



Published in final edited form as:

Clin Exp Rheumatol. 2012 ; 30(1070): S15–S21.

The impact of vasculitis on patients' social participation and friendships

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Abstract

Objectives—Our objective is to explore how vasculitis, affects patients' friendships and social participation.

Methods—Vasculitis patients (n=221) completed an online questionnaire that asked if, and how, relationships with friends have changed since receiving a vasculitis diagnosis. Participants' written responses were imported into Atlas.ti, and two independent researchers used both structured and unstructured coding to identify themes. After reaching 100% consensus on the themes present in each participant's responses, the coders determined how themes were interrelated across participants.

Results—Over half of patients (52%) expressed that vasculitis negatively impacted their friendships and 25% noted a negative impact on their social participation. At times, this negative impact was related to structural changes in patients' social networks due to loss of friendships. Reduced social participation was also associated with friends' inability to understand vasculitis and its effects, vasculitis-related fatigue, and lifestyle changes such as not being able to drink alcohol and avoiding infection-prone events. Additionally, patients withdrew from social engagements due to fatigue or because of physical symptoms and side effects.

Conclusion—The unique circumstances associated with a rare chronic illness like vasculitis can create significant barriers to friendships, including loss of these relationships. Interventions designed to help patients cope with the social impact of vasculitis are implicated, especially if they increase patients' ability to engage in dialogue about their illness with their friends.

Keywords

vasculitis; quality of life; friends

Introduction

It is well-documented that vasculitis is associated with compromised quality of life (1–13). Negative impacts include deterioration in physical functioning, financial issues related to medical treatment and employment changes, and psychological impacts such as increased risk of depression and anxiety. Social relationships with spouses, family members, co-workers, and friends can also be impacted, though few studies have examined how vasculitis impacts these relationships. Understanding how vasculitis affects patients' social networks is of interest because chronic disease patients often seek support from others to help cope with disease-related stressors, which can lead to improved physical and mental health (14).

Friendships differ from relationships with family by being long-term, voluntary, and based on intimacy, mutual interest, and reciprocity (15). The few studies that have investigated how vasculitis affects patients' friendships have found that the majority of patients report friendships remain essentially unchanged after diagnosis (1, 4). However, patients who reported changes often reported negative ones. For example, Boomsma *et al.* (1) found that 25% of vasculitis patients reported that their friendships had worsened since receiving a diagnosis; whereas, only 7% of patients reported that their friendships had improved. Similarly, Hoffman *et al.* (4) found that 21% of patients having granulomatosis with polyangiitis (formerly known as Wegener's Granulomatosis) reported that their friendships had worsened after diagnosis, while 14% reported that friendships improved.

The current paper addresses a gap in the literature by providing greater detail about *how* friendships have been affected by vasculitis. Considering previous research (1, 4), we anticipated that patients would report both positive and negative impacts. We primarily focused on issues that negatively impacted patients' ability to participate in social activities with friends.

Methods

Overview

All data were collected as part of the Accessing Social Support in Symptom Treatment (ASSIST) Study, which evaluated the level of support of vasculitis patients' social networks. Eligible patients had a self-reported diagnosis of vasculitis, were at least 18 years of age, were able to read and write in English, had Internet access, and were taking at least one medication to treat their vasculitis. This study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill.

Sample

We recruited 106 participants by distributing study information at a vasculitis patient conference (n=39) and mailing physician-diagnosed vasculitis patients who were part of the Glomerular Disease Collaborative Network (n=38) and prior vasculitis studies (n=29). We also contacted members of vasculitis support groups and posted announcements on vasculitis websites, in patient newsletters, and on patient list serves, which yielded 147 eligible and interested participants. Carpenter *et al.* (16) provide a more thorough description of recruitment procedures.

Of the 253 eligible patients, 232 (91.7%) completed the one-hour questionnaire. Reasons for non-completion included technical issues (n=7), being too sick (n=4) or too busy (n=3) to participate, or never responding to study correspondence (n=7). When compared with completers, non-completers were not significantly different in terms of gender or vasculitis type.

