

Original Research Article

Care Recipient Concerns About Being a Burden and Unmet Needs for Care

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Abstract

Background: Disabled older adults' needs for help with daily activities sometimes go unmet with potentially long-term negative consequences for health and well-being.

Objectives: To examine the relationship between care recipient unmet needs and (1) concerns about being a burden; (2) perceptions of caregiver burden; and (3) and caregiver self-reports of burden in community-dwelling care recipient–caregiver dyads.

Research Design and Methods: Telephone surveys with 196 linked caregiver–care recipient dyads from the 2017 *Pittsburgh Regional Caregiver Survey*. Of 376 caregivers who gave initial permission to contact the recipient (February–July), 262 caregivers were recontacted and gave permission to attempt a care recipient survey (September–October; $n = 196$ completed; 74.8% response rate). In addition to the burden measures, we controlled for several covariates, including disability level, receipt of paid help, and care recipient and caregiver sociodemographics.

Results: Slightly more than one fourth (27.2%) of care recipients were “very concerned” about being a burden, and 43.6% were “somewhat concerned.” Care recipient concerns about being a burden ($\exp(B) = 1.71$, 95% confidence interval [CI] $\exp(B) [1.15, 2.54]$); and caregiver self-reported burden ($\exp(B) = 1.82$, 95% CI $\exp(B) [1.17, 2.85]$) were independent predictors of more care recipient unmet needs. Recipient perceptions of caregiver burden were not independently predictive. Care recipients with higher disability levels, those without paid help, and those whose caregiver was not a spouse/child also reported more unmet needs. The impact of burden on unmet needs was stronger for instrumental activities of daily living/mobility needs than for activities of daily living needs.

Discussion and Implications: Potential interventions to reduce unmet needs should take a dyadic approach, focusing on reducing both care recipient perceptions of being a burden and caregiver experienced burden.

Translational Significance: The results suggest that older adults who are transitioning to needing help with household chores and mobility due to health problems would benefit from explicit discussions with family regarding concerns about being a burden. Open discussions with caregivers, who may also have concerns about their own abilities to provide adequate help, may help families navigate complex decisions about obtaining needed supports. Ideally, such care recipient–caregiver discussions about help needed should be routinely incorporated into health care provider visits.

Keywords: Caregiving dyads, Caregiver stress, Disabilities, Informal caregiving

According to a recent national survey, nearly 10 million older adults in the United States receive help in their homes with household or self-care activities due to limitations in physical health and functioning, mental health, and/or cognitive functioning (Freedman & Spillman, 2014; Schulz & Eden, 2016). The majority of this help is provided by family and friends, though formal paid helpers can also supplement or provide an alternative to care provided by family and friends. Unfortunately, despite the best efforts of caregivers, older adults' needs for help with daily activities can sometimes go unmet, and this can have long-term negative consequences for health and well-being. The reasons for these unmet needs are complex and may involve care recipient, caregiver, or a variety of contextual or relationship factors. This paper focuses on one care recipient variable not previously examined in this context. Specifically, we examine the relationship between care recipient unmet needs and their *concerns about being a burden to their loved ones*. We use a dyadic approach, collecting data from caregiver and care recipient pairs to explore care recipient reports of unmet needs.

As noted above, family and friends play a critical role in maintaining the health of loved ones who suffer from chronic illness or disability (Schulz & Eden, 2016). While many informal family caregivers adequately meet the needs of disabled or chronically ill older adults, this may not always be the case. There is a growing literature on the prevalence, correlates, and consequences of unmet needs for help with basic activities of daily living (ADL) and instrumental activities of daily living (IADL) among disabled older adults (Allen & Mor, 1997; Beach & Schulz, 2017; Beach et al., in press; DePalma et al., 2013; Desai, Lentzner, & Weeks, 2001; Freedman & Spillman, 2014; Hass, DePalma, Craig, Xu, & Sands, 2017; He et al., 2015; Kennedy, 2001; Lima & Allen, 2001; Newcomer, Kang, LaPlante, & Kaye, 2005; Sands et al., 2006; Xu, Covinsky, Stallard, Thomas, & Sands, 2012). While prevalence of unmet needs for specific ADL/IADL tasks varies widely, studies using national probability samples of disabled older adults report overall prevalence for any unmet need during the past month of approximately 20–32% (Desai et al., 2001; Freedman & Spillman, 2014; Kennedy, 2001; Newcomer et al., 2005). A consistent finding across these studies was that higher levels of disability were associated with more unmet needs—the greater the needs for assistance, the less likely they were to be completely met (Allen & Mor, 1997; Beach & Schulz, 2017; Beach et al., in press; Desai et al., 2001; Freedman & Spillman, 2014; Kennedy, 2001; Lima & Allen, 2001; Newcomer et al., 2005). Other correlates of unmet needs included low income/poverty, living alone, minority status, and poor overall health. More recent research has linked unmet needs with increased risk of hospitalizations (Sands et al., 2006; Xu et al., 2012), hospital readmissions (DePalma et al., 2013), emergency department admissions, particularly for falls and injuries (Hass et al., 2017), and mortality (He et al., 2015).

