Impact of vasculitis on employment and income

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ABSTRACT

Objective. *Work disability associated with rheumatic diseases accounts for a substantial financial burden. However, few studies have investigated disability among patients with vasculitis. The purpose of this study was to examine the impact of vasculitis on patient employment and income.*

Methods. *Patients enrolled in the Vasculitis Clinical Research Consortium (VCRC) Patient Contact Registry, living in the USA or Canada, and followed for >1 year post-diagnosis, participated in an online survey-based study.*

Results. *421 patients with different systemic vasculitides completed the survey between June and December 2015. The majority of patients were female (70%) and Caucasian (90%); granulomatosis with polyangiitis (GPA) was the most common type of vasculitis (49%), and the mean age at the time of diagnosis was 53 years. At the time of their diagnosis of vasculitis 76% of patients were working a paid job, 6% were retired, and 2% were on disability. Over the course of their disease, and with a mean follow-up of 8±6.4 years post-diagnosis, 26% of participants became permanently work disabled or had to retire early due to vasculitis. Variables that were independently associated with permanent work disability included work physicality, less supportive work environment, and symptoms such as respiratory disease, pain, and cognitive impairment. Overall, patients reported a mean productivity loss of 6.9% and income was reduced by a median of 45%.*

Conclusion. *Due to their vasculitis, patients frequently suffer substantial limitations in work and productivity, and personal income loss.*

Introduction

Work disability associated with rheumatic diseases accounts for an important part of the burden on patients with these conditions (1). While there has been considerable interest in examining work disability associated with rheumatoid arthritis (RA) (2-5), fewer studies have examined patients with systemic vasculitis (SV) (6-8). Most of the data concerning work disability related to vasculitis pre-dates 2005 and focused on granulomatosis with polyangiitis (GPA, Wegener's) (9-13). For example, Mau *et al*. (12) used a comprehensive clinical database to compare employment rates among German patients with various rheumatic conditions and reported that those with RA, systemic lupus erythematosus, and GPA had low employment rates, while those with ankylosing spondylitis and psoriatic arthritis had employment rates only slightly lower than the general population, suggesting that the effects of auto-immune inflammatory diseases on work disability cannot be generalised across conditions. These early studies uniformly reported work disability rates, secondary to a diagnosis of vasculitis, of approximately 20-30% (11-13). Studies conducted in the last 5 years suggest that work disability has continued to affect 20-40% of patients with vasculitis (6-8).

Studies that have examined the financial impact of early retirement or disability as a consequence of a diagnosis of vasculitis have also reported substantial income reductions in 5-26% of patients (8-11). Thus, identifying, and possibly mitigating, risk factors associated with becoming work disabled could reduce the financial burden of those conditions.

The purpose of this study was to examine the employment status and the impact of vasculitis on income in a large cohort of North American patients with different vasculitides using a self-reported, online questionnaire. A further objective was to examine the relationship between disease- or work-related

variables and the risk of becoming work disabled post-diagnosis.

Materials and methods

Patients

Participants were recruited through the Patient Contact Registry of the Vasculitis Clinical Research Consortium (VCRC), a member of the Rare Diseases Clinical Research Network (RDCRN) (14-16). This registry is an international resource that has already been used for conducting online research in vasculitis (http://rarediseasesnetwork.org/vcrc/registry) (14-16). People who self-identify as having a particular form of vasculitis can join the registry. For the present study, all individuals with vasculitis and with a follow-up period of ≥1 year since a diagnosis of vasculitis were invited in June 2015 by email to respond to an online survey (n=1,888); participants could also register for the study directly through the online registry portal and other vasculitis patient websites. Reminder emails were sent monthly for 3 months, and a final reminder before closing the study in month 6 to encourage patient participation before the closure of the survey in December 2015. Other inclusion criteria included: ≥18 years of age, Canadian or American residency, and proficiency in the English language. This study was conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki, and consistent with Good Clinical Practice. Ethics approval was provided by the University of South Florida Institutional Review Board. Informed consent to participate was obtained online from each participant prior to completing study questionnaires.

