

BMJ Open Psychosocial impact of the COVID-19 pandemic on children with chronic health conditions in Germany: a qualitative interview study

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ABSTRACT

Objectives To investigate the psychosocial impact of the COVID-19 pandemic on children with chronic health conditions (CHC) and their legal guardians (LG) living in Germany.

Design Qualitative interview study based on the transcripts of semistructured individual telephone interviews.

Methods Data were collected from October to December 2021 and the time frame of reference was January–June 2021 with two interviewers. Discussed aspects were, for example, socioeconomic information, daily life, thoughts and feelings of both children and LG, as well as family communication, unmet needs and possible advantages. Data were analysed using qualitative content analysis. The category system and subsequent coding schemes with anchor examples were based on interviews and the interview guide. It was tested for integrity and feasibility with one interview and finalised. To ensure classification reliability within all 11 interviews, 1 specifically trained rater (who did not participate in the interviewing to separate data collection and analysis) coded all transcripts.

Participants 11 LG of children with CHC participating in the ikidS (ich komme in die Schule) study.

Results The three aspects that were mentioned most often in the interviews were a psychological impact on children, a psychological impact on LG and an impact on the daily routines of LG. The majority of children and LG were burdened, had changed their activities and spent more time together, while having more conflicts. Children did not worry about becoming infected with COVID-19, but were worried about the health of their relatives. It was further reported that children had become more autonomous. LG additionally reported unmet needs such as opportunities for childcare or psychotherapy.

Conclusions While the changes brought about by the COVID-19 pandemic and their impact were often seen as negative, the LG in our study also perceived some opportunities for personal development both in their children and themselves, underlining that future research on the impact of the COVID-19 pandemic should focus not only on negative consequences but also on opportunities and positive change. Qualitative methods can be used on an exploratory basis to inform quantitative studies, as they are able to delve deeper into the area being examined and

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A strength is the use of semistructured interviews, which enabled us to gain in-depth information about individual experiences and the factors that affected children with chronic health conditions (CHC).
- ⇒ Caregivers focus on the topics which were most relevant to their children with CHC, thus providing opportunities to clear up dark fields.
- ⇒ Another strength is that while many studies have focused on the impact of the COVID-19 pandemic during its early stages, our study is one of the few to focus on a later stage (January–June 2021), thus providing information about how the course of the pandemic was perceived by families.
- ⇒ Due to the qualitative methodology and the small sample size, and since our sample is not representative concerning socioeconomic status and migration background, our findings can only be applied to families with children with CHC, who have a high socioeconomic status and no migration background.

provide greater insight into which aspects interviewees focus on.

INTRODUCTION

The COVID-19 pandemic has exerted a devastating global impact since 2019. To date, about 7.06 million lives have been lost¹ and nearly 776 million people around the world have suffered from SARS-CoV-2 infection.²

Studies have indicated that overall, children were medically less endangered by infection with SARS-CoV-2 compared with other groups,³ but the mental health of children and adolescents deteriorated strongly throughout the pandemic. Indeed, research has demonstrated that the pandemic had a psychological impact on children around the world, for example, in China,^{4,5} Brazil,⁶ Spain,⁷ Turkey,⁸ the USA⁹ and Canada.¹⁰ Psychological changes were found in the domains of anxiety,^{4,5,11} depressive symptoms,^{4,5,11,12}

psychosomatic complaints,¹³ quality of life,¹³ psychological stress¹⁴ and problematic media use.¹⁵ With regard to Germany, the longitudinal COVID-19 and PSYchological Health study revealed reduced quality of life and increased depressive, anxiety and psychosomatic symptoms among children and adolescents over the course of the pandemic.¹⁶

Children who suffer from chronic medical or mental health conditions (chronically ill children, henceforth abbreviated as children with CHC) represent a particularly vulnerable population. Compared with healthy children, those with CHC frequently report a lower quality of life¹⁷ and have also often been found to show poorer school performance.¹⁸ Furthermore, chronic illnesses may necessitate lifestyle changes, and not all activities may be possible for children with CHC.¹⁹ Moreover, these children often have special treatment needs. Parents are more involved in their children's daily care and devote large amounts of time to attending frequent medical appointments.²⁰ Besides planned medical treatment, children with CHC may also require emergency treatment more often.¹⁹ As such, parents have a high degree of responsibility for the medical treatment of their children,²⁰ which can in turn make parenting children with CHC more challenging than parenting healthy children.²¹