Measures

Participants answered one item each about gender, race, age, education (in years), year of vasculitis diagnosis, health insurance status, vasculitis type, and whether they were currently experiencing a relapse. These variables were used to characterise the patient sample. Participants were also asked, “How, if at all, has your relationship with your friends changed since you were diagnosed with vasculitis? Please briefly describe any positive or negative changes that you have noticed.” Of the 232 patients that completed the questionnaire, all but 11 answered this open-ended question. Chi-square tests revealed that non-responders (n=11) and responders (n=221) were not significantly different in terms of gender, race, age, education, vasculitis type, or relapse/ remission status.

Patients’ written responses to the friendship question were used in the thematic analysis described below. In order to accurately capture patient impressions about changes in friendships, we have not altered the original textual responses. Thus, typographical and grammatical errors have not been corrected in the example quotations.

Data analysis

Qualitative data were analysed by two independent coders (first and second authors), who used both structured and unstructured coding to identify important themes. To facilitate structural coding, a codebook with definitions and example quotations was created sifter an initial review of patient responses. The codebook consisted of a table that was revised iteratively as necessary throughout the coding process (Table I). Focussed coding was then carried out using *Atlas.ti* (17). Interviews were “double-coded” by the first and second author, who met on a regular basis throughout the coding process to reach 100% consensus on all coding. After consensus had been met, coding reports were generated, which aggregated responses to the friendship question by theme. Unstructured coding led to the development of additional code-book entries and definitions. In order to provide a quantitative representation of the qualitative data, the number of patient responses was tallied for each theme.

Results

Sample characteristics

The majority of respondents (n=221, Table II) were female, white, and had a diagnosis of granulomatosis with poly-angiitis. On average, participants were middle-aged, had completed some college education, and had been living with vasculitis for over six years. Twenty-eight percent of patients were experiencing a relapse or flare at the time of the survey.

Positive changes to friendships

In response to the question about changes to friendships after receiving a vasculitis diagnosis, 21.3% of patients reported no change and 47.1% reported positive changes. Positive changes ranged from receiving various types of social support (22.4%), having understanding friends (6.9%), feeling closer to friends (3.4%), and gaining new friends (3.0%). Patients who gained friends often described developing highly empathetic relationships with other chronic disease patients.

Social support—Patients received many different types of support from their friends, including companionship, emotional support, informational support, and instrumental support. The level of support friends provided varied from simply “checking in” to see how the patient was doing to transporting patients to their medical appointments. Other types of

instrumental support included monetary support, cooking meals, and cleaning the patient's house. The three quotations provided below demonstrate the supportive actions of friends.

"I have been surprised at how supportive a number of (not very close) friends suddenly became. When first diagnosed I received phone calls from friends and work colleagues from around the world ... it was very 'touching' and humbling in a way and made me appreciate them so much more."

"My friends are more helpful and caring towards me. They arrange meals out and invite me to get me out of the house. They're always calling me on the telephone and giving me words of encouragement."

"When she can she goes with me to the doctors and also has taken me to the emergency room twice. Calls daily and even has gone shopping for me and has helped with the government, like helping with the Medicare and Medicaid."

Understanding—Understanding friends (6.9%) were described as those who showed some interest in vasculitis and its effects. Patients especially appreciated friends who understood and accepted that patients would not be able to engage in social activities at the same level as previous to diagnosis. To illustrate: "My friends understand I have limitations and encourage me to rest when needed."

"People have started to care about me in a different way and not in a bad way. Giving up things, like drinking alcohol, they know and help in making it easy for me to have fun and fit in."

Gained friends—Many patients noted that their friends knew little about vasculitis. This lack of knowledge and understanding led some patients to seek out new friends who could relate to them and understand what they were going through. In particular, patients were likely to make new friends who had vasculitis or, alternatively, become closer with existing friends who had other types of chronic diseases. Two respondents illustrate this point:

"I am closer now to friends who have chronic illnesses. We can talk about things that healthy people just do not understand. It's kind of like a club that no one wants to be a part of - but we're really glad that we can support each other, particularly when going through a flare and facing additional loss of function."

