Short Communication

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Experience of patients in Germany with the post-COVID-19 vaccination syndrome

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Abstract: The coronavirus disease 2019 (COVID-19) pandemic seems to have been overcome and replaced by other issues that influence risk perception, communication, and behaviour. However, for some people, the aftereffects continue to reverberate, either because they suffer from "long COVID" or from side effects of the COVID-19 vaccination. The aim of this article is to examine the experiences of patients in Germany who attribute health problems to COVID-19 vaccination. A literature search was conducted using four search engines, but no publications were found that shed light on this topic. This indicates that there remains a gap in the research landscape. The discussion considers what factors might influence patient experience and what factors might contribute to the lack of research on this topic.

Keywords: post-COVID-19 vaccination syndrome, vaccination campaign, communication, patient experience

1 Introduction

[i]Around the world, 702 million people fell ill with coronavirus disease 2019 (COVID-19) and more than 6.9 million died of it [1]. In Germany, nearly 39 million infections with COVID-19 and almost 182 thousand deaths with or due to COVID-19 were registered [2]. Many countries attempted to end the pandemic by vaccination against COVID-19. Governments tried to motivate people to get vaccinated; some governments installed (partial) compulsory vaccination. For example, Austria enacted a law that obliged vaccination for all [3]. In Germany vaccination against COVID-19 became mandatory in the military service [4] and in the healthcare sector [5]. In the course of time, data were gathered about the side effects of the vaccines, which include acute and long-term effects. After 4 months of the vaccination campaign, the Paul-Ehrlich-Institut, the Federal Institute for Vaccines and Biomedicines, which is responsible for drug monitoring, reported 49,961 suspected cases of adverse reactions or vaccination complications [6]. Adverse reactions after vaccination included headache, tiredness, flu-like illness, fever, chills, and pain at the injection site. In data covering the period from the start of the vaccination campaign to March 2023, 942,298 adverse reactions were reported [7]. In 39% of the cases, patients had not recovered at the time of reporting (ibid.) However, it is not possible to tell how much time has passed between the first onset of health complaints and reporting. The authors state that about 5% of the patients had permanent damage (ibid.).

Despite the comparatively short period during which COVID-19 vaccinations were administered, there were indications that longer-lasting adverse effects might occur. For example, Freisleben [8], a medical practitioner who was involved in vaccination against COVID-19, had collected cases of side effects and mentioned – if possible – how long they lasted. He put a list of 200 case reports on his homepage. This list showed complex health problems described by patients.

Long-lasting effects caused by vaccination were then called *post-vac syndrome*. Recurring symptoms are difficulties in concentrating, fluctuations in blood pressure, sudden palpitations, dizziness, nausea, visual disturbances, prolonged headaches, and chronic fatigue [9]. Often, patients seem to suffer from neurological manifestations [10]. However, the "post-vac syndrome" is neither defined nor a medical diagnosis [11]. For individuals, this might be irrelevant if they suffer from symptoms, which they attribute to a COVID-19 vaccination. Media have taken up the issue and occasionally report on the fates of patients with long-lasting health impairment caused by a COVID-19 vaccine [12–14].

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[i] All quotes from German sources have been translated by the author. Most parts of the text were checked for correctness in English with the help of AI-tool ChatGPT.

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Scientists have not only discussed the possible long-lasting effects of the vaccination. Also, long-lasting impairments from a COVID-19 infection have been observed and have become an important topic in both science and practice. This condition is referred to as *long COVID*, defined for example as "an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems" [15, p. 6].

In science, the similarities and differences between "long COVID" and the "post COVID-19 vaccination syndrome" are repeatedly discussed [16,17]. Sometimes the "post-vac syndrome" is called long COVID caused by vaccination [10].

This article focuses solely on "post-vac syndrome" and examines the experiences of patients when they seek medical help due to health impairments. Before we turn to their experience in detail, some information about the context of the COVID-19 vaccination strategy in Germany and knowledge about side effects is provided first.

1.1 COVID-19 vaccination strategy in Germany

When the first COVID-19 vaccines became available in Germany in December 2020, the German government had high hopes for them. In particular, the mRNA vaccines and the vector vaccines were strongly recommended to achieve herd immunity and to protect against infection and severe disease [18]. The National Vaccination Strategy emphasized the benefits of the vaccines: "The widespread use of existing and further development of effective and safe COVID-19 vaccines are decisive factors in bringing the ongoing pandemic to an end and to control SARS-CoV-2 infections in the long term. Vaccination makes it possible to achieve immunity in large parts of the population. This is intended both to counter the spread of the virus and to minimize the possible health consequences of an illness and prevent the healthcare system from being overburdened" [19, p. 3] (translated by the author). Yet, it turned out that vaccines were not able to stop transmission and there are doubts about their effectiveness for immunization [20,21]. Nowadays, state organizations announce that "the aims of the STIKO[ii] recommendations for coronavirus vaccination are still to prevent severe courses of COVID-19 (hospitalizations and deaths), to reduce possible long-term consequences of SARS-CoV-2 infections as far as possible, to protect employees in medical and nursing care from SARS-CoV-2 infections" [22].

