

Patients' Experiences With Therapeutic Approaches for Post-COVID Syndrome: Results of a Crowdsourced Research Survey

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ABSTRACT

Some patients develop multiple protracted sequelae after infection with SARS-CoV-2, collectively known as post-COVID syndrome or long COVID. To date, there is no evidence showing benefit of specific therapies for this condition, and patients likely resort to self-initiated therapies. We aimed to obtain information about therapies used by and needs of this population via inductive crowdsourcing research. Patients completed an online questionnaire about their symptoms and experiences with therapeutic approaches. Responses of 499 participants suggested few approaches (eg, mind-body medicine, respiratory therapy) had positive effects and showed a great need for patient-centered communication (eg, more recognition of this syndrome). Our findings can help design clinical studies and underscore the importance of the holistic approach to care provided by family medicine.

Ann Fam Med 2023;21:73-75. <https://doi.org/10.1370/afm.2898>

INTRODUCTION

After surviving an infection with SARS-CoV-2, about one-half of patients report long-term sequelae, collectively called post-COVID syndrome or long COVID. In a population-based study, the most common symptoms were fatigue, physical exhaustion, difficulty concentrating, and loss of taste and smell.¹ This spectrum of symptoms requires patient-centered care, as is provided by primary care physicians.² Because evidence of benefit for specific therapies for post-COVID syndrome is lacking, patients have been forming advocacy groups and resorting to easily accessible self-management strategies.³

The aims of our study were to identify therapeutic approaches used by patients with post-COVID syndrome and their perceived effectiveness, as well as to explore affected patients' experiences and needs concerning health care.

METHODS

From April to August 2021, we invited patients with persistent symptoms after a SARS-CoV-2 infection to participate in an online survey via advocacy group platforms, social media, and the homepage of the University Hospital in Tübingen, Germany, using an inductive crowdsourcing research approach.⁴ The survey was conducted in German (see an English version in [Supplemental Table 1](#)). Our questionnaire collected sociodemographic data, duration and nature of persisting symptoms, and self-initiated or physician-initiated therapeutic approaches as well as their perceived effectiveness, along with patients' needs concerning health care. Patients were asked to describe therapeutic approaches they used to alleviate a given symptom and to rate its effectiveness on a 5-point Likert scale: 1 (not at all), 2 (a little), 3 (medium), 4 (good), and 5 (very good). Because of the exploratory nature of the study, we asked patients to enter symptoms and therapies in free-text boxes. This information was then coded using an inductively developed categorization system (researcher-coder reliability: 92% agreement).

Our institutional ethics committee determined that an ethics vote was not required for this study because the survey was anonymous (protocol 279/2021A). The landing page and questionnaire were approved by the institution's data protection officer before the questionnaire was made available to patients.

Conflicts of interest: authors report none.

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RESULTS

A total of 699 patients completed the survey. Of those, 499 were included in the analysis as they met the definition of post-COVID syndrome with symptoms persisting for at least 12 weeks.⁵ The participants had a mean age of 45 years (range = 13 to 81 years), and 81% were female.

The most frequently reported symptoms were fatigue (404 patients, 81%), poor concentration (335 patients, 67%), psychological impairments (266 patients, 53%), shortness of breath (245 patients, 49%), headaches (198 patients, 40%),

and loss of smell or taste (191 patients, 38%). On average, patients reported 4.3 symptoms (range = 1 to 12 symptoms). Only 6% of patients reported 1 symptom, whereas 12% reported 2 symptoms, 17% reported 3 symptoms, and 65% reported 4 or more symptoms.

We grouped the reported therapeutic approaches into 30 categories (Table 1). The most frequently mentioned were nutritional supplements (267 patients), including vitamins B, C, and D, and sports/exercise (142 patients). Only 27.3% and 33.8% of patients rating these approaches, respectively,

reported their effectiveness to be good or very good (4 or 5 on the 5-point scale), however. Vaccination against SARS-CoV-2 was mentioned by 8 patients, of whom 7 (87.5%) rated it as at least good. Other therapies rated mostly effective were mind-body medicine, especially for respiratory and psychological symptoms, as well as respiratory therapy and non-cortisone-containing inhalants for respiratory symptoms such as shortness of breath. Sports/exercise, rest, and nutritional supplements were rated as moderately effective for fatigue. Olfactory training was used for curing the loss of smell and taste but rated as not effective.

