

# What Everybody is Doing but No One is Talking About: Use of Complementary and Alternative Medicine in the ANCA Associated Vasculitis Population

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**Abstract:** The use and impact of complementary and alternative medicine (CAM) for anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis (AAV) has not been reported. AAV patients seeking care at our center inquired about CAM, prompting a formal study. Study objectives were to discern how many AAV patients used CAM and its perceived helpfulness in disease management.

**Methods:** AAV patients completed a CAM questionnaire between July 2011 and May 2012. Patients were 18 years or older and had biopsy proven and/or clinical evidence of AAV. Medical record abstraction supplemented data. Classification detailed CAM type including "Mind" or "Mind-Body". Perceived helpfulness of CAM was assessed as "very", "somewhat" or "not at all/don't know".

**Results:** A total of 107 patients participated and were a mean age of 53 (range: 18-85), 62% female; 48% proteinase 3 (PR3)-ANCA, 44% myeloperoxidase (MPO)-ANCA and 8% ANCA-negative. Top organs involved included kidney (87%), joints (55%), lung (53%) and upper respiratory (53%).

At least one type of CAM treatment or self-help practice was reported by 81% of study participants, with the most frequent being prayer (64%), exercise (27%) and massage therapy (19%). Mind-based practices were used by 28% (excluding prayer) and Mind-Body practices by 14%. Most practices were used to improve wellbeing, and Mind and Mind-Body were deemed very helpful by 83% and 87% respectively. Only 24% of study participants discussed CAM with their physician.

**Conclusion:** CAM practices were commonly used to improve well-being and found to be beneficial among AAV patients, but more open discussion is needed about CAM between physicians and patients.

**Keywords:** ANCA-Associated Vasculitis, Alternative Medicine, Complementary Medicine, Small Vessel Vasculitis, and Autoimmune Disease.

Small vessel vasculitis, frequently associated with anti-neutrophil cytoplasmic antibody (ANCA), is a multisystem autoimmune disease that affects about 1 of every 50,000 people. ANCA associated vasculitis (AAV) is characterized by periods of relapse and remission, management of organ damage from active disease, extreme fatigue and overall diminished quality of life [1, 2]. Treatment of AAV requires immunosuppressive drugs, all of which can be associated with adverse and sometimes life-threatening side effects. The use of complementary and alternative medicine (CAM) has been reported for managing a variety of medical conditions including cancer, neuropsychiatric disorders, and other autoimmune diseases [3-6]. However, CAM's use in AAV patients has not been thoroughly reported and most of the research to date has focused on a variety of autoimmune conditions with only relatively small numbers of AAV patients [7, 8].

Our medical center is a referral center for patients with AAV. As an allopathic medical center, there has been little focus on CAM when formulating a patient's care plan. Patients in our vasculitis clinic have begun discussing with greater frequency the use of a variety of CAM treatments for the management of disease symptoms and treatment side effects. The objective of this study was to systematically survey our AAV patients about their utilization of CAM practices and their perceived role of CAM in disease management.

## PATIENTS AND METHODS

A total of 107 patients with AAV completed a CAM questionnaire. Enrollment started July 2011 and ended May 2012. Research coordinators administered the questionnaire during regularly scheduled medical appointments at the University of North Carolina's (UNC) multidisciplinary outpatient vasculitis clinic. Participants were already being followed in an inception cohort within the Glomerular Disease Collaborative Network (GDCN). The GDCN and its methods for identifying and enrolling patients have

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previously been described [9-11]. CAM questionnaire data was combined with medical chart abstraction for analysis.

Eligible patients had biopsy proven and/or a strong clinical indication of AAV and were 18 years of age or older. Participants provided informed, written consent and participated in accordance with UNC's Institutional Review Board.

CAM has a broad and evolving definition. The version used for this study was adapted from the National Institutes of Health's National Center for Complementary and Alternative Medicine (NCCAM) and was provided in the patient administered questionnaire (<http://nccam.nih.gov/health/whatiscam>, accessed April 29, 2011). CAM is defined as a group of diverse medical and health care systems, practices and products that are not generally considered part of conventional medicine. Conventional medicine (also called Western or allopathic medicine) is practiced by medical doctors, doctors of osteopathy and allied health professionals, such as physical therapists, psychologists, and registered nurses. Differences between conventional medicine and complementary and alternative medicines are not absolute. CAM practices are often grouped into broad categories such as biologically based practices (e.g. herbal supplements, essential oils), mind and body medicine, and manipulative/ body-based practices (e.g. acupuncture, massage), and mind-body medicine (e.g. meditation, prayer). Other forms of CAM include traditional healers, manipulation of energy fields, and various cultural practices of medicine. None of the CAM categories are formally defined, and some practices fit into more than one category.