During the pandemic, the Ministry of Health emphasized the importance of an accompanying information policy to strengthen the motivation for vaccination and to counter hesitant attitudes [19, p. 17] (translated by the author): "At the same time, the motivation 'to get vaccinated' should be strengthened in the entire population and, in addition, possible skepticism towards new vaccines and targeted disinformation must be countered. A transparent, proactive, and target group-specific communication strategy, which also takes account of deliberately disseminated false reports about any vaccination reactions or side effects that may occur is therefore still indispensable."

The vaccination campaign included "positive" incentives, for example, free sausages [23] or a free ride on a roller coaster [24]. Vaccination should be associated with fun and the measure was rhetorically reduced to a little prick ("A little prick and it is over" [25]) or visualized with a small plaster ("Get the plaster!" [26]). Hesitant people or individuals who decided not to get vaccinated should be motivated – or sanctioned by negative sanctions of being excluded from parts of social life, as proclaimed by the former Minister of Health: "Consistently really 2G[iii] for all areas of life. […] Dear people, the year 2022 will be one, no matter how low the incidence is, be prepared, 2G, vaccinated or recovered, and indeed boostered, […] applies at least the year 2022. If you want to do anything more than visit your town hall or your supermarket, uh, you need to be vaccinated. That's a pretty clear message" [27] (translated by the author).

It is likely, that one aim of the political communication was to strengthen trust in COVID-19 vaccines, whereas surveillance was considered to be important, too. "The benefit and risk assessment of vaccines is a continuous process, ranging from vaccine development, the conduct of clinical trials prior to marketing authorization through to post-marketing surveillance" [19, p. 21] (translated by the author).

By February 2024, 76% of the population in Germany had received two doses of vaccines, 63% three doses, and 16% four [28]. Kluge [29], the regional director of WHO

[ii] STIKO (Ständige Impfkommission) is the "Standing Committee on Vaccination", which develops national recommendations for the use of licensed vaccines. https://www.rki.de/EN/Content/infections/Vaccination/German_Immunisation_Recommendations.html, (accessed 05/07/2024).

[iii] 2G stands for either vaccinated ("geimpft") or recovered ("genesen").

Europe, announced that 1.6 million lives had been saved by COVID-19 vaccines.

This brief description of the context makes the following clear: the hopes placed in the COVID-19 vaccination were high, related to several positive attributes. Politicians chose an information policy designed to motivate people to get vaccinated and emphasized its benefits. The majority of people in Germany decided to vaccinate against COVID-19.

1.2 Side effects of COVID-19 vaccines and the post-acute COVID-19 vaccination syndrome

From the beginning of the vaccination campaign, documents of the approval studies were available for the government and on the internet, which contained initial findings on possible side effects [30]. The Robert Koch Institute[iv] pointed out in its "The Vaccination Booklet for Everyone" that long-term side effects could not be ruled out: "It takes a lot longer to observe potential long-term effects. Of course, with a new vaccine that has only been in use for a matter of a few months, it's impossible to know whether and what long-term effects will occur years down the line" [31, p. 37].

Nevertheless, public political communication emphasized their safety and the Minister of Health once twittered that the vaccines were free of side effects: "[…] it's about why a minority of society doesn't want a side-effect-free vaccine, even though it's free and can save their lives and those of many others" [32] (translated by the author). Later on, the Ministry of Health pointed out the positive cost–benefit ratio but conceded that side effects could occur: "The development of highly effective vaccines against COVID-19 and the broad-based vaccination campaign have made it possible to prevent severe cases of the disease and protect particularly vulnerable groups of people. However, no vaccine is free from side effects. In very rare cases, it is possible that vaccination can lead to such serious side effects or vaccination complications that they can lead to permanent health impairments in individual cases" [33] (translated by the author).

International studies indicate a broad spectrum of possible adverse effects following COVID-19 vaccination. For example, they describe cardiovascular problems, such as myocarditis and pericarditis [34–38]. Hosseini and Askari [39, p. 1] point to neurological adverse events of COVID-19 vaccination: It could cause "cerebrovascular disorders, including cerebral venous sinus thrombosis, transient ischemic attack, intracerebral hemorrhage, ischemic stroke, and demyelinating disorders including transverse myelitis, first manifestation of MS, and neuromyelitis optica." Schönborn et al. [40, p. 2519] showed that patients with vaccine-induced immune thrombocytopenia and thrombosis "appear to be at low risk of recurrent thrombosis and/or thrombocytopenia." COVID-19 vaccination can lead to or exacerbate neurological problems, e.g. neuroimmunologic diseases, such as myasthenia gravis or the Guillain–Barre syndrome [39,41]. Some studies reported COVID-19 vaccination-induced autoimmune and inflammatory disorders [42,43]. Other studies referred to case studies and documented, for example, post-vaccine smell and taste disorders, which lasted between four and 42 days [44]. Some authors emphasize the need to analyse whether COVID-19 vaccination could cause acute pancreatitis [45] or psychosis [46]. Several studies discuss whether COVID-19 vaccines could trigger chronic fatigue syndrome (CFS) [47]. A large international study by Faksona et al. [48, p. 2201], which included 99,068,901 vaccinated individuals, finally confirmed "safety signals for myocarditis, pericarditis, Guillain–Barre syndrome, and cerebral venous sinus thrombosis."

