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Economic and Objective Burden of Caregiving on Informal Caregivers of Patients with Systemic Vasculitis

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Abstract

Objective: To evaluate and describe the economic impact and objective caregiving burden experienced by informal caregivers of patients with systemic vasculitis (SV).

Methods: We recruited adult patients with SV from academic centers and a glomerular disease registry cohort to participate in a web-based survey on the physical, emotional, social, and economic impacts of SV, including perceptions of how much of a burden they are to their identified caregiver. We used snowball sampling to recruit patients' caregivers. Caregivers reported the direct and indirect economic impact of SV including employment disturbance, income loss, and relative time investment of caregiving for their care recipient's SV. We used the Inventory of Caregiving Activities Questionnaire to compute the objective caregiving burden.

Results: We analyzed data from 68 SV patient-caregiver dyads. The most common vasculitis type reported by patients included Granulomatosis with polyangitis (GPA) and other anti-neutrophil cytoplasmic autoantibodies (ANCA) associated vasculitides. Patients reported moderate levels of subjective burden to their caregivers. Over one-quarter of caregivers reported ever having lost some income due to caregiving for SV. Caregivers reported spending a median of 19 weekly hours on various caregiving tasks, including a median 17 weekly hours on household activities.

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Conflicts of Interest Statement

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Conclusion: Caregiving for SV results in a broad range of economic burden on caregivers. Future research should examine the relationship between the objective burden of caregiving for SV and the overall physical health, mental health, and quality of life of caregivers.

Keywords

systemic vasculitis; economic burden of disease; caregivers

INTRODUCTION

Systemic vasculitis (SV) is a group of rare, chronic, autoimmune conditions that involve the inflammation and necrosis of blood vessels and affect a variety of organs (Katysuyama et al, 2014; Watts et al, 2015). Epidemiological estimates in SV vary, though a recent study estimated that anti-neutrophil cytoplasmic antibody (ANCA)-associated vasculitis affects 42.1 per 100,000 in the US (Berti et al, 2017; Katsuyama et al, 2014). These conditions are associated with unpredictable disease course of relapse and remission, significant functional impairment, and intensive medication therapy (Raimundo et al, 2015). SV is associated with substantial economic impact to patients and the healthcare system; patients with SV often require significant healthcare services and rely on family members and friends to provide health-related support (Raimundo et al, 2015; Reinhold-Keller et al, Thorpe et al, 2018, Thorpe et al, 2008). One study showed that patients with relapsing events had four times the average annual healthcare costs compared to patients without relapse (Raimundo et al, 2015). Medicare beneficiaries with SV also had higher healthcare utilization compared to patients without SV, including dialysis, inpatient stays, and hospital readmissions (Thorpe et al, 2018).

Informal caregivers, hereafter referred to as caregivers, are family members or friends who provide unpaid care to those with physical or cognitive impairments making it difficult for them to complete daily living activities (Pinquart & Sorenson, 2007). Caregiving can result in a physical, psychological, and financial toll, commonly referred to as subjective caregiver burden (Pinquart & Sorenson, 2007; Buhse 2008). Perceived burden on caregivers can negatively affect patients' psychological health and overall care (Simmons, 2007). However, the literature is limited in describing the burden of SV on caregivers, including the type and extent of support that caregivers provide. Drawing upon work done with caregivers of rheumatoid arthritis (RA) patients, caregivers reported that caregiver burden was mostly due to disrupted schedules, financial problems, and lack of family support (Jacobi et al, 2003). Both direct and indirect economic impacts of SV on patients likely affect individuals in their support systems.

The goal of this study was to examine caregiver burden and economic impact of SV on caregivers. We summarize findings on the caregiver objective burden and economic impact on caregiving in SV, as well as patients' perceptions of the extent that they burden their caregivers.

METHODS

The Institutional Review Boards at the University of North Carolina at Chapel Hill and the University of Pittsburgh approved this study.

A convenience sample of patients with SV and their caregivers completed a cross-sectional web-based survey between April 2015 and August 2016 to evaluate the physical, emotional, social, and economic impacts of SV. We recruited patients with SV from two academic centers and the Glomerular Disease Collaborative Network inception cohort registry. We also recruited participants from vasculitis support groups and by distributing study information online through the Vasculitis Foundation and social media. Patients were eligible if they were at least 18 years of age, self-reported a diagnosis of SV, could read and write in English, had Internet access, and could identify a primary caregiver. We defined primary caregivers as a spouse, relative, or friend who helps the patient manage their SV and overall health. We recruited caregivers using a snowball method, in which participants recruit other participants for the study. Specifically, patients who completed the patient survey were asked to forward a link to the caregiver survey to their primary caregiver so he or she could participate. Caregivers were eligible if they were at least 18 years of age, could read and write in English, and had Internet access.