For this study, participants were clustered into CAM "users" and "non-users" based on either visiting/receiving CAM from a provider or practicing self-help practices within the last twelve months. Within the categorization of users were patients who used prayer as a form of healing, as prayer has been shown to illicit the relaxation response. Further, a subgroup of "users" was classified into Mind or Mind-Body categories. These categories provided mutually exclusive groups allowing for independent statistical comparisons between groups. Prayer was excluded from the Mind category due to the field's inconsistent opinion as to whether prayer is considered CAM. However, prayer was measured in this study and reported separately because our patient population expressed interest. CAM categorizations, such as in

the National Health Statistics Report [12] did not yield mutually exclusive groups. The Mind category included meditation, guided imagery and relaxation techniques, but excluded prayer, while Mind-Body included yoga, qigong, tai chi and Pilates. While Pilates focused more on the body component of the Mind-Body subgroup, it nevertheless was kept in the categorization due to its breathing awareness and precise controlled movements. General exercise was not included as a Mind-Body technique.

An adapted version of the International CAM Questionnaire (I-CAM-Q) was used [13]. The questionnaire was a product of an international workshop sponsored by the National Research Center in Complementary and Alternative Medicine (NCCAM). Adaptations included demographic and disease questions, educational outlets, reasons for practicing and communication questions. Questionnaire tables were adapted to include CAM practices that might resonate as familiar to participants. Please refer to Appendix A for the full questionnaire.

Patients could report using CAM as treatment for an acute illness, treatment for a long-term health condition, to improve well-being or other. Patients marked all that applied. Perceived helpfulness was also garnered for each CAM category and documented as "very", "somewhat" or "not at all/don't know".

The questionnaire elicited participants to document which CAM providers they visited within the last twelve months as well as documenting which types of CAM were practiced or received. For analysis, we consolidated these two categories. If a patient stated their reason for *visiting* a particular provider was acute and for the identical category in *receiving* said long-term, the patient was tabulated as acute and long-term, respectively. If an individual stated differing helpfulness measures for visiting and receiving, the receiving measure was documented, as the actual use of the specific CAM practice was deemed to be the most accurate measurement of CAM helpfulness. For Mind and Mind-Body categorizations, reasons for visiting or receiving CAM were counted separately. Pet and music therapy were included in relaxation techniques.

Demographics and information on health insurance, education and marital status were included in the questionnaire. ANCA specificity for myeloperoxidase (MPO)-ANCA, proteinase 3 (PR3)-ANCA or persistent ANCA-negativity, diagnosis category of granulomatosis with polyangiitis (GPA), microscopic polyangiitis (MPA),

renal limited pauci-immune necrotizing and crescentic glomerulonephritis, or eosinophilic granulomatosis with polyangiitis (EGPA), and specific organs affected by vasculitis were extracted from medical records.

P values were calculated using the Fisher Exact test for categorical variables, Wilcoxon two sample test and Kruskal-Wallis Test for continuous variables for comparisons between CAM groups and/or non-users of CAM. Control for multiple comparisons was not done because we were looking for hypothesis generating trends and therefore used a liberal p-value. This study's objective is to report the use and impact of CAM in the AAV population thus the use of a control group is beyond the scope of this paper.

## RESULTS

A total of 109 patients were invited to complete the CAM questionnaire. Two patients refused participation, yielding 107 patients for analysis. Patient demographics are displayed in Table 1. Of 107 patients surveyed, the majority was female (62%) and Caucasian (86%), and age at the time of the questionnaire ranged from 18 to 85, with a mean age of 53 years. Time from initial diagnosis and completion of the questionnaire was 0-28 years with a mean of  $6.4 \pm 5.8$ . Highest educational attainment included some college or less (n=57, 54%), college degree (n=30, 28%) or any level of post graduate education (n=19, 18%). The majority of patients were married, had a live-in partner, or were widowed or separated (n=83, 78%). Household income was at or below \$50,000 US dollars per year among 41 (43%) participants, with the remainder in households with income above this level. All patients had some form of health insurance with the majority covered by private insurance policies (n=86, 80%) and the remainder covered by non-private health insurance such as Medicare or Medicaid.

Disease designation of MPA (n=50, 47%) was more common than GPA (n=40, 38%), while PR3-ANCA positivity was more frequent (n=51, 48%) than MPO-ANCA (n=47, 44%), with 8% being ANCA-negative (n=9). The majority of patients had kidney involvement (n=93, 87%). Other organ involvement included joints (n=59, 55%), lung (n=57, 53%), upper respiratory (n=57, 53%), skin (n=31, 29%), neurological (n=22, 21%), muscular (n=14, 13%) and gastrointestinal (n=6, 6%).

Eighty-one percent of participants indicated they received at least one type of CAM treatment or self-

**Table 1: CAM Participant Description (n=107)**

DESCRIPTOR	n (%) or mean $\pm$ standard deviation; range
Sex (female)	66 (62%)
Race (White)	92 (86%)
Age years (mean)	53 $\pm$ 17; 18 – 85
Age at Diagnosis (range)	46 $\pm$ 17; 11 – 85
Years since diagnosis	6.4 $\pm$ 5.8; 0-28
Education:	
Some college or less	57 (54%)
Graduated college	30 (28%)
Post graduate-level schooling	19 (18%)*
Marital Status:	
Married/Live-in Partner/Widowed/Separated	83 (78%)
Never Married	17 (16%)
Divorced	7 (7%)
Total Household Income (in US dollars)*:	
<=50,000	41 (43%)
>50,000	54 (57%)
Insurance:	
Private	86 (80%)
Non-private	21 (20%)
ANCA-associated vasculitis diagnosis:	
Microscopic polyangiitis (MPA)	50 (47%)
Granulomatosis with polyangiitis (GPA)	40 (38%)
Renal-limited**	14 (13%)
Eosinophilic granulomatosis with polyangiitis (EGPA)	2 (2%)
ANCA Specificity:	
Proteinase 3 ANCA	51 (48%)
Myeloperoxidase ANCA	47 (44%)
ANCA Negative	9 (8%)
Organ Involvement (not mutually exclusive):	
Kidney	93 (87%)
Joints	59 (55%)
Lung	57 (53%)
Upper respiratory	57 (53%)
Dermatological	31 (29%)
Neurological	22 (21%)
Muscular	14 (13%)
Gastrointestinal	6 (6%)

