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Caregiver burden among those caring for patients with spina bifida

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Abstract

Objectives: 1) To identify baseline characteristics of caregivers of school-aged children with spina bifida; 2) To identify independent predictors of caregiver burden in this population.

Materials and Methods: A survey was distributed via Facebook advertising to caregivers of patients with congenital genitourinary anomalies from May to September 2018. Eligible participants (n=408) entailed English-speaking adults who are involved in the patient's care and attend 50% of their medical appointments. Caregiver burden was assessed using the Caregiver Burden Inventory (CBI), where higher scores indicate higher burden. CBI 24 indicates need for respite and CBI 36 indicates high risk of burnout. Bivariate analyses (t-tests and chi-square tests) were conducted using STATA software.

Results: Our analysis includes 408 caregivers caring for patients with spina bifida. In our study population, 59.3% of caregivers were in need of respite due to caregiver burden and 26.7% of caregivers were so burdened that they are at risk of burning out (CBI score 36). Bivariate analysis showed that caregiver gender and number of tasks performed by the caregiver were significantly associated with risk of burnout (CBI 36). Multivariable analysis of overall caregiver burden showed increased risk of burnout (CBI 36) among older caregivers, female caregivers, and those performing more caregiving tasks.

Conclusions: Caregiver burden is common among caregivers of patients with spina bifida, and further research is needed to identify strategies and resources for mitigating caregiver burden.

Keywords

Urology; Spina Bifida; Congenital; Caregivers; Burnout; Transitional care

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INTRODUCTION

Disorders involving the genitourinary (GU) system are among the most common types of congenital anomalies, with spina bifida being the most common congenital genitourinary disorder. Fortunately due to advances in treatment, patients with spina bifida are living well into adulthood.^{1,2} However, many of these patients require substantial support in managing the complex medical needs that accompany this chronic illness.^{3,4}

It is known that having a child with a chronic disease increases parents' and caregivers' levels of stress.^{5,6,7,8,9,10} Spina bifida has been associated with some of the highest levels of stress.^{5,11,12} Caregivers' lives are shown to be affected in a variety of ways that may contribute to stress, including work, finances, and social life.¹³

Many influencers have been identified in the literature that can affect caregivers' ability to cope with caring for a child with chronic condition, including child characteristics and available social support.¹⁴ By learning more about this caregiver population, we may better understand the prevalence and predictors of caregiver burden and, in so doing, discover opportunities for clinicians to take an active role in helping to reduce caregiver burden. The aim of the current study is to identify baseline psychosocial and demographic characteristics of caregivers of patients with spina bifida, establish caregiver burden levels, and determine predictors of caregiver burden. We hypothesize that caregiver burden is prevalent among this caregiver population and that both caregiver and patient characteristics impact caregiver burden levels.

MATERIALS AND METHODS

Recruitment

Caregivers of patients with spina bifida were recruited to complete an anonymous survey. We recruited through Facebook advertisement and online outreach to Facebook groups for spina bifida. Interested individuals were eligible to participate in the survey if they were English-literate adults aged 18 and over in the United States and (1) are involved in the care of a patient with spina bifida, (2) have self-reported reasonable knowledge of current health status of the patient with direct involvement or assistance with daily activities and medical care, and (3) have accompanied the patient to >50% of all clinic appointments. Institutional Review Board approval was obtained (UCSF IRB#17-23699).

Advertisement & Outreach

Facebook advertisement has been used successfully for recruitment in other health-related research studies with good success.¹⁶ We targeted advertising to Facebook users who have expressed an interest in or like pages related to the Spina Bifida Association from May to September 2018. We contacted these groups via Facebook messenger and asked them to distribute our survey to all group members. As incentive for participating, participants were entered in a lottery whereby 2 participants were randomly selected to receive an iPad Mini.

