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Assessing Barriers to Care for the Vaccine Injured: The Vaccination Injury Treatment and Access to Essential Care (VITAE) Survey

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Abstract: Post vaccination syndrome, either acute or long term, is a significant source of disease burden, affecting up to 1% of vaccine recipients. The medical and scientific community is only beginning to define and classify the condition, and presently those affected are left with very limited support. Gaps in patient needs include disease diagnosis, treatment (which requires research), and acknowledgement and compensation for injuries. More proactively, we may also look towards prevention, through an analysis of disease etiology, it is possible to minimize the risk of post vaccination syndrome by restricting the use of vaccines known to cause this condition. This research aims to assess the level of debility and current barriers to care in the vaccine injured population. An analysis of 706 responses reveals a high level of disruption, loss of income, and medical expenditure, a significant degree of it out-of-pocket, among the vaccine injured population. This research provides medical professionals, policymakers, and patient advocacy groups with the information they need to respond to this disease.

Keywords: post-vaccination syndrome; Covid-19; barriers to care; disease burden

Introduction

Covid-19 vaccines were developed to lower the severity of Covid-19 symptoms and to prevent progression of the disease to either hospitalization or death. Despite these benefits, Covid-19 vaccines have unfortunately caused harms in a small proportion of the people receiving the shot. Given the ubiquity of Covid-19 vaccination, even a small per shot risk can amount to a large population of vaccine injured.

Vaccine injury can be divided into acute and post acute versions [1]. The defined adverse events are largely treated similarly regardless of etiological agent, while post acute vaccine syndrome (PACVS) currently eludes diagnostic criteria as well as rigorous validation of treatment protocols. The development of diagnostics and treatment protocols are intertwined problems, as typically diagnostics can be used to guide and evaluate treatment, while treatments may be based on understandings of biological mechanisms associated with diagnostic biomarkers.

Importantly, a greater understanding of disease mechanism now as opposed to at the beginning of the vaccine rollout, or the start of the pandemic for that matter. Both Covid-19 and the vaccine rollout have introduced novel disease types in the population, motivating the development of clinical strategies.

PACVS is characterized by a disease phenotype similar to myalgic encephalomyelitis /chronic fatigue syndrome (ME/CFS), involving fatigue, dysautonomia, post exertional malaise and sometimes neuropathic pain and cognitive disturbances [2].

Barriers to Receiving Care

In addition to the difficulty in diagnosing and treating a condition that is currently ill defined and receives little research attention, there are other barriers to receiving care. The physical ailments can be debilitating [3], and the vaccine injured have difficulty accessing compensation [4], and the option of suing manufacturers is eliminated due to government legislation [5,6]. In addition to this, the vaccine injured can often face marginalization, which often makes it more difficult to have their condition accepted [7]. We launched a survey on October 25, 2024 and collected responses up to December 31, 2024 to assess what were the barriers to receiving care for the vaccine injured. Using a similar format to a previous survey for Lyme disease [8], we modified the questions to make them appropriate for vaccine injured participants.

Vaccine injury is unnecessarily politicized because the phenomenon undermines narratives of vaccine safety and calls into question objectives to achieve full vaccination coverage and to disempower vaccine hesitancy. Lyme disease may be an even more relevant comparison owing to conspiracism about its origin. If we examine the timeline of several controversial syndromes attributed to an etiological factor (i.e. not idiopathic). Besides Lyme disease, another controversial syndrome was ‘Gulf War Illness’, named because it afflicted US servicemen and women returning from Desert Storm.

Fortunately with PACVS, the etiological agent is known, though exact understanding of disease mechanisms are still elusive. While debate over the etiological factors driving Gulf War Illness, the literature attributes it to chemical hazards and toxins, including sarin gas. Other possible factors may drive Gulf War Syndrome.

Similarly Lyme disease emerged through epidemiology, where people in Lyme, Connecticut and surrounding areas began developing a novel syndrome in the 1960’s and 1970’s, leading to its recognition in 1976 [9]. It wasn’t until 1981 that the etiological agent, the spirochetal bacteria *Borrelia burgdorferi*, was identified [10].