\*Percents within subheadings represent those with available data with missing data noted as follows: Education n=1 (1%); Household income n=12 (11%); ANCA Diagnosis n=1. \*\* Renal limited patients separated from Microscopic Polyangiitis patients due to differences in relapse rates

help practice within the last year. Top CAM providers visited or CAM practices received included prayer (n=68, 64%), exercise promotion (n=29, 27%), massage therapy (n=20, 19%), chiropractic services

**Table 2: Reasons Participants Used CAM and Perceived Helpfulness (Participants Checked all that Applied)**

Visiting providers/receiving CAM	n = 107 (%)	Reason for Using CAM			CAM Provider or Treatment Helpfulness		
		Acute	Long-Term	Improve	Very	Somewhat	None/Don't know
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Prayer	68 (64)	12 (18)	35 (51)	36 (53)	46 (68)	5 (7)	7 (10)
Exercise promotion	29 (27)	1 (3)	5 (17)	25 (86)	20 (69)	8 (28)	0 (0)
Massage therapist	20 (19)	2 (10)	5 (25)	14 (70)	17 (85)	2 (10)	0 (0)
Chiropractor	14 (13)	11 (79)	4 (29)	5 (36)	9 (64)	4 (29)	1 (7)
Acupuncturist	7 (7)	0 (0)	6 (86)	2 (20)	1 (14)	2 (29)	4 (57)
<b>Mind</b>							
Relaxation techniques	22 (21)	1 (5)	8 (36)	15 (68)	13 (59)	8 (36)	0 (0)
Meditation	14 (13)	1 (7)	4 (29)	9 (64)	9 (64)	3 (21)	0 (0)
Guided imagery	5 (5)	9 (0)	4 (80)	2 (40)	3 (60)	2 (40)	0 (0)
Total Unique Mind	30 (28)	2 (7)	16 (53)	26 (87)	25 (83)	13 (43)	0 (0)
<b>Mind-Body-Based</b>							
Yoga	13 (12)	0 (0)	4 (31)	9 (69)	11 (85)	2 (15)	0 (0)
Qigong	2 (2)	0 (0)	1 (50)	2 (100)	1 (50)	0 (0)	0 (0)
Tai Chi	2 (2)	0 (0)	1 (50)	1 (50)	2 (100)	0 (0)	0 (0)
Pilates	1 (1)	0 (0)	0 (0)	1 (100)	1 (100)	0 (0)	0 (0)
Total Unique individuals using Mind/Body-Based	15 (14)	0 (0)	6 (40)	13 (87)	15 (100)	2 (13)	0 (0)
Mind OR Mind/Body-Based	31 (29)						

(n=14, 13%) and acupuncture (n=7, 7%). CAM use and stated reasons are summarized in Table 2. Thirty (28%) patients surveyed could be categorized as using Mind therapy and 15 (14%) were categorized as using Mind-Body therapy. Fourteen patients reported using both of these types of CAM.

Patients indicated the reason for prayer was mostly to improve well-being (n=36/68, 53%) and frequently classified it as being very helpful (n=46/68, 68%). Exercise promotion was also used mostly to improve well-being (n=25/29, 86%) and was also deemed very helpful (n=20/29, 69%). Massage therapy was used to improve well-being (n=14/20, 70%) and also considered very helpful (n=17/20, 85%). Chiropractic services were sought most often for acute issues (n=11/14, 79%) and were reported to be very helpful (n=9/14, 64%). Acupuncture was almost exclusively used to seek relief from a long-term ailment (n=6/7, 86%) with the majority (n=4/7, 57%) reporting that it was not clearly helpful.

Mind practices included relaxation techniques, meditation and guided imagery. These practices were used in a total of 30 patients, mostly to improve well-being (n=26/30, 87%) and also to treat long-term

disease symptoms (n=53%). A majority (n=25/30, 83%) indicated that the various Mind practices were very helpful while some stated that Mind practices were only somewhat helpful (n=13/30, 43%); no one indicated that they were not at all useful. Within the Mind category, relaxation techniques composed the greatest subgroup (n=22, 21%). Patients primarily used these techniques to improve their well-being (n=15, 68%) and generally found it very helpful (n=13, 59%).

Mind-Body based practices included yoga, qigong, tai chi and Pilates and were used by 15 patients. The Mind-Body practices were primarily used to improve well-being (n=13/15, 87%), but some also reported their use to alleviate long-term disease symptoms (n=6/15, 40%). Patients stated these practices were almost universally very helpful. Yoga was the most common Mind-Body practice reported (n=13/15) with 9/13 (69%) using it to improve wellbeing and 31% using it to manage long-term disease symptoms. Yoga was found to be very useful in 85% and somewhat useful in 15%.