Outcome Measure

Caregiver burden was assessed using an instrument called the Caregiver Burden Inventory (CBI) which was validated in multiple populations including caregivers of children with pediatric acute-onset neuropsychiatric syndrome and elderly patients with alzheimer's dementia.^{6,16} The CBI assesses caregiver burden in 5 domains: time dependency, development, physical health, emotional health, and social relationships. Higher CBI scores indicate more caregiving burden; we utilized cutoff scores based on prior studies on caregiver burden,^{16,17} where a CBI score of 24 or greater indicates the caregiver should seek respite and a score of 36 or greater indicates risk of burnout.

Predictor Variables

Self-reported sociodemographic information including age, gender, ethnicity, household size, and household income was collected about caregivers and the patients they care for. Clinical information including surgical history was ascertained about the patients. Marital status, years spent as caregiver, and the relationship to the patient was obtained for each caregiver. Validated questionnaires were used to assess patient urinary symptoms and patient independence. Patient urinary symptoms were assessed utilizing caregiver-report of the Neurogenic Bladder Symptom Score (NBSS), which quantifies specific domains of bladder symptoms including urinary incontinence (rated 0–29), bladder storage & voiding (rated 0–22), and consequences (rated 0–23), as well as overall quality of life (rated 0–4), where higher numbers correspond with worse symptoms and poorer quality of life.^{18,19} The Transitional Readiness Assessment Questionnaire (TRAQ) is a 20-item questionnaire designed to be completed by patients or caregivers, and is used to assess independence across 5 different subscales (managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities) and was given to caregivers to identify the degree of independence with which they themselves perform these activities.²⁰ Each subscale is rated from 1–5, where higher numbers correspond with greater independence, with subscales averaged to obtain the overall score. In our survey, we also asked caregivers whether or not they helped the patient perform various tasks from an itemized list, including mobility, hygiene, eating, catheterization, medication administration, and coordinating doctors' appointments. We used these data to analyze whether performing a higher quantity of tasks was associated with increased caregiver burden.

Statistical Analysis

Data were analyzed with STATA® 16.1, with a two-sided $p < 0.05$ considered statistically significant. Data are reported using totals and percentages for categorical variables and median and interquartile range for continuous variables. Bivariate analyses by caregiver burnout were performed using t-tests and chi-squared tests comparing sociodemographic, clinical, and caregiving characteristics between two groups of caregivers: those with CBI ≥ 36 (indicating burnout) versus < 36 . Specific caregiver tasks were analyzed to identify tasks associated with higher burden. A general linear model was fit to examine the importance of caregiver and patient characteristics and clinical covariates in predicting the overall CBI. A logistic model was also fit examining caregiver burnout as a binary outcome. A histogram of

the prevalence and severity of caregiver burden was constructed and also a plot of caregiver age by number of caregiver tasks.

RESULTS

A total of 503 participants who clicked on the advertisement link qualified for our survey. Out of those 503 eligible participants, 408 (81.1%) completed the survey and were included in our analysis. Caregivers were a mean of 43 years old (SD 10.3), were overwhelmingly female (95.6%), married (78.6%), and had been serving as caregiver for a mean of 9.9 years (SD 5.9). Almost all caregivers (92.2%) were mothers of the patients for whom they provided care, and 34.2% of caregivers possessed full-time jobs outside of their responsibilities as caregiver. (Table 1) The patients of these caregivers were a mean age of 10.3 years (SD 5.9; Table 2).

The median CBI for caregivers was 26 overall (IQR 19–37). We found that 59.3% of caregivers were in need of respite and 26.7% of caregivers were so burdened by the care they provide that they were considered at risk of burning out (see Supplemental Histogram). Among caregivers who were at risk of burning out (i.e. CBI \geq 36), the median CBI score was 43. Bivariate analyses by risk of burnout (Table 1 and 2) showed that caregiver burnout was significantly associated with caregiver gender ($p=0.042$) and number of tasks performed by the caregiver ($p=0.005$), with NBSS scores approaching significance ($p=0.055$). An additional bivariate analysis compared caregiver burnout by specific caregiver tasks (see Supplemental Table). Tasks associated with caregiver burnout were bathing/hygiene ($p=0.004$), bladder care ($p<0.001$), changing diapers & garments ($p=0.001$), catheterization ($p=0.010$), and medication administration ($p=0.010$).