Somewhat surprisingly, studies on care recipient unmet needs have rarely explored care recipient perceptions and attitudes as predictive factors, and dyadic approaches where both care recipient and linked caregiver data are included, are even rarer. In one recent study, Beach and Schulz (2017) found that care recipients reporting multiple unmet needs had caregivers who were more likely to spend > 100 hr/month caregiving and report caregiving as emotionally and physically difficult. They concluded that caregivers experiencing high levels of burden or stress may provide substandard/poor care to older adults, which may be a risk factor for neglect. While Beach and Schulz (2017) used a dyadic approach to data analyses, care recipient variables were limited to standard sociodemographic variables and disability level. This study expands on the dyadic approach to the study of unmet needs for care by focusing on *care recipient concerns about being a burden to their loved ones* as a potential key factor. Concerns about burdening loved ones may inhibit help seeking, resulting in unmet needs and potentially negative consequences for disabled older adults.

The broader literature on care recipients' reactions to being helped, and the health and well-being outcomes as a result of receiving care is also limited (Cotrell & Schulz, 1993; Lyons, Zarit, Sayer, & Whitlatch, 2002; Martire & Schulz, 2012; Martire, Schulz, Wrosch, & Newsom, 2003; Newsom, 1999; Newsom & Schulz, 1998). How care recipients feel about receiving help can have important consequences for the impact, quality, and adequacy of help received. Newsom and Schulz (1998) reported negative reactions to being helped, such as “concern about spouse being injured providing help” (66%); “wished could give more in return” (31%); and “felt would never be able to return the favor” (27%) in a sample of older care recipients with spouse caregivers. Another study found that negative reactions to being helped (“helping distress”) predicted depression one year later (Newsom & Schulz, 1998). Martire et al. (2003) found that care recipients' perceptions of lower quality care received from caregivers predicted increased care recipient depression and reduced mastery one year later.

This study extends previous work by exploring care recipient concerns about being a burden to loved ones as a predictor of unmet needs for care. We take a novel approach by examining concerns about being a burden as a potential impediment to actually getting the help needed. The Newsom and Schulz (1998) findings on concerns about caregiver injury, wishing they could give more in return, and not being able to return the favor could be interpreted as concerns about being a burden. They may also reflect perceptions that caregivers themselves are burdened. Might such concerns about being a burden and/or perceptions that the caregiver is burdened make the care recipient reluctant to ask for needed help? We predict that greater care recipient concerns about being a burden will be associated with more care recipient-reported unmet needs. Consistent with our emphasis on dyadic analysis, we also

assess the relationship between: (1) *care recipient perceptions of caregiver burden*; and (2) *caregiver self-reports of burden* and unmet needs of the care recipient. We distinguish between care recipient concerns about being a burden and perceptions of caregiver burden, and caregiver burden as directly reported by the caregiver. Consistent with prior research (e.g., Beach & Schulz, 2017), we predict that caregiver-reported burden will be positively associated with the number of unmet needs. Given that they involve inferences about another person's psychological state, no predictions were made about care recipient perceptions of caregiver burden and unmet needs. However, we were interested in exploring the role these perceptions of caregiver burden might play as a potential explanatory factor in unmet needs; and how they relate to directly reported care recipient burden concerns and caregiver-reported burden. Including care recipient perceptions of caregiver burden allows a more nuanced examination of dyadic processes related to unmet needs.

We also included a number of covariates in our analyses because of their potential association with care recipients' number of unmet needs. We controlled for care recipients' total number of needs for care as a proxy for disability, because having more needs has been shown to increase the likelihood of having one or more of these needs go unmet (Allen & Mor, 1997; Beach & Schulz, 2017; Beach et al., in press; Desai et al., 2001; Freedman & Spillman, 2014; Kennedy, 2001; Lima & Allen, 2001; Newcomer et al., 2005). We also reasoned that care recipients without *paid help* may have more unmet needs. We included both care recipients' and caregivers' *age and sex*, because both of these may be associated with greater number of unmet needs. For example, older care recipients may require more intense caregiving, and older caregivers may be more limited than younger caregivers in the amount and type of care they can provide, potentially resulting in greater number of unmet needs. It is possible, moreover, that caring for a male care recipient might be more difficult because males might be taller and/or heavier than females. In turn, female caregivers might be more limited in the type of care they can provide. We included both care recipients' and caregivers' *level of education* as a proxy for socioeconomic status, because lower socioeconomic status may be associated with fewer available resources and, therefore, a greater number of unmet needs. We also included *care recipient race* as cultural factors may play a role in unmet needs. Lastly, we included the *caregiver's relationship to the care recipient*. This could be relevant for unmet needs as greater distance from one's caregiver (e.g., a friend vs a spouse) might make it more difficult to ask for help.