Data collection

A questionnaire was developed by the authors (LB, CP, PM, and RB) and was reviewed and beta-tested by AS and members of the V-PPRN prior to deployment with study participants. Participants completed the questionnaire at one sitting by answering questions regarding: demographics, disease diagnosis, comorbidities, treatment, occupational status, physicality of employment (as assessed according to methods described in Allaire *et al*. (17)), productivity, and financial impact of diagnosis. Subjects were asked to recall details related to their symptoms at diagnosis and impact of disease at any time during the disease since diagnosis. Permanently work disabled was defined as retiring early or having to stop working and not being able to return to work because of vasculitis in subjects that were working at the time of their diagnosis. As part of the survey, patients also completed the Chalder Fatigue Scale (18) and the short form of the Work Limitations Questionnaire (WLQ-8) (19), which is designed to assess job productivity in workers with any illness, covering multiple employment dimensions, including: physical output, cognitive demands, time management, and overall productivity levels.

Statistical analyses

Quantitative variables were compared by Student's *t*-test and categorical variables by chi-square or Fisher's exact test, as appropriate. Univariable analyses were performed to investigate age, sex, race, and education level, and several disease characteristics (including neuropathy, end-stage renal disease, dyspnea, arthralgias/myalgias, and fatigue) that may affect employment status and productivity, specifically comparing those who did or did not become permanently work disabled. Multivariable analyses were performed to determine variables independently associated with permanent work disability. Variables were tested in the model using stepwise logistic regression if they were significantly associated with permanent work disability by univariable analysis ($p<0.1$) and the response rate was >25%. Pearson correlations were performed to identify relationships between WLQ score and disease and work variables.

A minimal sample size was estimated at 368 based on an expected prevalence of work disability of 40% that was previously reported in a similar North American study by Barra *et al*. (6)). This sample size was calculated with precision of ±5% (with an alpha = 0.05). $p<0.05$ was considered statistically significant. Missing values were not included and there was no imputation for missing values. Statistical analyses were performed using SAS v. 9.4 (Cary, NC, USA).

Results

Patient characteristics and work disability

Questionnaires were completed by 421 patients who satisfied the eligibility criteria. They were predominantly female (70%), Caucasian (90%), residents of the United States (85%), and had a mean age at time of their diagnosis of vasculitis of 53±13 years. The most frequent forms of vasculitis were GPA (49%), eosinophilic granulomatosis with polyangiitis (EGPA, Churg-Strauss; 16%), or microscopic polyangiitis (MPA; 7.8%); a complete breakdown of the vasculitis diagnoses is shown in Figure 1.

At the time of diagnosis, 76% of patients were working a paid job (65% were working full-time and 22% part-time), with 6% retired, and 2% on disability (Fig. 2). On average, employed patients reported working 40.5±10.6 hours per week. At the time of survey completion (8±6.4 years post-diagnosis), the rate of employment had decreased to 49% with a higher proportion of retired subjects (21%) and on disability (19%) (Fig. 2). Over the course of their disease, 26% of participants became permanently work disabled or had to retire early due to vasculitis.

Determinants of work disability

Patients provided details about their disease manifestations at time of diagnosis as well as at the time of survey completion (Table I). When these parameters were compared between those who became permanently disabled *versus* those who did not, the type of vasculitis and disease manifestations at the time of diagnosis of vasculitis and at the time of survey completion were significantly different between the two groups (Table I). There were no statistically significant differences in age, sex, country of residence, race, education, delay in diagnosis, body mass index, marital status, or treatment type between those who