In a general linear multivariate model evaluating predictors of overall CBI score, older caregiver age ($p=0.048$), gender (i.e. being a female caregiver; $p=0.029$), and increased number of care tasks ($p<0.001$) were significantly associated with higher CBI score. Two plots (Figure 1 and Figure 2) show increased risk of caregiver burnout by caregiver age and by number of caregiver tasks, aligning with the results from our general linear model.

DISCUSSION

Caregiver burden is prevalent among caregivers of spina bifida patients, with 59.3% of caregivers burdened enough that they need respite, and 26.7% of caregivers are so burdened that they are at high risk of burning out. Moreover, the mean CBI score (28.1, SD 13.7) among this population was above the cutoff score of 24 which indicates a need for respite from the demands of being a caregiver. Being older, being a female caregiver, and performing more care tasks was significantly associated with a higher CBI score.

Caregiver burden has been explored in some other childhood chronic and congenital conditions. One cross-sectional survey investigating burden among caregivers of patients with primary congenital glaucoma found that caregiver burden was significantly associated with patient age and duration of disease.²¹ Among caregivers of children with autism spectrum disorder, caregiver strain was significantly associated with caregiver age, patient age, and household income—which aligns with findings from the our study.²² Our data paint

a picture of caregiver burden as a multifactorial phenomenon, arising from a combination of caregiver and patient characteristics. Some of the factors associated with caregiver burden (such as the caregiver's age) are readily identifiable upon meeting the patient, whereas others (such as number of caregiving tasks performed by the caregiver) require that the clinician engages in a conversation with the caregiver—serving as an opportunity to work with both the patient and caregiver on strategies to mitigate burden.

In our study population, caregivers tended to be mothers of the patients for whom they provide care—a trend that has been consistently reported in the literature on caregivers.^{23,24,25} Most of the caregivers in our study population (78.6%) were married or in a domestic partnership. The literature has mixed results on the impact of marital status on caregiver burden; Malm-Buatsi et al²⁶ showed that caregiver burden was higher if caregivers were living with a partner, whereas Rofail et al²⁷ found that living with a partner may help the caregiver cope with their caregiving duties. Other research has shown that caregiver burden is significantly associated with being unemployed or having low income¹², which was not substantiated by our study.

Our findings shed light on the impact of patient characteristics on caregiving burden. We found a nearly significant association ($p=0.055$) between the patient's NBSS score (which includes information about the patient's urinary symptoms) and caregiver burden in bivariate analysis, where higher NBSS scores correlated with increased risk of burnout. Prior studies investigating the association between caregiver burden and patient functional independence have reported mixed findings.^{23,28,29} We did find that caregiver burden was significantly associated with the number of caregiving tasks that the caregiver had to perform, and this measure likely serves as a proxy for functional independence of the patient. The caregiving tasks we identified as significantly associated with burnout were bathing/hygiene, bladder care, diaper/garments, catheter care, medication purchase/preparation, and medication administration. Many of these caregiving tasks could potentially be modified by improving patients' independence and by treating urinary or fecal incontinence or considering alternative methods for bladder care that do not require so much caregiver involvement.

Understandably, caregiving can place a significant strain on caregivers, and others have described the burden placed on caregivers of patients with spina bifida, identifying different aspects of caregivers' lives that are affected by caring for these patients, including activities of daily living, personal finances, feelings and emotions, and family relationships.¹³ The first step in addressing this problem is to increase awareness among both caregivers and clinicians of the potential for caregiver burden, and to start screening for caregiver burden among those who are likely to be affected. The Caregiver Burden Inventory is a short, less than 5 minute questionnaire that caregivers could easily fill out while in the waiting room but provides valuable data to identify those that are in need of respite.

