


Mental health of children with and without special healthcare needs and of their caregivers during COVID-19: a cross-sectional study

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ABSTRACT

Objective To describe mental health outcomes and measures of pandemic burden of children with and without special healthcare needs, and their caregivers following the second wave of the COVID-19 pandemic in Germany.

Design This is the second of a sequential series of cross-sectional online surveys conducted among caregivers of children ≤18 years since the onset of the COVID-19 pandemic, administrated between 2 April 2021 and 31 July 2021.

Main outcome measures Child and parental mental health were assessed using the Strengths and Difficulties Questionnaire and WHO-5 Well-being index. Children with Special Healthcare Needs (CSHCN) were identified using the CSHCN-Screener. Descriptive statistics, linear and hierarchical logistic regression modelling assessed associations between parent-reported child mental health problems and measures of pandemic burden, disease complexity, caregiver mental well-being and socioeconomic status.

Results 521 participants were included in the final sample. There was a high prevalence of parent-reported mental health problems in n=302 (66.7%) children, particularly in CSHCN. Among caregivers, n=372 (72.5%) screened positive for depression. Logistic regression modelling showed a strong association of child mental health problems and disease complexity, parental mental well-being, increase in family conflict and inadequate social support.

Conclusions Our study identifies CSHCN as a particularly vulnerable group in terms of mental health outcomes. Psychosocial factors were important predictors of parent-reported child mental health problems. Policy measures should consider the importance of social support systems for vulnerable children and their families, and aim to provide accessible mental health support for caregivers.

INTRODUCTION

The COVID-19 pandemic has substantially disrupted the everyday lives of children and their families worldwide. Recurring lockdowns, contact restrictions and school closures have affected children and adolescents repeatedly over the past 2 years. Home schooling, social isolation and difficulties in

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Increasing evidence points towards a rising mental health burden in children and adolescents during the COVID-19 pandemic.
- ⇒ Few studies conducted during the pandemic so far have focused on mental health outcomes of children with special healthcare needs and their caregivers.

WHAT THIS STUDY ADDS

- ⇒ This study found a high prevalence of mental health problems in both children and their caregivers, particularly in families with children with special healthcare needs.
- ⇒ Parent-reported child mental health problems were strongly associated with pandemic-related variables, that is, increase in family conflict and inadequate social support, and with caregivers' mental health.
- ⇒ It highlights the importance of social support systems for vulnerable children and their families, and provision of accessible resources for caregiver's mental health support.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Longitudinal studies are needed to examine the long-term mental health impact of the COVID-19 pandemic on children with special healthcare needs.
- ⇒ Policy responses to the current and any future pandemic should consider the importance of social support systems for vulnerable children and their families, and include their voices and experiences in health-related decision-making.

accessing routine health services for children have placed considerable strain on families.¹⁻⁶

Concern about the mental health impact of the pandemic on children and adolescents has been raised repeatedly.⁷ Increasing evidence suggests a rising mental health burden in children and adolescents: a recent meta-analysis reports a pooled prevalence of 25.2% for depression and 20.5% for elevated anxiety, which are double prepandemic

estimates.⁸ This evidence from largely cross-sectional studies is echoed by longitudinal studies.^{9 10} In Germany, child mental health problems increased from 17.6% pre-pandemic to 29.1% by September–October 2021.^{10 11}

Associations between young people's mental health, caregiver burden and mental well-being, social support and socioeconomic status (SES) have been described previously.^{10 12 13} Child behavioural problems during the pandemic predicted parental strain, and parents reporting high parental strain were more likely to report child behavioural problems.¹⁴ Caregiver burden was a predictor for parental depression and anxiety.¹⁵

Fluctuating public health measures and need for frequent adaptation of family routines were a challenge for families with children with special healthcare needs (CSHCN) in particular. These children have chronic conditions which require more support than average.¹⁶ There is concern about the mental health impact of the pandemic on CSHCN and about an increasing burden on their caregivers.^{17–19} However, few studies to date have focused on the mental health of CSHCN and their caregivers. As countries worldwide are faced with the long-term challenge of COVID-19 recovery, research should support an equitable approach by providing evidence on the impact of the pandemic on vulnerable populations.²⁰ Hence, our study aims

1. To describe mental health outcomes and measures of pandemic burden of children with and without special healthcare needs and their caregivers following the second wave of the COVID-19 pandemic in Germany.
2. To explore associations between parent-reported child mental health problems and measures of pandemic burden, disease complexity, caregiver mental well-being and SES.