When patients were asked about their needs related to post-COVID syndrome, only 13% (51) indicated that they did not have any needs; 35% (232) expressed a desire for more or more widespread understanding and recognition of their situation; and 33% (223) expressed a need for specific post-COVID health care services and better information (Table 2).

DISCUSSION

Our study identified a wide range of therapeutic strategies patients use, most of them easily accessible, to self-manage post-COVID syndrome. Of these, only a few approaches, such as mind-body medicine, were rated as having good or very good effectiveness. These approaches could be promising options and warrant investigation in future studies. The fact that certain approaches were rated highly effective by some patients but of no benefit by others underscores the lack of a one-size-fits-all therapy and

Table 1. Therapeutic Approaches Used by Patients With Post-COVID Syndrome and Their Perceived Effectiveness (N = 499)

Therapeutic Approach	Patients Mentioning Approach, No.	Patients Rating Approach, No.	No. (%) of Ratings Good/Very Good ^a
Nutritional supplements (eg, vitamins B, C, D)	267	54	15 (27.3)
Sports/exercise	142	68	23 (33.8)
Mind-body medicine (eg, yoga, tai chi)	114	38	22 (57.9)
Rest	74	42	20 (47.6)
Cortisone/corticosteroids (inhaled, oral, or topical)	73	43	17 (39.5)
Other medications (eg, β-blockers, cold remedies)	70	31	17 (54.8)
Physiotherapy	70	31	15 (48.4)
Pain medication	56	26	7 (26.9)
Phytotherapy/herbal medication	53	18	9 (50.0)
Respiratory therapy	52	26	18 (69.2)
Rehabilitation	51	23	12 (52.2)
Medical consultation	45	13	3 (23.1)
Manual medicine	42	26	12 (46.2)
Psychotherapy	36	21	10 (47.6)
Inhalants (noncortisone)	35	13	8 (61.5)
Other (eg, mouthwash, singing)	32	17	8 (47.1)
Dietary change	31	14	7 (50.0)
Other physical therapy (eg, thermotherapy, contrast bath therapy)	29	9	5 (55.6)
Occupational therapy	27	14	6 (42.9)
Homeopathy	26	16	4 (25.0)
Memory training/concentration exercises	26	14	4 (28.6)
Olfactory training	26	20	3 (15.0)
CIM generally, other CIM approaches (eg, neural therapy, Ayurveda)	23	12	6 (50.0)
Acupuncture/acupressure	22	9	4 (44.4)
Psychotropic drugs	15	7	2 (28.6)
Traditional Chinese medicine/pharmacotherapy	13	4	0 (0.0)
Massage	12	6	2 (33.3)
Vaccination against SARS-CoV-2	9	8	7 (87.5)
Aromatherapy	9	3	2 (66.7)
Speech therapy	8	6	3 (50.0)

CIM = complementary and integrative medicine.

Notes: Therapeutic approaches are sorted in descending order according to how many patients mentioned them (first column). Multiple responses were possible. Bold denotes therapeutic approaches for which more than 50% of ratings were very good or good.

^a Rating of 4 or 5 on the 5-point Likert scale.

Table 2. Expressed Needs of Patients With Post-COVID Syndrome (N = 432)

Need	Patients Mentioning Need, % (No.)
More support/understanding/recognition	34.7 (232)
More (specific) therapies	20.2 (135)
More contact points/prompt appointments	16.5 (110)
Better information	7.6 (51)
Rehabilitation	5.5 (37)
More research	3.9 (26)
Exchange with other people affected	2.7 (18)
Better cost coverage by health insurances	2.7 (18)
Holistic therapies	1.6 (11)
Other	6.9 (30)

reflects the heterogeneity of symptoms and pathophysiology.⁶ It seems, however, that nonpharmacologic complementary and holistic approaches, such as mind-body practices and respiratory therapies, have a therapeutic potential. As long as there are no proven effective therapies for post-COVID syndrome, a comprehensive and patient-centered strategy is most important.