Some adverse effects can be short-term and transient, others can be severe and long-lasting. Data of Czech healthcare workers, who received the Pfizer–Biontech COVID-19 vaccine, show that 5.3% reported adverse symptoms for longer than a week and 1.4% for longer than a month [49]. Data from the Paul Ehrlich Institute [11] document only a "reporting rate of less than one suspected case per 100,000 vaccinations (0.73/100,000)".

Due to this variety of side effects and their duration, some authors address the need to differentiate between a "post-COVID vac-syndrome" (PCVS), which includes "symptoms a person experiences after a COVID-19 vaccination (independent of the time after vaccination and the duration of the symptoms)," an acute COVID-19 vaccination syndrome and a post-acute COVID-19 vaccination syndrome (PACVS) [17, p. 4].

Regarding PCVS there are no official data about it in Germany. The German pharmacy journal questioned whether the PCVS exists at all and stressed that causality and coincidence cannot (yet) be distinguished [50]. The Paul-Ehrlich-Institut [11] commented on PCVS: "The Paul-Ehrlich-Institut, Federal Institute for Vaccines and Biomedicines, received a total of 1,547 reports of suspected cases

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[iv] The Robert Koch Institute (RKI) is "the government's central scientific institution in the field of biomedicine. It is one of the most important bodies for the safeguarding of public health in Germany" (https://www.rki.de/EN/Content/Institute/institute_node.html).

of adverse reactions at different intervals after COVID-19 vaccination that contained a reference to chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) with similarities to long COVID/post-COVID; postural tachycardia syndrome (POTS), including symptoms referred to as post-exertional malaise (PEM); or symptoms referred to as 'post-vac.'" The institute stresses the high number of administered COVID-19 vaccine doses and the low number of adverse effects. Due to missing diagnostic certainty, causality, and the possibility of coincidences, knowledge about PCVS is limited, and many questions remain unanswered.

Legal action is possible, nevertheless. Vaccinated people who have complained of health damages for at least six months after their vaccination can apply to the responsible pension office in their federal state for recognition of vaccination damage and compensation. Media reported that 11,827 individuals submitted an application [51]. This is 0.018% of the approximately 65 million people vaccinated in Germany. A total of 467 were successful, while 5,000 applications were not approved. Another 5,597 applications have not yet been processed (ibid.).

In summary, the following can be noted: While COVID-19 vaccines were declared to be safe and there were intense efforts to motivate individuals to achieve vaccination, side effects occurred. Yet, for PCVS, possible scientific mechanisms seem to be complex and there are still many unknowns. Compared to conventional vaccines, which underwent years of development and have been in use for a long time, such as vaccines against tetanus or polio, the rapidly developed and novel COVID-19 vaccines present a different situation in this regard [52]. There are already applications for compensation for adverse events; yet, most of those that were already decided on were not approved by the authorities.

It should be emphasized that this short communication does not aim to clarify how a COVID-19 post-vaccine syndrome could possibly occur, how it might be defined, whether there might be underreporting or overreporting, nor how many people might "actually" be affected by it. Rather, the aim is to enlighten the perspective of individuals who attribute health problems to a COVID-19 vaccine and to find out more about their patient experience.

1.3 Patient experience with PCVS

Patient experience is based on interactions, organizational culture, patient perceptions, and experiences across the continuum of care [53,54]. Interactions with families and care partners also influence their experience [54]. The Beryl Institute's definition, hence, emphasizes "the interactive, dynamic nature of the patient experience, as a whole" [53, p. 12]. A patient, who experiences his illness, gathers experiences with the health care setting as a user [55]. The British National Health Service (NHS) points out that a positive patient experience relies on "respect for patient-centered values, preferences, and expressed needs," "coordination and integration of care across the health and social care system," "information, communication, and education on clinical status," "progress, prognosis, and processes of care to facilitate autonomy, self-care and health promotion," "physical comfort including pain management, help with activities of daily living, and clean and comfortable surroundings," "emotional support and alleviation of fear and anxiety," "transition and continuity as regards information that will help patients care for themselves away from a clinical setting," and "access to care" [56]. Ahmed et al. [57, p. 239] emphasize the need to listen "to and [to] act[ing] upon the views and feelings of patients within healthcare" to achieve improvement for a better patient experience.