The surveys were designed to take 30–60 minutes to complete and could be completed in more than one sitting. Patients and caregivers provided demographic information including age, gender, race, education level, and annual income. Caregivers identified their relationship to the patient as either a child, spouse, other relative, or non-relative. Patients selected their vasculitis type from a list, including anti-glomerular basement membrane (GBM) disease, granulomatosis with polyangitis (GPA), other ANCA-associated vasculitides including microscopic polyangitis (MPA), eosinophilic granulomatosis with polyangitis (EGPA), or other ANCA disease, Behcet's disease, Cogan syndrome, cryoglobulinemia, giant cell arteritis (temporal arteritis), IgA vasculitis, Kawasaki disease, polyarteritis nodosa, Takayasu's arteritis, urticarial vasculitis, or other vasculitides not otherwise specified. We used the patients' self-reported month and year of SV diagnosis to calculate disease duration.

We asked patients about their perceived burden to their identified caregiver using a validated subjective burden scale originally developed to assess self-perceived burden among patients with chronic conditions (Cousineau et al, 2003; Simmons 2007). Patients responded to a 10-item questionnaire using a five-point Likert scale measuring the degree to which they perceive various feelings, such as concern about being too much trouble. Survey items were summed to assign patients a subjective burden score ranging from 0 to 50, with higher scores indicating higher subjective burden (Cousineau et al, 2003; Simmons 2007).

To assess financial burden of SV to caregivers, we asked caregivers to provide information on employment status and income loss in the past year or other years due to caregiving for the patient's vasculitis based on validated questionnaires developed by Brouwer, et al. We asked caregivers to report direct and indirect changes to time and economic investments due to caregiving by reporting changes to weekly hours spent on household activities, assistance

with personal care, paid or unpaid work, or leisure time due to caregiving (Brouwer et al, 2004).

We used the Inventory of Caregiving Activities Questionnaire to analyze caregiver objective burden, in which respondents report time spent in minutes per day or hours per week on different household, daily living and other tasks related to their care recipient's SV (Brouwer et al, 2004). In cases where caregivers provided a range of hours spent on a specific caregiving task, we calculated the average of the reported time for the specified task. We summed the total time reported by caregivers on each caregiving task, and total weekly hours spent on all SV-related caregiving tasks.

We analyzed data for valid, non-missing responses using Stata version 15 (StataCorp, College Station, Texas, United States). Across variables, up to 11% of caregiver respondents and 6% of patient respondents had missing data. We computed frequencies and percentages for categorical variables. Due to observed skewness, we calculated median values and interquartile ranges for continuous variables. We analyzed two groups of respondents to more completely characterize the collected data. This included caregiver-patient dyads (n=68) and those patients or caregivers without a confirmed associated caregiver (n=76) or patient (n=23), respectively, hereafter referred to as non-dyad respondents. We compared data across dyad and non-dyad respondents using Pearson chi-squared and non-parametric equality of medians tests for frequency and median observations, respectively.

RESULTS

Ninety-one caregivers and 144 patients with SV, including 68 caregiver-patient dyads, completed the survey. Table 1 summarizes the characteristics of the patients and caregivers. Most caregivers were spouses of SV patients and college educated, with a median age of 61 years. Dyad caregivers were less likely to be female and more likely to be spouses; no other characteristics were significantly different across caregivers. There were also no statistically significant differences in demographic and clinical variables among dyad and non-dyad patients.

Patients reported moderate subjective burden scores, with a median score of 20 (IQR: 14 – 27). Table 2 summarizes the time investment and economic burden of SV reported by caregivers. In general, dyad and non-dyad caregivers reported similar economic impact of SV. Approximately 52% of caregivers reported a median weekly reduction of six (IQR: 4–10) hours in leisure time due to caregiving. Overall, 28% of caregivers reported some income loss during the previous year (18%) or at any time during other years (23%) due to their care recipient's SV.

Eighty percent of surveyed caregivers reported some caregiving objective burden. Figure 1 illustrates objective burden in weekly hours spent on caregiving for SV. The median total weekly hours spent on household, daily living, and other caregiving activities was not significantly different across dyad and non-dyad caregivers. Caregivers reported spending a median 19 weekly hours on household, daily living, and other activities related to caregiving for SV.

