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Which healthcare services did children and adolescents use before presentation at specialised outpatient clinics for post-COVID-19 condition? Descriptive findings from the Post-COVID Kids Bavaria study

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ABSTRACT

Objective Measuring the utilisation of healthcare services in children and adolescents with symptoms suggesting post-COVID-19 condition (PCC) until their presentation at specialised outpatient clinics (SOC).

Methods 117 patients (aged 4–17 years) with symptoms suggesting PCC were recruited for study participation in SOCs of the comprehensive care network 'Post-COVID Kids Bavaria' for children and adolescents with PCC in Bavaria, Germany. Information on healthcare utilisation from their initial SARS-CoV-2 infection until presentation at an SOC was collected via telephone interviews with parents.

Results Participants had a median of 6.5 physician contacts (Q1–Q3: 3.8–11.5), mainly in person (99.1%, n=116) and rarely used telemedicine (21.4%, n=25). Contacts were mainly with paediatricians (72.6%, n=85), followed by general practitioners (46.2%, n=50). Non-pharmacological measures were used by 56 participants (47.9 %), with therapies by Heilpraktiker and osteopaths being used most commonly (30.8%, n=36). 76 participants (65.0%) were prescribed medications, and 71 (60.7%) used non-prescribed medications or supplements.

Conclusions Children and adolescents with PCC symptoms frequently consult healthcare services, often self-initiated measures provided by Heilpraktiker and osteopaths, until their presentation at an SOC. This may be due to unclear care pathways. Paediatricians and general practitioners are key providers, making their expertise and strong connections with SOCs essential for early diagnosis and appropriate treatment.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Persistent somatic symptoms following SARS-CoV-2 infection in children and adolescents can be severe and long-lasting, leading to restrictions in everyday functioning and complex healthcare needs.

⇒ Patients and their caregivers describe challenges in seeking appropriate healthcare.

WHAT THIS STUDY ADDS

⇒ The study gives a first comprehensive overview of the healthcare utilisation of children and adolescents with symptoms suggestive of post-COVID-19 condition (PCC) before their presentation at a specialised outpatient clinic (SOC).

⇒ Healthcare utilisation is diverse but mostly high among affected children and adolescents, use of self-initiated services by Heilpraktiker and osteopaths is common and primary care plays a central role.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ To ensure early diagnosis and appropriate treatment, it is crucial that paediatricians and general practitioners have sufficient expertise and are integrated into networks with specialised healthcare institutions

INTRODUCTION

The acute course of a SARS-CoV-2 infection in children and adolescents is usually mild or asymptomatic but some children and adolescents experience severe, persistent symptoms, within 3 months of acute infection, lasting for at least 2 months and affecting everyday functioning.[1 2] This COVID-19 triggered post-viral syndrome is among others referred to as long COVID, post-COVID-19 syndrome or post-COVID-19 condition (PCC). The symptoms and consequences of PCC have an impact on everyday functioning (eg, poor school performance) and contribute to a reduced quality of life.[3 4] Common symptoms of PCC in the paediatric population according

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Table 1 Socio-demographic characteristics

N=117 socio-demographic characteristics	n	%	Md	Q1–Q3
Gender				
Male	44	40.0	/	/
Female	66	60.0	/	/
Age (years)	117	/	14.0	11.0–16.0
Household				
Household size (persons)	115	/	4.0	3.0–5.0
Number of children in household	115	/	2.0	2.0–2.0
Migration background (min. one parent not born in Germany)				
No	97	84.3	/	/
Yes	18	15.7	/	/
One parent	11	9.6	/	/
Both parents	7	6.1	/	/
Educational institution attended by the patient				
Nursery	2	1.7	/	/
Primary school	16	13.9	/	/
Secondary school*	82	71.2	/	/
Elementary secondary school (until 9th grade)	9	7.8	/	/
Intermediate secondary school (until 10th grade)	28	24.3	/	/
Academic secondary school (until 12/13th grade)	45	39.1	/	/
Special school	/	/	/	/
Occupational school/ occupational training	8	7.0	/	/
University/higher education institution	/	/	/	/
Other	7	6.1	/	/
Health insurance patient				
Public health insurance	96	83.5	/	/
Beihilfe (state aid for the healthcare of state employees in Germany)	4	3.5	/	/
Private health insurance	19	16.5	/	/
Foreign health insurance	/	/	/	/
Other entitlement to healthcare	3	2.6	/	/
No health insurance	/	/	/	/
Highest parental education—CASMIN classification				
Low education	6	5.2	/	/
Intermediate education	54	47.0	/	/
High education	54	47.0	/	/
Other	1	0.9	/	/

