


ORIGINAL ARTICLE

Nutrition

Impact of COVID-19 on paediatric chronic intestinal failure: A tertiary care children's hospital experience

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Abstract

Objectives: Paediatric patients with intestinal failure (IF) are at risk for both gastrointestinal (GI) and systemic complications, thus depending on a functioning network of multidisciplinary care. Data on the clinical impact of coronavirus disease 2019 (COVID-19) or the pandemic-related restrictions are limited. We aimed to analyse the clinical course of COVID-19 in children with IF, and to evaluate the perceived impact of the COVID-19 pandemic on IF patients and their caregivers by analysing quality of life (QoL), health-related QoL (HRQoL) and health care.

Methods: Children with IF presenting at our intestinal rehabilitation centre were enrolled and interviewed about test-proven COVID-19 infection. A standardised questionnaire was offered to all caregivers of IF patients and to two control groups (children with inflammatory bowel disease and gastrointestinal healthy children).

Results: Between December 2020 and November 2022, 25 out of 127 patients with IF contracted COVID-19. Forty-eight per cent had GI symptoms, 32% required additional intravenous fluids and 20% were hospitalized. Only 25% of vaccinated children showed signs of GI dysfunction, compared to 52% of unvaccinated children. Analysis of 93 questionnaires showed a negative impact on QoL and HRQoL (>66.7% and >27.8%, respectively). IF patients frequently experienced restrictions in health care, including appointments, services and supply of parenteral nutrition or medications. Caregiver burden increased significantly more often in caregivers of children with IF ($p = 0.007$).

Conclusions: Paediatric patients with IF contracting COVID-19 have an increased risk for GI dysfunction which may be alleviated by vaccination. Children and their caregivers were highly burdened by pandemic-related restrictions and reductions in health care provision.

Abbreviations: COVID-19, Coronavirus disease 2019; GI, gastrointestinal; HC, healthy children; HPN, home parenteral nutrition; HRQoL, health-related quality of life; IBD, inflammatory bowel disease; IF, intestinal failure; QoL, quality of life; SARS-CoV-2, severe acute respiratory syndrome coronavirus 2.

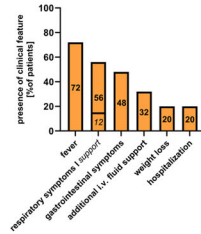
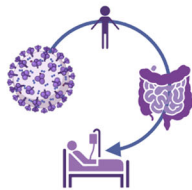
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Patients with paediatric chronic intestinal failure are particularly burdened by COVID-19

1. Clinical course of COVID-19

Increased risk for gastrointestinal dysfunction



2. (HR-)QoL & health care utilization during the pandemic

Burdened (health related, HR) quality of life (QoL)



Reduced accessibility and utilization of health care



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KEYWORDS

healthcare utilization, quality of life, SARS-CoV-2, short bowel syndrome

1 | INTRODUCTION

Paediatric intestinal failure (IF) is a rare disorder characterized by a reduction of functional gut mass, which results in a complex clinical condition that frequently requires parenteral nutrition to support survival.^{1,2} Children with IF are at risk for metabolic, infectious and other systemic complications and therefore are dependent on a functioning multidisciplinary model of care in intestinal rehabilitation programs.³ In addition to complex medical needs, children with IF require high-level individual care by their caregivers including administration of home parenteral nutrition (HPN) and medication. The high demands in medical care impact both QoL and HRQoL in patients with IF and their caregivers.^{4,5}

The coronavirus disease 2019 (COVID-19) pandemic caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and consecutive restrictions in everyday life and health care were a particular challenge for children with chronic diseases.⁶ Surveys among healthcare providers have shown that providing care for adult and paediatric patients with IF was compromised during the pandemic.^{7,8} However, the pandemics impact on patients (HR)QoL and healthcare provision in children with IF are unknown. In addition, as gastrointestinal (GI) dysfunction is a well-described clinical manifestation of COVID-19, children with IF may be vulnerable and at risk for a severe disease course. Data on the clinical course of SARS-CoV-2-infected children with IF is lacking.