Specifically, understanding patient experience in relation to vaccinations is of particular importance. According to Holt et al. [58], the "voice of the patient" should be heard in the professional healthcare setting. Individuals weigh and treat information sources according to their value system and risk perception. The authors [59, p. S147] argue for a "communication style that is trust-based and science-informed" and for more attention to the patient voice in vaccination and vaccine safety.

Five aspects should be mentioned at this point: first, knowledge of patient experiences can serve as a basis for improving healthcare [59]. As Doyle et al. [60] outline, patient experience is positively associated with patient safety and clinical effectiveness. Second, listening to the patient's voice can be utilized to learn more about the effects of new therapies, drugs, or vaccines. This seems particularly necessary in light of the newly introduced vaccines. Third, patient experiences can, in turn, influence patients' trust in the healthcare system, medications, or vaccinations [58]. With regard to the specific situation of the vaccination campaign during the COVID-19 pandemic, a fourth aspect should be added: patient experiences can also affect their understanding of solidarity, especially if patients were vaccinated out of considerations of solidarity and are now assessing, based on their experiences, the level of solidarity they experience as PCVS-patients. Finally, communicating about patient experiences can also contribute to social representations of a matter [61]. If individuals experience adverse effects from a new vaccine and, from their perspective, have a good or less favourable patient experience, it can either strengthen or weaken trust in future therapies or vaccinations.

For these reasons, it seems worthwhile to examine patient experience, especially considering that new vaccines were used on an extremely large scale. This article is less focused on physical complaints in relation to PCVS, but, on psychological aspects of patient experience of individuals who attribute their health problems to a prior vaccination against COVID-19.

2 Methods

To shed light on the experiences of patients with health problems after COVID-19 vaccination, a literature search was conducted. The following four search engines were used:

(1) BASE (Bielefeld Academic Search Engine) is open source and provided by Bielefeld University. It is “one of the world’s most voluminous search engines, especially for academic web resources. The index contains more than 400 million records from more than 11,000 content providers” (https://base-search.net/).
(2) PubMed “comprises more than 37 million citations for biomedical literature from MEDLINE, life science journals, and online books” (https://pubmed.ncbi.nlm.nih.gov/).
(3) Google Scholar is the third search engine resorted to. It does not provide data about its records. Yet, it is assessed to be another suitable source to enlarge search opportunities.
(4) PsycINFO is “the world’s largest resource devoted to peer-reviewed literature in behavioral science and mental health” (https://www.ebsco.com/products/research-databases/apa-psycinfo). It includes more than 5 million records.

Although these are well-established search engines that encompass a large number of records, using only four search engines introduces certain limitations.

The search terms were derived from the previously described research into potential adverse effects:

- Post-acute COVID-19 vaccination syndrome;
- Post-COVID-19 vaccination syndrome;
- Post-Covid vac syndrome;
- PCVS + COVID;
- PCVS + patient experience; and
- Post-vac syndrome.

It is important to note that English terms were used for the search without a priori focus on Germany. This was done for two reasons: (1) studies conducted in Germany are mostly published in English. If there happens to be a German-language publication, results would still appear due to the usually additional English abstracts. Therefore, using English search terms seemed appropriate. (2) There was no initial restriction set to Germany. This allows the findings to be discussed in an international context if applicable.

The following criteria have been applied. A hit was discarded in the column “PCVS patient experience” if

- not related to PCVS;
- it was on medical/general aspects of PCVS without patient experience;
- it concerned medical/general aspects of vaccines against COVID-19 without PCVS or patient experience;
- it included a psychological perspective, but not a patient experience;
- it was only a registered protocol; and
- it did not include an English/German abstract.

The last check of the search was on September 27, 2024.

3 Results

Table 1 shows the results. Sometimes an article appears more than once in the results. The table displays the number of hits returned by the search engine.

Table 1: Search terms and hits

	Base		PubMed		Google Scholar		PsycINFO	
Search terms	**Hits**	**PCVS patient experience**	**Hits**	**PCVS patient experience**	**Hits**	**PCVS patient experience**	**Hits**	**PCVS patient experience**
Post-acute COVID-19 vaccination syndrome	8	0	5	0	14	0	0	0
Post-COVID-19 vaccination syndrome	20	0	2	0	102	0	1	0
Post-Covid vac syndrome	5	0	1	0	2	0	24	0
PCVS + COVID	24	0	18	0	1,400	18	2	0
PCVS + patient experience	6	0	5	0	758	83	0	0
Post-vac syndrome	0	0	2	0	49	0	0	0

As a result, there are few hits on patient experience of people who attribute their symptoms to COVID-19 vaccination. Most of them result from Google Scholar. However, a review shows that these hits do not provide information about PCVS patient experience. For example, some hits include publications on “long COVID,” and others refer to pneumococcal conjugate vaccines. One study conducted in India is on PCVS and quality of life [62], but patient experience is not part of the analysis.