*Secondary education in the German school system is divided into three different types of school. They offer different academic and vocational opportunities after graduation.
CASMIN, Comparative Analysis of Social Mobility in Industrial Nations; Md, median.

to the definition of the WHO include fatigue, altered smell or anosmia and anxiety. Additionally, PCC is associated with a wide range of symptoms, such as cognitive difficulties, dizziness and light sensitivity.[1] PCC can also present with post-exertional malaise, which is, together with fatigue, the cardinal symptom of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).[5] Patients who develop ME/CFS after a SARS-CoV-2 infection suffer from particularly severe and prolonged consequences, including long-term school absence.[5–7] Evidence on the prevalence of PCC in children and adolescents is low. Studies with uninfected controls estimated highly heterogeneous prevalences, ranging between 0.8%–13.3%.[8–11]

Healthcare for young PCC patients is complex, considering the variety of symptoms, psychosocial needs and the elaborate differential diagnostic process, given the lack of a biomarker for PCC.[12 13] Managing school attendance and addressing the potential social, physical, emotional, cognitive and educational impact of PCC on the individual development represents a particular challenge in paediatric care.[14] Therefore, specialised, tailored and comprehensive care for patients with PCC is needed to improve early diagnosis and therapy,[15–18] but is currently missing. Until now, PCC is not sufficiently known among paediatricians, which increases the risk for delayed diagnosis.[19] Finally, there is a lack of guidance on how PCC should be managed in clinical practice,[20] possibly compromising quality of healthcare.

A few qualitative studies have described challenges of children, adolescents and their parents when navigating the healthcare system in search for a diagnosis and care for PCC.[3 21 22] Torres *et al* reported increased utilisation of healthcare services as well as delayed diagnosis and treatment due to disbelief of healthcare professionals towards those affected and their relatives.[3] These findings suggest that the early phase of seeking care may be particularly challenging for young patients with PCC. In addition, perceived uncertainty before a confirmed diagnosis, experienced stigmatisation and the high demand on individual resources can contribute to negative healthcare experiences during this period. Diagnostic delays and their possible consequences, such as delayed or inappropriate care, underscore the importance of investigating the pre-diagnostic period and the access to specialised care. Despite these concerns, to the best of our knowledge, there is no quantitative evidence on the healthcare

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Table 2 Visits and telemedical contacts to physicians prior to presentation at the SOC due to PCC-associated symptoms

	Contact		No. of visits (contact in person)		No. of telemedical contacts	
N=117	n	%	n	Md (Q1–Q3)	n	Md (Q1–Q3)
Paediatrician	85	72.6	83	3.0 (2.0–5.0)	15	2.5 (1.0–10.0)
General practitioner	54	46.2	50	3.8 (2.0–10.0)	9	2 (1.5–10.0)
Internist	6	5.1	6	1.0 (1.0–2.0)	/	/
(Paediatric) cardiologist	27	23.1	27	1 (2.0–2.0)	1	3 (/)
(Paediatric) pneumologist	23	19.7	23	1 (1.0–2.0)	/	/
Otorhinolaryngologist	17	14.5	17	1 (1.0–2.0)	/	/
(Paediatric) neurologist	13	11.1	13	1 (1.0–2.0)	1	3 (/)
(Paediatric) psychiatrist	11	9.4	11	2 (1.0–4.0)	/	/
Dermatologist	5	4.3	5	1.0 (1.0–2.5)	/	/
Gastroenterologist	4	3.4	4	1 (1.0–20)	/	/
Other physicians*	45	38.5				
Specialists total	116	99.1	116	6.3 (3.5–10.3)	25	3.0 (1.5–10.3)
None	1	0.9%				

*Further open-text responses on physician contacts included physicians and diverse therapists: allergist, (n=1) ophthalmologist (n=7), ambulance (n=20), emergency service/on-call service (n=14), homeopath (n=1), immunologist (n=1), orthopedist (n=6), psychologist (n=7), radiologist (n=8), dentist/orthodontist (n=2), gynaecologist (n=1), study participation (n=1). Md, median; PCC, post-COVID-19 condition; SOC, specialised outpatient clinic.