When asked about their needs, patients very often expressed the desire for greater recognition of the syndrome. A frequent comment was that patients having post-COVID syndrome feel that they are “not taken seriously” in consultations. Patients also noted the difficulty in accessing proper and specific care, expressing a desire for faster access to appointments with specialists. These findings demonstrate the need for enhanced patient-centered communication and underscore the importance of primary care, both to serve as the first point of contact for all patients and to ensure comprehensive and trustworthy care over the long term. As long as evidence-based therapies for post-COVID syndrome are lacking, physicians and nurses should personalize patient care by providing patients with suitable information on the condition, by educating them about potential risks of self-initiated approaches, and by avoiding potentially harmful diagnostics through shared decision making. Primary care is therefore central for managing the heterogeneous symptoms of post-COVID syndrome.⁷

A limitation of the exploratory nature of this study is its lack of representativeness. Using an online survey may have

resulted in recruitment of predominantly Internet-savvy participants. Similarly, promoting the survey in advocacy groups could have led to the participation of mainly well-informed or more active patients. The symptoms our participants reported are, however, consistent with those reported in previous large studies.^{1,2}

In summary, our findings show that it is essential for clinicians, especially family physicians, to adopt a patient-centered perspective to their patients with post-COVID syndrome. Such a perspective means having open communication about the lack of evidence for therapeutic strategies as well as recognizing, naming, and taking seriously patients' symptoms. Furthermore, our experience shows the potential of a crowdsourced research approach to gather the experiences of many patients with post-COVID syndrome in a short period of time and suggests this approach may be promising for conducting studies of therapies.



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Key words: COVID-19/complications; long COVID; COVID-19/therapy; chronic disease/therapy; family medicine; crowdsourcing research; surveys and questionnaires; patient needs; self-management; self-medication; patient-centered communication; holistic care

Submitted April 25, 2022; submitted, revised, September 9, 2022; accepted September 20, 2022.



[Supplemental materials](#)

References

- Förster C, Colombo MG, Wetzel AJ, Martus P, Joos S. Persisting symptoms after COVID-19—prevalence and risk factors in a population-based cohort. *Dtsch Arztebl Int.* 2022;119(10):167-174. [10.3238/arztebl.m2022.0147](https://doi.org/10.3238/arztebl.m2022.0147)
- Knight M, Vancheeswaran R. Post-acute COVID-19 in primary care. *BMJ.* 2021;375(3080):n3080. [10.1136/bmj.n3080](https://doi.org/10.1136/bmj.n3080)
- Brown K, Yahyouche A, Haroon S, Camaradou J, Turner G. Long COVID and self-management. *Lancet.* 2022;399(10322):355. [10.1016/S0140-6736\(21\)02798-7](https://doi.org/10.1016/S0140-6736(21)02798-7)
- Wang C, Han L, Stein G, et al. Crowdsourcing in health and medical research: a systematic review. *Infect Dis Poverty.* 2020;9(1):8. [10.1186/s40249-020-0622-9](https://doi.org/10.1186/s40249-020-0622-9)
- Yong SJ. Long COVID or post-COVID-19 syndrome: putative pathophysiology, risk factors, and treatments. *Infect Dis (Lond).* 2021;53(10):737-754. [10.1080/23744235.2021.1924397](https://doi.org/10.1080/23744235.2021.1924397)
- Soriano JB, Murthy S, Marshall JC, Relan P, Diaz JV; WHO Clinical Case Definition Working Group on Post-COVID-19 Condition. A clinical case definition of post-COVID-19 condition by a Delphi consensus. *Lancet Infect Dis.* 2022; 22(4):e102-e107. [10.1016/S1473-3099\(21\)00703-9](https://doi.org/10.1016/S1473-3099(21)00703-9)
- Vance H, Maslach A, Stoneman E, et al. Addressing post-COVID symptoms: a guide for primary care physicians. *J Am Board Fam Med.* 2021;34(6):1229-1242. [10.3122/jabfm.2021.06.210254](https://doi.org/10.3122/jabfm.2021.06.210254)