Therefore, we aim to analyse the clinical course of COVID-19 in paediatric patients with IF and to evaluate the perceived impact of the COVID-19 pandemic on such patients regarding (HR)QoL and health care.

What is Known

- Paediatric patients with chronic intestinal failure (IF) depend on a network of medical specialists and healthcare structures and are at risk for both gastrointestinal and systemic complications.
- In paediatric coronavirus disease 2019 (COVID-19), gastrointestinal dysfunction is a well-described clinical manifestation.
- COVID-19 pandemic-related restrictions are a particular challenge for children with chronic diseases including deterioration of quality of life and compromised utilization of healthcare.

What is New

- Paediatric patients with IF contracting COVID-19 have an increased risk for gastrointestinal dysfunction which may be alleviated by vaccination.
- Children with IF and their caregivers are burdened by pandemic-related restrictions in quality of life and healthcare provision.

2 | METHODS

The present study reports data from the University Children's Hospital Tübingen, a large tertiary care centre with a paediatric IF rehabilitation program with

a case load of more than 400 visits for a mean of 133 patients per year.

The retrospectively analysed data comprised two subprojects (Figure 1): (1) clinical features of COVID-19 in paediatric patients with chronic IF and (2) perceived impact of the COVID-19 pandemic on (i) (HR)QoL, and (ii) health care of children with chronic IF and their caregivers.

Both study projects were conducted according to the ethical principles of the Declaration of Helsinki and approved by the local institutional ethics board (195/2020/BO2 and 390/2021/BO2).

2.1 | Clinical features of COVID-19 in paediatric IF

Between December 2020 and November 2022 parents or other caregivers of children with chronic IF presenting at our paediatric intestinal rehabilitation centre were interviewed about COVID-19 using a standardised data sheet (Supporting Information S1: File S1). Only children with a laboratory proven COVID-19 infection were included. The survey covered patients' characteristics including vaccination history, comorbidities, symptoms and management.

2.2 | Impact of the COVID-19 pandemic on (HR)QoL in paediatric IF

The design of a disease-specific pen-and-paper questionnaire to assess the caregivers perceived impact of the COVID-19 pandemic on their children's (HR)QoL and medical care was supported by the Institute of

Occupational and Social Medicine and Health Services Research and the local Centre for Paediatric Clinical Studies. The questionnaire with 20 items was validated concerning its content, internal consistency and construct validity. Pseudonymised participation was offered between May 2021 and February 2022 through convenience sampling to caregivers of patients with paediatric IF. For comparison, caregivers of paediatric patients with inflammatory bowel disease (IBD) or otherwise gastrointestinal healthy children (HC) were also offered participation in the study. Children with IBD presented at our outpatient clinic. GI-healthy children underwent elective surgery or diagnostic tests at our hospital and were managed as outpatients.

The first part of the questionnaire contained questions about the participants sociodemographic parameters and their child's medical characteristics including underlying disease and medical needs. In the second part, caregivers were asked about the perceived impact of the COVID-19 pandemic and the associated restrictions on their children's physical and mental health and (health-related) quality of life, as well as on the pandemic's impact on their own life. Given examples for impact on mental health included sadness, depression, anger, frustration, despair and fears. In the third part, questions were asked about impact on healthcare utilization. Response options contained an indifferent option (Supporting Information S1: File S2).

2.3 | Statistical analyses

Microsoft Excel (Microsoft Corporation), GraphPad Prism (GraphPad Prism Version 9.4.1, GraphPad Software) and SPSS (IBM® SPSS® Statistics 28, IBM) were used for data collection and analysis. Patients' and caregivers' variables were evaluated by descriptive analysis. Differences between groups were evaluated using a χ^2 test or nonparametric Mann–Whitney *U*-test for independent samples. A *p*-value < 0.05 was defined as statistically significant.

3 | RESULTS

One hundred and twenty-seven families, originating from Germany, Austria and Switzerland, presented at our intestinal rehabilitation centre between December 2020 and November 2022.

3.1 | Clinical course of COVID-19

Twenty-five out of 127 children with chronic IF (19.7%) were reported with confirmed COVID-19 (Table 1).