DISCUSSION

We investigated the economic impact and objective caregiving burden for caregivers of patients with SV. Few studies have examined caregiver burden in autoimmune conditions using validated measures; studies in patient populations with multiple sclerosis and RA may provide the most similar comparators to SV. We found that over a quarter of surveyed caregivers reported some loss of income due to caregiving for SV. In contrast, the proportion of caregivers reporting income loss due to informal care for RA was lower (8.1%) in another study (Brouwer et al, 2004). A lower proportion of RA caregivers reported reduced paid work, unpaid work, and leisure time due to informal care than the SV caregivers in our study. This suggests that caregiving for SV may have a greater economic impact than caregiving for patients with other rheumatic conditions.

To date, prior research has not specifically examined burden for caregivers of patients with SV, though some studies have described the general impact of SV on spouses, family, and friends. In one study on patients with GPA, investigators noted that spouses reported altering employment arrangements to provide care for patients (Hoffman et al, 1998). Other studies have noted that 5–18% of caregivers have had changes to employment or work situations due to caregiving for SV (Abularrage et al, 2008; Boomsma et al, 2002). Our findings support these observations and have implications for future research. Given the extensive reported hours spent on caregiving in our study, future research could also focus on a more detailed investigation between patient subjective burden and the extent of received caregiving.

Compared to patients with cancer, the median overall subjective burden score in our study sample was higher (20 vs 17) (Simmons 2007). Patients who perceive they are a burden may be less likely to solicit help from their caregiver for fear of “burning out” caregivers (Simmons 2007). Self-perceived burden may also negatively affect patient’s psychological well-being. Further qualitative work should explore how perceptions of burden affects interpersonal caregiving dynamics. Future research should also examine whether any clinical or social factors are associated with subjective burden and the impact that those factors on physical and mental health of patients and caregivers.

The results from this convenience sample may not generalize to the larger population of SV patients and caregivers. Most surveyed caregivers were college educated and reported an annual income of greater than \$75,000. The economic burden of caregiving for patients with SV in this study may underestimate the burden among those of lower socioeconomic status. Further, the median duration of SV in our study population was around five years. It is likely that the burden of caregiving for patients with SV may differ depending on disease severity or occurrence of relapsing events over time. Patients with more severe forms of SV in cases with chronic organ damage also require additional medical care resulting in different levels of caregiving burden. Patients and caregivers with less objective or subjective burden may have been more likely to complete the survey, which introduces a potential for selection bias. Thus, our results may underestimate the subjective burden and economic impact that SV may have on more negatively impacted patient-caregiver dyads. Lastly, although the subjective burden scale has been used with patients with other disease states such as cancer

and stroke (Simmons 2007; McPherson et al, 2010), there may be dimensions of subjective burden that are specific to SV that are not captured by this measure.

The results of this study demonstrate the economic impact and caregiving burden of SV on patients and their caregivers. Given the extended hours that caregivers spend caring for patients, caregiver respite services may provide a potential intervention framework to reduce the probability of caregiver burnout in the SV population. Future research should evaluate the relationship between objective burden of caregiving for patients with SV and other factors such as quality of patient care received and caregiver quality of life.

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Figure 1: Reported Weekly Hours Spent on Caregiving Tasks Related to Systemic Vasculitis Caregiver (N=91)

IQR: interquartile range. Frequencies calculated among survey participants with valid, non-missing data. Maximum frequency of missing data among caregiver respondents for above analyzed variables was 10 (11.0%). Bars represent IQR of reported weekly hours spent on respective caregiving tasks. Grey bars represent dyad caregiver respondents. Black bars represent non-dyad caregiver respondents.

[†]Non-parametric equality of medians tests were conducted to compare the median total weekly hours between dyad and non-dyad caregivers.

[‡]Caregiving duration reported by only one respondent.

Table 1:

Characteristics of Study Population of Patients with Systemic Vasculitis and Caregivers

Caregiver Characteristics	Caregiver Dyads [‡] (N=68)	Non-Dyad Caregivers (N=23)	p-value [†]
Relation to Patient			0.004
Spouse	59 (88.1%)	14 (60.9%)	
Other (child, parent, grandparent, sibling, other relative, other non-relative)	8 (11.9%)	9 (39.1%)	
Median Age (IQR) years	59.5 (49.5 – 68)	61 (54 – 75)	0.852
Female	31 (45.6%)	16 (69.6%)	0.050
Education level			0.746
High school	7 (10.3%)	2 (8.7%)	
Some college	18 (26.5%)	8 (34.8%)	
Bachelor's degree or higher	43 (63.2%)	13 (56.6%)	
Income level			0.185
Less than \$75,000	18 (26.5%)	9 (39.1%)	
\$75,000 or greater	37 (54.4%)	13 (56.5%)	
Prefer not to answer	13 (19.1%)	1 (4.4%)	
Patient Characteristics	SV Patient Dyads (N=68)	Non-Dyad SV Patients (N=76)	
Median Age (IQR) years	58.5 (47.5 – 67)	61 (47 – 72)	0.389
Female	45 (66.2%)	55 (72.4)	0.421
Vasculitis Type[§]			0.835
GPA or other ANCA-associated disease	44 (64.7%)	50 (69.4%)	
Other vasculitis	23 (33.8%)	21 (29.2%)	
Don't know	1 (1.4%)	1 (1.4%)	
Median disease duration (IQR) years	4.8 (2.6 – 14.2)	4.7 (1.8 – 9.5)	0.799
Median Subjective Burden (IQR)	20.5 (15 – 28.5)	20 (14 – 26)	0.864