"My closest friends also have WG. My dearest friend in the world was an email buddy when I was on my first WG online support group in 2000. We have since met a couple of times in person which has made the bond stronger. We email each other every day about 5 times! Non-WG friends are constantly asking how I feel, am I overdoing it, etc., until I tell them to knock it off! (I feel like I'm a rat on display in a research centre sometimes)."

Negative changes to friendships

Over half of patients (52.0%) reported negative changes to friendships and approximately one fifth (21.8%) reported both positive and negative changes. Twenty-five percent of patients reported participating in fewer social activities with friends. Losing friends was the most commonly cited cause of less social participation, with 40 patients (18.1%) reporting losing a friend as a result of their vasculitis diagnosis. Friends' lack of understanding and knowledge about vasculitis (14.9%) was also related to reduced social participation. Additionally, vasculitis-related fatigue (7.7%), lifestyle and physical changes related to vasculitis (10.9%), and patient withdrawal (5.4%) also negatively impacted patients' ability

and desire to engage in social activities with friends. These themes are described in detail below.

Loss of friends—Many participants noted that they lost friends as a result of their diagnosis. Some patients remarked that they no longer had any friends, for example, “MY FRIENDS HAVE ALL GONE AWAY,” and “embarrassingly my friends are now my cat and characters from tv.” Other patients only lost a few friends, which oftentimes resulted in identification of “true friends.” True friends were described as those friends who stood by the patient during and after their diagnosis. In one patient’s words: “Interesting how a life-threatening event shows you who your real friends are, who comes to see you while in the hospital and who doesn’t.”

A few I haven’t heard from since diagnosis, others that I have years later typically respond with ‘Oh, yeah, I heard you were sick.’ Other friends have been truly there not just for me, but my family as well, during tough times.”

Some patients noted that loss of friendships was temporary and that friendships returned to normal after an initial adjustment period: “When I was first diagnosed I was so sick that my friends were pretty much staying away from me, as I spent most of my time in bed. Now that I am healthy as a result of the right medications, my friendships have gone back to the way they were before.”

In contrast, other patients indicated that they may never see their friends again: “I lost a very close friend after my illness, she only visited me 2 times in the hospital when I nearly died. After when I came home she stopped calling and when I called her she just wasn’t the same. I haven’t talked with her now for over 2 years. It hurt, we were always out and doing things together weekly.”

Friendships that were primarily defined by engaging in shared physical activities suffered more than more robust friendships. For example, two participants explained: “We used to do a lot of walking, even mountains and organised an annual weekend for friends to gather for it. Since diagnosis my disability means I can’t walk as I used to so we don’t see these friends as we used to and our social life with them is not the same.”

“I have been very impaired in my ability to participate in activities that I enjoy with my friends that I used to be able to do – go on hikes, go on trips, go to evening events at some distance away (45 minutes to an hour), etc. This has been very difficult.”

Lack of knowledge and understanding—Many patients noted that their friends did not understand vasculitis or how it affected them personally. This lack of understanding was often related to reduced participation in social activities either through friends distancing themselves or patient withdrawal. As an example of friend distancing, one respondent noted: “I am no longer included in any events. I think that since little is known about Wegener’s they avoid me.” In some cases, patients speculated that friends distanced themselves because they were “afraid” or “scared” of the patient. Some friends even believed that vasculitis was contagious: “when I came down with my vasculitis most friends disappeared because they thought I would get them sick.”

As noted above, friends’ lack of understanding sometimes led to patient frustration and withdrawal. The following quotation provides an example of withdrawal: “I don’t socialise with friends anymore. Have become a hermit actually. It’s hard to expect someone to understand how chronic illness and pain affects your life. Very few people do. Most feel you can just shake it off or take meds and fix it.”

Although patients often believed that friends were well-intentioned, their lack of understanding could lead to frustration, as in the following example: “Friends don’t really understand Vasculitis. They seem to think I have a cold or something simple. They care and are always asking about how I feel and when I expect to be normal again. They mean well, but asking everyday how I am is a little frustrating.”

Patients often attributed friends’ lack of understanding to the lack of public awareness about vasculitis. Most frequently, patients compared vasculitis to cancer. The following quotation demonstrates how understanding and empathy may be more complicated for friends of patients with a rare illness: “No one has heard of Wegener’s, so its hard for them to understand that this is a lifelong issue I’ll have to deal with. Its awful to say, but sometimes (rarely!) I’m jealous of the cancer patients because they get a lot of public support and many of them will get well and live a ‘normal’ life.”