As would be expected, patients who reported they exercised were more likely to participate in Mind-Body practices (10/29 = 34%) compared to those who did not

**Table 3: Association Between CAM Practices**

CAM Type	Exercise		P-value*
	No	Yes	
<b>Mind-Body</b>			0.0006
No	73 (94%)	19 (66%)	
Yes	5 (6%)	10 (34%)	
<b>Mind</b>			0.0015
No	63 (81%)	14 (48%)	
Yes	15 (19%)	15 (52%)	
<b>Praying</b>			0.99
No	28 (36%)	11 (39%)	
Yes	50 (64%)	18 (62%)	

\*P values calculated by Fisher Exact test.

report exercising (5/78 = 6%,  $p=0.0006$ ). Patients who reported that they exercise ( $n=29$ ) were also more likely to use Mind-Based practices (15/29=52%) compared to non-exercisers (15/78=19%,  $p=0.0015$ , Table 3). This relationship did not hold for those who reported using prayer as it was similar between those who did exercise (18/29 = 62%) and those who did not (50/78 = 64%).

Table 4 shows descriptive information for those who used Mind or Mind-Body practices and also for those who used either or neither of these practices, with statistical comparisons between the latter two groups. Those who used either Mind or Mind-Body CAM were on average a decade younger than those who did not use either of these ( $p=0.0016$ ), but users and non-users were similar with respect to sex and race. There was a trend for those who used the practices to have had the disease longer than non-users (8.5 versus 6.8 years,  $p=0.15$ ). Those who used Mind or Mind-body practices were more likely to be in the lower income category ( $\leq \$50,000/\text{year}$ ) compared to non-users (60% versus 35%,  $p=0.0282$ ) and far more likely to have never been married (35% versus 8%,  $p=0.0019$ ). Disease characteristics including category of disease, ANCA specificity and organ involvement were not statistically different between users and non-users.

Table 5 provides a summary of the general associations of patient and disease characteristics and their strengths among different types of CAM users compared to non-users. Overall, younger age and lower income were most consistently associated with more use of CAM. Some practices were more common among females and among those who had never been married. Disease characteristics were generally not

associated with CAM practices with the exception of acupuncture which was more common among those who were PR3-ANCA positive and who had neurological or skin disease manifestations.

Patients who indicated they had used any form of CAM were asked to supply further information. Of those who responded ( $n=94$ ), 24% said their physician has talked to them about CAM, while 40% said they would like to talk with their physician regarding CAM and 88% (73/83) would be comfortable sharing their CAM practices with their physician. When asked if they would recommend CAM to other vasculitis patients, 48% (36/75) of those who indicated they used CAM responded positively. Common patient recommendations included exercise, yoga, massage and meditation.

Of note, at the beginning of the survey, a general CAM definition was presented (see methods). After reading the definition, patients were asked according to the definition if they practiced CAM. Interestingly, only 36% of participants answered yes to using CAM but 81% of total respondents indicated they had used some form of CAM in the next section of the questionnaire. This indicates that a number of patients didn't think they used CAM, when in fact they did. Among 61 patients providing reasons for not using CAM, the most common answers included not receiving information (66%), worries it may interfere with their conventional medicine (34%), and concern that their health insurance did not cover it (10%).

## DISCUSSION

This study shows that CAM is clearly being used in our AAV patient population. CAM treatments chosen

**Table 4: Descriptive Information of Patients Using Mind, Mind-Body, Mind or Mind-Body and Neither**

	p-value*	Mind		Mind-Body		Mind OR Mind-Body		Neither	
		n=30	%	n=15	%	n=31	%	n=76	%
Age (mean)	0.0016	44±18.36		43±15.57		45±18.21		56±15.23	
Sex (female)	0.8272	19	63%	11	73%	20	65%	46	61%
Race (white)	0.7610	25	83%	12	80%	26	84%	66	87%
Yrs diagnosed (mean)	0.1502	8.64±7.92		9.88±7.38		8.48±6.21		6.75±5.47	
<b>Education**</b>	<b>0.1931</b>								
Some college or less		12	41%	4	27%	12	40%	45	59%
College Grad/Post Grad		17	57%	11	73%	18	58%	31	41%
<b>Income</b>	<b>0.0282</b>								
≤50,000		18	62%	7	50%	18	60%	23	35%
>50,000		11	38%	7	50%	12	40%	42	55%
Missing		1		1		1		11	
<b>Insurance</b>	<b>0.7889</b>								
Private		25	83%	13	87%	26	84%	60	79%
Non-private		5	17%	2	13%	5	16%	16	21%
<b>Marital Status</b>	<b>0.0019</b>								
Never Married		11	37%	7	47%	11	35%	6	8%
Married/Live-in Partner/ Widowed/Separated		17	57%	7	47%	18	58%	65	86%
Divorced		2	7%	1	7%	2	6%	5	7%
<b>ANCA Type</b>	<b>0.6600</b>								
MPA		13	43%	11	73%	13	42%	37	49%
GPA		13	43%	4	27%	13	42%	27	36%
Renal-Limited		3	10%	4	27%	4	13%	10	13%
eGPA		1	3%	0	0%	1	3%	1	1%
Missing		0	0%	0	0%	0	0%	1	1%
<b>Serology</b>	<b>1.0000</b>								
MPO		13	43%	9	60%	14	45%	33	43%
PR3		15	50%	5	33%	15	48%	36	47%
Negative		2	7%	1	7%	2	6%	7	9%
<b>Organ Involvement</b>									
Lung	0.6697	17	57%	5	33%	18	58%	39	51%
Upper Resp	0.3932	19	63%	8	53%	19	61%	38	50%
Joints	0.5213	19	63%	7	47%	19	61%	40	53%
Neurological	0.6013	5	17%	4	27%	5	16%	17	22%
Derm	0.6447	9	30%	7	47%	10	32%	21	28%
Kidney	0.7531	27	90%	14	93%	28	90%	65	86%