Design and Methods

Participants

Participants were from the 2017 *Pittsburgh Regional Caregivers Survey*. Data were collected during telephone

interviews from 1,008 caregivers and a subsample of 196 of their linked care recipients. Caregivers were asked at the end of the interview if they would be willing to have the care recipient contacted for a separate interview. Care recipients with Alzheimer's disease or related dementia were not eligible, as they are less likely to be able to provide valid self-reports. Caregivers were unpaid friends and relatives taking care of adults age 50 years and older living in Pittsburgh, Pennsylvania and the vicinity. The caregivers could be any age (18 years and older).

Caregiver Sampling and Data Collection

A variety of sampling and recruitment methods were utilized to identify caregivers, including random digit dialing (RDD) of landline and cellular phones, listed household samples, research registries, and recruitment flyers through local service providers. Caregivers were screened and included in the study if they provided care to a relative, partner, or friend aged 50 years or older. The following questions were used to screen for caregivers:

- (1) "Are you or anyone in your household currently providing unpaid care to a relative, partner, or friend age 50 years or older to help them take care of themselves because of a chronic illness or disability? This may include helping with personal needs, household chores, or medical / nursing tasks. It might also be managing a person's finances or arranging for outside services. This adult need not live with you";
- (2) "Do you currently help with PERSONAL CARE TASKS, such as bathing, dressing, grooming, eating, moving from bed to chair, or going to the toilet?";
- (3) "Do you currently help with HOUSEHOLD TASKS, such as shopping, managing personal finances, arranging for outside services, or providing transportation?";
- (4) "Do you currently help with MEDICAL OR NURSING TASKS, such as managing medications, changing dressing on wounds, or monitoring equipment like oxygen tanks?";

To be eligible, respondents had to answer "yes" to item 1, AND "yes" to at least one of items 2, 3, and 4.

Telephone interviews were conducted by staff from the University Center for Social and Urban Research (UCSUR) at the University of Pittsburgh from February 2017 to July 2017. The survey took approximately 60 min and was approved by the Institutional Review Board. Respondents received a \$15 debit card for participating. The final survey sample contained 1,008 caregivers. The cooperation rate was 67.8% among identified eligible caregivers.

Care Recipient Sampling and Data Collection

Both the caregiver, then the care recipient had to agree to the care recipient interview. Of 376 caregivers who gave

initial permission to contact the recipient (in February–July), we were able to recontact 262 caregivers and get permission (69.7%) to attempt a care recipient survey (in September–October; $n = 196$ completed; 74.8% care recipient completion rate; 52.1% overall completion rate [$.697 \times .748$]). Of the remaining 114 caregivers, we were unable to contact 38, 60 refused to allow the care recipient to be interviewed, and 16 reported that care recipient was too ill to conduct the interview. Telephone interviews with care recipients were conducted by UCSUR staff in September 2017 and October 2017. The survey took approximately 30 min to complete and was approved by the Institutional Review Board. Respondents received a \$15 debit card for participating.

Care Recipient-Reported Measures

Number of unmet needs

Care recipients were asked 12 questions about their needs for care during the last month. Specifically, they were asked whether they had needed help with any of the following activities due to poor health or functioning: “eating,” “bathing,” “toileting,” “getting dressed,” (ADL); “leaving home,” “moving inside home,” “getting out of bed,” (*mobility* needs); “doing laundry,” “shopping,” “making hot meals,” “handling bills and banking,” and “keeping track of taking prescribed medications” (IADL). If care recipients answered “yes” to these questions, they were then asked if they had to go without having this specific need met because there was nobody around to help them (see [Supplementary Appendix Table 2A](#) for item wording).

We first summed care recipients’ number of needs to create a total score of number of needs (ranging from 0 to 12). We excluded participants who had reported zero needs ($n = 23$; 11.7%) and retained all participants who had reported one or more needs ($n = 173$, 88.3%). We did this because we were interested in predicting the number of care recipients’ needs that had gone unmet. The number of unmet needs was then summed for analyses.