Fatigue—Vasculitis-related fatigue was cited as a cause of reduced social participation and even withdrawal. In one patient’s words: “When i was worse or am having hard times i don’t always feel able to talk to people. my energy level and inability to stand for long, rules out activites I’d do with friends-concerts, galleries, etc. so really I haven’t seen my friends at all. it has completely changed my life in social terms. I do not exist!”

Another example reads: “I just want to be left alone ... And I’m too worn out to go anywhere with anyone. It sucks.” Patients were aware that they had a limited amount of energy in any given day. Some chose to focus that energy on activities with close family, while others became more selective in the types of activities in which they participated. One participant noted: “I am not as sociable. I don’t have as much energy, I am aware that if I go out tonight I’m likely to be tired and unproductive tomorrow, so I choose what I do with friends ... So I feel as though I have become quite boring.”

Other patients noted that attempts to maintain the same level of social participation often resulted in negative consequences; for example, “I do not go out as much as I did, very limited on nights out, as I know I will not be able to keep up and then regret it. As it will take about a week to get back to ‘normal’.”

Lifestyle and physical changes—Effective vasculitis self-management is often associated with lifestyle changes that can impact social relationships. For example, patients often have to restrict alcohol intake because alcohol is contraindicated with some vasculitis medications. Since drinking is a common social activity, several participants noted that their relationships have suffered. One respondent stated that their friends viewed him/her as a “partypooper” because he/she could no longer drink alcohol. Another wrote: “The not drinking at parties and leaving early did cost me a few friendship, which was very unfortunate.”

Vasculitis patients who are taking immunosuppressive medications also have to be vigilant about avoiding infection. This leads patients to restrict the types of activities they engage in, especially activities that involve large groups of people. In one patient’s words, their friendships have changed because he/she can’t go out as much anymore; “Friends have cancelled dates when they have been ill as they are aware that I need to be careful regarding infections.” Though patients are aware that avoiding these social engagements is in their best interest, one participant expressed that having to ask infection-related questions and decline party invitations is “not fun.” Another patient wrote that: “I get tired of people making decisions for me about what I can and can not do physically. For example: I delivered meals on wheels and now their excuse is you should not expose yourself to some

of the homes that meals are delivered. That might be true during the flu season, but not all the time.”

Patients also mentioned that friends were uncomfortable with the physical effects of vasculitis and/or the patient’s prognosis. One patient described a friend’s discomfort thus: “All of my friends stopped visiting and inviting me out, my first symptom was cutaneous vasculitis and got unsightly and painful. My longest friend (known for over 15+ years) told me he had a very hard time dealing with my illness and thought I would die and could not deal with watching me die.”

Withdrawal—Some patients withdrew from social activities. Vasculitis-related fatigue and lifestyle changes were cited as reasons for withdrawal, as noted previously. Additionally, some patients withdrew from activities because of physical changes related to vasculitis and its treatment. For example, “I do not want to go out as much or see many people, the predisona has made me moon faced and a weight gain and I feel as if I look like the Cambell Soup kids or Philbury Doughboy.”

Discussion

Unlike previous studies (1, 4), we found that a majority of patients reported that vasculitis negatively impacted their friendships and social participation. Almost 1 in 5 patients reported losing a friend as a result of their vasculitis diagnosis. Moreover, quality of friendships was compromised due to reduced social participation, with 25% of patients engaging in fewer social activities after their diagnosis. Reduced social participation was often attributed to friends’ lack of understanding about vasculitis, vasculitis-related fatigue, lifestyle changes related to medication contraindications and infection precautions, as well as patient withdrawal.