Therefore, the search could not answer the underlying research question of the experience of patients in Germany with post-COVID-19 vaccination syndrome. Considering the high number of vaccinations and the ongoing discussion about PCVS, it is surprising that no studies were found on the experience of patients with PCVS, even if it might involve relatively small case numbers.

4 Discussion

Therefore, the question remains about the experiences of PCVS patients. In addition, the results raise the question of why the patient experience has been analysed so little. Hence, two levels can be distinguished for the discussion (Figure 1). On the first level, factors that may influence the object of knowledge, the patient experience, can be considered. At a second, higher level, one can ask why there exists so little research to date. This level draws attention to possible barriers to research.

Factors that might explain the lack of studies on PCVS include not only limited knowledge of PCVS but also political and social influences, healthcare barriers, and stigma. As mentioned above, the interactive, dynamic nature of the patient experience results from the needs and perceptions of the patient, on the one hand, and the information, communication, and support provided by the environment, on the other hand.

To avoid repetition, some potential influencing factors will be discussed not for each observation order, but in summary below.

4.1 Limited scientific knowledge about PCVS

To begin with, research on patient experience may be hindered by the preliminary nature of the knowledge about PCVS. Although vaccines have been administered billions of times, the first-time use of an mRNA technology for vaccines and the brief timeframe contribute to uncertainty, prompting questions about suspected links between vaccination and observed health outcomes, and resulting in only tentative conclusions on PCVS. Some authors point to limited information, for example, about nonclinical studies on potential toxicity/adverse effects of the COVID-19 vaccines in laboratory animals, particularly from manufacturers of mRNA vaccines [63]. Boros et al. [64, p. 1] note that “despite their worldwide use, very little is known about how nucleoside modifications in mRNA sequences affect

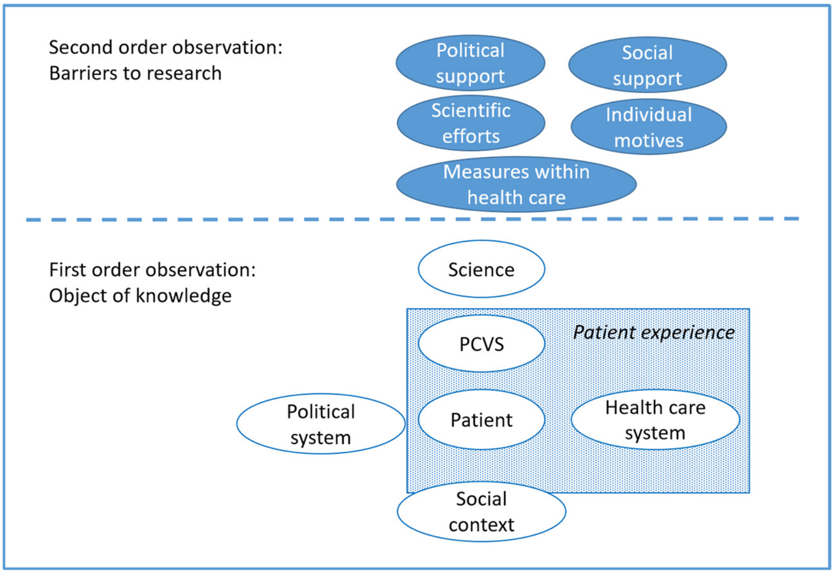

Figure 1: First- and second-order observation of PCVS patient experience.

their breakdown, transcription, and protein synthesis." A critical – and controversially discussed – analysis by Mead et al. [65] attributes limited information to an insufficient timeframe for proper safety evaluation, which, they suggest, resulted in compromises in the usual safety testing protocols and toxicology requirements. This could have led to an underestimation of the occurrence of side effects. This, in turn, could contribute to the knowledge about PCVS being incomplete. Although this could have led to more research in this area, too, including an analysis of patients' experiences of PCVS, this was not the case for the latter.

On a meta-level, Georgiev and Rinner [66] also identify potential quality compromises that may have occurred in the wake of the publication surge of COVID-19-related scientific contributions. Non-conforming, critical contributions might counteract groupthink and be rejected in the review process, resulting in heterodox views being underrepresented. According to the authors, this seems particularly problematic when scientific findings are used to inform political decisions. Applied to the context of patient experiences, research findings might exist but not be publicly accessible due to a lack of timely publication.

4.2 Political influences

While a study by Guan et al. [67], which conducted a content analysis of 138 studies on factors affecting patient experience, primarily views the policy level as related to payment style, in the context explored in this article, macro-level factors such as political communication and strategies appear to be more significant.