Concern about being a burden

Care recipients were asked “How concerned are you about being a burden to others due to needing help with everyday tasks?” They answered this question on a 3-point scale: 1 (*Not concerned at all*); 2 (*Somewhat concerned*); 3 (*Very concerned*).

Perceived caregiver burden

Care recipients answered four questions: “To what extent do you think that providing help to you is emotionally difficult for your caregiver?,” “How worried are you that the emotional stress of caregiving might make them ill?,” “To what extent do you think that providing help to you is physically difficult for your caregiver?,” and “To what extent are you worried that your caregiver might hurt themselves because of the care they provide to you?,” They answered

all questions using the following 4-point scale: 1 (*Not at all*); 2 (*A little*); 3 (*Somewhat*); 4 (*Very*). We created a composite score by averaging across participants’ answers, with higher scores reflecting higher perceived caregiving burden (Cronbach’s $\alpha = .80$).

Caregiver-Reported Measures

Caregiver burden

Caregivers were asked to report on the extent to which they experienced negative aspects of caregiving by reporting the extent to which they “are exhausted when they go to bed at night,” “have more things to do than they can handle,” “don’t have time for themselves,” and “as soon as they get a routine going, the care recipient needs change.” Caregivers answered these questions on the following 3-point scale: 1 (*Not so much*); 2 (*Somewhat*); 3 (*Very much*). We created a composite score by averaging across these items, with larger values reflecting greater caregiver burden (Cronbach’s $\alpha = .78$).

Covariates

Care recipients’ paid help

Care recipients indicated whether or not they received paid help (*yes/no*), with no paid help coded “1.”

Age and sex

Caregiver and care recipient age were entered as continuous variables. Gender was entered as dummy variables with female coded “1.”

Race

Care recipient and caregiver race were identical for all dyads, so only care recipient race was included. We coded race as African American versus all other (coded “1”), because approximately 98% of the sample was either African American or Caucasian.

Level of education

We coded for caregiver and care recipient level of education as follows: high school (equivalent) or less; some college education and/or an Associate’s degree; a Bachelor’s degree; and a Master’s degree or higher.

Caregiver’s relationship to the care recipient

We coded this variable as follows: spouse, adult child, or other.

Data Analytic Plan

We tested the associations between care recipient concern about being a burden, care recipient perceived caregiver burden, caregiver self-reported burden, and care recipients’ number of unmet needs using a negative binomial

regression model. We chose this type of analysis to account for the fact that our outcome variable—unmet needs—was a count variable that was over-dispersed, with its variance being greater than its mean (Pearson χ^2 (151) = 217.13; Pearson $\chi^2/151 = 1.44$). We used traditional regression modeling rather than a formal dyadic data analysis approach since we were not collecting parallel data from caregivers and care recipients (Kenny, Kashy, & Cook, 2006). Rather, caregivers and care recipients reported independently on concerns about being a burden, perceptions of caregiver burden (care recipient), and caregiver burden (caregiver). Recipient perceptions of caregiver burden and caregiver-reported burden were also measured using different items.

As noted above, we controlled for a number of variables that might potentially be associated with care recipients' number of unmet needs, including care recipients' total number of needs, whether or not they also received paid help, care recipients' age, sex, race, and level of education. We also controlled for caregivers' age, sex, and level of education, as well as their relationship to the care recipient. We should note that including these covariates did not change the pattern of our findings compared to analyses that only tested our variables of interest as predictors.

As described in the Design and Methods section, we excluded all data from care recipients who reported not having any needs for care ($n = 23$). We also excluded data from participants with one or more missing values in our predictor variables ($n = 3$), resulting in a final sample of 170 care recipients and their linked caregivers. Descriptive statistics of our sample are displayed in Table 1, bivariate Pearson and Spearman correlations among key variables are displayed in Table 2, and the results of our multivariate negative binomial analyses are displayed in Table 3. Supplementary negative binomial analyses broken down by type of unmet needs (ADL, mobility, IADL) are displayed in Supplementary Appendix Table 1A. Supplementary Appendix Table 2A also contains bivariate associations between care recipient burden concerns and each of the individual unmet needs indicators.

Results

Sample Characteristics

As can be seen in Table 1, our sample consisted of older care recipients who were between 50 and 100 years old ($M = 75.4$, $SD = 12.3$). Caregivers were more diverse with respect to their age and were between 20 and 86 years old ($M = 60.4$, $SD = 13.0$). Care recipients were predominantly female (61.2%), as were caregivers (71.2%). The majority of care recipients were cared for by their spouse (42.9%) or child (39.4%) and did not have access to additional paid help (82.9%).