MPA = microscopic polyangiitis; GPA = granulomatosis with polyangiitis; eGPA = eosinophilic granulomatosis with polyangiitis; MPO = myeloperoxidase ANCA; PR3 = proteinase 3 ANCA.

\*p-value for Mind OR Mind-Body vs. Neither.

\*\*Data missing for one individual in Mind and Mind OR Mind-Body categories.

are based on a variety of factors, including health status, patient characteristics, available resources, and underlying reason for initiating CAM. As seen from this study, AAV patients turn to CAM to improve well-being and to help with long-term health management. Importantly, patients with AAV who are using Mind or Mind-Body techniques are finding them helpful. Prayer, exercise, massage, and chiropractor treatments were also deemed helpful.

AAV is often a systemic disease that leads to significant morbidity and mortality. Current therapeutic standards include use of immunosuppressive drugs, which have improved outcomes significantly over the past two decades. However, both adverse events from therapy and chronic disease damage can leave a lasting and ongoing impact on patients' lives, diminishing their ability to return to wellness. Infections, steroid induced diabetes, cancer, cardiovascular

**Table 5: CAM Association Chart**

More likely to be/have:	Mind	Mind-Body	Mind or Mind-Body	Prayer	Exercise	Chiropractor	Acupuncture	Massage Therapy
Younger	++	++	++	0	+	0	0	++
Female	0	+	0	0	+	+	++	+
White	0	0	0	--	0	0	0	0
Employed	+	++	+	0	+	0	--	++
Graduated college	+	++	0	0	++	0	-	++
Income <\$50,000	++	-	++	++	-	0	0	--
Private insurance	0	0	0	0	0	0	0	++
Never married	++	++	++	0	+	0	0	0
GPA	0	0	0	0	0	+	--	-
PR3	0	-	0	0	+	+	++	0
Diagnosed > 5 yrs	+	+	+	0	0	0	0	0
Diagnosed longer ago	+	+	+	0	+	+	0	+
Lung	0	-	0	0	0	0	+	0
Upper respiratory	+	0	+	+	0	0	+	0
Joints	+	0	0	-	0	+	0	+
Gastrointestinal	0	0	0	0	0	0	0	0
Muscular	0	0	0	0	0	0	0	0
Neurological	0	0	0	0	0	0	++	0
Dermatologic	0	+	0	0	0	0	++	+
Kidney	0	0	0	0	0	0	0	0

0 = no association; + = 10-20% association; ++ = >20% association; - = 10-20% no association; -- = >20% no association; GPA = granulomatosis with polyangiitis; PR3 = proteinase 3.

\*Association was determined with P values calculated by Fisher Exact test for categorical variables and Wilcoxon two-sample test and Kruskal-Wallis test for continues variables in two or three groups.

events, osteoporosis/osteopenia, and leucopenia are common complications of AAV therapy [14-17]. Furthermore, chronic disease damage can impact many organs and can lead to debilitating and ongoing physical and mental struggles [18]. In fact, overall quality of life is known to be diminished in patients with vasculitis [2] and fatigue is frequently noted to be a major issue among patients [1]. We believe CAM may offer support for patients with AAV to help manage a diagnosis that many say is life changing and constantly out of their control. However, for this to happen, supportive input from traditional health care providers is needed.

Unfortunately, patients do not always share CAM experiences with allopathic practitioners. This may be for many reasons including the short amount of time available for interaction between allopathic practitioners and their patients. There may be a lack of knowledge about CAM on the part of allopathic practitioners. Patients may presume that allopathic practitioners are not open to CAM practice or that CAM is not relevant to care plans outlined by allopathic practitioners. It has been shown that CAM practices most used by patients

are not those that allopathic health providers best understand [19]. Reasons for not discussing CAM include patients not knowing they should bring it up and practitioners not asking the right questions [19]. Establishing a relationship where patients can discuss all realms of treatment possibilities is vital. As discovered by our questionnaire, only a fourth of our AAV patients indicated their physician has talked about CAM. Weaving opportunities for CAM dialogue within physician visits can enable a broader picture of the patients' whole health. The vast majority of people who said they have not used CAM state that this is because they know nothing about CAM or are concerned it would adversely impact their traditional AAV treatment-which is not necessarily the case although specific data on this does not exist.