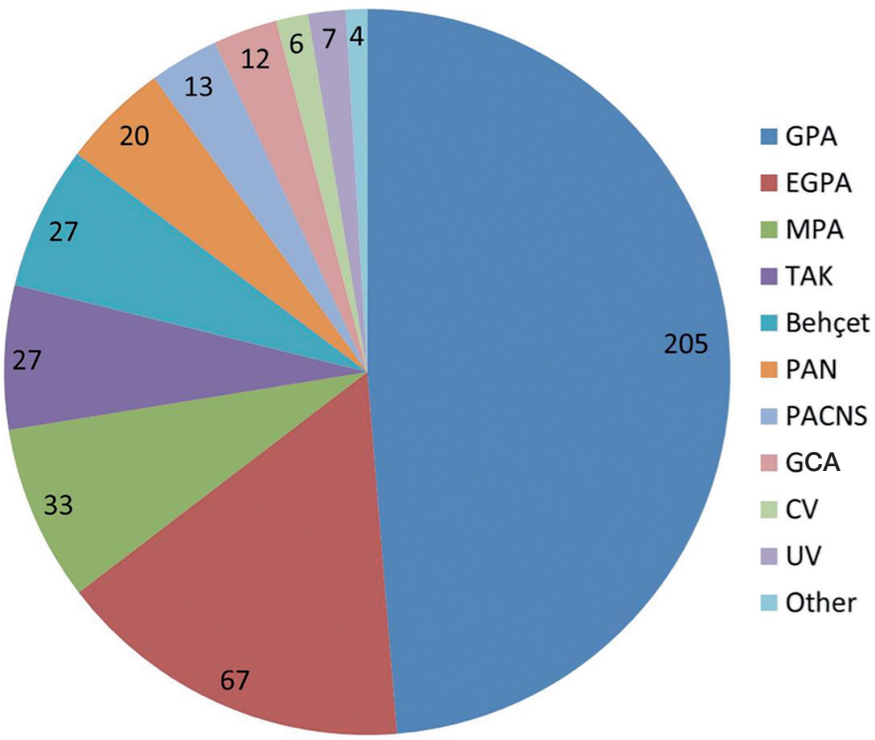

Fig. 1. Diagnosis of the 421 patients with vasculitis who completed the survey.
CV: cryoglobulinaemic vasculitis; EGPA: eosinophilic granulomatosis with polyangiitis (Churg-Strauss); GCA: giant cell arteritis; GPA: granulomatosis with polyangiitis (Wegener's); IgAV: IgA-vasculitis (Henoch-Schönlein); MPA: microscopic polyangiitis; PACNS: primary angiitis of the central nervous system; PAN: polyarteritis nodosa; TAK: Takayasu arteritis; UV: urticarial vasculitis.

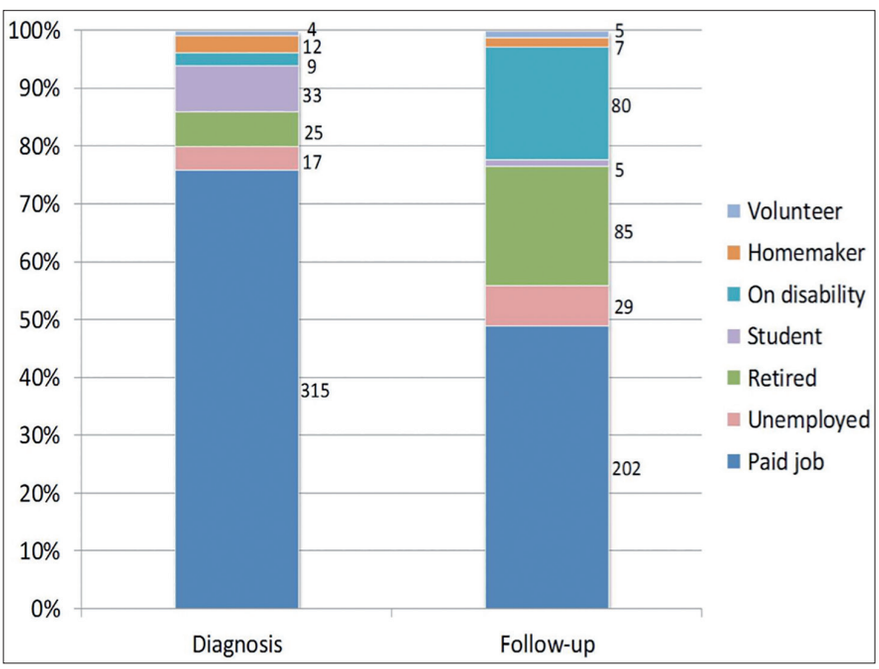

Fig. 2. Work status of patients at time of diagnosis of vasculitis and at time of survey completion (mean of 8±6.4 years post-diagnosis).

did or did not become permanently work disabled.