Understanding the true prevalence of caregiver burden can help provide advocacy for increased psychosocial and respite support for caregivers of patients with chronic childhood illnesses such as spina bifida. The next step is then understanding how we can address and ameliorate caregiver burden once we know how it affects patients' caregivers. For example—since most of the caregivers in our study population were parents of the patients (92.2%)

—we should consider basing our attempts to reduce caregiver burden on interventions that have been shown to improve quality of life among parents of children with chronic conditions (e.g. type 1 diabetes), such as telephone-based counseling and problem-solving.³⁰ In advocating for screening for caregiver burden, the next question that arises is how we implement this and then manage those that have positive screens. Providers are often already overwhelmed in managing this complex patient population, and it is important to provide holistic care for these patients by involving social workers who can help to address positive screens. Like transitional readiness assessment, this may be one further assessment that can help guide what help and resources families need to be successful and optimize outcomes for these patients.

Our study design is predisposed to several limitations. First, there is inherent risk of selection bias as caregivers are identified via social media which requires moderate level of literacy and may not represent the population affected. We cannot know the extent to which our study was biased by recruiting participants through Facebook, although a review of studies that used Facebook to recruit study participants found that 86% of Facebook-recruited study populations were as representative as study populations that are recruited by more conventional means.¹⁵ Furthermore, in selecting the caregivers for the study only those that were involved in the patient's care were eligible, and thus our study population may represent caregivers of patients with higher needs. In addition, all the data obtained in this study rely on self-report, which is prone to bias. To address this, we used validated questionnaires in each domain where possible in order to improve the quality of all the data we collected; and in some cases, such as measuring functional independence, we used both validated questionnaires (i.e. the TRAQ) as well as self-reported values (i.e. number of caregiver tasks). Despite these limitations, we believe this is a novel and important study that showcases the prevalence of caregiver bias among those caring for patients with spina bifida. While our study helps to define this particular population of caregivers and illuminate the prevalence of caregiver burden, future studies that investigate caregivers' perceived needs and strategies for meeting those needs will allow clinicians to improve the standard of care for patients and caregivers alike.

In conclusion, this cross-sectional study of caregivers of patients with spina bifida showed that caregivers experience significant burden, and that caregiver burden was predicted by older caregiver age and increased number of tasks performed as caregiver. As this patient population and their caregivers continue to age, it will be important for future research to identify effective strategies and resources for mitigating caregiver burden. By doing so, clinicians can adapt their practice to detect and address caregiver burden among caregivers of patients with spina bifida.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Conflicts of Interest:

The authors have no conflicts of interest to disclose. The sponsor did not contribute to the study design, data collection, analysis, interpretation, the writing of the report, or the decision to submit the manuscript for publication. The manuscript's first draft was written by Michael Sadighian without an honorarium, grant, or any other form of payment.

Abbreviations:

GU	Genitourinary
CBI	Caregiver Burden Inventory
NBSS	Neurogenic Bladder Symptom Score
TRAQ	Transition Readiness Assessment Questionnaire