There was great variation in the extent to which vasculitis altered patients’ social networks. While some patients lost all of their friends, others gained new friends in addition to strengthening existing friendships. This variation may be explained by both patient characteristics and disease-related factors. For example, patients with good communication skills may be able to better communicate their situation and needs to friends. Additionally, depression, which has a prevalence of 23.6% in vasculitis patients *versus* 7.6% of the general population (18), may affect patients’ ability and confidence to maintain friendships after diagnosis. It is also possible that patients with less severe disease may more effectively maintain friendships because their energy level and physical appearance are not greatly affected. Future research should investigate what factors are associated with patients’ ability to successfully maintain friendships. That way, changeable factors can be identified for interventions designed to help patients maintain healthy friendships after their diagnosis.

Patients noted that vasculitis symptoms and lifestyle changes compromised their ability to participate in social activities to the same extent as they did before diagnosis. Vasculitis-related fatigue is a major issue for patients (19) and has been more strongly associated with impaired quality of life than clinical measures of disease activity and damage (20). Diseases with fatigue as a major symptom are often discounted by others (21). Thus, even though fatigue causes patients a great deal of hardship, friends may not be able to understand this. If patients could share educational materials that specifically discuss fatigue with their friends, friends may then perceive the patient as more credible and be more supportive and understanding when patients decline social events or leave early. Similarly, educational materials that describe drug interactions with alcohol and the need to avoid infection-prone events may serve as a tool for discussing these issues with friends.

Rare diseases like vasculitis may pose an additional obstacle to friendships that is not seen with more common illnesses. When a patient is coping with a well-known disease, others often know what to expect and are able to respond with empathy and understanding. However, in the case of a rare disease like vasculitis, an effort must be expended to learn about the disease in order to understand its effects (22). Many of the participants in our study noted that friends did not understand vasculitis and how it affected them personally, which has also been found with lupus and rheumatoid arthritis patients (23). Some patients even expressed that they would rather have cancer instead of vasculitis because then they would not have to explain the disease to others. Patients' reticence to talk to their friends about vasculitis suggests that communication-focused interventions are needed to help patients act as their own advocates in explaining their disease to their friends.

Not all changes to friendships were negative; 47.1% of patients reported positive changes, which included feeling closer to friends, gaining new friends, and receiving emotional and instrumental support. Indeed, many patients commented that losing some friendships was less painful when they had "true friends" who stood by them during and after their diagnosis. This finding is in accord with previous studies, which found that the quality of social support – rather than the number of relationships – was associated with better outcomes for women with rheumatoid arthritis (24,25). Relationships with other chronic disease patients were especially meaningful due to shared understanding about the limitations caused by chronic-disease. Unfortunately, because vasculitis is an extremely rare condition, patients often do not have access to a local vasculitis support group. However, online support groups may help patients identify and connect with other patients. Because friendships with other vasculitis patients were noted as especially beneficial, health care providers should consider providing patients with Internet-based support resources to help them connect with others.

This study has several important limitations. First, like all qualitative studies, our results are not generalisable to the greater population. Generalisability is particularly limited because all participants had access to the Internet and online support resources. The impact of vasculitis on friendships may be more severe for patients who do not have access to online resources. Additionally, our results may be biased if patients who accessed the study survey had fewer friends than patients who did not access our survey. For example, patients who were socially isolated or functionally impaired may have had fewer friends and spent more time online than individuals who were physically able to attend social events and maintain key friendships.

Second, our data was derived from written answers to an open-ended question, so we could not probe for additional information about changes to friendships. However, having people's written responses allows us to capture their intended emphases and express their meaning verbatim without risk of transcriptional error. Because only 11 patients did not respond to the friendship question, we have a broad range of patient perspectives. Last, our data are limited to patients' subjective perspectives of changes to friendships. Future studies should document the experiences of friends to provide a more holistic assessment of how friendships are impacted by vasculitis.

Conclusion

Vasculitis affected both the quantity and quality of patients' friendships. Patients were more likely to report negative impacts to friendships than positive impacts. Since we did not include patients with other types of rheumatic disease, we could not determine whether vasculitis patients are unique in their needs for friendship and social interaction. However, it is possible that disease severity and pain may have stronger impacts on patients' ability to

participate in social activities than disease type (e.g. vasculitis, rheumatoid arthritis, osteoarthritis). Future research should explore whether the ability to maintain healthy friendships varies by patient demographic and clinical characteristics, such as age and depression. Quantitative studies that explore correlations between patient demographic/clinical characteristics and friendship outcomes may be particularly insightful. Because over half of patients reported negative changes to their friendships, interventions and educational materials designed to help patients communicate their situation and needs to their friends are warranted. Materials of this nature may increase friends' understanding of vasculitis and reduce patient burden in explaining their disease to their friends.