Patient global assessment score decreased by 3.7 points on a visual analogue scale (ranging from 0 to 10) from disease diagnosis to time of survey completion (Table I; 7.9±2.0 *vs*. 4.2±2.6; $p \leq 0.0001$). Patients who became work disabled had statistically significantly higher patient global assessment scores both at the time of diagnosis of vasculitis and at survey completion (Table I). When adjusted for age and sex, those who became work disabled were less likely to have health insurance (odds ratio (OR) 0.36; 95% confidence interval (CI) 0.15-0.90) and to have been educated beyond high school (OR 0.51; 95% CI 0.26-0.99). In multivariable logistic regression analysis (Table II), those who had become disabled were less likely to have a supportive work environment and more likely to have a physically intensive job. Disease symptoms that were independently associated with a higher risk of work disability included respiratory disease, neuropathic pain, and cognitive impairment.

Work environment

At the time of diagnosis, a self-perceived physically demanding job was significantly higher in those who became disabled compared to those who did not (Table III; 5.7±2.7 *vs*. 4.1±2.7 on a 10-point scale, $p<0.0001$) whereas job stress was not significantly different (6.9±2.5 *vs*. 6.6±2.2, $p=0.1900$). The difference in self-perceived work physicality was statistically significant across all subdomains with patients who became work disabled reporting jobs requiring higher levels of walking, stair climbing, standing, stooping/crouching/kneeling, reaching, and lifting, but lower levels of sitting or use of hands, compared with patients who did not become work disabled (Supplementary Table).

The perceived work environment was also different between patients who did *versus* those who did not become work disabled. At the time of diagnosis, patients who eventually became work disabled were more likely to report lack of accommodation with respect to job pace and job freedom compared to those who did not become work disabled. When surveyed about their work environment at any time since their diagnosis of vasculitis, patients who were work disabled reported statistically significantly lower rates of supportive employers and co-workers, suitable work conditions, and having had job accommodations, compared to patients who did not become work disabled (Table III).

Table I. Demographics, disease characteristics, and comparisons of subjects who were and were not permanently work disabled* due to vasculitis.

	All subjects	n	WD	n	Non-WD	n	*p*-value
Age, years, mean (SD)	53 (13)	418	56 (11)	111	53 (11)	187	0.0599
Sex, female, n (%)	293 (70)	417	81 (73)	111	129 (69)	186	0.5074
Body mass index, kg/m^2, mean (SD)							
At diagnosis	27 (8)	234	28 (10)	63	26 (7)	96	0.1819
At survey completion	35 (36)	124	34 (15)	39	40 (53)	53	0.4604
Cigarette smoking history, n (%)		412		108		185	0.0155
Never smoked	263 (64)		55 (51)		125 (68)		
Former smoker	114 (28)		40 (37)		48 (26)		
Current smoker	35 (9)		12 (12)		12 (6)		
Delay in diagnosis, months, median (IQR)	7.0 (18)	189	12 (21)	51	7 (12)	82	0.0670
Disease duration, months, mean (SD)	95.9 (76.2)	228	78.2 (60.7)	59	108.7 (85.1)	96	0.0176
Disease manifestations at diagnosis, n (%)		420		111		188	
Fatigue	376 (90)		106 (96)		65 (88)		0.0267
Joint pain	309 (74)		88 (79)		137 (73)		0.2149
Skin lesions	196 (47)		51 (46)		81 (43.1)		0.6303
Ear, nose & throat	307 (73)		78 (70)		149 (79)		0.0792
Nerve pain	188 (45)		70 (63)		67 (36)		<0.0001
Stroke	25 (6)		11 (10)		3 (2)		0.0010
Gastrointestinal	109 (26)		35 (32)		35 (19)		0.0108
Cardiac	46 (11)		16 (14)		12 (6)		0.0213
Genitourinary	128 (31)		31 (28)		58 (31)		0.5933
Pulmonary	205 (49)		66 (59)		88 (47)		0.0345
Disease damage, at survey completion, n (%)							
Chronic dyspnea	287 (69)	411	90 (82)	110	122 (66)	186	0.0028
Neuropathic pain	284 (68)	412	92 (84)	110	112 (60)	188	<0.0001
Joint or muscle pain	345 (83)	410	100 (90)	111	150 (80)	187	0.0249
Persistent fatigue	296 (75)	394	95 (88)	108	124 (70)	177	0.0005
Cognitive impairment	219 (53)	413	72 (66)	109	81 (43)	187	0.0002
Muscle weakness	277 (67)	413	89 (81)	110	113 (60)	187	0.0003
Treatments received at any time since diagnosis of vasculitis, n (%)							
Glucocorticoids	392 (94)	417	108 (97)	111	174 (93)	188	0.1204
Cyclophosphamide	219 (54)	409	64 (58)	110	96 (52)	184	0.3169
Other immunosuppressant drugs	353 (86)	410	95 (90)	106	165 (89)	186	0.8102
Patient global assessment, mean VAS (SD)							
At diagnosis	7.9 (2)	412	8.3 (2.0)	109	7.7 (2.3)	186	<0.0001
At survey completion	4.2 (2.6)	412	5.3 (2.3)	110	3.5 (2.3)	186	<0.0001