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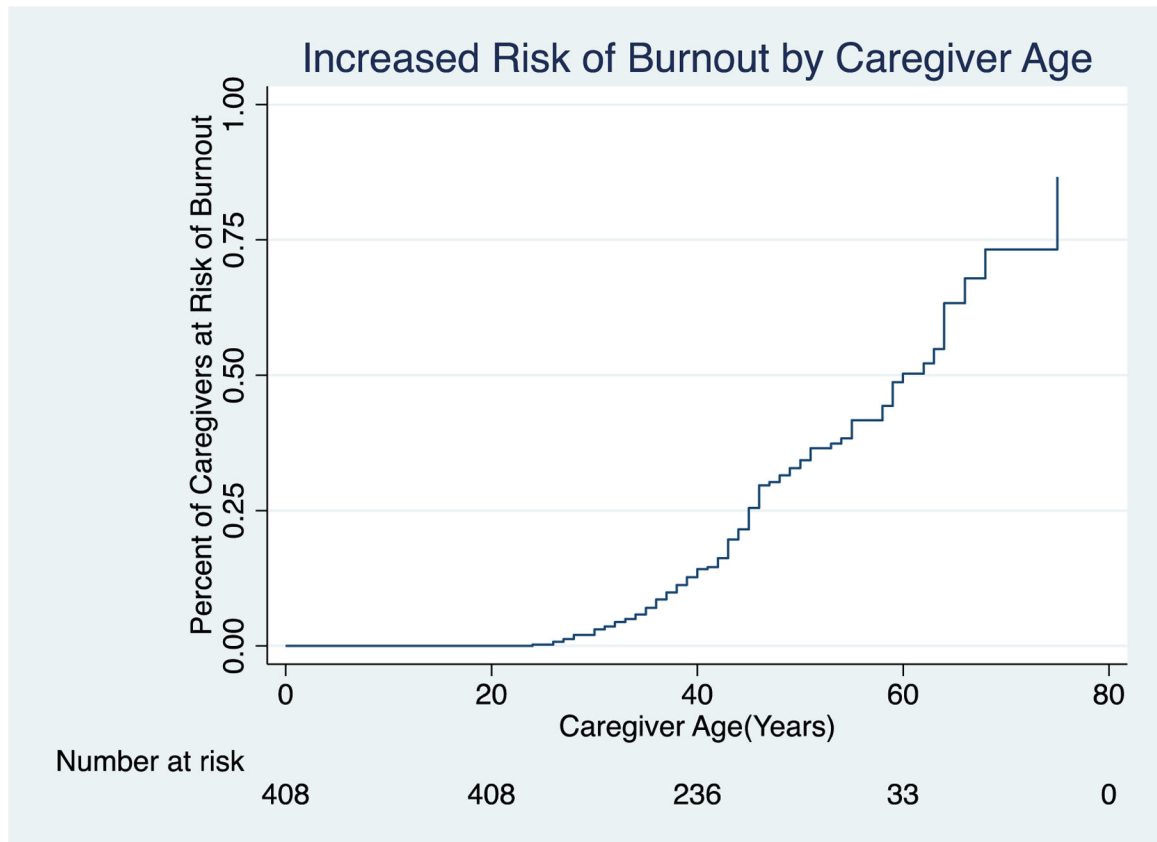


Figure 1: Survival curve showing percentage of caregivers at risk of caregiver burnout by caregiver age