Research suggests that the COVID-19-related lockdowns made it harder for children with CHC to receive the necessary support, for example, because medical appointments were cancelled or non-urgent appointments were postponed.^{19 22} Moreover, in a focus group study, Reed *et al*¹⁹ described that legal guardians (LG) of children with CHC perceived the loss of personal contacts with clinicians as affecting their children's treatment. It is further possible that LG had to take on additional duties in terms of managing their children's illness.¹⁹ With regard to children with CHC who have mental health problems, the pandemic-related disruptions to daily routines may have been difficult, especially for children with ADHD and autism spectrum disorders.^{23–25} Yet, despite the inherent challenges of the pandemic and the associated containment measures, there may also have been some positive opportunities for children with CHC, for example, the use of online learning, which offered children the chance to learn at their own pace,²⁶ and spending more time with family.^{22 24} Moreover, online appointments may have made it easier for families to contact clinicians while also saving time due to the lack of visits to the hospital.¹⁹ Finally, the development of online learning tools potentially made it easier for children with CHC to keep up with their classes and enabled them to miss fewer lessons due to medical appointments or hospital stays.²²

From mid-December 2020 to February 2021, schools in Germany were closed nationwide due to a high number of infections beginning in fall 2020 ('second wave'). In addition, public life was largely closed down and citizens were called to reduce contacts around Christmas 2020.²⁶ This was also decided due to the presence of the Alpha variant of COVID-19 in Germany in the beginning of 2021. At the

beginning of January 2021, about 34 000 people had died from COVID-19 in Germany (7-day incidence=141),²⁷ which rose to about 57 000 at the beginning of February (7-day incidence=91).²⁸ From the end of February 2021, schools were gradually reopened and classes were taught in shifting mode from either at home or at school. Since infections started to rise again in March 2021 in a lot of cities (eg, at the end of March 2021, more than half of German cities had a 7-day incidence higher than 100),²⁹ schools had to close if the 7-day incidence was above 165 cases.²⁶ Since infections decreased again during May 2021 (7-day incidence 35, no cities with an incidence higher than 100),³⁰ schools remained open from that point on except in rare cases where the infections crossed the above-mentioned 7-day incidence rate. At the end of June 2021, there were about 90 000 deaths due to COVID-19 and the 7-day incidence was 5.2.³¹

International studies have demonstrated an impact of the COVID-19 restrictions on children with CHC.^{17 19} We wanted to explore the psychosocial well-being of children with CHC in Germany in different domains to gain in-depth knowledge about how they experienced the COVID-19 pandemic.

METHODS

Design, instrument development and recruitment

To ascertain the impact of the COVID-19 pandemic on children with CHC and their families, we conducted semi-structured telephone interviews, which were subsequently analysed using qualitative content analysis.³²

The present study was part of a project (ABCDEF-COOP), which addressed different aspects of children's health during the COVID-19 pandemic. Our sample consisted of parents or LG from the *ich komme in die Schule—'I'm starting school'* (ikidS) cohort, a cohort study on the associations between chronic health conditions (CHC) and educational outcomes in school-aged children,¹⁸ who had indicated that their child had a chronic disease or required specialist healthcare. Following a two-stage cluster sampling approach with equal proportions of children with a physical or mental disorder, as well as a balanced sex ratio, 12 LG out of 24 who provided written informed consent were asked to participate.

The development of the semistructured interview guide included a staged approach: first, a literature review was conducted to identify potential psychosocial impacts both in groups of children with CHC and during pandemics (SL and FH). Second, the resulting set of questions was discussed and revised within the entire research group (SL, FH, TS, CD and MSU). Third, to ensure feasibility, this prefinal set of questions was tested within a small sample of parents (n=2) with children at the age of the target group, who were not involved in the study. This resulted in minor changes to finalise the set of questions for the interview.