METHODS

Study design

This study is the second of a sequential series of cross-sectional online surveys at various time points since the onset of the pandemic. The first survey was conducted from August to October 2020.²¹ This second survey was initiated shortly after the second national lockdown in Germany (16 December 2020–7 March 2021) and administered via REDcap between 2 April 2021 and 31 July 2021.

Caregivers of children ≤ 18 years were eligible to participate. Recruitment involved convenience and non-probabilistic snowball sampling, study promotion via partner organisations, social and public media, and through free access websites. The study is registered with the German Registry for Clinical Studies (DRKS00022868).

Patient and public involvement

Representatives of the Kindernetzwerk e.V., a large patient organisation for families of children with chronic diseases and disabilities, were consulted about relevant topics when designing the questionnaire and approved

the final version. The Kindernetzwerk e.V. promoted the study; results were shared in online meetings, and disseminated to its members through free access websites and newsletters.

Measures

Child mental health was measured using the parent-report version of the Strengths and Difficulties Questionnaire (SDQ).²² It applies to children aged 4–16 years, with a preschool version differing in three items.²³ Both the German standard parent-report version of the SDQ and the preschool version are valid and reliable instruments.^{23 24} We used age-appropriate versions of the SDQ for caregivers of children older than 2 years and a cut-off of 13 on the Total Difficulties score^{10 25} (online supplemental material).

Caregiver mental health: The WHO-5 is a five-question screening tool for mental health with good validity and reliability.²⁶ Scores range from 0 to 100, where 100 represents the best imaginable mental well-being. The cut-off point for depression screening is 50.²⁶

CSHCN: The CSHCN Screener is a five-item parent-reported screening instrument to identify children with chronic physical, mental, behavioural and other conditions, who require more support through services than average for their peers.¹⁶ Higher scores indicate higher disease complexity. We stratified children into three groups²⁷: no special healthcare needs (CSHCN score=0), chronic conditions ($0 < \text{CSHCN score} \leq 2$) and complex chronic conditions (CSHCN score ≥ 3).

SES: An SES index was constructed as the sum of three indicators: household net equivalent income, caregiver education and occupation²⁸ (online supplemental material).

COVID-19-related burden: Items assessed financial difficulties, inadequate social support, family conflict and general burden by pandemic restrictions.

Sociodemographic characteristics included age and gender, relationship status, education, occupation, monthly household income, household size, area of residence and country of birth. Caregiver education was categorised according to the international CASMIN classification.²⁹

Statistical methods

Participants with no more than two missing values in any of the following key variables were included in the analysis: SDQ total score, WHO-5 total score, CSHCN screener score and SES variables (monthly household income, occupation and education). Missing values for household net income (15%) were replaced by multiple imputation. Analyses involving the SDQ were restricted to children older than 2 years of age. Associations between SDQ-subscales and WHO-5 were examined using Pearson's correlations. Simple linear regression modelling was performed for WHO-5 total score on SES-Index and for SDQ total score on SES-Index. Associations between