The vaccination campaign led to a positive portrayal of the COVID-19 vaccines, leaving little room for negative experiences. If individuals trusted political communication that emphasized the safety and benefits of vaccination, they might have felt disillusioned if they later encountered health issues they associated with the COVID-19 vaccine. Unlike the positive rhetoric – emphasizing enjoyment, minimal discomfort, and personal and societal benefits – PCVS patients face prolonged negative outcomes. This could lead them to feel that, while the majority benefitted, they were unlucky to suffer adverse effects.

Additionally, vaccination motives matter. If individuals were vaccinated due to confidence in the vaccines' safety, they might experience a loss of trust alongside illness. Conversely, if they were vaccinated primarily out of solidarity – a key political communication strategy during the pandemic [68] – they might feel let down by a lack of reciprocal support when they became ill. For example, the media reported such stories [14,69]. Finally, there might be a group of people who may have been vaccinated against their own convictions because they would have suffered considerable professional disadvantages or been prevented from working, e.g. because of mandatory vaccination in the healthcare sector. Their patient experience might be influenced by feelings of anger. According to a law firm, which represents 600 clients suffering from PCVS and needing legal support, these patients often feel ignored by politicians and the administration [70].

It is questionable whether political decision-makers who strongly supported vaccination during the pandemic would actively support efforts to address the problem of PCVS. Yet, Bardosh et al. [71] explain that there was at least one form of COVID-19 public inquiry in Germany, which would reflect a certain openness and willingness to reflect on experiences made during the pandemic.

Public fund allocation is another concern. With the abovementioned PEI, a public institution already exists that monitors drug safety. It has been collecting data on suspected adverse reactions from the beginning of the COVID-19 vaccination campaign. There are several low-threshold options for reporting observed or suspected side effects. This contributes to the discussion of whether this might be a reason why so many cases have been reported in Germany [72]. Apart from that, it remains to be seen whether political decision-makers will, for example, advocate for research funding to investigate and treat PCVS. This, in turn, could then expand the knowledge of patient experience and improve it. So far, the focus has been rather on "long COVID." From 2021 to 2024, the government provided 6.5 million euros for "long-COVID" research [73], but no comparable funding exists for research on PCVS.

4.3 Social influences

Patient experience might be affected by the social environment, too. Several media reports describe people who suffer from PCVS and lack support in their social environment [69,74–76].

This could be attributed to the influence of stigmatization. Related to other issues, studies have shown that stigma can influence patient experience, for example, in patients with neurological disorders [77,78], or weight-related stigmatization [79,80]. A qualitative study by Norouzadeh et al. [81] also highlighted experiences of stigmatization related to a COVID-19 infection; Deng et al. [82]

report similar findings. Eberhardt et al. [83] also detect stigmatization in relation to long COVID and its significance for patient experience. Stigmatization processes can originate from the general social environment as well as within the professional context of health care.

It can be a challenge in some social contexts to accept the rare but serious consequences of vaccination, too. During the pandemic, vaccine hesitancy, critical discussions about COVID-19 vaccines or the vaccination strategy in Germany were sometimes associated with “COVID-deniers” (Corona-Leugner), right-wing extremists, conspiracy thinking or “Querdenker”[v]; they were called “covidiots” or “tyrants” [84–89]. PCVS could contribute to a critical reflection that the social environment would have to engage in, which may be inconvenient. This can go at the expense of social support for patients suffering from PCVS. Even social groups formed for those affected by PCVS (e.g. support groups or forums) do not necessarily support research on patient experience.[vi] In such an emotionally charged context, individuals may hesitate to share their experiences in a scientific study. Having shifted from being part of the majority of vaccinated individuals with social recognition to a minority facing health issues they attribute to the vaccination, they might fear similar negative perceptions as experienced by vaccine critics during the pandemic. This may explain why interviewed PCVS patients repeatedly stress that they are not against vaccination [69,73,90].

Finally, the topic of the long-term adverse effects of a COVID-19 vaccination is currently overshadowed by other issues, as most people wish to move past the pandemic and its memories. Additionally, other risk-related issues, such as the climate crisis, and the wars in Ukraine and Gaza, have arisen. While there is a discussion about evaluating pandemic experiences (Corona-Aufarbeitung) [91,92], it is mainly a communicative exchange about the necessity of doing so. Moreover, this attempt focuses on the chosen way of risk management and not on dealing with people who suffer from the long-term consequences of a COVID-19 vaccination. For those affected, however, this could make them feel that their needs are not getting the attention they deserve. In turn, this could impede research on PCVS as well as on patient experience.

4.4 Possible influence of the healthcare setting

As described above, patient experience could be influenced by access to the healthcare setting, by information and communication, and by the support provided by it. Media reported individual cases of PCVS patients who do not receive sufficient support from the professional medical setting [69,74–76,93–95].