Md, median; PCC, post-COVID-19 condition; SOC, specialised outpatient clinic.

utilisation due to symptoms of PCC in the period before young patients present for specialised care so far. This gap limits our understanding of how young patients navigate through the healthcare system and where barriers may arise on the way to a specialised outpatient clinic (SOC), particularly prior to a confirmed diagnosis.

This study therefore aims to describe the utilisation of healthcare services of children and adolescents because of post-COVID-19 associated symptoms from the time of their initial SARS-CoV-2 infection until their first presentation at SOCs for PCC.

MATERIALS AND METHODS

This study was part of the Post-COVID Kids Bavaria network, established in Bavaria, Germany, as a model project for comprehensive paediatric PCC care in 2021. It consisted of physicians in outpatient care, 16 SOCs located in major paediatric hospitals as well as rehabilitation and acute care clinics. The data for this study was derived from a prospective longitudinal study evaluating the healthcare services provided within the network. Detailed information is reported elsewhere.[21 23] Data are reported following the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) checklist for cross-sectional studies.[24]

Ethics and consent

Written informed consent was obtained from all parents/legal guardians (hereinafter referred to as 'parents') and, from age 12, additionally from patients. Patients and parents were informed in written and verbal form of the study details, could ask questions and were assured of withdrawal anytime without consequences. The study was conducted in concordance with the Declaration of Helsinki, as amended in 2013.

Study design and population

For study inclusion, patients had to show clinically evident symptoms or abnormalities indicative of PCC and have a positive test for SARS-CoV-2 (chain reaction test, antigen test or SARS-CoV-2 antibodies) or a confirmed SARS-CoV-2 infection in the family environment. The study was designed as a cohort study with four measurement points (baseline at inclusion, follow-up at 4 weeks, 3 and 6 months). This analysis used data from baseline and 4 weeks assessments.

Data collection and data management

Socio-demographic characteristics were assessed at baseline via paper-based self-report questionnaires filled out by the parents. The characteristics of healthcare utilisation before presentation at the SOC were assessed after 4 weeks via standardised telephone interviews to ensure completeness of data. The telephone interview was piloted beforehand with three affected families from an SOC. The data was manually entered and managed with the electronic database Qnome (qnome.eu) using patient identifiers (IDs). Additionally, medical characteristics relating to COVID-19 were assessed via routine data from the hospital information system and entered into Qnome.

Data assessment

Socio-demographic characteristics: Patient data were collected on sex, age, current education, health insurance,