For both case, sufferers of each disease have experienced marginalization, a lack of effective treatment options, and gaslighting by physicians and the medical establishment. A comparison of the conditions is available in Table 1.

Table 1. A comparison on the timelines and degree of official recognition between Lyme disease, Gulf War Illness and Post acute covid-19 Vaccination Syndrome (PACVS).

Event	Lyme disease	Gulf War Syndrome	Post Covid-19 vaccination syndrome
Emergence of symptoms	1975 in Lyme, CT [11]	1991 [12]	2020 during trials 2021 during vaccine rollout
Recognition as disease entity	1977 [13]	2008 [14]	Recognized by scientific community early on in 2022 [15] but lacking official recognition
Etiological agent discovered	*Borrelia burgdorferi* discovered in 1981 [10]	Strong evidence for exposure to sarin nerve gas being the cause in 2022 [16]	Known at time of injuries, i.e. in 2021
First clinical trials of treatment options	1980 [17]	1994: US Department of Defense establishes Gulf War Veterans' Illnesses	None

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		Research Program (GWVIRP) [18] 1999 [19,20]	
Prevalence of fatigue in those with condition	51.9% (early Lyme) [21]	28.1% [22]	69% [3]
Number Affected	476 000 diagnosed per year in USA [23]	250 000 [24]	Approximately 0.9% of vaccine recipients [25] or up to 2 million people in the USA
Annual Funding	$43 million (2023) [26]	$20 million [27]	No specific funding

Methods

We created an online survey using Google Forms (**geni.us/VITAE**) and disseminated it through a series of social media posts of the FLCCC. We ran the survey from October 25, 2024 until December 31, 2024 and received completed surveys from 705 participants. The structure of the survey was based off a previous survey performed for Lyme disease, which is another condition in which patients feel marginalized and have difficulty receiving care (8).

Results

Demographic Characteristics of Respondents

Referring to Table 2 we can see that the survey encompassed a broad age distribution, with the largest group of respondents born between 1960–1969 (190 participants, 26.95%), followed by those born between 1950–1959 (162 participants, 22.98%). Representation of younger age groups was minimal, with only 2 respondents (0.28%) born between 2000–2010. Gender distribution indicated a predominance of females (63.92%), compared to males (36.08%).

Regional representation was diverse but primarily focused on North America, with 82.7% of respondents residing there. Contributions from Australia/Oceania (7.23%) and Europe (5.82%) underscore the global nature of the issue. These demographic insights establish a foundational understanding of the respondent pool, critical for contextualizing subsequent findings.

Table 2. Demographic Characteristics of Respondents (n = 705).

Birth Year	n	%
2011 or later	1	0.1
2000–2010	20	2.8
1990–2000	33	4.7
1980–1989	79	11.2
1970–1979	114	16.2
1960–1969	190	27.0

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1950–1959	162	23.0
1940–1949	87	12.3
1930–1939	19	2.7
Gender	**n**	**%**
Male	254	36.1
Female	450	63.9
Region	**n**	**%**
North America	583	82.7
Australia/Oceania	51	7.2
Europe	41	5.8
Others	30	4.3

Duration and Diagnosis of Post-Vaccination Syndrome

Table 3 shows that a majority of respondents (79.57%) reported symptoms persisting for over two years, illustrating the chronicity of the condition. Only 4.4% experienced symptoms for less than six months, emphasizing the long-term burden experienced by the vaccine-injured population. Chronic symptoms lasting six months or more post-treatment were reported by 91.35% of participants, highlighting the inadequacy of current interventions.

Interestingly, 33.33% of participants had preexisting chronic health conditions, while 66.67% reported no prior health issues, suggesting that post-vaccination syndrome affects individuals irrespective of their baseline health status. Diagnosis predominantly relied on patient history and non-specific laboratory tests (78.87%), with only 21.13% being diagnosed through specific spike protein or antibody tests. Diagnostic delays were notable, with 33.65% seeing 2-3 physicians, and 30.95% consulting 4-6 physicians before receiving a diagnosis. A significant subset (5.87%) saw over 20 physicians, underscoring the systemic challenges in timely identification.

Table 3. Duration and Diagnosis of Post-Vaccination Syndrome (n = 705).