The semistructured interview focused mainly on two aspects: direct effects, such as a possible threat

experienced by COVID-19, and indirect effects associated with the restrictions in daily life. Additionally, the interview addressed relevant predictors derived from the existing literature, such as limited living space and socioeconomic status.¹³ To encourage participants to talk freely about their impressions, the first question included relevant socioeconomic information. Furthermore, the interview focused on the children: threat due to chronic disease, thoughts and feelings, social contacts, school performance, daily routines, somatic complaints and impact of restrictions. Further questions referred to communication between child and parent, burden on the parent (threat to family, impact of restrictions, thoughts and feelings, impact on health, social contacts, daily routines, job performance, problem-solving, utilisation of support). The interview concluded with questions about unmet needs and possible advantages of the pandemic-related restrictions. An English translation of the interview guide can be found in the online supplemental material.

Data collection and analysis

The data were collected during telephone interviews, which were scheduled with the participants individually. The interviewers had not been involved in the earlier investigations of ikidS and consisted of one male and one female interviewer. Interviewers were randomly assigned to the participants in order to balance possible influences of sex.

The interviews were audio-recorded using the Audacity software³³ with the interviewers taking additional notes. The recordings were subsequently transcribed verbatim by a scientific transcription service.

The process of analysis was analogous to content analysis by Mayring.³² The research questions (direct effects and indirect effects of the pandemic) were developed on the basis of the literature background and the state of knowledge. All transcribed material from the telephone interviews formed the textual basis for the further evaluation steps. Afterwards, the coding scheme was developed to depict the primary objectives (deductive development). To ensure objectivity, SL, TS and FH initially developed the coding scheme. The coding scheme was inductively developed based on the interview material. During the process of analysis, categories that were hitherto not represented were included in the final scheme. The final scheme was then compared with the initial research questions to ensure validity in regard to the object of research. To ensure independence of category development and analysis and to maximise reliability, ED coded all interviews and compiled paraphrases. Ambiguous paraphrases were discussed with FH, who was not involved in interviewing the participants, and finally classified by ED and FH. The final steps of the analysis were summarising the paraphrases according to the categories and integrating the key paraphrases to form a body of meaning.

Patient and public involvement

The study was initiated as a response to the COVID-19 pandemic and funded by the German Federal Ministry of Health. Accordingly, the study was driven by public interest in the intensity of the burden caused by the pandemic. Due to the qualitative nature of the study, the primary objective was to evaluate the individual extent of burden, with selected open questions to stimulate all possible answers. Patients were involved during the development of the interview guide, since it was tested and discussed with LG with children with CHC, and their feedback was used to revise the interview guide. No patients were involved in analysing the findings. The results were published in a report on the website of the German Federal Ministry of Health,³⁴ so that they could be perceived by the public as well as participants of the study.

RESULTS

Sample

The interviews took place in October and November 2021. Of the 12 LG, 1 person could not be reached despite intensive efforts; therefore, 11 LG participated in the interviews, none of whom dropped out. The mean duration of the interviews was 30 min (range 13–40 min).

The characteristics were as follows: nine LG reported a living space between 110 and 208 m². Two LG did not mention the exact size of their living space but noted that each of their children had their own bedroom. All LG mentioned that there were possibilities for retreat for every family member.

Three LG (27 %) reported a financial loss due to COVID-19. With regard to educational level, six LG (55 %) had a general qualification for university entrance, while three LG (27 %) did not, and two LG (18 %) did not provide information about educational level. None of the LG reported having a migration background or being a single parent. The mean age of the children was 12.5 years (SD=0.5), and six of the children (55 %) were boys. Reported CHC referred in one half of the cases to somatic health issues and in half to mental health issues. LG reported bronchial asthma, ametropia, neurodermatitis, dyslexia, attention deficit disorder, symptoms of autism, problems with emotional attachment and depression with non-suicidal self-injury.

Qualitative content analysis

The content analysis of 1393 text sections identified 21 categories, which are displayed in table 1. Interviews were conducted and analysed in German and have been translated into English for the purpose of publication.

All LG mentioned that they lived in either a house or a flat with sufficient space and rooms for every family member. Most LG stated that their financial situation did not change due to the pandemic.