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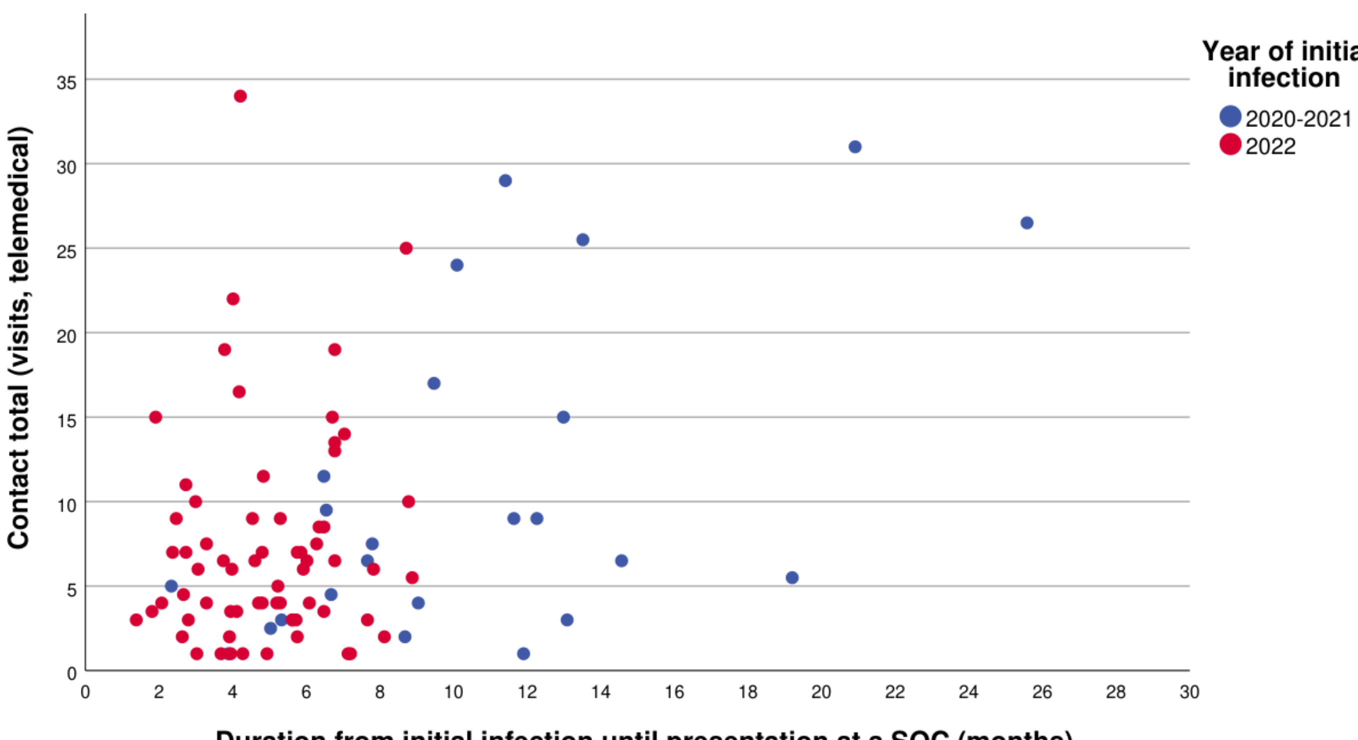

Figure 1 Contacts to physicians by duration from initial infection to presentation at the SOCs due to PCC associated symptoms for patients with initial infection in 2020-2021 and 2022 (N=91). PCC, post-COVID-19 condition; SOC, specialised outpatient clinic.

migration background (parental country of birth) and parental data on level of school and vocational education. Parental education was classified using the Comparative Analysis of Social Mobility in Industrial Nations classification.[25]

Healthcare utilisation related to PCC associated symptoms: The telephone interview contained questions on the following domains:

1. Contacts to physicians: number of visits/telemedical contacts; specialisation of physicians with 10 selection options and an open-text field: paediatrician, general practitioner, internist, (paediatric) cardiologist, (paediatric) pneumologist, otorhinolaryngologist, (paediatric) neurologist, (paediatric) psychiatrist, dermatologist and gastroenterologist.
2. Inpatient admissions: number and length of stay in days.
3. Utilisation of non-pharmacological measures based on prescription/recommendation/self-initiation with 10 therapeutic measures and an open-text-field: sport and exercise, physiotherapy/manual therapy/medical gymnastics/physical therapy (hereinafter referred to as 'physiotherapy'), respiratory therapy, occupational therapy, logopaedia, psychotherapy, therapy by a remedial paedagogue and services from *Heilpraktiker* ("healing practitioner", eg. providing homeopathy), osteopaths and chiropractors.
4. Name of prescribed medication and use of medication or supplements without recommendation as open-text responses.

The distinction between recommended and prescribed therapies was made because recommendations on health behaviour (sport and exercise) cannot be prescribed. Parents were asked how they knew about the SOC.