Acknowledgments

We would like to thank the Vasculitis Foundation, its support group leaders, Vasculitis Foundation Canada, Wegener's Granulomatosis Support Group Of Australia Inc., the Glomerular Disease Collaborative Network, the UNC Kidney Centre (especially Ronald J. Falk, Kristen Hendrickson, and Caroline E. Jennette) and Jim Bornac for their help with recruitment.

Funding: This work was supported by the Renal Epidemiology Predoctoral Traineeship at the UNC Kidney Center, the Thurston Arthritis Research Center Postdoctoral Fellowship (5T32-AR007416), and the ACR REF/Abbott Health Professional Graduate Medical Student Research Preceptorship.

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Table I

Qualitative codebook with definitions of themes, example quotations, and percentage of patients with quotations about themes.

Theme	Theme Definition	Example Quotation	%
Social support	References to receiving support from network members, including emotional, instrumental, and companionship support.	<i>"They were very supportive when I was sick and bought over meals and tried to help my husband."</i>	22.4
Closer to friends	References to feeling closer to social network members after a vasculitis diagnosis.	<i>"It has brought us even closer than before. It has made us all realize how fortunate we are to have each other's support and love."</i>	3.4
Gained friends	References to making new friends after the vasculitis diagnosis.	<i>"I made alot of new friends because of the illness too."</i>	3.0
Lost friends	References to losing friends after the vasculitis diagnosis.	<i>"lost half my friends due to illness because they don't know how to deal with my behcet's"</i>	18.1
True friends	References to how the patient was able to identify true friends after the vasculitis diagnosis.	<i>"My friends were scared at first and worried alot but in the end the true friends were the ones that stuck by me."</i>	4.5
Social participation	How vasculitis impacted the patient's ability to engage in social activities, such as church, visiting with friends, and recreational activities.	<i>"in general I do a lot less with others because I am not feeling well (ie don't have the energy) or I don't want to talk about my disease/vasculitis. I think in general the family is less social because we have to juggle time around the need I have to get rest in the afternoon (lie down)."</i>	24.9
Knowledge & understanding of vasculitis	References to social network members' knowledge of vasculitis and degree of understanding about how vasculitis impacts the patient specifically (understanding of patient vasculitis symptoms and effects of medications).	<i>I have several other close friends who are also extremely supportive and try very hard to understand what the disease is about. The most important thing is that they learn a little bit - not a lot - but at least have some sort of understanding of what has happened to my body and how it affects my daily life, because to everyone else, I generally look healthy.</i>	(+) 14.9 (-) 6.9
Lifestyle& Physical Changes	References to any vasculitis-related changes in appearance (e.g. weight gain related to steroids) or lifestyle, such as restricting alcohol intake, avoiding infection, monitoring symptoms, & taking medications.	<i>"With medication interactions-we dine out less, and don't drink at all with friends."</i>	10.9
Withdrawal	Patient references to withdrawing from social network members.	<i>"I don't want to go anywhere or do anything with anybody. I pretty much isolate myself to the house most of the time because I usually don't feel good. Everbody annoys me because I have NO patience anymore."</i>	5.4

Table II

Characteristics of vasculitis patients who responded to the friendship question (n=221).

Characteristics	Mean (SD) or %	Range
Socio-demographic		
Age	51.0 (13.7)	20.0–82.0
Male	29.9%	–
White	91.0%	–
Education (in years)	15.6 (2.9)	4.0–22.0
Clinical		
Self-reported vasculitis type		
Granulomatosis with polyangiitis	59.7%	
Churg Strauss syndrome	12.7%	
Microscopic polyangiitis	8.1%	
Takayasu arteritis	5.4%	
Other	14.0%	–
Years with disease	6.4 (6.4)	0.5–36.0
Currently experiencing flare/relapse	27.6%	–
Have health insurance	93.2%	–