Did daily routines change?

Children's daily life changed greatly during the pandemic. Children had to become accustomed to alternating

Table 1 Categories and frequency of belonging text sections arising from the interviews

Category	Frequency of belonging text sections
Psychological impact on children with CHC	218
Psychological impact on LG	208
Impact on daily routines of LG	156
Unmet need for support	112
Impact on daily routines of children with CHC	111
Impact on the social contacts of children with CHC	83
Impact on the social contacts of LG	61
Housing situation	60
Impact on the school performance of children with CHC	59
Impact on the quality of conversation between children with CHC and their LG	56
Organisation of distance learning by school	46
Impact on the quantity of conversation	34
Coverage of need for support	29
Impact on the health of children with CHC	27
Type of health threat	25
Other impact on behaviour	24
Content of conversations	23
Impact on job performance	20
Pandemic-related financial losses	15
Newly initiated approaches of coping	13
Impact on the health of LG	13
Note that the frequencies do not represent how many LG mentioned these topics, but merely show which topics were mentioned most in the interviews, so that the frequencies must be interpreted in the broader framework of the analysis. CHC, chronic health conditions; LG, legal guardians.	

between ‘homeschooling’, meaning that they were more often at home, and classroom teaching. Moreover, LG reported that routines frequently changed and many activities were not possible during the pandemic, such as attending sports clubs, outdoor sports, spontaneous activities, visiting friends from school or taking music lessons. Instead, it appears that both children and LG used more technical devices in daily life, both for school and work and during their leisure time. LG themselves often tried to uphold routines and were frequently required to work from home while taking care of their children and providing support for their online learning. Some LG mentioned that they spent less time driving children to appointments and that there were fewer appointments overall, and all LG mentioned that they spent more time together as a family, which was often depicted as ‘calm’. However, LG experienced an increase in workload.

Did the pandemic affect social life?

The frequency of social contacts was strongly reduced for all children. For example, one LG reported that their child “had the great pleasure of not being able to celebrate their birthday for the second time” (ID7) or “contacts were minimized as much as possible. We really withdrew” (ID8). Almost all LG reported that social contacts were reduced both for themselves and for their children. Nevertheless, they established alternative ways of keeping in touch, and children were able to meet friends outside while maintaining a physical distance. Children were often unable to meet with their relatives. LG reported that some children were less motivated to keep in touch with friends or had difficulties maintaining their contacts (“I also felt like he couldn’t be bothered to meet up with anyone”, ID4). One LG said that they did not reduce their contacts as they had already only had a few contacts before the pandemic.

Families as a whole used digital strategies to maintain contact with broader family and friends, such as “[...] just seeing grandma and grandpa over skype or on the cell-phone.” (ID10).

Was mental health affected?

The analyses revealed a large heterogeneity in how children coped with the changes in daily life. According to the LG, most children felt burdened by the pandemic-related changes, as expressed, for instance, by feelings of pressure, uncertainty, sadness and anger, depressive mood (“because she can now put it into words, that she says well ‘I don’t have any positive feelings anymore, or if one turns up, it just goes away again straight away’”, ID11), irritability, negative thoughts, suicidal ideation without plan or intention (“not so drastic that we would have thoughts about suicide, but he was definitely considerably burdened”, ID2), crying, withdrawal from social contacts (“isolated”, ID11), feelings of loneliness, higher use of technology, changes in eating behaviour, loss of motivation or self-harming behaviour (“So, [he/she] started cutting,” ID12). Yet, there was also a positive impact on some children, such as becoming more independent (“And it did her good, because she was able to determine the pace”, ID1; “He was quite independent during that time. It was real progress”, ID3), talking about thoughts and feelings, developing new hobbies, being relaxed and being more empathetic. Moreover, LG also mentioned changes for the whole family, such as being more physically active outdoors, becoming closer as a family, although associated with more conflicts. About one-third of participants stated that there were more family conflicts and that communication became more tense (“an incredibly aggressive tone of voice developed”, ID12). About one-third expressed that communication had become better, more emotional and more empathetic, and one-third did not observe changes in communication.