A deterrent for CAM use may also be cost. Clearly those who used CAM in this study had higher incomes, however among the users of Mind and Mind-Body practices there was a higher proportion of low income patients. There may be cost-effective or free introductory classes, specifically for Mind and Mind-Body practices that can be utilized. Also, some

insurance companies do cover wellness and CAM-type practices and patients and their providers can explore this on an individual basis. It is imperative to study the impact of CAM in diseases such as AAV where the economics of disease management significantly drain the patients, insurance companies and health care system. It may be that inclusion of CAM practices into the AAV therapeutic plan could not only improve patient wellness but could also reduce financial burden of managing what has now become both an acute as well as chronic disease.

This study notes that allopathic practitioners cannot assume which patient will be open to or already is including CAM in his or her treatment plan. In our study, CAM users were significantly younger, employed, and in a higher income bracket, but we found CAM well-represented across all demographic groups. CAM practices and specifically Mind and Mind-Body practices are entirely doable across all ages and disease manifestations, so it may be that information on CAM can help patients who are traditionally unexposed to these practices to incorporate them into their disease management.

CAM is gaining overall popularity [12, 20] and a number of studies show that CAM can be used to ameliorate pain, alleviate gastrointestinal conditions, help with depression, reduce stress, improve sleep and promote general health in a variety of ages and across a number of disease populations [20-22]. One specific example is a small study with rheumatoid arthritis (RA) patients who used a structured bi-weekly yoga program with positive outcomes by lowering disease activity scores, decreasing fatigue and reducing medication use [23]. As noted in our study, AAV patients described using CAM primarily to address long-term issues related to chronic disease and to improve overall well-being.

It is important to incorporate new approaches to the challenges presented with treating chronic diseases like AAV. It may be that Mind and Mind-Body therapy has community and socialization benefits. A large percentage of patients who use Mind or Mind-Body in this study had been diagnosed for longer than five years. This may reflect that patients dealing with the chronic manifestations of AAV look to CAM as an option for dealing with long-term illness.

In this study exercise promotion was included as CAM because exercise is not a routine prescription for patients with AAV. It is noteworthy that patient who participate in practice are more likely to perform Mind-

Body techniques. Exercise and Mind-body techniques appear to both be useful and may have an additive effect on wellness in some patients.

This study has a number of strengths and several limitations. The surveyed population is representative of our overall AAV cohort, so results of this study are likely representative of our larger population of patients in the southeastern United States (US). Numerous studies within this cohort have helped to elucidate predictors of outcomes, quality of life and therapeutic advantages and risks in AAV patients [9; 24-28]. Studying the use of CAM in this patient population helps us further expand our understanding of the uses of CAM to fill in the full picture of clinician and patient management of the disease. It is possible that patients who participated in this study might have had a greater openness to CAM due to inherent biases of our patient population including geography, economics and demographics. Regardless, this study does suggest that CAM is being used by AAV patients, emphasizing the importance of further study into the impact of CAM on AAV outcomes and patient-perceived quality of life. Future studies can evaluate the true effect and risk-benefit ratio of CAM use over time.

It is important to note that not all studies on CAM include prayer. We report prayer because repetitive prayer has been shown to illicit the relaxation response [28], and because individuals who pray for their health are known to more frequently engage in health-promoting activities [29]. A majority of our patients indicated they used prayer.

As with all surveys, the information collected relies on patients' memory and ability to accurately report data. Our data was collected at a single time point and has inherent recall bias. The definitions and terms related to CAM used in our survey may not be familiar to our patients and there may have been undetected literacy barriers that could have prevented appropriate understanding or reporting in this study. We feel this was balanced by the presence of study personnel for all surveys so that patient questions regarding definitions could be clarified.

In summary, there is a need for greater recognition among allopathic or western medicine practitioners for how CAM is being used by patients being treated for serious medical conditions, including AAV. With more knowledge, practitioners will be better equipped to recommend for or against specific CAM treatments. It is exciting to consider a more inclusive approach to treatment of AAV using CAM to improve the wellness



of our patients and to provide patients with a more active way to manage their disease. In doing so, perhaps we increase patient quality of life, reduce financial burden to our health care system and limit adverse events due to the toxic therapies.

**ACKNOWLEDGEMENT**

Our sincere thanks and appreciation to Sara A. Quandt, PhD for allowing usage of the I-CAM-Q.

**APPENDIX A**

**Complementary and Alternative Medicine Patient Questionnaire**

Thank you for your participation in helping understand how patients with small vessel vasculitis use complementary and alternative medicine in conjunction with their standard care. Completing this survey should take under 10 minutes and **will not alter the care you receive at UNC**. Thanks!

---

Name: \_\_\_\_\_  
(Last)
(First)
(Middle)

When is your birthday? Month \_\_\_\_\_ Day \_\_\_\_\_ Year \_\_\_\_\_ Current Age: \_\_\_\_\_

What is your sex:  Male  Female

What category best describes your race and ethnicity?  
 White  American Indian/Alaska Native  
 Black or African American  Asian, Pacific Islander  
 Hispanic or Latino  Other: Please specify \_\_\_\_\_

Please circle the highest level of schooling you have completed:

- Grade School or less (K-8)
- Some College
- Some high school (9-12)
- Graduated College
- High School Degree
- Post Graduate
- Vocational / Technical Degree

Are you employed?  Yes  No If so, what is your occupation? \_\_\_\_\_

Are you retired?  Yes  No If so, what was your occupation? \_\_\_\_\_

Did you retire due to a disability?  Yes  No

What was your total household income from wages and any other sources the last 12 months?