Medical characteristics: The date of the initial infection with SARS-CoV-2 was recorded via the hospital information system at baseline. The duration between the initial infection and the date of presentation at the SOC was calculated. Initial infection was defined as the infection from which patients experienced persistent symptoms. Information on confirmation of a PCC diagnosis ('Post COVID-19 condition, unspecified'; ICD-10-GM code U09.9, International Statistical Classification of Diseases and Related Health Problems, 10th Revision, German Modification) or a lacking PCC diagnosis was obtained via hospital information system.

Statistics

All data are presented by descriptive statistics. Variables related to healthcare utilisation are described using the median and IQR (Q1–Q3). For descriptive analysis, we used IBM SPSS Statistics V.28.0.0.0. Missing data were excluded from analysis; missing data were not imputed.

Patient and public involvement

Patients were not involved in the research process.

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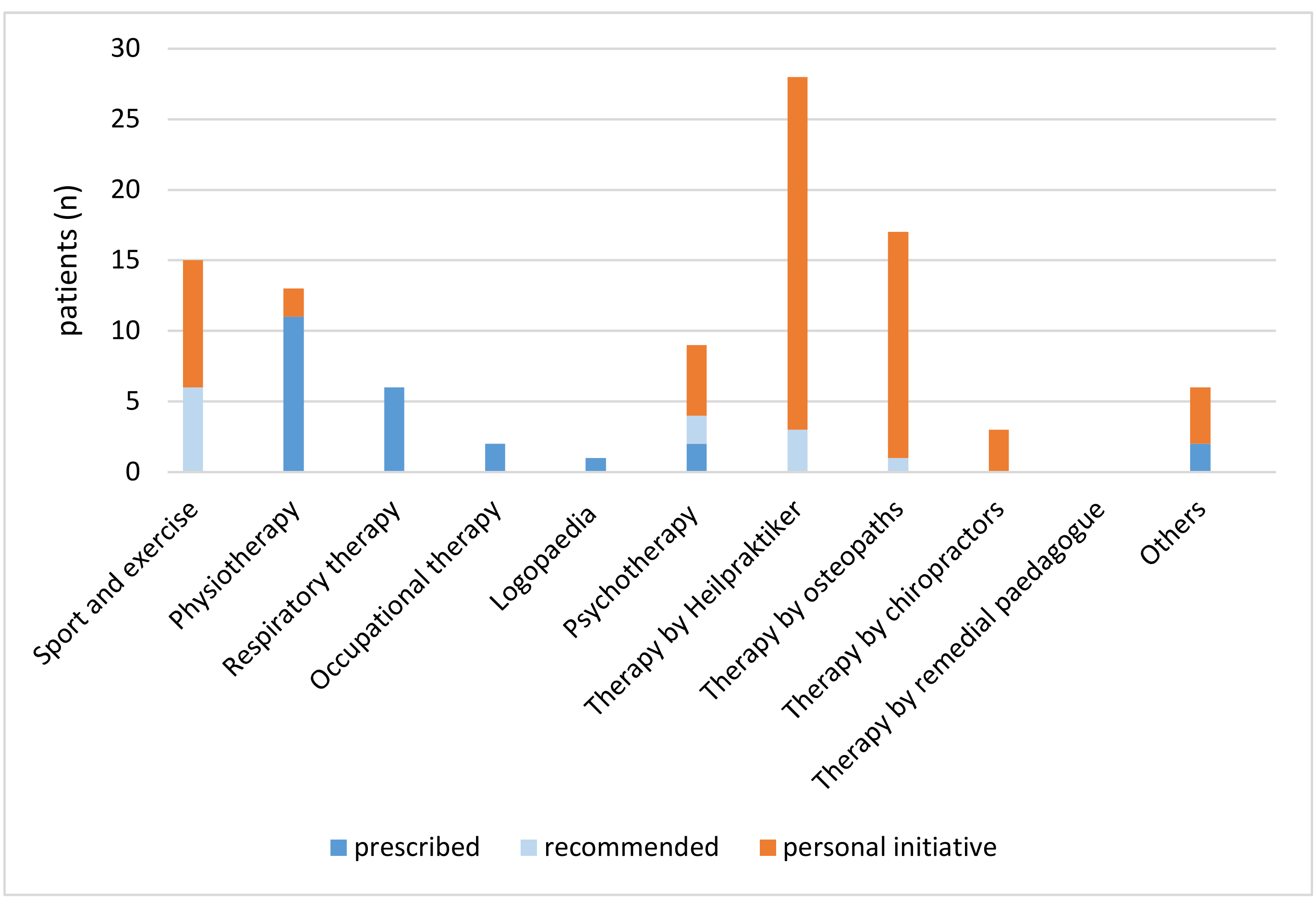