With regard to their own mental health, all LG in our sample expressed feeling burdened, especially due to homeschooling or changing schedules as well as having

to fulfil multiple roles (working and taking care of their children, also during schooling hours): “I [laughs slightly] was simply shattered” (ID4). Due to this, LG also mentioned that they had to reduce time for their own self-care.

Was there an impact on school performance?

According to LG, the organisational changes had an impact on their children’s school performance: some LG mentioned that their children showed lower motivation at school, that their school performance deteriorated and learning delays developed. For instance, one stated that: “Has deteriorated, even though the whining is at a high level. So it hasn’t gotten much worse, although it’s hard for me to judge because I simply don’t have the feedback from the teachers. What’s clear is that his knowledge is definitely behind his older sister’s at that age.” (ID7). The LG attributed this to different factors, such as less feedback from teachers, less supervision during online learning, lower motivation and the impact of psychological distress. However, some LG reported an improvement in their children’s academic performance, mentioning that there was less distraction and that their children were working more autonomously and handling the technology well: “Because she was less distracted. She’s the type of person who gets distracted by everything, has to be everywhere. And is incredibly fast or it’s incredibly difficult for her to stick to a topic, I would say. And they were much better during this emergency COVID period, because the groups were smaller in this emergency childcare. And there were fixed groups and not so much change. So it was easier for her. So it’s had a positive impact, even though it’s awful, but that’s the way it is.” (ID9). According to some LG, their children’s school performance did not change.

Were children anxious because of their CHC?

It appears that the children in the sample did not feel personally threatened by COVID-19 but were worried about sick or elderly relatives. For instance, one LG reported that: “Well, she (X) was partly afraid that, not so much that we’d get it, but that her grandparents would get it, so.” (ID12). LG worried more than their children and were often concerned about their children’s performance in school or their children’s health.

What unmet needs were there during this time?

LG experienced that some of their needs during the pandemic were not met, mentioning a lack of opportunities and social contacts for children (“If they could just have entered the school grounds again, met up with each other and maybe somehow done some sport together or something”, ID12) and a lack of support in the form of childcare services (“We tried to get support from the youth welfare office/and they rejected it”, ID4). Moreover, some LG mentioned that they were not sufficiently informed about support opportunities: “It was also a bit that there was no information about what / what’s next, what are we able to claim, possible solutions”, ID3). Finally, LG stated

a need for easier access to psychotherapy for children and adolescents.

Was there a positive impact on children with CHC?

LG did also observe positive changes in their children: LG often reported that their children became more independent, gained expertise concerning technology and tried out new leisure activities.

DISCUSSION

The present study investigated the impact of the COVID-19 pandemic on children with CHC and their LG. Using a qualitative research design, we evaluated whether the mental health of chronically ill children was affected by the pandemic and if so, which factors exerted an influence in this regard.

LG observed several changes in their children during the pandemic: they spoke about changed daily routines, social changes such as less direct contact and more contact via technical devices, changes in school performance and effects on mental health, such as feeling burdened, but also a different kind of family communication. Moreover, LG also reported that they also felt burdened by a higher workload and had less time for self-care. While many of the reported changes were perceived as negative, some LG also mentioned advantages of the situation, such as more independence of their children, better school performance or more time spent as a family. Last but not least, LG mentioned several unmet needs, such as support via psychotherapy or support in child care as well as opportunities for social interaction with peers.

To reduce virus transmission, Germany underwent several lockdowns in the run-up to our survey period (January–June 2021), which meant that schools were largely closed, children were often taught via online learning, and public life was reduced to a large extent (eg, closure of recreational facilities, limitations on meeting with people who were not part of one’s immediate family, for an overview see, eg, Sonnenburg *et al*²⁶). This meant that children often spent more time at home with their families and less time with peers and friends.