*Permanently work disabled was defined as retiring early or having to stop working and not being able to return to work because of vasculitis in subjects that were working at the time of their diagnosis of vasculitis. *p*-values for comparison of WD *vs*. non-WD. IQR: interquartile range; SD: standard deviation; VAS: visual analogue scale; WD: work disabled.

Table II. Variables independently associated with permanent work disability due to vasculitis as determined by multivariable logistic regression.

Variable	OR (95% CI)
Respiratory disease	2.21 (1.09, 4.49)
Neuropathic pain	2.12 (1.09, 4.12)
Cognitive impairment	1.90 (1.07, 3.39)
Ear, nose and throat manifestations	0.44 (0.23, 0.87)
Physically intensive job	2.19 (1.11, 4.32)
Supportive work environment	0.23 (0.12, 0.42)

Other variables tested that were not independently associated with work disability: age, type of vasculitis, smoking status, patient global assessment visual analogue scale, musculoskeletal pain, fatigue, and muscle weakness. CI: confidence interval; OR: odds ratio.

Work productivity and financial impact of vasculitis

Subjects reported an overall productivity loss of 6.9±7.7%. Productivity loss was consistent across all domains: time management (26.5%±36.4%), physical (20.4%±26.4%), mental-interpersonal (29.5%±27.1%), and output (33.5%±29.9%) scales. Correlation analysis indicated that the patient global assessment score and several disease and job variables were positively correlated with WLQ score, with musculoskeletal pain and fatigue having the strongest positive associations (Table IV).

Several finance-related variables were also examined. Notably, 38% of respondents reported a decrease in income following diagnosis (by a median of 45% [range 2–95]; n=66). The majority of patients (61%) reported out-of-pocket expenses for treatments (*i.e.* not covered by insurance). A further 14% of respondents did not obtain medications, treatments, or diagnostic tests because they could not afford the cost, with a greater percentage of those who

Table III. Characteristics of the work environment and insurance coverage of patients who did and did not become permanently work disabled* due to vasculitis.