Figure 2 Non-pharmacological measures used on recommendation/prescription or personal initiative due to PCC associated symptoms. PCC, post-COVID-19 condition.

RESULTS

Sample characteristics

Table 1 shows socio-demographic characteristics of patients and their parents. N=117 children and adolescents aged between 5 and 17 years with symptoms suggesting PCC participated in the study (60% female, n=66). The majority were aged between 12–17 years (n=85). The diagnosis of PCC was confirmed for 91 participants after the diagnostic process in one of the SOCs. For 26 participants, the PCC diagnosis was not confirmed because either not all required findings from examinations were available or not all diagnostic criteria were met.

Duration from initial infection to presentation at the SOCs

76.1% (n=89) reported persistent symptoms since their first SARS-CoV-2 infection and 3.4% (n=4) reported their second infection as initial for their PCC symptoms. The date of the initial SARS-CoV-2 infection was available for n=91 participants. Those participants were presented at the SOCs in 2022 and reported being infected with SARS-CoV-2 for the first time between April 2020 and July 2022. The median duration from initial infection to presentation at one of the SOCs was 5.7 months (Q1–Q3: 4.0–7.7, n=91, maximum=26 months). The median duration for those with initial infection in 2021 was 8.9 months (Q1–Q3: 6.5–13.5, n=20), for those with initial infection in 2022 4.8 months (Q1–Q3: 3.7–6.3, n=67).

Information sources on the SOCs

Most of the participants and their parents were informed about SOCs by their paediatrician (42.7%, n=50) or another person in the healthcare setting, including the general practitioner (GP) (6.8%, n=8) or other physicians from inpatient and outpatient care (22.2%, n=26). Outside the healthcare system, the internet was the most frequently used information source to find SOCs (25.6%, n=30), followed by friends or colleagues (6.8%, n=8) and the media in general (6.0%, n=7).

Healthcare utilisation before presentation at the SOCs related to PCC associated symptoms

Healthcare utilisation is reported for all participants with post-COVID-19 associated symptoms who presented to any of the SOCs (N=117).

Visits to physicians, utilisation of telemedicine and inpatient stays

All participants except one (n=116) reported at least one contact (visits in person or telemedical) to a physician (outpatient) regarding their PCC symptoms, with a median of 6.5 contacts (Q1–Q3: 3.8–11.5,

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Table 3 Use of medications and supplements before presentation at a specialised outpatient clinic due to post-COVID-19 symptoms (N=117)

	Participants	
N=117	n	%
Vitamins and minerals	65	55.6
Analgesics	42	35.9
Anti-asthmatics	29	24.8
Homeopathic substances	18	15.4
Phytopharmaceuticals	13	11.1
Probiotics	7	6.0
Antidepressants	7	6.0
Antibiotics	6	5.1
Antiemetics	5	4.3
Neurohormones	5	4.3
Proton pump inhibitors	5	4.3
Laxative	4	3.4
Further nutraceuticals	4	3.4
Antihistamines	3	2.6
Other gastrointestinal therapeutics	3	2.6
Reflux suppressant/antacid	2	1.7
Expectorants	3	2.6
Virostatics	1	0.9
Ear anti-inflammatories	1	0.9
Beta-2 sympathomimetics (salbutamol)	1	0.9
Sympathomimetics (etilefrine)	1	0.9
Saline solution	1	0.9
Unknown	2	1.7

maximum=148). In the median, the participants reported contacts to physicians of two different specialisations (Q1–Q3: 1.0–4.0). Contacts to physicians of four or more different specialisations were reported by 26.5% patients (n=31). The contacts included primarily visits (contacts in person, 91.1%, n=116) and far less frequently telemedical contacts (21.4%, n=25).