- \$ 10,000 or less
- \$ 20,001 - \$ 30,000
- \$ 70,001 - \$ 90,000
- \$ 10,001 - \$ 15,000
- \$ 30,001 - \$ 50,000
- \$ 90,001 - \$ 100,000
- \$ 15,001 - \$ 20,000
- \$ 50,001 - \$ 70,000
- greater than \$ 100,000

What type of health insurance do you have? (Please check all that apply)

- Medicare
- Private – Through my or my spouse’s employer
- Medicaid
- Do not know
- Veteran’s Benefits
- Other: \_\_\_\_\_
- Private – I bought myself

**GRANTS OR OTHER FINANCIAL SUPPORTERS OF STUDY**

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What is your current marital status?

- Married or have a live-in partner       Widowed       Never married  
 Separated       Divorced

When were you diagnosed with vasculitis? Month \_\_\_\_\_ Year \_\_\_\_\_ Age \_\_\_\_\_

The next set of questions will ask you about your use of therapies that are considered **complementary** (“in addition to”) and **alternative** (“instead of”) to medicines/therapies prescribed by your doctors (conventional therapy). The following definition for conventional and complementary or alternative medicines is adapted from National Institutes of Health:

**Complementary and alternative medicine** is a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. **Conventional medicine** (also called Western or allopathic medicine) is medicine practiced by medical doctors, doctors of osteopathy and allied health professionals, such as physical therapists, psychologists, and registered nurses. Differences between conventional medicine and complementary and alternative medicines are not absolute. **Complementary and alternative medicine** examples include but are not limited to herbs/vitamins/minerals, meditation/yoga/acupuncture/massage, magnet therapy and traditional healers.

**Using the definition above, do you use complementary and alternative medicines?**

- Yes     No

If you answered NO, why have you not used complementary and alternative medicines?

- Have not received information  
 Worried it may interfere with my conventional medicine  
 My insurance does not cover it  
 Other: \_\_\_\_\_

If you answered YES, please complete the following 2 questions:

When did you start using complementary and alternative medicines?

- Before vasculitis diagnosis  
 After vasculitis diagnosis  
 Do not remember

What was your disease status when you decided to use complementary and alternative medicines?

- Active disease (having symptoms)  
 During remission (not having symptoms)  
 Do not remember

The next questions will ask about the doctors you have seen and the types of medications and therapies you have used in the last 12 months. Please use the list of definitions provided to fill out questions 1-4.

<<Modified>> NAFKAM International CAM Questionnaire (I-CAM-Q):

1. Visiting health care providers: Health problems may be attended by a variety of complementary and conventional health care providers

Have you seen any of the following providers in the last 12 months?	Yes No	Number of times you saw this provider in the last 3 months?	Please indicate the <i>main</i> reason you <i>last</i> saw the provider (Check only one).				How helpful was it for you to see this provider? (Check only one) Very Somewhat Not at all Don't know
			For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify the other reason)	
Physician, Physician's Assistant or Nurse	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Practitioner Chiropractor	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Homeopath	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Acupuncturist	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Herbalist	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Spiritual healer	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Massage therapist	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Have you seen any of the following providers in the last 12 months?	Yes No	Number of times you saw this provider in the last 3 months?	Please indicate the <i>main</i> reason you <i>last</i> saw the provider (Check only one).				How helpful was it for you to see this provider? (Check only one) Very Somewhat Not at all Don't know
			For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify the other reason)	
Nutritionist	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Naturopath	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Reiki Practitioner or Reflexologist	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Other (please specify):	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

**2. Complementary treatments received from health care providers**

\*\*If you have not seen a provider in the past 12 months, please go to question 3.

Have you received any of the following complementary treatments from a provider in the last 12 months?	Yes No or Do Not Know	Number of times you received this treatment in the last 3	Please indicate the <i>main</i> reason you <i>last</i> received this treatment (Check only <i>one</i> ).				How helpful was it to receive treatment from the provider? (Check only one)
			For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify the other reason)	
<b>Chiropractic services</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Homeopathy</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Acupuncture</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Herbs</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Spiritual healing</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Exercise Promotion</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Nutritional Supplements</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Massage</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Chinese Medicine</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Reflexology</b>	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<b>Other (please specify):</b> _____	<input type="checkbox"/> <input type="checkbox"/> _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

**3. Use of Herbal Medicine and Dietary Supplements (including tablets/capsules/liquids)**

For each category below, please list up to three products you have used in the last 12 months.	Do you currently use this product?		Please indicate the <i>main</i> reason that applies to your <i>last</i> use (Check only one).				How helpful did you find this product? (Check only one)			
	Yes	No	For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify)	Very	Somewhat	Not at all	Don't know
<b>Herbs/Herbal Medicine</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Vitamins/Minerals</b>										
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Homeopathic remedies</b>										
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other Supplements</b>										
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 4. Self Help Practices