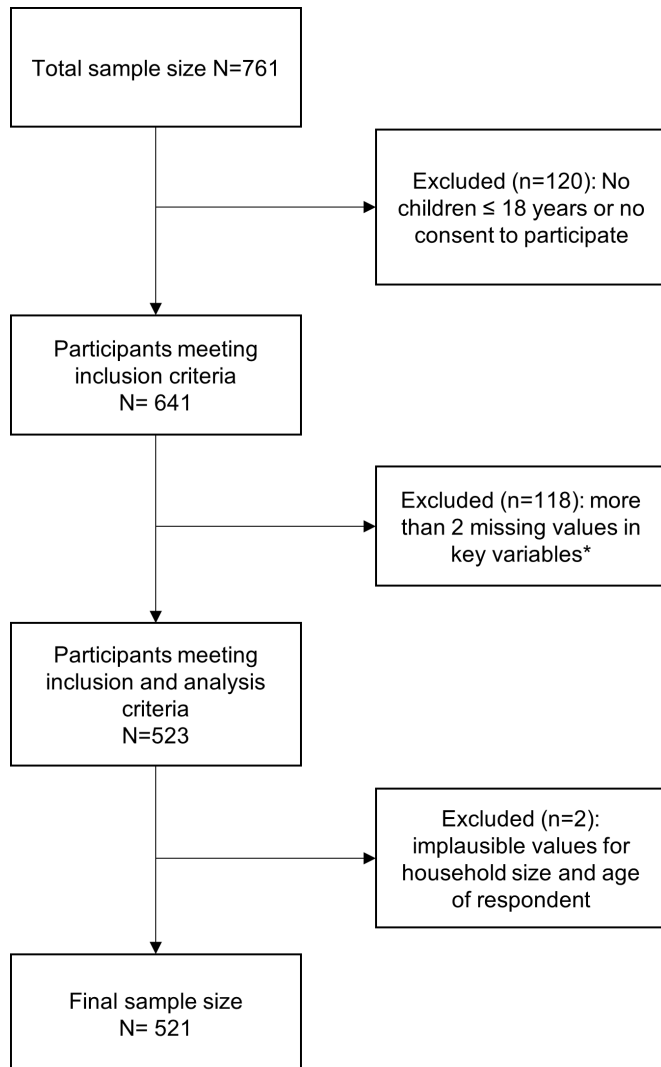


Figure 1 Flow diagram of final study sample. *Key variables: SDQ total score, WHO-5 total score, CSHCN screener score and SES variables (monthly household income, occupation and education). CSHCN, Children with Special Healthcare Needs screener; SDQ, Strengths and Difficulties Questionnaire; SES, socioeconomic status.

COVID-19 related burden and SES were analysed using simple logistic regression modelling.

Theory-driven hierarchical logistic regression modelling was performed on complete datasets ($n=427$; 82% of total sample size) to estimate adjusted ORs for the association of parent-reported child mental health problems with disease complexity, caregiver mental health, SES and pandemic burden. Variables were added in three blocks (see online supplemental material). Analyses were adjusted for age and gender. We compared model 1 including all children with two models stratifying for disease complexity (models 2 and 3). Effect modification was explored by including interaction terms for family conflict and caregiver well-being, as well as for social support and caregiver well-being in model 1. Multicollinearity between exposure variables was assessed by

calculating the variance inflation factor. Analysis was performed using IBM SPSS V.27.0.

RESULTS

Of 761 participants accessing the survey, 521 were included in the final sample (figure 1). Participants' sociodemographic characteristics are displayed in table 1. Exclusion from further analysis ($n=120$) affected families with and without CSHCN equally (see online supplemental material for further details).

Among all children, 56.2% ($n=293$; 0.6% missing) had special healthcare needs. Of these, 79.2% ($n=232$) had a physical impairment, 76.8% ($n=225$) a behavioural or sensory impairment and 52.2% ($n=153$) had impaired speech or understanding.

The mean SDQ score was 16.4 (SD 8.6; 8.3% missing), with 66.7% ($n=302$) of children having a score ≥ 13 , indicating slightly raised to high scores. Caregivers' mean WHO-5 score was 35.7 (SD 22.6; 1.5% missing) and 72.5% ($n=372$) had a score ≤ 50 , that is, below the cut-off point for depression screening. There was strong evidence for a negative correlation between all SDQ-subcales and WHO-5 score (online supplemental table S2).

There was very strong evidence for an association between disease complexity and SDQ score: 77.6% ($n=156$) of children with complex chronic disease had raised to high SDQ scores compared with 55.7% ($n=112$) of children without special healthcare needs ($\chi^2(df=2)=21.7$, $p<0.001$; 13.6% missing; online supplemental table S3). CSHCN scored higher on all SDQ subscales than children without; group differences were significant for the hyperactivity/inattention and peer problems subscales (table 2).

Most caregivers felt burdened by pandemic restrictions ($n=489$ (94.2%); 0.4% missing) and about half reported increased family conflict and inadequate social support ($n=248$ (47.8%) and $n=270$ (52.0%), respectively; 0.4% missing). Financial difficulties were reported by 17.5% of families ($n=91$; 0.4% missing).

Stratified analysis revealed differences according to SES. Among children with complex chronic conditions, 26% ($n=61$) lived in families with low SES, compared with 14.4% ($n=31$) of children without ($\chi^2(df=4)=11.7$; $p=0.02$; online supplemental table S4). There was some evidence for associations between SES and both caregiver and child mental health. WHO-5 scores increased with increasing SES, while SDQ scores increased with decreasing SES (table 3). For additional results, see online supplemental table S5.