Duration Of Post Vaccination Syndrome	n	%
Greater than 2 years	561	79.6
1 to 2 years	81	11.5
6 months to 1 year	32	4.5
Less than 6 months	31	4.4
Did you have any chronic health problems	**n**	**%**

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before your Post-Vaccination Syndrome diagnosis?		
Yes	235	33.3
No	470	66.7
Do you have chronic symptoms (lasting 6 months or more) after receiving treatment for Post-Vaccination Syndrome?	**n**	**%**
Yes	644	91.3
No	61	8.7
How were you diagnosed with Post-Vaccination Syndrome?	**n**	**%**
Laboratory test for spike protein or spike antibodies with patient history	149	21.1
Patient history with other laboratory tests	556	78.9
How many physicians did you see between your onset of symptoms and a Post-Vaccination Syndrome diagnosis?	**n**	**%**
21 or more	37	5.2
16-20	26	3.7
10-15	70	9.9
7–9	90	12.8
4–6	195	27.7
2–3	212	30.1
1	75	10.6

Treatment Accessibility and Healthcare Barriers

From Table 4 we can see that the treatment access varied, with 73.05% of respondents traveling less than 50 miles for care, whereas 6.52% traveled over 500 miles, reflecting geographic inequities in care availability. Approximately 55.18% sought treatment at local hospitals, yet nearly half of these (49.93%) reported difficulties in obtaining care. Such barriers highlight the pressing need for more accessible and equitable healthcare systems.

Insurance coverage emerged as a critical issue, with 86.1% of participants not applying for new medical insurance post-diagnosis. Of those who applied, 5.56% faced rejection due to their condition. Moreover, 15.6% reported that insurers mandated a diagnosis of long COVID to cover treatment, adding bureaucratic hurdles to an already burdensome condition. Public support or disability benefits were accessed by only 12.77% of respondents, indicating systemic limitations in financial assistance for the vaccine-injured.

Table 4. Responses related to treatment access (n = 705).

What is the distance you currently travel for treatment of your Post-Vaccination Syndrome?	**n**	**%**
Greater than 500 miles	46	6.5
101–500 miles	61	8.7
51–100 miles	83	11.8
Less than 50 miles	515	73.1
Have you ever visited your local hospital for treatment of your Post-Vaccination Syndrome?	**n**	**%**
Yes	389	55.2
No	316	44.8
If you visited your local hospital, did you experience difficulty in obtaining treatment?	**n**	**%**
Yes	351	49.9
No	352	50.1
Since your Post-Vaccination Syndrome diagnosis, have you applied for a new medical insurance policy?	**n**	**%**
Yes	98	13.9
No	607	86.1
If you applied for a new medical insurance policy, were you turned down based on your Post-Vaccination Syndrome diagnosis?	**n**	**%**
Yes	39	5.6
No	663	94.4

Has your medical insurer ever required that you see a long COVID specialist or modify your diagnosis to long COVID to cover your treatment?	**n**	**%**
Yes	110	15.6
No	595	84.4
Have you ever been on public support or received disability benefits due to Post-Vaccination Syndrome?	**n**	**%**
Yes	90	12.8
No	615	87.2
If you have received public support or disability benefits, how long did you receive them?	**n**	**%**
More than 2 years	42	6.0
12–23 months	20	2.8
7–11 months	11	1.6
6 months or less	29	4.1
Non-Applicable	601	85.5
How many times have you visited an emergency department because of Post-Vaccination Syndrome?	**n**	**%**
Greater than 10 times	30	4.3
6–10 times	37	5.3
3–5 times	112	15.9
Twice	104	14.8
Never	295	41.8
Once	127	18.0

Financial Impacts and Employment Disruptions

Referring to Table 5 we see that the monthly medical expenses varied widely, with 34.96% spending less than $200, while 12.75% incurred costs exceeding $2500. Out-of-pocket costs followed a similar pattern, with 39.83% spending under $200 and 5.73% exceeding $2500. These figures underscore the financial strain experienced by affected individuals.

Employment outcomes were significantly impacted, with 26.79% not working at the time of injury and 26.36% becoming unemployed due to their condition. Among employed respondents, 16.19% reported working at slightly reduced capacity, while 9.89% managed significantly reduced workloads. Only 10.89% maintained their pre-injury work capacity. Annual income reductions were stark; the proportion of respondents earning less than $30,000 annually increased from 21.95% pre-injury to 46.2% post-injury, highlighting the economic toll of the syndrome.