Table 2 shows the frequency of contacts to different physician specialists. The most frequently visited physician was the paediatrician, followed by the GP. The vast majority of participants (96.6%, n=113) had consulted either a paediatrician or a GP (74.4%, n=87), or both (22.2%, n=26). Telemedical contact to physicians was reported by n=25 participants, in median three times (Q1–Q3: 1.5–10.3). Those telemedical contacts included paediatricians, GPs, neurologists and cardiologists. Detailed information on the contact with physicians is presented in table 2.

15 (12.8%) participants had an inpatient stay due to PCC associated symptoms, 5 of whom (33.3%) reported 2 stays. The median duration of hospitalisations was 3 days (Q1–Q3: 2.0–6.0).

Figure 1 shows the number of outpatient physician contacts in relation to the duration between initial infection until presentation at the SOCs. Participants with durations over 6 months had more physician contacts in median (n=40, Md=8.0, Q1–Q3: 4.3–14.5) than those with a duration of 6 months or less (n=50, Md=4.3, Q1–Q3: 3.0–7.0). Particularly participants initially infected in 2020–2021 who experienced longer durations until presentation at an SOC often reported many physician contacts.

Non-pharmacological measures

Almost half of the participants (47.9%, n=56) used any non-pharmacological measure before SOC presentation, either on recommendation/prescription or self-initiation. Of these measures, 36.0% were used on recommendation/prescription, 64.0% self-initiated. Almost one-third of participants (29.1%, n=34) used one measure, and 18.8% (n=22) used multiple different measures (maximum=7). Figure 2 displays which non-pharmacological measures were used. Among these measures, those provided by *Heilpraktiker* and osteopaths were most commonly used (30.8%, n=36). A measure from the group comprising physiotherapy, manual therapy, gymnastic therapy and physical therapy (in figure 2 referred to as 'physiotherapy'), was used by 11.1%, mostly on recommendation. Sport and exercise were done by 12.8%, partly on recommendation, partly self-initiated (figure 2).

Prescribed medication

65% of participants (n=76) reported receiving prescriptions, most for one (n=31) or two (n=23) medications (46.2%). A smaller group reported three to four (11.9%, n=14) or five to six prescriptions (6.8%, n=8; Md=1.0, Q1–Q3: 0–2).

Non-prescribed medication or supplements

The use of non-prescribed medications or supplements was reported by 60.7% (n=71) of participants with a median of one (Q1–Q3: 0–2). Of the participants, 37.6% used one (n=27) or two (n=17) non-prescription medications or supplements, 8.5% (n=10) used five to six.

Exclusive use of prescribed medications was reported by 24.8% (n=29) of participants, 40.2% (n=47) used both prescribed medications and non-prescribed medications or supplements, while 14.5% (n=17) reported that they had not used any.

Vitamins/minerals, analgesics and anti-asthmatics were most frequently used. Table 3 shows which medications and supplements were used in detail.

DISCUSSION

This study provides insights into healthcare utilisation among children and adolescents with post-COVID-19 symptoms, from their initial SARS-CoV-2 infection to their presentation at one of 16 SOCs within the Bavarian

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Post-COVID Kids Bavaria network (PoCo) network. Most patients presented within the first year after infection. Time to SOC presentation decreased for those first infected in 2022. Healthcare utilisation was mostly high with considerable variability among participants. Paediatricians and GPs were central to care, which underscores their importance as gatekeepers to therapy and specialised care. However, therapeutic measures were often used self-initiated. Non-pharmacological measures were primarily self-initiated and involved a high proportion of services by *Heilpraktiker* and osteopaths. Besides, sport and exercise as well as physiotherapy were most commonly used, with physiotherapy being prescribed most commonly. Utilisation of psychological care was low. More than half of the patients reported prescription of medication and almost an equal proportion of patients used non-prescribed medications or supplements. Only a few patients relied only on prescribed medications, and no use at all was rare.