Determinants of child mental health

Table 4 shows the results of hierarchical logistic regression modelling. Overall, model 1 explained 32.9% of variance after block 3, and correctly predicted an SDQ-score ≥ 13 in 88.1% of cases. The biggest increase in explained variance resulted from adding caregiver mental well-being in block 2. Model 1 provided very

Table 1 Sociodemographic characteristics (N=521); percentages reported as row percentages

	Mean (SD)	Range
Age in years		
Responding parent (N=500)	41.1 (6.5)	18–66
All children	8.4 (4.2)	1–18
Children with SHCN (N=293)	8.6 (4.5)	0–18
No of children per household	2.0 (0.9)	1–6
Household size	3.96 (1.03)	2–9
Household net equivalent income (N=505; monthly, in Euros)	2117 (773)	192–5619
Partner living in the same household (n=441)	2193 (745)	298–5619
Partner living in a different household (n=12)	2060 (1085)	750–4375
No partner (n=51)	1474 (645)	192–3462
	n	%
Gender of respondent (N=502)		
Male	54	10.8
Female	444	88.6
Diverse	3	0.6
Gender of child		
Male	281	53.9
Female	237	45.5
Diverse	3	0.6
Relation to child (N=503)		
Biological mother	443	88.1
Biological father	50	9.9
Other	10	2.0
Relationship status (N=504)		
With partner, in same household	441	87.5
With partner, not in same household	12	2.4
No partner	51	10.1
Country of birth of parents (N=505)		
Both in Germany	421	83.4
One parent in Germany, one elsewhere	63	12.5
Both elsewhere	21	4.1
Place of residence (N=506)		
City (>100 000 inhabitants)	206	40.7
Surroundings of a city with >100 000 inhabitants	59	11.7
Town (20 000–100 000 inhabitants)	87	17.2
Small town (5000–20 000 inhabitants)	56	11.1
Rural municipality (<5000 inhabitants)	98	19.4

Continued

Table 1 Continued

	n	%
Disease complexity of child (N=518)		
No special healthcare needs (CSHCN=0)	225	43.3
Chronic disease (CSHCN ≤2 criteria)	52	10.0
Complex chronic disease (CSHCN ≥3 criteria)	241	46.5
Educational level according to CASMIN classification (N=505)		
1 a: Inadequately completed general education	1	0.2
1b: General elementary education	2	0.4
1 c: General elementary education and vocational qualification	10	2.0
2 a: Intermediate general qualification and vocational qualification	60	11.9
2b: Intermediate general qualification	16	3.2
2 c_gen: General maturity certificate	32	6.3
2 c_voc: General maturity certificate and vocational qualification	68	13.5
3 a: Lower tertiary education	53	10.5
3b: Higher tertiary education	263	52.1
Employment status of respondent (N=503)		
Inactive or unemployed	82	16.3
Short term or temporary employment	28	5.6
Part time	285	56.7
Full time	108	21.5
CSHCN, Children with Special Healthcare Needs; SHCN, Special Healthcare Needs.		

strong evidence that elevated SDQ scores were associated with disease complexity, age of child, caregiver mental well-being, increase in family conflict and inadequate social support. Children with complex chronic conditions had three times the odds of having an elevated SDQ score compared with children without special healthcare needs. Children whose caregivers scored ≤50 on the WHO-5 were 2.9 times more likely to have an elevated SDQ score than children in the baseline group. Children whose caregivers reported an increase in family conflict during the pandemic or experienced inadequate social support had 3.6 times and 2.4 times the odds of having an elevated SDQ score compared with children in the baseline group. After controlling for confounding effects of

Table 2 SDQ subscales (N=450)

			Children with SHCN		Children without SHCN		T	df	P value
	Mean	SD	Mean	SD	Mean	SD			
Emotional symptoms	4.02	3.48	4.13	3.45	3.90	3.52	-0.71	448	0.48
Conduct problems	4.62	2.87	4.80	2.93	4.40	2.78	-1.46	448	0.14
Hyperactivity/inattention	4.55	3.24	4.92	3.23	4.10	3.20	-2.66	448	0.008
Peer problems	3.19	3.21	4.37	3.39	1.74	2.25	-9.42	448	<0.001

SDQ, Strengths and Difficulties Questionnaire; SHCN, Special Healthcare Needs.

disease complexity, age, gender, caregiver mental health and psychosocial variables, there was no evidence of an association between SES and elevated SDQ scores.