Of the 511 individuals employed at the time of injury, the average income drop was 0.80 categories, using the categories shown in Table 5. Breaking down the results, only 2.5% of individuals experienced an increase in their income category, while 31.7% retained their original category. The majority of the sample, 46.2%, dropped by one income category. Notably, a significant portion, 24.3% of individuals, experienced a more severe decline, dropping by more than one income category. These figures suggest a general downward trend in income categories for the studied population, with nearly 70% of individuals experiencing some level of decline.

Therefore, this analysis underscores the profound health, financial, and systemic challenges faced by individuals with post-vaccination syndrome. Chronic symptoms, diagnostic delays, barriers to care, and significant economic impacts collectively illustrate the urgent need for targeted interventions. Enhanced diagnostic criteria, equitable healthcare access, and robust financial support systems are imperative to alleviate the burden borne by this vulnerable population.

Table 5. Financial Impacts of Post-Vaccination Syndrome (n = 705).

What is the total cost of your medical treatment per month?	**n**	**%**
Greater than $2501	89	12.75
$1001 to $2500	90	12.89
$501 to $1000	106	15.19
$201 to $500	169	24.21
Below $200	244	34.96
What is the out-of-pocket cost of your medical treatment per month?	**n**	**%**
Greater than $2501	40	5.73
$1001 to $2500	74	10.6
$501 to $1000	113	16.19
$201 to $500	193	27.65
Below $200	278	39.83
Have you been able to continue working since your injury?	**n**	**%**
Yes, at significantly reduced capacity (~50% of previous workload)	69	9.89

Yes, at greatly reduced capacity (25% or less of previous workload)	69	9.89
Yes, at slightly reduced capacity (75% or greater of previous workload)	113	16.19
Yes, at the same capacity	76	10.89
Was not working at time of injury	187	26.79
No, Unemployed	184	26.36
What was your yearly income prior to your injury?	**n**	**%**
$200,000 or more	77	11.05
$100,000 - $199,999	150	21.52
$60,000 - $99,999	174	24.96
$30,000 - $59,999	143	20.52
Less than $30,000	153	21.95
What is your yearly income after your injury?	**n**	**%**
$200,000 or more	49	7.03
$100,000 - $199,999	75	10.76
$60,000 - $99,999	127	18.22
$30,000 - $59,999	124	17.79
Less than $30,000	322	46.2

Discussion

In this article, we present the result of a survey of people experiencing post vaccination syndrome, revealing a high degree of continuing debility and financial impacts. The survey received 705 responses, and accompanies a body of work on the disease burden of post-vaccination syndrome [3]. One limitation of the study is that it is self-reported, and we could not verify the diagnosis of post vaccination syndrome. Currently, each diagnosis of PACVS must be done in a bespoke manner, and it is not recognized as an official disease entity. The development of diagnostic tests for Lyme disease aided the recognition for that disease, and similarly, an urgent task exists for acknowledgement and diagnostics development for PACVS [2,25,28].

Further development of this work could be quantifying the disease burden of PACVS, and comparing it to other diseases. Given the relationship between disease burden and level of NIH funding [29], quantitative estimates may help to make the case for greater research funding. Additionally, producing educational resources for physicians, and disseminating information on post vaccination syndrome may improve accessibility, the average number of doctors visited before diagnosis was 6.9. Accessibility of care is also a concern, as 15% of those surveyed travel over 100 miles for treatment (Table 3).

Lastly, financial resources for those affected should be mustered, as the average out-of-pocket treatment cost was $573, and those affected have also had significantly reduced work capacity, affecting their income. Almost 2/3 (63%) of the respondents employed at the time of their injury have had a 50% or greater reduction in their work capacity, with a full 36% of respondents employed at the time of their injury now unemployed (Table 5). For those employed at the time of injury, the average decrease in yearly income was $29 178.

These results help to establish the disease burden of PACVS and the barriers to care that PACVS patients experience. Our results may motivate research into treatments, as well as reform for compensation for this condition.

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