Have you used any of the following self-help practices in the last 12 months?	Yes No		Number of times you used this practice in the last 3	Please indicate the <i>main</i> reason that applies to your <i>last</i> use of the self-help practice (Check only <i>one</i> ).				How helpful did you find this self-help practice? (Check only one)			
				For an acute illness/condition, one that lasted less than one month	To treat a long-term health condition (one that lasted more than one month) or its symptoms	To improve well-being	Other (Please specify the other reason)	Very	Somewhat	Not at all	Don't know
<b>Meditation</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Yoga</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Qigong</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Tai Chi</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Relaxation techniques</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Hypnosis</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Guided imagery</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Attended traditional healing ceremony</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Praying for own health</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other (please specify):</b> _____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other (please specify):</b> _____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**\*\*\*If you checked YES in any of the tables above, please answer the following questions:**

How did you learn about complementary and alternative medicines? (Check all that apply)

- Physician
- Nurse
- Another health care provider
- Patient or patient support group
- Library/magazine/newspaper or other printed source?
- Online
- Television program
- Friend
- Other: \_\_\_\_\_

Of the complementary and alternative medicines you use most, what is your primary information source?

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Was your interest in complementary and alternative medicine to assist with managing vasculitis symptoms and effects or to tolerate vasculitis treatment side effects?

- Assist with managing symptoms
- Tolerate side effects

Has your physician talked with you about complementary and alternative medicine?

- Yes
- No

Do you want to talk with your physician about complementary and alternative medicine?

- Yes
- No

Do you feel comfortable sharing your complementary and alternative medicine practices with your physician?

- Yes
- No

Have you or would you recommend any specific complementary and alternative medicines to other patients with vasculitis?

- Yes
- No

If YES, what did/would you recommend: \_\_\_\_\_

Has using complementary and alternative medicines improved your quality of life? Please explain how they have had a positive or negative effect:

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**Additional Questions:**

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Chelation therapy is a chemical process using a substance that binds to molecules, such as metals or minerals, creating tight bonds so they can be removed from a system or body. Chelation has been proven to rid the body of excess or toxic metal. For example, an individual who has lead poisoning may be given chelation therapy to bind and remove excess lead from the body before damage occurs.

- adapted from National Institutes of Health

Have you ever had chelation therapy?  Yes  No

If you answered YES, what was the main reason for receiving chelation therapy?

To remove heavy metals

Other: \_\_\_\_\_

If chelation therapy was used to remove heavy metals, which metal was removed?

Lead

Plutonium

Arsenic

Mercury

Iron

Other: \_\_\_\_\_

Uranium

Have you ever been diagnosed with a tickborne disease?  Yes  No

If you answered YES, which tickborne disease were you diagnosed with?

Anaplasmosis

Rocky Mountain Spotted Fever (RMSF)

Babesiosis

STARI(Southern Tick-Associated Rash Illness)

Ehrlichiosis

Tickborne relapsing fever (TBRF)

Lyme disease

Tularemia

364D Rickettsiosis

*Rickettsia parkeri* Rickettsiosis

Other: \_\_\_\_\_

### Definitions (in alphabetical order)

Acupuncture - stimulation of specific points on the body by a variety of techniques, including the insertion of thin metal needles through the skin. Acupuncture is intended to remove blockages in the flow of qi (a person's vitality or "life force") and restore and maintain health.

Chinese medicine - based on the concept that disease results from disruption in the flow of qi and imbalance in the forces of yin and yang (opposing forces). Practices such as herbs, meditation, massage and acupuncture seek to aid healing by restoring the yin-yang balance of the flow of qi.

Guided imagery - a relaxation technique using the visualization of calm and peaceful images. Individuals visualize their body free of the specific problem or condition.

Homeopathy - basic principle is "let like be cured by like." This practice seeks to stimulate the body's ability to heal itself by giving small doses of a highly diluted substance that in larger doses would produce illness or symptoms.

Hypnosis - an altered state of consciousness (being hypnotized) characterized by increased responsiveness to suggestion.

Naturopathy - treatments based on the healing power of nature that use a holistic ("whole body") approach to diagnosing and treating disease. Practitioners, known as naturopaths, work with patients with the goal of supporting



health through treatments such as nutrition, lifestyle counseling, dietary supplements, medicinal plants, exercise, homeopathy and treatments from traditional Chinese medicine.

Qigong - a form of traditional Chinese medicine combining movement, meditation, and controlled breathing. The intent is to improve blood flow and the flow of qi.

Reflexology - incorporates the use of specific pressure techniques to the feet, hands or ears.

Reiki - a therapy in which practitioners seek to transmit a universal energy to a person, either from a distance or by placing their hands on or near that person. The goal is to heal the spirit, which will then heal the body.

Tai Chi - a mind-body practice in which individuals move their bodies slowly, gently and with awareness while breathing deeply.

Adapted from:

Mayo Clinic <http://www.mayoclinic.com/health/alternative-medicine>

NIH NCCAM <http://nccam.nih.gov/health/>

*Completed by investigator:*

ANCA Type:

- Microscopic Polyangiitis  
 Granulomatosis with polyangiitis  
 Churg Strauss Syndrome  
 ANCA GN  
 Other

Serology

- PR3  
 MPO  
 Negative  
 Dual Positive

Biopsy

- Yes  No

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