Other analyses

Stratified regression modelling according to disease complexity revealed no substantial differences for children without special healthcare needs. For children with complex chronic disease, only a strong association between inadequate social support and elevated SDQ scores prevailed (table 4). The inclusion of interaction terms showed no evidence of a varying effect of family conflict or social support on elevated SDQ scores according to the WHO-5 score. There was no evidence for multicollinearity between independent variables included in the regression modelling.

DISCUSSION

This study demonstrates that prevalence of mental health problems in both children and their caregivers is high, particularly in families with CSHCN. Parent-reported child mental health problems were strongly associated with pandemic-related variables, that is, increase in family conflict and inadequate social support, as well as with caregiver mental health. After adjusting for confounding, no association of SES and child mental health remained.

The prevalence of parent-reported mental health problems, as measured by elevated SDQ score, in our sample was 66.7%. This is much higher than estimates of 30.4% and 29.1% reported in a representative German study.¹⁰ The higher prevalence in our study is likely due

to the high proportion of children with chronic disease or disability. Other studies assessing child mental health during the COVID-19 pandemic in non-representative samples have described elevated mental health symptoms for children with special educational needs and neurodevelopmental disorders.^{9 17 30} The first survey of our study found a prevalence of parent-reported mental health problems of 57.4%, with a higher prevalence among CSHCN.²¹ Though this study is not based on the same sample, we still observe very high SDQ scores for CSHCN.

Our findings suggest both lower caregiver well-being and high prevalence of depression based on the WHO-5 compared with general population estimates (²⁶, supplement; ³¹). Our sample likely constitutes a particularly high-burdened sample of caregivers. Compared with our first survey, we here observed even lower caregiver well-being and mental health.²¹ Other studies have reported high psychological distress in families during the COVID-19 pandemic and associations of parental stress, younger age of both parents and children with poorer parental mental health.^{5 10 32-34} The reciprocal relationship between caregiver and child mental well-being warrants further exploration. We observed strong correlations of caregiver mental health with child mental health. This could reflect the fact that the child mental health measure was a parent-reported outcome measure,^{14 35} that is, highly burdened caregivers might be more likely to report child internalising or externalising problems.

Caregivers of CSHCN are particularly at risk of experiencing psychological distress.^{19 36} A study found moderate to severe depression in 45% of carers of children with

Table 3 Analysis of associations between psychometric outcomes and SES

	Coefficient	SE	T	P value	95% CI
WHO-5 (N=504)					
SES-Index	0.67	0.31	2.15	0.032	0.06 to 1.28
Constant	24.69	5.24	4.71	<0.001	14.40 to 34.98
SDQ (N=438)					
SES-Index	-0.37	0.13	-2.94	0.003	-0.62 to -0.12
Constant	22.39	2.11	10.63	<0.001	18.25 to 26.53

Estimation by linear regression of WHO-5 and SDQ total scores on SES-Index, respectively. Estimates for regression coefficients are reported with their corresponding t-statistic, p value and 95% CI.

SDQ, Strengths and Difficulties Questionnaire; SES, socioeconomic status.



Table 4 Impact of SES and psychosocial burden on child mental health problems

Variables	Model 1			Model 2			Model 3		
	OR	95% CI	P value	OR	95% CI	P value	OR	95% CI	P value
All children (N=427)									
Block 1									
Disease complexity									
No special healthcare needs (reference)									
Chronic condition	1.63	0.73 to 3.63	0.234						
Complex chronic condition	2.98	1.73 to 5.14	<0.001						
SES-Index									
Low	0.62	0.28 to 1.38	0.238	0.58	0.17 to 1.96	0.381	0.28	0.06 to 1.21	0.087
Middle	1.09	0.59 to 2.03	0.780	1.33	0.59 to 3.01	0.490	0.45	0.12 to 1.78	0.257
High (reference)									
Age of child	1.15	1.05 to 1.25	0.002	1.21	1.06 to 1.39	0.006	1.06	0.95 to 1.19	0.301
Gender of child									
Male (reference)									
Female	0.95	0.59 to 1.53	0.819	1.03	0.54 to 2.02	0.941	0.73	0.33 to 1.62	0.432
Age of respondent	0.93	0.89 to 0.98	0.005	0.91	0.83 to 0.97	0.012	0.97	0.91 to 1.05	0.457
Gender of respondent									
Male (reference)									
Female	0.55	0.23 to 1.30	0.175	0.42	0.14 to 1.24	0.116	1.16	0.26 to 5.11	0.85
Diverse	<0.001	<0.001; -	1.0	<0.001	<0.001; -	1.0	-	-	-
Model fit after block 1									
Nagekerke's R ²	0.096			0.068			0.047		
Block 2									
WHO-5 Score ≤50	2.85	1.70 to 4.80	<0.001	3.07	1.42 to 7.01	0.005	2.22	0.95 to 4.96	0.066
Model fit after block 2									
Nagekerke's R ²	0.230			0.197			0.118		
Δ R ²	0.134			0.129			0.071		
Block 3									
Increase in family conflict	3.55	2.13 to 5.92	<0.001	3.53	1.70 to 7.33	0.001	2.20	0.99 to 4.90	0.053
Financial difficulties	1.05	0.51 to 2.18	0.894	2.54	0.62 to 10.47	0.198	0.61	0.24 to 1.53	0.289
Inadequate social support	2.38	1.46 to 3.89	0.001	1.97	0.98 to 3.94	0.057	2.94	1.31 to 6.58	0.009
Area of residence									
City or suburb (reference)									