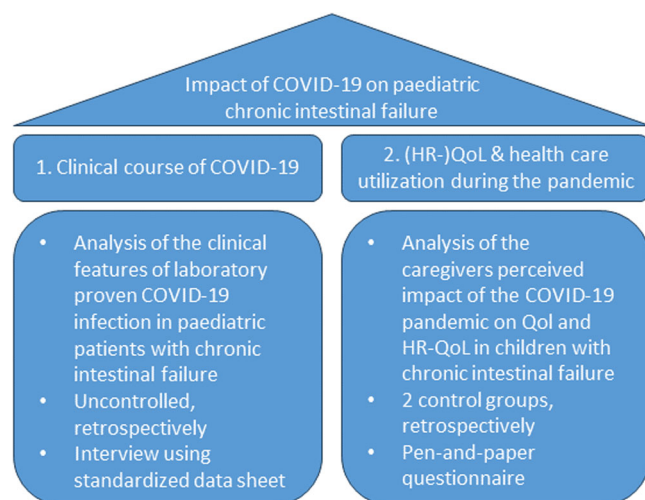


FIGURE 1 Study design on the impact of COVID-19 on paediatric chronic intestinal failure. The study comprises two research projects, as depicted. HR-QoL, health-related quality of life; QoL, quality of life.

TABLE 1 Patients' characteristics at onset of COVID-19 in paediatric intestinal failure (IF).

#	Age (years)	Sex	IF diagnosis	Bowel stoma	Comorbidities	SARS-CoV-2 vaccination
1	5	F	SBS	-	-	-
2	1	F	SBS	-	IFALD	-
3	12	M	SBS	-	IFALD	Yes
4	8	F	SBS	-	-	-
5	3	M	SBS	Yes	Haddad syndrome	-
6	6	M	SBS	-	-	-
7	1	M	SBS	-	-	-
8	3	M	SBS	-	-	-
9	13	M	ME (MVID)	Yes	-	-
10	18	F	SBS	-	-	Yes
11	3	M	SBS	-	-	-
12	1	F	SBS	-	Cystic fibrosis	-
13	9	M	PIPO (MMIHS)	-	-	-
14	6	M	SBS	-	IFALD	-
15	3	F	PIPO (aganglionosis)	Yes	-	-
16	1	F	SBS	-	IFALD	-
17	3	M	SBS	-	-	-
18	12	F	PIPO (hypoganglionosis)	-	Epilepsy	Yes
19	2	F	SBS	-	-	-
20	7	M	SBS	-	IFALD	Yes
21	10	F	PIPO (secondary)	Yes	-	-
22	12	M	SBS	-	Status post liver transplantation	-
23	2	F	PIPO (MMIHS)	-	-	-
24	8	F	PIPO (aganglionosis)	-	-	-
25	13	F	ME (MVID)	-	-	-

Abbreviations: F, female; IFALD, intestinal failure associated liver disease; M, male; ME, mucosal enteropathy; MMIHS, megacystis microcolon intestinal hypoperistalsis syndrome; MVID, microvillus inclusion disease; PIPO, paediatric intestinal pseudo obstruction; SBS, short bowel syndrome.

Patients mean age was 6.8 years while 48% were female. The underlying diseases leading to IF were in 68% short bowel syndrome, in 24% motility disorders and in 8% mucosal enteropathy. All patients were dependent on HPN. Four patients were stated being fully vaccinated against SARS-CoV-2, and one patient received a single vaccination.

Of the 25 patients with paediatric IF infected with SARS-CoV-2, the most frequent symptom was fever (72% of patients), followed by respiratory symptoms (56%) (Figure 2). Twelve patients (48%) presented with gastrointestinal dysfunction: of those patients, 66.7% showed diarrhoea or increased stoma losses,

33.3% reported nausea and vomiting and in 16.7% abdominal pain. Eight patients (32%) needed additional intravenous fluid support to cover for increased demand and five children (20%) lost weight. While five patients (20%) had to be hospitalized due to severity of symptoms, three of them (12%) required respiratory support (intubation and mechanical ventilation [one patient], noninvasive ventilation [one patient], oxygen supply [one patient]). One patient had an asymptomatic infection. No fatal course of COVID-19 was observed.