IQR: interquartile range; SV: systemic vasculitis; GPA: granulomatosis with polyangitis; ANCA: anti-neutrophil cytoplasmic autoantibodies. Sums may not total due to rounding. Frequencies calculated among survey participants with valid, non-missing data. Maximum frequency of missing data among respondents for above analyzed variables was 1(1.1%) for caregiver characteristics and 9 (6.3%) for patient characteristics.

[†] Pearson χ^2 and one-tailed t-tests were conducted to compare frequencies or mean/median characteristics, respectively, between dyad and non-dyad survey respondents.

[‡] Dyad respondents defined as patient with designated linked caregiver; we defined non-dyad respondents as individuals without a designated linked caregiver or patient.

[§] ANCA-associated vasculitis included microscopic polyangitis (MPA), eosinophilic granulomatosis with polyangitis (EGPA)/Churg-Strauss syndrome, or other ANCA disease not otherwise specified. Due to low frequencies, we combined other reported vasculitides, including anti-GBM disease, Kawasaki's disease, Behcet's disease, Cogan syndrome, cryoglobulinemia, giant cell arteritis/temporal arteritis, IgA vasculitis, polyarteritis nodosa, Takayasu's arteritis, urticarial vasculitis, or other vasculitis not otherwise specified.

Table 2:

Reported Economic Impact of Systemic Vasculitis Caregiving Among Caregiver-Patient Dyads (N=91)

	Caregiver Dyads (N=68)	Non-Dyad Caregivers (N=23)	p-value [†]
Currently employed	38 (56.7%)	11 (50.0%)	0.619
Employed at time of care recipient's vasculitis diagnosis	52 (77.6%)	15 (65.2%)	0.486
Income loss due to caregiving for care recipient's vasculitis in the last year	11 (16.4%)	5 (21.7%)	0.713
Median reported estimated income loss in the last year (IQR)	\$3,000 (\$700-\$5,500)	\$10,000 (\$3,000 – 30,000)	0.347
Income loss due to caregiving for care recipient's vasculitis in previous years	14 (20.9%)	7 (30.4%)	0.544
Reduced time spent on paid work due to caregiving for care recipient's vasculitis	9 (13.4%)	5 (22.7%)	0.623
Median reduced time per week spent on paid work due to caregiving for care recipient's vasculitis (IQR)	6.5 (3.5 – 17.5) hours	40 (20 – 40) hours	0.026 [†]
Reduced time spent on unpaid work due to caregiving for care recipient's vasculitis	9 (13.4%)	6 (28.6%)	0.148
Median reduced time per week spent on unpaid work due to caregiving for care recipient's vasculitis (IQR) [‡]	12.5 (7.5 – 16.5) hours	3 (1–5) hours	0.014
Reduced leisure time due to caregiving for care recipient's vasculitis	31 (46.3%)	15 (68.2%)	0.181
Median reduced time per week spent on leisure due to caregiving for care recipient's vasculitis (IQR)	5 (4 – 10) hours	9 (4 – 12) hours	0.517
Median time spent in last week on household activities due to care recipient's vasculitis (IQR)	7 (2 – 15) hours	8.5 (2 – 18) hours	0.937
Median time spent in last week on practical support due to care recipient's vasculitis (IQR)	4 (2 – 6) hours	8 (2 – 10) hours	0.170
Median time spent in last week on personal care due to care recipient's vasculitis (IQR)	3 (2 – 5) hours	2 (1 – 5) hours	0.705

IQR: interquartile range. Frequencies calculated among survey participants with valid, non-missing data. Maximum frequency of missing data among respondents for above analyze variables was 3(3.3%).

[†] Pearson χ^2 and non-parametric equality of medians tests were conducted to compare frequencies of employment characteristics or median time investment, respectively, between dyad and non-dyad survey respondents.

[‡] Three out of five non-dyad respondents reported hours for reduced paid work. Four out of six non-dyad respondents reported hours for reduced unpaid work. Differences between dyad and non-dyad groups for these variables are likely driven by low response rates.