Regarding our predictor variables of interest, on average, care recipients reported feeling somewhat concerned about being a burden ($M = 2.04$, $SD = 0.74$). They also perceived their caregiver as being “a little” burdened ($M = 1.99$,

$SD = 0.79$). Caregivers also reported being somewhat burdened ($M = 1.75$, $SD = 0.58$). Among those with at least one ADL/IADL/mobility needs, care recipients reported an average of just under five needs ($M = 4.86$, $SD = 3.2$), and an average of slightly less than one unmet need ($M = 0.85$, $SD = 1.98$), for an overall unmet need rate of 17.5%. Note also that while the majority of the reported needs were for IADL tasks ($M = 2.85$), the highest proportion of unmet needs was for mobility tasks ($M = 0.95$ needs; $M = 0.32$ unmet needs = 33.7% unmet). In contrast, 19.8% of ADL and 11.2% of IADL needs were reported as unmet.

Bivariate Correlations Among Key Variables

As shown in Table 2, our main predictor variable of interest—care recipients' concern about being a burden—was associated with caregiver burden as perceived by care recipients ($r = .38$, $p < .01$). This suggests that care recipients' concern about being a burden might potentially stem from the perception that their caregiver is currently burdened. It is interesting that caregiver burden as reported by caregivers themselves was not associated with care recipients' concern about being a burden ($r = .05$, ns), even though there was a weak association between care recipient perceived and actual caregiver burden ($r = .16$, $p < .05$). Finally, our outcome variable—number of unmet needs—was significantly correlated all three key predictors: concern about being a burden ($r = .32$, $p < .01$), caregiver burden as perceived by care recipients ($r = .21$, $p < .05$), burden as reported by caregivers ($r = .19$, $p < .05$).

Number of Unmet Needs: Negative Binomial Regression Analyses

As seen in Table 3, our predictors as a whole were significantly associated with care recipients' number of unmet needs, χ^2 (18) = 133.071, $p < .001$. Of the care recipient variables, our key predictor—concern about being a burden—was significantly associated with more unmet needs, such that the number of unmet needs increased by 1.71 times for every unit increase in concern about being a burden ($B = 0.53$, $\exp(B) = 1.71$, 95% confidence interval [CI] $\exp(B)$ [1.15, 2.54]). Care recipient perceptions of caregiver burden were not related to unmet needs.

Our caregiver variable—caregiver-reported burden—was also associated with more care recipient unmet needs, such that the number of care recipient unmet needs increased by 1.82 times for every unit increase in caregiver burden, ($B = 0.60$, $\exp(B) = 1.82$, 95% CI $\exp(B)$ [1.17, 2.85]).

Of the covariates that we included in our analyses, the following were significantly associated with number of unmet needs: total number of needs for care; whether or not care recipients' received paid help; and caregiver relationship to the care recipient. Specifically, number of unmet needs increased by 1.41 times for every additional need for

Table 1. Descriptive Statistics for Analytical Sample ($n = 170$)

	<i>M</i>	<i>SD</i>	Minimum	Maximum
<i>Continuous</i>				
Care Recipient Concern about Being a Burden	2.04	0.74	1	3
Care Recipient Perceived Caregiver Burden	1.99	0.79	1	4
Caregiver-Reported Burden	1.75	0.58	1	3
Care Recipient Age	75.4	12.3	50	100
Caregiver Age	60.4	13.0	20	86
Total # ADL/IADL Mobility Needs (≥ 1 ; max. 12)	4.81	3.15	1	12
Total # Unmet needs	0.84	1.97	0	12
# ADL Needs (among Total ≥ 1 ; max. 4)	1.01	1.27	0	4
# Unmet ADL needs	0.20	0.65	0	4
# IADL Needs (among Total ≥ 1 ; max. 5)	2.85	1.46	0	5
# Unmet IADL needs	0.32	0.87	0	5
# Mobility Needs (among Total ≥ 1 ; max. 3)	0.95	1.02	0	3
# Unmet Mobility needs	0.32	0.71	0	3
<i>Discrete</i>				
	<i>n (%)</i>			
Care Recipient Concern about Being a Burden				
Not at all	57 (29.1%)			
Somewhat	85 (43.6%)			
Very	53 (27.2%)			
Paid Help				
Yes	29 (17.1%)			
No	141 (82.9%)			
Care Recipient Sex				
Male	66 (38.8%)			
Female	104 (61.2%)			
Care Recipient Education				
High School or Less	70 (41.2%)			
Some College	57 (33.5%)			
Bachelor's Degree	26 (15.3%)			
Master's Degree or Higher	17 (10%)			
Care Recipient Race				
African American	32 (18.8%)			
Caucasian/Other	138 (81.2%)			
Caregiver Sex				
Male	49 (28.8%)			
Female	121 (71.2%)			
Caregiver Education				
High School or Less	37 (21.8%)			
Some College	59 (34.7%)			
Bachelor's Degree	37 (21.8%)			
Master's Degree or Higher	37 (21.8%)			
Caregiver Relationship to Care Recipient				
Spouse	73 (42.9%)			
Adult Child	67 (39.4%)			
Other	30 (17.6%)			