	All subjects	n	WD	n	Non-WD	n	*p*-value
Work environment							
Job stress scale VAS, mean (SD)							
At diagnosis	6.7 (2.3)	310	6.9 (2.5)	110	6.6 (2.2)	185	0.1949
At survey completion	6.2 (2.5)	201	NA		6.3 (2.4)	153	NA
Job physical demand VAS, mean (SD)							
At diagnosis	4.7 (2.8)	311	5.7 (2.7)	111	4.1 (2.7)	185	<0.0001
At survey completion	3.3 (2.7)	196	NA		3.5 (3.8)	150	NA
Work environment at any time since diagnosis, n (%)		420		111		185	
Supportive employer	167 (34)		42 (38)		120 (64)		<0.0001
Supportive co-workers	73 (17)		14 (13)		57 (30)		0.0005
Suitable work conditions	100 (23)		13 (12)		86 (46)		<0.0001
Accommodations made	106 (25)		21 (19)		81 (43)		<0.0001
Insurance and benefits							
Health insurance coverage at diagnosis, n (%)	281 (92)	306	94 (87)	108	175 (95)	184	0.0134
Type of insurance, n (%)		279		94		173	0.0463
Private	186 (67)		55 (59)		125 (72)		
Public	31 (11)		11 (12)		18 (10)		
Private and public	62 (22)		28 (30)		30 (17)		
Utilised health insurance at time of diagnosis, n (%)	276 (98)	281	2 (2)	94	3 (2)	175	0.8108
Utilised disability benefits at time of diagnosis, n (%)	96 (35)	275	53 (60)	89	40 (23)	174	<0.0001
Utilised retirement benefits at time of diagnosis, n (%)	49 (18)	272	33 (37)	89	14 (8)	171	<0.0001
Affordability of vasculitis treatment at any time since diagnosis, n (%)							
Self-pay for some treatment	253 (61)	413	71 (65)	110	112 (61)	185	0.4931
Did not receive treatment because could not afford	32 (14)	228	11 (19)	58	9 (8)	109	0.0431
Income							
Receiving disability pension at time of survey	60 (92)	65	44 (94)	47	NA		
Income reduction at time of survey		200		8		153	0.0023
Not at all	124 (62)		2 (25)		96 (63)		
A small amount	32 (16)		2 (25)		24 (16)		
A moderate amount	22 (11)		0 (0)		19 (12)		
A significant amount	22 (11)		4 (50)		14 (9)		

*Permanently work disabled was defined as retiring early or having to stop working and not being able to return to work because of vasculitis in subjects that were working at the time of a diagnosis of vasculitis. *p*-values for comparison of WD vs. non-WD. NA: not available; SD: standard deviation; VAS: visual analogue scale; WD: work disabled.

were disabled foregoing treatments or tests due to financial constraints (Table II; 19% *vs*. 8%; $p=0.0431$). Most often, this consisted of hearing tests, referrals to specialists, physiotherapy, and prescription medications. The utilisation of disability and retirement benefits was significantly higher among the work disabled patients: 60% *vs*. 23% ($p<0.001$) and 37% *vs*. 8% ($p<0.001$), respectively.

Table IV. Correlations between Work Limitations Questionnaire scores and disease and work variables.

Variable	Correlation coefficient (rho)	*p*-value
Patient global assessment scale	0.67	<0.0001
Dyspnea VAS	0.44	0.0685
Neuropathic pain VAS	0.45	0.0188
Musculoskeletal pain VAS	0.68	<0.0001
Fatigue VAS	0.68	<0.0001
Job physical demands score	0.32	0.0059
Job stress score	0.29	0.0133

WLQ : Work Limitations Questionnaire, 8-item; VAS: visual analogue scale.

Discussion

This large, North American study using patient self-reported data demonstrates a substantial negative impact of vasculitis on employment status, work productivity, and income, with 26% of participants becoming permanently work disabled or having to retire early secondary to vasculitis.

These findings are consistent with, update, and expand previous reports. In the study by Hoffman *et al*. (11) 31% of US patients with GPA who were employed before a diagnosis of vasculitis became disabled after their diagnosis. Reinhold-Keller *et al*. (13) reported that employment among German patients with GPA fell from 73% to 53% within 3 years after their diagnosis, with women three-fold more likely to stop working compared with men. In the present study, women were not more likely to become work disabled than men. More recently, a cross-sectional study from a UK vasculitis clinic reported that of 149 patients who were of working age, 26% were considered work disabled (7), while a French study

reported a 40% prevalence of work disability due to vasculitis (8). A previous single-center study on 103 Canadian patients with vasculitis found that 21% were work disabled secondary to vasculitis and that of those patients able to work, their mean loss of work productivity following diagnosis was 8.2% (6). Importantly, these studies suggest that rates of work disability secondary to vasculitis have remained largely unchanged since the 1980s despite advances in treatment.