Of the four SARS-CoV-2 vaccinated children only one reported of a gastrointestinal symptom (nausea).

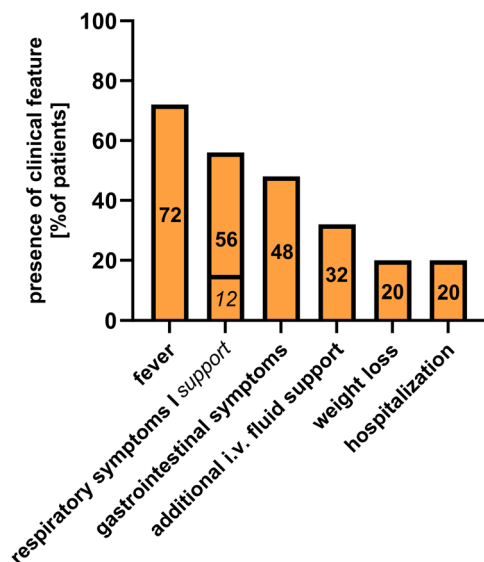


FIGURE 2 Clinical features of COVID-19 in 25 children with chronic intestinal failure. i.v., intravenous.

3.2 | Perceived impact of the COVID-19 pandemic on (HR)QoL and medical care

The questionnaire on (HR)QoL and healthcare was offered to caregivers presenting with children with IF during May 2021 and February 2022. Forty-four out of 54 families with a child with chronic IF participated (response rate 81.5%). In addition, caregivers' questionnaires from 18 (out of 19) children with IBD and 31 (out of 32) HC were eligible for analysis (Table 2). Two questionnaires were filled out incorrectly, resulting in exclusion from analysis. Therefore, 93 questionnaires were evaluated. A higher proportion of female caregivers (72.0%) than male caregivers participated in the study (Table 2). While more HC were male (83.9%, $p = 0.022$), gender differed not significantly between the two groups with chronically ill children ($p = 0.883$) (Table 2). Patients with IBD were significantly older than patients with chronic IF ($p = 0.044$) while there was no difference to HC ($p = 0.132$). 81.8% of patients with IF and 66.7% of patients with IBD were on oral long-term medication which is no significant difference ($p = 0.195$). Only one patient in the IBD group regularly required medical aids versus 38 children with IF ($p < 0.001$). Sixteen caregivers in the IF group (36.4%) reported to be supported by a medical care service. Five children with IF (11.4%), three patients with an IBD (16.7%) and three HC (16.1%) were diagnosed with a COVID-19 infection.

3.3 | Impact on (HR)QoL

Most participants in all three medical history groups recognized a deterioration of their child's QoL (Figure 3A): With 81.8%, 66.7% and 80.6% recognizing

such a deterioration, there was no significant difference between chronic IF, IBD and HC (IF vs. IBD $p = 0.195$, HC vs. IBD $p = 0.273$, IF vs. HC $p = 0.898$). None of the participants stated that the pandemic had a positive effect, while seven (15.9%), six (33.3%), and six (19.4%) caregivers of patients with IF, IBD or HC, respectively, reported no change on their child's QoL.

Regarding an impact on their child's physical health, caregivers of children with IF reported a perceived deterioration in 31.8% (Figure 3A). This is similar and not significantly different compared to what was reported by parents of children with IBD (33.3%) and HC (35.5%).

According to the caregiver's perspective, the COVID-19 pandemic had a negative impact on mental health of their child in 43.2%, 27.8% or 38.7% for patients with IF, IBD or otherwise gastrointestinal HC (Figure 3A). There was no significant difference between groups (IF vs. IBD $p = 0.423$, HC vs. IBD $p = 0.664$, IF vs. HC $p = 0.658$). None of the respondents in any of the groups reported an improvement in mental health.

3.4 | Health care in paediatric IF during the COVID-19 pandemic

Caregivers of patients with chronic IF and corresponding medical needs reported supply difficulties due to the COVID-19 pandemic in 9.5% for HPN, in 16.7% for long-term medication and in 52.6% for supply with medical aids. In comparison, no caregiver of children with IBD experienced difficulties with obtaining medication or medical ancillaries. However, due to low numbers in the IBD group this is not of statistical significance ($p = 0.125$ and $p = 0.299$).