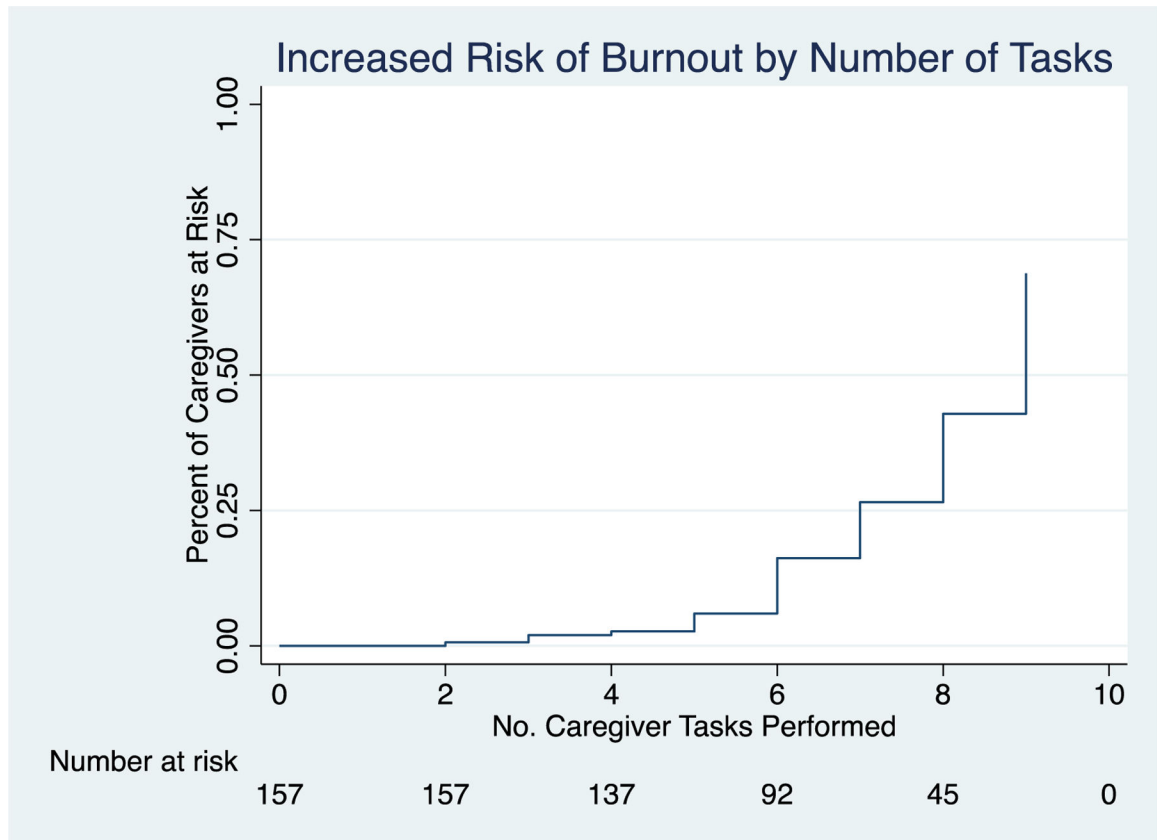


Figure 2: Survival curve showing percentage of caregivers at risk of caregiver burnout by number of care tasks egend for Supplemental Figure (Histogram): Caregivers with a burden score 24 (yellow) are in need of respite and 36 (red) are at high risk for burnout

Table 1:Caregivers with a burden score ≥ 36 are at high risk for burnout

Caregiver Characteristics by Caregiver Burden				
	Total Population N=408	Caregivers with CBI <36 N=299	Caregivers with CBI ≥ 36 N=109	p-value
Age in years, Mean (SD)	42.7 (10.3)	42.5 (10.3)	43.1 (10.4)	0.619
Ethnicity, No. (%)				0.410
White	340 (89.0)	243 (87.7)	97 (92.4)	
Hispanic/Latino	22 (5.8)	18 (6.5)	4 (3.8)	
African American	6 (1.6)	4 (1.4)	2 (1.9)	
Native American	2 (0.5)	2 (0.7)	0 (0.0)	
Asian/Pacific Islander	7 (1.8)	7 (2.5)	0 (0.0)	
Other	5 (1.3)	3 (1.1)	2 (1.9)	
Primary Language, No. (%)				0.690
English	375 (98.2)	271 (97.8)	104 (99.1)	
Spanish	6 (1.6)	5 (1.8)	1 (1.0)	
Other	1 (0.3)	1 (0.36)	0 (0.0)	
Gender, No. (%)				0.042
Male	16 (4.2)	15 (5.4)	1 (1.0)	
Female	365 (95.6)	262 (94.6)	103 (98.1)	
Other	1 (0.3)	0 (0.0)	1 (1.0)	
Marital Status, No. (%)				0.243
Never Married	20 (9.3)	12 (7.7)	8 (13.6)	
Married/Domestic Partnership	169 (78.6)	127 (81.4)	42 (71.2)	
Divorced/Separated/Widow	26 (12.1)	17 (10.9)	9 (15.3)	
Household Size, Mean (SD)	4.1 (1.4)	4.1 (1.3)	4.2 (1.5)	0.530
Employment Status, No. (%)				0.900
Full Time	150 (36.8)	108 (36.1)	42 (38.5)	
Part Time	68 (16.7)	50 (16.7)	18 (16.5)	
Other	190 (46.6)	141 (47.2)	49 (45.0)	
Hours Worked Per Week, No. (%)				0.937
>35	139 (34.2)	102 (34.3)	37 (33.9)	
1–35	86 (21.2)	64 (21.6)	22 (20.2)	
0	181 (44.6)	131 (44.1)	50 (45.9)	
Household Income, No. (%)				0.105
<\$20,000	29 (7.6)	15 (5.4)	14 (13.3)	
\$20,000–49,000	94 (24.6)	68 (24.6)	26 (24.8)	
\$50,000–99,000	134 (35.1)	99 (35.7)	35 (33.3)	
>\$100,000	109 (28.5)	84 (30.3)	25 (23.8)	
Not reported	16 (4.2)	11 (4.0)	5 (4.8)	