There were important differences over time between patients with vasculitis who became work disabled compared to those who did not become work disabled. Those patients with a higher patient global assessment score at the time of diagnosis of vasculitis were significantly more likely to become work disabled than those with a lower score. Some disease manifestations were independently associated with future work disability, including neuropathic pain, cognitive impairment, and respiratory disease. Basu *et al*. (7), reported significant associations between obesity and fatigue with work disability among patients with vasculitis; however, in this study, the rates of being overweight or obese were not significantly different between patients with vasculitis who did or did not become work disabled. The current study found that fatigue correlated strongly with loss of work productivity as measured by the validated WLQ.

Vasculitis had a substantial negative impact on patients' financial situation. Overall, the median income loss secondary to vasculitis was 45% in those who became work disabled. Other studies have shown income reductions secondary to vasculitis ranging from 5–75% (6, 9-11). Variations may be secondary to differences in patient demographics and disease factors among the studies as well as potential regional differences in social programs that may impact the perception of financial burden. Patients who became work disabled were also significantly more likely to forego treatments or tests that they had to pay for out-of-pocket compared to those who did not become work disabled.

Prior studies did not assess the impact of work-related factors on work disability in systemic vasculitis. In the current study, self-perceived physicality of work and a non-supportive work environment were significantly associated with future disability in a multivariable regression analysis. Work accommodations early after a diagnosis of vasculitis may mitigate future work disability. However, trials of intervention programs to improve work ability in rheumatologic conditions have yielded conflicting results regarding efficacy and cost-effectiveness (20, 21).

This study has several strengths. Notably, this was a large study of patients with vasculitis from Canada and the US. Patients had a variety of types of vasculitis, mostly GPA, EGPA, and MPA, but less common types of vasculitis were also represented. Self-reported data is considered sufficiently reliable as compared to information from administrative databases (1, 22). In the context of this study, self-reports allowed for information to be obtained on factors that would be difficult to account for from an administrative database including: patient-perceived limitations in work and productivity, suitability of work conditions, and net personal income loss, all of which are important determinants of the impact of work disability and risk of becoming work disabled.

There are several limitations to this study. First, as with most surveys, the findings may be limited by selection bias. This study utilised a well-established, international vasculitis registry, which has been used in other survey studies (14-16), and advertisements on other vasculitis patient networks and websites to recruit patients. Second, the results are subject to recall bias since patients were asked to retrospectively assess several disease- and work-related factors at the time of their diagnosis of vasculitis. Third, disease diagnosis was self-reported and not cross-referenced against diagnoses made by qualified health professionals. However, patients were asked (at enrolment in the registry and for this study) about their use of medications at any time since their diagnosis; the prevalent use of glucocorticoids and other immunosuppressant drugs, as well as the reported disease manifestations, supports the diagnosis of vasculitis in these patients. Fourth, patients could choose not to answer certain survey questions; this generated missing data for questions that could be considered more sensitive, such as income, use of health insurance benefits, and out-of-pocket expenses. Lastly, some other factors that may impact on work disability, productivity and income loss, were not considered such as family support and depression.

Conclusion

Advances in the medical treatment of vasculitis have resulted in patients living longer. However, a substantial proportion of patients with vasculitis continue to become permanently work-disabled, or less work productive, secondary to their diagnosis, with rates of work disability and income loss largely unchanged over the last 35 years. The identification of disease- and work-related factors that are associated with the highest risk for work limitation could help inform policies and programs to optimise supportive work environments and to better support patients with vasculitides.

Overall, our these findings also suggest that minimising damage associated with vasculitis, especially chronic pain, cognitive impairment, and functional impairment may help mitigate future work limitations.

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