In children with IF, both parenteral nutrition (three out of four cases) and medical aids (five out of 20 cases) could not be provided as usual due to the pandemic. Affected caregivers responded that this had a negative impact on their child's health.

In 11 out of 16 families with a child with IF (68.8%) who were supported by a medical care service, the caregivers noted that the service was unable to fulfil its tasks due to pandemic-related restrictions.

Postponing or cancellation of appointments due to the COVID-19 restrictions occurred significantly more often in patients with IF (38.6%) than in children with IBD (5.6%) ($p = 0.007$). In addition, three out of six planned surgeries in children with IF had to be postponed due to the pandemic restrictions.

3.5 | Impact on caregivers of children with IF

We analysed whether there is a pandemic-related impact to the caregivers that would affect care of their

TABLE 2 Caregivers' and children's characteristics analysed for (HR)QoL, health and medical care during the COVID-19 pandemic.

Participants <i>n</i> = 93	Chronic intestinal failure <i>n</i> = 44	Inflammatory bowel disease <i>n</i> = 18	GI-healthy children <i>n</i> = 31
<i>Caregivers' characteristics</i>			
Sex (F/M)	34/10 (77.3/22.7%)	13/5 (72.2/27.8%)	20/11 (64.5/35.5%)
Age (years)			
16–20	-	-	1 (3.2%)
21–30	4 (9.1%)	-	3 (9.7%)
31–40	22 (50.0%)	5 (27.8%)	15 (48.4%)
41–50	13 (29.5%)	8 (44.4%)	11 (35.5%)
51–60	4 (9.1%)	4 (22.2%)	1 (3.2%)
61–70	1 (2.3%)	1 (5.6%)	-
<i>Patients' characteristics</i>			
Sex (F/M)	18/26 (40.9/59.1%)	7/11 (38.9/61.1)	5/26 (16.1/83.9%)
Age (years; mean [median])	7.4 (6.0)	10.9 (12.0)	6.8 (6.5)
Underlying disease/reason for presentation (<i>n</i> , %)	SBS = 29 (65.9%) PIPO = 11 (25.0%) ME = 4 (9.1%)	CD = 13 (72.2%) UC = 3 (16.7%) IBDU = 2 (11.1%)	Elective surgery = 29 (90.6%) Diagnostics = 2 (6.3%)
COVID-19 infection (<i>n</i> , %)	5 (11.4%)	3 (16.7%)	5 (16.1%)
Home parenteral nutrition	42 (95.5%)	-	-
Long-term medication (<i>n</i> , %)	36 (81.8%)	12 (66.7%)	0 (0%)
Medical aids (<i>n</i> , %)	38 (86.4%)	1 (94.4%)	0 (0%)
Support by medical care service (<i>n</i> , %)	16 (36.4%)	0 (0%)	-

Note: Group differences were analysed by χ^2 test or nonparametric Mann–Whitney *U*-test for independent samples.

Abbreviations: -, not applicable; CD, Crohn's disease; F, female; GI, gastrointestinal; HR, health-related; IBDU, inflammatory bowel disease unclassified; M, male; ME, mucosal enteropathy; PIPO, paediatric intestinal pseudo obstruction; QoL, quality of life; SBS, short bowel syndrome; UC, ulcerative colitis.

