.6	-2.15, 0.95	0.448	0.89	-1.31, 3.09	0.428
Attending the clinic visit	-0.56	-2.52, 1.39	0.57	1.53	-0.04, 3.09	0.055	-0.82	-3.05, 1.42	0.473
Speaking with the patient	3.72	2.02, 5.42	<0.001	0.34	-1.04, 1.73	0.627	-0.39	-2.35, 1.58	0.697
Printed paper summary	1.98	0.40, 3.56	0.014	1.88	0.61, 3.15	0.004	0.14	-1.67, 1.94	0.88
Patient portal	0.74	-0.86, 2.34	0.363	1.18	-0.10, 2.46	0.072	0.49	-1.34, 2.32	0.596

“Burden Scale for Family Caregivers – Short” was 16.8 (7.1), while our study was 17.4 (7.6) (Pendergrass *et al.* 2018). A pre/post-study of 78 family caregivers found that preparedness for caregiving at baseline was 24.0, compared to our sample of 23.3 (Archbold *et al.* 1990). A large study of 1,219 caregivers found a baseline positivity of 36.0, compared to our 35.7, though that sample was focused on dementia caregivers (Tarlow *et al.* 2016). These baseline similarities suggest our sample was similar to samples included in previous literature.

Our study found that methods of communication, including the printed paper AVS and receiving information directly from the patient, were associated with caregiver preparedness and the positive aspects of caregiving. A study of 252 patient–caregiver dyads where caregivers were given access to shared visit notes and after-visit materials found that caregivers were using visit notes because they were unable to attend doctor visits and wanted to know what was discussed (Wolff *et al.* 2017). They hypothesized that shared note access reduces uncertainty regarding the clinician-recommended plan of care (Wolff *et al.* 2017). Our results expand this hypothesis by indicating an association between the printed AVS and caregiver preparedness. The printed AVS could be reducing uncertainty regarding care planning by providing caregivers with valuable information that prepares them for caregiving. Despite the benefits of the AVS, awareness of and access to AVS remains a challenge (Wolff *et al.* 2017).

Improvements in knowledge through receiving visit information, and by extension caregiver outcomes, could be due to the shared sense of partnership between patients and caregivers. A study of 164 patient–caregiver dyads found that dyads with greater interaction between family members observed improvements to caregiver positivity (Park *et al.* 2012). It is notable that speaking with patients about their visit was not associated with perceived improvements to caregiver preparedness, as patients tend to recall more information about diagnosis, while caregivers find information about treatment to be more useful in preparing them for their caregiving tasks (Kessels 2003; Washington *et al.* 2011). Further, that we observed a positive association between positive aspects of caregiving and preparedness when using both an AVS and speaking with the patient about their visit speaks to the potential benefit of multiple information sources: caregivers may find utility from both patient and after-visit materials. The human connection that occurs when speaking with the patient could be influencing the positive association we found, while more technical information may come from the after-visit materials. Multimodal methods of communicating visit information should be explored to further understand whether a compounding effect exists.

We found less support for an association between method of visit communication and caregiver burden. While the effect could be smaller and thus perhaps detectable with a higher-powered study, further work is needed to determine if an association exists. It is possible that burden is independent of information, and more closely tied to the behavior of the patient and stress levels of the caregiver (Lillo *et al.* 2012).

While not the primary focus of our analysis, we found differences in caregiver outcomes when considering sociodemographic and contextual factors including caregiver gender, relationship type, race, and ethnicity. Prior literature has found that these factors are associated with different communication in caregivers: for instance, spouses communicate differently than children and parents or grandparents (Fenton *et al.* 2022), and communication has been shown to be affected by gender (Carmel *et al.* 2020), and cultural factors (Starr *et al.* 2022). While we controlled for these factors

in our modeling, indicating that an association between method of visit communication and caregiver outcomes exists that is robust to these factors, future work could consider understanding the visit communication needs of these groups.

Strengths and limitations

This project is not without limitations. The study occurred in the summer of 2020, after the first surge of the COVID-19 pandemic: most caregivers usual routines were interrupted and changed. We asked questions about both usual routines and caregiving during the COVID-19 pandemic and to minimize confusion, we split the survey into clear sections that delineated what aspect of caregiving the questions related to. Because we used online panels and social media to recruit members of the general public, it is not possible to create an overall response rate as there is no defined population denominator (Callegaro and Disogra 2008). However, studies have shown probability sampling methods and online panel-based sampling produce comparable estimates for self-reported physical and mental health outcomes (Riley *et al.* 2013). While our sample had more male respondents than female respondents, research has called for understanding the experience of caregivers identifying as male. We could not determine the overall number of participants removed for failing Qualtrics quality checks, and Qualtrics participants may receive compensation from Qualtrics for completing surveys. However, we found no statistically significant differences between the Qualtrics sample and the NAC sample in our modeling.

While we considered the potential issues associated with multiple testing, the tendency for common adjustment methods such as the Bonferroni Correction or the Benjamini–Hochberg Procedure to inflate the Type 2 error rates is less ideal for studies of an exploratory nature (Rothman 1990). While we cannot explore causation in this cross-sectional survey, we explored possible associations between mode of receiving information and caregiver outcomes including preparedness, burden, and the positive aspects of caregiving scale. As such, our conclusions should be viewed tentatively and require further directed studies to help determine whether causal relationships exist. Additionally, caregivers self-selected their mode of receiving with clinic visit information, so these results could be based on variation in the needs, conditions, or limitations of patients. While we controlled for multiple methods of receiving with visit information in the regression modeling, methods of receiving information were not mutually exclusive in the survey; thus, a possibility exists that receiving information from multiple modes could have influenced caregiver outcomes.

We also did not specify in the survey that caregivers should respond based on visits they did not attend. As such, we are unable to comment on the potential effect of triadic communication on their survey responses. We are limited in our ability to examine the details of patient–caregiver illness communication due to the phrasing of our survey. Patients could have chosen to disclose or not disclose information based on factors including stigma, relationship quality, and anticipated caregiver reaction (Greene 2009). Future studies could include examination of the effect of triadic communication on caregiver information-seeking behavior. Future work should consider the differences in needs of specific caregiver populations, though our results provide a useful overview on caregiving more generally. We also did not specify between general primary care visits and specialty visits addressing specific concerns, which could have impacted caregiver informational needs.

Implications

Given our primary findings, the implementation of accessible AVS for family caregivers may improve caregiver preparedness and the positive aspects of caregiving. While the CARE Act requires participating hospitals to enable family caregivers with information from the clinic visit (Griffin et al. 2022), our results indicate that states who have yet to introduce the CARE Act could optimize after-visit communication to family caregivers and positively impact caregiver preparedness and the positive aspects of caregiving.

When taken in context with prior literature, it is clear that communication of information from visits has benefits to family caregivers but implementation is poor (Reinhard 2019). Health systems should focus efforts on improving the implementation of after-visit materials by understanding what caregivers value most and facilitating access to this information to improve patient and caregiver outcomes (Wolff et al. 2017).

Conclusions

This study provides preliminary evidence for an association between higher preparedness and positive aspects of caregiving and provision of clinic visit information, so health systems should consider how to leverage technological advancements to facilitate the sharing of information with family caregivers. Additional effort should be given to understand and address the drivers of burden among caregivers, which may be independent of information-sharing.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951524000427>.

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