Continued

Table 4 Continued

Block 3	OR	95% CI	P value	OR	95% CI	P value	OR	95% CI	P value
Outside a city	1.45	0.89 to 2.36	0.135	1.41	0.69 to 2.88	0.347	1.40	0.65 to 2.98	0.389
Model fit after block 3									
Nagelkerke's R ²	0.329			0.325			0.202		
Δ R ²	0.099			0.128			0.088		
% correct prediction of SDQ Score ≥13	88.1			79.0			95.4		

Hierarchical logistic regression modelling of the outcome SDQ total score ≥13 in children older than 2 years of age. Adjusted OR and the corresponding 95% CI are reported for associations of the outcome and the respective exposure variable.

CSHCN, Children with Special Healthcare Needs Screener; SDQ, Strengths and Difficulties Questionnaire; SES, socioeconomic status.

intellectual disabilities during the first UK lockdown.³⁷ Family functioning and social support are important factors related to caregiver mental well-being.^{10 30 33} In households of young CSHCN, several dimensions of social support correlated with lower emotional distress in caregivers and fewer behavioural problems in children during the pandemic.¹⁸ Our study identifies family conflict and social support as predictors of child mental health. Pandemic control measures included different degrees of social distancing, hence our findings may reflect the impact of disintegrating social support systems on families with CSHCN.

Associations between SES and child mental health have been described both before and during this pandemic.^{9 10 12 30 38} Contrary to results of the unadjusted analysis and to our first survey,²¹ we did not find associations between SES and parent-reported child mental health problems after adjusting for confounding. This might be due to responding bias, as our study sample mainly included participants with a high educational and occupational level. However, we found strong evidence for an association between low SES and disease complexity. Higher odds of all-cause disabling conditions have been described for children from low SES, though the causal mechanisms remain uncertain.³⁹ CSHCN from low SES are likely to be a particularly vulnerable group, both with regard to their underlying condition and their mental health.

Limitations

The results and in particular the generalisability of this study are limited by the non-representative nature of our sample. Due to the recruitment process, the respondents are likely to have been a highly self-selected sample with a high educational level. Participants from lower educational and occupational levels, and those from a minority or ethnic background are under-represented. Hence, this study might underestimate the prevalence of parent-reported child mental health problems in this group. Regarding non-response, it can be assumed that there was no systematic bias due to disease severity based on the data available, as both families with and without children with SHCN were equally affected. Finally, the cross-sectional design of this study does not allow inference of causality. Hence, caregiver mental health problems may cause child mental health problems, but child mental health problems and disease complexity may also affect caregiver mental health.

CONCLUSION

The results presented here suggest a high mental health burden in both children and caregivers in a large sample of German families with children with and without special healthcare needs. In the context of the COVID-19 pandemic, our study identifies children with complex chronic disease as a particularly vulnerable group in terms of mental health outcomes. Psychosocial factors

related to social support, family functioning and caregiver mental well-being were important predictors of parent-reported child mental health problems. Consequently, there is a need for longitudinal studies examining the long-term mental health impact of the pandemic on CSHCN. Appropriate policy responses should focus on and reach out to vulnerable groups by including their voices and experiences in health-related decision making.²⁰ Future pandemic preparedness should adopt a child-rights-based approach, consider the importance of social support systems for vulnerable children and their families, and establish accessible resources for caregivers' mental health support.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Ethics Committee of Freiburg University (Approval number 377/20). Participants gave informed consent to participate in the study before taking part.

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