First, it may be a question of *access* to healthcare services that affects the patient experience. With regard to PCVS, it should be noted that there are – but only limited – resources in the medical system in Germany. For example, Marburg University Hospital has a combined outpatient clinic for post-COVID-19 and PCVS requests. In May 2023, the university hospital already had 7,500 people on the waiting list [96]. The outpatient clinic can handle about eight patients per day [13]. Hippen [97] concluded that the treatment of PCVS patients in Germany would be disgraceful. They would be left alone and suffer in the shadows [93]. Whether this is actually the case would need to be scientifically investigated. Considering findings from other areas, such as Rowe and Knox [98], which, based on an analysis of several articles, suggest that – albeit in the context of emergency department care – such conditions are likely to negatively affect patient experience, it appears probable.

Another important factor is *communication* [98]. Due to a lack of data, it is not possible to say what care is provided by general practitioners and by other therapists. However, non-reactive data [99] suggest that some health professionals have reservations about PCVS. An illustrative example could be found at doccheck.com. DocCheck is an online community for members of the medical profession, providing information, communication exchange, and commerce (www.doccheck.com). In December 2023, it published an article by a journalist about the high number of reported PCVS in Germany, which was qualified as a

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[v] Querdenker are “supporter, sympathiser of the political movement ‘Querdenken’, which is particularly opposed to government measures to contain the corona pandemic, vaccinations, etc. (and also spreads conspiracy narratives)” (https://www.duden.de/rechtschreibung/Querdenker, accessed 09/29/2024, translated by the author).

[vi] Because of the lack of data, the idea of collecting primary data was considered. One obvious attempt was to interview people who suffer from PCVS. Surprisingly, however, this attempt failed due to barriers to field access. Inquiries to PCVS self-help groups were unsuccessful. In open Facebook groups, a post was not approved by the administrators. After these two attempts, the endeavour was not pursued further. There may be reasons to prevent people from sharing their experiences - and, in the case of support group administrators and self-help group leaders, to protect group members from requests. This may protect others from such requests, but it also patronises them by depriving them of the opportunity to make an autonomous decision. In addition, an issue that is actually relevant remains in the shadows more and for longer than would be beneficial for individuals and for social discourse - and for improving health care support for PCVS patients.

"German neurosis" [72]: "Germany is the country of post-VAC […] Germany is responsible for more than 50% of all reported cases worldwide. And that's with only 192 million of the eleven billion vaccine doses administered worldwide" (ibid., translated by the author). Lagger [64] offers two explanations: "This envy threshold access is important and brings many advantages, but it could also lead to falsification of reports. Especially when it comes to topics that are heavily covered and hotly debated in the media. Another reason could be the general anti-vaccination attitude of the Germans" (ibid., translated by the author). It is instructive to see how health professionals comment on this article.[vii]

Some commenters welcome the article and agree that suspected PCVS reports are merely the result of German neurosis. They either question whether PCVS exists at all or criticize the number of cases reported. One biologist, emphasizing his expertise in assessing statements, mentions that "epidemiologically it is extremely unlikely that there are so many cases in Germany, if such a syndrome exists at all." Other commenters condemn the criticism of COVID-19 vaccines. They call such criticism "ridiculous" (neurologist) and colleagues who criticize the article would be "unbelievably stupid" (paediatrician).

When patients suspect or claim to suffer from PCVS, some commenters believe this could be explained by underlying psychological conditions or problems (e.g. GP). One comment goes even further, suggesting that some patients are just trying to get a sick note when referring to PCVS (urologist). An anonymous commenter claims that it would be mainly unvaccinated people who report PCVS. In these examples, PCVS is not acknowledged as a "real" disease, but as a manifestation of a psychological disorder, or as an excuse for freeloading. PCVS is implicitly interpreted as a criticism of vaccines, which in turn is presented as stupid.

If patients come into contact with professionals who share such attitudes, it could shape their experience. They may feel not taken seriously, even psychiatrised. Here, too, the aforementioned stigmatization processes can have an effect.

On the other hand, some commenters criticize colleagues who question the possibility of PCVS. Those who still defend COVID vaccination are portrayed as ignoring scientific evidence, or the so-called "vaccinators" are accused of having an economic motive; they would have gained a "golden nose" by administering the vaccination. A surgeon reports several cases of severe side effects from the COVID-19 vaccine and concludes that the problem is that patients who suffer side effects are labelled as idiots and conspiracy theorists. "We don't know what you have either, we can't help you, but it can't have been the so-called vaccine. It is politically undesirable and legally illegal." Another commenter believes that because of the large number of people who are anti-vaccination in general, there is suspicion whenever PCVS is mentioned.

Occasionally, some healthcare professionals report on PCVS they have experienced themselves or in their families. Their comments reveal a kind of patient experience. One commenter, who admits to having been affected by PCVS, perceives the article as a harsh assessment. Another commenter talks about her daughter who became disabled after her booster. Doctors had told her: "There's nothing you can do now anyway." She bemoans that she would get no help or support in Germany.