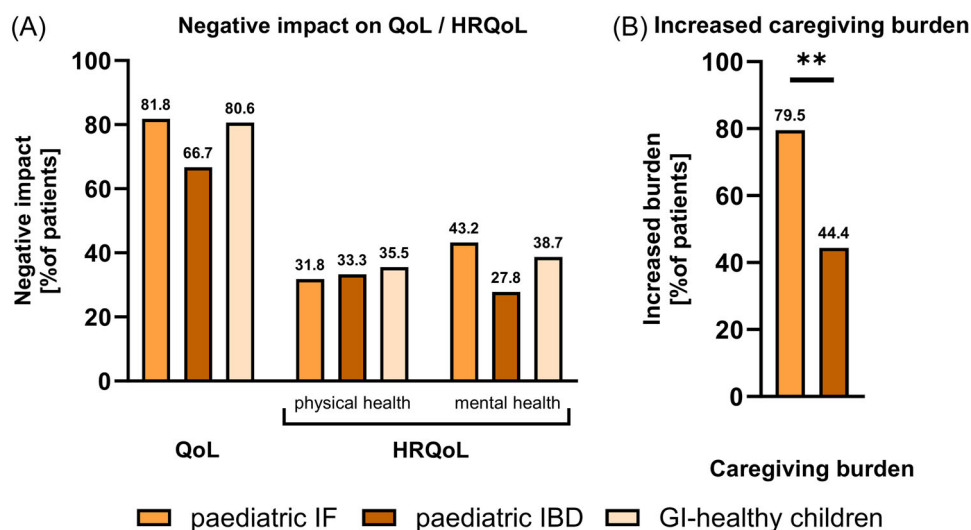


FIGURE 3 (A) COVID-19 pandemic-related impact on (HR)QoL and healthcare in paediatric intestinal failure compared to paediatric IBD and GI healthy children. Caregivers' assessment is shown by number of mentions in % analyzing QoL, HR-QoL (impact on physical and mental health). (B) COVID-19 pandemic-related impact on parenteral burden of care for paediatric IF and IBD. Group differences were analyzed using a χ^2 test (***p* < 0.007). GI, gastrointestinal; HR-QoL, health-related quality of life; IBD, inflammatory bowel disease; IF, intestinal failure; QoL, quality of life.

children. Thirty-five out of 44 caregivers (79.5%) of patients with IF report an increase in burden of care due to the COVID-19 pandemic (Figure 3B). This perceived impact is significantly more prevalent than in the IBD group (44.4%) ($p = 0.007$).

Of note, 31 of the 35 caregivers in IF (70.5%) and six of the eight caregivers in IBD (75%) with an increased burden, state that this has a negative effect on their own health ($p = 0.318$).

4 | DISCUSSION

Paediatric patients with IF depend on a functioning network of medical services and care structures which is impacted by the COVID-19 pandemic.⁸ As gastrointestinal symptoms are well described in patients with a SARS-CoV-2 infection and the virus infects human gut enterocytes,⁹ children with IF may be vulnerable and at risk for a severe disease course. Furthermore, pandemic-related restrictions in everyday life and healthcare could increase the burden of psychosocial and health impairments.

This is the first study analysing the clinical course of children with IF contracting COVID-19, and the first study evaluating the impact of the pandemic on QoL, HRQoL and healthcare perceived by the caregivers.

With 48% a high frequency of GI symptoms in children with IF infected by SARS-CoV-2 was found in our study including diarrhoea or increased stoma losses (32%), nausea and vomiting (16%) and abdominal pain (8%). Lu et al. reported vomiting in 6.6% and diarrhoea in 8.8% of 171 COVID-19-infected children.¹⁰ A systematic literature and database search by Ashktorab et al. consisted of 6639 children with COVID-19 and found vomiting as the predominant GI symptom (13.2%), followed by abdominal pain (10.1%) and diarrhoea (11%).¹¹ Stopyra et al. reported higher rates of GI dysfunction with diarrhoea in 18%–31% in infected children.¹² However, these patients were all hospitalized and up to 34.8% of patients had a chronic disease other than IF. Looking only at the hospitalised patients in our group, 60% showed diarrhoea. Additionally, weight loss in 20%, need for extra intravenous fluids in 32% and hospitalization in 20% further indicate that children with IF may be a vulnerable group.

In adults, lack of SARS-CoV-2 vaccination was associated with a higher risk of death.¹³ None of our patients died, however, only one of the four fully SARS-CoV-2 vaccinated patients developed GI symptoms which was very mild (nausea) and none needed additional intravenous fluids. Due to small numbers, no firm conclusion can be made, but vaccination may alleviate GI dysfunction in patients with IF. A recommendation to offer vaccination should be considered.