Note: ADL = Activities of daily living; IADL = Instrumental activities of daily living.

care ($B = 0.34$, $\exp(B) = 1.41$, 95% CI $\exp(B)$ [1.30, 1.53]); increased by 2.92 times when they did not (vs did) have additional paid help ($B = 1.07$, $\exp(B) = 2.92$, 95% CI $\exp(B)$ [1.52, 5.61]); and increased by 2.17 times when the caregiver was someone other than a spouse or child ($B = 0.77$, $\exp(B) = 2.17$, 95% CI $\exp(B)$ [1.06, 4.42]).

Supplementary Analyses: Number of Unmet ADL, Mobility, and IADL Needs

The results of our supplementary analyses are reported in [Supplementary Appendix A](#). In [Supplementary Table 1A](#), we used our model to test associations with number of

unmet ADL, mobility, and IADL needs separately. As can be seen in the table, concern about being a burden was associated with greater likelihood of having unmet mobility ($B = 0.60$, $\exp(B) = 1.82$, 95% CI $\exp(B)$ [1.16, 2.85]) and IADL ($B = 0.59$, $\exp(B) = 1.81$, 95% CI $\exp(B)$ [1.03, 3.20]) needs. Concern about being a burden was not significantly associated with unmet ADL needs. Caregiver-reported burden was associated with higher likelihood of having unmet IADL needs ($B = 1.01$, $\exp(B) = 2.75$, 95% CI $\exp(B)$ [1.39, 5.47]), but not unmet ADL or mobility needs. As in the main analyses in Table 3, care recipient

perception of caregiver burden was not associated with unmet needs.

Regarding covariates, the number of ADL, mobility, and IADL activities care recipients needed help with was significantly associated with greater number of unmet ADL needs, respectively ($B = 0.86$, $\exp(B) = 2.35$, 95% CI $\exp(B)$ [1.41, 3.72]), mobility ($B = 0.85$, $\exp(B) = 2.33$, 95% CI $\exp(B)$ [1.65, 3.29]), and IADL ($B = 0.31$, $\exp(B) = 1.37$, 95% CI $\exp(B)$ [1.27, 1.47]). Care recipients not receiving paid help was associated with more unmet IADL needs ($B = 0.76$, $\exp(B) = 2.14$, 95% CI $\exp(B)$ [1.17, 3.91]). Finally, care recipient sex was associated with unmet IADL needs ($B = -1.13$, $\exp(B) = 0.32$, 95% CI $\exp(B)$ [0.12, 0.86]), with female care recipients reporting fewer unmet needs than male care recipients.

In Supplementary Table 2A, we focused on each of the 12 individual unmet needs for care and computed mean concern about being a burden between care recipients who had each specific need being met versus unmet. We also conducted exploratory binary logistic analyses using only concern about being a burden to predict the likelihood of each of the 12 needs being met versus unmet. We focused on concern about being a burden, because the sample size for these analyses was often very small (e.g., only 24 care recipients reported that they needed help with eating), and this variable appeared to be the most consistent predictor associated with unmet needs.

Table 2. Correlations Among Key Predictor Variables and Number of Unmet Needs

Variable	1	2	3	4
1. Care Recipient Concern about Being a Burden	-			
2. Care recipient Perceived Caregiver Burden	.38***	-		
3. Caregiver-Reported Burden	.05	.16*	-	
4. Number of Unmet Needs	.32***	.21**	.19*	-

Note: Associations among continuous predictor variables (1,2,3) were calculated using Pearson correlations; associations between our predictors and number of unmet needs (1,2,3 with 4) were calculated using Spearman's correlations in order to account for the fact that number of unmet needs was a count variable.

[†] $p < .10$; * $p < .05$; ** $p < .01$; *** $p < .001$.