According to Lewinsohn’s social reinforcement theory, a loss of positive reinforcement can lead to psychological disorders such as depression.³⁵ Children often felt lonely during the lockdowns and reported missing their friends.³⁶ LG in our study described that their children were, for example, ‘depressed’, sad, aggressive, lonely, insecure and lacking in motivation. In terms of their children’s behaviour, LG mentioned a tendency towards social retreat, eating more frequently, higher use of mobile phones and other technology and in some cases self-harming behaviours. It can be assumed that institutional rules of ‘social distancing’ led to a loss of positive reinforcement, which may, apart from changed daily routines and changed social interactions, in turn have impacted children’s mental health. These findings are in line with previous studies that reported a psychological impact of

the COVID-19 pandemic on children, such as increased technology use,^{8 15} depressive symptoms,^{4 11 16} feelings of loneliness,⁷ irritability,⁷ self-harming behaviour³⁷ and increased eating frequency.³⁸

LG also experienced an impact on their own mental health: they often felt burdened, and like their children, presumably experienced a loss of positive reinforcement because leisure activities, support services and meetings with friends had to be abandoned. Moreover, many of the LG in our study mentioned the increased burden of childcare during regular working hours, which frequently meant that parents had little time for their own self-care. Thus, in addition to a loss of positive reinforcement, LG also often had more duties and responsibilities during the pandemic. These findings are in accordance with studies by McLoone *et al*²² and van Tilburg *et al*,²¹ who likewise reported a negative impact of the COVID-19 pandemic on the caregivers of chronically ill children.

Furthermore, studies have indicated that the well-being of LG might be interwoven with the psychological well-being of their children, since a lower well-being of LG has been found to be a risk factor for health impairments in their children.^{16 39 40} For example, Güzelsoy *et al*⁴¹ found that parental depressive symptoms were a predictor of depressive and anxiety symptoms in their children 6 months later. With regard to depression, for example, it is known that depressive mothers tend to be less emotionally responsive toward their child, characterised by being passive, not responding to the child's emotions and being less able to perceive and understand the child's signals.⁴² On the other hand, it has been shown that LG can support their children during crises and can lessen psychological strain,⁴³ whereas spending less time with LG might be associated with poorer psychological well-being in children. If the well-being of LG is reduced, they may be less able to offer support to their children.²² Thus, when considering children's well-being, it is important to keep in mind the crucial role of LG in supporting children's mental health.

During the pandemic, family conflicts often increased.^{41 44} Such conflicts can be associated with reduced quality of life and more psychosomatic complaints,¹⁶ whereas a positive family climate can be a protective factor.¹⁶ Similar to McLoone *et al*,²² we found that while LG mentioned a negative psychological impact on their families, they also perceived the greater amount of time spent together as a family as a resource to cope with the current situation. Some LG in our study reported more frequent conflicts, while other LG tried to spend more quality time as a family and improve communication as a way to reduce the psychological burden experienced by their children.

Prior to the pandemic, a meta-analysis by Pinquart and Teubert⁴⁵ revealed that chronically ill children show a lower academic performance compared with their healthy peers. In the present study, some LG observed that their children showed school-related difficulties such as poorer school performance and diminished motivation.

However, others mentioned that their children's school performance improved and that the children were less distracted in class. Overall, evidence suggests reduced school performance in Germany during the pandemic,⁴⁶ although some studies also indicated increased performance.⁴⁷ There are several factors relating to homeschooling that might have made it easier for children to learn, such as being able to learn at their own pace and not being restricted by preset conditions.²⁶ In addition, it is known that repeated school absences, for example, due to medical appointments or stays in hospital, are associated with poorer academic performance⁴⁸ and homeschooling might therefore be beneficial for chronically ill children in terms of both of these aspects. Research has further shown that parental support is an important factor determining the success of homeschooling, but this is influenced by parents' working hours and the family socioeconomic background, with more working hours and a lower socioeconomic background being related to a lower ability to support children.⁴⁹ The families in our study were from a higher socioeconomic background and were thus well equipped to support phases of online learning, both in terms of possessing the necessary technology and having the ability to supervise their children. Overall, therefore, the families in our study seem to have been less impacted during this time than families with lower resources.