According to the nationally representative German KiGGS study (2014–2017), representing children and adolescents from the general population, children and adolescents (0–17 years) had on average 3.7 annual contacts with paediatricians and 2.9 with GPs. The mean annual number of contacts was the lowest among adolescents aged between 11–13 years and highest among children aged between 0–2 years.[26] In comparison, healthcare utilisation in our predominantly 12–17 years old sample was relatively high. Our findings showing high healthcare utilisation among children and adolescents with post-COVID-19 symptoms align with research in adults.[27–30] The variations observed in our study can be attributed to several influencing factors. Tartof *et al* showed that different post-COVID-19 symptoms are associated with different healthcare utilisation time frames,[31] which may partly explain the variability in our study. Additionally, ongoing and repeated use of healthcare services may reflect unclear care pathways. This is consistent with a qualitative study including participants from the PoCo network, who described diverse pathways to specialised care.[21] Another qualitative study among young patients with PCC described their difficulties in conveying the severity of symptoms which led to questioning of their candidacy in healthcare interactions.[22] Challenges like this can be exacerbated in children and adolescents as they are sometimes perceived as 'unreliable narrators'.[22] Otherwise, according to a study by DeVoss *et al*, healthcare can shift from acute to the outpatient setting following a PCC diagnosis, which may indicate improved care management to some extent compared with the pre-diagnosis period.[32] The use of services by *Heilpraktiker* and osteopaths was high in this study, which reflects general high use of complementary medicine among children and adolescents, or even exceeds it.[33] This aligns with research on adults with PCC regarding the use of complementary medicine.[34] Because evidence for defined services by *Heilpraktiker* and osteopaths in PCC is lacking,[35] its widespread use may expose children and adolescents to risks and burden families. Only a few participants used prescribed non-pharmacological measures, suggesting a lack of available therapists or uncertainty among physicians regarding PCC diagnosis and its management options, including off-label drug therapy. Combined with frequent self-initiated measures, this indicates unmet healthcare needs among children and adolescents with PCC.

Our study provided a comprehensive assessment of the healthcare utilisation among the hard-to-reach and vulnerable group of children and adolescents with PCC symptoms. Making the diagnosis of PCC is challenging and can be associated with uncertainty; this represents both a limitation of our study and a central rationale for conducting it, as it directly contributes to barriers in accessing adequate healthcare. Further, our study was only descriptive. The scope was limited to providing a first insight into healthcare utilisation among patients with post-COVID-19 associated symptoms before SOC presentation. Future studies could analyse differences in the utilisation of healthcare services between subgroups based on the severity of PCC or defined symptom clusters (eg, patients with/without ME/CFS). Our study is limited regarding the generalisability by a small sample size and the recruitment strategy. Data were only collected on children and adolescents in Bavaria who were able to access an SOC of the PoCo network. Therefore, healthcare utilisation could be different for patients who were unable to present at an SOC for various reasons. Additionally, the sample primarily consists of well-educated families without a migration background, also limiting generalisability. Access to specialised care may vary by region due to differences in availability of specialised clinics. We were unable to compare our findings to the source population of children experiencing symptoms of PCC because until now no comparable data is available. There is also a risk of recall bias due to the retrospective design and the use of information provided by the parents.

High diversity in healthcare utilisation and the use of many different specialists may reflect unclear care pathways. This indicates a need for improved coordination regarding the healthcare of young patients with PCC. Paediatricians and GPs in primary care function as potential gatekeepers. To promote early diagnosis and appropriate care, it is essential that paediatricians and GPs have adequate knowledge and are part of networks with specialised healthcare institutions. Those aspects should be considered in political decision-making. Future research should explore healthcare utilisation in a larger, more diverse population across different regions. It should also include the recruitment of patients from primary care settings to include patients who may not attend an SOC at all.

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Contributors SB, CA, MK and UB designed the study. CR, MP, MA, SS, CW and SG contributed to data collection. MK and TB conducted the data analysis. MK wrote the original manuscript draft. SB and CA provided guidance on data interpretation and manuscript writing. All authors reviewed and approved the manuscript. SB acted as guarantor.

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