The bottom-line comments reveal a rather polarized discussion. One nurse calls it a "war of beliefs." A general practitioner points to the problem that critical comments have led to storms of hatred, and people who have PCVS feel ashamed that they have not been able to cope with the only drug that seemed to have overcome the pandemic.

The example of bottom-line comments further illustrates the importance of the language of health care [53] which can have an influence on the patient experience.

It is possible that experiences of contact with doctors and therapists who question the existence of PCVS may contribute to negative emotional reactions and/or increased distress. Findings from other studies on patient experience suggest this. In general, in relation to other aspects of the COVID-19 pandemic, there are studies on patient experience, such as those related to virtualized or pandemic-adapted care services during the pandemic [100–103], or patient experiences associated with the organization of vaccinations, for instance in vaccination centres or through pharmacies [104,105] or the general vaccination program [106]. When considering only patient experiences gathered in Germany, similar research focuses can be found, e.g. with respect to specific health topics (e.g. asthma [107], lung cancer [108], or experience of cardiovascular prevention during the pandemic [109]) or pandemic-adapted care services [110], or with the vaccination procedures [111,112]. These examples demonstrate that institutional and interactional factors influence patient experience. The mentioned studies enlighten patient experience during the COVID-19 pandemic; however, they have different foci. This contrasts even more with the lack of studies on the patient experience of those affected by PCVS.

[vii] https://www.doccheck.com/de/detail/articles/43966-post-vac-eine-deutsche-neurose (accessed 04/17/2024).

5 Limitations

The considerations in this "short communication" have several limitations. Relevant specific search engines (PubMed and PsycINFO) and comprehensive databases (BASE and Google Scholar) were used for the search, but they did not yield any relevant results. This limited search may have missed hits available in other databases. The same applies to the selected search terms; while they were chosen based on usage in publications and media reports, it is possible that other suitable terms were overlooked.

Additionally, non-reactive data that were not collected in a scientific context but on doccheck.com were utilized for the discussion. This poses the limitation that such data can only be used as they are. For instance, some commenters question whether contributors truly come from the medical field, a question that has to remain unanswered. Examples from media reports also provide only a limited and potentially biased view of segments of social reality. Thus, the comments are treated as "non-reactive" [99] or "natural data" [113] without verification. However, this approach has the advantage of allowing for more open statements that might be less influenced by social desirability, which can be significant in this context. At the same time, media-driven framing can also influence social perception [114]. Related to social media, Modgil et al. [115] describe that a confirmation bias contributes to strengthening echo chambers, which in turn accelerates social media-induced polarization. Accordingly, using media reports can capture potentially influential information within specific social contexts, but they must always remain at a purely illustrative level.

Finally, in the absence of scientific studies, only general, sometimes speculative considerations could be made in the discussion, highlighting the need for further research.

Within the scope of the considerations presented here, there was no room for international comparisons. Undoubtedly, these could offer interesting insights in further studies.

6 Conclusion

Despite the limitations mentioned, it can be assumed that patient experience is influenced by some of the factors outlined above. For example, negative effects may arise from the preliminary state of research on PCVS. Access to care is limited, as there are only a few specialized outpatient clinics available for PCVS, resulting in long waiting lists. Emotional support and respect could be affected by health professionals' attitudes towards PCVS, which could influence their behaviour. These aspects may impair what the English National Health Service defines as a "good" patient experience [57].

In the context of further research, three primary directions could be pursued. To begin with, it would be beneficial to collect more systematic data on PCVS than seems to be the case so far [10,116]. Second, it is important to identify factors that inhibit or fail to promote research on patients' experiences with PCVS. Third, patient experiences should be analysed to develop recommendations and starting points for improvement.

Regarding all three points, policymakers would have the opportunity to both establish research funding programs and simultaneously expand healthcare structures for those affected by PCVS. Scientific findings would also be helpful for appropriate resource allocation. Given the importance of vaccinations for public health, this is crucial. Vaccinations are an efficient tool for reducing infectious disease burdens and safeguarding health [59]. Therefore, understanding patients' experiences with potential side effects and their subjective views on vaccine safety is vital not only for their health but also for future vaccination decisions.

The ultimate goal should be to foster a positive patient experience. At the very least, the professions within the medical system should strive to support patients who attribute their health complaints to a COVID-19 vaccination. Even with many unknowns, all physicians should treat patients without reservation, as outlined in the WMA Declaration of Geneva: "The health and welfare of my patient will be my first consideration; I will respect the autonomy and dignity of my patient; I will maintain the utmost respect for human life; I will not allow considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social status, or any other factor to come between my duty and my patient" [117]. In line with this ethical principle, all patients experiencing side effects from COVID-19 vaccines should receive necessary care, and efforts should be made to promote a positive patient experience.

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