Caregiver Characteristics by Caregiver Burden				
	Total Population N=408	Caregivers with CBI <36 N=299	Caregivers with CBI 36 N=109	p-value
Relationship to Patient, No. (%)				0.102
Mother	376 (92.2)	270 (90.3)	106 (97.3)	
Father	12 (2.9)	12 (4.0)	0 (0.0)	
Other relatives	12 (2.9)	9 (3.0)	3 (2.8)	
Other acquaintance	7 (1.7)	7 (2.3)	0 (0.0)	
Professional Care Provider	1 (0.3)	1 (0.3)	0 (0.0)	
Years as Caregiver, Mean (SD)	9.9 (5.9)	9.7 (6.0)	10.2 (5.8)	0.468
Distance to Urologic Care, No. (%)				0.756
<10 miles	78 (19.1)	61 (20.4)	17 (15.6)	
10–30 miles	130 (31.9)	95 (31.8)	35 (32.1)	
31–60 miles	74 (18.1)	55 (18.4)	19 (17.4)	
>60 miles	118 (28.9)	82 (27.4)	36 (33.0)	
Not reported	8 (2.0)	6 (2.0)	2 (1.8)	
Overall TRAQ Score, Mean (SD)	4.2 (0.5)	4.2 (0.5)	4.2 (0.5)	0.848
# of Care Tasks, Mean (SD)	6.0 (1.9)	5.7 (2.0)	6.7 (1.7)	0.005

Table 2:Caregivers with a burden score ≥ 36 are at high risk for burnout

Patient Characteristics by Caregiver Burden				
	Total Population N=408	Caregivers with CBI <36 N=299	Caregivers with CBI ≥ 36 N=109	p-value
Patient Age in years, Mean (SD)	10.3 (5.9)	10.3 (5.9)	10.5 (5.8)	0.818
Patient Age Group, No. (%)				0.989
Adult	105 (25.7)	77 (25.8)	28 (25.7)	
Pediatric	303 (74.3)	222 (74.3)	81 (74.3)	
Patient Gender, No. (%)				0.616
Male	173 (42.4)	129 (43.1)	44 (40.4)	
Female	235 (57.6)	170 (56.9)	65 (59.6)	
Patient Insurance, No. (%)				0.649
Medicaid/Medical	117 (28.7)	84 (28.1)	33 (30.3)	
Medicare	24 (5.9)	17 (5.7)	7 (6.4)	
Private	258 (63.2)	190 (63.6)	68 (62.4)	
None	3 (0.7)	2 (0.7)	1 (0.9)	
Not reported	6 (1.5)	6 (2.0)	0 (0.0)	
NBSS, Mean (SD)	27.2 (10.4)	26.0 (10.0)	30.0 (10.9)	0.055
Prior surgery for urologic condition, No. (%)				0.556
Yes	211 (51.7)	152 (50.8)	59 (54.1)	
No	197 (48.3)	147 (49.2)	50 (45.9)	