Table 3. Negative Binomial Regression Analyses Predicting Total Number of Unmet Needs

	Beta	Exp(B)	Exp(B) 95% CI
Key Predictors			
Care Recipient Concern about Being a Burden	0.53	1.71**	(1.15, 2.54)
Care Recipient Perceived Caregiver Burden	0.02	1.02	(0.71, 1.46)
Caregiver-Reported Burden	0.60	1.82**	(1.17, 2.85)
Covariates			
# Activities Care Recipient Needs Help with	0.34	1.41***	(1.30, 1.53)
Care Recipient Does not Receive Paid Help	1.07	2.92*	(1.52, 5.61)
Care Recipient Sex (Female)	-0.45	.64	(0.31, 1.33)
Care Recipient Age	-0.01	.99	(0.97, 1.02)
Care Recipient Race (Non-African American)	-0.20	.82	(0.39, 1.70)
Care Recipient Education (Some College)	-0.10	.91	(0.50, 1.64)
Care Recipient Education (Bachelor's Degree)	0.27	1.31	(0.62, 2.77)
Care Recipient Education (Master's Degree+)	-0.34	.71	(0.23, 2.27)
Caregiver Sex (Female)	0.46	1.58	(0.76, 3.27)
Caregiver Age	0.00	1.00	(0.98, 1.03)
Caregiver Education (Some College)	-0.12	.88	(0.45, 1.74)
Caregiver Education 2 (Bachelor's Degree)	0.32	1.38	(0.57, 3.34)
Caregiver Education (Master's Degree+)	-0.74	.48	(0.18, 1.28)
Relationship to Care Recipient (Child)	0.38	1.46	(0.61, 3.51)
Relationship to Care Recipient (Neither Spouse nor Child)	0.77	2.17*	(1.06, 4.42)

Note: For care recipient and caregiver sex, "male" was the reference condition; for care recipient and caregiver race, "African American" was the reference condition; for care recipient and caregiver education, "high school or less" was the reference condition; for relationship to the care recipient, "spouse" was the reference condition.

Collinearity diagnostic Variance Inflation Factor (VIF) statistics for all model predictors were less than 1.7, indicating low multicollinearity.

* $p < .05$; ** $p < .01$; *** $p < .001$.

Concern about being a burden was associated with a significantly higher likelihood of having an unmet need for the following needs: bathing ($B = 2.10$, $\exp(B) = 8.15$, 95% CI $\exp(B)$ [1.73, 38.77]); leaving the home ($B = 1.69$, $\exp(B) = 5.39$, 95% CI $\exp(B)$ [2.27, 12.81]); doing laundry ($B = 1.52$, $\exp(B) = 4.57$, 95% CI $\exp(B)$ [1.30, 16.10]); and shopping ($B = 1.95$, $\exp(B) = 7.05$, 95% CI $\exp(B)$ [1.61, 30.96]). Concern about being a burden was also associated with a marginally higher likelihood of having an unmet need for the following needs: hot meals; bills and/or banking; and managing medications. After applying Bonferroni corrections ($\alpha_{\text{Adjusted}} = .05/12 = .004$), concern about being a burden was only associated with a higher likelihood of having an unmet need regarding leaving the home.

DISCUSSION AND IMPLICATIONS

We tested the associations between care recipient concern about being a burden and other care recipient and caregiver-reported variables—specifically caregiver burden as perceived by the care recipient and as reported by the caregiver—and care recipient-reported number of unmet needs for care. We reasoned that concern about being a burden and, potentially, these other variables might contribute to care recipients' number of unmet needs. Our analyses suggested that two of these variables were independently associated with greater number of unmet needs for care: care recipients' *concern about being a burden*—possibly because experiencing concern about (further) burdening loved ones might inhibit one from asking for additional help—and *caregiver-reported burden*—possibly because burdened caregivers may be limited in the extent to which they can provide help. It is important to note that these were independently associated with unmet needs reported by care recipients. That is, the results suggest two separate pathways to unmet needs, one care recipient related, and the other caregiver related. This highlights the importance of the dyadic approach to the study of care recipient unmet needs for care. We should also note that the caregiver-reported burden results replicate the Beach and Schulz (2017) findings reviewed above, but the care recipient concerns about being a burden provide an important extension to that work.

Of these two variables, it appears that care recipients' concern about being a burden might be a more reliable predictor of unmet needs. Specifically, supplementary analyses looking at type of need for care (ADL, mobility, IADL) found that concern about being a burden was significantly associated with both mobility and IADL unmet needs, while caregiver burden was only significantly associated with IADL unmet needs. It is interesting that neither care recipients' concern about being a burden nor caregiver burden were significantly associated with number of ADL unmet needs. This, however, might partially have resulted from constraints in statistical power, given that the subgroup of

care recipients with one or more unmet ADL needs was relatively small ($n = 86$). It might also be the two “pathways” to unmet needs operate simultaneously in the earlier phases of the disability and caregiving trajectory (Schulz & Eden, 2016), when more advanced IADL activities begin to require attention. As disability progresses to issues with mobility, care recipient perceptions of burden may become the more important factor. Once disability advances to the basic self-care ADL stages, factors other than burden seem to be more relevant to unmet needs.