Paediatric studies demonstrated a negative impact of the COVID-19 pandemic on QoL and HRQoL.^{14–16}

As children with IF face many challenges at baseline and are shown to have a lower HRQoL than healthy children, the pandemic may add to that burden.⁴ However, only a few studies were focusing on chronically ill children and so far, none had addressed the caregivers perceived impact in patients with IF during the pandemic.^{17–19} In our study, a high rate of caregivers stated a negative impact on their child's QoL and HRQoL without a significant difference between children with IF, IBD or otherwise HC. Our study underlines that from a caregiver's perspective, children are highly burdened by the COVID-19 pandemic.

A relevant portion of caregivers in our study reported pandemic-related difficulties on receiving medical supplies for their children. Allan et al. showed an adverse impact of the COVID-19 pandemic on adult patients with IF receiving HPN.⁷ Aside from difficulties with HPN which occurred in 9.5% in our study, there were no significant differences regarding provision problems with medication and ancillaries when comparing IBD and IF patients. Nevertheless, the pandemic-related problems in the supply of medication in 16.7% and ancillaries in 52.6% of patients with IF in our study are of concern. This is further supported by the fact that affected caregivers responded that the supply shortage had a negative impact on their child's health. More than two-thirds of IF families that were receiving support by a medical care service experienced a reduction of service due to pandemic-related restrictions. While Allan et al. also describe implications of the pandemic on service provision in adult IF patients, we could observe similar clinical relevant impacts in our cohort.⁷ Participants reported that medical appointments including surgery were postponed or cancelled due to the pandemic. With 38.6% of postponed or cancelled appointments in paediatric IF, this was significantly more frequently reported than in the IBD group. It can be speculated that the knowledge gained during the pandemic about risk groups for a severe disease course has contributed to this difference. While children with IBD appeared to be at no greater risk of contracting COVID-19 and have a predominantly benign course,^{20,21} no information about risk and disease course was available for paediatric IF patients.

Remppis et al. showed that the cancellation of medical appointments as part of prevention measures during the COVID-19 pandemic was perceived as particularly burdening by healthcare providers in a children's hospital.²² From a family and patient perspective, there is evidence that fear of contracting the Coronavirus results in children presenting late to emergency care.^{23–25} Overall, this analysis points to the need for healthcare systems to adapt and prepare for chronic ill children during pandemics. In particular, the implementation of telemedical care options could enable to provide disease-specific information,

counteract avoidance behaviour and support patient care in such a setting. A personalized telehealth model for treatment and follow-up in chronic paediatric diseases during the COVID-19 pandemic was designed by Mercuri et al.²⁶

These observations may explain the high rate of perceived increase in caregiver burden found in our study. Caregivers of patients with IF reported this significantly more frequent than in the IBD group. More than 70% of the parents who experienced an increase in care burden, also noted a negative impact on their own health. This is remarkable as it has been shown that caregivers of children with IF are already significantly burdened by the high medical needs of their children outside of a pandemic.⁵

Our analysis is limited by the small sample size, reflecting a single centre experience and therefore may not be representative. In addition, despite the fact that a test obligation was partially in place, for example, in hospitals, as only laboratory proven infections were assessed, subclinical or mild infections could have been missed. However, this limitation also applies to other published studies, so that the noticeably high rate of gastrointestinal complaints is still remarkable.

The first part of the study—analysing the clinical impact of COVID-19 infection in IF—was uncontrolled which limits the conclusion. However, it provides first data in a rare disease group and is mainly in line with the published adult and paediatric data. It has to be acknowledged that the study did not use validated questionnaires for assessing QoL and HRQoL, like the Paediatric QoL Inventory (PedsQL),²⁷ but rather single questions. Nevertheless, the consistency of findings with results from other studies suggest that the results can be applied to a larger cohort. This is further strengthened by the fact that the second part of our study was controlled by two other groups of patients (children with IBD and HC) allowing for comparison.

5 | CONCLUSION

In summary, our study shows that children with IF infected with COVID-19 have an increased risk for gastrointestinal dysfunction which may be alleviated by vaccination. Paediatric patients with IF, and their caregivers, are highly burdened by the pandemic-related restrictions in health care and everyday life. Healthcare professionals should be aware of the special needs and unique risks of these patients and their families during a pandemic and provide targeted support.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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