From a medical perspective, COVID-19 infection could be potentially more dangerous for chronically ill children than for healthy children,²⁴ and several studies reported that children with CHC exhibited higher anxiety surrounding possible infection compared with their healthy peers.^{43 50 51} In our study, LG reported that their children did not fear an impact of a possible COVID-19 infection for themselves, but that they were afraid of infecting other family members. This suggests that children with CHC did not view COVID-19 as a threat to their own health, regardless of their chronic health condition. At the start of the pandemic in Germany, media reports were dominated by calls for the public to keep senior citizens safe (see, eg, Federal Ministry for Family Affairs⁵² and Simon⁵³). Therefore, it is possible that LG and their children were not primarily focusing on potential infection in children with CHC. It is also possible that most of the specific CHC present in our sample were not health conditions that could be severely impacted by an infection with COVID-19, since only one child was reported to have bronchial asthma. It may be possible that in a sample with different health conditions, such as lung diseases or cancer, to whom COVID-19 could be more threatening,²⁴ children could have more fear of COVID-19 infection due to an increased health risk for themselves.⁵⁴

Previous research suggested that during the pandemic, children had unmet mental healthcare needs.^{22 55} Moreover, social support for chronically ill children and their families was restricted.²² Our results support these findings, as the LG in our study highlighted the difficulty of obtaining psychotherapy appointments for their

children. Furthermore, they reported that their children would have required more daily care services and opportunities for social interactions with peers. However, it should also be noted that due to a high socioeconomic status of the families in our sample, it is possible that LG with a lower socioeconomic status or less private support opportunities would have reported even more unmet needs, and since our sample is not representative in this aspect, it could even underestimate what families with children with CHC would have needed during the pandemic.

Studies have shown that parents of chronically ill children often find it difficult to promote their children's autonomy or might be overprotective of their children.⁵⁶⁵⁷

It is possible that the COVID-19 pandemic offered children with CHC the opportunity to gain more autonomy from their parents, simply out of need: LG mentioned that their children gained new knowledge about handling technological devices and many had the impression that their children became more independent. Furthermore, some children tried out new activities and hobbies in their leisure time. Thus, while on the one hand, support structures in daily life were often interrupted due to the pandemic, on the other hand, this situation may have also provided opportunities for personal development for chronically ill children and their families.

In our study, we presented findings about the psychosocial impact of the COVID-19 pandemic in Germany from January to June 2021. The effects may vary at other points of the pandemic, in other countries or even due to a combination of both factors. As the randomly selected participants mainly had a high socioeconomic background and no migration background, our sample is homogeneous, so that our findings cannot be translated onto families with a lower socioeconomic background or migration background. As mentioned before, families with such disadvantages could be even more impacted by the pandemic and its restrictions. Moreover, due to the small sample size and the nature of the qualitative research design, our findings cannot be generalised to the population of chronically ill children, but focus on discovering and identifying potential aspects that were focused on by participants and which should be further evaluated using bigger sample sizes and, for example, quantitative methodology. Future research could focus on reaching more socially disadvantaged families. Moreover, it seems important to observe how children's mental health is affected in the longer-term aftermath of the pandemic.

CONCLUSION

Overall, our study demonstrates an impact of the COVID-19 pandemic on several domains of life for children with CHC and their families: LG mentioned a negative psychological impact on both themselves and their children, as well as changes in social contacts, daily routines and communication with their children.

Interestingly, children with CHC did not worry about their own health, but did worry about the health of their family members. Some children and LG also benefited from the pandemic and its restrictions, as reflected, for instance, in improved school performance, developing new skills and becoming more independent more quickly.

To understand the mechanisms underlying the impact of the COVID-19 pandemic on chronically ill children and their families, the qualitative methodology employed in the present study seems to be an appropriate approach and it can offer valuable insights into which factors should be explored more deeply in future research.

Contributors The research was led by FH and coordinated by SL. Both developed the interview guidelines in cooperation with CD. The interviews were executed by SL and TS. All are psychologists who are trained in research as well as conducting interviews and working with clients and patients. The coding scheme was developed by FH, SL and TS and was applied to all interviews by ED, who has experience with coding qualitative data but was not involved in developing the interview guidelines or conducting the interviews. SL drafted the first version of the manuscript, which was revised by all authors and all authors approved of the final manuscript. SL is the guarantor.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the ethics committee of Rhineland-Palatinate (No. 2018-13254_5). Participants gave informed consent to participate in the study before taking part.

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