It is interesting that perceived caregiver burden (by the care recipient) was not associated with number of unmet needs in the full model. As it appears, unmet needs may not stem from the perception that one's caregiver is burdened, but from the concern that one will (further) burden them. We should note, however, that perceived caregiver burden was correlated with greater concern about being a burden, suggesting that such concern might partially arise from the perception that one's caregiver is already burdened. Actual caregiver burden was not associated with care recipients' concern about being a burden, and actual and perceived caregiver burden were associated, but this association was small ($r = .16$), suggesting that care recipients might not reliably recognize the extent to which their caregiver is burdened. This is further evidence for the two independent “pathways” to unmet needs discussed above. Our results also show the additional risk for unmet needs of not having paid help to supplement care provided by family and friends. Our analyses also replicated the commonly reported relationship between disability level (i.e., number of needs) and unmet needs (Allen & Mor, 1997; Beach & Schulz, 2017; Beach et al., in press; Desai et al., 2001; Freedman & Spillman, 2014; Kennedy, 2001; Lima & Allen, 2001; Newcomer et al., 2005). Finally, we showed that caregivers with more distant relationships to the care recipient (i.e., not a spouse or child) was associated with more unmet needs, perhaps as a result of recipients not feeling comfortable asking for help; or the caregiver not having enough time to provide adequate help.

Contributions, Limitations, and Directions for Future Research

The present study had several important strengths, including that it considered both care recipient and caregiver-reported variables in predicting unmet needs for care. As mentioned in the introduction, combining care recipient and caregiver variables in a single study is not (yet) common practice. The findings of this study can help provide potentially meaningful suggestions for practical applications in the caregiving realm and, specifically, for reducing care recipients' unmet needs for care. For example, if our findings are replicated in larger samples, interventions could be designed to reduce care recipients' concern about being a burden to their caregivers. Such care recipient oriented interventions could perhaps be combined with already

existing interventions meant to reduce caregiver burden (e.g., see Sörensen, 2002), which was shown to be an independent predictor of unmet needs in the present research.

Regarding limitations, the most important limitation of the present research was that it was cross-sectional, and, thus, determining causal direction of effects was not possible. Even though we assumed that experiencing concern about burdening one's caregiver might lead to more unmet needs, for instance by deterring one from asking for help, the correlational nature of our design did not allow us to explicitly test this prediction. It is possible, for example, that care recipients' concern about being a burden might stem from having a large number of needs for care. A similar causality question could be asked regarding caregiver-reported burden and unmet needs. Perhaps having a care recipient with many unmet needs causes the caregiver to feel burdened, rather than caregiver burden leading to unmet needs. Longitudinal designs are necessary to answer these questions.

The present study also did not investigate potential boundary conditions for the associations between concern about being a burden, caregiver burden, and number of unmet needs. Important contextual factors might moderate these associations, including the intensity of care a care recipient requires. A combination of multiple, intense needs, such as toileting and bathing, as opposed to fewer and easier to fulfill needs, such as driving to doctor's appointments once a month, might strengthen the potential effect of care recipients' concern about being a burden and actual caregiver burden on number of unmet needs. Future research could investigate this possibility.

Finally, the study has a limited geographic sampling area and involved sampling methods that may not be representative of that region. Care recipients with Alzheimer's disease and dementia were by necessity excluded. Only care recipients with at least one unpaid caregiver were included, mostly spouse/adult child caregivers. Thus, our findings are most relevant to cognitively intact individuals with lower care needs utilizing primarily unpaid family help.

Conclusions

This study provides unique dyad-level data—incorporating both caregiver and care recipient perspectives—on care recipient reports of unmet needs for IADL, mobility, and ADL care. We found two independent pathways to unmet needs: (1) *care recipient* concerns about being a burden due to needing help and (2) *caregiver* reports of burden due to providing help. It is interesting that these two phenomena were not correlated, but the results suggest the importance of studying unmet needs for care as a dyadic process. Potential interventions to reduce unmet care recipient needs should also take a dyadic approach, focusing on reducing both care recipient perceptions of being a burden and caregiver experienced burden. These interventions may be most effective for cognitively intact care recipients in

the earlier stages of disability relying primarily on unpaid family caregivers.

Supplementary Material

Supplementary data are available at *Innovation in Aging* online.

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Conflict of Interest

None reported.

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